

Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Sex Anatomy



**NGO Report
to the 2nd, 3rd and 4th Periodic Report of Switzerland
on the Convention on the Rights of the Child (CRC)**

+ Supplement “Background Information on IGMs”

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Executive Summary

Intersex children are born with variations of sex anatomy, including atypical genetic make-up, atypical sex hormone producing organs, atypical response to sex hormones, atypical genitals, atypical secondary sex markers. While intersex children may face several problems, in the “developed world” the most pressing are the ongoing **Intersex Genital Mutilations**, which present a distinct and unique issue constituting significant human rights violations (A).

IGMs include non-consensual, medically unnecessary, irreversible, **cosmetic genital surgeries**, and/or other harmful medical treatments that would not be considered for “normal” children, without evidence of benefit for the children concerned, but **justified by societal and cultural norms and beliefs**. (B 1.) Typical forms of IGMs include “masculinising” and “feminising” genital “correction,” castration, sterilisation, imposition of hormones, forced genital exams, vaginal dilations and medical display, human experimentation and selective abortion (B 2., Supplements “Historical Overview”, “Medical Textbooks”).

Since 1950, IGMs have been practised systematically and on an increasingly industrial scale all over the “developed world”, with **Switzerland taking a leading role** in the global dissemination, and **all typical forms still practised** in Switzerland today. Because “*a hole*” is surgically easier to shape than “*a pole*”, most “ambiguous” children were made into girls, until the 1990s often by amputation of their “enlarged clitoris.” Parents and children are misinformed, kept in the dark, sworn to secrecy and denied appropriate support (B 2.–3., Cases No. 1–6, Supplements “Historical Overview”, “Medical Textbooks”).

With Swiss government, health departments, health care providers, and health assurances **refusing to disclose statistics**, no actual numbers are available neither on the frequency of intersex births, estimated at 1:500–1:1000 (A 4.), nor on the frequency of IGMs, estimated at 90% of all intersex children and youths (B 3.).

IGMs cause **lifelong serious physical and psychological complications**, including loss or impairment of sexual sensation, painful scarring, painful intercourse, incontinence, serious problems with passing urine, increased sexual anxieties, less sexual activity, dissatisfaction with functional and aesthetic results, impairment or loss of reproductive capabilities, lifelong dependency of artificial hormones, significantly elevated rates of self-harming behaviour and suicidal tendencies, lifelong mental suffering and trauma. (B, Cases No. 1–6)

For more than 20 years, intersex people, NGOs, human rights and bioethics experts have criticised IGMs as harmful and traumatising, as a **fundamental human rights violation**, as western genital mutilation, and child sexual abuse, and called for legislation to end it (B, D).

The Swiss National Advisory Commission on Biomedical Ethics (NEK), the UN Special Rapporteur on Torture (SRT), the UN-Committees CEDAW and CAT, the UN High Commissioner for Human Rights (UNHCHR), the World Health Organisation (WHO) and the Council of Europe (COE) criticise these interventions as a violation of human rights, **demand legislative measures** (NEK, SRT, COE), historical reappraisal, acknowledgement by society of suffering inflicted (NEK) and compensation for victims (NEK, CAT) (D).

The Swiss Federal Government, Cantonal Health Departments and National Medical Bodies still refuse to take action, but allow the human rights violations of intersex children and adolescents to continue unhindered (B 3., C, D, E, Annexe 2).

This NGO Report to the 2nd, 3rd and 4th Swiss state report was compiled by Zwischengeschlecht.org, Intersex.ch, and SI Selbsthilfe Intersexualität. Elaborating on the paragraphs on IGM in the **Child Rights Network Switzerland NGO Report** (p. 25–26), it contains **concluding recommendations** (F).

NGO Report to the 2nd, 3rd and 4th Periodic Report of Switzerland on the Convention on the Rights of the Child (CRC)

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Introduction

Switzerland will be considered for its combined 2nd, 3rd and 4th periodic review by the Committee on the Rights of the Child in its 67th Session in 2015. Unsurprisingly, human rights violations of intersex children weren't mentioned in any of the State Reports. However, this NGO Report submitted to the Committee demonstrates that the current medical treatment of intersex infants and children in Switzerland constitutes a breach of Switzerland's obligations under the Convention on the Rights of the Child. Swiss doctors are performing non-consensual, irreversible, unnecessary cosmetic genital surgeries, forced excessive genital examinations, human experimentation, and other harmful medical treatments on intersex infants and adolescents, which have been described by persons concerned as genital mutilations, and as a form of child sexual abuse, causing lifelong physical and psychological pain and suffering, and recognised by UN and other human rights and ethics bodies as constituting at least cruel, inhumane or degrading treatment, or even torture. What's more, Swiss doctors have been at the heart of the global implementation of these systematic human rights violations from year one, and the Swiss State not only does nothing to prevent this continued abuse, but in fact colludes to keep it hidden from public view and legal scrutiny, and keeps providing public funds for these acts, thus violating its duty to protect intersex children (Art. 3, 12, 16, 19, 24, 34, 36, and 37). What's more, intersex children are singled out for these treatments (Art. 2), which are designed to change their bodies as well as their identities (Art. 8). In addition, the treatments include selective abortions, preimplantation genetic diagnosis and prenatal therapy to eliminate intersex children (Art. 6), and in fact leave many children disabled and without appropriate care, same as some intersex children born with disabilities (Art. 23).

This report has been prepared by the Swiss NGO *Zwischengeschlecht.org* in collaboration with Swiss peer support groups *Intersex.ch* and *SI Selbsthilfe Intersexualität*. *Zwischengeschlecht.org*, founded in 2007, is an international Human Rights NGO based in Switzerland, lead by intersex persons, their partners, families and friends, and works to represent the interests of intersex people and their relatives, raise awareness, and fight IGMs and other human rights violations perpetrated on intersex people, according to their motto, "*Human Rights for Hermaphrodites, too!*"¹ *Intersex.ch* is a Swiss intersex peer support group founded in 2005.² The Verein *SI Selbsthilfe Intersexualität* is a Swiss peer support group for parents of intersex children founded in 2003.³

This Report includes six anonymised case studies of intersex persons, spanning the whole period of systematic genital surgeries on intersex children. The stories were obtained from the persons concerned or their parents, their identity being known to *Intersex.ch* and *SI Selbsthilfe Intersexualität*. Each first-person narrative is preceded with a standardised abstract composed by the Rapporteurs. The small number of case studies is due to the fact that many patients, their families, and parents find it hard to speak about what happened to them, and do not wish their story to become public, even anonymously. These cases, however, show in an exemplary manner that surgeries on intersex children is not just a thing of the past, but still happen in Swiss hospitals today with hardly any change over decades, often without disclosing sufficient information both on the surgery and its alternatives, without consent by the persons concerned and/or their parents, and often without an established diagnosis. All patients who were submitted to cosmetic genital surgeries report problems as a result of the procedures performed on them, both physical and psychological.

1 <http://zwischengeschlecht.org/>, English pages: <http://StopIGM.org/>

2 <http://intersex.ch/>

3 <http://si-global.ch/>

Intersex Genital Mutilations are a special and emerging human rights issue, unfortunately still often neglected by human rights bodies concerned, mostly due to lack of access to comprehensive information. However, to assess the current practice at national level, it is crucial to gain some general knowledge of the most pressing human rights violations faced by intersex people in Switzerland as well as all over the “developed world.” Therefore, this NGO report includes some summarised general information on intersex and IGMs. For further reference, and to facilitate access to more comprehensive information for the Committee, the Rapporteurs attached thematic Supplements.

The Rapporteurs are aware that IGMs are a global issue, which can’t be solved on a national level alone. However, this report illustrates why Switzerland would be a most appropriate place to begin with.

A. What is Intersex?

1. Variations of Sex Anatomy

Intersex persons, also known as hermaphrodites, or persons with Differences of Sex Development (DSD) (see **p. 12 “Terminology”**), are people born with “atypical” sex anatomies (or “atypical” reproductive anatomies), or variations of sex anatomy, including

a) “ambiguous genitalia”, e.g. “enlarged” clitoris, fused labia (Congenital Adrenal Hyperplasia CAH), absence of vagina (vaginal agenesis, or Mayer-Rokitansky-Küster-Hauser syndrome MRKH), urethral opening not on the tip of the penis, but somewhere below on the underside of the penis (hypospadias), unusually small penis or micropenis (e.g. Androgen Insensitivity Syndrome AIS), breast development in males (gynaecomastia); and/or

b) atypical hormone producing organs, or atypical hormonal response, e.g. a mix of ovarian and testicular tissue in gonads (ovotestes, “True Hermaphroditism”), the adrenal gland of the kidneys (partly) producing testosterone instead of cortisol (Congenital Adrenal Hyperplasia CAH), low response to testosterone (Androgen Insensitivity Syndrome AIS), undescended testes (e.g. in Complete Androgen Insensitivity Syndrome CAIS), little active testosterone producing Leydig cells in testes (Leydig Cell Hypoplasia), undifferentiated streak gonads (Gonadal Dysgenesis GD if both gonads are affected, or Mixed Gonadal Dysgenesis MGD with only one streak gonad); and/or

c) atypical genetic make-up, e.g. XXY (Klinefelter Syndrome), X0 (Ullrich Turner Syndrome), different karyotypes in different cells of the same body (mosaicism and chimera).

Variations of sex anatomy include

- “atypical characteristics” **either on one or on more of the above three planes a)–c)**,
- **or**, while individual planes appear “perfectly normal”, **together they “don’t match”**, e.g. a newborn with male exterior genitals but an uterus, ovaries and karyotype XX (some cases of Congenital Adrenal Hyperplasia CAH), or with female exterior genitals but (abdominal) testicles and karyotype XY (Complete Androgen Insensitivity Syndrome CAIS).

While many intersex forms are usually detected at **birth** or earlier during **prenatal testing**, others may only become apparent at **puberty** or **later in life**.

2. Everybody started out as a Hermaphrodite – until the 7th Week of Pregnancy

While on the genetic level (karyotype) sex differentiation happens at conception,⁴ on the gonadal level (sex hormone producing organs, e.g. testes and ovaries) and on the level of genital appearance, sex differentiation begins only at later stages of embryonic development. Until the 7th week of gestation,

- we all had **bipotential gonads** in our bellies,⁵
- we all had **two sets of basic reproductive duct structures** for both an uterus plus uterine tubes, and for spermatic ducts,⁶
- and we all had **“indeterminate genitals”**.^{7,8}

Only between the 7th and the 20th week of gestation,

- the bipotential gonads develop into a) ovaries, b) testicles (which usually later descend into the scrotum),⁹ or c) **a mixture of both** (ovotestes), or **stay undifferentiated** (streak gonads),
- the basic duct structures develop, either a) the Müllerian ducts develop into an uterus plus uterine tubes, while the Wolffian ducts vanish, or b) the Wolffian ducts develop into spermatic ducts, while the Müllerian ducts vanish,¹⁰ or c) **something of both**,
- the “indifferent genitals” develop into a) clitoris, labia and vagina, or b) penis and scrotum,¹¹ or c) **something in-between**.¹²

If an intersex child is born with in-between genitals and/or other variations of sex anatomy, that is because something happened prenatally to make her or his development happen along a less common sex development pathway, e.g. due to unusual level of certain hormones, or an unusually high or low ability to respond to them.

4 For an excellent online animation explaining **genetic sex differentiation** see <http://www.aboutkidshealth.ca/En/HowTheBodyWorks/SexDevelopmentAnOverview/SexualDifferentiation/Pages/ChromosomalSex.aspx>

5 For an excellent online animation showing how **gonadal development** happens before birth in children see <http://www.aboutkidshealth.ca/En/HowTheBodyWorks/SexDevelopmentAnOverview/SexualDifferentiation/Pages/DuctDifferentiation.aspx>

6 *ibid.* **Müllerian ducts** and **Wolffian ducts**

7 For an excellent online animation showing how **genital development** happens after the 7th week of gestation, see <http://www.aboutkidshealth.ca/En/HowTheBodyWorks/SexDevelopmentAnOverview/SexualDifferentiation/GenitalDevelopment/Pages/default.aspx>

8 Male and female genitals are both built out of the same basic parts (**Genital Homologues**). There is an excellent online animation comparison at <http://www.aboutkidshealth.ca/En/HowTheBodyWorks/SexDevelopmentAnOverview/SexualDifferentiation/GenitalDevelopment/Pages/GenitalHomologues.aspx>

9 see above footnote 5

10 see above footnote 5

11 see above footnote 7

12 In-between genitals are usually described by medicine using the Prader Scale or Hypospadias Stages:

For an excellent online animation explaining the **Prader Scale**, see <http://www.aboutkidshealth.ca/En/HowTheBodyWorks/SexDevelopmentAnOverview/CongenitalAdrenalHyperplasiaCAH/Pages/ThePraderScale.aspx>

For an excellent online animation explaining **Hypospadias Stages**, see <http://www.aboutkidshealth.ca/En/HowTheBodyWorks/SexDevelopmentAnOverview/Hypospadias/Pages/ClassificationofHypospadias.aspx>

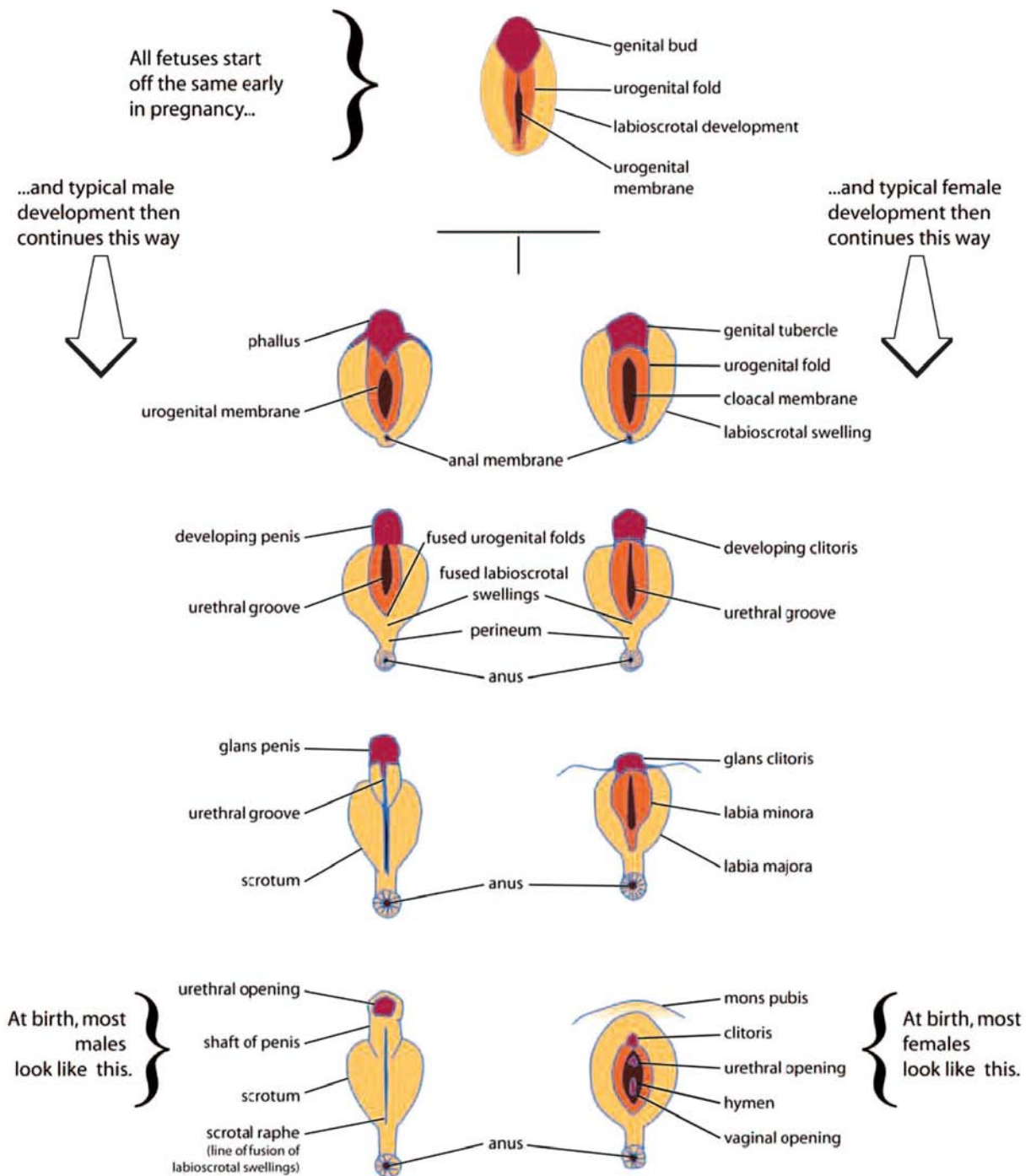


Figure 1 “Genital Development Before Birth”

Source: Accord Alliance (2006), Handbook for Parents, at 72, <http://www.accordalliance.org/dsdguidelines/parents.pdf>

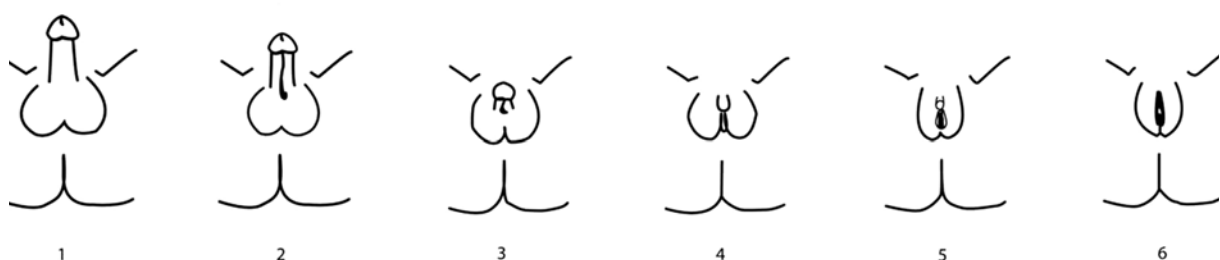


Figure 2 “Genital Variation” (Diagrams 1–6 corresponding to Prader Scale V–0)

Source: Accord Alliance (2006), Handbook for Parents, at 73, <http://www.accordalliance.org/dsdguidelines/parents.pdf>

3. Genital Development and Appearance

Figure 1 “**Genital Development Before Birth**” (p. 9) shows how genitals develop prenatally during gestation. The top image shows how all people start off about seven weeks after conception with the same basic set of reproductive structures. After that point, genitals start to differentiate into a) male-type, b) female-type, or c) in-between types.

The left side of the diagram shows how most males develop (note how the urethral opening only ascends to the tip of the penis during the very last stage via tubularisation of the urethral folds). The right side shows how most females develop. Some intersex children end up with genitals that look something in-between, or with genitals typical to one sex and internal organs typical to the other (see above “Variations of Sex Anatomy”).

Figure 2 “**Genital Variation**” (p. 9) shows some of the ways genitals can look when a child is born. Most boys are born with genitals looking something like the diagram numbered 1. Most girls are born with genitals looking something like the diagram numbered 6.

Some intersex children are born with genitals that look like the other pictures. Children with genitals resembling diagrams 2–3 may be diagnosed as “boys with hypospadias” and submitted to “masculinising hypospadias repair”. Children with genitals resembling diagrams 1–5 may be diagnosed as “girls with an enlarged clitoris” and submitted to “feminising clitoris reduction” and “vaginoplasty”. (Diagrams 1–6 correspond to Prader Scale V–0.)

For further illustration of prenatal genital development, and genital variation, see the excellent online animations referred to in footnotes 4–12.

4. How common is Intersex?

Since Swiss hospitals, government agencies and health assurances, as well as the Swiss federal invalidity assurance (Invalidenversicherung IV) covering intersex surgeries on children until the age of 20,¹³ **refuse to disclose statistics and costs**, there are no exact figures or statistics available (for contradicting figures given by Swiss Cantonal, Federal Governments, as well as Clinics and doctors in **Zurich, Luzern, Bern, Basel, St. Gallen**, see p. 43–44). Also, the definition of intersex is often arbitrarily changed by doctors and government agencies in order to get favourable (i.e. lower) figures. Therefore, all available numbers are mere estimates and extrapolations. Intersex persons and their organisations have been calling for **independent data collection and monitoring** for some time, however to no avail.

An often quoted number is 1:2000 newborns, however this obviously disregards variations of sex anatomy at risk of “masculinising corrections” (hypospadias). **In medical literature**, often two different sets of numbers and definitions are given depending on the objective:

- a) **1:1000** if it’s about getting access to new patients for paediatric genital surgery,¹⁴ and
- b) 1:4500 or less¹⁵ if it’s about countering public concerns regarding human rights violations, often only focusing on “*severe cases*” while refusing to give total numbers. On the other hand,

13 Swiss National Advisory Commission on Biomedical Ethics NEK-CNE (2012), On the management of differences of sex development. Ethical issues relating to “intersexuality”, Opinion No. 20/2012, at 15–17, http://www.bag.admin.ch/nek-cne/04229/04232/index.html?lang=en&download=NHZLpZeg7t,lnp6I0NTU042l2Z6lnladlIZn4Z2qZpnO2Yuq2Z6gpJCKfX96f2ym162epYbg2c_JjKbNoKSn6A--

14 Rainer Finke, Sven-Olaf Höhne (eds.) (2008), *Intersexualität bei Kindern*, Preface, at 4

15 e.g. “*fewer than 2 out of every 10,000 births*”, Leonard Sax (2002), How common is intersex? a response to Anne Fausto-Sterling, *The Journal of Sex Research* 39(3):174-178, at 178

researchers with an interest in criticising the gender binary often give numbers of up to “as high as 2%”.¹⁶

However, from a **human rights perspective**, the crucial question remains: How many children are at risk of human rights violations, e.g. by non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries or other similar treatments justified by a psychosocial indication? Here, the best known relevant number is **1:500 – 1:1000 children are submitted to (often repeated) non-consensual “genital corrections”**.¹⁷

5. Intersex is NOT THE SAME as LGBT

Unfortunately, there are several **harmful misconceptions about intersex** still prevailing in public, some of which are LGBT-related, e.g. if intersex, and/or intersex status, are represented as a sexual orientation (like gay or lesbian), and/or as a gender identity, as a subset of transgender, as the same as transsexuality,¹⁸ or as a strange, peculiar form of sexual preferences.

The underlying reasons for such misconceptions include **lack of public awareness** of the situation of real-life intersex persons and the real-life problems they’re facing, as well as – often despite best intentions – a long **history of (political) appropriation of intersex** going back to the 19th century, including often leading LGBT proponents, scholarly authorities and/or interest groups instrumentalising intersex as a means to an end for their own agenda, and/or presenting themselves as intersex and speaking publicly for intersex people.

While some intersex persons position themselves within an LGBT context and many intersex organisations collaborate with LGBT groups on an equal footing to address e.g. discrimination issues, **intersex persons and their organisations**, as well as their allies, again and again have **spoken out clearly against instrumentalising intersex issues as a means for other ends**,¹⁹ maintaining that intersex stands for distinct and unique physical variations, and intersex status is *not* about gender identity or sexual orientation.

16 Melanie Blackless, Anthony Charuvastra, Amanda Derryck, Anne Fausto-Sterling, Karl Lauzanne, Ellen Lee (2000), How sexually dimorphic are we? Review and synthesis, *American Journal of Human Biology* 12:151-166.

17 Intersex Society of North America (ISNA), How common is intersex?, <http://www.isna.org/faq/frequency>

18 E.g. the **Swiss Federal Government** in 2011 consistently described intersex as “**True and Untrue Transsexualism**”, e.g. 11.3286, http://www.parlament.ch/d/suche/seiten/geschaeft.aspx?gesch_id=20113286 (see p. 46, **Annexe 2 “Swiss Government on IGMs”**)

19 • Raven Kaldera (2001), Dangerous Intersections: Intersex and Transgender Differences, <http://www.ravenkaldera.org/gender-archive/intersection/dangerous-intersections.html>

• Emi Koyama, Lisa Weasel (2002), From Social Construction to Social Justice: Transforming How We Teach About Intersexuality, *Women’s Studies Quarterly* 30(3-4), <http://www.ipdx.org/pdf/wsqr-intersex.pdf>

• Chris Somers (2002), The appropriation of the Intersexed, dAISy, AIS Support Group Australia’s Newsletter, Issue Sept 2002:20, <http://www.aissga.org.au/daisy/dAISy%20Sept02.pdf>

• Georg Klauda (2002), Fürsorgliche Belagerung. Über die Verstümmelung von Hermaphroditen, *Out of Dahlem* 1, <http://web.archive.org/web/20070603233246/http://gigi.x-berg.de/texte/belagerung>

• Morgan Holmes, in: Cindra Feuer (2005), Is there an I in LGBT?, *Pride* 05:63-64, at 64, http://stop.genitalverstuemmelung.org/public/Pride05_Feuer_Is-there-an-I-in-LGBT_web.pdf

• Joke Janssen (2006/2009), Theoretisch intersektuell. Wie intersexuelle Menschen zwischen den Zeilen bleiben, in: AG Queer Studies (eds.): *Verqueerte Verhältnisse. Intersektionale, ökonomische*

Although intersex children born with variations of sex anatomy may face several problems, in the “developed world” the most pressing are the ongoing Intersex Genital Mutilations, which present a distinct and unique issue constituting **significant human rights violations**, which are different from those faced by the LGBT community. Therefore human rights violations of intersex people can’t be addressed properly by framing and addressing them as LGBT issues, but need to be adequately addressed in a separate section as **specific intersex issues**.²⁰

6. Terminology

There is no terminology universally accepted by all persons concerned. All current terms were or are used by medicine in connection with non-consensual, medically not necessary “genital corrections”, and as insult or verbal abuse in society, and as underpinnings of popular preconceptions, and have other (personal) negative connotations – but all have also been (re-)claimed by persons concerned and their organisations.

While **“Intersex”** remains the term most frequently used by persons concerned, especially human rights related, in public it may still lead to misconceptions, e.g. “intersex is a sexual orientation” (see above). While **“Hermaphrodite”** is considered as derogatory by some persons concerned, and in public may lead to misconceptions related to the ancient mythic notion of intersex persons “having both sets of genitals and being able to impregnate themselves,” it remains the term most frequently used by the public, and may be used to dispel misconceptions of intersex as a sexual orientation, or sexual preference. The current medical term “Disorders of Sex Development” – mostly referred to by the acronym **“DSD”** – was introduced in 2005. While **“disorders” was unequivocally abhorred** within the community,²¹ some reforms in taxonomy and guidelines were welcomed, and **“DSD” spelled out as “Differences of Sex Development”** remains in use by persons concerned and their organisations (see **Supplement 3 “Historical Overview”, p. 61**).

Words are important, words can hurt – however, more important than a wrong word is the continuous regard – or disregard – of the human rights and dignity of the children concerned.

mickritische und strategische Interventionen, at 165-184f

- Gabriele Dietze (2006), Schnittpunkte. Gender Studies und Hermaphroditismus, in: Gabriele Dietze, Sabine Hark (eds.): Genderkontroversen. Genealogie und Grenzen einer Kategorie, 46-68, at 56
- Zwischengeschlecht.info (2007), Die Rede von der “psychischen Intersexualität”, <http://blog.zwischengeschlecht.info/post/2007/12/11/Die-Rede-von-der-psychischen-Intersexualitat>
- Natasha Jiménez, Mauro Cabral (2009), Con voz propia. Conversación con Natasha Jiménez, in: Mauro Cabral (ed.) (2009), Interdicciones. Escrituras de la intersexualidad en castellano, 123-130, at 128, <http://www.mulabi.org/Interdicciones2.pdf>
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- Public Statement by the Third International Intersex Forum (2013), <http://ilga.org/ilga/en/article/op4kdORISR>
- OII Australia (2014), NSW Registrar of Births, Deaths and Marriages v. Norrie: implications for intersex people, <http://oii.org.au/wp-content/uploads/2014/01/OII-Aus-NSW-v-Norrie-High-Court.pdf>

20 Zwischengeschlecht.org, Advocates for Informed Choice (AIC) (2013), CONCERNS Re: Intersex Genital Mutilation, Joint Statement for UN Special Rapporteur on Torture, 05.03.2013, http://zwischengeschlecht.org/public/Zwischengeschlecht_AIC_SRT-meeting.pdf

21 Peter Trinkl (2006), I Am Neither “Pseudo” nor “Disordered”, in: Proceedings of the ISNA/GLMA DSD Symposium: 48-49, http://www.isna.org/files/DSD_Symposium_Proceedings.pdf

B. IGMs / Non-Consensual, Unnecessary Medical Interventions

1. What are Intersex Genital Mutilations (IGMs)?

Intersex Genital Mutilations include non-consensual,²² medically unnecessary,^{23 24} irreversible,²⁵ cosmetic²⁶ genital surgeries, and/or other similar medical treatments, including imposition of hormones, performed on children with variations of sex anatomy, without evidence of benefit for the children concerned,^{27 28} but justified by “*psychosocial indications [...] shaped by the clinician’s own values*”,²⁹ the latter informed by societal and cultural norms and beliefs,^{30 31} enabling clinicians to withhold crucial information from both patients and parents,^{32 33} and to submit healthy intersex children to risky and harmful invasive procedures “*simply because their bodies did not fit social norms*”.³⁴

- 22 **UN SRT (2013)**, A/HRC/22/53, at para 77: “*Children who are born with atypical sex characteristics are often subject to [...] involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents*”, http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf
On why parents actually *can’t* legally consent to medically unnecessary cosmetic genital surgeries on their healthy children, see **p. 22, Article 3: “Best Interest”**.
- 23 Council of Europe (2013), Resolution 1952 (2013), at 2 (7.5.3.): “*unnecessary medical or surgical treatment that is cosmetic rather than vital for health*”, <http://www.assembly.coe.int/nw/xml/XRef/X2H-Xref-ViewPDF.asp?FileID=20174&lang=en>
- 24 Jörg Woweries (2010), Intersexualität: Eine kinderrechtliche Perspektive, frühe Kindheit 0310: 18-22, at 20-21, http://kastrationsspital.ch/public/fK_0310_Woweries.pdf
- 25 “*2. The surgery is irreversible. Tissue removed from the clitoris can never be restored; scarring produced by surgery can never be undone.*” Intersex Society of North America (ISNA) (1998), ISNA’s Amicus Brief to the Constitutional Court of Colombia, <http://www.isna.org/node/97>
- 26 “*It is generally felt that surgery that is performed for cosmetic reasons in the first year of life relieves parental distress and improves attachment between the child and the parents [48–51]; the systematic evidence for this belief is lacking.*” Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes, LWPES/ESPE Consensus Group (2006), **Consensus statement on management of intersex disorders**, Pediatrics 118:e488-e500, at e491, <http://pediatrics.aappublications.org/content/118/2/e488.full.pdf>
- 27 “*The final ethical problem was the near total lack of evidence—indeed, a near total lack of interest in evidence—that the concealment system was producing the good results intended.*” Alice Domurat Dreger (2006), Intersex and Human Rights: The Long View, in: Sharon Sytsma (ed.) (2006), Ethics and Intersex: 73-86, at 75
- 28 Jörg Woweries (2010), Intersexualität: Eine kinderrechtliche Perspektive, frühe Kindheit 0310: 18-22, at 21, http://kastrationsspital.ch/public/fK_0310_Woweries.pdf
- 29 Swiss National Advisory Commission on Biomedical Ethics NEK-CNE (2012), On the management of differences of sex development. Ethical issues relating to “intersexuality”, Opinion No. 20/2012, at 16 (footn. 18), http://www.bag.admin.ch/nek-cne/04229/04232/index.html?lang=en&download=NHZLpZeg7t,lnp6I0NTU042l2Z6lnladlIZn4Z2qZpnO2Yuq2Z6gpJCkfX96f2ym162epYbg2c_JjKbNoKS6A--
- 30 *ibid.*, at 18 and 15.
- 31 “*sociological and ideological reasons*”, WHO Genomic Resource Centre, Genetic Components of Sex and Gender, <http://www.who.int/genomics/gender/en/index1.html>
- 32 “*In cases of intersex clinicians were intentionally withholding and misrepresenting critical medical information.*” Alice Domurat Dreger (2006), Intersex and Human Rights: The Long View, in: Sharon Sytsma (ed.) (2006), Ethics and Intersex: 73-86, at 75
- 33 **UN SRT (2013)**, A/HRC/22/53, at para 77, http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf
- 34 Alice Domurat Dreger (2006), Intersex and Human Rights: The Long View, in: Sharon Sytsma (ed.) (2006), Ethics and Intersex: 73-86, at 75

Genital surgery is not necessary for gender assignment, and **atypical genitals are not in themselves a health issue**.³⁵ There are only very few situations where some surgery is necessary for medical reasons, such as to create an opening for urine to exit the body.^{36 37}

In addition to the usual risks of anaesthesia and surgery in infancy, IGMs carry a **large number of known risks of physical and psychological harm**, including loss or impairment of sexual sensation, poorer sexual function, painful scarring, painful intercourse, incontinence, problems with passing urine (e.g. due to urethral stenosis after surgery), increased sexual anxieties, problems with desire, less sexual activity, dissatisfaction with functional and aesthetic results, lifelong trauma and mental suffering, elevated rates of self-harming behaviour and suicidal tendencies comparable to those among women who have experienced physical or (child) sexual abuse, impairment or loss of reproductive capabilities, lifelong dependency on daily doses of artificial hormones.^{38 39}

2. Most Frequent Surgical and Other Harmful Medical Interventions

Due to space limitations, the following paragraphs summarise the most frequent and egregious forms only. **The injuries suffered by intersex people have not yet been adequately documented**.⁴⁰ For a more comprehensive list and sources, see **Supplement 2, p. 63–76**.

a) Clitoris Amputation/“Reduction”, “Vaginoplasty”, Forced Vaginal Dilatation

“I can still remember, how it once felt differently between my legs.” (Case No. 3)

In 19th Century Western Medicine, clitoris amputations a.k.a. **“clitoridectomies”** on girls were prevalent as a “cure” for a) masturbation, b) hysteria, and c) “enlarged clitoris.” While amputations motivated by a) and b) attracted mounting criticism within the medical community and were mostly abandoned between 1900 and 1945, **amputations of “enlarged clitorises” took a sharp rise after 1950**, and in the 1960s became the predominant medical standard for “ambiguous” newborns all over the “developed world,” according to the infamous surgeon’s motto, *“you can dig a hole, but you can’t build a pole”* (p. 63), i.e. it’s surgically possible to remove an “enlarged clitoris” (i.e. longer than 9 mm) or an “inadequately small penis” (i.e. shorter than 2.5 cm), as well as to enlarge an existing “insufficient vagina”, or create an artificial “neo vagina”, but it’s surgically not possible to actually build an “adequate penis”.

35 Anne Tamar-Mattis (2013), Report to the Inter-American Commission on Human Rights: Medical Treatment of People with Intersex Conditions as a Human Rights Violation, at 2, <http://www.aph.gov.au/DocumentStore.ashx?id=432c5135-4336-472e-bb24-59c89eb4a643>

36 *ibid.*, at 3

37 Jörg Woweries (2010), Intersexualität: Eine kinderrechtliche Perspektive, frühe Kindheit 0310: 18–22, at 20, http://kastrationsspital.ch/public/fK_0310_Woweries.pdf

38 Anne Tamar-Mattis (2013), Report to the Inter-American Commission on Human Rights: Medical Treatment of People with Intersex Conditions as a Human Rights Violation, at 2–7, <http://www.aph.gov.au/DocumentStore.ashx?id=432c5135-4336-472e-bb24-59c89eb4a643>

39 Heinz-Jürgen Voß (2012), Intersexualität – Intersex. Eine Intervention, at 50–65

40 Rare examples of publications documenting and reviewing reports by persons concerned include:

- J. David Hester (2006), Intersex and the Rhetorics of Healing, in: Sharon Sytsma (ed.) (2006), *Ethics and Intersex*: 47–72
- Cheryl Chase (1998), Surgical Progress Is Not the Answer to Intersexuality, in: Alice Dreger (ed.) (1999), *Intersex in the Age of Ethics*: 148–159
- Katrina Karkazis (2008), *Fixing Sex: Intersex, Medical Authority, and Lived Experience*
- Kathrin Zehnder (2010), *Zwitter beim Namen nennen. Intersexualität zwischen Pathologie, Selbstbestimmung und leiblicher Erfahrung*
- Claudia Lang (2006), *Intersexualität. Menschen zwischen den Geschlechtern*

For four decades, doctors again and again claimed early clitoris amputation on intersex children would **not interfere with orgasmic function**. Only in the 1980s–1990s, intersex clitoris amputations were eventually replaced by “more modern” techniques a.k.a. **“clitoral reduction”** (p. 78), again claimed to preserve orgasmic function, despite persons concerned reporting loss of sexual sensitivity, and/or painful scars (**Cases No. 2 and 3**) – complaints also corroborated by recent medical studies. Tellingly, a current paediatric surgeon’s joke on the topic of potential loss of sexual sensation goes, *“They won’t know what they’re missing!”*⁴¹

Despite that in infants there’s *no* medical (or other) need for surgically creating a vagina *“big enough for normal penetration”* (**“vaginoplasty”**), but significant risks of complications (e.g. painful scarring, vaginal stenosis), this is nonetheless standard practice. What’s more, in order to prevent “shrinking” and stenosis, the “corrected” (neo) vagina has to be **forcibly dilated** by continuously inserting solid objects (**Case No. 3**), a practice experienced as a form of rape and child sexual abuse by persons concerned, and their parents.

Switzerland has been crucial for the introduction of systematic early clitoris amputations and “vaginoplasty” on intersex children on a global scale (p. 54, 56). Clitoris amputations justified by psychosocial indications were taught in Swiss university paediatric surgery courses as a suitable *“therapy”* for intersex children diagnosed with *“hypertrophic clitoris”* until at least 1975 (p. 87). Despite recent public denials by Swiss doctors, hospitals, and health departments, **systematic early “clitoris reductions”** and **“vaginoplasty”** performed on intersex infants “too young to remember afterwards”, and justified by **psychosocial indications**, are still considered imperative in most **Swiss University Children’s Clinics**. (**Cases No. 2–6.**)

b) Hypospadias “Repair”

“My operated genital is extremely touch-sensitive and hurts very much when I’m aroused.” (**Case No. 1**)

Hypospadias is a medical diagnosis describing a penis with the **urethral opening** (“meatus”, or “pee hole”) **not situated at the tip of the penis**, but somewhere below on the underside, due to incomplete tubularisation of the urethral folds during prenatal formation of the penis (see p. 10 **“Genital Development and Appearance”**). Hypospadias “repair” aims at “relocating” the urethral opening to the tip of the penis. **The penis is sliced open**, and an artificial “urethra” is formed out of the foreskin, or skin grafts (p. 77).

Hypospadias per se does *not* constitute a medical necessity for interventions. The **justification** for early surgeries is **psychosocial**, e.g. to allow for *“sex-typical manner for urination (i.e. standing for males).”* According to a Swiss **“pilot study”**, surgery is *“intended to change the anatomy such that the penis looks normal.”*⁴² The current AWMF guidelines with **Swiss participation** explicitly include *“aestetical-psychological reasons”*.⁴³

Hypospadias “repair” is notorious for high **complication rates of 50%** and more, as well as causing serious medical problems where none had been before (e.g. urethral strictures leading to kidney failure requiring dialysis), and frequent “redo-surgeries”. Tellingly, for more than 30 years, surgeons have been officially referring to “hopeless” cases of repeat failed “repair” surgeries as **“hypospadias cripples”** (i.e. made to a “cripple” by unnecessary surgeries, *not* by the condition!, p. 65, 77), while in medical publications on hypospadias, *“[d]ocumentation on complication rates has declined in the last 10 years”* (p. 66).

41 Personal communication by a doctor attending the 23rd Annual Meeting of ESPU, Zurich 2012

42 Daniel Weber, Verena Schönbucher, Rita Gobet, A. Gerber, MA. Landolt (2009), Is there an ideal age for hypospadias repair? A pilot study, *Journal of Pediatric Urology* 5(5):345–350, at 351

43 Deutsche Gesellschaft für Kinderchirurgie (2002), AWMF-Leitlinie 006/026 Hypospadias, http://www.awmf.org/uploads/tx_szleitlinien/006-026.pdf

For more than 15 years, persons concerned have been criticising **impairment or loss of sexual sensitivity (Case No. 1)**. However, doctors still refuse to even consider these claims, let alone promote appropriate, disinterested long-term outcome studies.

Switzerland was leading in introducing hypospadias surgeries in German language European countries after World War II.⁴⁴ Since the “2nd Hypospadias Boom” in the 1990s, hypospadias “repair” is arguably by far the **most frequent** cosmetic genital surgery done on children with variations of sex anatomy also in Switzerland. In **Swiss University Children’s Hospitals**, systematic hypospadias “repair” within the first 18 months of life is still considered imperative for children concerned and raised as boys (**Cases No. 1 and 6**).

c) Castrations / “Gonadectomies” / Hysterectomies / (Secondary) Sterilisation

“At 2 1/2 months they castrated me, and threw my healthy testicles in the garbage bin.” (Case No. 2)

Intersex children are frequently subjected to treatments that **terminate or permanently reduce their reproductive capacity**. While some intersex people are born infertile, and some retain their fertility after medical treatment, many undergo early removal of viable (and **hormone producing**) gonads (e.g. testes, ovaries, ovotestes) or other reproductive organs (e.g. uterus), leaving them with “*permanent, irreversible infertility and severe mental suffering*”.⁴⁵ When unnecessary sterilising procedures are imposed on children e.g. to address a low or hypothetical risk of cancer, **the fertility of intersex people is not being valued as highly as that of non-intersex people (p. 68)**. What’s more, also in **Switzerland**, persons concerned often have to **pay themselves for adequate Replacement Hormones**. Even some doctors have been criticising unnecessary intersex gonadectomies for decades, e.g. renowned Swiss endocrinologist G. A. Hauser (of MRKH fame), “*The castration of patients without a tumour converts symptomless individuals into invalids suffering from all the unpleasant consequences of castration.*”⁴⁶

For almost two decades, persons concerned have protested unnecessary gonadectomies and other irreversible, potentially sterilising treatments, and denounced **non-factual and psychosocial justifications**, e.g. “*psychological benefit*” to removing “*discordant*” reproductive structures, demanding access to screening for potential low cancer risks instead of preemptive castrations, and urged to remove gonads only in known limited cases with lack of hormone production and actual high cancer risk (e.g. certain forms of 46,XY Gonadal Dysgenesis, see **Table p. 79**). What’s more, psychosocial justifications often reveal underlying racist preconceptions by clinicians (reminiscent of the **racist and eugenic medical views of intersex** predominant during the 1920s–1950s, see **Supplement “Historical Overview”, p. 52**, but which obviously persist), namely the infamous premise, “*We don’t want to breed mutants.*”

Nonetheless, and despite recent discussions in medical circles, **unnecessary gonadectomies** and other sterilising treatments persist in most **Swiss University Children’s Hospitals**. Only a while ago, in a Swiss Cantonal Children’s Hospital, when the Rapporteurs criticised unnecessary gonadectomies, a paediatric surgeon replied: “*Well, if a CAIS person is living as female, what do they need their testes for anyway?*” (**Cases No. 2, 4 and 6**.)

44 E.g. Ernst Bilke, born 1958 in South Germany, was sent to Basel for paediatric hypospadias “repair”, because the local German doctors refused to do it, wanting to make him into a girl instead, see Ulla Fröhling (2003), *Leben zwischen den Geschlechtern*, at 90–105

45 **UN SRT (2013)**, A/HRC/22/53, at para 77, http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

46 Georges André Hauser (1963), Testicular feminization, in: Claus Overzier (ed.) (1963), *Intersexuality*:255–276, relevant excerpts http://kastrationsspital.ch/public/Intersex_CAIS_Castration_1961_1963.pdf (original German edition 1961)

d) Systematic Misinformation, “Code of Silence”, Lack of Informed Consent

Systematic misinformation, refusal of access to peer support, and **directive counselling** by doctors frequently prevent parents from learning about options for postponing permanent interventions, which has been criticised by persons concerned and their parents for two decades (**Cases No. 2–6**), seconded by bioethicists, and corroborated by studies, including a **recent exploratory study from Switzerland** (p. 71).

Nonetheless, in **Switzerland** it’s still paediatricians, endocrinologists and surgeons managing diagnostics and counselling of parents literally from “*day one*.”⁴⁷ Parents often complain that they only get access to psychological counselling if they consent to “corrective surgery” first, while doctors openly admit seeking early surgeries to **facilitate compliance**, e.g. referring to “*easier management when the patient is still in diapers*” (p. 72).

Intersex children are systematically lied to and refused access to peer support in order to keep them in the dark about being born intersex, and, if ever told at all, are **sworn to secrecy**, e.g. “*You are a rarity, will never meet another like yourself and should never talk about it to no one*” (p. 72), severely compounding shame, isolation and psychological trauma in the aftermath of IGMs. (**Cases No. 1–3**.)

e) Other Unnecessary and Harmful Medical Interventions and Treatments

“The assistant called in some colleagues to inspect and to touch my genitals as well.” (**Case No. 3**)

Other harmful treatments include Forced Mastectomy (p. 70), Imposition of Hormones (p. 70), Forced Excessive Genital Exams, Medical Display and (Genital) Photography (p. 73), Human Experimentation (p. 74), Denial of Needed Health Care (p. 75), Prenatal “Therapy” (p. 75), Selective (Late Term) Abortions (p. 76), Preimplantation Genetic Diagnosis (PGD) to Eliminate Intersex Fetuses (p. 76). (See also **Cases No. 2–6**.)

3. How Common are Intersex Genital Mutilations?

Same as with intersex births (see above **A 4.**, p. 10), Swiss Hospitals, Government Agencies and Health Assurances, as well as the **Swiss federal invalidity assurance (Invalidenversicherung IV)** covering intersex surgeries on children until the age of 20, **refuse to disclose statistics and costs**, as well as ignoring repeated calls for **independent data collection and monitoring** (see below **B 5.**, p. 20).

What’s more, Swiss doctors, government and other institutions involved in IGMs, if questioned about statistics, are notorious for going to extreme lengths following internationally established patterns of **a) disclosing only tiniest fractions** of actual treatments, often **arbitrarily changing definitions** of intersex and variations of sex anatomies in order to justify favourable (i.e. lower) figures (**Swiss Federal Government, Zurich, Luzern, Basel**, see p. 43–47), or **b) flatly denying any occurrence or knowledge** of IGMs, while at the same time the same doctors and hospitals, including such under the auspices of said departments, are continuing to publicly promote and perform IGM (**Bern**, see p. 43–44). Or, in the rare cases of studies actually “disclosing” numbers, yet another related tactic involves **c) manipulation of statistics**, e.g. the world’s largest outcome study on 439 participants, with **Swiss participation**, the 2008 “**Netzwerk DSD**” intersex study, in official publications only gave an overall total figure of “*almost 81% of all participants had at least once surgery [...] most of them before entering school*.”⁴⁸

47 e.g. Eastern Switzerland Children’s Hospital St. Gallen (2014), Zwischen den Geschlechtern, slide 8, http://www.kispisg.ch/downloads/cms/09_vortrag_zwischen_den_geschlechtern_2.pdf

48 Eva Kleinemeier, Martina Jürgensen (2008), Erste Ergebnisse der Klinischen Evaluationsstudie

Operationen nach Altersgruppen:

	keine OP	1 OP	2 OPs	>2 OPs
Kinder 0-3 J.:	42 %	34 %	12 %	7 %
Kinder 4-12 J.:	13 %	47 %	19 %	17 %
Jugendliche:	9 %	50 %	17 %	20 %
Erwachsene:	10 %	32 %	24 %	24 %

Figure 3 “Surgeries by Age Groups” (No Surgery, 1 Surgery, 2 Surgeries, >2 Surgeries, Children 0–3 Years, Children 4–12 Years, Adolescents, Adults)

Source: Martina Jürgensen: “Klinische Evaluationsstudie im Netzwerk DSD/Intersexualität: Zentrale Ergebnisse”, Presentation 27.05.2009, Slide 6, http://kastrationsspital.ch/public/Corpus-delicti_27-5-09.pdf

However, the most significant numbers on intersex children submitted to IGMs available stem from a semi-official 2009 presentation of the same “**Netzwerk DSD**” intersex study with participation of **Swiss Cantonal Clinics (Bern and St. Gallen)**,⁴⁹ revealing that, contrary to declarations by doctors as well as cantonal and federal governments (see **p. 43–47**), in the most relevant **age groups of 4+ years, 87%–91%** have been submitted to IGMs at least once, with increasing numbers of repeat surgeries the older the children get (see **Figure 3** above – note, how the table conveniently stops at “>2” surgeries, though especially with “hypospadias repair”, **a dozen or more repeat surgeries** are not uncommon).

Considering about 82’000 live births annually in Switzerland, and using the estimate of 1:500–1:1000 children born with variations of sex anatomy (see above **A 4., p. 10**), this sums up to about **annually 82–164 intersex births**, and about **74–148 initial cosmetic genital surgeries on intersex children** in Switzerland.

In contrast, the **Swiss Federal Government** claims annually 1–2 intersex births on the national level, and on average 30 intersex children aged 0–20 years, as well as total estimate of 100–200 intersex people living in Switzerland (**p. 46**). The **Zurich University Children’s Hospital** serving “20-25% of the Swiss population” claims on average 1 cosmetic genital surgery on children with variations of sex anatomy every year – while unofficially performing 1–2 “hypospadias corrections” *every week* alone (**p. 43**). The **Luzern Cantonal Children’s Hospital** serving “about 10% of the Swiss population” also claims on average 1 cosmetic genital surgery on children with variations of sex anatomy every year – while its chief surgeon publicly boasts of 50 intersex surgeries in 30 years (**p. 43**). The **Bern University Children’s Hospital “Insel”** claims zero surgeries annually on an estimated “about 40 children with DSD born annually” – while leading doctors publicly admit surgeries taking place (**p. 43**). The **University Children’s Hospital of Basel (UKBB)** claims annually about 22 children born with variations of sex anatomy in the region, while only admitting to 1 genital surgery on intersex children “in the more strict definition” every 5 years (**p. 44**). And the **Eastern Switzerland Children’s Hospital** claims “less than one clitoral reduction plastic surgery annually (using the nerve-sparing method),” again without disclosure of other cosmetic genital surgeries (**p. 44**). Conclusion, while all listed parties closely follow the established patterns of non-disclosure and denial, their differing claims don’t add up by far (**Annexe 2 “Swiss Government on IGMs”**).

im Netzwerk Störungen der Geschlechtsentwicklung/Intersexualität in Deutschland, Österreich und Schweiz, Januar 2005 bis Dezember 2007, at 16, http://www.netzwerk-dsd.uk-sh.de/fileadmin/documents/netzwerk/evalstudie/Bericht_Klinische_Evaluationsstudie.pdf

49 <http://www.netzwerk-dsd.uk-sh.de/index.php?id=28>

What's more, though for Switzerland officially no current figures are available, internationally the **total number** of cosmetic genital surgeries performed on intersex children evidentially **is still rising**.^{50 51}

4. Lack of Disinterested Review, Analysis, Outcome Studies and Research

Persons concerned and their organisations have stressed for almost two decades “*the unreliability of research conducted in the setting where the harm was done*”,⁵² and stressed the imminent need for **disinterested** research and analysis (see also p. 74).

Currently, millions of Euros are spent on “intersex research projects” involving **Swiss funding**⁵³ and/or **participation**,⁵⁴ as well as **Swiss Federal Government representation**.⁵⁵

“DSD-Life” and “DSDnet”, two current examples, are **conducted by the perpetrators themselves**, e.g. in “DSDnet” paediatric endocrinologists,⁵⁶ and in “DSD-Life” paediatric endocrinologists and paediatric surgeons⁵⁷ taking the lead – exactly the professional groups responsible for IGMs in the first place. If other disciplines are included at all in the “multi-disciplinary teams,” like e.g. psychology or bioethics, let alone persons concerned, they only play a secondary role, and are only included at a later stage, and especially persons concerned serve mostly to recruit participants – same as in the precursor projects “Netzwerk DSD” and “EuroDSD”.

What's more, all of these “research projects” continue to openly advocate IGMs,⁵⁸ as well as to promote the usual psychosocial and non-factual justifications, e.g. “DSDnet” (with **Swiss funding, Swiss participation, and Swiss Government Representation**, see above).

50 e.g. “*The UK National Health Services Hospital Episode Statistics in fact shows an **increase in the number of operations on the clitoris in under-14s since 2006***”, Sarah M. Creighton, Lina Michala, Imran Mushtaq, Michal Yaron (2014), Childhood surgery for ambiguous genitalia: glimpses of practice changes or more of the same?, Psychology & Sexuality 5(1):34-43, at 38

51 e.g. Italy: “**Boom in Surgeries on Children with ‘Indeterminate’ Sex, in Rome 50% Increase during the Last 5 Years, 25% Increase on National Level**”, according to Aldo Morrone, Director General of the Ospedale San Camillo-Forlanini di Roma, quoted in: “*Boom di bimbi con sesso ‘incerto’, a Roma un aumento del 50 per cento*”, leggo.it 20.06.2013, <http://www.leggo.it/NEWS/ITALIA/boom-di-bimbi-con-sesso-quot-incerto-quot-a-roma-aumentano-del-50-per-cento/notizie/294638.shtml>

52 Tiger Howard Devore (1996), Endless Calls for “More Research” as Harmful Interventions Continue, Hermaphrodites With Attitude, Fall/Winter 1996:2, <http://www.isna.org/files/hwa/winter1996.pdf> (emphasis in original)

53 <http://www.fp7peoplenetwork.eu/200811214/fp7/fp7-the-7th-framework-programme-of-the-european-union-for-research-and-development.html>

54 e.g. “DSDnet”: **Bern, Lausanne**, http://www.cost.eu/domains_actions/bmbs/Actions/BM1303?management

“Netzwerk DSD”: **Bern, St. Gallen**, <http://www.netzwerk-dsd.uk-sh.de/index.php?id=28>

55 http://www.cost.eu/about_cost/who/%28type%29/5/%28wid%29/1438

56 http://www.cost.eu/domains_actions/bmbs/Actions/BM1303?management

57 <http://www.dsd-life.eu/the-group/consortium/>, for a more accessible graphic overview of the consortium see: <http://stop.genitalmutilation.org/post/IGM-Primer-2-The-Global-Cartel>

58 E.g. “*Children with DSD may be born with genitalia that range from being atypical to truly ambiguous and the sex assignment process may be extremely challenging for families and health care professionals. Often, **multiple surgical interventions are performed for genital reconstruction to a male or female appearance. The gonads are often removed to avoid malignant development.***” “DSDnet” (2013), Memorandum of Understanding, at 4, http://w3.cost.eu/fileadmin/domain_files/BMBS/Action_BM1303/mou/BM1303-e.pdf

5. Lack of Independent Data Collection and Monitoring

With no statistics available on intersex births, let alone surgeries and costs, and perpetrators, governments and health departments obviously consistently colluding to keep it that way as long as anyhow possible, persons concerned as well as civil society **lack possibilities to effectually highlight and monitor** the ongoing mutilations. What's more, after realising how intersex genital surgeries are increasingly in the focus of public scrutiny and debate, perpetrators of IGMs respond by suppressing complication rates (see e.g. p. 15 “**Hypospadias Repair**”), as well as refusing to talk to journalists “on record”.⁵⁹

6. Urgent Need for Legislation to Ensure an End to IGMs

For more than two decades, persons concerned and sympathetic clinicians and academics have tried to reason with the perpetrators, and for 18 years they've been lobbying for legal measures, approaching governments as well as national and international ethics and human rights bodies year after year after year, calling for **specific legislation** to finally end IGMs.

In 2012, the **Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE)** was the first official body to eventually pay heed to this call and support legal measures, followed by the **Special Rapporteur on Torture (SRT)** and the **Council of Europe (COE)** in 2013. **Swiss paediatric Surgeon Blaise Meyrat**, one of only a handful of paediatric surgeons worldwide refusing to do unnecessary surgeries on intersex children, in 2013 was the first doctor to go on record and frankly admit that in the end only legislation will succeed in ending IGM, “*It's a pity that, because of a lack of ethical clarity in the medical profession, we have to get legislators involved, but in my opinion it's the only solution.*”⁶⁰

C. Civil Registration

As many as 8.5%–20% intersex children will ultimately reject their assigned sex.⁶¹ This not only compounds the problem of the irreversible surgeries, but additionally forces older children or adults to go before a court and counterfactually claim to be transsexual in order to be allowed to amend their sex registration. The **Swiss National Advisory Commission on Biomedical Ethics** therefore proposed in their Recommendation 11: “*In a case of DSD, it must be possible for the sex recorded in the official registration of births to be unbureaucratically amended.*”⁶² The **Swiss Federal Government** pledged to implement Recommendation 11.⁶³ However, eventually a communication of the Federal Department for Civil Status states, while parents (and only if supported by a clinician) can amend the civil status unbureaucratically, “*in particular cases even for some years*”, adolescent or adult persons concerned have still to call a court,⁶⁴

59 Personal communication by journalist SRF (Swiss National Radio and TV), 2013

60 Isabelle Eichenberger, (2013), A human right: Third gender fights for recognition, http://www.swissinfo.ch/eng/swiss_news/Third_gender_fights_for_recognition.html?cid=34791620

61 Anne Tamar-Mattis (2013), Report to the Inter-American Commission on Human Rights: Medical Treatment of People with Intersex Conditions as a Human Rights Violation, at 10, <http://www.aph.gov.au/DocumentStore.ashx?id=432c5135-4336-472e-bb24-59c89eb4a643>

62 Swiss National Advisory Commission on Biomedical Ethics NEK-CNE (2012), at 19, [online](#)

63 13.5300 – Heure des questions. Question: Intergenre. Eviter la stigmatisation, Réponse du Conseil fédéral du 16.09.2013, http://www.parlament.ch/F/Suche/Pages/geschaefte.aspx?gesch_id=20135300

64 Eidgenössisches Amt für das Zivilstandswesen (2014), Amtliche Mitteilung Nr. 140.15, Intersexualität: Eintragung und Änderung des Geschlechts und der Vornamen im Personenstandsregister, at 4–5, <http://www.ejpd.admin.ch/content/dam/data/gesellschaft/cazw/weisungen/>

i.e. claim they were transsexual – **exactly, what the Commission called to prevent:** “sparing (already overstrained) parents, or the person of ambiguous sex, the need for court proceedings.”⁶⁵

D. The Treatment of Intersex Persons in Switzerland as a Violation of International Law

“Genital mutilation of intersex children damages genital sensitivity in irreversible ways; it causes post-surgical trauma, and the internalization of brutal prejudices denying or stigmatizing the diversity that in reality human bodies show. [...] The difference in genitalia cannot justify, under any pretext whatsoever, ethical and political hierarchies: cannot justify mutilation, because it never normalizes but does the opposite. For us, mutilation creates a permanent status of human rights violation and inhumanity.”

Mauro Cabral, CESCRO NGO Statement 2004⁶⁶

For 21 years now, intersex people from all over the world, and their organisations have been publicly denouncing IGMs as destructive of sexual sensation, and as a violation of basic human rights, notably the right to physical integrity.⁶⁷ For 18 years, they have lobbied for legislation against IGMs to end the impunity of perpetrators due to statutes of limitation.⁶⁸ For 17 years, they have been invoking the UN Convention on the Rights of the Child to fight IGMs,⁶⁹ and for 10 years they have been reporting IGM to the UN as a human rights violation.⁷⁰ This NGO report marks the 5th time that persons concerned, NGOs and/or a NHRI report IGMs as a relevant issue to the Commission on the Rights of the Child, and the 3rd Swiss NGO report to an UN commission to highlight IGMs (see **Bibliography, p. 30**).

In Switzerland, like in every intersex community, meanwhile several generations of intersex persons, their partners and families, as well as NGOs and other human rights and bioethics experts, have again and again described IGM as a **human rights issue**,⁷¹ as **harmful and traumatising**,⁷² as a **western form of genital mutilation**,⁷³ as **child sexual abuse**,⁷⁴ and have called for **legislation to end it**.⁷⁵ (**Cases No. 1–6**)

[mitteilungen/140-15-d.pdf](#)

65 Swiss National Advisory Commission on Biomedical Ethics NEK-CNE (2012), at 15

66 Mauro Cabral (2004), NGO Statement: Intersexuality, <http://ilga.org/ilga/en/article/61>

67 Cheryl Chase (1993), Letter to The Sciences RE: The Five Sexes, <http://www.isna.org/articles/chase1995a>

68 Cheryl Chase (1996), Female Genital Mutilation in the U.S. Discussion, <https://www.h-net.org/~women/threads/mut.html>

69 Cheryl Chase (1998), ISNA's Amicus Brief on Intersex Genital Surgery, <http://www.isna.org/node/97>

70 Mauro Cabral (2004), NGO Statement: Intersexuality, <http://ilga.org/ilga/en/article/61>

71 Clare O'Dea (2009), Doctors “playing God with children's sex”, swissinfo 26.08.2009, http://www.swissinfo.ch/eng/Home/Archive/Doctors_playing_God_with_childrens_sex.html?cid=981950

72 Nikola Biller-Andorno (2006), Zum Umgang mit Intersex: Gibt es Wege jenseits der Zuordnung des «richtigen Geschlechts»? Schweizerische Ärztezeitung 47:2047-2048, at 2047, <http://www.saez.ch/docs/saez/archiv/de/2006/2006-47/2006-47-283.PDF>

73 Mirjam Werlen (2008), Rechtlicher Schutz für Kinder mit uneindeutigem Geschlecht, in: Michael Groneberg, Kathrin Zehnder (eds.) (2008), «Intersex». Geschlechtsanpassungen zum Wohle des Kindes? Erfahrungen und Analysen: 178–215, at 184

74 Kathrin Zehnder (2010), Zwitter beim Namen nennen. Intersexualität zwischen Pathologie, Selbstbestimmung und leiblicher Erfahrung, at 201

75 Swiss National Advisory Commission on Biomedical Ethics NEK-CNE (2012), On the management of differences of sex development. Ethical issues relating to “intersexuality”, Opinion No. 20/2012, Recommendation 15, at 19, [online](#)

The UN Committees **CEDAW**, **CESCR** and **CAT**, the **UN High Commissioner for Human Rights (UNHCHR)**, the **UN Special Rapporteur on Torture (SRT)**, the **World Health Organisation (WHO)**, the **Council of Europe (COE)**, and last but not least the **Swiss National Advisory Commission on Biomedical Ethics (NEK)** have already recognised the human rights violations perpetrated on intersex children, and demanded legislative measures (**NEK**, **SRT**, **COE**), historical reappraisal, acknowledgement by society of suffering inflicted (**NEK**) and compensation for victims (**NEK**, **CAT**) (see **Bibliography**, p. 28).

1. Switzerland's Commitment to the Protection of the Rights of the Child

By ratifying the **Convention on the Rights of the Child (CRC)**, Switzerland has committed itself to ensuring that no child within its jurisdiction is subject to torture and other cruel, inhuman or degrading treatment or punishment (CIDT), nor to other human rights violations specified in the convention. In addition, Switzerland has ratified the **Convention against Torture (CAT)**, and the **European Convention on Human Rights (ECHR)**, which both prohibit CIDT, as well as the **International Covenant on Civil and Political Rights (ICCPR)** which in its Art. 7 contains a similar clause and explicitly includes freedom from forced medical experiments. Last but not least, the **Swiss Federal Constitution (SFC)**⁷⁶ ensures the right to life and personal freedom, particularly the right to physical and mental integrity, and explicitly prohibits CIDT (Article 10), emphasises the right of special protection of the integrity of children and young people (Art. 11), as well as ensuring the respect for, and the protection of, their dignity (Art. 7), and ensuring equality and non-discrimination (Art. 8).

2. Violated Articles of the Convention

This section will demonstrate that IGMs, including unnecessary, irreversible cosmetic genital surgeries, and other harmful medical treatments referred to above, constitute human rights violations under Articles 2, 3, 6, 8, 12, 16, 19, 23, 24, 34, 36, and 37 of the Convention on the Rights of the Child.

Article 2: Non-Discrimination

On the basis of their “indeterminate sex,” intersex children are singled out for experimental harmful treatments, including surgical “genital corrections” and potentially sterilising procedures, that would be “*considered inhumane*” on “normal” children, by reverting to a “*monster approach*” implying intersex children are “*so grotesque, so pathetic, any medical procedure aimed at normalizing them would be morally justified*”,⁷⁷ so that, according to a specialised surgeon, “*any cutting, no matter how incompetently executed, is a kindness*.”⁷⁸ Clearly, IGMs therefore not only violate Article 2 CRC, but also Articles 8 (protection from discrimination) and 7 (protection of human dignity) of the Swiss Federal Constitution (SFC).⁷⁹

Article 3: Best Interest of the Child

Consideration of best interests must embrace both short- and long-term considerations for the child, must be consistent with the spirit of the entire Convention, and cannot be interpreted

⁷⁶ <http://www.admin.ch/ch/e/rs/1/101.en.pdf>

⁷⁷ Alice Domurat Dreger (2006), Intersex and Human Rights: The Long View, in: Sharon Sytsma (ed.) (2006), *Ethics and Intersex*: 73-86, at 75

⁷⁸ Cheryl Chase (1998), Surgical Progress Is Not the Answer to Intersexuality, in: Alice Dreger (ed.) (1999), *Intersex in the Age of Ethics*: 148-159, at 150

⁷⁹ Mirjam Werlen (2008), Rechtlicher Schutz für Kinder mit uneindeutigem Geschlecht, in: Michael Groneberg, Kathrin Zehnder (eds.) (2008), «Intersex». Geschlechtsanpassungen zum Wohle des Kindes? Erfahrungen und Analysen: 178-215, at 181

tend in an overly culturally relativist way to deny e.g. protection against harmful practices.⁸⁰ The physical and mental suffering caused by IGMs is well-established also in medical literature (see above **B 1.–2.**). Clearly, early “genital corrections” as “*the natural path*” best to be undertaken in the “*first two years of life*” (**p. 43**), justified by notions of e.g. discarding “*abstract ethical and legal perspectives of future adolescents and their title to disposal over their bodies*” in favour of “*the eminent best interest and welfare of the child growing up in his family*,” leading to the conclusion, “*If [...] it appears that a family is not capable of accepting a child with ambiguous genitals, for us it is the better way to perform a medically not urgently indicated surgery, than to expose the child to rejection and ostracism*” (**p. 44**), go directly against Article 3 CRC, as well as violating Article 11 SFC (special protection of children and young people).

Article 6: Children’s Right to Life and Maximum Survival and Development

While after 60 years of systematic IGMs there’s still no evidence of benefits for the children concerned, the physical and mental suffering caused by IGMs is well-established also in medical literature (see above **B 1.–2.**). What’s more, the Preamble to the Convention on the Rights of the Child recalls the provision in the United Nations Declaration of the Rights of the Child that “*the child [...] needs special safeguards and care, [...] before as well as after birth,*” and “[t]he Committee has commented adversely on [...] selective abortions [...]”⁸¹ Therefore, IGMs, including Selective (Late Term) Abortions, as well as Preimplantation Genetic Diagnosis (PGD) to Eliminate Intersex Fetuses, clearly violate Article 6 CRC.

Article 8: Preservation of Identity

As the Swiss National Advisory Commission on Biomedical Ethics has commented, “genital correction” surgery was one part of imposing a gendered identity on an infant.⁸² What’s more, IGMs including deliberately performing “genital corrections” on intersex infants “too young to remember afterwards,” followed by non-disclosure of the body an intersex child was born with, as well as hiding their medical history from them, persist (see above **B 1.–2.**). Therefore, IGMs clearly are in violation of Article 8 CRC.

Article 12: Respect for the Views of the Child

Article 12 asserting the right of the child to express their views freely in all matters affecting the child, and the views of the child being given due weight in accordance with the age and maturity of the child, is a general principle of fundamental importance.⁸³ However, IGMs deliberately create *faits accomplis* before the child is capable of forming his or her own views, as well as actively hindering the children to form and contribute their own views due to deliberately keeping them in the dark (see above **B 1.–2.**).

What’s more, the Swiss Civil Code (ZGB) includes the concept of inalienable “*höchstpersönliche Rechte*” (Article 19c ZGB), variously translated in English as “*highly personal rights*” (NEK-CNE at 12) “*imping[ing] on intimate areas of the child’s life and its identity*” (NEK-CNE at 17), or “*strictly personal rights.*”⁸⁴ According to the Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE), referring to decisions of the Swiss Federal Supreme Court (BGE 114 Ia

80 UNICEF (2007), Implementation Handbook for the Convention on the Rights of the Child, at 38

81 UNICEF (2007), Implementation Handbook for the Convention on the Rights of the Child, at 85

82 Swiss National Advisory Commission on Biomedical Ethics NEK-CNE (2012), On the management of differences of sex development. Ethical issues relating to “intersexuality”, Opinion No. 20/2012, at 8, http://www.bag.admin.ch/nek-cne/04229/04232/index.html?lang=en&download=NHZLpZeg7t,lnp6I0NTU042l2Z6lnladlIZn4Z2qZpnO2Yuq2Z6gpJCKfX96f2ym1l62epYbg2c_JjKbNoKS6A--

83 UNICEF (2007), Implementation Handbook for the Convention on the Rights of the Child, at 149

84 <http://www.admin.ch/opc/en/classified-compilation/19070042/index.html#a19c>

350, 360; BGE 134 II 235 ff),⁸⁵ medically unnecessary “genital corrections” affect the inalienable “höchstpersönliche Rechte”. And according to Swiss legal experts,^{86 87} they do so in an absolute way, in fact legally barring parents from giving valid informed consent to “genital corrections” on behalf of their intersex children, urging legislative measures to ensure protection of the right to participation of the child, as well as of their best interests.⁸⁸ Therefore, IGMs clearly violate Article 12 CRC, and go against CRC General Comment No 12 “*The right of the child to be heard*”,⁸⁹ as well as violating Article 11.2 SFC (children may personally exercise their rights to the extent that their power of judgement allows),⁹⁰ and Article 19c of the Swiss Civil Code (ZGB).

Article 16: Child’s Right to Privacy

Unnecessary, forced excessive genital exams, medical display and (genital) photography (p. 73) and other persisting forms of IGMs clearly violate Article 16 CRC.

Article 23: Rights of Children with Disability

While some intersex children are born with conditions resulting in special needs (e.g. for daily cortisol substitution for salt-wasting CAH), many are made invalids only by IGMs, e.g. by castration in children with (C)AIS, resulting in need for daily hormone doses from the age of puberty on for the rest of their lives, however health assurances refuse to pay for adequate Hormone Replacement Therapy (HRT) with testosterone. What’s more, many children suffer from PTSDs as a result of IGMs and other harmful treatments, but are refused adequate psychological and psychosocial support. Clearly, such treatments violate Article 23 CRC.

Article 24: Child’s Right to Health and Health Services

Article 24.3. CRC calls on states to abolish harmful “traditional practices prejudicial to the health of children”. While the initial point of reference for the term was the example of Female Genital Mutilation/Cutting (FGM/C), the term consciously wasn’t limited to FGM/C, but meant to include all forms of harmful, violent, and/or invasive traditional or customary practices.⁹¹

Intersex persons have early stressed that they experience especially “genital corrections” as

85 Swiss National Advisory Commission on Biomedical Ethics NEK-CNE (2012), On the management of differences of sex development. Ethical issues relating to “intersexuality”, Opinion No. 20/2012, at 12, 17, http://www.bag.admin.ch/nek-cne/04229/04232/index.html?lang=en&download=NHZLpZeg7t,lnp6l0NTU042l2Z6lnladlIZn4Z2qZpnO2Yuq2Z6gpJCKfX96f2ym162epYbg2c_JjKbNoKSn6A--

86 Michelle Cottier (2013), Zivilrechtliche Aspekte der Intersexualität, at 5, <http://www.merh.uzh.ch/veranstaltungen/archiv/intersexualitaet/CottierIntersexualitaet.pdf>

87 Andrea Büchler, quoted in: Tages-Anzeiger 05.02.2008, at 52, <https://web.archive.org/web/20080212022857/http://www.tagesanzeiger.ch/dyn/wissen/medizin/838834.html>

88 Michelle Cottier (2013), Zivilrechtliche Aspekte der Intersexualität, at 8, <http://www.merh.uzh.ch/veranstaltungen/archiv/intersexualitaet/CottierIntersexualitaet.pdf>

89 German Institute for Human Rights (2013), Suggested topics to be taken into account by the Committee on the Rights of the Child, at 4, http://www.institut-fuer-menschenrechte.de/uploads/tx_commerce/GIHR_Suggested_topics_to_be_taken_into_account_for_the_preparation_of_a_list_of_issues_by_the_CRC_on_the_implementation_of_the_Convention_on_the_Rights_of_the_Child_in_Germany.pdf

90 Mirjam Werlen (2008), Rechtlicher Schutz für Kinder mit uneindeutigem Geschlecht, in: Michael Groneberg, Kathrin Zehnder (eds.) (2008), «Intersex». Geschlechtsanpassungen zum Wohle des Kindes? Erfahrungen und Analysen:178–215, at 181

91 UNICEF (2007), Implementation Handbook for the Convention on the Rights of the Child, at 371

mutilitating, and called these interventions Intersex Genital Mutilations (IGMs). In the meantime, also many experts have confirmed the similarities and the comparability of IGMs to FGM/C, stressing how IGMs as a harmful practice are not guided by medical evidence, but by traditional and sociocultural values. What's more, until FGM/C was widely recognised as the fundamental human rights violation that it is, doctors involved in IGMs themselves have freely likened the practices, even defending the latter with the alleged harmlessness of the former (p. 57), and until today continue to justify IGMs with apologetics and objectifications of the victims typically also used to defend FGM/C (p. 44).

In addition, with proven harm afflicted by IGMs, these practices are fundamentally incompatible with the right of the child to the enjoyment of the highest attainable standard of health affirmed in Article 24.1 CRC.

Therefore, IGMs clearly violate Article 24 CRC.

Article 19: Child's Right to Protection from All Forms of Violence

Article 34: Protection from All Forms of Sexual Exploitation of Children

Article 36: Protection from Other Forms of Exploitation

Persons concerned have denounced IGMs in general, and especially “genital corrections,” castrations / “gonadectomies” / hysterectomies / (secondary) sterilisations, human experimentation, forced excessive genital exams, medical display and (genital) photography, and vaginal dilations as physical and psychological violence, exploitation, and as a form of child sexual abuse, the latter has also been acknowledged by leading perpetrators for decades.⁹² Clearly, IGMs are in violation of Articles 19, 34 and 36 CRC.

Article 37: Protection from Torture or other Cruel, Inhuman or Degrading Treatment

The **Special Rapporteur on Torture (SRT)**⁹³ and the **Committee against Torture (CAT)**⁹⁴ already recognised IGMs as serious human rights violations constituting Cruel, Inhuman or Degrading Treatment (CIDT), or even torture. IGMs clearly violate Article 37 CRC, as well as Article 10.3 SFC (prohibition of torture and any other form of CIDT).

92 John Money, Margareth Lamacz (1987), Genital Examination and Exposure Experienced as Nosocomial Sexual Abuse in Childhood, *Journal of Nervous and Mental Disease* 175(12)

93 **UN SRT (2013)**, A/HRC/22/53, at para 77, 76, http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

94 UN CAT (2011), CAT/C/DEU/CO/5, at para 20, http://www2.ohchr.org/english/bodies/cat/docs/co/CAT.C.DEU.CO.5_en.pdf

E. Conclusion: Switzerland is Failing its Obligations towards Intersex Children under the Convention on the Rights of The Child

The surgeries and other harmful treatments intersex people endure in Switzerland cause severe physical and mental pain. Doctors perform the surgery for the discriminatory purpose of making a child fit into societal and cultural norms and beliefs, although there is plenty of evidence on the suffering this causes. The Swiss State is responsible for these violations amounting to CIDT or even torture, committed by publicly funded doctors, cantonal clinics, and universities, relying on money from the federal invalidity assurance (Invalidenversicherung IV), mandatory health insurance, and public grants. Although IGMs are common knowledge, and Swiss authorities have been repeatedly called to action both on cantonal and federal level, Switzerland fails to prevent these grave violations from happening both in public and in private settings, but allows the human rights violations on intersex children and adolescents to continue unhindered.

Switzerland is thus in breach of its obligation to protect intersex children affirmed in Articles 2, 3, 6, 8, 12, 16, 19, 23, 24, 34, 36, and 37 of the Convention on the Rights of the Child.

F. Recommendations

The Rapporteurs respectfully suggest that the Committee recommends the following measures to the Swiss Government with respect to the treatment of intersex children:

- A. To **immediately implement the full range of recommendations** by the Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE) “On the management of differences of sex development. Ethical issues relating to ‘intersexuality’”, beginning with:
 1. Legal review of the liability implications of unlawful interventions in childhood, including the associated limitation periods, and investigations into the applicability of the criminal law regarding assault and genital mutilation (Recommendation 12), including **legislative measures** to ensure the protection of the integrity of intersex children, and **to end cosmetic genital surgeries** justified by psychosocial indications on children who lack capacity (Recommendation 4).
 2. To advance and facilitate the **acknowledgement by society of the suffering** experienced by intersex children, caused by a medical practice guided by traditional sociocultural values incompatible with fundamental human rights (Recommendation 1), including a **historical appraisal of the human rights violations** inflicted on intersex children and youth in society.
 3. To facilitate **disinterested, representative review, analysis, outcome studies and research** on patient satisfaction and on the effectiveness of various treatment methods and surgical procedures (Recommendation 9), in direct collaboration with intersex representatives and organisations.
 4. To ensure that the constitutional principle that no-one is to be subjected to discrimination on grounds of sex also applies to people with intersex status (Recommendation 10), and to **include intersex status in existing anti-discrimination regulations**.
- B. To facilitate and ensure **independent data collection and monitoring** of births of children with variations of sex anatomy, and their medical treatment, in direct consultation with intersex representatives and organisations.
- C. To **compensate victims** of Intersex Genital Mutilations (IGMs) in an appropriate manner.

Bibliography

1. International Bodies Recognising Human Rights Violations of Intersex Children

2006: UN WHO, Genomic resource centre, Gender and Genetics: Genetic Components of Sex and Gender (online)

<http://www.who.int/genomics/gender/en/index1.html>

Gender Assignment of Intersex Infants and Children

Intersex is defined as a congenital anomaly of the reproductive and sexual system. An estimate about the birth prevalence of intersex is difficult to make because there are no concrete parameters to the definition of intersex. The Intersex Initiative, a North-American based organization, estimates that one in 2,000 children, or five children per day in the United States, are born visibly intersex. (36) This estimate sits within range; from genital anomalies, such as hypospadias, with a birth prevalence of around 1:300 to complex genital anomalies in which sex assignment is difficult, with a birth prevalence of about 1:4500. (37) Many intersex children have undergone medical intervention for health reasons as well as for sociological and ideological reasons. An important consideration with respect to sex assignment is the ethics of surgically altering the genitalia of intersex children to “normalize” them.

Clitoral surgery for intersex conditions was promoted by Hugh Hampton Young in the United States in the late 1930s. Subsequently, a standardized intersex management strategy was developed by psychologists at Johns Hopkins University (USA) based on the idea that infants are gender neutral at birth. (38) Minto et al. note that “the theory of psychosexual neutrality at birth has now been replaced by a model of complex interaction between prenatal and postnatal factors that lead to the development of gender and, later, sexual identity”. (39) However, currently in the United States and many Western European countries, the most likely clinical recommendation to the parents of intersex infants is to raise them as females, often involving surgery to feminize the appearance of the genitalia. (40)

Minto et al. conducted a study aiming to assess the effects of feminizing intersex surgery on adult sexual function in individuals with ambiguous genitalia. As part of this study, they noted a number of ethical issues in relation to this surgery, including that:

- *there is no evidence that feminizing genital surgery leads to improved psychosocial outcomes;*
- *feminizing genital surgery cannot guarantee that adult gender identity will develop as female; and that*
- *adult sexual function might be altered by removal of clitoral or phallic tissue. (41)*

2009: UN CEDAW, CEDAW/C/DEU/CO/6, 10 February 2009, para 61–62:

<http://www2.ohchr.org/english/bodies/cedaw/docs/co/CEDAW-C-DEU-CO6.pdf>

Cooperation with non-governmental organizations

61. [...] *The Committee regrets, however, that the call for dialogue by non-governmental organizations of intersexual [...] people has not been favourably entertained by the State party.*

62. *The Committee request the State party to enter into dialogue with non-governmental organizations of intersexual [...] people in order to better understand their claims and to take effective action to protect their human rights.*

Follow-up to concluding observations

67. *The Committee requests the State party to provide, within two years, written information on the steps undertaken to implement the recommendations contained in paragraphs 40 and 62.*

2011: UNHCHR, A/HRC/19/41, 17 November 2011, para 57:

http://www.ohchr.org/Documents/Issues/Discrimination/A.HRC.19.41_English.pdf

“In addition, intersex children, who are born with atypical sex characteristics, are often subjected to discrimination and medically unnecessary surgery, performed without their informed consent, or that of their parents, in an attempt to fix their sex.”

2011: UN CAT, CAT/C/DEU/CO/5, 12 December 2011, para 20:

http://www2.ohchr.org/english/bodies/cat/docs/co/CAT.C.DEU.CO.5_en.pdf

Intersex people

20. *The Committee takes note of the information received during the dialogue that the Ethical Council has undertaken to review the reported practices of routine surgical alterations in children born with sexual organs that are not read-*

ily categorized as male or female, also called intersex persons, with a view to evaluating and possibly changing current practice. However, the Committee remains concerned at cases where gonads have been removed and cosmetic surgeries on reproductive organs have been performed that entail lifelong hormonal medication, without effective, informed consent of the concerned individuals or their legal guardians, where neither investigation, nor measures of redress have been introduced. The Committee remains further concerned at the lack of legal provisions providing redress and compensation in such cases (arts. 2, 10, 12, 14 and 16).

The Committee recommends that the State party:

- (a) Ensure the effective application of legal and medical standards following the best practices of granting informed consent to medical and surgical treatment of intersex people, including full information, orally and in writing, on the suggested treatment, its justification and alternatives;
- (b) Undertake investigation of incidents of surgical and other medical treatment of intersex people without effective consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation;
- (c) Educate and train medical and psychological professionals on the range of sexual, and related biological and physical, diversity; and
- (d) Properly inform patients and their parents of the consequences of unnecessary surgical and other medical interventions for intersex people.

2013: UN SRT, A/HRC/22/53, 1 February 2013, paras 77, 76, 88

http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

77. Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, “in an attempt to fix their sex”, [107] leaving them with permanent, irreversible infertility and causing severe mental suffering.

76. [...] These procedures [genital-normalizing surgeries] are rarely medically necessary,[106] can cause scarring, loss of sexual sensation, pain, incontinence and lifelong depression and have also been criticized as being unscientific, potentially harmful and contributing to stigma (A/HRC/14/20, para. 23). [...]

88. The Special Rapporteur calls upon all States to repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, unethical experimentation, medical display, “reparative therapies” or “conversion therapies”, when enforced or administered without the free and informed consent of the person concerned. He also calls upon them to outlaw forced or coerced sterilization in all circumstances and provide special protection to individuals belonging to marginalized groups.

2013: Council of Europe (COE), Resolution 1952 (2013) “Children’s right to physical integrity”, 1 October 2013, paras 2, 6, 7:

<http://www.assembly.coe.int/nw/xml/XRef/X2H-Xref-ViewPDF.asp?FileID=20174&lang=en>

2. The Parliamentary Assembly is particularly worried about a category of violation of the physical integrity of children, which supporters of the procedures tend to present as beneficial to the children themselves despite clear evidence to the contrary. This includes, amongst others, female genital mutilation, the circumcision of young boys for religious reasons, early childhood medical interventions in the case of intersex children and the submission to or coercion of children into piercings, tattoos or plastic surgery.

6. The Assembly strongly recommends that member States promote further awareness in their societies of the potential risks that some of the above mentioned procedures may have on children’s physical and mental health, and take legislative and policy measures that help reinforce child protection in this context.

7. The Assembly therefore calls on member States to:

7.1. examine the prevalence of different categories of non-medically justified operations and interventions impacting on the physical integrity of children in their respective countries, as well as the specific practices related to them, and to carefully consider them in light of the best interests of the child in order to define specific lines of action for each of them;

7.2. initiate focused awareness-raising measures for each of these categories of violation of the physical integrity of children, to be carried out in the specific contexts where information may best be conveyed to families, such as the medical sector (hospitals and individual practitioners), schools, religious communities or service providers; [...]

7.4. initiate a public debate, including intercultural and interreligious dialogue, aimed at reaching a large consensus on the rights of children to protection against violations of their physical integrity according to human rights standards;

7.5. take the following measures with regard to specific categories of violation of children's physical integrity: [...]

7.5.3. undertake further research to increase knowledge about the specific situation of intersex people, ensure that no-one is subjected to unnecessary medical or surgical treatment that is cosmetic rather than vital for health during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to persons concerned, and provide families with intersex children with adequate counselling and support; [...]

7.7. raise awareness about the need to ensure the participation of children in decisions concerning their physical integrity wherever appropriate and possible, and to adopt specific legal provisions to ensure that certain operations and practices will not be carried out before a child is old enough to be consulted.

2. State Bodies Recognising Human Rights Violations of Intersex Children

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2010: CESCARGERMANY, Intersexuelle Menschen e.V./XY-Frauen

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[CAT_2011.pdf](#)

2012: UPR Switzerland, Swiss NGO Coalition for the UPR, para 18

http://lib.ohchr.org/HRBodies/UPR/Documents/Session14/CH/JS3_UPR_CHE_S14_2012_JointSubmission3_E.pdf

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2012: WHO, Advocates for Informed Choice (AIC), Zwischengeschlecht.org,
2 unpublished submissions for forthcoming WHO Statement on Involuntary Sterilization

2013: UPR Germany, German Institute for Human Rights (GIHR), para 23

http://lib.ohchr.org/HRBodies/UPR/Documents/Session16/DE/GIHR_UPR_DEU_S16_2013_GermanInstituteForHumanRightsE.pdf

- German CRPD ALLIANCE, para 15

http://lib.ohchr.org/HRBodies/UPR/Documents/Session16/DE/js4_upr16_deu_s16_2013_joints submission4_e.pdf

- National Coalition for the Implementation of the UN Convention on the Rights of the Child in Germany (NC), para 4

http://lib.ohchr.org/HRBodies/UPR/Documents/Session16/DE/js5_upr_deu_s16_2013_joints submission5_e.pdf

- Forum Menschenrechte, paras 38, 39, 58

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- National Coalition for the Implementation of the UN Convention on the Rights of the Child in Germany (NC), lines 789–791, 826–828

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+ Hearing

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<http://oii.org.au/24756/intersex-human-rights-panel-meeting-un-human-rights-council/>

2014: CRC Switzerland, Child Rights Network Switzerland, p. 25–26

http://www.netzwerk-kinderrechte.ch/fileadmin/nks/aktuelles/ngo-bericht-UN-ausschuss/NGO_Report_CRC_CRNetworkSwitzerland_English.pdf

5. Swiss Government Documents

See **Annexe 2** “Swiss Cantonal, Federal Governments, and Clinics on IGMs”, p. 43-44, 45-47

Annexe 1 “Case Studies”

The first-person narratives have been collected via the peer support groups Intersex.ch and SI Selbsthilfe Intersexualität. The abstracts were composed by the Rapporteurs. The identity of all persons concerned and/or their parents is known to Intersex.ch and SI Selbsthilfe Intersexualität.

Case Study No. 1

The child was born in 1942 and grew up as a boy. He has a micropenis, one testis is very small, after puberty he had little facial and body hair. Because of his physical characteristics he realised he was different. He spent his entire life looking for answers, but was constantly lied to by parents and doctors. Only a day before his marriage his mother told him, he had had genital surgery shortly after birth, and that intercourse would probably not work. The scar on his penis derives from a hypospadias “repair”. He suffers to this day from painful erections and an extremely touch sensitive genital, which make a sexual life almost impossible. As a child, he was a patient of the eminent paediatrician Heinrich Willi, Zurich University Children’s Hospital. In his seventies, he learned he was intersex and was eventually diagnosed with 46,XY Partial Gonadal Dysgenesis.

The person concerned tells their story:

For 70 years doctors, my parents, and relatives affirmed, that everything was normal. For 70 years I felt that this couldn’t be the truth.

I realised at the age of fourteen, that I was looking different, when for the first time I took a shower with other boys. My classmates laughed at me and called me missy. I didn’t grow a beard like the other boys, and my biceps didn’t develop. In fact I continued paying half price on the bus because I looked much younger for my age. I couldn’t talk to my parents about it, and my doctor just told me that everything was OK and prescribed Vitamin E to stimulate the production of testosterone. But it wasn’t of any use.

I always got along wonderfully with girls, but as soon as they came nearer, I reached my limit. I knew a little about how a man has to put his penis into a woman to make a baby. I looked down on myself and wondered how on earth that should work. However I never felt abnormal for this reason. Sex was a taboo, we hadn’t a clue about what was normal and what wasn’t. That’s why I couldn’t figure out what was wrong with me and how bad it was.

After 30 years of silence and secrecy, my mother told me one day before my wedding, that I had undergone surgery as a baby, and that not everything will be working in the wedding night. But she didn’t want to talk about it. She died two years later, and took the secret to her grave. I will never know what happened after my birth.

My particularity would soon affect my marriage. I have a very small penis. Moreover my operated genital is extremely touch-sensitive and hurts very much when I am aroused. My wife very soon insisted on separated bedrooms. However I was able to father a son with the aid of in vitro fertilisation.

I studied and worked a lot during my life, and was always looking for answers about my difference. I am a scientist, for me something only becomes true when it’s proved. I wanted a proof. There were several doctors in our family and circle of friends. I asked them all one by one, wanted to know, what had been done. Everyone told me: No, everything is normal, that’s just your imagination. I couldn’t believe them, something was obviously wrong. I even went to an erotic masseuse who finally told me, that my genital looks completely different than the genital of a man, that there is nothing there.

Many years later I accidentally overheard the conversation of two familiar doctors, because they had forgotten to close the door to the study, “Did you see, he hasn’t got a penis. He’s intersex.” When I took them to task they only said, “No, it’s nothing, everything is OK.”

It was the advent of Internet that procured me some answers, and an incredible amount of information. All the informations that they refused to give to me for all these years, doctors who were my friends lying to me for ages. When I eventually met other intersex people, we all had a lot to tell.

When I turned 70, I went to see an endocrinologist. And I finally got some answers: I have XY Partial Gonadal Dysgenesis. I was born with a hypospadias and underwent surgery shortly after birth. The doctor told me, I have been lucky because they didn’t turn me into a girl.

There are still a lot of unanswered questions, but I don’t bother too much. I am well. I had a good life, despite of this insecurity. But it would have been nice to know, who I am and why. Some decisions would have been easier. But I am grateful for finally get some answers I have been looking for my whole life.

Case Study No. 2

The child was born 1965 with ambiguous genitals. The doctors couldn’t tell whether it was a micropenis or an enlarged clitoris. Due to a severe hearth problem the child had to stay in the hospital for three months. Meanwhile the doctors performed tests, identifying the child as 46,XY, but with unknown diagnosis. They found abdominal testes, which were removed at the age of 2 1/2 months. Later a doctor said this was a mistake, because the child was a boy with micropenis and severe hypospadias, but as the castration had already been done, they had to proceed on this way and surgically make a girl. The parents weren’t informed about the gonadectomy. Only years later they were told that “rudimentary ovaries” had been removed, and that a hormonal treatment will be necessary during puberty. The parents were instructed to raise the child as a girl, and never talk to anybody about how the child was born. At the age of 7 the micropenis was surgically “reduced”, from the age of 12 the child had to take female hormones. At the age of 18 the doctors performed a vaginoplasty.

The person concerned tells their story:

I was born in 1965 with a severe heart defect and ambiguous genitalia. The doctors couldn’t tell if I was a girl or a boy. According to the medical file, they cut me open between my legs to see, if they find a vagina. Later they opened my abdomen and found testes. Further tests showed that I am chromosomal male. Like 50% of all XY-intersex, I don’t have an exact diagnosis.

Due to the heart defect, I was given an emergency baptism only a few days after my birth, as the doctors thought I would not survive much longer. Consequently, they kept me in the hospital and would not allow my parents to take me home. My father had to work, but my mother travelled to the city as often as possible from our small town, though she was only allowed to see me through a windowpane.

Like most intersex persons I learned fractions of the truth only after decades of ignorance and denial. In my case I was lucky to obtain my medical records. However, like with most persons concerned, the responsible hospital initially assured me that my medical records didn’t exist anymore. After I insisted, they eventually sent me some recent sheets and told me that the older documents were missing. Only when I threatened to return with a lawyer, a few days later the hospital sent me a large pile of documents.

Finally I had it in black and white: Despite of my life threatening heart defect the doctors castrated me at the age of 2 1/2 months. They opened my abdomen, removed my healthy testes, and threw them into the garbage bin. According to my medical records, this procedure was done without the consent of my parents.

Later the castration was declared a mistake, one doctor said that I was a boy with hypospadias, but as they had already removed the testes, they had “to continue this way and the small patient must be made a girl”.

According to my medical records the doctors continued to systematically lie to my parents. They were instructed to raise me as a girl and never talk to me or anybody else about “the gender issue”. When they asked the doctors whether I would be able to have children, the doctors said that it was “doubtful”. Still in 1972, when I was 7 years old, they told my parents they had to remove the ovaries. And in 1979 the doctors still claimed I didn’t menstruate because my uterus was “very small”.

I would eventually get older than initially expected. At the age of seven the doctors decided to carry out the heart surgery. On February 1972 I was in the hospital for a cardiac catheterization to examine my heart before the surgery. Because of an infection however, they couldn’t perform the pre-examination. But given that I was already in the hospital, the doctors decided to correct my genital. On February 10th they shorten my micropenis to the size of a “normal” clitoris.

9 days later they put me back to the cardiology, where they performed the cardiac catheterization, and a few months later I had heart surgery. The doctors saved my life and destroyed it in the same year.

I spent a lot of time in doctor’s offices and hospitals, the doctors kept looking between my legs. Once our family doctor examined my genitals when I was very little. He stuck his finger and needles in my urethral opening, I was screaming very loud my father says. Later at home my mother put me into warm water because every time I had to pee I screamed in pain. I was sweating a lot and my whole body was shaking. A few days later they had to hurry to the hospital because of a bad infection.

I knew very early that I was different. When I took a bath with my two younger sisters I asked my mother why my genital looked different. My mother just told me that it’s nothing and that it will be fixed later.

I spent my entire childhood in fear and isolation. When I think of me as a child, I see a wide-eyed little skinny girl, scarred stiff, that never cried, enduring everything without ever protesting. I recall countless exams and visits to the hospital and how much I hated it. I felt sick days in advance, and in front of the doctors I felt like the mouse facing the snake – completely paralysed.

The doctors always looked between my legs, but nobody talked to me. I was very ashamed. Sometimes I asked a question but was fobbed off with half-truths. It was all very embarrassing, so I stopped asking.

I learned early to dissociate during the countless medical exams: I wasn’t there, it didn’t happen to me. I suppressed my feelings, my anger, my despair, because I saw the despair in my mother’s eyes, my father’s helplessness. They were all over-strained. And also embarrassed. So I tried to be strong. I perfectly recall this pressure, having to be brave, again and again. My mantra was: it will soon be over!

It became very important to me not to show my feelings, like it was my strength. I was strong and they were weak. That was my strategy to cope with the despair and fear that filled me up. I didn't want to be the one destroying everything by losing control, so I started to play along. But inside I felt empty and hollow.

We were very isolated as a family, because of my "secret". I was always together with my two younger sisters, we barely had friends. I couldn't talk to anybody and had to hide all the time, always afraid my "monstrosity" might shine through, someone might find out my true nature. They would laugh at me or even spit in my face. I was somehow repellent, I wasn't right. They had to cut my genitals to make me acceptable. I felt like someone who had done something very wrong and who had to be thankful to be allowed to live.

But still, there was something deep inside me, something good, a joy of life. I loved animals, spend a lot of time in the countryside reading a lot of books. I was a loner and very confused, but still open. This completely changed when I was twelve years old and the doctors told me that I had to take female hormones to develop breasts. Soon my body was changing. I felt completely ashamed and disgusted. I was a construct, an abomination, something artificial. Like the hormones I had to take: I had hot flushes like a woman during menopause, I got depressed and I lost my drive. I still didn't know what's wrong with me.

I got a first lead when I was about 14 years old. My mother had tasked me once again to ask the family doctor why they had to remove my ovaries. The doctor got furious and yelled at me: these were no ovaries, these were testes! Then he left the room. I remember thinking: now I want to know. I threw a glance at the medical records lying on the table and read: pseudo-hermaphroditismus masculinus. I wasn't really shocked, it somehow made sense to me. The doctor eventually came back, he acted as nothing had happened. I never told my parents about the episode, but started to look up books in the library and got a real mess in my head, leaving me with the fear that a penis might grow overnight. I didn't realise that they actually had shortened my penis years ago.

As I found the document of the genital surgery in my medical records, I first couldn't believe that this was about me. I had completely erased the memory of the genital surgery. As my psychoanalyst told me later, I did this to protect myself, because it had been so painful and scary. My mind had even constructed an alternative memory basing on the saying of my mother "that it had only been a little piece of skin which had to be removed ambulantly".

Because of this surgery I suffer from periodical phantom pain, bladder infection, scars and pain in the genital area. Due to the castration I have to deal with several health problems: a ruined metabolism, often fatigue and vertigo, and a reduced bone density. However I was lucky because I still have sexual feelings left, although often combined with hypersensitivity and pain.

When I was 18 years old, the endocrinologist at the hospital told me during the last consultation that I was born with male chromosomes. I remember the two of us standing side by side looking out of the window. He advised me not to tell my boyfriend, because "he might not understand". I told my boyfriend anyway straight away and he was OK with it.

I then tried to live a normal life with my longtime companion, family, job and studies, but it didn't work. When I turned 35 I started a psychoanalysis which took me 10 years. It was a very painful but also liberating experience. I tried to come to terms with what happened to me, and to realise that the surgeries and lies had been very traumatic for me, and had influenced all aspect of my existence. I finally had to meet the scared little child inside me and take it in my arms.

I will suffer for the rest of my life, living with the torture of this inhuman treatment. I am neither a man nor a woman, but above all, I am no longer a hermaphrodite. I will remain a patchwork created by doctors, bruised and scarred.

Case Study No. 3

The child was born 1978 with ambiguous genitals and was diagnosed with 46,XX Congenital Adrenal Hyperplasia (CAH). Four genital surgeries were performed at the age of 5, 6, 16, and 23, resulting in loss of sexual sensations, painful scars, pain during penetration, several complications, and trauma. After phases of severe depression and stays in psychiatric hospitals the client is trying to cope with the fact that her problems are connected to the trauma resulting of the treatment.

The person concerned tells their story:

During the first 8 years of my life it was a single woman doctor, who mostly took care of me. I first met her when she was still an assistant doctor. Afterwards I was looked after and examined by assistant doctors, at least every 2 years by a new one. Before I turned 16, my genitals were examined almost every time, and often the assistant doctor called in some colleagues to inspect and to touch my genitals as well. Back then I didn't realise yet, that this wasn't right.

Until today, I've had 4 genital surgeries, and I hope that there will be no other, already the third was in fact supposed to be the last one. But obviously nobody can guarantee me that.

With the aid of my medical record I found out some things I couldn't remember before. I probably have blocked out a lot as well. Apparently it wasn't clear in the beginning, whether I should be operated on as a child at all. Originally a first surgery was intended during puberty. However the first two interventions were done at the age of five and six years. I haven't found out the reason yet. I can still remember, how it once felt differently between my legs. Above all I could feel significantly more before the surgeries. Because wherever they cut, every time they cut nerve fibres as well. At that time (1983/84) their textbooks contained the same advice as today: perform surgery as soon as possible during the first 24 months, to establish a basis for a clear gender identity.

When I was about 13 years old, I felt very lonely. I mostly went alone to the examinations. I hardly had anybody to talk to about my problems. I only really confided in my diary, like I still use to do. There is only one friend that stood by my side to this day. She is 16 years older than me. Peers didn't understand what bothered me, and I didn't understand what my peers worried about. I couldn't identify with other girls. I primarily feel like a human being and not as woman. My sex is secondary to me.

I grew up with two brothers in a very religious farming family, I was the middle child of three. We didn't talk about things like sexuality and love in our family or what has to do with it. These matters were taboo, and so I couldn't address my mother or another family member with my problems.

When I was 16, I had to undergo a third surgery, an extension of the lower vagina, which was separated from the urethra during the first surgery. The surgeon just briefly explained the surgery technique to me, but I wasn't informed about pros and cons, possible following treatments or complications. I wasn't told that additionally I would have to dilate my vagina, to become like they say "penetrable." Neither I was told that I would have to do this for the rest of my life, to prevent my vagina from shrinking. Eventually I asked a doctor, how much longer

I had to dilate my vagina. He said, that he didn't know exactly. My gynaecologist couldn't tell me either. I never again asked such questions.

When I was in hospital they advised me to get psychosocial support. I had been crying every day during my stay. I didn't want to talk to my mother. I still felt misunderstood and very lonely. I didn't accept the offer. At that time it was too late for me. Now I no longer wanted support, too much had already gone wrong.

After the third surgery I was often asked whether I had a boyfriend. Mostly I denied, although it mostly wasn't the truth. This didn't matter before the surgery. Actually they just wanted to know if I was so-called "penetrable", if it actually works. They didn't care about the fact that I barely had feelings in my genital area. During a checkup a doctor gave me the advice, I wouldn't necessarily have to tell my partner. But what shall I tell him, when it hurts? For a doctor it just has to work and look cosmetically good. But I feel my painful scars, over and over, anyway when I am with a man, and sometimes even when the weather is changing. And that will probably always be this way.

Life went on. The last school trip came, I had to nurse my scars, and of course dilate my vagina. I went to my teacher and explained everything to her. Fortunately she was sympathetic, but I couldn't tell it to anybody else from my class. I continued to be a loner, and they often teased me, up to the last class.

I started an apprenticeship as electrician, and a lot changed. Almost only young men around me, with whom I got along much better than with women. Finally no teasing anymore about me and my size. Now I was simply a short person, and became more and more an original character, being almost the only woman in a technical profession. I developed into a self-confident personality, who knows how to stand her ground and even how to answer back. I began to take a lot with irony and sarcasm. I just managed to successfully finish my apprenticeship, when the next depression occurred in my life. It came slowly and creeping. I noticed, how my performance diminished in every way. Everything got darker and bleaker. I became scared like never before, panic was my constant companion. My family doctor referred me to a psychiatrist because of my suicidal thoughts, since the psychiatric medication he prescribed me didn't help. For months I had severe depressions, anxiety, and panic attacks like I'd never experienced before.

The low spirits passed at the same time as did the fear. After months I was finally able to work again. I helped my parents on the farm, until I had found a job again. I struggled through every day, it went on somehow. I learned to enjoy things again. However a little fear was always present, sometimes but the memory of it. I was looking for a reason for my fear. It took me a long time to find out.

I just turned 23 and overreached myself again with work, and also in my private life everything went haywire. The husband of my best friend died suddenly. I applied all my energy to help my friend, where I could. At the same time I was working and attending the instructor-course. I completely forgot to look after myself. Another little surgery had to be done that summer, because I'd stopped to dilate my vagina out of ignorance. During a time, when everything already seemed to go wrong anyway, my vaginal skin broke, as I was sleeping with a man. Only at that time I found out through a woman doctor that I wasn't born with a vagina at all. I almost couldn't believe it, for years I only knew half of the truth! So I had to go to the hospital again for two days, and I sensed that I was on the verge of losing control of everything again, but I ignored it, pushed it aside and continued to function.

Slowly I began to see a connection between my psychological problems and the traumatising intersex treatment. I read about it, but I actually didn't want to link it with myself yet. This might affect other people, I thought, but certainly not myself, I am standing above these things.

Not even when I later hold my medical records in my hands and had the information from the Internet, was I able to make a connection between my history and what I was reading. It took another stay in a psychiatry, during which I fought very badly against my addiction to medication. I had a lot of time to think, more than 10 weeks, and I slowly connected everything.

Even today, about a year after the medication withdrawal and the last stay in an institution so far, I still have to take psychiatric medication, and I am also in walk-in psychological treatment. I try to handle the matter as openly as possible, but it hurts me again and again to deal with my very personal past. Because I always firmly believed that everything was only for my own good. Nothing had been purposefully hidden from me. Nevertheless a world collapsed, when the truth surfaced. What's left is an expanse of rubble, which I'll have to clean up sooner or later.

Case Study No. 4

The child was born 1999 with ambiguous genitals. In the following weeks, at the Basel University Children's Hospital, blood, urine and other tests were conducted to establish the sex of the newborn. One day the doctors came and said that it's rather a girl, the next day it was a boy and so forth. The word "intersex" was never mentioned. After countless tests the doctors diagnosed a 46,XY Mixed Gonadal Dysgenesis. The doctors then insisted on genital surgery, they wanted to make a girl. After obtaining informations from the internet and meeting persons concerned, the parents cancelled the surgery a few days before the scheduled appointment. The parents raise their child as a girl, but want herself to decide later.

The mother of the person concerned tells their story:

After I had given birth to my first child, I noticed that the doctors were whispering something about a "slightly swollen genital, but it's normal, probably the baby got too much hormones during pregnancy." The midwife took the child for check-up to the next room. A doctor, who was there by chance, wanted to know more about the genital. The midwife could just prevent him to put a cotton stick into the child to see, if there was a vagina, and how deep it went in. Nobody seemed to have the situation under control, or knew how to act towards us. We felt completely helpless. The midwife had never seen such a child, and didn't know about intersex.

The doctors wanted to further examine the newborn. Still dizzy because of the anaesthesia, I agreed, and so my child, my husband and the midwife left for the children's hospital. Next was a check in the Basel University Children's Hospital that took several weeks, blood, urine and other tests to establish the sex of the newborn. One day the doctors came and said it's rather a girl, the next day it was a boy and so forth. The word "intersex" was never mentioned.

We couldn't give our child a name which wasn't easy for me. Family and friends called and wanted to know whether it's a boy or a girl. I said: I don't know. They thought that I was joking.

I was never sad, but angry instead, because the doctors experimented around with this little innocent creature. I as well disapproved of the doctors position of power, they always came into the room in twos or threes. I didn't understand the technical terms they used, and I felt like an idiot. I feared that my child might be seriously ill.

During one of the countless consultations, the physicians finally told us our child is chromosomal male (XY), but shows a lot of the characteristics of a girl, for example an enlarged clitoris. They couldn't clearly determine whether there were testes or ovaries in the abdomen. The doctors recommended to remove the gonads as soon as possible, because later there could be a cancer risk. I consented under the pressure of the doctors, it was our first child, we were afraid to lose it over cancer. I still don't know if this surgical intervention was necessary.

Six month after birth, the doctors advised us to let our child undergo genital surgery. They wanted to make a girl. I didn't know at that time that there are a lot of testimonies by persons concerned who suffer from such surgeries. I just knew that this surgery isn't right. I continued to ask the doctors why they would want to perform surgery. They always answered the same way: A child without a clearly defined sex is socially worthless. The other children will tease and exclude it, there will be problems while exercising or swimming at school. The child has to know where it belongs to. The expression "intersex" still wasn't mentioned at that time.

The doctors continued to insist on surgery: they wanted to shorten the enlarged clitoris, adjust the labia and construct a vagina during puberty – it had to become a girl. I wanted to know if the child would be able to have sexual sensations at all after the surgery. They hesitated, and then told me that the chances were good, but that they didn't know for sure. Then one of the doctors said: It's worse for a man not being able to pee standing, than it is for a woman to have sex without feelings. It would be easier for a woman to deal with it. I was outraged.

It was a very difficult time. My husband, who until then supported the idea of a surgery, began to have doubts. Then my father began to search in the internet and found a lot of information which we gratefully absorbed. Suddenly we knew that our child is intersex, and that there are self-help groups. We contacted such a group immediately and went to a meeting, where we learned about many tragic fates, countless surgeries with bad outcomes, fears and pains. We then cancelled the surgery few days before the scheduled appointment. The doctors were almost furious with us, and called us irresponsible.

What always made me angry all over these years, is the fact that every doctor wanted to look at our child's genitals. That's still the case, whether we have to go to the hospital because of a bone fracture or whatever. As soon as the doctors read the diagnosis "intersex" in the medical records, they ask: "Could we take a look at the child's genital?"

Our child grows up as a girl, but she knows that she is a special girl and can decide for herself how she wants to live. Being intersex is no problem for our daughter. "There are boys and there are girls, and there is me," she says. The most important thing is to constantly inform the children according to their age, and to explain intersex to the neighbourhood. The family and close friends know about our daughters particularity. Although we live in a small village where everybody knows everyone, the social exclusion predicted by the doctors didn't happen.

Retrospectively I can say, we were completely over-strained both because of the insecurity of the doctors and our missing know-how. But thank God we always were able to accept our child with his particularity.

I think it's important to be honest and give her the possibility to go her own way. As a boy, a girl or none of both. We had to fight against the doctors in order to preserve the freedom of choice for our child. I am happy that we had the strength to stand up to them!

Case Study No. 5

The child was born 2008 with ambiguous genitals: micropenis with hypospadias and undescended testes. Blood tests confirmed the diagnosis PAIS (Partial Androgen Insensitivity Syndrome), which already occurs in the family. As a result of this syndrome, the body doesn't completely masculinise. One week after birth the parents had an appointment with a hormone specialist in the Eastern Switzerland Children's Hospital. The doctors insisted on surgery from the beginning, and put a lot of pressure on the parents. It would be easier to make a girl, but if the parents preferred a boy, that would be feasible. When the parents refused surgery, they were accused of being irresponsible. The parents also refused a painful hormonal treatment with possible premature virilisation (artificial puberty) to establish the reaction of the body to male hormones. In 2012 a bilateral hernia required a surgical intervention. The testes were descended in a surgically shaped scrotum, to prevent them to adhere with the scars of the hernia surgery. The child is raised as a boy, happy and healthy, knowing about being intersex.

The father of the person concerned tells their story:

Our son was born with PAIS, which is an inheritable intersex condition. Although because of the ultrasonic testing we expected a boy, we were prepared because there had already been a case in our family. At birth his genitals looked ambiguous, but a blood test confirmed that he has male chromosomes (XY). He was in good health and so we could soon take him home.

One week later we had an appointment in another hospital, where the hormone specialist would inform us about the effect of this condition on our son's body, and what should be done. A blood test confirmed the diagnosis PAIS.

The doctors then began to put a lot of pressure on us to surgically determine the sex of our child, although it was perfectly healthy and didn't have any troubles. The hormone specialist made very clear, in our case the child should be raised as a girl and therefore undergo surgery: first we should remove the (healthy!) testicles, then shorten the micropenis, and form labia, later then an artificial vagina. It would be an imposition for this child to grow up with an undetermined sex. The society couldn't cope with such people. She literally said it would be a "social disaster" to let our child grow up without surgery. She then assured us, that they could also make a boy, if we'd prefer, but that this would be more complicated. She told us all of this not in a friendly, but in a reproachful way and tried to put pressure on us.

We refused the surgery. Then the doctors wanted to at least perform a hormonal test, which is called "artificial puberty", to determine the reaction of our son's body to testosterone. They couldn't tell us exactly how our son would react, growth of hair, even beard growth could be possible. The only thing they knew for sure was that the procedure would be painful. Our son was then three weeks old! After this shocking experience we refused other blood tests and didn't take any further tests, and stopped this medical experiment.

When the doctors were confronted later in a documentary about intersex, they spoke about a "misunderstanding", that surgery had always been an option and not an obligation.

We didn't want the surgery, because our son is healthy, and because a genital surgery on a baby is completely unnecessary. Nobody has the right to make such decisions for a child. God gave us this child the way it is. We receive it thankfully and love it.

Today our child is a happy and healthy 5 1/2 years old boy, who has a lot of friends, and acts like every other boy. He knows, why his genital looks different, and he is OK with that. He sees himself as perfectly normal. A lot of our friends know about our son, and support us very much. It's important to communicate openly, and always tell the truth and to treat the

intersex child as a human being. When he is older and wants to change something, our son can make decisions for himself. And we will always support him.

A child's happiness depends not on how it looks, but whether it feels safe and loved!

Case Study No. 6

The child was born 2008 with a micropenis. It was assigned as a boy and given a boys name. Three days later the mother noticed discharge from the penis and asked the pediatrician to further examine the child. The child was then taken to the Bern University Children's Hospital and diagnosed with Congenital Adrenal Hyperplasia (CAH). The parents were told that the child is a girl, and explained which surgeries would have to be done, but everything would be well and the child would look like a normal girl. After further tests the parents learned that the situation looks more complicated than presumed, that the child has 46,XY male chromosomes, undifferentiated streak gonads and an uterus. The doctors recommended a biopsy of the gonads to definitely determine the sex of the child, however to no avail because the gonadal tissue was necrotic. The parents then consented to remove the gonads, but refused to remove the uterus. After countless attempts of the doctors to push the parents towards surgery, the parents eventually changed the hospital. In the end, the child was diagnosed with Mixed Gonadal Dysgenesis (MGD). In 2010 the gonads were removed.

The mother of the person concerned tells their story:

During the first five days after the birth of our son he was first declared a boy, then it was a girl, and finally nonetheless a boy. This was a very confusing experience, we didn't know about intersex.

We were quickly transferred to the children's clinic, where our child was diagnosed with Congenital Adrenal Hyperplasia (CAH). The doctors advised us to give the child a girls name to get used to it as soon as possible.

We soon noticed, that apparently these kind of treatments and interventions were habitually done with a certain urgency. We felt there was too little time for the necessary considerations. We couldn't figure out the reason for such a run against the clock, the more so as there was no evidence for a medical urgency. Besides, there was an obviously high risk to be wrong, as the daily changing sexing showed us.

The doctors pushed us from the beginning to do surgeries. Every time I got back to them to tell them for the moment we wouldn't want to do anything, they dug up a new argument pro surgery, that they hadn't told me so far. That of course left the impression that they just wanted to convince us to do the surgery. They considered it would be better for us to have a more conform child, but never actually asked us about our opinion.

The doctors had some sort of table, on the one side they wrote "XX" and on the other side "XY". They would mark every test result with an "x". When they found out that our child has XY male chromosomes, they'd put a cross under "XY", when they found out about the uterus, they'd put it under "XX", and so forth. The funny thing was, at the end there was almost the same number of crosses on each side.

The doctors told us, during the removal of the gonads the uterus should be removed as well because of a cancer risk. The specialist who should do the surgery, would arrive on the eve of the day of the surgery from London, so we wouldn't be able to ask him questions until shortly before the surgery. Like this it is impossible to be properly informed, and to be able to think about it.

We started to look on the internet about uterus and cancer risk and couldn't find anything. So we asked the doctors why this information is not available. They told us that an increased cancer risk only occurs after the age of 50. We therefore requested not to remove the uterus during the removal of the gonads, but the doctors told us, that would be a decision which can only be taken by the doctors during the surgery.

This compounded our loss of trust regarding getting information, and we decided to go to another clinic. We found a children's clinic and a physician which proved better at supporting us to face this situation.

What struck me most during this difficult experience, was the lack of transparency and information. There was uncertainty from the beginning, but the doctors never considered the option to wait and see. They never outlined different possibilities, but pushed for quick surgery instead.

Today our son is five years old, healthy and lively, what confirms our decisions. It just seemed more reasonable to me to have done as little as possible, just what is necessary for his health, and let him decide for the rest later, instead of making a decision that couldn't be undone, like taking away tissue, that would be irreversible. Doing nothing is of course also a decision, but it seemed a safer one.

Annexe 2

“Swiss Cantonal, Federal Government, Clinics on IGMs (2009–2012)”

a) Cantonal Answers to Four Parliamentary Questions (2009–2010)

1) Zurich

According to the Cantonal Health Department, on the national level, concerning “*the most frequent diagnosis within DSD diseases, Congenital Adrenal Hyperplasia (CAH), in average seven to eight children are born annually.*” At the Zurich University Children’s Hospital, “*one newborn patient annually gets diagnosed as DSD,*” and “*in 2004–2009, five cosmetic genital surgeries on female patients were performed, three patients had their gonads removed because of high risk of cancer, and about five patients had hormone treatments.*”⁹⁵

However, according to nurses working at the Zurich children’s hospital, **1–2 children per week** are submitted to hypospadias “repair”.⁹⁶ Both a leading paediatric endocrinologist and a paediatric surgeon publicly claim **gonadectomies on children with AIS** to be justified by “*high cancer risk*”,⁹⁷ and described them not a matter of “if”, but only of “when”.⁹⁸ See also Zurich surgeon Ricardo González on Forced Genital Exams (p. 73) and Human Experimentation (p. 75), see also **Case No. 1**.

2) Luzern

According to the Cantonal Health Department, at the Luzern Cantonal Children’s Hospital, “*from 1999 until the end of 2010, six patients born in Central Switzerland were treated. This means, about one child every two years, and one child affected to 15,000 to 20,000 live births.*” “*The number of patients is declining, the last diagnosis occurred in summer 2007. [...] Between 1999 and 2010, twelve patients with DSD had genital surgery. Three patients had dysplastic gonads removed, which in one case showed signs of cancerous degradation.*”⁹⁹ (Note: “Signs” does not equal actual cancer, which, if present, surely would have been corroborated by the histological analysis.)

However, Marcus Schwöbel, chief of paediatric surgery 1999–2013 (after practicing at the Zurich University Children’s Hospital since 1983), in the media repeatedly boasted of having been participating in “**about 50” intersex genital surgeries**¹⁰⁰ in **30 years**, as well as publicly claiming early “genital corrections” to be “*the natural path,*” and best to be undertaken in the “*first two years of life*”.¹⁰¹

3) Bern

The Cantonal Health Department quotes “*estimates of about 40 children with DSD born annually, which includes children with hypospadias.*” The department **flatly denies IGMs**, then lists “ex-

95 Regierungsrat des Kantons Zürich (2009), 2109. Antwort, KR-Nr. 327/2009, at 1, 5, <http://www.kantonsrat.zh.ch/Dokumente/D4050e235-3f43-4ade-ba5d-cae7d182c495/R09327.pdf>

96 Personal communication to Zwischengeschlecht.org outside 23rd Annual Meeting of ESPU, May 09-12, 2012 Zurich, Switzerland

97 Eugen Schoenle, chief paediatric endocrinology, Der Landbote 06.02.2008, <http://blog.zwischengeschlecht.info/pages/Offener-Brief-an-das-Kinderspital-Zurich-von-Zwischengeschlechtorg>

98 Peter Sacher, consulting paediatric surgeon, “Management bei Androgen Insensitivity Syndrome (testikuläre Feminisierung),” http://www.kinderchirurgie.ch/manag/test_feminisierung.html

99 Regierungsrat des Kantons Luzern (2010), Antwort A 777, at 1–2 http://www.lu.ch/downloads/lu/kr/vorstoesse/2007-2011/a_777_antwort.pdf

100 see e.g. Katrin Hafner (2008), Ein Intersexueller klagt seinen ehemaligen Arzt an, Tages-Anzeiger 05.02.2008: 52, <https://web.archive.org/web/20080212022857/http://www.tagesanzeiger.ch/dyn/wissen/medizin/838834.html>

101 Zwischengeschlecht.org (2010), Open Letter to Luzern Cantonal Children’s Hospital, at 1, http://zwischengeschlecht.org/public/Offener-Brief_Luzern-22-8-10.pdf

ceptions” without providing actual figures: *“In the canton of Bern, no cosmetic surgeries, castrations or hormone treatments on children with atypical sex characteristics are performed. [...] In rare cases, surgical corrections on girls with Congenital Adrenal Hyperplasia (CAH) are performed. [...] More frequently, children with hypospadias are submitted to surgery for urethral reconstruction, according to effective guidelines.”*¹⁰²

However, both “girls with CAH” and “children with hypospadias” are indeed children with atypical sex anatomies and at risk of IGM, and especially doctors of the **Bern University Children’s Hospital “Insel”** repeatedly admitted to being actively involved in IGM in the media.¹⁰³ (See also **Cases No. 2** and **6**.)

What’s more, the **Bern University Children’s Hospital “Insel”** is continuously involved in major non-disinterested human experimentation on intersex children, taking part e.g. in “**Netzwerk DSD**” and “**DSDnet**” (see **B 4.**, p. 19).

4) Basel Stadt

According to the Cantonal Health Department, *“in the region of Basel [...] 1–2”* intersex children are born annually, plus *“about 20”* children with hypospadias, the latter *“receiving surgery mostly between the first and the second year of life, according to effective guidelines.”* Intersex children are treated at **Basel University Hospital (USB)** and at the **University Children’s Hospital of Basel (UKBB)**, surgeries are performed at the UKBB surgery unit. Regarding surgeries on intersex children *“in the more strict definition,”* the department lists *“one genital surgery”* on a 14 year old CAH patient *“during the last five years.”*¹⁰⁴ (See also **Case No. 4**.)

b) Public Declarations by Doctors of Cantonal Children’s Clinics (2010–2012)

St. Gallen

In 2010–2011, Christian Kind, director of the cantonal **Eastern Switzerland Children’s Hospital St. Gallen**, as well as president of both the **Swiss Society of Paediatrics**, and the **Central Ethics Commission (ZEK) of the Swiss Academy of Medical Sciences (SAMW)**, mounted a continued, staunch public defence of IGM.

In addition to the established patterns of non-disclosure and trivialisation of IGM (e.g. *“less than one clitoral reduction plastic surgery annually (using the nerve-sparing method)”*), Kind **reverted to typical apologetics also established in the context of FGM**, e.g. explicitly disregarding *“abstract ethical and legal perspectives of future adolescents and their title to disposal over their bodies”* in favour of *“the eminent best interest and welfare of the child growing up in his family. If, after extensive counselling and discussions, it appears that a family is not capable of accepting a child with ambiguous genitals, for us it is the better way to perform a medically not urgently indicated surgery, than to expose the child to rejection and ostracism.”*¹⁰⁵

Kind further declared the **mutilations acceptable if performed in a state of the art clinical environment**: *“Christian Kind adopts a pragmatic view: «I find it preferable, we*

102 Regierungsrat Bern (2010), Antwort I 052/2010, at 3, <http://www.gr.be.ch/etc/designs/gr/media.cdwsbinary.DOKUMENTE.acq/96495f2266224e06825c3ef6cc7742aa-332/5/PDF/2010.0600-Vorstossantwort--31206.pdf>

103 • Zacharias Zachariou, chief paediatric surgery Bern University Children’s Hospital “Insel”, NZZ am Sonntag 13.07.2008, <http://www.nzz.ch/aktuell/startseite/das-dritte-geschlecht-1.782938>
• Primus Mullis, chief paediatric endocrinology, Bern University Children’s Hospital “Insel”: *“The often enlarged clitoris gets reduced to avoid social stigma,”* quoted in: Der Bund 15.11.2008: 40, http://blog.zwischengeschlecht.info/public/Der_Bund_intersex_15-11-08.pdf

104 Regierungsrat des Kantons Basel-Stadt (2010), Antwort 10.5018.02, at 3, 4–5, <http://www.grosserrat.bs.ch/dokumente/100350/000000350657.pdf>

105 Christian Kind, Walter Kistler, Dagmar L’Allemand-Jander, Josef Laimbacher (2011), Answer of the Eastern Switzerland Children’s Hospital to the Open Letter of Zwischengeschlecht.org, 10.02.2011, http://zwischengeschlecht.org/public/Antwort_OB_Kispi_SG.pdf

*treat the children here, than the parents travelling to the East for having the surgeries performed there.»*¹⁰⁶

Chief paediatric endocrinologist Dagmar L'Allemand-Jander publicly **objectified intersex children**: «It is the duty of the parents to decide for their child. This begins at inception», opines L'Allemand. «[...] Why shouldn't the sex be [surgically] assigned at once, instead of letting the child grow up with uncertainty? Why shouldn't we have it done immediately, so that everyone – also the parents – don't have to be reminded daily that their child has a physical infirmity?», asks L'Allemand.¹⁰⁷

In his role as president of both the **Swiss Society of Paediatrics** and of the **Central Ethics Commission (ZEK) of the Swiss Academy of Medical Sciences (SAMW)**, Christian Kind generally dismissed ethics concerns: «The Central Ethics Commission of the Swiss Academy of Medical Sciences indeed publishes guidelines on ethics problems, that, as we see it, are of importance and concern for medical professionals, and we're geared to signals from medical professionals and the public. And I must say, **it is our perception that up to now the problem of disorders of sex development isn't seen as a pressing issue** afflicted with urgent need for action. [...] It appears rather that [dissatisfaction of intersex adults] only represents individual protests by a very, very small group, as well as referring to something of the past.»¹⁰⁸

(See also **Case No. 5**.)

Fribourg

Although no statistics on current treatments are available to the authors of this NGO report, the **Fribourg University Children's Hospital (HFR)** is participating in “DSDnet” (see **p. 19**), which strongly suggests current practice of IGM.

Geneva

Although no statistics on current treatments are available to the authors of this NGO report, a gynaecologist at the **Geneva University Children's Hospital (HUG)** reported on television of seeing adolescent patients with impaired sexual sensibility due to early “genital corrections.”¹⁰⁹

c) Federal Answers to Three Parliamentary Questions (National Council, 2011–2012)

Note: In Switzerland, IGMs are covered by the **Swiss Federal Invalidity Assurance (Invalidenversicherung IV)**, bearing the costs for surgery on children with congenital conditions, listed in a conclusive “Annexe: List of Congenital Conditions” of 499 descriptive diagnoses, itemised by No.s 1–499, and compiled by the **Swiss Academy of Medical Sciences (SAMW)**,¹¹⁰ of which Zwischengeschlecht.org identified **12 No.s as including IGMs**.¹¹¹

106 St. Galler Tagblatt (und Regionalausgaben) 11.02.2011, <http://www.thurgauerzeitung.ch/ostschweiz/ostschweiz/tb-os/Zwist-um-Zwitter-Operationen;art120094,1686613>

107 Beobachter 20/2012: 24–35, at 25–26, <http://dl.dropbox.com/u/48497954/Webseite/Er%2C%2Bsic%2C%2Bes.pdf>

108 SRF “Kontext” 21.10.2010, http://podcasts.srf.ch/world/audio/Kontext_07-12-2011-0906.mp3, German transcript: <http://blog.zwischengeschlecht.info/post/2011/02/05/Christian-Kind-Genitalverstueummelung-Ok-Kispi-SAMW>

109 RTS “36.9” 14.01.2012, at about 23 min., <http://www.rts.ch/emissions/36-9/4302695-un-corps-deux-sexes.html>, German transcript: <http://blog.zwischengeschlecht.info/post/2013/03/1/Intersex-Empfindungsfahigkeit-beeintrachtigt-Michal-Yaron-HUG-Genf%29>

110 831.232.21 Verordn. über Geburtsgebrechen (GgV), Annexe Liste d. Geburtsgebrechen, <http://www.admin.ch/opc/de/classified-compilation/19850317/201203010000/831.232.21.pdf>

111 Zwischengeschlecht.org (2011), Kosmetische Genitaloperationen: Relevante Ziffern der “Liste der Geburtsgebrechen”, <http://blog.zwischengeschlecht.info/pages/Kosmetische-Genitaloperationen-Ziffern-Liste-der-Geburtsgebrechen>

1) Parliamentary Question 11.3265 (18.03.2011 – Answer 06.06.2011) ¹¹²

Question 5 asked specifically for numbers of patients registered at the **Swiss federal invalidity assurance (IV)** due to “*Intersexuality (resp. due to relevant main syndromes, like CAH, AIS, Seyer Syndrome, and others)*,” as well as for figures for surgeries related to the specific numbers in the “List of Congenital Conditions” identified as including IGMs: “*how many surgeries are performed annually on children covered by the IV - No.s 113, 350, 352, 355, 357, 358, 359, 453, 462, 465, 466, 486, 488?*” In their **Answer 5**, the **Swiss Federal Government** asserted, “*In the years 2006–2010, on average 30 children had medical treatments covered by the IV due to intersexuality (Congenital Conditions - No. 359, Hermaphroditismus verus and Pseudohermaphroditism). Information on the number of surgeries is not available, because the type of medical treatments covered by the IV is not evident from the statistics.*” What’s more, the Federal Government elaborated, No. 359 would be the only No. listed to comprise “**true transsexualism**”, while regarding all other No.s not comprising “**true transsexualism**,” no surgeries would be indicated in case of “*severe somatic problems*”, but “*no purely psychological indications.*”

Question 6 asked for figures of surgeries covered not by the IV, but by compulsory health insurance. In their **Answer 6**, the **Swiss Federal Government** asserted, “*According to extrapolations in expert literature, in Switzerland there are between 100 and 200 people with true transsexualism, for whom a surgery was considered or who already had surgery. An indication for surgery in early childhood is only given in cases of true transsexualism.*” (Apparently, the Federal Government was **not willing or able to distinguish Intersex from Transsexuality**, however still managed to follow the **established patterns of non-disclosure**.)

On the 17.06.2011 the discussion of the answers in the federal council was **adjourned**, and on the 22.03.2013 **written off** due to being pending for more than two years.

2) Parliamentary Question 11.3286 (18.03.2011 – Answer 06.06.2011) ¹¹³

Question 1 asked for detailed figures of “*cosmetic genital surgeries on children with atypical physical sex characteristics,*” “*including redo-surgeries and complications.*” In their **Answer 1**, the **Swiss Federal Government** asserted, “*According to the statistics of the IV, since [...] January 1st, 1986 [...], one to two children per age-group had medical treatments covered by the IV due to the condition ‘No. 359, Hermaphroditismus verus and Pseudohermaphroditism.’ [...] A break down into cantons and age-groups is not advisable due to this low figure. What’s more, the IV statistics doesn’t list details on the kind of the treatment (surgery) covered.*” In addition, the Swiss Federal Government elaborated their definition of “**true**” vs. “**untrue transsexualism**”.

On the 17.06.2011 the discussion of the answers in the federal council was **adjourned**, and on the 22.03.2013 **written off** due to being pending for more than two years.

3) Parliamentary Question 12.3920 (28.09.2012 – Answer 30.11.2012) ¹¹⁴

Question 2 asked, “*How many cosmetic genital surgeries are performed on children born with atypical sex?*” In their **Answer 2**, the **Swiss Federal Government** repeated the above given numbers of “*approximately 30 children annually*”, as well as that the IV statistic wouldn’t record details.

Question 3 asked, “*If data isn’t available, is the Federal Government willing to collect it?*” In their **An-**

112 Margret Kiener-Nellen (2011), 11.3265 – Interpellation: Umgang mit Varianten der Geschlecht-sentwicklung, http://www.parlament.ch/d/suche/seiten/geschaefte.aspx?gesch_id=20113265

113 Ida Glanzmann-Hunkeler (2011), 11.3286 – Kosmetische Genitaloperationen bei Kindern mit uneindeutigen körperlichen Geschlechtsmerkmalen, http://www.parlament.ch/d/suche/seiten/geschaefte.aspx?gesch_id=20113286

114 Jacqueline Fehr (2012), 11.3920 – Schutz der körperlichen Unversehrtheit von Kindern am Beispiel von kosmetischen Genitaloperationen und Knabenbeschneidungen, http://www.parlament.ch/d/suche/seiten/geschaefte.aspx?gesch_id=20123920

swer 3, the **Swiss Federal Government** generally elaborated on plans to improve collection of walk-in treatments, data on intersex surgeries would then become available. However, most IGMs are done in in-patient clinics.

Questions 4 and 5 asked, **what the Federal Government would intend to do in this context to strengthen the UN Convention on the Rights of the Child**, and the Swiss constitution (upholding the right to physical integrity,¹¹⁵ and the right of children and young people to special protection of their integrity¹¹⁶), as well as to postponing unnecessary early surgeries, raising public awareness, and better support parents of intersex children.

In their answers 4 and 5, the **Swiss Federal Government** claimed to prioritise the right of intersex children to physical integrity, and declared he was in the process of analysing the recommendations of the Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE) and then to decide about appropriate steps, but did not recognise further need for action. **However, since this declaration, another 15 months have passed without any “appropriate steps” with regards to intersex children ...**

115 Article 10, <http://www.admin.ch/opc/en/classified-compilation/19995395/index.html#a10>

116 Article 11, <http://www.admin.ch/opc/en/classified-compilation/19995395/index.html#a11>

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Supplement 1 “Historical Overview”

Hermaphrodites in the “Developed World”: From Legal Self-Determination to IGM

1. Middle Ages: Legal Recognition vs. Infanticide

Infanticide of unwanted children was widespread in Europe, even more so for hermaphrodites, historically described as “deformed” newborns and **“monstrosities”**.

However, surviving hermaphrodites not only grew up intact, but were legally recognised, including their **right to self-determination**: Both the Canon Law of the Church and Civil Right Codes included specific **“Hermaphrodite Articles”**, granting them the privilege of choosing their legal sex before reaching adulthood (“Sex Oath”), possibly overthrowing the earlier decision granted to their parents. Unlike today, the persons concerned were allowed to decide themselves whether to live (and to be able to marry) as males or females.¹¹⁷

The **existence of hermaphrodites in society**, of Intersex as a **natural variation**, was **common knowledge**,¹¹⁸ in humans as well as in (farm) animals, although associated with **stigma**.

2. Modern Age: Medical Takeover and Erasure

1763: Call for early “Cutting” of “perversely enlarged” Clitorises

In the 18th century, western medicine “discovered” **“hermaphroditism”**, described as *“physiologically [...] degenerate”*¹¹⁹ and stereotypically supposed to be particularly common e.g. in Africa, India and the Caribbean.^{120 121} Calls by doctors for **“cutting”** of *“perversely enlarged clitorises”* **during “childhood or youth”** ensued, arguing the amputation would be **harmless** due to no significant loss of *“blood vessels or nerve branches to be feared”*,¹²² followed by sporadic reports of **“successful” clitoris amputations** specifically on children with atypical sex anatomies.^{123 124}

117 Konstanze Plett (2001), Intersexualität aus rechtlicher Perspektive, in: polymorph (eds.): (K)ein Geschlecht oder viele? Transgender in politischer Perspektive. Berlin (Querverlag) 2002, 31-42, at 31 [First published under the title “Recht auf ein eigenes Geschlecht”, in: Gigi – Zeitschrift für sexuelle Emanzipation, Nr. 13 (Mai/Juni 2001), 24-27]

118 **“Hermaphrodites were integrated quite forthrightly into the social fabric.”** Maria I. New, Elizabeth Kitzinger (1993), Pope Joan: A Recognizable Syndrome, Journal of Clinical Endocrinology and Metabolism 76 (1):3-13, at 10

119 Elizabeth Reis (2009), Bodies in Doubt. An American History of Intersex, at 55

120 *ibid.*, at 21

121 Also during the 19th century, **“enlarged clitorises” were still considered a “racially distinctive feature”**, see e.g. the remarks of German gynaecologist surgeon Alfred Hegar (1830-1914) recommending amputation, quoted in: Marion Hulverscheidt (2002), Weibliche Genitalverstümmelung. Diskussion und Praxis der Medizin während des 19. Jahrhunderts im deutschsprachigen Raum [original doctoral thesis 2000], at 128-139

122 Gottfried Heinrich Burghart (1763), Gründliche Nachricht an seinen Freund *** von einem neuerlich gesehenen Hermaphroditen, at 18

123 Franz Ludwig von Neugebauer (1908), Hermaphroditismus beim Menschen, at 282, 264

124 Marion Hulverscheidt (2002), Weibliche Genitalverstümmelung. Diskussion und Praxis der Medizin während des 19. Jahrhunderts im deutschsprachigen Raum [original doctoral thesis 2000]

1800s–Today:

Clitoris Amputations/“Reductions” on Children in Western Medicine

Beginning in the 19th century, many prominent doctors in Europe and North America propagated and perpetrated medically unnecessary **clitoris amputations on young girls as a “cure” for a) masturbation, b) hysteria, and c) “enlarged clitoris”**,¹²⁵ e.g. Carl Ferdinand von Graefe (Germany, 1787-1840), James Marion Sims, “The Father of Gynecology” (U.S.A., 1813-1883), Isaac Baker Brown (UK, 1811–1873), Alfred Hegar (Germany, 1830-1914) and Gustav Braun (Austria, 1829-1911). Again, the amputations were described as **“harmless”**.¹²⁶

While amputations motivated by a) and b) attracted mounting criticism within the medical community and were mostly abandoned between 1900 and 1945,¹²⁷ **amputations of “enlarged clitorises” took a sharp rise after 1950** and became the global de facto medical standard on newborns in the 1960s (partly in combination with castrations / “gonadectomies” / administration of hormones). Only in the 1980s–1990s¹²⁸ intersex clitoris amputations were eventually replaced by the “better” and more modern techniques of **“clitoris reduction surgeries”**, again claimed to be “completely harmless” until today, despite complaints by survivors of loss of sexual sensitivity also corroborated by medical studies.

1800s: “Pseudo Hermaphrodites” vs. “True Hermaphrodites” – Medical Authority and Cultural Invisibility

19th century medicine claimed to be able to determine the **“true sex”** by surgically examining the hormone producing organs (gonads) of hermaphrodites, **contesting the traditional right to self-determination** of the persons concerned.

According to the doctors, only persons with either both testicular and ovarian and/or mixed gonadal tissue (“ovotestes”) qualified as actual or **“true hermaphrodites”**, narrowing down the formerly accepted social category to literally only a handful of extremely rare individuals, while the remaining **big majority of “ambiguous” persons was classified as “male or female pseudo hermaphrodites”**, i.e. actually men or women deceptively posing as something else.¹²⁹

1900: End of Legal Self-Determination for Hermaphrodites in Europe

The General Prussian Common Law (Allgemeines Preußisches Landrecht, 1798-1900) was the **last European law to include a “Hermaphrodite Article”** (“Zwitterparagraph”, §§19-21), though already with an exception clause giving *“experts”* the right to override the

125 Marion Hulverscheidt (2002), *Weibliche Genitalverstümmelung. Diskussion und Praxis der Medizin während des 19. Jahrhunderts im deutschsprachigen Raum* [original doctoral thesis 2000]

126 Elizabeth Sheehan (1985), Victorian clitoridectomy: Isaac Baker Brown and his harmless operative procedure, *Feminist Issues* 5(1):39-53

127 However, as Karkazis and Eder note, the **rationale of preventing masturbation still lives on in intersex clitoris “reductions”** as a strong motivator for originally hesitant parents to eventually “consent” to “corrections”. Katrina Karkazis (2008), *Fixing Sex. Intersex, Medical Authority, and Lived Experience*, at 148-149. Sandra Eder, *The Volatility of Sex: Intersexuality, Gender and Clinical Practice in the 1950s*, *Gender & History* 22(3): 692–707, at 700-701

128 Naomi Crouch, Sarah Creighton, Christopher Woodhouse (2003), *Changing Attitudes to Intersex Management*, *European Urology Today* 14(2):1, 5, at 1

129 Alice Dreger (1998), *Hermaphrodites and the Medical Invention of Sex*

decision granted first to parents, and before adulthood to the persons concerned (§§ 22-23). After 1900, **hermaphrodites as a legal category ceased to exist**.¹³⁰

3. 20th Century:

From Experimentation to Global Medical Extermination

1900–1950: Basic Research – Genital Surgery, Hormones, Genetics/Eugenics

For medicine to be able to systematically erase hermaphrodites as a species from western societies, certain scientific achievements and techniques were required. These were researched and published mostly during the first half of the 20th century, including:

Cosmetic genital surgeries to make “ambiguous genitalia” appear more male or female, including clitoris amputations, “vaginoplasty”, hypospadias “repair”, surgical removal / transfixion of undescended testes. Prominent centres advancing such surgeries on children included Buenos Aires (Carlos Lagos García, **p. 81**),¹³¹ Paris (Louis Ombrédanne, **p. 83**),¹³² Baltimore (Hugh Hampton Young, **p. 82**),¹³³ and Zurich (Max Grob, **p. 86**).¹³⁴ Everywhere the justification for the genital surgeries was explicitly **psychosocial**.

Isolation and synthesis of sex hormones: First experiments included transplantation of hormone producing organs in animals as well as in humans performed e.g. in Austria (Eugen Steinach),¹³⁵ Germany (Magnus Hirschfeld)¹³⁶ and the U.S. (Leo Stanley).¹³⁷ Prominent centres for isolation and synthesis of sex hormones (e.g. estrogen and testosterone) were Berlin (Adolf Butenandt) and Zurich (Leopold Ružička), sharing the 1939 Nobel Prize in Chemistry.¹³⁸

Combination of genital surgery and administration of hormones started as early as 1933 in Germany (Hans Naujoks),^{139 140} with claims of having transformed a “true hermaphrodite” into a “real” menstruating woman by clitoris amputation plus experimental hormone treatment, “*although in the interest of the public the procreation of this being would hardly be desirable*”.¹⁴¹

130 Konstanze Plett (2001), Intersexualität aus rechtlicher Perspektive, in: polymorph (eds.): (K)ein Geschlecht oder viele? Transgender in politischer Perspektive. Berlin (Querverlag) 2002, 31-42, at 31 [First published under the title “Recht auf ein eigenes Geschlecht”, in: Gigi – Zeitschrift für sexuelle Emanzipation, Nr. 13 (Mai/Juni 2001), 24-27]

131 Carlos Lagos García (1925), Las deformidades de la sexualidad humana, see **p. 81**

132 Louis Ombrédanne (1939), Les Hermaphrodites et la Chirurgie, see **p. 83**

133 Hugh Hampton Young (1937), Genital Abnormalities, Hermaphroditism, and Related Adrenal Diseases [2nd edition 1958 and 3rd edition 1971 edited by Jones and Scott], see **p. 82**

134 Max Grob (1957), Lehrbuch der Kinderchirurgie, see **p. 86**

135 Homosexuality: The Testicles, Institute for Sexual Science (1919-1933), Online-Exhibition by the Magnus-Hirschfeld Society, http://www.hirschfeld.in-berlin.de/institut/en/theorie/theo_11.html

136 Florian Mildenberger (2002), “... in der Richtung der Homosexualität verdorben” - Psychiater, Kriminalpsychologen und Gerichtsmediziner über männliche Homosexualität 1850 - 1970

137 Ethan Blue (2009), The Strange Career of Leo Stanley: Remaking Manhood and Medicine at San Quentin State Penitentiary 1913–1951, Pacific Historical Review 78(2):210–241

138 Christina Ratmoko (2010), Damit die Chemie stimmt. Die Anfänge der industriellen Herstellung von weiblichen und männlichen Sexualhormonen 1914–1938

139 Hans Naujoks (1933), Operative und hormonale Therapie bei Hermaphroditismus verus, in: Archiv für Gynäkologie 1156(1-2): 93-99

140 Hans Naujoks (1934), Über echte Zwitterbildung beim Menschen und ihre Beeinflussung, Zeitschrift für Geburtshilfe und Gynäkologie 109(2): 135-161

141 *ibid.*, at 160

Genetics/Eugenics: Though the XY sex determination system was discovered in the U.S. in 1905 (Edmund Beecher Wilson and Nettie Stevens), and animal experiments published in France (Alfred Jost) lead the way for later human experiments highlighting the role of the Y-chromosome in sex differentiation, the most notorious contribution of early genetics is **coining the term “intersex”** in 1915 (U.S. and Germany: Richard Goldschmidt)¹⁴² in a publication about experimental cross-breeding of “*geographically different races*” of moths, describing intersex as a “*degeneration*” caused by “*racial mixing*”.¹⁴³

1920-1950s: Racist Diagnosis “Intersexual Constitution”, Hermaphrodites selected for Mengele, Auschwitz Sex Change Twin Experiment

The Austrian gynaecologist Paul Mathes applied Goldschmidt’s 1916 findings of “degenerated” intersex moths to humans, and in 1924 published his findings of a **female “intersex constitutional type”**, including working women and intellectuals, describing them as “degenerated by racial mixing” and prone to hirsutism and infertility.¹⁴⁴ Mathes diagnosis was picked up by colleagues mostly in German speaking countries, and republished in **gynaecology textbooks** until at least the 1950s, often associated with mental diseases (“*schizoid*”, Wilhelm Weibel, **p. 84**)¹⁴⁵ and/or described as “*not fit for marriage*” (Walther Stoeckel).¹⁴⁶

In the same vein, Goldschmidt’s findings of intersexes as “*degenerates*” due to “*bastardisation*” were applied to humans by leading German speaking proponents of “**racial hygiene**” including Robert Stigler,¹⁴⁷ Lothar Gottlieb Tirala,¹⁴⁸ and Fritz Lenz,¹⁴⁹ the latter soon to become a prominent Nazi, repeatedly publishing on “**intersexuality**” for more than two decades.

Josef Mengele had **hermaphrodites selected for medical experiments in Auschwitz**^{150 151} as part of his endeavour to prove the biological inferiority of the “Jewish race”.¹⁵² Auschwitz survivors also reported a **twin experiment including a surgical sex-change**,¹⁵³ foreshadowing John Money’s infamous “John/Joan” experiment of the 1960s (see **p. 55**).

142 Helga Satzinger (2004), Rasse, Gene und Geschlecht. Zur Konstituierung zentraler biologischer Begriffe bei Richard Goldschmidt und Fritz Lenz, 1916–1936, Forschungsprogramm “Geschichte der Kaiser-Wilhelm-Gesellschaft im Nationalsozialismus”, Ergebnisse 15, at 11

143 *ibid.*, at 7

144 *ibid.*, at 17-20

145 Wilhelm Weibel (1944), Lehrbuch der Frauenheilkunde, at 647-648

146 Walther Stoeckel (1940), Lehrbuch der Gynäkologie, at 110-112

147 Robert Stigler (1920), Die rassenphysiologische Bedeutung der sekundären Geschlechtscharaktere, in: Leo Bouchal (ed.), Sitzungsberichte der Anthropologischen Gesellschaft in Wien, Jahrgang 1919-1920, at 6-9

148 Lothar Gottlieb Tirala (1935), Homosexualität und Rassenmischung. In: Verhandlungen der Gesellschaft für deutsche Naturforscher und Ärzte. 93. Versammlung zu Hannover vom 16. bis 20. September 1934

149 Helga Satzinger (2004), Rasse, Gene und Geschlecht. Zur Konstituierung zentraler biologischer Begriffe bei Richard Goldschmidt und Fritz Lenz, 1916–1936, Forschungsprogramm “Geschichte der Kaiser-Wilhelm-Gesellschaft im Nationalsozialismus”, Ergebnisse 15, at 20-24

150 Robert J. Lifton (1986), The Nazi Doctors: Medical Killing and the Psychology of Genocide, at 360

151 Yehuda Koren, Eilat Negev (2009), In Our Hearts We Were Giants: The Remarkable Story of the Lilliput Troupe - A Dwarf Family’s Survival of the Holocaust, at 77

152 Gerald Posner, John Ware (2000), Mengele. The Complete Story, at 51

153 Edwin Black (2003), War Against the Weak: Eugenics and America’s Campaign to Create a Master Race, at 358, 494

In 1944, experiments on male patients involving an **artificial gland** for administering testosterone were conducted in the KZ Buchenwald by SS-doctor Carl Værnet.¹⁵⁴

Nazi doctors who managed to avoid detection, continued to **experiment on intersex children after the war**, e.g. Carl Bennholdt-Thomsen (1903–1971), a leading figure in the “euthanasia” of children in the Nazi-Protectorate of Bohemia and Moravia,¹⁵⁵ supervised a doctoral dissertation at the Cologne University Children’s Clinic (where he was the director) on a population of intersex children with CAH and **30% mortality** 1949-1966, many **conveniently ending up on the dissecting table** for the dissertation.¹⁵⁶

1950–Today: Medical Extermination by Systematic Early “Corrections”

Medical publications on hermaphrodites often mentioned lack of compliance by adults refusing to have their genitals surgically cut or their bellies opened for surgical examination, as well as by parents of children of some years, who had grown to love their children as they were. Often prospective patients simply didn’t return for the next appointment, prompting historian Elizabeth Rice to conclude:

*“We can see why doctors, frustrated by the struggle with patients’ and parents’ preferences and conflicting indications of sexual compositions, ultimately sought ways to manage intersex in infants rather than adults.”*¹⁵⁷

A notion still echoed by doctors performing genital surgeries today, preferring **“easier management when the patient is still in diapers”**.¹⁵⁸

By 1950, all the basic techniques and science required for systematic “genital corrections” of hermaphrodites in infancy were in place, as well as specialised paediatric clinics providing experienced, coordinated surgical and endocrine departments regularly “correcting” children as early as possible. What still was missing was a treatment model, a unifying treatment policy, and a rationale to implement and spread it. The discovery of cortisone for treating the life-threatening effects of the salt-wasting form of Congenital Adrenal Hyperplasia (CAH) brought it all together in 1950 (see **p. 54**).

By the 1960s, medically unnecessary, systematic cosmetic surgeries on *all* children with variations of sex anatomy justified by a psychosocial indication became the **de facto standard all over the “developed world”**.

By the end of the 20th century, **hermaphrodites and the knowledge of intersex as a natural variation had all but vanished from “developed” societies**.

154 Hans Davidsen-Nielsen, Niels Høiby, Niels-Birger Danielsen, Jakob Rubin (2004), Carl Værnet – Der danske SS-Arzt im KZ Buchenwald

155 Michal Simunek (2004), Getarnt – Verwischt – Vergessen. Die Lebensgänge von Prof. Dr. Franz Xaver Lucksch und von Prof. Dr. med. Carl Gottlieb Bennholdt-Thomsen im Kontext der auf dem Gebiet des Protektorates Böhmen und Mähren durchgeführten NS-Euthanasie, in: Bayer / Sparong / Woelk (eds.): Universitäten und Hochschulen im Nationalsozialismus und in der frühen Nachkriegszeit: 125–146, at 142–145

156 Manutscheher Mohtaschemi (1966), Adrenogenitales Syndrom (AGS) und Salzverlustsyndrom (SVS) im Kindesalter – 15 Beobachtungen in der Universitäts-Kinderklinik Köln von 1949 bis 1966, medical dissertation University of Cologne

157 Elizabeth Reis (2009), Bodies in Doubt. An American History of Intersex, at 113

158 Marrocco et al (2004), Hypospadias surgery: a 10-year review. Pediatric surgery international 20:200–203, at 202

Baltimore and Zurich 1950: From Experimentation to Medical Extermination

Lawson Wilkins (1894-1963), hailed as “the father of pediatric endocrinology”¹⁵⁹ and director of the newly established clinic for paediatric endocrinology at the Johns Hopkins University Clinic in Baltimore, was arguably the first clinician to run a **programme** combining systematic early “genital corrections” with administration of hormones, “fixing” the children based on genital appearance, not on gonadal status¹⁶⁰, to prevent “*a high level of anxiety in parents*”.¹⁶¹

Wilkins’ influential 1950 monograph¹⁶² promised, the younger the children submitted, the better the outcomes.¹⁶³ Page 238 containing “*Figure 3*” titled “*Congenital Adrenal Hyperplasia – Female Pseudohermaphroditism*” depicts photographs of five naked children, aged 2–9, in front of a dark wall with a white grid. The child on the left has the caption, “*Normal age 9 yrs.*” The other four children were indexed A–C, and their captions all included either “**Clitoris amputated. Raised as a girl**”, or “**Raised as a boy. Plastic operation on hypospadiac penis and scrotum.**”¹⁶⁴ (See **Supplement 3 “Medical Textbooks,” p. 85.**)

Wilkins’ bold new treatment commanded international attention, however, most of his peers remained sceptical about early surgical interventions.¹⁶⁵ The break-through came later in 1950 with Wilkins’ discovery of using **cortisone** to counteract the life-threatening metabolic symptoms of **salt-wasting CAH**, an exceptional form of “female hermaphroditism” presenting not only “ambiguous genitalia”, but also **an actual (metabolical) medical problem**.¹⁶⁶ Wilkins combined this new, for said CAH patients medically necessary treatment with his earlier programme of early genital “corrections”, and used it as the model for a new **uniform treatment policy** for *all* children with variations of sex anatomy that became globally known as the “Baltimore model”. **The medically necessary aspects of the programme were used to ensure compliance as well as a to convince the less surgery-friendly clinicians.** While the new treatment paradigm actually saved lives of babies with salt-wasting CAH, at the same time it condemned not only *all* children with CAH to psychosocially motivated early genital “corrections”, but furthermore *any* child with “atypical genitals”, **irrespective of any actual medical needs** – or lack thereof.

In 1950, while Wilkins established cortisone, up-and-coming Swiss paediatric endocrinologist **Andrea Prader** (1919-2001) was a visiting doctor at Johns Hopkins, and on his return introduced the new programme in Europe. In 1954, Prader developed the influential “**Prader Scale**” soon adopted all over the world as reference to determine whether a clitoris was “enlarged” and needed cutting (**p. 56**), and in 1957 he qualified as a professor with a **habilitation thesis on “Intersexuality”**. In 1962 Prader founded the European Society for

159 Delbert Fisher (2004), A Short History of Pediatric Endocrinology in North America, *Pediatric Research* 55(4):716-726, at 717

160 Alison Redick (2004), *American History XY: The Medical Treatment of Intersex, 1916–1955*, Dissertation, at 234

161 Sandra Eder (2010), ‘The Volatility of Sex: Intersexuality, Gender and Clinical Practice in the 1950s’, *Gender & History* 22(3): 692–707, at 700

162 Lawson Wilkins (1950), *The Diagnosis and Treatment of Endocrine Disorders in Childhood and Adolescence*

163 Ulrike Klöppel (2010), XX0XY ungelöst. Hermaphroditismus, Sex und Gender in der deutschen Medizin. Eine historische Studie zur Intersexualität, at 308-309, 331

164 Lawson Wilkins (1950), *The Diagnosis and Treatment of Endocrine Disorders in Childhood and Adolescence*, at 238, see **Supplement 3 “Medical Textbooks,” p. 85**

165 Elizabeth Reis (2009), *Bodies in Doubt. An American History of Intersex*, at 113

166 Sandra Eder (2011), From ‘following the push of nature’ to ‘restoring one’s proper sex’ – cortisone and sex at Johns Hopkins’s, *Endeavour* 36(2):69-76

Paediatric Endocrinology (ESPE), 1962–1986 he served as director of the Zurich University Children’s Hospital. He became one of the most influential doctors for the global propagation of early “genital corrections” of intersex children.¹⁶⁷

Sexologist **John Money** (1921–2006) gets often erroneously credited for inventing the “Baltimore protocols” and being in charge of treatments, however he only joined the team at Johns Hopkins years after the fact, and was not involved in practical treatment decisions either.¹⁶⁸ In 1952, Money was still at Harvard, completing his doctoral thesis on “*Hermaphroditism*”,¹⁶⁹ which “*somewhat disconcerting[ly]*” found that among intact hermaphrodites who didn’t undergo “surgical corrections”, “*the incidence of the so-called functional psychoses [...] was extraordinarily low*”, i.e., contrary to medical assumptions and beliefs both then and now, actually lower than in the general population.¹⁷⁰ Nonetheless, by 1955 John Money, after following a call to Baltimore, developed a theoretical “**scientific**” rationale for the ongoing systematic early surgeries, proposing children were born as blank slates and gender identity was all nurture, not nature. What’s more, in addition to the already established psychosocial justifications, Money successfully postulated a need for **strict secrecy and non-disclosure (“code of silence”)**, e.g. if at all, patients are told, “*You are a rarity, will never meet another like yourself and should keep your situation secret.*”¹⁷¹ When challenged on lacking evidence for his “*Optimal Gender Policy*” guidelines, Money conducted the infamous “**John/Joan**” twin experiment, having David Reimer, an eight-month-old boy who had lost his penis in a botched circumcision, surgically made into a girl according to the “intersex protocols,” using his identical twin brother Brian as control group. Money published the experiment as a success and publicly never withdrew this claims, despite the fact that David Reimer as a teenager refused to live as a girl,¹⁷² and both “test subjects” later took their own life.

The “**intersex protocols**” developed by Wilkins, Prader, Money et al. included **systematic early “feminising” or “masculinising” “genital corrections”**(p. 63–67, 77–78), often in combination with **gonadectomy / castration / hysterectomy** (p. 67–69, 79) and **imposition of hormones** (p. 70), based on genital appearance and justified by **psychosocial indications**. Within ten years, the “protocols” became the de-facto global standard, and, despite some recent minor modifications, notably a partial relaxation regarding non-disclosure and secrecy (“**code of silence**”, p. 72),¹⁷³ still persist today – same as

167 Ulrike Klöppel (2010), XX0XY ungelöst. Hermaphroditismus, Sex und Gender in der deutschen Medizin. Eine historische Studie zur Intersexualität, at 348

168 Alison Redick (2004), American History XY: The Medical Treatment of Intersex, 1916–1955, Dissertation, at 234

169 John Money (1952), Hermaphroditism: An Inquiry into the Nature of a Human Paradox, doctoral dissertation, Harvard University

170 ISNA, What evidence is there that you can grow up psychologically healthy with intersex genitals (without “normalizing” surgeries)?, online <http://www.isna.org/faq/healthy>; ISNA: Medicalization of Intersexuality: History Resources, online <http://www.isna.org/library/earlyhistory>

171 Milton Diamond (1999), Pediatric Management of Ambiguous and Traumatized Genitalia, The Journal of Urology 162:1021-1028, online: <http://www.hawaii.edu/PCSS/biblio/articles/1961to1999/1999-pediatric-management.html>

172 John Colapinto (2000), As Nature Made Him: The Boy Who Was Raised As A Girl

173 However, the 2008 “Lübeck Intersex Study” with 439 participants (children/parents and adults) from Germany, Austria and Switzerland still found **50% of the children aged 8–12 years were not informed** about why they had to undergo regular medical examinations, and 18–27% of the children aged 13–18 years were not informed about a) the reason why they had genital surgery, that b) their genital (had) looked different, that they c) won’t be able to have biological children, and why. Moreover, 20% of the parents “*could not say whether their children were*

that it's still paediatric endocrinologists assisted by paediatric surgeons that are leading current “multidisciplinary DSD treatments,” and continue to persuade overwhelmed parents to “consent” to unnecessary cosmetic genital surgeries on their “atypical” but healthy children.

1954–Today: The “Prader Scale” as Reference for Systematic Clitoris Amputations/“Reductions” for Psychosocial Reasons

Untouched by World War II, in 1950 the Zurich University Children's Hospital, like Johns Hopkins in Baltimore, already combined a state of the art paediatric endocrine unit as well as an experienced paediatric surgery unit, both specialised in “correcting” “(pseudo) hermaphrodites”, and patients readily available for research purposes. Inspired by his recent stay in Baltimore, Andrea Prader developed a means to standardise the “genital continuum” observed on “virilised” children with Congenital Adrenal Hyperplasia (“female pseudohermaphrodites”) by studying 19 in-clinic patients.¹⁷⁴ His findings, the famous “Prader Scale” published in 1954,¹⁷⁵ divided “atypical” genitals in five stages, henceforth called **“Prader I–V”, separating “Prader 0” (“normal” / “female”) from “Prader I–V” (slightly enlarged clitoris to completely virilised outer appearance).** (Supplement 3, p. 86.)

Until today, the “Prader Scale” remains the **global reference**¹⁷⁶ for endocrinologists, surgeons, and medical guidelines to decide whether an “enlarged clitoris” needs surgical “correction” or can be spared.

The only small adjustment since 1954, arguably due to the growing public controversy about unwanted cosmetic clitoris “corrections”: While the **standard for surgery set by Prader and his chief surgeon, Max Grob** (1901-1976), director of the Zurich paediatric surgery unit 1939-1971, recommended clitorises classified “Prader II–V” to be “*surgically corrected*” by “*amputation*” (p. 64, 86)¹⁷⁷ the international “DSD Consensus Statement 2006” generously recommends leaving children classified “Prader II” intact – however still recommends the cutting of “enlarged clitorises” classified as “*cases of severe virilization (Prader III–V).*”¹⁷⁸ Notably with the very same **psychosocial justifications** already brought forward by Prader and Grob, maintaining “*It is generally felt that surgery that is carried out for cosmetic reasons in the first year of life relieves parental distress and improves attachment between the child and the parents [48–51]; the systematic evidence for this belief is lacking.*”¹⁷⁹

informed or not that they couldn't have biological children”, and 71 parents initially responding to participate in the study later declined “mostly” because their children were “not or only little informed about their difference in sex development”, hinting at even higher levels of non-disclosure in the general intersex populace outside the study. Eva Kleinemeier, Martina Jürgensen (2008), Erste Ergebnisse der Klinischen Evaluationsstudie im Netzwerk Störungen der Geschlechtsentwicklung/Intersexualität in Deutschland, Österreich und Schweiz, Januar 2005 bis Dezember 2007, at 32-33 and 13

174 Max Grob (1957), Lehrbuch der Kinderchirurgie, at 583, see p. 86

175 Andrea Prader (1954), Der Genitalbefund beim Pseudohermaproditismus femininus des kongenitalen adrenogenitalen Syndroms. Morphologie, Häufigkeit, Entwicklung und Vererbung der verschiedenen Genitalformen, Helvetica Paediatrica Acta 9: 231-248

176 see e.g. NIH, The Prader Scale https://science.nichd.nih.gov/confluence/download/attachments/23920688/Prader_Scale.pdf; Universitäts-Klinikum Gießen, Genital Status, at 2: http://www.ukgm.de/ugm_2/deu/ugi_kia/PDF/Anforderungsschein_GC-MS_Urinsteroidprofil_%281%29.pdf

177 Max Grob (1957), Lehrbuch der Kinderchirurgie, at 587, see p. 86

178 Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes, LWPES/ESPE Consensus Group (2006), Consensus statement on management of intersex disorders, Pediatrics 118:e488-e500, at e491

179 *ibid.* (emphasis added)

1955–1993: Doctors claim “No Evidence for Loss of Orgasm after Clitoris Amputation”, link Surgeries to FGM

To counter criticism of the newly established “intersex protocols” recommending **systematic amputation and raising the infant as female** whenever an “enlarged” clitoris was deemed “too big” for a newborn girl (i.e. bigger than 9 mm¹⁸⁰), or a “micropenis” was deemed “too small” for a “successful” boy (i.e. smaller than 2.5 cm¹⁸¹), John Money and fellow Hopkins psychologist couple Joan and John Hampson conducted two studies on 6 respectively 12 patients. Despite the small cohort, and the fact that many had clitorectomy in infancy and therefore no possibilities of a comparison, Money and the Hampsons thereafter again and again claimed:

“There has been no evidence on the deleterious effect of clitoridectomy. None of the women experienced in genital practices reported a loss of orgasm after clitoridectomy.”¹⁸²

*“As far as it goes, the evidence demonstrates that clitoral amputations in childhood or later proved detrimental neither to subsequent responsiveness, nor to capacity for orgasm.”*¹⁸³

Money himself published these and similar claims until at least 1961.^{184 185} The Hampsons’s and Money’s “evidence” based on 6 respectively 12 patients was **instrumental in convincing hesitant doctors** to adopt the new model of systematic early genital “corrections”,¹⁸⁶ and was regularly quoted, e.g. in the influential textbook on “Intersexuality” (original German edition 1961, international English edition 1962):

*“As Hampson (1956) was able to show in a large series of women subjected to operation, removal of the clitoris does not interfere with the ability to achieve orgasm.”*¹⁸⁷

Another influential statement widely quoted for decades by clinicians in order to vindicate systematic genital “corrections” came from three Harvard paediatric surgeons, who, denouncing colleagues still “reluctant to advocate excision of even the most grotesquely enlarged clitoris” on the basis of “the belief that the clitoris is necessary for normal sexual function”, in 1966 openly **linked western clitoris amputations to FGM**, justifying the former by the alleged “proven harmlessness” of the latter:

“Evidence that the clitoris is not essential for normal coitus may be gained from certain sociological data. For instance, it is the custom of a number of African tribes to excise the clitoris and other parts of the external genitals. Yet normal sexual function is observed in these females.”¹⁸⁸

180 Suzanne Kessler (1998), *Lessons from the Intersexed*, at 43

181 *ibid.*

182 John Money, Joan G. Hampson, John L. Hampson (1955), *Hermaphroditism: Recommendations Concerning Assignment of Sex, change of sex, and psychologic management*, *Bulletin of the Johns Hopkins Hospital* 97(4): 284-300, at 295

183 Joan G. Hampson (1955), *Hermaphroditic genital appearance, rearing and eroticism in hyperadrenocorticism*, *Bulletin of the Johns Hopkins Hospital* 96(6):265–273, at 270

184 Katrina Karkazis (2008), *Fixing Sex. Intersex, Medical Authority, and Lived Experience*, at 149

185 Ulrike Klöppel (2010), *XX0XY ungelöst. Hermaphroditismus, Sex und Gender in der deutschen Medizin. Eine historische Studie zur Intersexualität*, at 318

186 *ibid.*

187 Jürgen R. Bierich (1962), *The Adrenogenital Syndrome*, in: Claus Overzier (ed.), *Intersexuality*, 345–386

188 Robert E. Gross, Judson Randolph, John F. Crigler (1966), *Clitorectomy for Sexual Abnormalities: Indications and Technique*, *Surgery* 59: 300-308

Matter-of-factly **likening of intersex “corrections” to FGM amongst doctors** “correcting” intersex children were not uncommon. From a 1976 German medical dissertation (also emphasising the “social significance” of FGM):

“Lesser known is the circumcision of girls. BRYK’s (1931) and JENSEN’s (1933) investigations of African primitive tribes describe circumcisions or incisions of the clitoris on adolescent girls. LAMBERT (1956) reveals the social significance of these acts in his study ‘Kikuyu: social and political institutions’ [...]

***In paediatrics, the indication to clitorrectomy is given if, within the context of virilisation of girls, an excessive growth of the clitoris occurs. [...]**”¹⁸⁹*

As late as in **1993**, none of his peers publicly disputed a paediatric surgeon when he wrote in a peer-reviewed publication that in forty years of clitoral surgery on intersex children, **“not one has complained of loss of sensation, even when the entire clitoris was removed.”**¹⁹⁰

However, later in 1993 survivors of genital “corrections” broke the “code of silence” implemented in “intersex protocols” since 1955, and organised and spoke out publicly for the first time (see p. 59), ending **four decades** of doctors’ claims of “no complaints by patients” and **“no evidence of harm from clitoris amputations on children”**.

What remains until today are the ongoing “corrections”, as well as the ongoing medical denial of the consequences to the children concerned (henceforth under the new motto “surgery is better now”, see p. 59), including the repetition of the same old excuses, e.g. **“adequate intercourse was defined as successful vaginal penetration.”**¹⁹¹

1960s: 1st Genetics Boom

The discovery of the karyotypes XXY (Klinefelter Syndrome) and XO (Turner Syndrome) in 1959, and the ensuing decade-long search for a testis-determining factor (TDF) on the Y chromosome triggered by the latter, brought mounting interest by genetics in **intersex for research purposes**. Due to the increasing availability of genetic testing for X and Y chromosomes (sex chromatin or barr body test), geneticists became more involved in the **day-to-day diagnostics and medical treatments** of intersex children.

1970s: 1st Hypospadias “Repair” Boom

The development of more surgical techniques in combination with advances in anaesthesia led to a significant **increase in hypospadias “repair” surgery**,¹⁹² especially in “minor cases” that earlier were more often left intact. At the same time, a large move within paediatric

189 Hans Martin Wisseler (1976), Harnwegsinfektionen nach Klitorektomien bei Mädchen mit kongenitalem adrenogenitalem Syndrom (AGS), medical doctoral thesis, at 1

190 Milton T. Edgerton (1993), Discussion: Clitoroplasty for Clitoromegaly due to Adrenogenital Syndrome without Loss of Sensitivity (by Nobuyuki Sagehashi), Plastic and Reconstructive Surgery 91:956

191 See the comments of John P. Gearhart in Maria M. Bailez, John P. Gearhart, Claude Migeon, John A. Rock (1992), Vaginal Reconstruction After Initial Construction of the External Genitalia in Girls with Salt-Wasting Adrenal Hyperplasia, Journal of Urology 148: 680-684, at 684; for criticism by persons concerned see e.g. Cheryl Chase, Affronting Reason, in: Dawn Atkins (ed.): Looking Queer (1998), 205-219

192 e.g. **“In the Unites States, the rate of hypospadias doubled from 1970-1993.”** John M Gatti, Hypospadias: Frequency, Medscape, online: <http://emedicine.medscape.com/article/1015227-overview#a0199>

atrics as a whole to encourage parents to stay with their child led to **recommendations of earlier “corrections”**.¹⁹³ In 1973, the diagnosis **“hypospadias cripple”** is coined, to describe “hopeless cases” after repeat “failed hypospadias repair.”¹⁹⁴

1993–Today:

“Unfortunately the surgery is immensely destructive of sexual sensation and of the sense of bodily integrity” – IGM Survivors Organise and Speak Out

In 1993, Cheryl Chase announced the formation first intersex NGO, the Intersex Society of North America (ISNA), publicly refuting four decades of doctor’s claims of “no harm from clitoris amputations” and “no one ever complained” (see **p. 58**), as well as denouncing the biased societal and cultural traditions at the core of IGMs:

*“Medical dogma on sex assignment of intersexuals centers on the “adequacy” of the penis. Because a large penis cannot be constructed from a small one, female assignment is preferred. Because a large clitoris is considered “disfiguring”, extensive surgery is employed to remove, trim, or relocate it. While a male with an “inadequate” penis (small, but with normal erotic sensation) is considered tragic, the same individual transformed into a female with reduced or absent genital sensation and an artificial vagina is considered normal. The capacity to inflict such monstrous “treatment” on children, who cannot consent, is ultimately a clear expression of the hatred and fear of sexuality which predominate in our culture.”*¹⁹⁵

In the following 21 years, dozens of other intersex NGOs were founded, and countless survivors have spoken out publicly against IGMs, while not one came forward to back the doctor’s claim of “happy patients.”

1993–Today: Doctors claim “Surgery is better now”

As a response to criticisms by survivors regarding harm and damage done by IGMs, doctors quickly changed their earlier mantra of “no evidence of harm” and “no complaints” to “surgery is better now,” however again without evidence, and still refusing to collect and analyse outcomes.¹⁹⁶

1990s–Today: 2nd Hypospadias “Repair” Boom

By the mid 1995, doctors are so bent on operating, that in a sample of 500 adult “normal” men presenting for prostate surgery, 225 men were classified as “suffering” from an “abnormal” position of the meatus – despite no complaints, “normal” function and lack of awareness of their “abnormality” even in patients diagnosed with “significant hypospadias.”¹⁹⁷ With still increasing rates of hypospadias “repair,” eventually the timing and psychosocial rationale becomes aligned with that of with the ongoing “feminising corrections” of intersex children.¹⁹⁸

193 Christopher R.J. Woodhouse, Deborah Christie (2005), Nonsurgical factors in the success of hypospadias repair, *British Journal of Urology International* 96(1):22-27

194 Stecker JF, Horton EC, Devine JE, McCraw J (1981), Hypospadias cripples. *Urol Clin North Am* 8:539–545

195 Cheryl Chase (1993), Letter to The Sciences RE: The Five Sexes, *The Sciences* 3, <http://www.isna.org/articles/chase1995a>

196 Cheryl Chase (1998), Surgical Progress Is Not the Answer to Intersexuality, in: Alice Dreger (ed.) (1999), *Intersex in the Age of Ethics*:148–159

197 J. Fichtner, D. Filipas, A. M. Mottrie, G. E. Voges, R. Hohenfellner (1995), Analysis of meatal location in 500 men: Wide variation questions need for meatal advancement in all pediatric anterior hypospadias cases, *Journal of Urology* 154:833-834

198 Ricardo González, Barbara M. Ludwikowski (2014), Should the genitoplasty of girls with CAH

1998: Call for a Moratorium on Non-Consensual Cosmetic Genital Surgeries on Intersex Children until Evidence of Benefits for Intersex Persons themselves

In 1998, Milton Diamond and Kenneth Kipnis revealed the true outcome about John Money's infamous twin experiment used for decades to justify IGM, and proposed three recommendations:

1. *"That there be a general moratorium on such surgery when it is done without the consent of the patient."*
2. *"That this moratorium not be lifted unless and until the medical profession completes comprehensive look-back studies and finds that the outcomes of past interventions have been positive."*
3. *"That efforts be made to undo the effects of past physician deception."*¹⁹⁹

Diamond et al. upheld these recommendations repeatedly during the following years, backing them up with medical evidence,²⁰⁰ ethics and legal considerations,^{201 202} and analysis on recent historical and current developments.^{203 204}

While a limited medical debate ensued, and some clinicians welcomed the proposals, mostly they were just **ignored or discredited by clinicians concerned**,²⁰⁵ **often explicitly referring to "cultural beliefs" and societal "traditions,"** while at the same time blatantly disregarding ethics and/or human rights considerations.²⁰⁶

be done in one or two stages?, *Frontiers in Pediatrics*, <http://journal.frontiersin.org/Journal/10.3389/fped.2013.00054/full>

199 Kenneth Kipnis, Milton Diamond (1998), *Pediatric Ethics and the Surgical Assignment of Sex*, *The Journal of Clinical Ethics*, Volume 9(4):398-410, <http://www.hawaii.edu/PCSS/biblio/articles/1961to1999/1998-pediatric-ethics.html>

200 Milton Diamond (1999), *Pediatric Management of Ambiguous and Traumatized Genitalia*, *Journal of Urology* 162:1021-8, <http://www.hawaii.edu/PCSS/biblio/articles/1961to1999/1999-pediatric-management.html>

201 Hazel Glenn Beh, Milton Diamond (2000), *An Emerging Ethical and Medical Dilemma: Should Physicians Perform Sex Assignment on Infants with Ambiguous Genitalia?*, *Michigan Journal of Gender & Law* 7(1):1-63, <http://www.hawaii.edu/PCSS/biblio/articles/2000to2004/2000-emerging-ethical-dilemma.html>

202 Hazel Glenn Beh, Milton Diamond (2005), *David Reimer's Legacy: Limiting parental discretion*, *Cardozo Journal of Law & Gender*. Vol. 12:(1):5-30, <http://www.hawaii.edu/PCSS/biblio/articles/2005to2009/2006-david-reimers-legacy.html>

203 Milton Diamond (2004), *Sex, Gender, and Identity over the Years: A changing perspective*, *Child and Adolescent Psychiatric Clinics of North America*, 13:591-607, <http://www.hawaii.edu/PCSS/biblio/articles/2000to2004/2004-sex-gender-and-identity.html>

204 Milton Diamond (2004), *Pediatric Management of Ambiguous and Traumatized Genitalia*, *Contemporary Sexuality*. 38(9):i-viii, <http://www.hawaii.edu/PCSS/biblio/articles/2000to2004/2004-pediatric-management.html>

205 Laura Hermer (2002), *Paradigms Revised: Intersex Children, Bioethics & the Law*, *Annals of Health Law* 11(1):195-236, <http://lawcommons.luc.edu/cgi/viewcontent.cgi?article=1263&context=annals>

206 *"First, the ultimate decision regarding early surgery rests with the parents and should be made in the context of their own cultural beliefs [...]. Affording parents this authority does not present an ethical dilemma, since in our society all major decisions regarding minor children are traditionally made by parents."*

Erica A. Eugster (2004), *Invited Critique*, *Archives of Pediatrics and Adolescent Medicine* 158(5):428-429, <http://www.childrensmc.org/content/uploadedFiles/Health%20Care%20Professionals%20and%20Intersex%20Conditions.pdf>

4. 21st Century: “DSD” Nomenclature Shift – IGM persists

2005: Medical Nomenclature Shift from “Intersex Disorders” to “Disorders of Sex Development (DSD)”

The current medical term “Disorders of Sex Development”, mostly referred to by the acronym “DSD,” was introduced at the **“Chicago Consensus Conference 2005”** with limited input by persons concerned, but in an intransparent way and without proper consultation.²⁰⁷ The new nomenclature also included a **new taxonomy** based on karyotype and focused on conditions (instead of the persisting “Pseudo Hermaphrodite” taxonomy based on gonadal status and focused on “male” and “female”), also the new taxonomy was supposed to more clearly include genital variations irrespective of gender of rearing issues, such as hypospadias, Klinefelter, and MRKH,^{208 209} reflecting the new definition **“congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical.”**²¹⁰ Furthermore, in some cases a more cautious approach to early surgery was suggested.

While the use of an acronym for medical purposes, the new taxonomy focused on conditions, clearer inclusion of all genital variations, and the instances of calling for more caution regarding early surgeries were welcomed by persons concerned and their organisations, the term **“disorders” was unequivocally abhorred** and condemned within the community,²¹¹ because it frames the persons concerned as in need of being (surgically) “put in order”, or “fixed”, e.g. to *“relieve[...] parental distress”*.²¹² However, clinicians readily embraced “disorders.” “Variations of Sex Development (VSD)”²¹³ was proposed as a less stigmatising alternative in 2006, but rejected by medicine arguing the acronym VSD was already taken. Nonetheless, another proposal in 2008 of “Differences of Sex Development”²¹⁴ keeping the DSD acronym has been equally refused by doctors.

207 Peter Trinkl (2006), I Am Neither “Pseudo” nor “Disordered”, in: Proceedings of the ISNA/GLMA DSD Symposium: 48-49, http://www.isna.org/files/DSD_Symposium_Proceedings.pdf

208 David Sandberg PhD, Cheryl Chase, Eric Vilain: Report on Chicago Consensus Conference, in: Proceedings of the ISNA/GLMA DSD Symposium (2006): 17-38, at 22, http://www.isna.org/files/DSD_Symposium_Proceedings.pdf

209 Barbara Thomas: The Chicago Consensus – a patient perspective, at 2, <http://www.aissg.org/PDFs/Barbara-Lubeck2-Talk.pdf>

210 Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes, LWPES/ESPE Consensus Group (2006), Consensus statement on management of intersex disorders, Pediatrics 118:e488-e500, at e488, <http://pediatrics.aappublications.org/content/118/2/e488.full.pdf>

211 Peter Trinkl (2006), I Am Neither “Pseudo” nor “Disordered”, in: Proceedings of the ISNA/GLMA DSD Symposium: 48-49, http://www.isna.org/files/DSD_Symposium_Proceedings.pdf

212 **“It is generally felt that surgery that is performed for cosmetic reasons in the first year of life relieves parental distress and improves attachment between the child and the parents [48–51]; the systematic evidence for this belief is lacking.”** Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes, LWPES/ESPE Consensus Group (2006), Consensus statement on management of intersex disorders, Pediatrics 118:e488-e500, at e491, <http://pediatrics.aappublications.org/content/118/2/e488.full.pdf>

213 Milton Diamond, Hazel Beh (2006), Variations of Sex Development Instead of Disorders of Sex Development, Letter to the Editor, published in: Archives of Disease in Childhood (26 July 2006), <http://www.hawaii.edu/PCSS/biblio/articles/2005to2009/2006-variations.html>

214 Milton Diamond, Hazel Beh (2008), Changes in the Management of Children with Intersex Conditions, Nature Clinical Practice, Endocrinology & Metabolism 4(1), <http://www.hawaii.edu/PCSS/biblio/articles/2005to2009/2008-changes-in-management.html>

2000s–Today: Doctors claim, “Hypospadias Repair, Clitoral Reductions and Vaginoplasty Not Really Intersex Surgeries”

With increasing public debate and criticism of IGMs, doctors again referred to the proven old methods narrowing intersex definitions in an effort to exclude the vast majority of IGMs from public, ethics and legal scrutiny, specifically hypospadias “corrections” and “feminising” procedures for 46,XX CAH. Persons concerned and their organisations have denounced this endeavour as an obvious ruse.^{215 216}

2000s–Today: 2nd Genetics Boom

With greater affordability of advanced genetics analysis instruments on the molecular level, genetics gained major influence especially in intersex human experimentation, but also regarding the course of IGMs. Today, most big intersex “research” projects are genetics driven (eg. “EuroDSD”, “DSDnet”, see **p. 19**), and genetics plays a major role in most IGM “treatments”.

2010s: Criticism by Human Rights Bodies – IGMs persist

In the past decade, IGMs finally started being recognised as the serious human rights violations that they are by some ethics, government and international human rights bodies (see **Bibliography**).

However, IGMs still persist, and even worse, **total numbers** of non-consensual, unnecessary, early genital surgeries on intersex children **are internationally increasing** (see **p. 17–19 “How Common are Intersex Genital Mutilations?”**).

215 Zwischengeschlecht.info (2011), Intersex: Warum eine Diskussion um die Beendigung kosmetischer Genitaloperationen an Kindern unter Ausklammerung von “Hypospadiekorrekturen” unethisch ist, <http://blog.zwischengeschlecht.info/post/2011/10/04/Ausklammerung-Hypospadiе-unethisch>

216 Katrina Karkazis (2008), Fixing Sex. Intersex, Medical Authority, and Lived Experience, at 143-44

Supplement 2 “Most Common Forms of IGMs”

The following itemisation focuses on the most egregious and well known practices, based on claims that can be readily documented in the medical literature, in official publications, or have been reported by persons concerned to the organisations compiling this NGO Report. **Injuries suffered by intersex people have not been adequately documented**, neither in Switzerland nor elsewhere, and additional *disinterested* research is needed in this area to document widespread anecdotal reports of additional harm stemming from unnecessary and harmful medical treatment, and to collect, summarise, and analyse the reports that have been documented.²¹⁷

a) Clitoris Amputation/“Reduction”/“Recession”

In Western Medicine, **clitoris amputations, or clitoridectomies on children with “enlarged clitorises”** have been infrequent but not uncommon since at least the 19th century. In 1950, when systematic early “genital corrections” on intersex infants were introduced in Baltimore and Zurich (see **Supplement 1 “Historical Overview,” p. 54**), clitoris amputations on intersex children took a sharp rise, soon becoming the **predominant treatment for “ambiguous children”** for more than four decades, according to the infamous surgeon’s motto “*you can dig a hole, but you can’t build a pole*”,²¹⁸ i.e. it’s surgically possible to remove an “enlarged clitoris” (i.e. longer than 9 mm) or an “inadequately small penis” (i.e. shorter than 2.5 cm), as well as to enlarge an existing “insufficient vagina” or create an artificial “neo vagina”, but it’s surgically not possible to actually build an “adequate penis”. While more “advanced” techniques of clitoridectomy dubbed “clitoral recession” and “clitoral reduction” were introduced in the 1960s, clitoris amputations persisted until the 1990s (**Supplement 1 “Historical Overview,” p. 50**).

The most common and well-known diagnoses leading to surgical “corrections” of “enlarged clitorises” include **46,XX Congenital Adrenal Hyperplasia (CAH)**, i.e. persons with karyotype XX, uterus and ovaries, but “masculinised” external “in-between” genitals due to prenatal exposure to testosterone produced in the adrenal glands (instead of cortisol), and **46,XY Partial Androgen Insensitivity Syndrome (PAIS)**, i.e. persons with karyotype XY, (often undescended) testicles and “undermasculinised” external “in-between” genitals due to an unusually low ability of their bodies to respond to androgens, or “male sex hormones”, e.g. testosterone.

Switzerland and the **Zurich University Children’s Hospital** in particular were crucial for the global propagation of early “genital corrections” on intersex children,²¹⁹ including

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- 217 Rare examples of publications documenting and reviewing reports by persons concerned include:
- J. David Hester (2006), *Intersex and the Rhetorics of Healing*, in: Sharon Sytsma (ed.) (2006), *Ethics and Intersex*: 47–72
 - Cheryl Chase (1998), *Surgical Progress Is Not the Answer to Intersexuality*, in: Alice Dreger (ed.) (1999), *Intersex in the Age of Ethics*: 148–159
 - Katrina Karkazis (2008), *Fixing Sex: Intersex, Medical Authority, and Lived Experience*
 - Kathrin Zehnder (2010), *Zwitter beim Namen nennen. Intersexualität zwischen Pathologie, Selbstbestimmung und leiblicher Erfahrung*
 - Claudia Lang (2006), *Intersexualität. Menschen zwischen den Geschlechtern*
- 218 Cheryl Chase (2002), “Cultural Practice” or “Reconstructive Surgery”? U.S. Genital Cutting, the Intersex Movement, and Medical Double Standards, in: Stanlie M. James, Claire C. Robertson (eds.) (2002), *Genital Cutting and Transnational Sisterhood. Disputing U.S. Polemics*: 126–151, quoting Melissa Hendricks (1993), *Is it a Boy or a Girl?*, *Johns Hopkins Magazine* 45(5), at 10
- 219 Ulrike Klöppel (2010), *XX0XY ungelöst. Hermaphroditismus, Sex und Gender in der deutschen*

clitoris amputations (**Supplement 1 “Historical Overview,” p. 54, p. 56**). The influential 1957 “Textbook on Paediatric Surgery” by Max Grob²²⁰ (director of the Zurich paediatric surgery unit 1939–1971, founder and first president of the Swiss Society for Paediatric Surgery, honorary member of the German, Austrian, British and U.S. societies), in 2009 still hailed as “*internationally renowned*” and “*translated in 6 languages*” by the Zurich University Children’s Hospital,²²¹ stated (**Supplement 3 “Medical Textbooks,” p. 86**):

“Surgical correction of the exterior genital: In pseudohermaphroditismus femininus, the surgical correction of the exterior genital, i.e. the removal of the enlarged clitoris and the exposure of the vaginal opening in the described Prader Stages II–V, suggests itself. The amputation of the clitoris, which may appear bothersome due to its size and erections, and may lead to embarrassment for these girls in the changing room or while swimming, is surely justified [...].

*Technique: [...] Usually we leave a very short clitoris stump [...].”*²²²

In Switzerland, clitoris amputations justified by psychosocial indications were taught in university paediatric surgery courses as a suitable “*therapy*” for intersex children diagnosed with “*hypertrophic clitoris*” until at least 1975.²²³

While “clitoral recession” and “clitoral reduction”, the more “advanced” current techniques of clitoridectomy subsumed in medical publications under “clitoroplasty”, aim at preserving the main nerve bundle as well as sexual sensation, it’s still a massive intervention that involves cutting the clitoris into three “stripes”, with of most of the organ, often including parts of the glans, gets cut off (**Supplement 3 “Medical Textbooks,” p. 78**). **Persons concerned** still report e.g. loss or impairment of sexual sensation and painful scars (see **Cases No. 2** and **3**), claims that have also been again and again corroborated by medical studies, e.g.:

*“Adult women who have undergone clitoral surgery in infancy report reduced sexual sensation and poorer sexual function when compared to normal controls and also to women with clitoromegaly who had not undergone surgery.”*²²⁴

Tellingly, a popular paediatric surgeon’s joke of on the topic of potential loss of sexual sensation goes, “*They won’t know what they’re missing!*”²²⁵

Justifications for current “clitoris reductions” on children remain **psychosocial**,²²⁶ strikingly similar to those offered by Max Grob 1957 (see above).

Medizin. Eine historische Studie zur Intersexualität, at 348

220 Max Grob (1957), Lehrbuch der Kinderchirurgie, unter Mitwirkung von Margrit Stockmann und Marcel Bettex, see **Supplement 3 “Medical Textbooks” p. 86**

221 Reinhard Seger (2009), Vorreiter der Forschung, in: Kinderspital Zürich (ed.), Forschungsmagazin 3 / 2009: 18–20, at 19, <http://www.kispi.uzh.ch/Kinderspital/Forschungsmagazin09.pdf>

222 Max Grob (1957), Lehrbuch der Kinderchirurgie, unter Mitwirkung von Margrit Stockmann und Marcel Bettex, at 587 (bold in original), see **Supplement 3 “Medical Textbooks” p. 86**

223 Marcel Bettex, François Kuffer, Alois Schärli (1975), Wesentliches über die Kinderchirurgie [paediatric surgery lecture notes], at 255, see **Supplement 3 “Medical Textbooks” p. 87**

224 Sarah Creighton, Steven D. Chernausek, Rodrigo Romao, Philip Ransley, Joao Pippi Salle (2012), Timing and nature of reconstructive surgery for disorders of sex development – Introduction, Journal of Pediatric Urology 8(6):602–10, at 603

225 Personal communication by a doctor attending the 23rd Annual Meeting of ESPU, Zurich 2012

226 Sarah Creighton, Steven D. Chernausek, Rodrigo Romao, Philip Ransley, Joao Pippi Salle (2012), Timing and nature of reconstructive surgery for disorders of sex development – Introduction, Journal of Pediatric Urology 8(6):602–10, at 604: “*There is a perception that girls with virilized genitalia left intact may suffer unwarranted social interactions with their peers (e.g. the **locker room** time at school), leading to **embarrassment** and social withdrawal.*”

Nonetheless, and despite public denials by doctors, systematic “clitoris reductions” as early as possible (e.g. 0–12 months)²²⁷ are still considered imperative for intersex children in western paediatric clinics, including Swiss university children’s hospitals (see **B 3. “How Common are Intersex Genital Mutilations?”**, as well as **Cases No. 2–6**).

b) Hypospadias “Repair”

Hypospadias is a medical diagnosis describing a penis with the **urethral opening** (“meatus”, or “pee hole”) **not situated at the tip of the penis**, but somewhere below on the underside, either still on the glans (“distal” or “anterior”), or farther below somewhere on the shaft (“middle”), or on the scrotum (“proximal”, or “posterior”), due to incomplete tubularisation of the urethral folds during prenatal formation of the penis (see **p. 10 “Genital Development and Appearance”**).

In addition, hypospadias is often associated with a downward curvature of the penis, especially when erect (“chordee”), in shape resembling the (mostly internal) structures of the clitoris. In about 10% of cases, hypospadias is associated with undescended testes. Sometimes, hypospadias is also associated with an unusually small penis (“micropenis”). Mostly, hypospadias is associated with a hooded appearance of the foreskin (untubularised foreskin), again slightly resembling the clitoral hood.

Hypospadias “repair” surgery aims at **“relocating” the urethral opening** to the tip of the penis, and, if applicable, to straighten the penis. The penis is sliced open, and an artificial “urethra” is formed out of the foreskin of skin grafts (see **Supplement 3 “Medical Textbooks”, p. 77**). **Switzerland** was leading in introducing hypospadias surgeries in German language European countries after World War II.²²⁸

While in very rare cases hypospadias can be associated with an urethral opening too small to allow unobstructed passing of urine, which makes appropriate surgical intervention (and only such) a medical necessity, and in older boys curvature can sometimes be associated with pain during (involuntary) erections, which also constitutes an actual medical problem, these are the only exceptions to the rule that hypospadias per se does *not* constitute a medical necessity for interventions.

Furthermore, since the ongoing 2nd “Hypospadias Boom” (**Supplement 1 “Historical Overview,” p. 59**) doctors are so bent on operating, that in a sample of 500 adult **“normal” men** presenting for prostate surgery, 225 men, i.e. **45%** were classified as “suffering” from an “abnormal” position of the meatus – despite no complaints, “normal” function and lack of awareness of their “abnormality”: *“However, all patients participated in sexual intercourse without problems and were able to void in a standing position with a single stream,”* all were *“without complaints about cosmetic or functional aspects,”* even those with *“significant hypospadias.”* What’s more, all but one homosexual patient had fathered children, and even in patients diagnosed with *“significant hypospadias,”* 60% of the patients and 55% of their partners were *“unaware of the abnormality.”*²²⁹

227 Barry Kogan, David Sandberg, Melissa Gardner, Tola Oyesanya, Dan Anderson, Patricia Szmál (2012), Changes in Urologist DSD Treatment Recommendations from 2003 to 2011, Programme of the 23rd Annual Meeting of ESPU, Zurich May 09-12, at 314, http://www.espu2012.org/images/ESPU_2012_Programme.pdf

228 E.g. Ernst Bilke, born 1958 in South Germany, was sent to Basel for paediatric hypospadias “repair”, because the local German doctors refused to do it, wanting to make him into a girl instead, see Ulla Fröhling (2003) *Leben zwischen den Geschlechtern. Intersexualität – Erfahrungen in einem Tabubereich*, at 90–105

229 J. Fichtner, D. Filipas, A. M. Mottrie, G. E. Voges, R. Hohenfellner (1995), Analysis of meatal

Hypospadias “repair” is notorious²³⁰ for very **high complication rates**, e.g. 42%–57%,²³¹ as well as for grave complications which can result in serious medical problems where none had been before (for example urethral strictures have lead to kidney failure requiring dialysis), and frequent “redo-surgeries”. Tellingly, for more than 30 years, surgeons have been officially referring to “hopeless” cases of repeat failed “repair” surgeries as “**hypospadias cripples**” (i.e. made to a “cripple” by unnecessary surgeries, not by the condition!).²³² However, as a 2012 international medical conference in Switzerland revealed, in medical publications on hypospadias, “[d]ocumentation on complication rates has declined in the last 10 years.”²³³

For more than 15 years, persons concerned have been criticising **impairment or loss of sexual sensitivity**²³⁴ (see also **Case No. 1**):

*“My childhood was filled with pain, surgery, skin grafts, and isolation. And I still have to sit to pee.”
“It would have been just fine to have a penis that peed out of the bottom instead of the top, and didn’t have the feeling damaged.”*²³⁵

However, doctors still refuse to even listen to these serious claims, as well as to undertake appropriate long-term outcome studies.

The **justification** for early surgeries is **psychosocial**, e.g. to allow for “sex-typical manner for urination (i.e. standing for males)”, as well as for “vaginal-penile intercourse”.²³⁶ According to a **Swiss “pilot study”**, surgery is “intended to change the anatomy such that the penis looks normal.”²³⁷ The effective AWMF guidelines with direct Swiss participation explicitly include “aestetical-psychological reasons.”²³⁸

Nonetheless, despite lack of evidence for benefits for children concerned, but abundant evidence for (massive) harm due to repeat surgeries, systematic hypospadias “repair” as early as within the first 18 months²³⁹ is still considered imperative for children concerned in western

location in 500 men: Wide variation questions need for meatal advancement in all pediatric anterior hypospadias cases, *Journal of Urology* 154:833-834

230 e.g. Guido Barbaglia (2010), Failed Hypospadias Repair. How Often Is It, and How to Prevent It?, <http://www.failedhypospadias.com/files/Belgrado2.pdf>

231 Pierre Mouriquand (2006), Surgery of hypospadias in 2006 – Techniques & outcomes, Symposium International de Paris – Surgery of hypospadias in 2006, slides 13, 15, http://www.canal-u.tv/video/canal_u_medicine/symposium_international_de_paris_surgery_of_hypospadias_in_2006_techniques_and_outcomes.2212

232 e.g. *ibid.*, slide 19

233 Katherine Pfistermuller, Peter Cuckow (2012), Analysis of Data Quality from 30 Years of Published Data on Hypospadias Outcomes, Programme of the 23rd Annual Meeting of ESPU, Zurich May 09-12, at 204, http://www.espu2012.org/images/ESPU_2012_Programme.pdf

234 Zwischengeschlecht.info (2012), “Sehr taube Eichel nach Operation” vs. “unbehandelt gut leben”: Erfahrungsberichte zu Hypospadie, blog.zwischengeschlecht.info/post/2012/04/13/Erfahrungsberichte-zu-Hypospadie

235 Tiger Howard Devore (1997/1999), Growing up in the surgical Maelstrom, in: Alice Dreger (ed.) (1999), *Intersex in the Age of Ethics*: 79-82. <http://www.isna.org/books/chrysalis/mcclintock>

236 Sarah Creighton, Steven D. Chernausk, Rodrigo Romao, Philip Ransley, Joao Pippi Salle (2012), Timing and nature of reconstructive surgery for disorders of sex development – Introduction, *Journal of Pediatric Urology* 8(6):602-10, at 603

237 Daniel Weber, Verena Schönbucher, Rita Gobet, A. Gerber, MA. Landolt (2009), Is there an ideal age for hypospadias repair? A pilot study, *Journal of Pediatric Urology* 5(5):345–350, at 351

238 Deutsche Gesellschaft für Kinderchirurgie (2002), AWMF-Leitlinie 006/026 Hypospadie, http://www.awmf.org/uploads/tx_szleitlinien/006-026.pdf

239 Daniel Weber, Verena Schönbucher, Rita Gobet, A. Gerber, MA. Landolt (2009), Is there an

paediatric clinics, including Swiss university children's hospitals (see **p. 17 “How Common are Intersex Genital Mutilations?”**, as well as **Cases No. 1 and 6**). Today, hypospadias “repair” is arguably by far the **most frequent** cosmetic genital surgery done on children with variations of sex anatomy.

c) Castrations / “Gonadectomies” / Hysterectomies / (Secondary) Sterilisation

Medically unnecessary surgical removal of healthy hormone-producing organs and reproductive organs (testes, ovaries, gonads, uterus) have been common in intersex treatments for a wide range of diagnoses, e.g.:

46,XY Complete Androgen Insensitivity Syndrome (CAIS), i.e. persons usually living as females, with female exterior primary and secondary sex characteristics due to their bodies not being able to “use” (or “respond” to) testosterone produced by the (usually undescended) testes during gestation and after puberty, however converting the “unusable” testosterone via aromatisation into natural, “usable” oestrogens leading to female physical appearance. Nonetheless, their healthy and health-necessary testes are removed soon after diagnosis on the grounds of an alleged, but non-factual “high cancer risk” (actual cancer risk: 0.8%²⁴⁰, see **Table p. 79**), as well as an alleged, but unproven “*psychological benefit*” to removing structures discordant with sex assignment.²⁴¹ Persons concerned (and parents) are often wrongly told by doctors that “*cancerous*” or “*twisted ovaries*” had to be removed. After gonadectomy, persons usually receive an off-label (i.e. not clinically tested) Hormone “Replacement Therapy” (“HRT”) with synthetic oestrogens starting at age of puberty, despite that many persons concerned report better results with testosterone HRT, and complain of negative effects of estrogen “HRT”, including depression, adiposity, metabolic and circulatory problems, osteoporosis, limitation of cognitive abilities and of libido. However, also in **Switzerland** health insurances refuse to pay for testosterone for these persons (**Case No. 2**). Persons with CAIS submitted to castration is arguably the **3rd most frequent diagnosis** in children submitted to IGM.

46,XY Partial Androgen Insensitivity Syndrome (PAIS), i.e. persons with bodies only partly “responding” to testosterone, and **46,XY Leydig Cell Hypoplasia**, i.e. persons with lack of active testosterone producing Leydig cells in testes, **46,XY 5-Alpha-Reductase Deficiency**, i.e. a person that can be born with a rather female appearance and undescended testes due to lack of 5-alpha-dihydrotestosterone (DHT) necessary to form male genitals during gestation, but who will usually “masculinise” during puberty. If such persons are assigned female, they’re usually surgically “made into girls” via castration (as well as “clitoral reduction” and surgical construction of a “neo vagina”), followed by off-label (i.e. not clinically tested) Hormone “Replacement Therapy” (“HRT”) with synthetic oestrogens at the age of puberty. Again, healthy and health-necessary testes are removed on the grounds of an alleged, but non-factual “high cancer risk” e.g. of “50%” for PAIS²⁴² (actual cancer risk for

ideal age for hypospadias repair? A pilot study, *Journal of Pediatric Urology* 5(5):345–350

240 Australian Senate, Community Affairs References Committee (2013), Second Report: Involuntary or coerced sterilisation of intersex people in Australia, at 84, http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/~media/Committees/Senate/committee/clac_ctte/involuntary_sterilisation/second_report/report.ashx see **Table p. 79**

241 Anne Tamar-Mattis (2013), Report to the Inter-American Commission on Human Rights: Medical Treatment of People with Intersex Conditions as a Human Rights Violation, at 4–5, <http://www.aph.gov.au/DocumentStore.ashx?id=432c5135-4336-472e-bb24-59c89eb4a643>

242 Australian Senate, Community Affairs References Committee (2013), Second Report: Involuntary or coerced sterilisation of intersex people in Australia, at 86, http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/

PAIS: 15%²⁴³, see **Table p. 79**), as well as to prevent possible (partial) “masculinisation” at puberty. Again, patients (and parents) are often wrongly told by doctors that “*cancerous*” or “*twisted ovaries*” had to be removed. (See also **Case No. 2**)

46,XX Congenital Adrenal Hyperplasia (CAH), i.e. persons with karyotype 46,XX and internal female reproductive organs, but the adrenal gland of their kidneys (partly) producing testosterone instead of cortisol. In persons with “severe masculinisation” (“**Prader V**”) raised as boys, the uterus and the ovaries are often removed in reverse, again usually without disclosure to patients (and parents), and on the grounds of an alleged, but unproven “*psychological benefit*” to removing structures “discordant with sex assignment”.²⁴⁴

Persons with **ovotestes** (gonads composed of tissue of both ovaries and testes) get “discordant” parts removed, or everything.

In general, intersex children may be subjected to non-consensual treatments that, in some cases, terminate or permanently reduce their reproductive capacity. While some intersex people are born infertile, and some retain their fertility after medical treatment, many undergo removal of viable gonads or other internal and external reproductive organs, leaving them with **permanent, irreversible infertility and severe mental suffering**.²⁴⁵

When sterilising procedures are imposed on children to address a low or hypothetical risk of cancer, the **fertility of intersex people is not being valued as highly as that of non-intersex people**. Furthermore, where prevention of the emergence of undesired secondary sex characteristics is the goal of gonadectomy, the procedure could be postponed until puberty, at which time the child can have input and it will be clearer whether or not the characteristics are indeed undesired by the patient. If retention of potential fertility causes distressing cross-sex changes at puberty, puberty-suppressing agents are a viable option.²⁴⁶

In addition, for infants, there is a lack of age-appropriate hormone therapy, so that operated babies usually do not receive any hormone substitution up until puberty. This results in a pre-pubertal hormone deficiency during an important phase of their development with largely unexplored associated consequences.²⁴⁷ (**Case No. 2, p. 33**)

Some doctors have been criticising unnecessary gonadectomies of intersex patients for decades, e.g. Swiss endocrinologist Georges André Hauser (of MRKH fame) (1961/1963):

*“The castration of patients without a tumour converts symptomless individuals into invalids suffering from **all the unpleasant consequences of castration**.”*²⁴⁸

[Sec_Report/~ /media/Committees/Senate/committee/clac_ctte/involuntary_sterilisation/second_report/report.ashx](#)

243 *ibid.*, at 84, see **Table p. 79**

244 Anne Tamar-Mattis (2013), Report to the Inter-American Commission on Human Rights: Medical Treatment of People with Intersex Conditions as a Human Rights Violation, at 4–5, <http://www.aph.gov.au/DocumentStore.ashx?id=432c5135-4336-472e-bb24-59c89eb4a643>

245 *ibid.*, at 4

246 *ibid.*

247 Intersexuelle Menschen/XY-Frauen, Humboldt Law Clinic (2011), Parallel Report to the 5th Periodic Report of the Federal Republic of Germany on the Convention Against Torture and other Cruel, Inhuman and Degrading Treatment or Punishment, at 10, http://intersex.shadowreport.org/public/Association_of_Intersexed_People-Shadow_Report_CAT_2011.pdf

248 Georges André Hauser (1963), Testicular feminization, in: Claus Overzier (ed.) (1963), Intersexuality:255–276, relevant excerpts http://kastrationsspital.ch/public/Intersex_CAIS_Castration_1961_1963.pdf (original German edition 1961)

Persons concerned have protested medically unnecessary gonadectomies and other irreversible, potentially sterilising treatments, and denounced **non-factual and psychosocial justifications**, e.g. “*psychological benefit*” to removing “discordant” organs, for almost two decades, demanding access to screening for potential low cancer risks instead of preemptive castrations, and urged to remove gonads only in known limited cases with lack of hormone production and actual high cancer risk (e.g. certain forms of 46, XY Gonadal Dysgenesis).²⁴⁹ What’s more, persons concerned and parents of intersex children report and denounce sterilising treatments on the basis of racist preconceptions by clinicians (reminiscent of the **racist and eugenic medical views of intersex** predominant during the 1920s–1950s, see **Supplement 1 “Historical Overview”, p. 52**, but which obviously still persist), namely the infamous premise, “*We don’t want to breed mutants.*”^{250 251}

Nonetheless, and despite recent discussions in medical circles, **unnecessary gonadectomies** and other sterilising treatments persist in **Switzerland**: Only a while ago, in a Swiss Cantonal Children’s Hospital, when the authors of this report criticised unnecessary gonadectomies, a paediatric surgeon replied: “*Well, if a CAIS person is living as female, what do they need their testes for anyway?*” (See p. 17 “**How Common are Intersex Genital Mutilations?**”, as well as **Cases No. 2, 4 and 6**)

d) “Vaginoplasty”, Construction of Artificial “Neo Vagina”

Intersex children raised as girls and diagnosed with a “too small” vagina (e.g. CAH, CAIS, PAIS) or an “absent” vagina (e.g. Mayer-Rokitansky-Küster-Hauser-Syndrome MRKH) usually have their vagina surgically “widened” (“vaginoplasty”, often in conjunction with “clitoral reduction”), or have an artificial vagina constructed by cutting a hole and lining it with skin grafts or a piece of colon (“neo vagina”).

In both cases, there’s no medical or other necessity for a vagina “big enough for normal penetration” in little children, but the procedures are done as early as possible nonetheless, under the usual psychosocial justifications and premises of making the child “more normal”, and that it’s best if everything is done as long as the children are “too young to remember afterwards.” However, there’s a significant risk of complications (e.g. painful scarring, vaginal stenosis) and repeat “redo-surgeries.”²⁵² (See **Case No. 3.**)

e) Forced Vaginal Dilation

After “vaginoplasty”, the dreaded regular **painful and traumatising** “dilations”: In order to prevent “shrinking” and stenosis, after surgery the (neo) vagina has to be widened mechanically by inserting “bougis” in increasing sizes, which may have to be kept in overnight, often with the aid of parents. In the meantime, some hospitals only do this procedure under regular full anaesthesia. For almost two decades, persons concerned and parents have denounced this

249 *ibid.*, at 12

250 Claudia Lang (2006), *Intersexualität. Menschen zwischen den Geschlechtern*, at 247

251 Simon Zobel, quoted in ARTE Journal (2013), *Das dritte Geschlecht*, 31.10.2013, Beitrag “Das ging in den Bereich Eugenik”, https://www.youtube.com/watch?v=7KL_rO-UoNs

252 Anne Tamar-Mattis (2013), Report to the Inter-American Commission on Human Rights: Medical Treatment of People with Intersex Conditions as a Human Rights Violation, at 3, <http://www.aph.gov.au/DocumentStore.ashx?id=432c5135-4336-472e-bb24-59c89eb4a643>

practice as a form of rape and **child sexual abuse**.^{253 254 255} (See **Case No. 3.**)

f) Forced Mastectomy

If intersex children raised as boys develop breasts at puberty (e.g. 47,XXY Klinefelter Syndrome), usually these are surgically removed, often **against the will** of the persons concerned or without their informed consent, also in **Switzerland**.²⁵⁶

g) Surgical Transfixation of Undescended Testes

If an intersex child with undescended testes is raised as a boy (e.g. 10% of boys diagnosed with hypospadias, as well as boys diagnosed with PAIS), usually their undescended testes are surgically brought down and fixed in the scrotum (which sometimes has to be constructed first). One justification is to improve fertility, since in the abdomen temperatures are too high to allow for (later) production of sperms, however, there seems to be no actual evidence, and the NGOs compiling this report have heard testimony of clinicians arguing that abdominal gonads may be significantly less fertile per se and independent of their location, and infertility due to elevated temperatures may be reversible (as with testes in a too warm environment due to varicocele, i.e. broken veins in the scrotum). Other justifications include the usual psychosocial premises, as well as allegation of “high cancer risk” (see **p. 67–69**, as well as **Table p. 79**). We have received reports of persons concerned telling of **strong pain** caused by surgically transfixed testes, stating they’d preferred to having them left untouched. However, doctors refuse to consider such complaints.

h) Imposition of Hormones

Certain hormone treatments in many intersex conditions are either life-saving (substitution of missing corticosteroid, i.e. cortisol or hydrocortisone, in salt-wasting CAH), or medically necessary to avoid early puberty and lack of growth (CAH), or to conclude puberty to avoid excessive and disproportionate growth (“eunuchoid somatomegaly”) (e.g. 47,XXY Klinefelter Syndrome), and organisations of persons concerned advocate such necessary hormone treatments for children and youths. However, there have been many reports by persons concerned of doctors imposing **painful excessive dosages** despite protests and against the expressed will of the persons concerned. However, doctors usually refuse to consider such complaints.

i) Misinformation and Directive Counselling for Parents

“Genital corrections” are often done without the consent of parents and without taking into consideration the views of the children involved. Doctors refuse to inform parents of peer support and self-help groups, arguing they don’t want parents to be “confused by conflicting information.” **Swiss peer support groups** report how parents only find them via the inter-

253 Tamara Alexander (1997), The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse, <http://www.isna.org/articles/analogue>

254 Emi Koyama (2003), Medical Abuse of Intersex Children and Child Sexual Abuse, in: Introduction to Intersex: A Guide for Allies (2nd Edition):2, <http://www.intersexinitiative.org/publications/pdf/intersex-activism2.pdf> (page 5 in the PDF)

255 Intersexuelle Menschen/XY-Frauen, Humboldt Law Clinic (2011), Parallel Report to the 5th Periodic Report of the Federal Republic of Germany on the Convention Against Torture and other Cruel, Inhuman and Degrading Treatment or Punishment, at 15, http://intersex.shadowreport.org/public/Association_of_Intersexed_People-Shadow_Report_CAT_2011.pdf

256 Ernesta, a Swiss person concerned, tells on air how this was done to her in the cantonal hospital Aarau, in: Katharina Bochsler (2010), Wenn der Arzt das Geschlecht bestimmt, Sendung “Kontext” 21.10.2010, at 07:35, http://podcasts.srf.ch/world/audio/Kontext_07-12-2011-0906.mp3

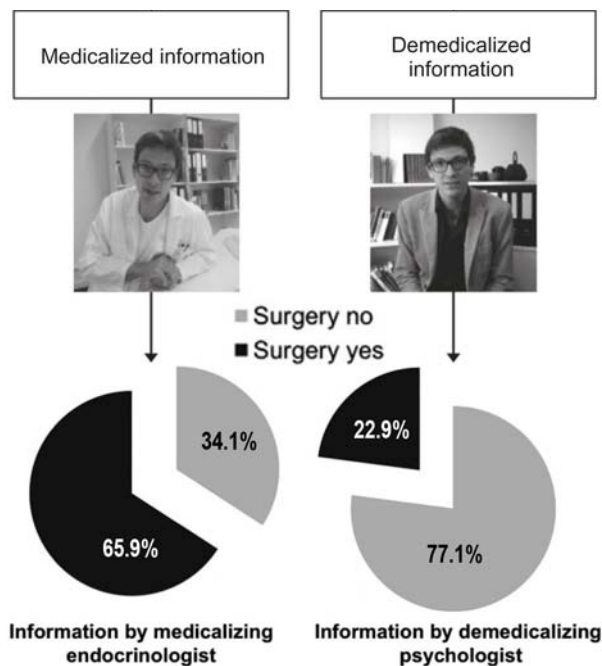


Figure 4 “Medicalised vs. Demedicalised Counselling”

Source: Streuli JC, Vayena E, Cavicchia-Balmer Y, and Huber J. Shaping parents: Impact of contrasting professional counseling on parents’ decision making for children with disorders of sex development, *The Journal of Sexual Medicine* 10:1953–1960

net, because the very same doctors who assured to inform parents of intersex newborns about self-help groups and provide leaflets in fact withheld such information.

Systematic misinformation and directive counselling frequently prevent parents from learning about options for postponing permanent interventions, which has been continuously criticised by persons concerned and their parents^{257 258 259} for two decades (see also **Cases No. 2-6**), seconded by bioethicists^{260 261 262} and corroborated by exploratory studies,²⁶³ including a **recent study from Switzerland**²⁶⁴ (**Figure 4 “Medicalised vs. Demedicalised Counselling”**).

257 Intersex Society of North America (ISNA), What’s wrong with the way intersex has traditionally been treated?, <http://www.isna.org/faq/concealment>

258 Intersexuelle Menschen/XY-Frauen, Humboldt Law Clinic (2011), Parallel Report to the 5th Periodic Report of the Federal Republic of Germany on the Convention Against Torture and other Cruel, Inhuman and Degrading Treatment or Punishment, at 14, http://intersex.shadowreport.org/public/Association_of_Intersexed_People-Shadow_Report_CAT_2011.pdf

259 Anne Tamar-Mattis, Arlene Baratz, Katharine Baratz Dalke, Katrina Karkazis (2013), Emotionally and cognitively informed consent for clinical care for differences of sex development, *Psychology & Sexuality*, <http://www.katrinakarkazis.com/informed-consent-psychsex.pdf>

260 Katrina Karkazis, Anne Tamar-Mattis, Alexander A. Kon (2010), Genital Surgery for Disorders of Sex Development: Implementing a Shared Decision-Making Approach, *Pediatric Endocrinology and Metabolism* 23(3):789-806, <http://bioethics.stanford.edu/people/resumes/documents/KarkazisJPEMFINAL.pdf>

261 J. David Hester (2004), Intersex(es) and Informed Consent: How Physicians’ Rhetoric Constrains Choice, *Theoretical Medicine* 25: 21–49, <http://www.aissg.org/PDFs/Hester-informed-Consent-2004.pdf>

262 Erik Parens (ed.) (2006), *Surgically Shaping Children: Technology, Ethics and the Pursuit of Normality*

263 Suzanne Kessler (1998), *Lessons from the Intersexed*, at 100–104

264 Jürg C. Streuli, E. Vayena, Yvonne Cavicchia-Balmer, J. Huber (2013), Shaping parents: Impact of contrasting professional counseling on parents’ decision making for children with disorders of sex development, *The Journal of Sexual Medicine* 10:1953–1960

Nonetheless, in 90% of European children's clinics it's still paediatric endocrinologists and paediatric surgeons counselling the parents.²⁶⁵ If psychologists and social pedagogues are called in at all, they usually play only a minor part in the so-called "multidisciplinary team." In **Switzerland**, literally from "*day one*" on it's still paediatricians, endocrinologists and surgeons managing diagnostics and counselling of parents.²⁶⁶ Parents often complain that they only get access to psychological counselling if they consent to "corrective surgery" first.

j) Taking Advantage of the Powerlessness and Vulnerability of Intersex Infants

Persons concerned and historians have further criticised the motivation of clinicians for starting to perform "genital corrections" as soon as possible on infants in 1950 was ultimately not the best interest of the children concerned, but to **ensure compliance**, and

*"[...] at least partly motivated by the resistance offered by the adult intersex people [...]. Frightened parents of ambiguously sexed infants were much more open to suggestions of normalizing surgery than were intersex adults, and the infants themselves could, of course, offer no resistance whatsoever."*²⁶⁷

"That people might resist surgical invasion should not be surprising. [...] We can see why doctors, frustrated by the struggle with patients' and parents' preferences and conflicting indications of sexual compositions, ultimately sought ways to manage intersex in infants rather than adults".²⁶⁸

This criticism is reinforced by continued statements by clinicians performing genital surgeries on intersex infants themselves, e.g. referring to "**easier management when the patient is still in diapers.**"²⁶⁹

k) Systematic Lies and Imposition of "Code of Silence" on Children

For more than two decades, persons concerned have criticised how, after having been submitted to "genital correction" deliberately at an age "too young to remember afterwards," in continuation they were systematically lied to in order to keep them in the dark about being born intersex, as well as about the past, ongoing, and future treatments, allegedly all in their best interest and to protect them from shame, distress and social stigma. Same goes for, if at all, being told, e.g. "You are a rarity, will never meet another like yourself and should never talk about it to no one." (See **Supplement 1 "Historical Overview," p. 55.**)

Persons concerned have maintained that this systematic withholding of the truth and the imposition of secrecy severely **compound shame, isolation and psychological trauma** in the aftermath of IGM, and may be perceived as even more damaging than the surgeries themselves. Like with their parents (see above **p. 70–72**), this being sworn to lifelong secre-

265 Eckhard Korsch (2006), Überlegungen zur praktischen Umsetzung des DSD-Consensus-Statements, Presentation APE 2006, slide 16, http://kastrationsspital.ch/public/AG-DSD_2006-Vortrag-Korsch.pdf

266 e.g. Eastern Switzerland Children's Hospital St. Gallen (2014), Zwischen den Geschlechtern, slide 8, http://www.kispig.ch/downloads/cms/09_vortrag_zwischen_den_geschlechtern_2.pdf

267 Cheryl Chase (2002), "Cultural Practice" or "Reconstructive Surgery"? U.S. Genital Cutting, the Intersex Movement, and Medical Double Standards, in: Stanlie M. James, Claire C. Robertson (eds.) (2002), Genital Cutting and Transnational Sisterhood. Disputing, U.S. Polemics: 126–151, at 129

268 Elizabeth Reis (2009), Bodies in Doubt. An American History of Intersex, at 109, 113

269 Marrocco et al (2004), Hypospadias surgery: a 10- year review. Pediatric surgery international 20:200–203, at 202

cy is used by doctors to **ensure compliance** of intersex children and youths.^{270 271 272 273 274}
(**Cases No. 1–3.**)

Like their parents, intersex persons themselves are also refused access to peer support groups by doctors withholding information about such groups.

I) Forced Excessive Genital Exams, Medical Display and (Genital) Photography

In addition to the physical and emotional problems that can be caused by surgical intervention, many intersex individuals suffer lasting physical and psychological effects as a result of repeated (and often brutal) genital examinations in childhood. *“Repeated examination of the genitalia, including medical photography, may be experienced as deeply shaming. [...] Medical interventions and negative sexual experiences may have fostered symptoms of posttraumatic stress disorder and referral to a qualified mental health professional may be indicated.”*²⁷⁵ While some genital exams are deemed necessary for diagnosis or monitoring of medical conditions, others are done without specific indication, sometimes to satisfy provider curiosity or for purposes of training providers.²⁷⁶ (See also **Cases No. 2–6.**)

For example paediatric surgeon Ricardo González, Senior Consultant Surgeon in Urology at the **Swiss Zurich University Children’s Hospital**,²⁷⁷ in 2014 still publicly advocates “early one-stage reconstruction” (“vulvoplasty”, “vaginoplasty” and/or “clitoral reduction”, “according to Prader stage”) for intersex children diagnosed with CAH as soon as “the infant is endocrinologically stable”, despite 10 times higher re-operation rates and the proclaimed need for regular examinations under anaesthesia “**to evaluate the adequacy of the vagina for sexual intercourse**”:

*“We perform a brief examination under anesthesia 3 months later to assess the early result and then perform an examination under [anesthesia] [sic!] at puberty to assess the vaginal introitus in a non-traumatic way before the onset of sexual activity and recommend revision or dilatation when needed.”*²⁷⁸

*“These girls need follow-up till adulthood to evaluate the adequacy of the vagina.”*²⁷⁹

270 ISNA Homepage, <http://www.isna.org/>

271 Tamara Alexander (1997), The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse, <http://www.isna.org/articles/analog>

272 Milton Diamond (1999), Pediatric Management of Ambiguous and Traumatized Genitalia, The Journal of Urology 162:1021-1028, <http://www.hawaii.edu/PCSS/biblio/articles/1961to1999/1999-pediatric-management.html>

273 Emi Koyama (2003), Medical Abuse of Intersex Children and Child Sexual Abuse, in: Introduction to Intersex: A Guide for Allies (2nd Edition):2, <http://www.intersexinitiative.org/publications/pdf/intersex-activism2.pdf> (page 5 in the PDF)

274 [Zwischengeschlecht.info](http://www.zwischengeschlecht.info) (2011), “Sag es niemandem!” – Das verinnerlichte Schweigegebot, Zwittertabu & Medizynermacht (II), <http://blog.zwischengeschlecht.info/post/2011/02/18/Schweigegebot-Zwittertabu-Medizynermacht-II>

275 Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes, LWPES/ESPE Consensus Group (2006), Consensus statement on management of intersex disorders, Pediatrics 118:e488-e500, at e493, <http://pediatrics.aappublications.org/content/118/2/e488.full.pdf>

276 Anne Tamar-Mattis (2013), Report to the Inter-American Commission on Human Rights: Medical Treatment of People with Intersex Conditions as a Human Rights Violation, at 5–6, <http://www.aph.gov.au/DocumentStore.ashx?id=432c5135-4336-472e-bb24-59c89eb4a643>

277 http://www.kispi.uzh.ch/Kinderspital/Chirurgie/Chirurgie-1/Leitende-2_en.html

278 Ricardo González, Barbara M. Ludwikowski (2014), Should the genitoplasty of girls with CAH be done in one or two stages?, Frontiers in Pediatrics, <http://journal.frontiersin.org/Journal/10.3389/fped.2013.00054/full>

279 Ricardo González, Barbara M. Ludwikowski (2013), The surgical correction of urogenital sinus

m) Human Experimentation on Intersex Children

Several researchers have referred to people with intersex conditions as “**experiments of nature**,” and indeed this population, and especially intersex children, have attracted a great deal of attention from researchers in fields interested in sex, gender, and sexual differentiation, including biology, (paediatric) endocrinology, urology, gynaecology, genetics, sexology and gender studies,²⁸⁰ using this vulnerable population, and especially the non-consensual unnecessary medical interventions, as a means for their own ends, e.g. to correlate genetic findings with behavioural characteristics, summarised in research titles like e.g. “From Gene to Gender”²⁸¹ or “From Biology to Behaviour,”²⁸² or to “*deconstruct the notions of binary sexes (and thus, sexism and homophobia)*.”²⁸³ Persons concerned have been consistently criticising how most of this research conveniently ignores the severe ethics and human rights implications for the persons concerned, as well as that most **researchers are directly or indirectly involved in the perpetration of IGMs**. On the other hand, e.g. collection of data, evaluation of surgical outcomes after early interventions and other physical and psychological **problems identified by the intersex community**²⁸⁴ **are conveniently ignored**:

*“It is also critical to understand that **intersex people have unique concerns that should impact the design of research, and that have not been well-understood by researchers in the past**. For example, many intersex children and adults have suffered symptoms of PTSD related to repeated genital exams throughout childhood. Therefore, a research activity that would be minimal-risk for most people, such as examination of or photography of genitals, could be much higher risk for a child with an intersex condition/DSD. For this reason (among others), it is critical to have intersex community participation in the earliest stages of research design and on IRBs that review this research.”*²⁸⁵

(For more on such projects with **Swiss funding and/or participation**, see **B 4., “Lack of Disinterested Research”, p. 19.**)

Last but not least, the more than six decades of systematic, non-consensual, unnecessary early medical interventions on intersex children in the “developed world” in themselves constitute **one giant, highly problematical, uncontrolled medical field experiment**, lead by paediatric endocrinologists and surgeons refusing to disclose the truth to persons concerned and parents, as well as refusing collection of data and disinterested review and outcome studies, and employing what has been repeatedly criticised²⁸⁶ as a “catch 22” and “epistemological

in patients with DSD: 15 years after description of total urogenital mobilization in children, *Frontiers in Pediatrics*, <http://journal.frontiersin.org/Journal/10.3389/fped.2013.00041/full>

280 Anne Tamar-Mattis (2013), Report to the Inter-American Commission on Human Rights: Medical Treatment of People with Intersex Conditions as a Human Rights Violation, at 2, <http://www.aph.gov.au/DocumentStore.ashx?id=432c5135-4336-472e-bb24-59c89eb4a643>

281 EuroDSD Consortium: From Gene to Gender – 3rd International Symposium on Disorders of Sex Development, <http://www.dsdturk.org/documents/L%C3%BCbeck-DSD.pdf>

282 11th EMBL/EMBO Science and Society Conference: The Difference between the Sexes - From Biology to Behaviour, <http://www.embl.de/training/events/2010/SNS10-01/>

283 Emi Koyama, Lisa Weasel (2002), From Social Construction to Social Justice: Transforming How We Teach About Intersexuality, *Women’s Studies Quarterly* 30(3-4), <http://www.ipdx.org/pdf/wsqr-intersex.pdf>

284 Anne Tamar-Mattis, Henry Ng (2014), AIC response to NICHD RFI, <http://aiclegal.org/wordpress/wp-content/uploads/2014/02/AIC-response-to-NICHD-RFI.pdf>

285 Anne Tamar-Mattis, Henry Ng (2014), AIC response to NICHD RFI, at 2 (emph. in orig.), <http://aiclegal.org/wordpress/wp-content/uploads/2014/02/AIC-response-to-NICHD-RFI.pdf>

286 Tiger Howard Devore (1996), Endless Calls for “More Research” as Harmful Interventions Con-

black hole”²⁸⁷ as a convenient excuse to **continue indefinitely with harmful experimental treatments**, or, as paediatric surgeon Ricardo González, Senior Consultant Surgeon in Urology at the **Swiss Zurich University Children’s Hospital** put it:

*“Summary: Although results for surgery for congenital adrenal hyperplasia have been less than satisfactory when adults who had surgery in childhood are evaluated, all present reports include patients operated on using a variety of techniques many years ago. Rather than abandoning the efforts to repair this malformation early, we favor the continued development of more refined surgical techniques that may yield better results in the future.”*²⁸⁸

n) Denial of Needed Health Care

While infants and children with intersex conditions may suffer from an excess of medical attention and treatment, older children, youths and adults with intersex conditions often have a difficult time finding providers who are educated about their needs. Additionally, some have reported discrimination in health care settings and denial of care once their atypical anatomy is known.²⁸⁹ Another example is health insurances refuse to pay for adequate HRT with testosterone after gonadectomies for these persons with (C)AIS (see above **p. 67–69 “Castrations”**), also in **Switzerland (Case No. 2)**.

o) Prenatal “Therapy”

Bioethicists, physicians, and persons concerned have raised alarms about the long-standing practice of giving the powerful steroid Dexamethasone (DEX) to women pregnant with a child who might have virilising 46,XX Congenital Adrenal Hyperplasia (CAH) without adequate clinical trials or the protections normally afforded to human research subjects.^{290 291 292} The treatment is intended to prevent “masculinising” effects of the condition, including atypical gender development, “tomboy” behaviour, and lesbianism. While the pregnant women were told for decades that the treatment was the standard of care and had been shown to be “safe and effective,” American researchers were enrolling the prenatally treated children in research studies after treatment, in order to determine if it was in fact safe. Especially problematical is the fact that because the treatment has to start before the 7th week of gestation, for every single actually targeted 46,XX CAH fetus, almost 9 other fetuses are indiscriminately treated, receiving **none of the alleged benefits but all of the reported complications**. Recently a Swedish study of the same treatment was shut down after high rates of birth defects were noted in the treated population, prompting study authors to state, “*We find it unacceptable that, globally, fetuses at risk for CAH are still treated prenatally with DEX without follow-*

tinue, Hermaphrodites With Attitude, Fall/Winter 1996:2, <http://www.isna.org/files/hwa/winter1996.pdf>

287 Cheryl Chase (1998), Surgical Progress Is Not the Answer to Intersexuality, in: Alice Dreger (ed.) (1999), *Intersex in the Age of Ethics*:148–159, at 151

288 Ricardo González, Lisandro A Piaggio (2006), Ambiguous genitalia, *Current Opinion in Urology* 16(4):273-276, http://journals.lww.com/co-urology/Abstract/2006/07000/Ambiguous_genitalia.14.aspx

289 Anne Tamar-Mattis (2013), Report to the Inter-American Commission on Human Rights: Medical Treatment of People with Intersex Conditions as a Human Rights Violation, at 7, <http://www.aph.gov.au/DocumentStore.ashx?id=432c5135-4336-472e-bb24-59c89eb4a643>

290 fetaldex.org, <http://www.fetaldex.org/home.html>

291 Alice Dreger, Ellen K. Feder, Anne Tamar-Mattis (2012), Prenatal Dexamethasone for Congenital Adrenal Hyperplasia. *Journal of Bioethical Inquiry* 9:277–294

292 Hida Vioria (2012), Open Letter: A Call for the Inclusion of Human Rights for Intersex People, <http://oii.org.au/wp-content/uploads/downloads/2012/12/UNltrPramanik.pdf>

Tables 1 Rates of pregnancy termination following a prenatal diagnosis of Klinefelter syndrome

Country	Number of pregnancies	Termination rate (%)	Period of study	References
Germany	23	17	1989–1998	(3)
Uruguay	22	23	1982–2003	(4)
France	12	42	1990–1998	(5)
5 European countries	111	44	1986–1997	(6)
USA	75	45	Not specified	(7)
Hawaii	24	46	1986–1999	(8)
Finland + UK	15	66	1979–1984	(9)
Denmark	163	70	1970–2000	(10)
USA (California)	40	70	1983–2003	(11)
Switzerland	23	74	1980–2001	(12)
Israel	20	85	1989–1998	(13)
Canada (BC)	24	88	1971–1997	(14)

Figure 5 “Termination Rates” Switzerland: 74%

Source: Céline M. Girardin, Guy van Vliet (2011), Counseling of a couple faced with a prenatal diagnosis of Klinefelter syndrome, *Acta Paediatrica* 100:917-922

up.”²⁹³ Nonetheless, also in **Switzerland** exactly this is still practised (see **Annexe 2 “Swiss Cantonal, Federal, Governments, and Clinics on IGMs”**).

p) Selective Abortion, Selective Late Term Abortion

With the increasing availability of prenatal tests, in combination with the social stigma attributed to intersex, and the social taboo surrounding the real lives of intersex persons, fetuses diagnosed with a risk of having an intersex condition are especially vulnerable to selective abortion, also in **Switzerland**, as the findings of a termination rate of 74% for fetuses diagnosed with 47,XXY Klinefelter syndrome demonstrates (**Figure 5 “Termination Rates”**, above). Persons concerned have been internationally criticising this development.

What’s more, in many countries, fetuses considered “*at risk of intersex deformities (pseudo hermaphroditism)*” are approved for selective late term abortions.²⁹⁴ For Switzerland, there’s no data available to the authors of this NGO report.

q) Preimplantation Genetic Diagnosis (PGD) to Eliminate Intersex Fetuses

The use of PGD “*to prevent the birth of children with intersex conditions/disorders of sex development (DSDs), such as Congenital Adrenal Hyperplasia (CAH) and Androgen Insensitivity Syndrome (AIS)*,” has been publicly declared by scientists as “*morally permissible*” and “*more defensible than might first appear*.”²⁹⁵ Although there’s no data available to the Rapporteurs, we are very concerned about this development.

293 Hirvikoski, T., A. Nordenström, T. Lindholm, et al. (2007), Cognitive functions in children at risk for congenital adrenal hyperplasia treated prenatally with dexamethasone. *The Journal of Clinical Endocrinology and Metabolism* 92(2): 542–548

294 <http://blog.zwischengeschlecht.info/post/2013/01/27/Abtreibung-Indikation-intersexuelle-Missbildungen>

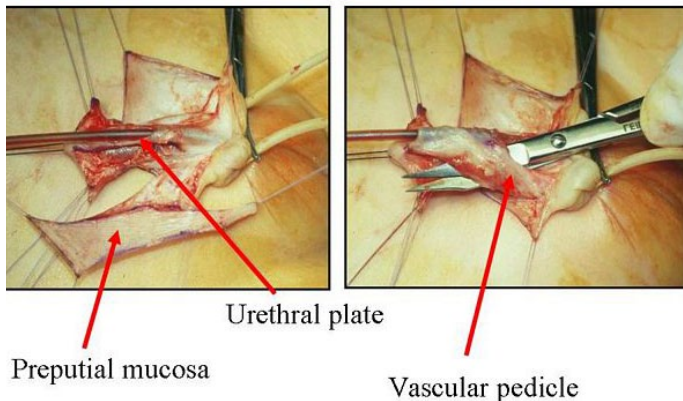
295 Robert Sparrow (2013), Gender eugenics? The ethics of PGD for intersex conditions, *American Journal of Bioethics* 13 (10): 29-38, <http://profiles.arts.monash.edu.au/rob-sparrow/download/GenderEugenicsForWeb.pdf>

1. "Hypospadias Repair" a.k.a. "Masculinising Surgeries"

"Hypospadias," i.e. when the urethral opening is not on the tip of the penis, but somewhere on the underside between the tip and the scrotum, is arguably the most prevalent diagnosis for cosmetic genital surgeries. Procedures include dissection of the penis to "relocate" the urinary meatus. Very high complication rates, as well as repeated "redo procedures" — "5.8 operations (mean) along their lives ... and still most of them are not satisfied with results!"

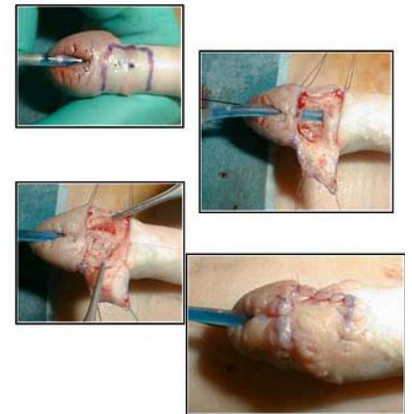
Nonetheless, clinicians recommend these surgeries without medical need explicitly "for psychological and aesthetic reasons." Most hospitals advise early surgeries, usually "between 12 and 24 months of age." While survivors criticise a.o. impairment or total loss of sexual sensation and painful scars, doctors still fail to provide evidence of benefit for the recipients of the surgeries.

Onlay island flap urethroplasty



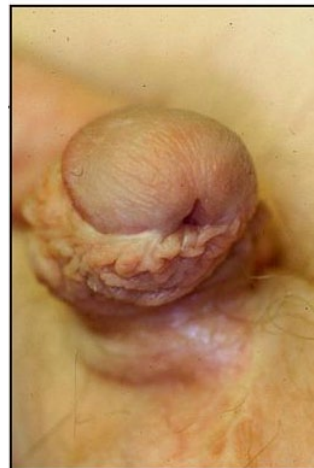
Treatment of isolated fistulae

- Rectangular skin incision around the fistula orifice, often lateral
- Dissection and excision of the fistula tract
- Urethral suture
- Multilayer cover with well-vascularized tissue (tunica vaginalis, dartos, dorsal subcutaneous flap ...)
- Problem: coronal fistula +++: Prefer redo urethroplasty
- Suprapubic diversion ? Elbakry



Onlay / Duckett - results

- Elbakry (BJUI 88: 590-595, 2001): 42% complications
 - 5 breakdowns (7%)
 - 17 fistulae (23%)
 - Urethral strictures (9%)
 - Urethral diverticulae (4%)
- Asopa / Duckett tube
 - 3.7% (El-Kasaby J Urol 136: 643-644, 1986)
 - 69% (Parsons BJU 25: 186-188, 1984)
 - 15% (Duckett - 1986)



Bad cosmetic result



infection

Hypospadias - Procedures for cripple hypospadias

- No standardized procedures
- Personal experience of the surgeon
- Importance of a uro-endocrine approach of complex cases to increase the healing abilities of the penile tissues



Official Diagnosis "Hypospadias Cripple"
= made a cripple by repeat cosmetic surgeries

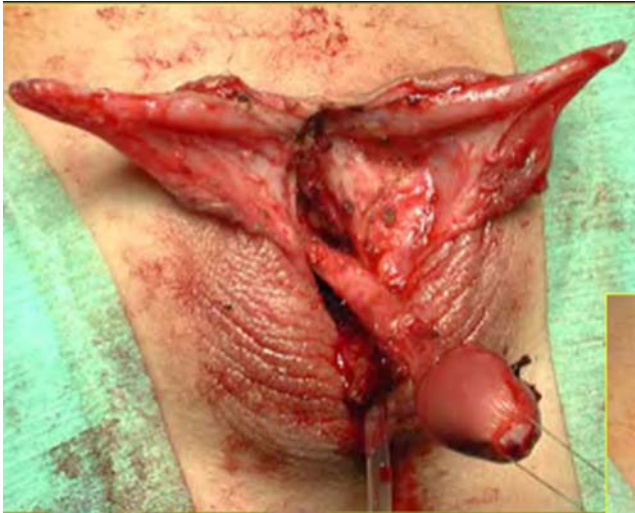
Hypospadias - Conclusions

- Hypospadias surgery remains a surgical challenge
- Long-term results are poorly reported
- Essential joint uro-endocrine approach
- Psychological consequences poorly assessed
- Informing parents is crucial: 50% of all hypospadias will require further surgical attention during their life.
- Research: Essential role of the placenta / Penile growth factors / healing factors / blood supply ...

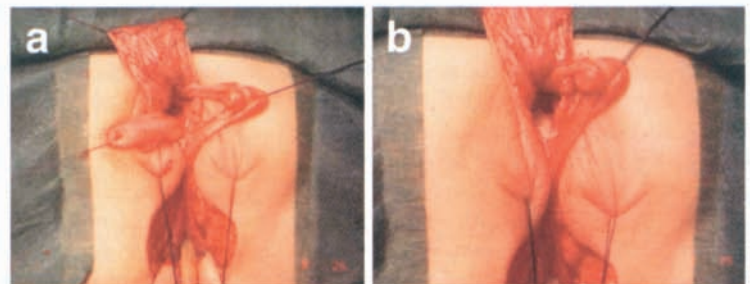
2. “Clitoral Reduction”, “Vaginoplasty” a.k.a. “Feminising Surgeries”

Partial amputation of clitoris, often in combination with surgically opening or widening of the vagina. “46,XX Congenital Adrenal Hyperplasia (CAH)” is arguably the second most prevalent diagnosis for cosmetic genital surgeries, and the most common for this type (further diagnoses include “46,XY Partial Androgen Insufficiency Syndrome (PAIS)” and “46,XY Leydig Cell Hypoplasia”).

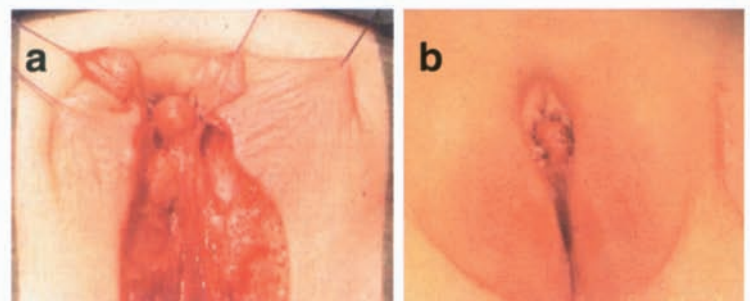
Despite numerous findings of loss of sexual sensation caused by these cosmetic surgeries and lacking evidence, current guidelines nonetheless advise surgeries „*in the first 2 years of life*”, most commonly “*between 6 and 12 months,*” and only 10.5% of surgeons recommend letting the persons concerned decide themselves later.



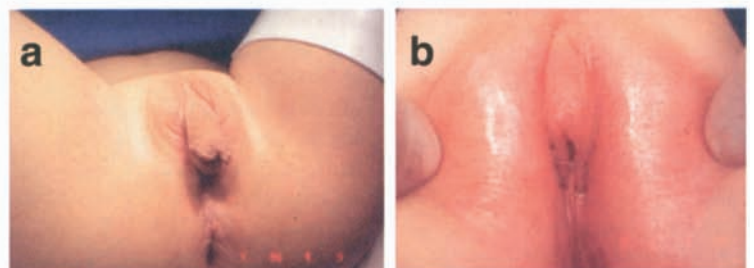
6a-c: Darstellung des Klitorischaftes (a) sowie der Schwellkörper (b+c).



7a+b: Partielle Resektion der Corpora cavernosa clitoridis.



8a+b: Refixation der Corpora cavernosa clitoridis. “Materialknappheit” bei der Rekonstruktion clitoridis und der kleinen Labien.



9a+b: Klitorisreduktion und Rekonstruktion des Praeputium clitoridis bei Prader IV.

Source: Finke/Höhne: *Intersexualität bei Kindern*, 2008

Note Caption 8b: “*Material shortage*” [of skin] while reconstructing the prepuce clitoridis and the inner labia.



Source: Christian Radmayr: *Molekulare Grundlagen und Diagnostik des Intersex*, 2004



Bottom Left - Source: Pierre Mouriouand: “Chirurgie des anomalies du développement sexuel - 2007”, at 81: “Labioplastie”

3. Castration / “Gonadectomy” / Hysterectomy / (Secondary) Sterilisation

Removal of healthy testicles, ovaries, or ovotestes, and other potentially fertile reproductive organs. “46,XY Complete Androgen Insufficiency Syndrome (CAIS)” is arguably the 3rd most common diagnosis for cosmetic genital surgeries, other diagnoses include “46,XY Partial Androgen Insufficiency Syndrome (PAIS)”, male-assigned persons with “46,XX Congenital Adrenal Hyperplasia (CAH)”, or other male assigned persons, who have their healthy ovaries and/or uteruses removed.

Castrations usually take place under the pretext of an allegedly blanket high risk of cancer, despite that an actual high risk which would justify immediate removal is only present in specific cases (see table below), and the true reason is “better manageability.” Although in many cases persons concerned have no or limited fertility, the gonads by themselves are usually healthy and important hormone-producing organs.

Nonetheless, clinicians still continue to recommend and perform early gonadectomies – despite all the known negative effects of castration, a.o. depression, obesity, metabolic and circulatory troubles, osteoporosis, reduction of cognitive abilities, loss of libido. Plus a resulting lifelong dependency on artificial hormones (and adequate hormones are often not covered by health insurance, but have to be paid by the survivors out of their own purse).



Fig. 91.6 An inguinal approach for gonadectomy in a CAIS patient with two palpable gonads

3 months old with scrotal hypospadias and right impalpable gonad

- Uterus and dysplastic gonad removed
- Hypospadias repaired
- Follow-up for surveillance of development testicular and/or renal tumors
- Testosterone required at puberty



Table 1. Prevalence of type II GCT in various forms of DSD

Risk	Type of DSD	Prevalence %
High	GD in general	12*
	46,XY GD	30
	Frasier syndrome	60
	Denys-Drash syndrome	40
	45,X/46,XY GD	15–40
Intermediate	PAIS	15
	17 β -hydroxysteroid dehydrogenase deficiency	17
Low	CAIS	0.8
	Ovotesticular DSD	2.6
Unknown	5 α -reductase deficiency	?
	Leydig cell hypoplasia	?

GD = Gonadal dysgenesis; PAIS = partial androgen insensitivity syndrome; CAIS = complete androgen insensitivity syndrome.

* Might reach more than 30%, if gonadectomy has not been performed.

Source (top left): Maria Marcela Bailez: “Intersex Disorders,” in: P. Puri and M. Höllwarth (eds.), *Pediatric Surgery: Diagnosis and Management*, Berlin Heidelberg 2009

Source (top right): J. L. Pippi Salle: “Decisions and Dilemmas in the Management of Disorders of Sexual [sic!] Development (DSD),” 2007, at 20

Source (bottom left): J. Pleskacova, R. Hersmus, J. Wolter Oosterhuis, B.A. Setyawati, S.M. Faradz, Martine Cools, Katja P. Wolffenbuttel, J. Lebl, Stenvert L.S. Drop, Leendert H.J. Looijenga: “Tumor risk in disorders of sex development,” in: *Sexual Development* 2010 Sep;4(4-5):259-69.



Abb. 2 ▲ a, b Schlechte Korrekturergebnisse nach Feminisierung und c, d nach Hypospadiaskorrektur

Source: M. Westenfelder: "Medizinische und juristische Aspekte zur Behandlung intersexueller Differenzierungsstörungen," *Der Urologe* 5 / 2011 · p. 593–599. Caption 2a,b: **"Bad Results of Correction after Feminisation, and"**, c,d: **"after Hypospadias Repair"**

PAIS

- Bilateral gonadectomy
- Skin Biopsy for genetics study of androgen receptors
- Female gender assignment
- Feminizing genitoplasty performed age 6 months



le extirpó, y presentaba en su base, bien manifiesto el surco determinado por las gomas constrictoras (dato suministrado por la historia clínica del Hospital Alvear, fotografía n.º 111).



Fotografía n.º 111.

He tenido oportunidad, posteriormente, de examinar la pieza anatómica extirpada.



Fotografía n.º 112.

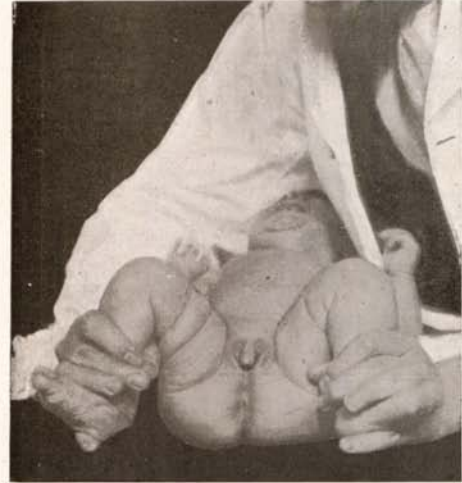


Fotografía n.º 112'.

El aspecto de ese clitoris es de un pene de tamaño semejante al que corresponde a un joven de catorce o quince años. Está constituido por un glande

quizá un poco exagerado, está cubierto por prepucio por su parte dorsal en casi toda su longitud. En su extremo anterior, termina por un glande, con su correspondiente surco balano-prepucial. Este glande es imperforado. Por debajo falta el prepucio y la uretra, existiendo sólo un débil surco en parte mucoso y en parte cutáneo. Detrás de la base de implantación de este miembro y vecino al periné, semioculto por un repliegue cutáneo, se advierte un orificio por donde sale orina, y por donde, introduciendo un estilete, se llega a una cavidad que, por su situación, debe ser la vejiga. Las bolsas escrotales no existen. En los repliegues cutáneos laterales, no se palpan glándulas sexuales, como tampoco en las regiones inguinales. No hay pelos en la piel del pubis.

Fuera de las deformidades de la esfera genital, muchas de las cuales se



Fotografía n.º 11.

ven en la fotografía, el niño presenta, por el resto, una buena constitución. Su estado general era muy bueno y se encontraba en perfectas condiciones de nutrición.

Habiéndose hecho el diagnóstico de hipospadia y teniendo en cuenta la corta edad del paciente así como la ausencia completa de trastornos funcionales, se resolvió esperar a que el niño cumpliera cuatro años de edad, para, entonces, someterlo a una intervención quirúrgica destinada a corregir su hipospadia.

Es cuando el niño cumplió cuatro años de edad, que fué traído nuevamente al Hospital, levantándose el estado actual que a continuación exponemos. Fué, entonces, también, que se obtuvieron las fotografías números 13 y 14.

Niño en buen estado general y en regular estado de nutrición. Coloración normal de la piel y las mucosas. Buena constitución esquelética. Fuera de la anomalía existente en su aparato genital, no presenta ninguna otra deformidad aparente.

Examinado desnudo, llama inmediatamente la atención el insólito des-

Buenos Aires 1925: Medical Display, “Trophy Shots”, and Cosmetic Genital Surgeries on Children

“Las deformidades de la sexualidad humana” by Carlos Lagos García (1880-1928) is arguably the first modern medical book dedicated exclusively to “genital abnormalities” and their surgical “cure”. It was highly influential both in Europe and the Americas, pioneering forced medical display, “trophy shots” of amputated healthy genitals and reproductive organs, and advocating cosmetic surgeries on little children, both “feminising” and “masculinising” – expressly without actual medical necessity, but as “correction” for “anomalies”.

Source: Carlos Lagos García: *Las deformidades de la sexualidad humana*. Buenos Aires, 1925, p. 438, 262.

Young to investigate the pelvic generative organs. It was decided to carry out the laparotomy through the inner edge of the right rectus muscle. A testicle was discovered on the left side, with a definite vas; also a Fallopian tube leading to an undeveloped uterus behind the bladder; and a Fallopian tube also on the right side, but no gonad. The conditions found are shown in the

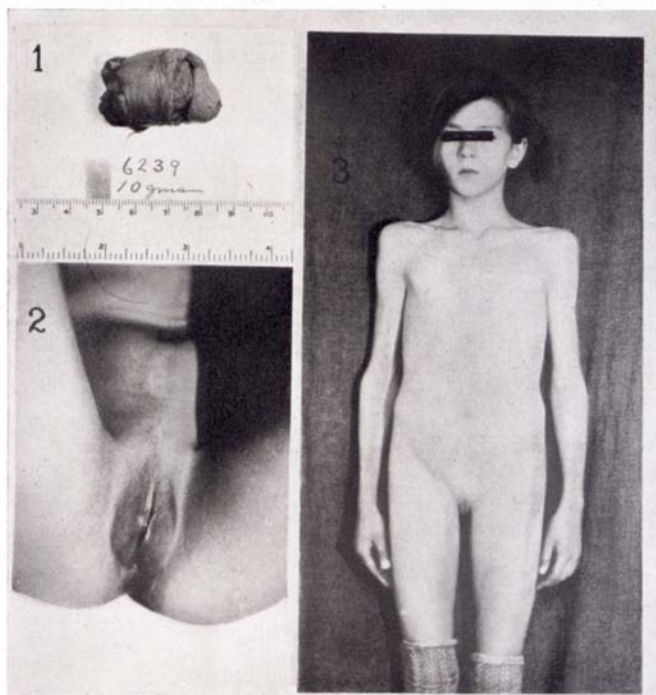


FIG. 63. Case 5. Age 9 years. 1, Phallus supposed to be hypertrophied clitoris; 2 and 3, condition after amputation. Note undeveloped labia majora. BUI 14127.

accompanying illustrations (fig. 65) by Mr. Didusch. Low down behind the bladder was a uterus about $1\frac{1}{2}$ cm. wide, perhaps 1 cm. thick, and Fallopian tubes, which extended outward and backward (fig. 65, 2). On the right side there was a scar (previous removal of the supposed ovary; found microscopically to be a gland). On the left side the tube ran backward, ended in a fimbriated end and partly encircled an ovoid body about 4 cm. long, $2\frac{1}{2}$ cm. wide

and $1\frac{1}{2}$ cm. thick, which was covered by smooth mucous membrane, rather firm, with no evidence of ovulation, which looked like a testicle (fig. 65, 3). Posterior to this was a mesentery in which the vas deferens could be palpated for a short distance, and then disappeared in the deep tissues at the pelvic brim. This could not be followed downwards toward the urethra nor upwards.

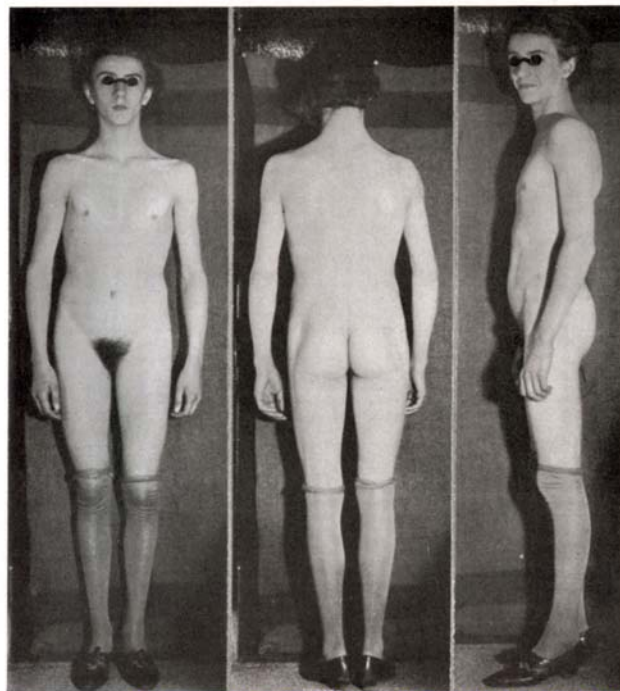


FIG. 64. Case 5. Patient, aged 15, raised as boy until 7 years; then diagnosed female. Phallus amputated; put in girl's clothes. At age of 16, operation for inguinal hernia, supposed ovary found to be testicle. Patient put back in male attire. BUI 14127.

No epididymis could be made out. The tip of the sex gland was excised and showed normal looking testicular tissue (fig. 65, 4). After a long discussion, it was decided that, as the penis had been excised 6 years before, it would be best to excise the testicle with as much as possible of its mesentery containing the supposed vas deferens, and also a large part of the Fallopian tube. This was accordingly done (fig. 65, 5). The peritoneal surfaces were then drawn

Baltimore 1937: Haphazard Decisions, more "Trophy Shots", Step by Step "Genital Corrections"

Hugh Hampton Young (1870-1945), "The Father of American Urology", also pioneered Intersex Genital Mutilations at the Johns Hopkins University Hospital in Baltimore – a fact nowadays often "neglected" in official hagiographies, despite that Young's disturbing textbook *Genital Abnormalities, Hermaphroditism, and Related Adrenal Diseases* was considered a breakthrough by his colleagues and was received globally. It saw two updated revisions, edited by Young's successors Howard W. Jones and William Wallace Scott, in 1958 and 1971 under the slightly modified title *Hermaphroditism, Genital Anomalies, and Related Endocrine Disorders*, and still contained many of Young's original step by step illustrated tutorials e.g. of *Plastic operations to construct a vagina and amputate hypertrophied clitoris*, or how to otherwise freely "cut up and re-assemble" so called *Genital Abnormalities*. Also the Fig. 64 above right showing the tragically mutilated young person "Case 5 / BUI 14127" appeared again in Jones' and Scott's editions, although erroneously attributed to another "Case." For the 1958 edition, Young's colleague at Johns Hopkins and the "inventor" of systematic cosmetic genital surgeries on children, Lawson Wilkins, contributed a foreword, praising Young's original 1937 edition as a "classic."

Source: Hugh Hampton Young: *Genital Abnormalities, Hermaphroditism, and Related Adrenal Diseases*. Baltimore, 1937, p. 88-89.

Se manifesteront-elles dans le sens féminin : on peut alors se demander si des érections survenant dans la verge enlissée ne seront pas cause de gêne, peut-être même de douleur. Il sera

toujours temps, à ce moment, d'amputer en totalité le membre à forme virile, si la femme avertie ne tient pas à conserver la sensibilité balanique.

Mais au moins, chez la fillette impubère que nous considérons, l'avenir n'est pas irrémédiablement orienté.

Ceci dit, nous apporterons nos observations personnelles concernant des fillettes à grande verge.

OBSERVATION PERSONNELLE XII. —
BILAN FÉMININ APRÈS LAPAROTOMIE. AMPUTATION DU CLITORIS. —

Le Dr Alberto Lagos Garcia, frère du regretté chirurgien que nous avons si souvent cité, nous a envoyé en espagnol l'observation que nous résumons ici.

Cécilia M... est une fillette de trois ans (fig. 56). Clitoris de 2 centimètres (fig. 57), avec un orifice unique ouvert au-dessous de lui. Aucune glande n'est perceptible dans les bourrelets génitaux.

Laparotomie exploratrice : utérus atrophique, deux ovaires et deux trompes.

On enlève l'ovaire gauche pour examen histologique ; le laboratoire a répondu : ovaire.

FIG. 56. — Cecilia M... (observation XII). (ALBERTO LAGOS GARCIA.)

Six mois après, incision qui sépare les deux bourrelets coalescents. Grâce à elle, on découvre deux conduits distincts, un antérieur, l'urètre, et un postérieur, qui est un vagin de 5 centimètres de profondeur et qui admet une sonde. Les bords de l'incision sont soigneusement ourlés.

Résection partielle du clitoris hypertrophique (fig. 58). Suites très simples. Il faudra procéder à des dilatations de son vagin.

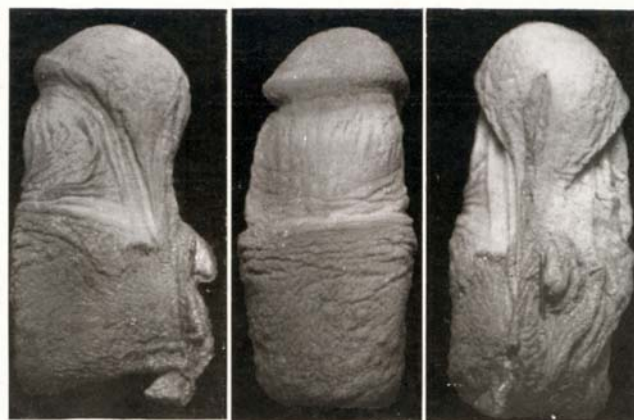


FIG. 93. — Le clitoris de Marguerite, après amputation (observation XX).



FIG. 94. — Aspect de la région génitale de Marguerite un mois après la dernière opération (observation XX).

OBSERVATION PERSONNELLE XXI. — ORGANES A FORME MASCULINE. FONCTIONS FÉMININES. ABLATION DE LA VERGE ET DES GLANDES. — Hortense F... est née le 26 décembre 1907, à Bathincourt (Belgique) ; elle a donc trente ans. Déclarée fille à sa naissance.

Paris 1939: "Embarrassing Erections", yet more "Trophy Shots", and even younger Children submitted to Cosmetic Genital Surgeries

Louis Ombrédanne (1871-1956) set the standard for "Hypospadias Repairs" a.k.a. "masculinising corrections" for more than 50 years, and even more so for medical musings on allegedly "embarrassing and maybe even painful erections" of "enlarged clitorises" (note how he's asking himself, NOT his patients), and was a teacher of Swiss paediatric surgeon Max Grob (Zurich University Children's Hospital). Ombrédanne's "Hermaphrodites and Surgery" drew heavily on Carlos Lagos García, as well as featuring a "personal observation" by García's Brother Alberto Lagos García involving a "partial resection of the hypertrophied clitoris" in combination with "continued vaginal dilatations" on a "girl aged three years" (p. 248), and was received internationally from Zurich to Baltimore and beyond.

Sources: Louis Ombrédanne: *Les Hermaphrodites et la Chirurgie*. Paris, 1939, p. 248, 284.



Abb. 863. Intersex-Typ (Schizoid).

Der **Intersex-Typus** (Mannweib, Schizoid) (Abb. 863) ist körperlich und psychisch ausgedrückt. Es kommen auch sexuelle Zwischenstufen vor, wobei feminine Zeichen nur schwach ausgebildet sind. Die Behaarung ist übermäßig und atypisch, die Züge sind männlich, die Stimme ist tief. Die Pubertät tritt verzögert auf, es besteht Frigidität und eine herabgesetzte Fruchtbarkeit bei Hypoplasie der Keimdrüsen und Hyperfunktion der Hypophyse, manchmal ein eunuchoider Hochwuchs, ferner Störungen in der Funktion der Thyreoidea. Häufig wird Dysmenorrhöe beobachtet.

Wilhelm Weibel: *Lehrbuch der Frauenheilkunde*, Berlin/Wien 1944
(note fresh "exploratory" scar on abdomen)

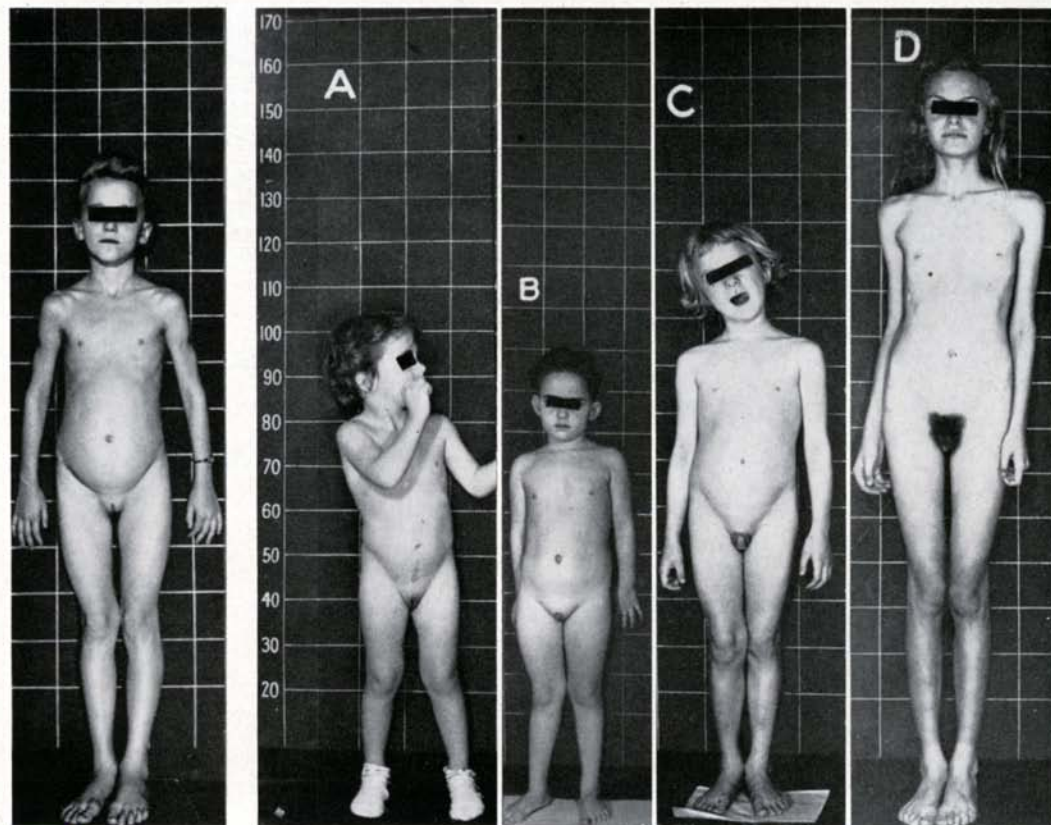
1916–1950s: "Intersexuality = Bastardisation" caused by "Racial Mixing"; Racist Diagnosis "Intersexual Constitution"

Geneticist Richard Goldschmidt (1878–1958), before serving as director at the "Kaiser-Wilhelm-Institut für Biologie" in Berlin, coined the terms "*Intersex*" and "*Intersexuality*" when internationally publicising his experiments of crossbreeding "different geographic races" of gypsy moths during a stay in the USA (first in English, later in German), claiming to be able to produce "hermaphroditic" a.k.a. "intersex" specimens of any grade and shape at will, and thereafter extrapolating his findings to humans. Of Jewish descent, Goldschmidt was forced to leave the "Kaiser-Wilhelm-Institute" in 1936 and emigrated to the United States. Despite Goldschmidt's downplaying the "racial" background of his findings since the early 1930's and later renouncing the underlying genetic theories altogether, the term "Intersex" and its racial implications prevailed. The derived diagnosis "*Intersexual Constitution*" (published by Austrian Gynecologist Paul Mathes in 1924), associated with "biological inferiority", mental illnesses, "*hypertrophied clitoris*," and a strict verdict "*not fit for marriage*," was particularly popular among prominent eugenicists and Nazi doctors, amongst others Fritz Lenz, Lothar Gottlieb Tirala, Robert Stigler, Wilhelm Weibel and Walther Stoeckel, and kept being used in publications years after World War II.

Sources: Richard Goldschmidt: "Die biologischen Grundlagen der konträren Sexualität und des Hermaphroditismus beim Menschen", in: *Archiv für Rassen- und Gesellschaftsbiologie* 12, 1916.

Helga Satzinger: *Rasse, Gene und Geschlecht. Zur Konstituierung zentraler biologischer Begriffe bei Richard Goldschmidt und Fritz Lenz, 1916–1936*. Research Program "History of the Kaiser Wilhelm Society in the National Socialist Era", *Ergebnisse* 15, 2004.

Wilhelm Weibel: *Lehrbuch der Frauenheilkunde*, 7th ed., Berlin/Wien 1944 p. 647 (photo), 648 (text).



Normal age 9 yrs.

Age 2 yrs. 11 mos.
Ht. age 4-3
Bone age 6-0
17-KS:
2 yrs. 9-12 mg/d.
3 yrs. 15-25 mg/d.
Pubic hair appeared at
20 mos.

Small urogenital sinus.
Siblings:
1. ♀ pseudohermaphro-
dite.
2. Female—normal.
3. ♂—macrogenitosomia
4. ♂—macrogenitosomia
Clitoris amputated.
Raised as girl.
(H.L.H. A59183)

Age 4 yrs., 2 mos.
Ht. age 5-0
Bone age 7-6
17-KS: 16-22 mg/d.

Urogenital sinus non-
communicating.
Raised as boy.
Plastic operations on
hypospadiac penis
and scrotum. (H.L.H.
A52394)

Age 4 yrs.,
5 mos.
Ht. age 7-0
Bone age 11-0
17-KS:
17-22 mg/d.
Pubic hair at
2½ yrs.

Small urogenital
sinus.
Raised as girl.
Clitoris excised.
(H.L.H. A47344)

Age 9 yrs.
Ht. age 14-6
Bone age 15-0
17-KS: 14-22 mg/d.

Pubic hair at 4½ yrs.
Axillary hair at 8 yrs.
Large urogenital sinus.
Raised as girl.
Clitoris excised.
(H.L.H. A26544)

Patients all had enlarged phallus, urogenital sinus and absent vagina at birth. Patient B had been mistaken for a boy and raised as such.

NOTE the excessive somatic growth, advanced skeletal development, high 17-ketosteroid output and early appearance of sexual hair. Patients were well developed muscularly, but did not seem especially "masculine."

Baltimore 1950: From Experimentation to Medical Extinction

Lawson Wilkins (1894-1963), "The Father of Pediatric Endocrinology", and teacher of the famous Swiss paediatric endocrinologist Andrea Prader in 1950, was also the "inventor" of systematic cosmetic genital surgeries on children. As his monograph illustrates, in 1950 at Johns Hopkins in Baltimore, any child diagnosed "not normal" was submitted to drastic "Genital Corrections", either "feminising" or "masculinising". Often John Money gets erroneously credited as having started the systematic mutilations, however, it was Wilkins and Prader who propagated systematic surgeries; Money "only" delivered a "scientific" rationale five years after the fact.

Sources: Lawson Wilkins: *The Diagnosis and Treatment of Endocrine Disorders in Childhood and Adolescence*. Springfield, 1950.
Alison Redick: *American History XY: The Medical Treatment of Intersex, 1916-1955*, Dissertation 2004

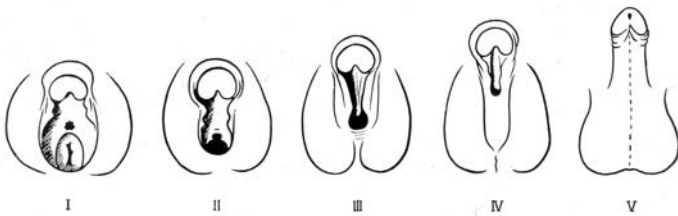


Abb. 673. Formen des äußern Genitale bei Mädchen mit adrenogenitalem Syndrom infolge angeborener NNR-Hyperplasie (nach Prader). Typ I: nur Clitoris vergrößert. Typ II: Vestibulum trichterförmig verengt, Urethral- und Vaginalöffnung getrennt, aber dicht übereinanderliegend. Typ III: Sinus urogenitalis mit etwa bleistiftlicher Mündung. Typ IV: Urethraartige Mündung des Sinus urogenitalis an der Basis der vergrößerten Clitoris (ähnlich einer Hypospadias peno-scrotalis beim Knaben). Typ V: Mündung des Sinus urogenitalis im Bereiche der Glans (selten).

als bei der echten Pubertas praecox. Im Röntgenbild läßt sich nach retroperitonealer Luftfüllung die vergrößerte Nebenniere meist gut erkennen (vgl. Abb. 668 und 669).

Äußere Genitalform: Für den Chirurgen sind die Veränderungen des äußern Genitale in therapeutischer und differentialdiagnostischer Hinsicht von besonderer Bedeutung. Es ist anzunehmen, daß der Grad der Vermännlichung der weiblichen Geschlechtsorgane beim adrenogenitalen Syndrom vom Zeitpunkt, in welchem die fetale Überproduktion androgener Hormone einsetzt, und von ihrer Intensität abhängt. Nach Prader, der 19 Fälle unserer Klinik zusammengestellt hat, lassen sich 5 verschiedene Typen auseinanderhalten (Abb. 673), die fließende Übergänge vom normalen weiblichen zum normalen männlichen äußern Genitale darstellen. Allen gemeinsam ist eine mehr oder weniger stark vergrößerte, erigierbare Clitoris. Diese ist dorsal und lateral von einem wohlentwickelten Praeputium umgeben. Auf der Ventralseite der Clitoris, die oft nach unten gekrümmt ist, findet sich eine rinnenförmige Eindellung, die zur Urogenitalöffnung hinzieht. Die Labia majora, die immer ausgebildet sind, zeigen eine scrotumartig gefaltete und pigmentierte Haut. Sie sind in ihren hintern Abschnitten oft miteinander zu einer Rhaps verwachsen. Bei allen Formen fällt die abnorme Länge des Damms auf.

Beim seltenen Typus I ist nur die Clitoris vergrößert, die Vulva zeigt sonst normale Verhältnisse. Diese Fälle werden deshalb oft im Säuglingsalter übersehen. Beim Typus II ist das Vestibulum trichterförmig verengt (Abb. 674). In seinem Grunde findet man nach Spreizung der Labien die Urethra- und Vaginalöffnung, die dicht übereinander liegen. Beim Typus III ist an der Basis der vergrößerten Clitoris nur eine einzige Uro-



Abb. 674. Äußeres Genitale bei Mädchen mit angeborenem adrenogenitalem Syndrom: Typ II.

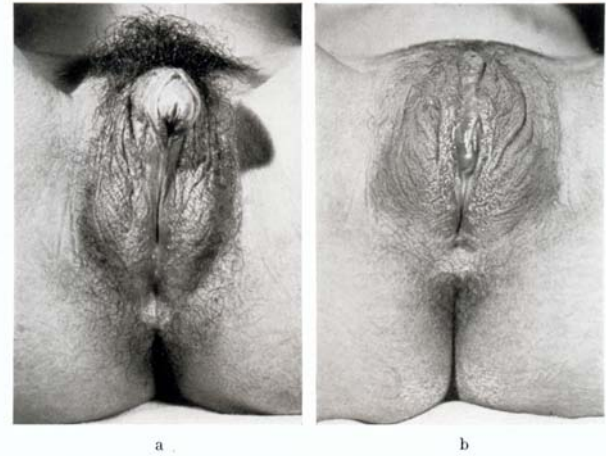


Abb. 679. Penisartige Vergrößerung der Clitoris bei angeborenem adrenogenitalem Syndrom. (7jähriges Mädchen.) a) Vor, b) nach Exstirpation der Clitoris.

Operative Korrektur des äußern Genitale: Beim Pseudohermaphroditismus femininus drängt sich eine operative Korrektur des äußern Genitale, d. h. die Entfernung der vergrößerten Clitoris und die Freilegung der Vaginalöffnung bei den beschriebenen Formtypen II-IV, auf. Die Amputation der Clitoris, die durch ihre Größe und Erektionen störend wirkt und diesen Mädchen beim Umkleiden, Baden usw. Verlegenheiten bereiten kann, ist sicher gerechtfertigt und wird nicht nur von den meisten Eltern, sondern – wie wir selbst erfahren haben – auch von solchen Patienten im Erwachsenenalter dringend gefordert. Die Clitorisamputation und die Freilegung der Vagina können in der gleichen Sitzung durchgeführt werden.

Technik: Die Haut des Clitorisschaftes wird unmittelbar vor der Symphyse zirkulär umschnitten. Nach Freilegung der Corpora cavernosa werden diese an der Symphyse mit einem Kocher abgeklippt und distal davon quer durchtrennt. Wir belassen gewöhnlich einen ganz kurzen Clitorisstumpf, der zur Blutstillung mit einer Durchstechungsligatur versorgt und mit der überschüssigen Clitorishaut gedeckt wird (Abb. 679).

Zur Freilegung der Vagina wird zunächst eine Hohlsonde in die Mündung des Sinus urogenitalis eingeführt und in der Richtung des Damms vorgeschoben (Abb. 677c). Hierauf ist die Haut über der Sonde so weit analwärts zu durchtrennen, bis der Introitus vaginae im hintern Wundwinkel allseitig frei liegt. Er schließt gewöhnlich unmittelbar an das Orificium externum der Urethra an und besitzt ein kleines Hymen. Die Schleimhautränder des eröffneten Sinus urogenitalis werden seitlich mit den Hauträndern, die zur Ausweitung des Vestibulum etwas reseziert werden, durch einige Knopfnähte vereinigt. Auf diese Weise gelingt es, wenn auch nicht normale anatomische Verhältnisse, so doch wenigstens ein ziemlich weites, trichterförmiges Vestibulum herzustellen (Abb. 676e).

Zurich 1957: Prader Scales, “Surely Justified” Clitoris Amputations, and even more “Embarrassing” Psychosocial Indications

Swiss paediatric surgeon Max Grob (1901-1976), trained in Paris by Ombrédanne, served as director of the Zurich University Children's Hospital's paediatric surgery unit 1939-1971, and in 1957 published his influential *“Textbook on Paediatric Surgery”* with contributing authors Margrit Stockmann (Luzern), and Marcel Bettex, then consulting paediatric surgeon in Zurich. Grob's *“Textbook”*, indiscriminately hailed by the Zurich University Children's Hospital till this day, stressed the *“special importance”* for surgeons of Andrea Prader's newly developed systematic classification of *“genital variations”* (“Prader Scales”). In its section on *“surgical correction of the external genital”* of children with 46,XX CAH (*“[T]he removal of the enlarged clitoris [...] suggests itself. [...] Technique: [...] Usually we leave a very short clitoris stump”*), Grob proclaimed the psychosocial justifications for cosmetic genital surgery on intersex children still prevalent today *“The amputation of the clitoris, which may appear bothersome due to its size and erections, and may lead to embarrassment for these girls in the changing room or while swimming, is surely justified.”*) Grob became the founder and first president of the Swiss Society for Paediatric Surgery, and honorary member of the German, Austrian, British and U.S. societies. Grob's recommendations in the *“Textbook”* (*“surgical correction”* in case of Prader Stages II-V, arguably devised at least with input by Prader himself), represented the global standard until the “Chicago DSD Consensus Conference” in 2005 (changing it to III-V).

Sources: Max Grob: *Lehrbuch der Kinderchirurgie*, with Margrit Stockmann and Marcel Bettex, Stuttgart, 1957, p. 583, 587.

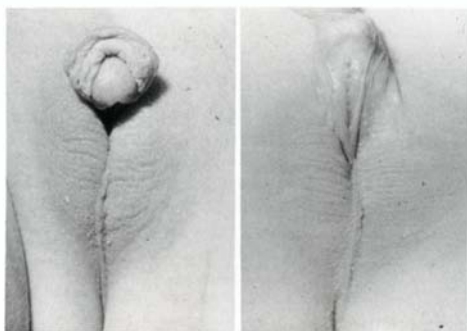


Abbildung 8.74: **Pseudohermaphroditismus femininus bei adrenogenitalem Syndrom** (vergleiche mit Hypospadias scrotalis, Abb. 8.71).

a **hypertrophische Klitoris**
b Verschluss des Sinus urogenitalis

b) **Nicht-adrenale Form:**

Infolge Androgen- oder Progesteronbehandlung der schwangeren Mutter oder als isolierte Missbildung.

4.2 **Therapie:**

a) **bei AGS:** Kortisondauertherapie und operative Korrektur der äusseren Genitalien (Verkürzung oder **Amputation der Klitoris**, Eröffnung des Sinus urogenitalis).

b) Bei anderen Formen nur **operative Korrektur** der äusseren Genitalien.

OVARIALZYSTEN UND OVARIALTUMOREN

1. **Klassifikation**

1.1 **Nicht-neoplastische Zysten** (Retentions-Zysten). Follikelzyste, Corpus-luteum-Zyste, „einfache“ Zyste (nicht klassifizierbare Zyste!).

1.2 **Echte primäre Neubildungen**

1.2.1 **Epitheliale Zysten und Tumoren**

A. Aus Epithelium des MÜLLERSchen Ganges

a) Seröses Zystadenom:

- einfaches → benigne
- papilläres → benigne
- papilläres → maligne (papilläres Zystadenokarzinom)



Abbildung 8.70: Hypospadias penis media mit Krümmung des Penis.



Abbildung 8.71: Hypospadias scrotalis.

6.7 **Hypospadias perinealis:** wie 6.6.

6.8 **Zur Technik:**

- Die Korrektur der Krümmung muss sehr sorgfältig durchgeführt werden!
- Zur Rekonstruktion der Urethra darf nur **unbehaarte Haut** verwendet werden (also keine Skrotalhaut)

6.9 **Zeitliche Indikation zur Operation:** aus **psychologischen Gründen** ist die Korrektur vor dem Schuleintritt vorzunehmen. Bei leichten Formen beginnen wir im Alter von 4 bis 4½ Jahren; bei schweren Formen etwas früher (3–5 Eingriffe notwendig, jeweils im Abstand von 6 Monaten). Kontrolle nach Pubertät sehr wichtig. **Evtl. Nachkorrekturen notwendig.**

7. **Resultate**

7.1 In der Regel gute funktionelle Resultate. Ästhetisch ordentlich, soweit man sich mit einem präputiumlosen Zustand abfinden kann! Bei allen Formen können Residual-Fisteln zurückbleiben! Sehr störend! **Nachkorrektur** unerlässlich. Erwachsene Patienten beanstanden meist nur die ungenügende Beseitigung der Krümmung.

Bern 1975: “Therapy: Amputation of the Clitoris”, Hypospadias “Repair” (“Possibly After-Corrections Necessary”)

Swiss paediatric surgeon Marcel Bettex (1920-1976), trained in Zurich by Max Grob, served as director of the Bern University Children’s Hospital “Insel”’s paediatric surgery unit 1958–1987. In 1975 Bettex was the principal author of the textbook “*Fundamentals of Paediatric Surgery*”, which still recommended “*amputations of the clitoris*” as “*therapy*” for 47,XX CAH and other diagnoses associated with “*hypertrophied clitoris*”. The textbook also recommended early “*surgical corrections*” for hypospadias justified by the same “*psychological*” indication still prevalent in current effective guidelines, despite admitted need for repeated surgeries, as well as frequent “*after-corrections*”. Nonetheless, “*Fundamentals*” was still indiscriminately hailed by the “*Journal of Pediatric Surgery*” in 1998. In 1970, Bettex became the first Swiss Professor for Paediatric Surgery. He served as a the first General Secretary of the Swiss Society for Paediatric Surgery, as council member of the British Association of Paediatric Surgeons (BAPS), 1984–87 as president of the World Federation of Associations of Pediatric Surgeons (WOFAPS), and was a honorary member of the paediatric surgical societies of Switzerland, the United States, Brazil, Belgium, and Greece.

Sources: Marcel Bettex, François Kuffer, Alois Schärli: *Wesentliches über die Kinderchirurgie*. Bern, 1975, p. 255, 251.



**by Zwischengeschlecht.org, Intersex.ch,
and SI Selbsthilfe Intersexualität**