

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



**HUMAN
RIGHTS FOR
HERM
APHRODITES
TOO !**

**NGO Report
to the 7th Periodic Report of Switzerland
on the Convention against Torture and Other Cruel,
Inhuman or Degrading Treatment or Punishment (CAT)**

+ Supplement “IGM – History and Current Practice”

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Executive Summary

Intersex people are born with variations of sex anatomy, including atypical genitals, atypical sex hormone producing organs, atypical response to sex hormones, atypical genetic make-up, 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).

IGM Practices 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 IGM Practices include “masculinising” and “feminising”, “corrective” genital surgery, castration and other sterilising procedures, imposition of hormones, forced genital exams, vaginal dilations and medical display, human experimentation and denial of needed health care (B 2., Supplement “IGM in Medical Textbooks”).

IGM Practices cause known **lifelong severe physical and psychological suffering**, including loss or impairment of sexual sensation, painful scarring, painful intercourse, incontinence, serious problems with passing urine, 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, increased sexual anxieties, less sexual activity, dissatisfaction with functional and aesthetic results. (B, Cases No. 1–6)

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. Parents and children are misinformed, kept in the dark, sworn to secrecy, kept isolated and denied appropriate support. (B 2.–3., Cases No. 1–6, Supplement “IGM in Medical Textbooks”).

For more than 20 years, intersex people, NGOs, human rights and bioethics experts have criticised IGM as harmful and traumatising, as a **fundamental human rights violation**, as **torture or cruel, inhuman or degrading treatment**, as a form of genital mutilation and child sexual abuse, and called for legislation to end it (B 4.–6., C).

The Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE), the UN Committees **CAT**, **CRC**, **CEDAW** and **CRPD**, the UN Special Rapporteur on Torture (**SRT**), the UN High Commissioner for Human Rights (**UNHCHR**), the World Health Organisation (**WHO**) and the Council of Europe (**COE**) have all criticised IGM Practices as a serious **violation of human rights**, and have called for **legislative measures** (**CAT**, **SRT**, **COE**, **NEK-CNE**), initiation of a process of coming to terms with past and current practices, and acknowledgement by society of suffering inflicted (**NEK-CNE**), and for **access to redress and justice** for victims (**CAT**, **CRC**, **CRPD**, **WHO**, **NEK-CNE**) (B 4., C, Annexe 3).

The **Swiss Federal Government**, **Cantonal Health Departments** and **National Medical Bodies violate the obligation to prevent torture and cruel, inhuman or degrading treatment** (Art. 1, 2, 16 CAT), **to ensure impartial investigation, access to redress, and the right to fair and adequate compensation and rehabilitation for victims** (Art. 12, 13 and 14 CAT), **and to train and inform medical staff** (Art. 10 CAT) (B 2.–6., C 2.–4., D, Annexe 2).

This NGO Report to the 7th Swiss state report was compiled by Swiss NGOs and self-help groups **Zwischengeschlecht.org**, **Intersex.ch**, and **SI Selbsthilfe Intersexualität**. It contains **Concluding Recommendations** (E).

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Introduction

Switzerland will be considered for its seventh periodic review by the Committee against Torture in its 55th Session in 2015. Unfortunately, human rights violations of intersex children and adults weren't mentioned in the State Report nor in the LoIPR. However, this NGO Report demonstrates that the current medical treatment of intersex infants and children in Switzerland constitutes a breach of Switzerland's obligations under the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.

In Switzerland's public, university and private clinics, doctors are regularly performing non-consensual, irreversible, medically unnecessary cosmetic genital surgeries, sterilising procedures, and other harmful treatments on intersex children, which have been described by survivors as genital mutilation and torture, which are known to cause lifelong physical and psychological pain and suffering, and which have been repeatedly recognised by UN bodies as constituting torture or cruel, inhuman or degrading treatment.

The Swiss State not only does nothing to prevent this abuse, but in fact directly finances it via the state funded invalidity insurance (Invalidenversicherung IV), thus violating its duty to prevent torture and inhuman or degrading treatment (Art. 2 and 16). Despite a specific call by its own National Advisory Commission on Biomedical Ethics (NEK-CNE) to undertake a legal review including of associated statutes of limitation to ensure access to redress and justice for survivors, to this day the Swiss Government refuses to take appropriate action (Art. 14), but refuses survivors the right to an impartial investigation and to redress and compensation (Art. 12, 13). Also, the Government refuses to provide adequate education and training of medical personnel on the prohibition of torture (Art. 10).

This report has been prepared by the Swiss Intersex 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. It is 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 IGM Practices and other human rights violations perpetrated on intersex people, according to its motto, "*Human Rights for Hermaphrodites, too!*"¹ According to its charter,² *Zwischengeschlecht.org* works to support persons concerned seeking redress and justice, and has continuously collaborated with members of parliament and other bodies in order to call on Governments and Clinics to collect and disclose statistics of intersex births and IGM practices.
- *Intersex.ch* is a Swiss intersex peer support group founded in 2005.³
- The Verein *SI Selbsthilfe Intersexualität* is a Swiss peer support group for parents of intersex children founded in 2003.⁴

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 for the 2014 CRC Thematic NGO Report 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

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

2 <http://zwischengeschlecht.org/post/Statuten>

3 <http://intersex.ch/>

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

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, and especially not about the fact that they are medically unnecessary, but are conducted without consent by the persons concerned and/or their parents nonetheless, and often without an established diagnosis. All patients who were submitted to cosmetic genital surgeries report suffering as a result of the procedures performed on them, both physical and psychological.

This thematic NGO report draws heavily on the 2014 CRC Swiss Thematic NGO Report on Intersex and IGM practices by the same rapporteurs,⁵ on the solicited 2012 Report to the UN Special Rapporteur on Torture “Medical Treatment of People with Intersex Conditions as Torture and Cruel, Inhuman, or Degrading Treatment or Punishment” by Advocates for Informed Choice,⁶ and the 2011 CAT German Thematic NGO Report on Intersex and IGM practices by Intersexuelle Menschen e.V./ XY-Frauen and Humboldt Law Clinic: Human Rights.⁷

IGM Practices are a special and emerging human rights issue. In order to assess the current practice at national level, some general knowledge of the most pressing human rights violations faced by intersex people can be crucial. Therefore, this NGO report includes some summarised general information on intersex and IGM Practices.

For further reference, and to facilitate access to more comprehensive information for the Committee, the rapporteurs attached a thematic **Supplement “IGM in Medical Textbooks”** (p. 54); and refer to the two additional Supplements “*IGM – Historical Overview*” and “*IGM – The 17 Most Common Forms*” contained in the *2014 CRC Thematic NGO Report*.⁸

The rapporteurs are aware that IGM Practices 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 State Party to issue recommendations to.

5 Zwischengeschlecht.org, Intersex.ch, SI Selbsthilfe Intersexualität: NGO Report to the 2nd, 3rd and 4th Periodic Report of Switzerland on the Convention on the Rights of the Child (CRC). Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

6 http://aiclegal.org/wordpress/wp-content/uploads/2012/10/AIC-Testimony-to-the-United-Nations-Special-Rapporteur-on-Torture_December-2012.pdf

7 http://intersex.shadowreport.org/public/Association_of_Intersexed_People-Shadow_Report_CAT_2011.pdf

8 http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

A. What is Intersex?

1. Variations of Sex Anatomy

Intersex persons, in the vernacular also known as hermaphrodites, or medically as persons with “*Differences*⁹ of Sex Development (DSD),” are people born with “atypical” sex anatomies and reproductive organs, including

a) “ambiguous genitalia”, e.g. “enlarged” clitoris, urethral opening not on the tip of the penis, but somewhere below on the underside of the penis (Hypospadias), fused labia, absence of vagina (vaginal agenesis, or Mayer-Rokitansky-Küster-Hauser syndrome MRKH), unusually small penis or micropenis, breast development in “males”; 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 androgens (e.g. 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**.

Everybody started out as a hermaphrodite: Until the 7th week of gestation, every fetus has “indeterminate” genitals, two sets of basic reproductive duct structures, and bipotential gonads. Only after the 7th week of gestation, fetuses undergo sexual differentiation mostly resulting in typically male or female sex anatomy and reproductive organs (see Figure 1). However, with some fetuses, sex development happens along a less common pathway, e.g. due to unusual level of certain hormones, or an unusually high or low ability to respond to them, resulting in intersex children born with in-between genitals (see Figure 2) and/or other variations of sex anatomy.

*For more information and references on genital development and appearance, please see 2014 CRC NGO Report (A 2–3, p. 8–10.)*¹⁰

9 The currently still official medical terminology “**Disorders of Sex Development**” is **strongly refused by persons concerned**. See 2014 CRC NGO Report, p. 12 “Terminology”, online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

10 http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

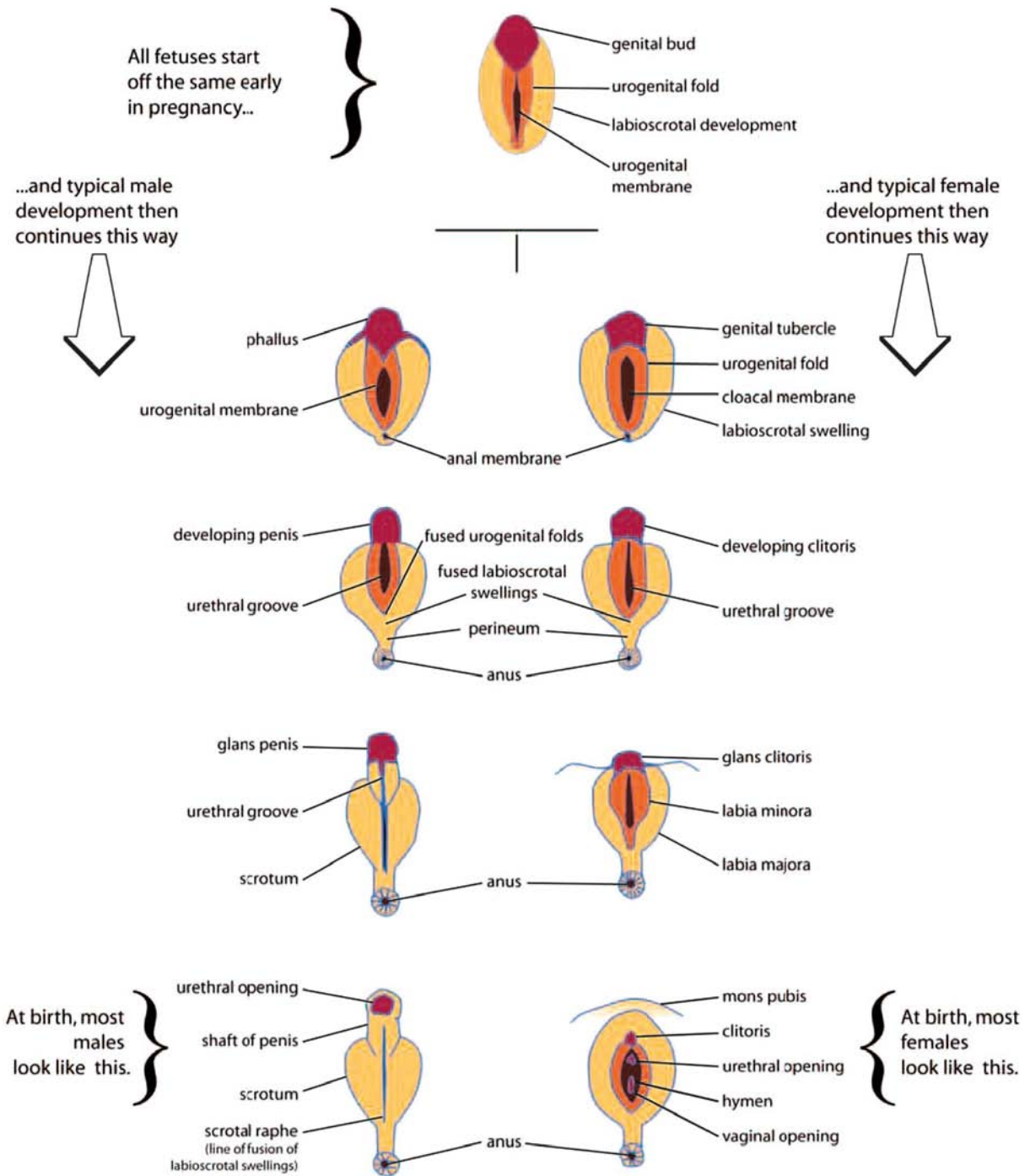


Figure 1 “Genital Development Before Birth”

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

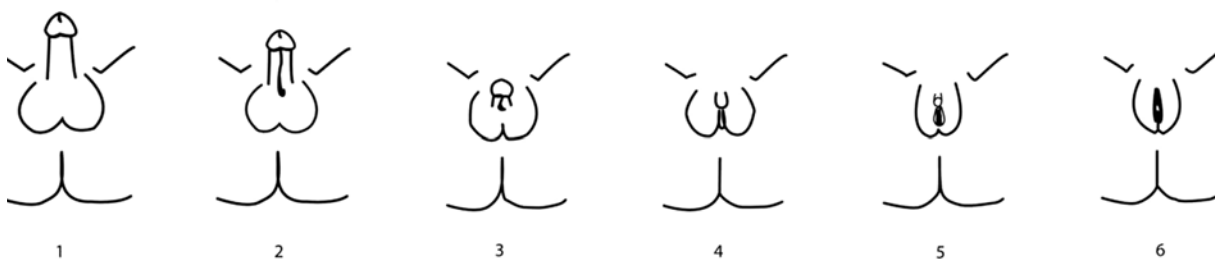


Figure 2 “Genital Variation” (Diagrams 1–6 corresponding to Prader Scale V–0)

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

2. How common is Intersex?

Since Swiss hospitals, government agencies and health insurances, as well as the Swiss federal invalidity insurance (Invalidenversicherung IV) covering intersex surgeries on children until the age of 20,¹¹ **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,¹² and
- b) 1:4500 or less¹³ 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, researchers with an interest in criticising the gender binary often give numbers of up to “*as high as 2%*”.¹⁴

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”**.¹⁵

11 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.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf

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

13 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

14 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.

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

B. IGM Practices / Non-Consensual, Unnecessary Medical Interventions

1. What are Intersex Genital Mutilations (IGM Practices)?

Intersex Genital Mutilations include non-consensual,¹⁶ medically unnecessary,^{17 18} irreversible,¹⁹ cosmetic²⁰ 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,^{21 22} but justified by “*psychosocial indications [...] shaped by the clinician’s own values*”,²³ the latter informed by societal and cultural norms and beliefs,^{24 25} enabling clinicians to withhold crucial information from both patients and parents,^{26 27} and to submit healthy intersex children to risky and harmful invasive procedures “*simply because their bodies did not fit social norms*”.²⁸

- 16 **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 *can’t* legally consent to medically unnecessary cosmetic genital surgeries on their healthy children, including IGM Practices, see: Mirjam Werlen (2014), *Persönlichkeitsschutz des Kindes*. Abhandlungen zum Schweizerischen Recht 180, at N 1026 (A–C), N 1032, N 698 ff.
- 17 **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>
- 18 Jörg Woweries (2010), *Intersexualität: Eine kinderrechtliche Perspektive, frühe Kindheit* 0310: 18-22, at 20-21, http://kastrationsspital.ch/public/fK_0310_Woweries.pdf
- 19 “*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>
- 20 “*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://www.ncbi.nlm.nih.gov/pmc/articles/PMC2082839/>
- 21 “*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
- 22 Jörg Woweries (2010), *Intersexualität: Eine kinderrechtliche Perspektive, frühe Kindheit* 0310: 18-22, at 21, http://kastrationsspital.ch/public/fK_0310_Woweries.pdf
- 23 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.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf
- 24 *ibid.*, at 18 and 15.
- 25 “*sociological and ideological reasons*”, WHO Genomic Resource Centre, *Genetic Components of Sex and Gender*, <http://www.who.int/genomics/gender/en/index1.html>
- 26 “*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
- 27 **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
- 28 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**.²⁹ 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.^{30 31}

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.^{32 33}

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**.³⁴ For a more comprehensive list and sources, see *2014 CRC NGO Report*, p. 63–76.

a) Sterilising Procedures:

Castration / “Gonadectomy” / Hysterectomy / (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**. Contrary to doctor’s claims, it is known that the gonads by themselves are usually healthy and *“effective” hormone-producing organs*, often with *“complete spermatogenesis [...] suitable for cryopreservation.”*³⁵ Nonetheless, many still undergo early removal of viable gonads (e.g. testes, ovaries, ovotestes) or other reproductive organs (e.g. uterus), leaving them with *“permanent, irreversible infertility and severe mental suffering”*³⁶ and **lifelong metabolic problems**. When unnecessary sterilising procedures

29 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>

30 *ibid.*, at 3

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

32 Anne Tamar-Mattis (2013), Report to the Inter-American Commission on Human Rights, at 2–7, <http://www.aph.gov.au/DocumentStore.ashx?id=432c5135-4336-472e-bb24-59c89eb4a643>

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

34 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*

35 K. Czeloth et al., “Function of Uncorrected Cryptorchid Testes”, 25th ESPU 2014, [online](#)

36 **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

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.**³⁷ Survivors often have to **pay themselves for adequate Replacement Hormones.**

For almost two decades, persons concerned have protested unnecessary 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. 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.*”³⁸

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, but which obviously persist), namely the infamous premise, “*We don’t want to breed mutants.*” (see 2014 CRC NGO Report, p. 52, 69)

Nonetheless, and despite recent discussions in medical circles, **unnecessary gonadectomies** and other sterilising treatments persist in **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.)

b) “Feminising Procedures”: Clitoris Amputation/“Reduction”, “Vaginoplasty”, Dilation

“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) 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 intersex children.

For four decades, doctors again and again claimed early clitoris amputation on intersex children **would not interfere with orgasmic function.**³⁹ Only in the 1980s–1990s, intersex clitoris amputations were eventually replaced by “more modern” techniques a.k.a. “**clitoral reduction**” (p. 55), 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.⁴⁰ 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**

37 see 2014 CRC NGO Report, p. 68 http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

38 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)

39 see 2014 CRC NGO Report, p. 57–58

40 Crouch NS, Minto CL, Laio LM, Woodhouse CR, Creighton SM (2004), Genital sensation after feminizing genitoplasty for congenital adrenal hyperplasia. *BJU Int* 93:135-138.

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

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 (see 2014 CRC NGO Report, 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. 64). Despite recent public denials by Swiss doctors, hospitals, and health departments, **systematic early “clitoris reductions”** and “**vaginoplasty**” performed on intersex infants and justified by **psychosocial indications**, are still practiced in most **Swiss University Children’s Clinics**. (**Cases No. 2–6**.)

c) “Masculinising Surgery”: 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. 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. 54).

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 latest 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. 54), while in medical publications on hypospadias, “[d]ocumentation on complication rates has declined in the last 10 years” (see 2014 CRC NGO Report, p. 54–56).

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 common practice for children concerned and raised as boys (**Cases No. 1 and 6**).

42 Daniel Weber, Verena Schönbacher, 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 Hypospadie, <http://kastrationsspital.ch/public/006-026-hypospadie-dgkch-2002.pdf>

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

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** (see 2014 CRC NGO Report, p. 71).

Nonetheless, in **Switzerland** it’s still paediatricians, endocrinologists and surgeons managing diagnostics and counselling of parents literally from “*day one*.”⁴⁵ 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*” (see 2014 CRC NGO Report, 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*” (see 2014 CRC Report, 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 common harmful treatments include (as detailed in the 2014 CRC NGO Report):⁴⁶

- **Forced Mastectomy** (p. 70)
- **Imposition of Hormones** (p. 73)
- **Forced Excessive Genital Exams, Medical Display, (Genital) Photography** (p. 73)
- **Human Experimentation** (p. 74)
- **Denial of Needed Health Care** (p. 75)
- **Prenatal “Therapy”** (p. 75)
- **Selective (Late Term) Abortion** (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 2., p. 10**), Swiss (university) hospitals, Government agencies and health insurance, 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 6., p. 20**).

What’s more, Swiss doctors, government and other institutions involved in IGM practices, if questioned about statistics, are notorious for going to extreme lengths following 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 IGM practices, while

45 e.g. Eastern Switzerland Children’s Hospital St. Gallen (2014), Zwischen den Geschlechtern, slide 8, http://kastrationsspital.ch/public/kispisg_09_vortrag_zwischen_den_geschlechtern_2.pdf

46 http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

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 a **misleading** overall total figure of “*almost 81% of all participants had at least once surgery [...] most of them before entering school.*”⁴⁷

Beschreibung des Samples



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

The only published numbers that include a breakdown by age groups available from the “**Netzwerk DSD**” intersex study with participation of **Swiss Cantonal Clinics (Bern and St. Gallen)**⁴⁸ stem from a semi-official 2009 presentation. They reveal that, contrary to declarations by doctors as well as cantonal and federal governments, in the most relevant **age groups of 4+ years, 87%–91% have been submitted to IGM surgeries** 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, although, 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. 45**). 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. 42**). 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 pub-

⁴⁷ 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 16, <http://kastrationsspital.ch/public/Bericht-Klinische-Evaluationsstudie.pdf>

⁴⁸ <https://web.archive.org/web/20130124010236/http://www.netzwerk-dsd.uk-sh.de/index.php?id=28>

licly boasts of 50 intersex surgeries in 30 years (p. 42). 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. 42–43). 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. 43). 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. 43–44). 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"**).

What's more, although for Switzerland officially no current figures are available, internationally the **total number** of cosmetic genital surgeries performed on intersex children is known to be **still rising**.^{49 50}

4. Lack of Legislative Prevention of IGM Practices (Art. 2, 16), Lack of Access to Redress and Justice for Victims (Art. 14)

For more than two decades, persons concerned and sympathetic clinicians and academics have tried to reason with the perpetrators, and for 19 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 eliminate IGM practices, and criticising the **factual impunity of IGM doctors** due to **statutes of limitations** that – both in criminal and civil law – **expire long before survivors of early childhood IGM practices would be able to call a court**.

In **Switzerland**, e.g. for Serious Assault ("serious injury on the person, or on an important organ or limb of another, [...]mak[ing] an important organ or limb unusable, [...] any other serious damage to the person or to the physical or mental health of another," Art. 122 Criminal Code)⁵¹ statutes of limitations expire **latest after 15 years** (Art. 97 Criminal Code),⁵² and for civil liability claims for damages or satisfaction **latest after 10 years** (Art. 60 Civil Code).⁵³

While in **Switzerland** statutes of limitations e.g. in the case of Female Genital Mutilation (FGM, Art. 124 Criminal Code) and sexual assault on children (Art. 187–188 Criminal Code) in 2014 have at least been extended until the age of 25 (Art. 97 Criminal Code),⁵⁴ survivors of early childhood IGM practices still face expiration of statutes of limitations long before they reach adulthood.

49 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

50 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>

51 <https://www.admin.ch/opc/en/classified-compilation/19370083/index.html#a122>

52 <https://www.admin.ch/opc/en/classified-compilation/19370083/index.html#a97>

53 <https://www.admin.ch/opc/en/classified-compilation/19110009/index.html#a60>

54 <https://www.admin.ch/opc/en/classified-compilation/19370083/index.html#a97>

In 2011, the **Committee against Torture (CAT)** was the first UN body to recognise the lack of adequate laws ensuring redress and investigations, explicitly calling on Germany to

*“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.**”*⁵⁵

In 2012, the **Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE)** was the first national body to eventually support the call of survivors for legal measures, in Recommendation 12 explicitly urging a **legal review** of both **criminal law** and **civil liability implications**, as well as for a review of **associated statutes of limitations**, with explicit reference to Art. 124 Criminal Code (FGM).

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 practices, *“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.**”*⁵⁶

In 2013, the survivors’s call for legislative measures was seconded by the **Special Rapporteur on Torture (SRT)**, who in his report on *“abuses in health-care settings that may cross a threshold of mistreatment that is tantamount to torture or cruel, inhuman or degrading treatment”* explicitly stated:

“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”, leaving them with permanent, irreversible infertility and causing severe mental suffering.

*These procedures [genital-normalizing surgeries] are rarely medically necessary, 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).”*⁵⁷

Also in 2013, this call was again seconded by the **Council of Europe (COE)** in their Resolution 1952 (2013) “Children’s right to physical integrity”, urging states to

*“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”*⁵⁸

In 2014, an **Interagency Statement on Forced Sterilisation by the WHO and 6 more UN bodies** explicitly also criticised IGM practices in general:

*“Children who are born with atypical sex characteristics are often subjected to cosmetic and other non-medically indicated surgeries performed on their reproductive organs, without their informed consent or that of their parents, and without taking into consideration the views of the children involved.”*⁵⁹

55 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

56 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

57 A/HRC/22/53, 1 February 2013, paras 77, 76: http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

58 Council of Europe (COE), Resolution 1952 (2013) “Children’s right to physical integrity”, 1 October 2013, para 7: <http://www.assembly.coe.int/nw/xml/XRef/X2H-Xref-ViewPDF.asp?FileID=20174&lang=en>

59 OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO, Eliminating forced,

In addition, the WHO interagency statement explicitly called for “*Remedies and redress*”, as well as for “*Monitoring and Compliance*.”

In 2015, the **Committee on the Rights of the Child (CRC)** criticised **Switzerland** for allowing IGM practices to continue, explicitly highlighting “*the lack of redress and compensation in such cases*,” and classifying IGM practices as “*violence against children*” and as a “*harmful practice*”,⁶⁰ thus clearly implicating the urgent need for legislative measures to eliminate them.

Also in 2015, the **Committee on the Rights of Persons with Disabilities (CRPD)**, referring to the 2011 CAT Concluding Observations, criticised the failure of “*upholding bodily integrity of intersex children*”, and urged Germany to “*take the necessary measures, including of a legislative nature to [...] [i]mplement all the recommendations of CAT/C/DEU/CO/5, para. 20 relevant to intersex children.*”⁶¹

Again in 2015, the **WHO Report “Sexual health, human rights and the law”** reiterated:

*“It has also been recommended [by human rights bodies and ethical and health professional organizations] that **investigation should be undertaken** into incidents of surgical and other medical treatment of intersex people without informed consent and that **legal provisions should be adopted** in order to provide remedies and redress to the victims of such treatment, including adequate compensation.”*⁶²

However, to this day the **Swiss Government** not only didn’t follow up on their commissioned recommendations of the National Advisory Commission on Biomedical Ethics (NEK-CNE), but **refuses to take legislative action**.

5. Lack of Impartial Investigation (Art. 12, 13), 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*”,⁶³ and stressed the imminent need for **impartial, disinterested investigation and research**, as called for in Art. 12 CAT and the Committee’s own 2011 Concluding Observations,⁶⁴ as well as by the 2012 Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE) (Recommendation 9), the 2013 COE Resolution 1952 (para 7), and the 2014 WHO Interagency Statement.

However, to this day, despite repeated calls for impartial investigation and disinterested research, also in **Switzerland** the only “investigations” taking place are the “research” facilitated by the perpetrators themselves, relying on massive state funding.

The only exception proving the rule is an **exceptional preliminary research study**

coercive and otherwise involuntary sterilization. An interagency statement, May 2014, http://www.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf?ua=1

60 CRC/C/CHE/CO/2-4, p. 8-9, paras. 42-43: http://tbinternet.ohchr.org/_layouts/treatybody-external/Download.aspx?symbolno=CRC/C/CHE/CO/2-4&Lang=En

61 CRPD/C/DEU/CO/1, p. 6–7, paras 37-38: http://tbinternet.ohchr.org/_layouts/treatybody-external/Download.aspx?symbolno=CRPD/C/DEU/CO/1

62 p. 27, http://apps.who.int/iris/bitstream/10665/175556/1/9789241564984_eng.pdf?ua=1

63 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)

64 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

“*Historic Evaluation of Treatment of Persons with Differences of Sex Development*”⁶⁵ examining 22 cases of clitoris amputations at the **Zurich University Children’s Clinic** between 1913 and 1968. This preliminary study was initiated and paid for by the University Children’s Clinic (after considerable pressure by intersex NGOs and self-help groups). However, the clinic is still **struggling with funding** to adequately continue this ground-breaking project constituting a global first, and so far **no Swiss state body considered supporting it**.

On the other hand, currently millions of Euros are spent on exculpating “intersex research projects” involving **Swiss funding**⁶⁶ and/or **participation**,⁶⁷ as well as **Swiss Federal Government representation**.⁶⁸

“**DSD-Life**” and “**DSDnet**”, two current examples, are **conducted by the perpetrators themselves**, e.g. in “DSDnet” paediatric endocrinologists,⁶⁹ and in “DSD-Life” paediatric endocrinologists and paediatric surgeons⁷⁰ taking the lead – exactly the professional groups responsible for IGM practices in the first place. If other disciplines are included at all in the “multidisciplinary 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 perpetrator’s “research projects” continue to openly advocate IGMs, 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):

*“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.”*⁷¹

On the other hand, to this day an **impartial investigation** into past and current IGM practices **isn’t even considered by the Swiss Government**.

6. Lack of Independent Data Collection and Monitoring (Art. 12, 13)

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 effectively highlight and monitor** the ongoing mutilations. What’s more, after realising how intersex genital surgeries are increasingly in the focus of public

65 http://www.kispi.uzh.ch/de/zuweiser/fachbereiche/urologie/Documents/Bericht_DSD_Sandra_Eder_Kinderspital_Zuerich.pdf

66 See associated countries: Switzerland, <http://www.fp7peoplenetwork.eu/200811214/fp7/fp7-the-7th-framework-programme-of-the-european-union-for-research-and-development.html>

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

“Netzwerk DSD”: **Bern, St. Gallen**, [online](#)

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

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

70 <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>

71: “DSDnet” (2013), Memorandum of Understanding, at 4, http://w3.cost.eu/fileadmin/domain_files/BMBS/Action_BM1303/mou/BM1303-e.pdf

scrutiny and debate, perpetrators of IGMs respond by suppressing complication rates, as well as refusing to talk to journalists “on record”.⁷² Despite **recent claims by the State Party** of “*the Federal Office for Statistics and the Federal Office for Public Health are now working together to develop a design for the collection of data*”,⁷³ on inquiry by the rapporteurs, to this day the Federal Government **wasn’t able to name anyone actually responsible** for this alleged project.

C. 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, CESCR NGO Statement 2004⁷⁴

For 22 years now, intersex people from all over the world, and their organisations have been publicly denouncing IGM Practices as destructive of sexual sensation, and as a violation of basic human rights, notably the right to physical integrity.⁷⁵ For 18 years, they have lobbied for legislation against IGM Practices to end the impunity of perpetrators due to statutes of limitation.⁷⁶ For 17 years, they have been invoking UN Conventions,⁷⁷ and for 11 years they have been reporting IGM Practices to the UN as a human rights violation.⁷⁸

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 Practices as a **human rights issue**,⁷⁹ as **harmful and traumatising**,⁸⁰ as **torture**,⁸¹ as a **western form of genital mutilation**,⁸² as **child sexual abuse**,⁸³ and have called for **legislation to end it**.⁸⁴ (**Cases No. 1–6**)

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

73 The Swiss delegation on occasion of the dialogue with CRC, 22 January 2015, Transcript: <http://stop.genitalmutilation.org/post/Transcript-Intersex-QA-CRC-Geneva-2015>

74 Mauro Cabral (2004), NGO Statement: Intersexuality, [online](#)

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

76 Cheryl Chase (1996), Female Genital Mutilation in the U.S. Discussion, <https://web.archive.org/web/20110602195403/http://h-net.org/~women/threads/mut.html>

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

78 Mauro Cabral (2004), NGO Statement: Intersexuality, [online](#)

79 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

80 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>

81 <http://blog.zwischengeschlecht.info/post/2008/12/30/Medizinische-Intervention-als-Folter-Michel-Reiter-3062000>

82 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

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

84 Swiss National Advisory Commission on Biomedical Ethics NEK-CNE (2012), On the man-

The UN Committees **CAT**, **CRC**, **CRPD**, **CEDAW**, the UN Special Rapporteur on Torture (**SRT**), the UN Special Rapporteur on Health (**SRH**), the UN High Commissioner for Human Rights (**UNHCHR**), the World Health Organisation (**WHO**), the Council of Europe (**COE**), and last but not least the Swiss National Advisory Commission on Biomedical Ethics (**NEK-CNE**) have all recognised the treatment of intersex children as a **serious human rights violation**, have called for **legislative measures** (**CAT**, **SRT**, **COE**, **NEK-CNE**), **historical reappraisal** and acknowledgement by society of suffering inflicted (**NEK-CNE**), and for **access to redress and fair compensation for victims** (**CAT**, **CRC**, **CRPD**, **WHO**, **NEK-CNE**) (see **Bibliography**, p. 47).

1. Switzerland's Commitment to the Prevention of Torture and Cruel, Inhuman or Degrading Treatment (CIDT)

By ratifying the **Convention against Torture (CAT)**, 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). In addition, Switzerland has ratified the **Convention on the Rights of the Child (CRC)**, 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 experimentation. The prohibition of torture is absolute and non-derogable.⁸⁵ All of these Conventions are enforceable statutory law by virtue of their ratification.⁸⁶ In addition, the **Swiss Federal Constitution (SFC)**⁸⁷ ensures the right to life and personal freedom, particularly the right to physical and mental integrity, and explicitly prohibits CIDT (Art. 10 Para. 3 SFC), and in addition emphasises the right of special protection of the integrity of children and young people (Art. 11 SFC), as well as ensuring the respect for, and the protection of, their dignity (Art. 7 SFC), and ensuring equality and non-discrimination (Art. 8 SFC).

2. The Treatment of Intersex Persons in Switzerland as Torture

In Article 1 of CAT, torture is defined as:

“any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as obtaining from him or a third person information or a confession, punishing him for an act he or a third person has committed or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity. It does not include pain or suffering arising only from, inherent in or incidental to lawful sanctions.”

Although many cases of torture happen in detention, torture is no longer understood to constitute solely interrogation, punishment or intimidation of a captive.⁸⁸ Rather, the definition includes any setting. The UN Special Rapporteur on Torture pointed out in 2008:

agement of differences of sex development. Ethical issues relating to “intersexuality”, Opinion No. 20/2012, Recommendation 15, at 19, [online](#)

85 Art. 2(2) CAT; Nowak/McArthur (2008), *Convention Against Torture*, Art. 3 para. 200; CAT, General Comment No. 2, CAT/C/GC/2, para. 5-6.

86 Swiss Federal Court, e.g. BGer 1C_247/2012, BGE 127 IV 15,4BGE 127 I 6, BG 131 I 455

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

88 Sifris (2010), *Conceptualising involuntary sterilisation as “severe pain or suffering” for the purposes of torture discourse*, *Neth. Qu. HR* 28(4), 523-547, at 526.

*“Whereas a fully justified medical treatment may lead to severe pain or suffering, medical treatments of an intrusive and irreversible nature, when they lack a therapeutic purpose, or aim at correcting or alleviating a disability, may constitute torture and ill-treatment if enforced or administered without the free and informed consent of the person concerned.”*⁸⁹

In light of this definition, medically unnecessary genital “normalizing” surgeries and hormone treatments that were not legally consented to by the patient constitute torture in violation of Article 1(1) of the Convention. That is, that such surgeries constitute acts that cause severe pain or suffering (a), they are intentional (b), they serve a specific purpose (c), there is a sufficient nexus with a public official (d) and they are not lawfully sanctioned (e).

a) Infliction of Severe Pain or Suffering

The infliction of severe pain or suffering on a person can be physical or mental. **Mental suffering** has been defined as the infliction of pain through the creation of a state of anguish and stress by means other than bodily assault.⁹⁰ Each circumstance of torture needs to be considered individually, in the context and circumstances, and there is no definitive list of what constitutes a tortuous act.⁹¹

The **severity** of pain and suffering is relative and therefore has to be evaluated in the specific context. Therefore, the severity of an act that might constitute torture needs to be assessed from an objective perspective that looks at each specific situation and each particular victim and his/her vulnerability.⁹² Thereby one needs to take into account different factors, such as the duration of the treatment, its physical/mental effects and the sex, age, state of health of the victim.⁹³ Thus, the UN Special Rapporteur on Torture has pointed out that children are more vulnerable to the effects of torture as they are in the critical stages of physical and psychological development where they may suffer graver consequences than similarly ill-treated adults.⁹⁴ The effects of torture/ill-treatment will also differ according to the age of the child, depending on the readiness of mind. Torture inflicted on a child might leave more long-lasting effects than on an adult.⁹⁵ As with children undergoing female genital mutilation (FGM), intersex children undergoing IGM Practices at an early age are in a situation of powerlessness, as they are under the complete control of their parents and have no means of resistance.⁹⁶

While the surgery performed on intersex persons will normally involve adequate pain management (anaesthesia), IGM Practices have severe effects on the intersex person’s physical and psychological wellbeing which constitute an infliction of severe pain or suffering:

- **Sterilising Procedures** (see above **p. 12**) leading to “*permanent, irreversible infertility [...] causing severe mental suffering*”⁹⁷, as well as to the **termination of**

89 Interim report of the Special Rapporteur on the question of torture and other cruel, inhuman or degrading treatment or punishment, A/63/175, of 28 July 2008, para. 47.

90 Eur. Com. Hum. Rts., Greek case, Op. Com., 15 Nov. 1969, Ybk. XII (1969), at 461.

91 Association for the Prevention of Torture (2001), The Definition of Torture: Proceedings of an Expert Seminar, at 28.

92 Ibid., p. 28.

93 ECtHR, Ireland v UK (1978) 2 EHRR 25, para. 162.

94 Report of the Special Rapporteur on Torture, E/CN. 4/1996/35, para. 10.

95 Association for the Prevention of Torture (2001), The Definition of Torture: Proceedings of an Expert Seminar, at 81.

96 Report of the Special Rapporteur on Torture, A/HRC/7/3, para. 53.

97 Report of the Special Rapporteur on Torture, A/HRC/22/53, 1 February 2013, para 77: <http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A>.

natural hormone production, which also causes mental suffering,⁹⁸ and which requires **life-long hormone substitution, which also results in severe physical suffering.**⁹⁹ In its General Recommendation No. 19, the CEDAW Committee notes that compulsory sterilisation adversely affects women’s mental health, and likewise will it affect a man’s mental health.¹⁰⁰ Moreover, in a recent case involving the sterilization of a Hungarian Romani woman without her knowledge or informed consent, the Committee noted the profound impact that the sterilization had on her life, resulting in her and her partner being treated medically for depression and psychological trauma.¹⁰¹ The Special Rapporteur on Torture has also taken up the subject in strong words.¹⁰² The sterilization of women without their consent has been recognized as a breach of the prohibition on torture.¹⁰³ Consequently, the Committee against Torture,¹⁰⁴ the Special Rapporteur on Torture¹⁰⁵ and the WHO¹⁰⁶ plus 6 more UN bodies¹⁰⁷ have issued strong statements specifically criticising forced sterilising procedures on intersex persons.

- **“Feminising” Surgical and Other Procedures** (see above **p. 13**) including removal or recession of the clitoris, vaginal surgery and dilation, leading to **impairment or loss of genital sensitivity, painful intercourse, sexual dysfunction and suicidal tendencies, causing severe physical and mental suffering.**¹⁰⁸

The **removal or recession of the clitoris** has been considered in international law as part of Female Genital Mutilation (FGM).¹⁰⁹ The UN Special Rapporteur on Torture, the UN Special Rapporteur on Violence against Women and the Human Rights Com-

[HRC.22.53 English.pdf](#)

- 98 2011 CAT German NGO Report on Intersex and IGM practices by Intersexuelle Menschen e.V./ XY-Frauen and Humboldt Law Clinic: Human Rights, at 18–19, http://intersex.shadow-report.org/public/Association_of_Intersexed_People-Shadow_Report_CAT_2011.pdf
- 99 Ibid., at 18.
- 100 CEDAW, General Recommendation No. 19 (1992): Violence against Women.
- 101 CEDAW, Andrea Szijjarto vs. Hungary, Communication No. 4/2004, A/61/38, 14 Aug. 2006.
- 102 Report of the Special Rapporteur on Torture, A/HRC/7/3, para. 39.
- 103 CCPR General Comment No. 28 (2000) on article 3 (The equality of right between men and women), para. 20. See also Concluding Observations on Slovakia, CCPR/CO/78/SVK, para. 12; on Japan, CCPR/C/79/ADD.102, para. 31; and on Peru, CCPR/CO/70/PER, para. 21. See also CAT, Concluding Observations on Peru, CAT/C/PER/CO/4, para. 23.
- 104 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
- 105 Report of the Special Rapporteur on Torture, A/HRC/22/53, 1 February 2013, para 77: http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf
- 106 WHO, “Sexual health, human rights and the law” (2015), http://apps.who.int/iris/bitstream/10665/175556/1/9789241564984_eng.pdf?ua=1
- 107 OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO, Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement (2014): http://www.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf?ua=1
- 108 2011 CAT German NGO Report on Intersex and IGM practices by Intersexuelle Menschen e.V./ XY-Frauen and Humboldt Law Clinic: Human Rights, at 17–18, http://intersex.shadow-report.org/public/Association_of_Intersexed_People-Shadow_Report_CAT_2011.pdf
- 109 This procedure is also called Female Genital Cutting (FGC). The World Health Organization defines FGM as “all procedures that involve partial or total removal of the external female genitalia, or other injury to the female genital organs for non-medical reasons“ and classifies it into four types, one of which is clitoridectomy.

mittee have made it clear that FGM constitutes torture¹¹⁰ and that, from a human rights perspective, the medicalisation of FGM – its performance in clinical surroundings – does not make this practice more acceptable.¹¹¹ This also holds for the mutilation of the clitoris of intersex children or adults as part of unnecessary feminising cosmetic surgery which, like FGM, is performed for purely cultural reasons. Accordingly, the Committee on the Rights of the Child explicitly considered “*medically unnecessary surgical and other procedures on intersex children, which often entail irreversible consequences and can cause severe physical and psychological suffering*” a “*harmful practice*”.¹¹²

Genital dilation is described as a very a painful experience. Other than the above treatments which are performed under anaesthesia, intersex persons are dilated repeatedly to prevent the downsizing of the tissue. The repeated insertion of a solid object into a young person’s vagina does not only pain the aggrieved persons, but it is also highly traumatic. Such invasions of the body, performed without the acquiescence of the victim, constitute rape. The ICTR in its Akayesu judgement, has established that in international law, rape is not limited to the penetration of the vagina with a penis but encompasses other bodily invasions, including with objects or with other parts of the body.¹¹³ The Inter-American Court of Human Rights thus considered a “*finger vaginal ‘examination’ [...] sexual rape that due to its effects constituted torture*”, an invasion similar to what is endured during dilation.¹¹⁴ As rape “*leaves deep psychological scars on the victims which do not respond to the passage of time as quickly as other forms of physical and mental violence*”,¹¹⁵ it has been found to constitute torture in many international settings.¹¹⁶ Intersex people who have endured dilation as children often report to reject any kind of penetration at adulthood, and to experience any kind of physicality as torment.¹¹⁷

110 Report of the Special Rapporteur on Torture, A/HCR/7/3, paras. 53, 54; Report of the Special Rapporteur on Violence against Women, E/CN.4/2002/83, para. 6 (severe pain and suffering element of CAT definition); see also A/HRC/4/34, para. 56. Breach of Art. 7 ICCPR: see CCPR general comment No. 28 (2000) on article 3 (The equality of rights between men and women), para. 11; see also Concluding Observations on Uganda, CCPR/CO/80/UGA, para. 10; Mali, CCPR/CO/77/MLI, para. 11; Sweden, CCPR/CO/74/SWE, para. 8; Yemen, CCPR/CO/84/YEM, para. 11.

111 Report of the Special Rapporteur on Torture, A/HCR/7/3, paras. 53, 54.

112 CRC/C/CHE/CO/2-4, p. 8-9, paras. 42-43: http://tbinternet.ohchr.org/_layouts/treatybody-external/Download.aspx?symbolno=CRC/C/CHE/CO/2-4&Lang=En

113 ICTR, Prosecutor v. Akayesu, ICTR-96-4, 13 Feb. 1996, amended 17 June 1997; see also ICC, Elements of Crimes, article 8(2)(b)(xxii)-1.

114 IACHR, Miguel Castro-Castro Prison v. Peru, 25 Nov. 2006, para. 312.

115 ECtHR, Aydin v. Turkey, Application no. 57/1996/676/866, 25 Sept. 1997.

116 Special Rapporteur on Torture, E/CN.4/1992/SR.21, para. 35, E/CN.4/1995/34, para. 19, A/HRC/ 7/3, para. 35 CAT, C.T. and K.M. v. Sweden, CAT/C/37/D/279/2005; V.L. v. Switzerland, CAT/C/37/D/262/ 2005; implicit (in line with X, Y, Z v. Sweden, No. 61/1996): T.A. v. Sweden, CAT/C/34/D/226/2003, and Mrs. Pauline Muzonzo Paku Kisoki v. Sweden, CAT/C/16/D/41/1996. For the Inter-American Convention to Prevent and Punish Torture: IACHR, Raquel Marí de Mejía v. Perú, Case 10.970, Rep. No. 5/96, OEA/Ser.L/V/II.91 Doc. 7 at 157 (1996), 1 March 1996; Dianna Ortiz v. Guatemala, Case 10.526, Rep. No. 31/96, OEA/Ser.L/V/ II.95 Doc. 7 rev. at 332 (1997), 16 Oct. 1996; for international humanitarian law: ICTY, Prosecutor v. Anto Furundzija (Trial Judgment), IT-95-17/1-T, 10.12.1998, para. 266f.; Prosecutor v. Mucic, Delic, Landzo, Delalic (Trial Judgment), IT-96-21-T, 16.11.1998, para. 940-943. ICTR, Prosecutor v. Akayesu (Trial Judgment), ICTR-96-4-T, 02.09.1998, para. 597.

117 Tamara Alexander (1997), “The Medical Management of Intersexed Children: An Analogue for

The most severe mental suffering, regardless of what form of surgery was performed, results in **suicidal tendencies**. In a study conducted in Hamburg, Germany, 50 % of those that had been subjected to irreversible surgical interventions were found to contemplate suicide.¹¹⁸ Another study found the elevated rates of self-harming behaviour and suicidal tendencies among “DSD” individuals comparable to those among women traumatised with physical or sexual abuse.¹¹⁹

In addition to the Committee on the Rights of the Child declaring IGM a “*harmful practice*” (see above), also the Committee against Torture,¹²⁰ the Special Rapporteur on Torture¹²¹ and the WHO¹²² plus 6 more UN bodies¹²³ have issued strong statements specifically criticising unnecessary surgical procedures on intersex persons.

- **“Masculinising” Surgical Procedures** (see above **p. 14**) are regularly resulting in severe complications,¹²⁴ obviously leading to **impairment or loss of genital sensitivity, painful intercourse, sexual dysfunction and suicidal tendencies, causing severe physical and mental suffering**. Also in what doctors refer to as “successful cases”, persons concerned report impairment of sensation.¹²⁵ Thus, the criticisms by CRC (“*harmful practice*”), as well as those by CAT, SRT, WHO and 6 more UN bodies referenced above under “Feminising’ Surgical and Other Procedures” also apply to “masculinising” procedures accordingly.

Childhood Sexual Abuse”, <http://www.isna.org/articles/analog>

- 118 “Hamburg IS Study”, quoted in the response of the Hamburg Senate to a formal parliamentary question: Antwort des Hamburger Senats auf die Grosse Anfrage von DIE LINKE, Drucksache 19/1993, 13 Feb. 2009.
- 119 Schützmann et al. (2009), Psychological distress, suicidal tendencies, and self-harming behaviour in adult persons with different forms of intersexuality, Arch Sex Behav. 2009 Feb;38(1):16-33.
- 120 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
- 121 Report of the Special Rapporteur on Torture, A/HRC/22/53, 1 February 2013, para 77: http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf
- 122 WHO, “Sexual health, human rights and the law” (2015), http://apps.who.int/iris/bitstream/10665/175556/1/9789241564984_eng.pdf?ua=1
- 123 OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO, Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement (2014): http://www.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf?ua=1
- 124 Guido Barbaglia (2010), “Failed hypospadias repair – How often is it and how to prevent it?”, Presentation 3rd Surgical Workshop CUGRS, <http://www.failedhypospadias.com/files/Belgrado2.pdf>;
Katrina Karkazis, Anne Tamar-Mattis, and Alexander A. Kron (2010), “Genital Surgery for Disorders of Sex Development: Implementing a Shared Decision-Making Approach”, Journal of Pediatric Endocrinology & Metabolism, 23, S. 789-806, at 793 (p. 14), <http://bioethics.stanford.edu/people/resumes/documents/KarkazisJPEMFINAL.pdf>
Adrienne Carmack, Lauren Notini, and Brian D. Earp (2015), “Should Surgery for Hypospadias Be Performed Before an Age of Consent?”, Journal of Sex Research, in press, https://www.academia.edu/13117940/Should_surgery_for_hypospadias_be_performed_before_an_age_of_consent
- 125 Lorenzo AJ, Pippi Salle JL, Zlateska B et al: Decisional regret after distal hypospadias repair: single institution prospective analysis of factors associated with subsequent parental remorse or distress. J Urol, suppl., 2014; 191: 1558.
Zwischengeschlecht.info (2012), “‘Sehr taube Eichel nach Operation’ vs. ‘unbehandelt gut leben’: Erfahrungsberichte zu Hypospadie”, <http://blog.zwischengeschlecht.info/post/2012/04/13/Erfahrungsberichte-zu-Hypospadie>

b) Intention

The Special Rapporteur on Torture points out that intent can be implied where the act had a specific purpose,¹²⁶ namely where a person has been discriminated against on the basis of disability.¹²⁷ Intent and purpose do not require a subjective inquiry into the motivation of the perpetrators, but rather an objective determination under the circumstances.¹²⁸ The Rapporteur emphasises this in the context of medical treatment, where such discriminations are often “*masked as ‘good intentions’ on the part of health professionals*”.¹²⁹ Where individuals are discriminated against on the basis of bodily features pathologised as “disorders of sex development” (DSD) in medical terms, this discrimination will thus imply intent.

Clearly, surgery on intersex persons is **always intentionally performed** and not merely the result of negligence. Doctors are also aware that there is usually no medical indication for such surgery but nonetheless approve of the irreversibility of the treatments and the heavy consequential physical and psychological damages of their patients. The physical and mental suffering caused by IGM Practices is well-established in medical literature (see above a). It is thus **foreseeable** to those intentionally inflicting the treatment that severe pain and suffering will ensue.

It does not detract from the intention that doctors perform surgery **for well-meant purposes**. This has been established in a case where a medical team discriminated against a person with disabilities.¹³⁰ The same is true for intersex persons where doctors believe to prevent cancer or social ostracism. The fact that there is no medical justification for the ill-treatment (above **B 1.**) means that good intentions cannot prevent the treatment from constituting torture.

c) Purpose of Discrimination

Article 1 of CAT requires that the pain or suffering be inflicted for one of the enumerated purposes, i.e. for the extraction of information or confession, punishment, intimidation and coercion, “*or for any reason based on discrimination of any kind*”.

The Committee against Torture emphasised that the protection of certain minority or marginalised individuals or populations especially at risk of torture is part of the State obligation to prevent torture. State parties must make sure that with respect to the Convention, their laws are in practice applied to all persons, “*regardless of [...] gender, sexual orientation, transgender identity, mental or other disability, health status, [...]*”. This includes fully prosecuting and punishing all acts of violence and abuse against these individuals and implementing positive prevention and protection measures.¹³¹

On the basis of their “indeterminate sex,” intersex children are singled out for experimental harmful treatments, including surgical “genital corrections” and 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*”,¹³² so that, according to a specialised surgeon, “*any cutting, no matter how incompetently executed, is a kindness.*”¹³³

126 Interim report of the Special Rapporteur on the Torture, UN Doc. A/63/175, para. 30.

127 Ibid. para. 49.

128 CAT, General Comment No. 2 (2007), CA/C/GC/2, para. 9.

129 Interim report of the Special Rapporteur on Torture, UN Doc. A/63/175, para. 49.

130 Ibid.

131 CAT, General Comment No. 2 (2007), para. 21.

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

133 Cheryl Chase (1998), Surgical Progress Is Not the Answer to Intersexuality, in: Alice Dreger (ed.)

By means of surgery, intersex children are penalised **compared to “normal” infants**, even where the perpetrator has benign intentions.¹³⁴

d) Involvement of a State Official

As underlined by the Committee, the prohibition of torture must be enforced in all institutions, including hospitals that engage in the care of children.¹³⁵ The Special Rapporteur on Torture underlined that the obligation to prevent torture extends “*to doctors, health professionals and social workers, including those working in private hospitals [or] other institutions.*”¹³⁶ The medical ill-treatment of intersex persons is attributable to the Swiss State as it is committed by or at the instigation of or with the **acquiescence** of a person acting in an official capacity, either by way of involvement of public hospitals, universities and insurances (IV), or by the **failure of the State to exercise due diligence** to protect this group of citizens from torture.

e) Lawful Sanction

Surgery performed on an intersex child or adult in Switzerland does not constitute a sanction. It is therefore not covered by the exception clause.

3. The Treatment of Intersex Persons in Switzerland as Cruel, Inhuman or Degrading Treatment (CIDT)

Article 16 of the Convention commits each State Party to the prevention of:

“other acts of cruel, inhuman or degrading treatment or punishment which do not amount to torture as defined in article 1, when such acts are committed by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.”

Acts which fall short of torture are thus still prohibited if they amount to cruel, inhuman or degrading treatment or punishment. This is the case if the treatment does not reach the requisite threshold of severity, or if the suffering was inflicted negligently¹³⁷ (see above 2.b).

Thus, if it is considered that the treatment that intersex persons suffer does not meet the severity threshold of Article 1 of the Convention, it certainly meets the threshold of Article 16. If it is considered that this suffering is not foreseeable to the surgeons, the insurance companies or the State, this lack of consideration constitutes negligence sufficient for Art. 16. As to State involvement and due diligence, the same applies as above. A discriminatory or other purpose is not required for CIDT.

Thus, even if it is considered that the treatment of intersexual people does not constitute torture, it certainly constitutes cruel, inhuman and degrading treatment which is equally prohibited by the Convention in absolute and non-derogable terms. According to the Committee’s General Comment 3, for CIDT also Article 14 applies.¹³⁸

(1999), *Intersex in the Age of Ethics*:148–159, at 150

134 2011 CAT German NGO Report on Intersex and IGM practices by Intersexuelle Menschen e.V./ XY-Frauen and Humboldt Law Clinic: Human Rights, at 21–22, http://intersex.shadow-report.org/public/Association_of_Intersexed_People-Shadow_Report_CAT_2011.pdf

135 CAT, General Comment No. 2 (2007), CAT/C/GC/2, para. 15.

136 Interim report of the Special Rapporteur on Torture, UN Doc. A/63/175, para. 51, referencing CAT General Comment No. 2 (2008), para. 17. See also A/HRC/7/3, para. 31.

See also: Report of the Special Rapporteur on Torture, A/HRC/22/53, 1 February 2013, paras 17, 18, 20, 23, 24, 32, 38

137 Interim report of the Special Rapporteur on Torture, UN Doc. A/63/175, of 28 July 2008, para. 59.

138 Committee against Torture (2012), General comment No. 3, CAT/C/GC/3, para. 1.

4. Obstacles to Redress, Fair and Adequate Compensation

Articles 12 and 13 of the Convention require that the State provide the means for an impartial inquiry into allegations of torture or CIDT (Art. 16 CAT). Article 14 requires an enforceable right to redress, fair and adequate compensation, including the means for as full rehabilitation as possible. However, intersex people encounter serious difficulties pursuing their rights.

As described above (B.4.–6.), the **statutes of limitation** prohibit survivors of early childhood IGM Practices to call a court long before they become adults, despite the fact that persons concerned often **do not find out** about their medical history until much later in life, and **severe trauma** caused by IGM Practices often prohibits them to act in time once they do.¹³⁹ The State Party **refuses to take legislative action** to change that, and **refuses to initiate impartial investigations**, as well as data collection, monitoring, and disinterested research. In addition, hospitals are often **unwilling to provide access to patient's files** (see Case No. 2).

This situation is not in line with Switzerland's obligations under Articles 12–14 of the Convention.

D. Conclusion: Switzerland is Failing its Obligations towards Intersex People under the Convention against Torture

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 torture or at least CIDT, committed by publicly funded doctors, cantonal clinics, and universities, as well as in private clinics, all relying on money from the federal invalidity insurance (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 take effective legislative, administrative, judicial or other measures to **prevent acts of torture** (Art. 2 CAT). It is also in breach of its obligation to prevent **other forms of cruel, inhuman or degrading treatment** (Art. 16 CAT).

While torture is a punishable offense in Swiss law, although not specifically (Art. 4 CAT), victims of such acts of torture encounter severe obstacles in the pursuit of their **right to an impartial investigation** (Art. 12, 13 CAT), and to **redress, fair and adequate compensation, including the means for as full rehabilitation as possible** (Art. 14 CAT).

It appears that Switzerland's efforts on **education and information regarding the prohibition against torture in the training of medical personnel** are grossly insufficient with respect to the treatment of intersex people (Art. 10 CAT).

¹³⁹ Globally, no survivor of early surgeries **ever** managed to have their case heard in court. All relevant court cases (3 in Germany, 1 in the USA) were either about surgery of adults, or initiated by foster parents.

E. Recommendations

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

Regarding cases of medically unnecessary surgical and other procedures on intersex children and adults, which often entail irreversible consequences and can cause severe physical and psychological suffering, without their informed consent, and the lack of redress and compensation in such cases:

1. To prevent torture and cruel, inhuman or degrading treatment (Art. 1, 2, 16 CAT), and in line with the recommendations on ethical issues relating to intersexuality by the National Advisory Commission on Biomedical Ethics (NEK-CNE):

Take all effective legislative, administrative, judicial or other measures, including review of associated limitation periods, to ensure that no-one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to children concerned, and provide families with intersex children with adequate counselling and support.

2. To ensure that any intersex person who alleges they have been subjected to torture has the right to complain to, and to have their case promptly and impartially examined by competent authorities (Art. 13 CAT), and that in the legal system an intersex victim of an act of torture obtains redress and has an enforceable right to fair and adequate compensation, including the means for as full rehabilitation as possible (Art. 14 CAT), and in line with the recommendations on ethical issues relating to intersexuality by the National Advisory Commission on Biomedical Ethics (NEK-CNE):

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; facilitate disinterested, representative review, analysis, and outcome studies, in direct collaboration with intersex representatives and organisations; advance and facilitate the acknowledgement by society of the suffering experienced by intersex persons because of IGM Practices, including a historical appraisal of the human rights violations inflicted on intersex children and adults in society.

3. To ensure that education and information regarding the prohibition against torture are fully included in the training of medical personnel (Art. 10 CAT), and in line with the recommendations on ethical issues relating to intersexuality by the National Advisory Commission on Biomedical Ethics (NEK-CNE):

Ensure that all medical professionals know that non-consensual surgical and other procedures on intersex children and adults justified by psychosocial indications amount to the infliction of torture or CIDT and constitute a punishable offence, in direct collaboration with intersex representatives and organisations.

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 advise 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 months 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.*”¹⁴⁰

However, according to nurses working at the Zurich children’s hospital, **1–2 children per week** are submitted to hypospadias “repair”.¹⁴¹ Both a leading paediatric endocrinologist and a paediatric surgeon publicly claim **gonadectomies on children with AIS** to be justified by “*high cancer risk*”,¹⁴² and described them not a matter of “if”, but only of “when”.¹⁴³ 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.*”¹⁴⁴ (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**¹⁴⁵ 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*”.¹⁴⁶

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-

140 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>

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

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

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

144 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

145 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>

146 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.”*¹⁴⁷ 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.¹⁴⁸ (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.”*¹⁴⁹ (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.”*¹⁵⁰

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*

147 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>

148 • 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

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

150 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.»*¹⁵¹

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.¹⁵²

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.”*¹⁵³

(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.”¹⁵⁴

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

Note: In Switzerland, IGMs are covered by the **Swiss Federal Invalidity Insurance (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)**,¹⁵⁵ of which **Zwischengeschlecht.org** identified **12 No.s as including IGMs**.¹⁵⁶

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

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

153 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>

154 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/2013/0/31/Intersex-Empfindungsfahigkeit-beeintraechtigt-Michal-Yaron-HUG-Genf%29>

155 831.232.21 Verordn. über Geburtsgebrechen (GgV), Annexe Liste d. Geburtsgebrechen, <http://www.admin.ch/opc/de/classified-compilation/19850317/201203010000/831.232.21.pdf>

156 **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) ¹⁵⁷

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, Sweyer 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 Pseudohermaphroditismus). 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) ¹⁵⁸

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 Pseudohermaphroditismus.’ [...] 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) ¹⁵⁹

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-**

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

158 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

159 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,¹⁶⁰ and the right of children and young people to special protection of their integrity¹⁶¹), 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 soon 4 years have passed without any “appropriate steps” with regards to intersex children ...**

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

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

Annexe 3 “Bibliography: IGM in Human Rights Mechanisms”

1. International Bodies Recognising Human Rights Violations of Intersex Persons

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.*

2009: UN SR Health, A/64/472, 10 August 2009, para 49:

<http://www.refworld.org/pdfid/4aa762e30.pdf>

IV. Vulnerable groups and informed consent

A. Children

49. *Health-care providers should strive to postpone non-emergency invasive and irreversible interventions until the child is sufficiently mature to provide informed consent. [67] [Fn. 67: This is particularly problematic in the case of intersex genital surgery, which is a painful and high-risk procedure with no proven medical benefits; see, e.g., Colombian Constitutional Court, Sentencia SU-337/99 and Sentencia T-551/99.] Safeguards should be in place to protect children from parents withholding consent for a necessary emergency procedure.*

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 readily 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 SR Torture, 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.

2014: UN CRPD, CRPD/C/DEU/Q/1, 17 April 2014, paras 12–13:

http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/DEU/CRPD_C_DEU_Q_1_17084_E.doc

Freedom from exploitation, violence and abuse (art. 16)

12. How many irreversible surgical procedures have been undertaken on intersexual children before an age at which they are able to provide informed consent? Does the State party plan to stop this practice?

13. Please provide up to date statistics on forced sterilizations of persons, i.e. without their free and informed consent.

2014: WHO, OHCHR, UN Women, UNAIDS, UNDP, UNFPA, and UNICEF, Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement, May 2014, paras 2, 6, 7:

http://www.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf?ua=1

Background

Some groups, such as [...] intersex persons, also have a long history of discrimination and abuse related to sterilization, which continues to this day. [...] Intersex persons, in particular, have been subjected to cosmetic and other nonmedically necessary surgery in infancy, leading to sterility, without informed consent of either the person in question or their parents or guardians. Such practices have also been recognized as human rights violations by international human rights bodies and national courts (15, 64).

[...] [I]ntersex persons

Intersex persons may be involuntarily subjected to so-called sex-normalizing or other procedures as infants or during childhood, which, in some cases, may result in the termination of all or some of their reproductive capacity. Children who are born with atypical sex characteristics are often subjected to cosmetic and other non-medically indicated surgeries performed on their reproductive organs, without their informed consent or that of their parents, and without taking into consideration the views of the children involved (64; 147, para 57; 148; 149). As a result, such children are being subjected to irreversible interventions that have lifelong consequence for their physical and mental health (64; 150, para

20; 151).

Medical procedures that might result in sterility may sometimes be justified because of benefits to health, including the reduction of cancer risk (152). Such treatments may be recommended for [...] intersex persons; however, they may be proposed on the basis of weak evidence, without discussing alternative solutions that would retain the ability to procreate (151, 153–157). Parents often consent to surgery on behalf of their intersex children, including in circumstances where full information is lacking (151, 158, 159).

It has been recommended by human rights bodies, professional organizations and ethical bodies that full, free and informed consent should be ensured in connection with medical and surgical treatments for intersex persons (64, 150) and, if possible, irreversible invasive medical interventions should be postponed until a child is sufficiently mature to make an informed decision, so that they can participate in decision-making and give full, free and informed consent (15, 149). It has also been recommended that health-care professionals should be educated and trained about bodily diversity as well as sexual and related biological and physical diversity, and that professionals should properly inform patients and their parents of the consequences of surgical and other medical interventions (149; 150, para 20; 160–162).

Remedies and redress

- *Recognize past or present policies, patterns or practices of coercive sterilization, and issue statements of regret or apology to victims, as components of the right to remedy for these practices.*
- *Provide notification, through appropriate and humane means, to people who have been subjected to coercive sterilization, and who may be unaware of their situation, and provide information on the possibility of seeking administrative and judicial redress.*
- *Promptly, independently and impartially investigate all incidents of forced sterilization with due process guarantees for the alleged suspect, and ensure appropriate sanctions where responsibility has been established.*
- *Provide access, including through legal aid, to administrative and judicial redress mechanisms, remedies and reparations for all people who were subjected to forced, coercive or involuntary sterilization procedures, including compensation for the consequences and acknowledgement by governments and other responsible authorities of wrongs committed. Enable adults to seek redress for interventions to which they were subjected as children or infants.*
- *Guarantee access to reversal procedures, where possible, or assisted reproductive technologies for individuals who were subjected to forced, coercive or otherwise involuntary sterilization.*

Monitoring and compliance

- *Establish monitoring mechanisms for the prevention and documentation of forced, coercive and otherwise involuntary sterilization, and for the adoption of corrective policy and practice measures.*
- *Collect data regarding forced, coercive and otherwise involuntary sterilization, in order to assess the magnitude of the problem, identify which groups of people may be affected, and conduct a comprehensive situation and legal analysis.*
- *Providers of sterilization services should implement quality improvement programmes to ensure that recommendations aimed at preventing forced, coercive and otherwise involuntary sterilization are followed and procedures are properly documented.*
- *Establish mechanisms for obtaining patient feedback on the quality of services received, including from marginalized populations.*

2015: UN CRC, CRC/C/CHE/CO/2-4, 4 February 2015, paras 42–43:

http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC/C/CHE/CO/2-4&Lang=En

E. Violence against children (arts. 19, 24, para. 3, 28, para. 2, 34, 37 (a) and 39) [...]

Harmful practices

42. *While welcoming the adoption of a new provision of criminal law prohibiting genital mutilation, the Committee is deeply concerned at: [...]*

(b) *Cases of medically unnecessary surgical and other procedures on intersex children, which often entail irreversible consequences and can cause severe physical and psychological suffering, without their informed consent, and the lack of redress and compensation in such cases.*

43. *The Committee draws the attention of the State party to the Joint General Comment No. 18 on harmful practices*

(2014), together with the Committee on the Elimination of Discrimination against Women, and urges the State party to: [...]

(b) *In line with the recommendations on ethical issues relating to intersexuality by the National Advisory Commission on Biomedical Ethics, ensure that no-one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to children concerned, and provide families with intersex children with adequate counselling and support.*

2015: UN CRPD, CRPD/C/DEU/CO/1, 13 May 2015, p. 6–7, paras 37-38:

http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/DEU/CO/1

Protecting the integrity of the person (art. 17)

37. *The Committee is concerned about: [...] c) the lack of implementation of the 2011 recommendations CAT/C/DEU/CO/5, para. 20, regarding upholding bodily integrity of intersex children.*

38. ***The Committee recommends that the State party take the necessary measures, including of a legislative nature to:***

[...]

(d) Implement all the recommendations of CAT/C/DEU/CO/5, para. 20 relevant to intersex children.

2015: Commissioner on Human Rights of the Council of Europe (COE), Issue Paper “Human rights and intersex people”, 12 May 2015, p. 1–62:

<https://wcd.coe.int/ViewDoc.jsp?Ref=CommDH/IssuePaper%282015%291&Language=lanEnglish&Ver=original&BackColorInternet=C3C3C3&BackColorIntranet=EDB021&BackColorLogged=F5D383>

2015: WHO, Report “Sexual health, human rights and the law”, June 2015, p. 27-28:

http://apps.who.int/iris/bitstream/10665/175556/1/9789241564984_eng.pdf?ua=1

“A major concern for intersex people is that so-called sex normalizing procedures are often undertaken during their infancy and childhood, to alter their bodies, particularly the sexual organs, to make them conform to gendered physical norms, including through repeated surgeries, hormonal interventions and other measures. As a result, such children may be subjected to medically unnecessary, often irreversible, interventions that may have lifelong consequences for their physical and mental health, including irreversible termination of all or some of their reproductive and sexual capacity.”

“Increasingly, concerns are being raised by intersex people, their caregivers, medical professionals and human rights bodies that these interventions often take place without the informed consent of the children involved and/or without even seeking the informed consent of their parents (178, 262, 264, 270–273).”

“It has also been recommended [by human rights bodies and ethical and health professional organizations] that investigation should be undertaken into incidents of surgical and other medical treatment of intersex people without informed consent and that legal provisions should be adopted in order to provide remedies and redress to the victims of such treatment, including adequate compensation (91, 264).”

2. State Bodies Recognising Human Rights Violations of Intersex Persons

2005: San Francisco Human Rights Commission (SFHRC), A Human Rights Investigation into the “Normalization” of Intersex People, 28 April 2005

<http://sf-hrc.org/modules/showdocument.aspx?documentid=1798>

2013: Australian Senate, Community Affairs References Committee, Involuntary or coerced sterilisation of intersex people in Australia, October 2013

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

2014: German Conference of Women's and Equality Ministers (GFMK), Resolution of the 24th GFMK Conference, 1–2 October 2013

https://www.gleichstellungsministerkonferenz.de/documents/2014_10_13_Beschluesse_GESAMT_Extern.pdf

2015: Maltese Parliament, Gender Identity Gender Expression and Sex Characteristics Act (GIGESC), 2 April 2015, Article 14(1–5) “Right to bodily integrity and physical autonomy”

<http://justiceservices.gov.mt/DownloadDocument.aspx?app=lp&itemid=26805&l=1>

3. National Ethics Bodies Recognising Human Rights Violations of Intersex Persons

2011: German Ethics Council, Opinion Intersexuality, 23 February 2012

<http://www.ethikrat.org/files/opinion-intersexuality.pdf>

2012: Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE), On the management of differences of sex development. Ethical issues relating to “intersexuality”, Opinion No. 20/2012, 9 November 2012

http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf

4. NGO, NHRI Reports on Human Rights Violations of Intersex Persons

2004: CESCARG Argentina, Mauro Cabral

<https://web.archive.org/web/20100306083552/http://ilga.org/ilga/en/article/61>

2008: CEDAW Germany, Intersexuelle Menschen e.V./XY-Frauen

http://intersex.shadowreport.org/public/Association_of_Intersexed_People-Shadow_Report_CEDAW_2008.pdf

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

http://intersex.shadowreport.org/public/Association_of_Intersexed_People-Shadow_Report_CESCARG_2010.pdf

2011: CEDAW Costa Rica, IGLHRC / MULABI, p. 8–11

http://intersex.shadowreport.org/public/IGLHRC_Shadow-Report_Costa-Rica_CEDAW_2011.pdf

2011: CAT Germany, Intersexuelle Menschen e.V./XY-Frauen, Humboldt Law Clinic

http://intersex.shadowreport.org/public/Association_of_Intersexed_People-Shadow_Report_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

2012: UN SRT, Advocates for Informed Choice (AIC),

http://aiclegal.org/wordpress/wp-content/uploads/2012/10/AIC-Testimony-to-the-United-Nations-Special-Rapporteur-on-Torture_December-2012.pdf

2012: CRC Luxemburg, Radelux

http://www.ances.lu/attachments/article/162/RADELUX_spp1%20report%202012%20English%20Version.pdf

2012: WHO, Advocates for Informed Choice (AIC), Zwischengeschlecht.org, 2 unpublished submissions for 2014 WHO Interagency Statement on Involuntary Sterilization

2013: CRPD Germany, BRK-Allianz, Germany, p. 36–37

http://www.brk-allianz.de/attachments/article/93/Alternative_Report_German_CRPD_Alliance

[final.pdf](#)

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_jointsubmission4_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_jointsubmission5_e.pdf

- Forum Menschenrechte, paras 38, 39, 58

http://lib.ohchr.org/HRBodies/UPR/Documents/Session16/DE/js6_upr_deu_s16_2013_jointsubmission6_e.pdf

2013: CRC Germany, German Institute for Human Rights (GIHR), para 2.b.

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

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

http://www2.ohchr.org/english/bodies/crc/docs/ngos/Germany_National%20Coalition%20for%20the%20Implementation%20of%20the%20UNCRC%20in%20Germany_CRC%20Report-CRCWG65.pdf

2013: Inter-American Commission on Human Rights, Advocates for Informed Choice (AIC)

<http://www.aph.gov.au/DocumentStore.ashx?id=432c5135-4336-472e-bb24-59c89eb4a643>

+ Hearing

2014: UNHRC, Canadian HIV/AIDS Legal Network, joined by ILGA

<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

2014: CRC Switzerland, Zwischengeschlecht.org, Intersex.ch, SI Selbsthilfe Intersexualität

http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

2014: CAT Australia, OII Australia, AISSGA, People with Disabilities, National LGBTI Health Alliance

<https://oii.org.au/wp-content/uploads/2014/10/OII-Australia-CAT-submission.pdf>

2015: CAT New Zealand, ITANZ

https://www.hrc.co.nz/files/3914/2950/4674/ITANZ_Submission_on_CAT_13_Jan_2015.pdf

2015: CRPD Germany, Zwischengeschlecht.org

http://intersex.shadowreport.org/public/2015-CRPD-LoI-Germany_NGO-Report_Zwischengeschlecht_Intersex-IGM.pdf

5. Swiss Government Documents

See **Annexe 2** “Swiss Cantonal, Federal Governments, and Clinics on IGMs”, p. 42-446, 44-46

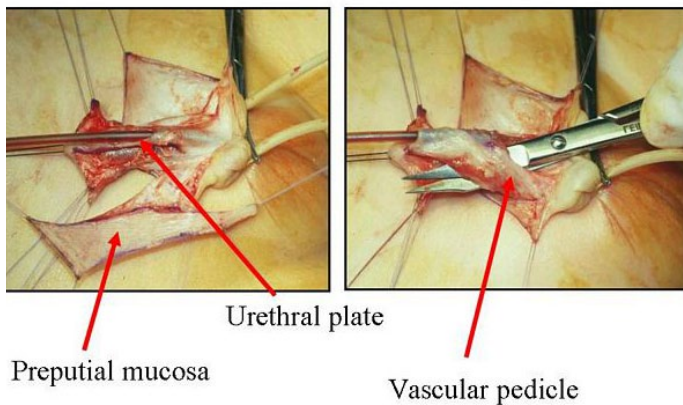
Supplement "IGM in Medical Textbooks – Part 1: Current Practice"

IGM 1 – "Masculinising Surgery": "Hypospadias Repair"

"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!"

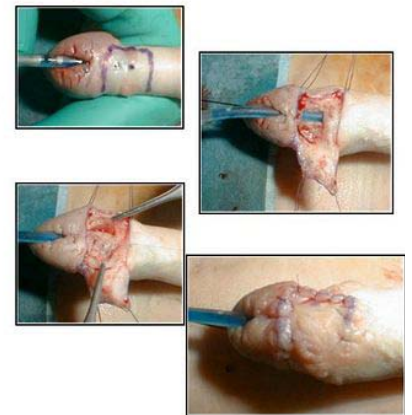
Nonetheless, clinicians recommend these surgeries without medical need explicitly "for psychological and aesthetic reasons." Most hospitals advise early surgeries, usually "between 12 and 24 months of age." While survivors criticise a.o. impairment or total loss of sexual sensation and painful scars,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

Onlay island flap urethroplasty



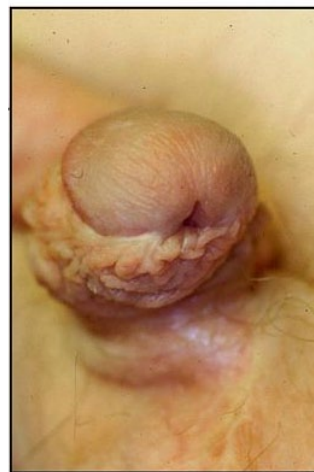
Treatment of isolated fistulae

- 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

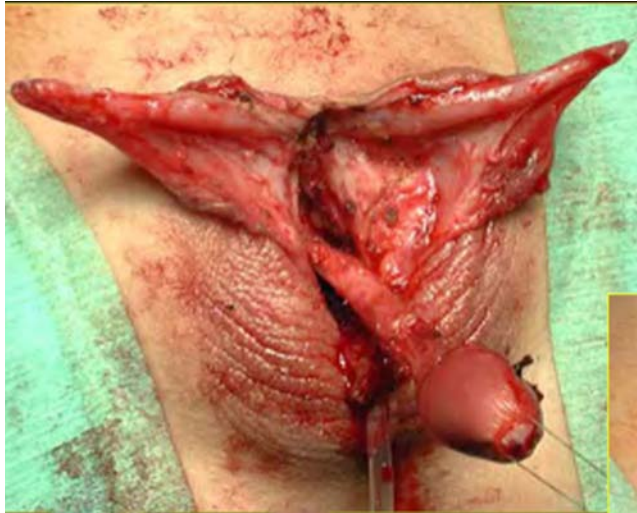
Hypospadias - Conclusions

- 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 ...

IGM 2 – “Feminising Surgery”: “Clitoral Reduction”, “Vaginoplasty”

Partial amputation of clitoris, often in combination with surgically widening the vagina followed by painful dilation. “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”).

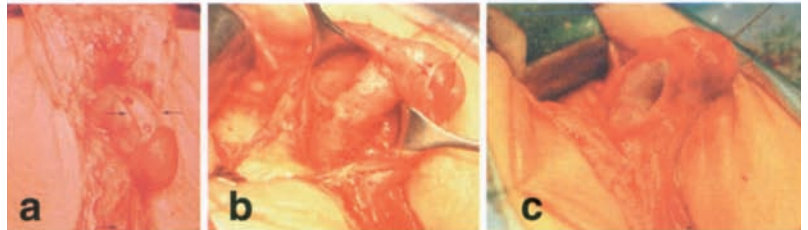
Despite numerous findings of impairment and loss of sexual sensation caused by these cosmetic surgeries, and lacking evidence for benefit for survivors, current guidelines nonetheless advise surgeries “in the first 2 years of life”, most commonly “between 6 and 12 months,” and only 10.5% of surgeons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



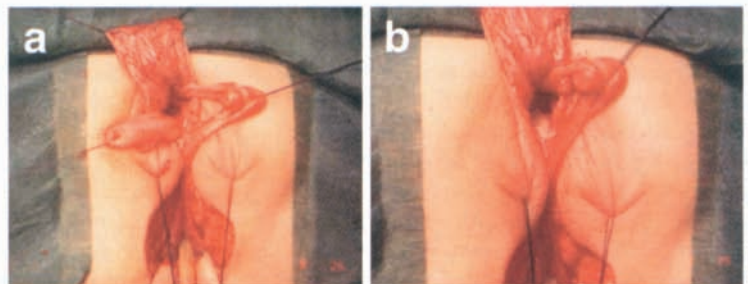
Source (above): Christian Radmayr: *Molekulare Grundlagen und Diagnostik des Intersex*, 2004



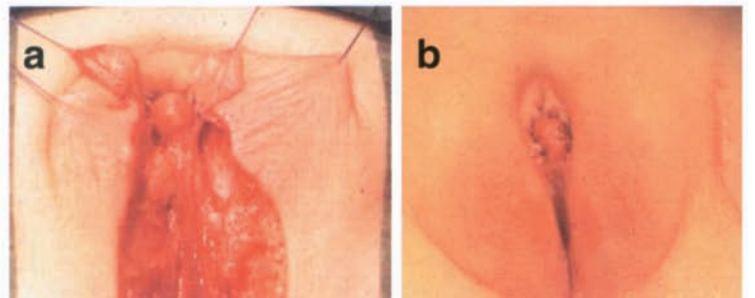
10. Indikationen und Ergebnisse von Korrekturoperationen beim intersex



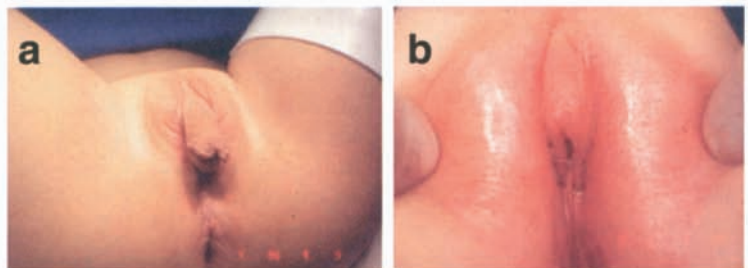
6a-c: Darstellung des Klitorischaftes (a) sowie der Schwellkörper (b+c).



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 (above): Finke/Höhne: *Intersexualität bei Kindern*, 2008

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

Source (left): Pierre Mouriquand: “Chirurgie des anomalies du développement sexuel - 2007”, at 81: “Labioplastie”

IGM 3 – Sterilising Surgery: Castration / “Gonadectomy” / Hysterectomy

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)”, and 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 admitted true reason is “better manageability.” Contrary to doctors claims, it is known that the gonads by themselves are usually healthy and “effective” hormone-producing organs, often with “complete spermatogenesis [...] suitable for cryopreservation.”

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

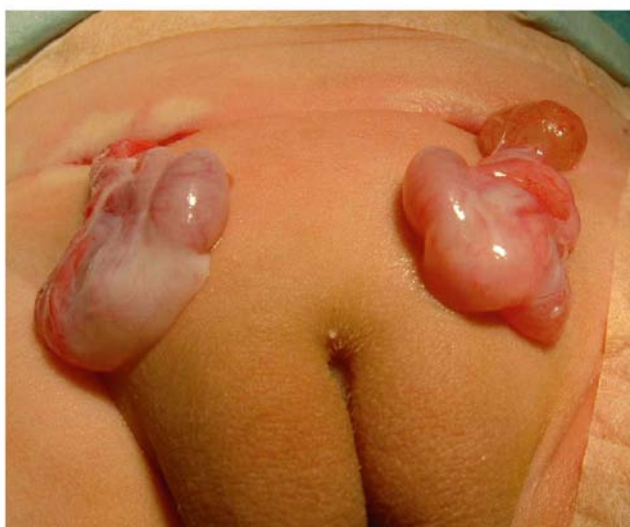


Fig. 91.6 An inguinal approach for gonadectomy in a CAIS patient with two palpable gonads

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
	17β-hydroxysteroid dehydrogenase deficiency	17
Low	CAIS	0.8
	Ovotesticular DSD	2.6
Unknown	5α-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 Hypospadiekorrekture

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 sureo 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.

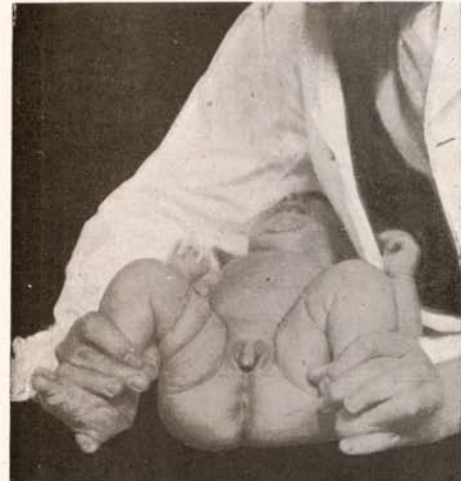


Fotografía n.º 112'.

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 sureo balano-prepucial. Este glande es imperforado. Por debajo falta el prepucio y la uretra, existiendo sólo un débil sureo 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

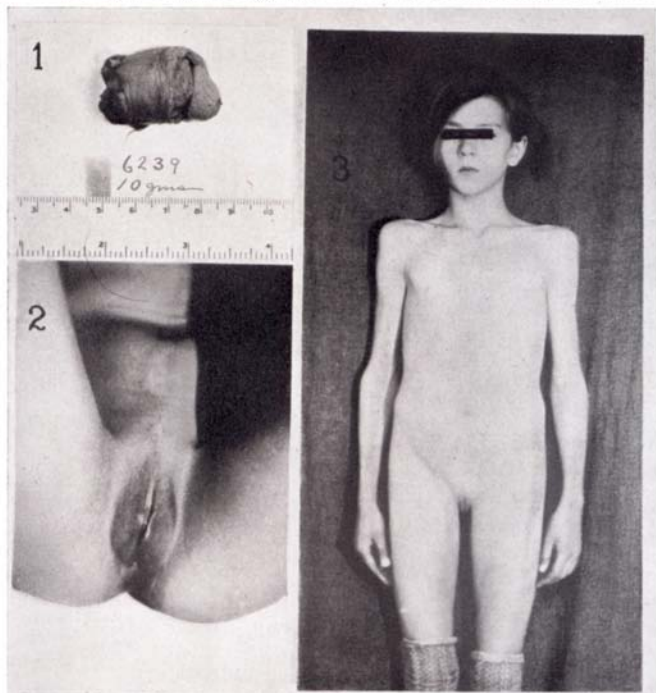


FIG. 63. Case 5. Age 9 years. 1, Phallus supposed to be hypertrophied clitoris; 2 and 3, condition after amputation. Note undeveloped labia majora. BUI 14127.

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.

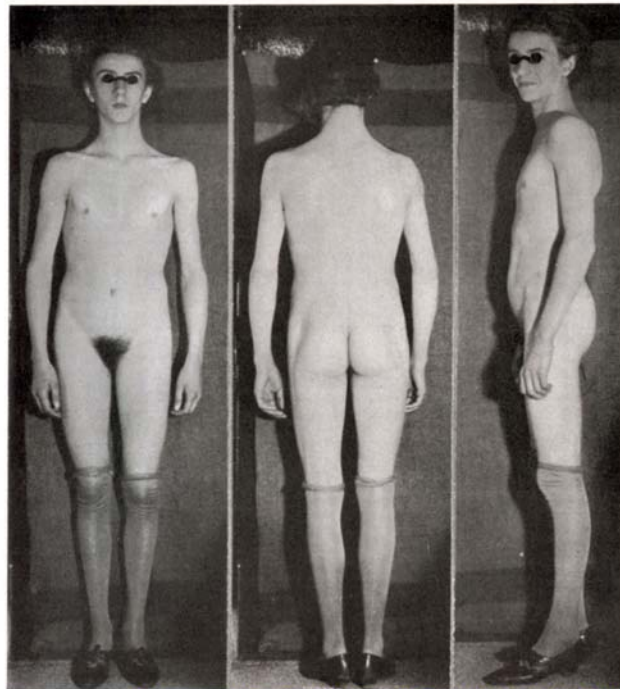


FIG. 64. Case 5. Patient, aged 15, raised as boy until 7 years; then diagnosed female. Phallus amputated; put in girl's clothes. At age of 16, operation for inguinal hernia, supposed ovary found to be testicle. Patient put back in male attire. BUI 14127.

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 enlisée 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.



FIG. 56. — Cecilia M... (observation XII). (ALBERTO LAGOS GARCIA.)

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.

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.

Six mois après, incision qui sépare

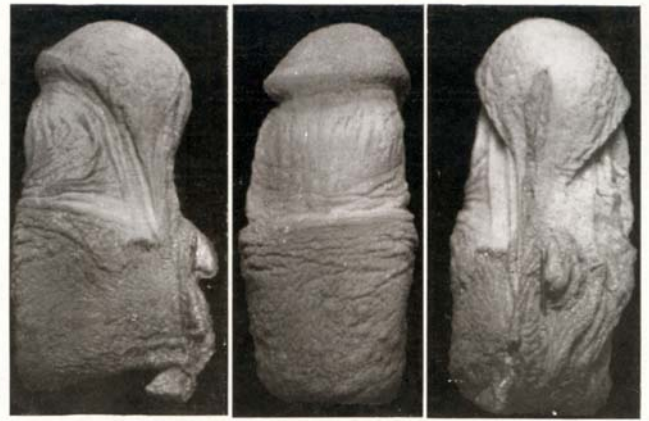


FIG. 93. — Le clitoris de Marguerite, après amputation (observation XX).



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.

Source: 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

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 Gynaecologist Paul Mathes and Swiss Gynaecologist Hans Guggisberg in 1924), allegedly most frequent amongst “Jews,” and associated with “biological inferiority”, mental illnesses (see above “*schizoid*”), “*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, Walther Stoeckel, and kept being used in publications years after World War II.

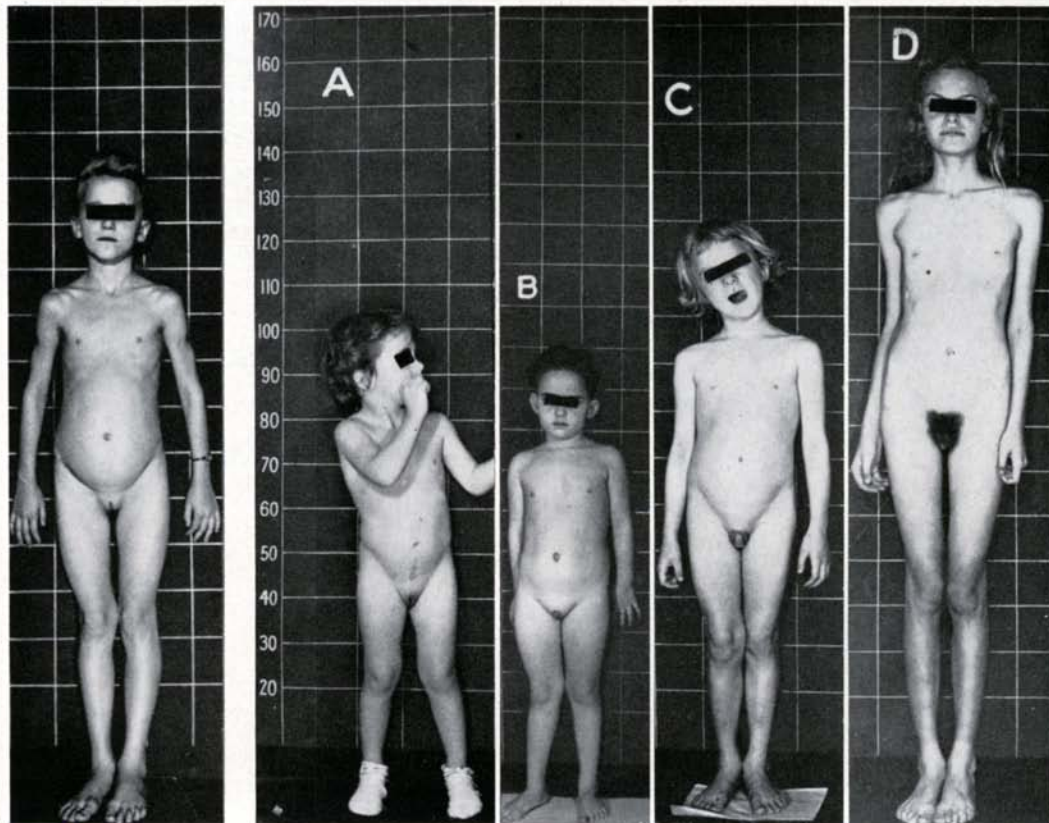
Sources: Wilhelm Weibel: *Lehrbuch der Frauenheilkunde*, 7th ed., Berlin/Wien 1944 p. 647 (photo), 648 (text).

Richard Goldschmidt: “Die biologischen Grundlagen der konträren Sexualität und des Hermaphroditismus beim Menschen”, in: *Archiv für Rassen- und Gesellschaftsbiologie* 12, 1916.

Paul Mathes, Hans Guggisberg: “Die Konstitutionstypen des Weibes, insbesondere der intersexuelle Typus”, in: Josef Halban, Ludwig Seitz: *Biologie und Pathologie des Weibes*. Bd.3, 1924.

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.

CONGENITAL ADRENAL HYPERPLASIA—FEMALE PSEUDOHERMAPHRODITISM



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. ♀ pseudohermaphrodite.
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.
No sexual hair.

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 Extermination

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 "invented" the systematic mutilations, however, it was Wilkins (and Prader) who started systematic surgeries; Money "only" delivered a "scientific rationale" five years after the fact.

Source: 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

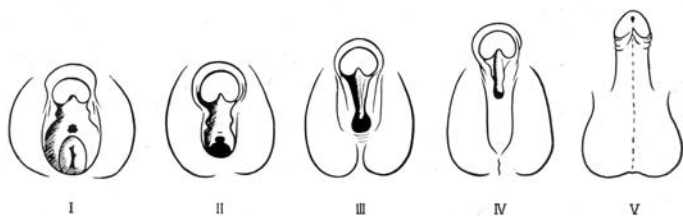


Abb. 673. Formen des äußern Genitale bei Mädchen mit adrenogenitalem Syndrom infolge angeborener NNR-Hyperplasie (nach Prader). Typ I: nur Clitoris vergrößert. Typ II: Vestibulum trichterförmig verengt, Urethral- und Vaginalöffnung getrennt, aber dicht übereinanderliegend. Typ III: Sinus urogenitalis 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 Rhaphe verwachsen. Bei allen Formen fällt die abnorme Länge des Dammes 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.

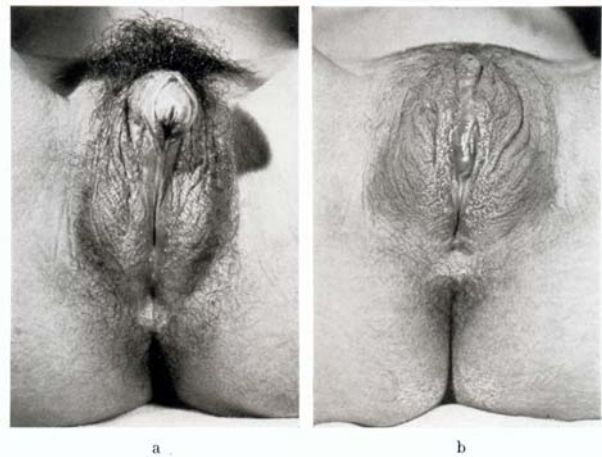


Abb. 679. Penisartige Vergrößerung der Clitoris bei angeborenem adrenogenitalem Syndrom. (7jähriges Mädchen.) a) Vor, b) nach Exstirpation der Clitoris.

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 abgeklemmt 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 Dammes vorgeschoben (Abb. 677c). Hierauf ist die Haut über der Sonde so weit analwärts zu durchtrennen, bis der Introitus vaginae im hinteren 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. 676c).

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).

Source: Max Grob: *Lehrbuch der Kinderchirurgie*, with Margrit Stockmann and Marcel Bettex, Stuttgart, 1957, p. 583, 587.

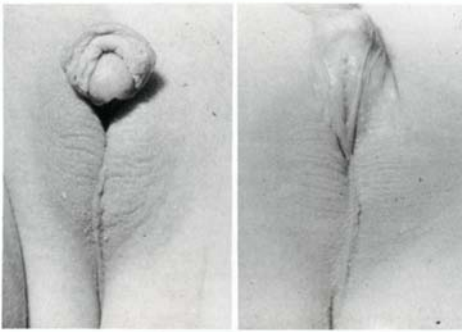


Abbildung 8.74: Pseudohermaphroditismus femininus bei adrenogenitalem Syndrom (vergleiche mit Hypospadias scrotalis, Abb. 8.71).

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
- 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 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.

Source: Marcel Bettex, François Kuffer, Alois Schärli: *Wesentliches über die Kinderchirurgie*. Bern, 1975, p. 255, 251.

Plastic Operations on the Genitalia

The **surgical correction** (see p. 474 *et seq.*) of the masculinized genitalia of girls with the congenital adrenogenital syndrome is desirable for several reasons: (1) in order to make the vagina a functional organ; (2) in order to prevent troublesome erections of the clitoris; (3) in order to prevent **psychological conflicts**, which are particularly liable to occur in girls with male characteristics.

Whenever possible surgery should be carried out **before the children reach four years** of age. In mild cases removal of the clitoris is all that is necessary. **The clitoris should be totally removed and not just amputated**, otherwise troublesome erections of the remaining stump may occur. 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**. If masculinization of the genitalia is more extreme further surgery may be required to open and enlarge the urogenital sinus.

Source:

Jürgen R. Bierich: "The Adrenogenital Syndrome"

In: Overzier (ed.), "Intersexuality" (New York 1962, at 379) / "Intersexualität" (Stuttgart 1961, at 387)

Plastische Operationen an den Genitalien

Die **operative Korrektur** (s. S. 476 ff.) der vermännlichten Genitalien beim kongenitalen adrenogenitalen Syndrom des Mädchens ist aus mehreren Gründen indiziert, 1. um eine regelrechte Funktion der Vagina zu ermöglichen, 2. um die unangenehmen Klitoriserektionen zu verhindern, 3. um seelische Konflikte zu vermeiden, die den Mädchen aus dem Vorhandensein männlicher Attribute erwachsen können.

Nach Möglichkeit soll die Operation schon vor dem vierten Lebensjahr durchgeführt werden. Bei leichteren Fällen ist lediglich die **Entfernung der Klitoris** erforderlich. Das Organ soll dabei **exstirpiert und nicht amputiert** werden, da sich sonst lästige Erektionen des zurückgebliebenen Stumpfes einstellen können. Wie HAMPSON (1956) bei einer größeren Reihe operierter Frauen festgestellt hat, **leidet die Orgasmusfähigkeit durch die Klitorisentfernung nicht**. Ist das Genitale stärker vermännlicht, so muß darüberhinaus die Eröffnung des Sinus urogenitalis vorgenommen werden.

1956–1993: "The Clitoris is not essential for normal Coitus." "No Evidence of Loss of Orgasm after Clitoris Amputation."

The number of "Intersex-Experts" and involved clinicians claiming that amputating "enlarged" clitorises was a rational and beneficent thing to do is legion – e.g. Joan Hampson (1956), John Money (1956, 1971), Max Grob (1957, see above), Jürgen Bierich (1963, 1971), Robert E. Gross (1966), Marcel Bettex (1957, see above). Even in 1993, surgeon Milton Edgerton claimed, unchallenged by his peers: *"Not one has complained of loss of sensation, even when the entire clitoris was removed."*

Since then: "Surgery is better now ..."

In 1993, Cheryl Chase founded the first Intersex Lobby Group ISNA by declaring: *"Unfortunately the surgery is immensely destructive of sexual sensation and of the sense of bodily integrity."* Since then, the mutilators just changed their mantra to *"Surgery is better now"* – again without evidence, but despite survivors deploring decrease or total loss of sexual sensation, painful scars and frequent complications also with the "modern improved techniques", and studies again and again corroborating their grievances.

Sources: See 2014 CRC NGO Report, p. 57–59, online:

http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf



**STOP
Intersex
Genital
Mutilation!**

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