

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



**HUMAN  
RIGHTS FOR  
HERM  
APHRODITES  
TOO!**

**NGO Report  
to the 4th Periodic Report of Switzerland on the  
International Covenant on Civil and Political Rights  
(CCPR)**

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## Executive Summary

**All typical forms of IGM practices are still practised in Switzerland today, facilitated and paid for by the State party via the Disability Insurance.** Parents and children are misinformed, kept in the dark, sworn to secrecy, kept isolated and denied appropriate support. (B.3.)

**Switzerland** is thus in breach of its **obligations** under the Covenant to **(a)** take effective legislative, administrative, judicial or other measures to **prevent involuntary, non-urgent surgery and other medical treatment of intersex persons**, and **(b)** to **ensure access to redress**, and the right to fair and adequate **compensation** and **rehabilitation for victims** (arts. 7 and 24, General recommendation No. 20). (B.4.)

**CAT, CRC, CEDAW, CRPD**, the UN Special Rapporteur on Torture (**SRT**), the UN High Commissioner for Human Rights (**UNHCHR**), the World Health Organisation (**WHO**), the Inter-American Commission on Human Rights (**IACHR**), the African Commission on Human and Peoples' Rights (**ACHPR**), the Council of Europe (**COE**) and others have **consistently recognised** IGM practices as a breach of international law and have called for **legislation** to **(a)** end the practice, **(b)** ensure redress and compensation, and **(c)** to provide access to free counselling. (B.1.)

**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 people 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. (B.2.)

**IGM practices** include **non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other harmful medical procedures** 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. **Typical forms** of IGM include “masculinising” and “feminising”, “corrective” genital surgery, sterilising procedures, imposition of hormones, forced genital exams, vaginal dilations, medical display, human experimentation and denial of needed health care. (B.3.)

IGM practices cause known **lifelong severe physical and mental pain and suffering**, including loss or impairment of sexual sensation, painful scarring, painful intercourse, incontinence, urethral strictures, impairment or loss of reproductive capabilities, lifelong dependency on 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.1.)

For almost 25 years, intersex people have criticised IGM as **harmful** and **traumatising**, as a form of **genital mutilation** and **child sexual abuse**, as **torture or ill-treatment**, and called for legislation to prevent it and to ensure remedies.

This **Thematic NGO Report** is compiled by the international intersex NGO **StopIGM.org / Zwischengeschlecht.org** and the Swiss peer support groups **Intersex.ch** and **SI Selbsthilfe Intersexualität**.

It contains **Suggested Recommendations** (C) and an Annexe with **6 Case Studies**. (D)

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## A. Introduction

### 1. Intersex, IGM Practices and Human Rights in Switzerland

During its 120th Session, the Human Rights Committee will consider **Switzerland's 4th periodic report** (on Intersex and Intersex Genital Mutilations, see **para 188**).

**IGM practices** are known to cause severe, lifelong physical and psychological pain and suffering, and have been consistently **recognised by UN treaty bodies**<sup>1</sup> as constituting **torture or ill-treatment, violence** and a **harmful practice**, the Swiss State report denies and trivialises IGM (para 188).

This NGO Report demonstrates that the **current medical abuse of intersex persons in Switzerland** – advocated, facilitated and paid for by the State party – constitutes a serious breach of Switzerland's obligations under the Covenant.

To this day the **Swiss Government refuses to take appropriate legislative, administrative and other measures** to protect intersex children, and refuses survivors the right to **justice, redress and compensation**, despite already having been **explicitly obliged** to do so by **CRC** (CRC/C/CHE/CO/2-4, paras 42-43) **CAT** (CAT/C/CHE/CO/7, para 20) and **CEDAW** (CEDAW/C/CHE/CO/4-5, paras 24–25, 38–39).

### 2. About the Rapporteurs

**This thematic NGO report** has been prepared by the international intersex NGO *StopIGM.org / Zwischengeschlecht.org* in collaboration with Swiss peer support groups *Intersex.ch* and *SI Selbsthilfe Intersexualität*:

- **StopIGM.org / Zwischengeschlecht.org**, founded in 2007, is an international Human Rights NGO based in Switzerland. It is led 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!*”<sup>2</sup> According to its charter,<sup>3</sup> *Zwischengeschlecht.org* works to support persons concerned seeking redress and justice. *StopIGM.org* regularly reports to UN treaty bodies.<sup>4</sup>
- **Intersex.ch** is a Swiss intersex peer support group founded in 2005.<sup>5</sup>
- The **Verein SI Selbsthilfe Intersexualität** is a Swiss peer support group for parents of intersex children founded in 2003.

### 3. Methodology

This thematic NGO report is an update to the 2014 Swiss CCPR LoIPR NGO Report by the same Rapporteurs.<sup>6</sup>

This Report includes **6 anonymised personal testimonies of intersex persons**, spanning the whole period of systematic genital surgeries on intersex children for the 2014 Swiss

1 **CAT, CRC, CRPD, SPT, SRT, SRSG VAC, COE, ACHPR, IACHR** (2016), “End violence and harmful medical practices on intersex children and adults, UN and regional experts urge”, <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E>

2 <http://Zwischengeschlecht.org/>, English pages: <http://StopIGM.org/>

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

4 <http://intersex.shadowreport.org/>

5 <http://intersex.ch/>

6 [http://intersex.shadowreport.org/public/2014-CCPR-LoIPR-Swiss\\_NGO-Report\\_Zwischengeschlecht\\_Intersex-IGM.pdf](http://intersex.shadowreport.org/public/2014-CCPR-LoIPR-Swiss_NGO-Report_Zwischengeschlecht_Intersex-IGM.pdf)

CRC NGO Report.<sup>7</sup> The stories were obtained from the persons concerned or their parents, their identity being known to Intersex.ch and SI Selbsthilfe Intersexualität. Each first-person narrative is preceded with a standardised abstract composed by the Rapporteurs. The small number of case studies is due to the fact that many patients, their families, and parents find it hard to speak about what happened to them, and do not wish their story to become public, even anonymously. These cases, however, show in an exemplary manner that involuntary surgeries and other treatments on intersex children are not just a thing of the past, but still continue in Swiss hospitals with hardly any change over decades, often without disclosing sufficient information to both parents and persons concerned, and often without an established diagnosis. All patients who were submitted to cosmetic genital surgeries report **severe physical and mental pain and suffering** as a result of the procedures performed on them.

## B. IGM Practices in Switzerland

### 1. Background: IGM Practices – Involuntary, unnecessary medical interventions

**IGM practices** include non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other similar medical procedures, including imposition of hormones, performed on **children with variations of sex anatomy**,<sup>8</sup> without evidence of benefit for the children concerned, but justified by “*psychosocial indications [...] shaped by the clinician’s own values*”, the latter informed by **societal and cultural norms and beliefs**, enabling clinicians to withhold crucial information from both patients and parents, and to submit healthy intersex children to risky and harmful invasive procedures that would not be considered for “normal” children, “*simply because their bodies did not fit social norms*”.<sup>9</sup>

**Typical forms of IGM** include “feminising” or “masculinising”, “corrective” genital surgery, sterilising procedures, imposition of hormones (including prenatal “therapy”), forced genital exams, vaginal dilations, medical display, involuntary human experimentation, selective (late term) abortions and denial of needed health care.

IGM practices are known to cause **lifelong severe physical and mental pain and suffering**,<sup>10</sup> 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.

**UN treaty bodies and other human rights experts have consistently recognised IGM practices as a serious breach of international law.**<sup>11</sup>

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7 [http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)

8 See “What is Intersex?”, 2016 CAT France NGO Report, p. 32–37, <http://intersex.shadowreport.org/public/2016-CAT-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

9 For references, see “What are Intersex Genital Mutilations (IGM)?”, 2016 CAT France NGO Report, p. 38.

10 See “IGM Practices – Non-Consensual, Unnecessary Medical Interventions”, 2016 CAT France NGO Report, p. 38–47

11 **CAT, CRC, CRPD, SPT, SRT, SRSG VAC, COE, ACHPR, IACHR** (2016), “End violence and harmful medical practices on intersex children and adults, UN and regional experts urge”, <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E>

## 2. Intersex is NOT THE SAME as LGBT or SOGI

Unfortunately, there are several **harmful misconceptions about intersex** still prevailing in public, notably if intersex is counterfactually described as being the same as or a subset of LGBT or SOGI, e.g. if intersex and/or intersex status are represented as a sexual orientation (like gay or lesbian), and/or as a gender identity, as a subset of transgender, as the same as transsexuality,<sup>12</sup> or as a form of sexual preference.

The underlying reasons for such harmful misconceptions include **lack of awareness**, third party groups **instrumentalising** intersex as a means to an end for their own agenda, and State parties **trying to deflect** from criticism of involuntary intersex treatments.

**Intersex persons and their organisations have spoken out clearly against instrumentalising intersex issues**,<sup>13</sup> maintaining that IGM practices present a **distinct and unique issue** constituting significant human rights violations, which are different from those faced by the LGBT or SOGI community, and thus need to be **adequately addressed in a separate section as specific intersex issues**.

## 3. IGM practices in Switzerland: Pervasive and unchallenged

### a) Overview: Lack of Protection for Intersex Persons in Switzerland

In **Switzerland** (CRC/C/CHE/CO/2-4, paras 42-43; CAT/C/CHE/CO/7, para 20; CEDAW/C/CHE/CO/4-5, paras 24–25, 38–39), same as in the **neighbouring states** of *France* (CRC/C/FRA/CO/5, paras 47-48; CAT/C/FRA/CO/7, paras 32–33; CEDAW/C/FRA/CO/7-8, paras 17e-f + 18e-f), *Germany* (CAT/C/DEU/CO/5; para 20; CRPD/C/DEU/CO/1, paras 37-38; CEDAW/C/DEU/CO/7-8, paras. 23–24), *Austria* (CAT/C/AUT/CO/6, paras 44-45), and *Italy* (CRPD/C/ITA/CO/1, paras 45-46), **there are**

- **no legal or other protections** in place to ensure the rights of intersex children to physical and mental integrity, autonomy and self-determination, and to prevent non-consensual, medically unnecessary, irreversible surgery and other harmful treatments a.k.a. IGM practices
- **no measures** in place to ensure **data collection and monitoring** of IGM practices
- **no legal or other measures** in place to ensure the **accountability** of IGM perpetrators
- **no legal or other measures** in place to ensure **access to redress and justice** for adult IGM survivors

To this day, the **Swiss government**, despite now acknowledging IGM practices having been “*denounced at the political level by the Federal Parliament and Council as well as by the National Ethics Commission in its Opinion No. 20/2012 ‘On the management of differences of sex development. Ethical issues relating to intersexuality’*” (**State Report**, para 188), and further acknowledging that IGM practices result in “*considerable consequential damage and severe suffering of persons concerned*”,<sup>14</sup> undeviatingly **refuses** to “*take effective legislative, administrative, judicial or other measures*” to protect intersex children, nor to facilitate data collection, but instead **counterfactually claims**:

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12 E.g. the **Swiss Federal Government** in 2011 in answers to parliamentary questions consistently described intersex as “*True and Untrue Transsexualism*”, e.g. 11.3286, [http://www.parlament.ch/d/suche/seiten/geschaefte.aspx?gesch\\_id=20113286](http://www.parlament.ch/d/suche/seiten/geschaefte.aspx?gesch_id=20113286)

13 For references, see 2016 CAT France NGO Report France, p. 35, fn 40.

14 Swiss Federal Government, press release 06.07.2016, *Personnes aux caractéristiques sexuelles ambiguës : sensibiliser davantage*, <https://www.admin.ch/gov/fr/accueil/documentation/communiqués.msg-id-62507.html>



- IGM practices would only be “*approved for between one and three children per year of birth*” (State Report, para 188)
- IGM practices would be **strictly a thing of the “past”**<sup>15</sup>
- the recommendations of the **Swiss National Ethics Commission (NEK-CNE)** concerning the Federal Government would all be “*already implemented or in the process of being implemented*” (with the only exception of the “*free psychosocial support*” for persons and families concerned which would be “*impossible*” to finance).<sup>16</sup>

At the same time, all forms of **IGM practices remain widespread and ongoing**, persistently **advocated, prescribed and perpetrated** by state funded University and Cantonal Children’s Clinics, and **paid for** by the **Swiss federal Disability Insurance** (Invalidenversicherung IV) covering intersex surgeries on children until the age of 20 – but not for consenting adults! – according to its **List of Birth Defects** (Liste der Geburtsgebrechen).<sup>17</sup>

### **b) IGM 3 – Sterilising Procedures:**

#### **Castration / “Gonadectomy” / Hysterectomy /**

#### **Removal of “Discordant Reproductive Structures” / (Secondary) Sterilisation<sup>18</sup>**

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

To this day, the **Swiss federal Disability Insurance** (Invalidenversicherung IV) covers sterilising procedures on intersex children until the age of 20 – but not for consenting adults! – according to its **List of Birth Defects** (Liste der Geburtsgebrechen) under **No.s 355, 359, 466, 488**.<sup>19</sup>

The 2016 Consensus Statement “Global Disorders of Sex Development Update” co-authored by the Global DSD Update Consortium including clinicians of the **Bern University Children’s Clinic “Inselspital”** (Christa Flück) and the **Geneva University Children’s Clinic** (François Ansermet) continues to advocate “*gonadectomy*” to obtain “*histological information*” (p. 16), repeatedly stipulates “*Low threshold for gonadectomy if ambiguous genitalia*” or in cases of “*Unclear gender*”, and continues to advocate “*Postpubertal gonadectomy*” of children diagnosed with “*Complete AIS*” (p. 17).<sup>20</sup>

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15 *ibid.*

16 *ibid.*

17 Swiss National Advisory Commission on Biomedical Ethics NEK-CNE (2012), On the management of differences of sex development. Ethical issues relating to “intersexuality”, No. 20/2012, at 15-17, [http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK\\_Intersexualitaet\\_En.pdf](http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf)  
For the relevant numbers in the List of Birth Defects, see <http://blog.zwischengeschlecht.info/pages/Kosmetische-Genitaloperationen-Ziffern-Liste-der-Geburtsgebrechen>

18 For general information, see 2016 CEDAW NGO Report France, p. 47. <http://intersex.shadow-report.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

19 see <http://blog.zwischengeschlecht.info/pages/Kosmetische-Genitaloperationen-Ziffern-Liste-der-Geburtsgebrechen>

20 Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care, Lee et al. and Global DSD Update Consortium, Horm Res Paediatr 2016;85:158-180, <http://www.karger.com/Article/Pdf/442975>



### c) IGM 2 – “Feminising Procedures”: Clitoris Amputation/“Reduction”, “Vaginoplasty”, “Labioplasty”, Dilation

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

To this day, the **Swiss federal Disability Insurance** (Invalidenversicherung IV) covers feminising procedures on intersex children until the age of 20 – but not for consenting adults! – according to its **List of Birth Defects** (Liste der Geburtsgebrechen) under **No.s 358, 359, 465, 466**.<sup>21</sup>

The **Eastern Switzerland Children’s University Hospital St. Gallen**, in its current flyer for parents titled “*Multiprofessional Consultation*” in cases of “*Disorders of Sex Development*”, advocates under “*Therapy*”: “*Corrective surgery*” for “*Hypertrophy of the clitoris*” (p. 1).<sup>22</sup>

The **Zurich University Children’s Hospital’s** surgical “*Department for Paediatric Urology*” lists as “*typical treated diagnoses*”: “*Congenital Adrenal Hyperplasia (CAH)*”, “*Intersexual Genitalia*”, “*Sinus urogenitalis*”,<sup>23</sup> i.e. the most common diagnoses typically “treated” by “feminising” surgeries, including “clitoral reduction”, “vaginoplasty” and “labioplasty”. On occasion of a 2015 presentation at the Hospital, the head surgeon openly admitted to regularly performing “vaginoplasty” on intersex children.<sup>24</sup>

The **Luzern Cantonal Children’s Clinic’s** surgical “*Department for Paediatric Urology*” offers on its homepage the “*full spectrum [...] of surgical treatment*” for congenital “*malformations [...] of the male and female genitalia*”.<sup>25</sup> And on 25-26 November 2016 it hosted the “51st Academy of Paediatric Surgery (AKIC)”, with scheduled lectures<sup>26</sup> on “*Congenital Adrenal Hyperplasia*” by Felicitas Eckoldt (in the programme falsely spelled as “Eckhold”), a staunch defender of “*early feminising genitoplasty*”,<sup>27</sup> and on “*Genital Malformations in Girls*” by Luzern surgeon Sandra Shavit.

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21 see <http://blog.zwischengeschlecht.info/pages/Kosmetische-Genitaloperationen-Ziffern-Liste-der-Geburtsgebrechen>

22 [http://www.kispisg.ch/images/kispisg/pdf\\_Dateien/kliniken\\_und\\_fachbereiche/fachbereiche\\_a-z/endokrinologie/Flyer\\_Sprechstunde\\_ENG\\_DEF.pdf](http://www.kispisg.ch/images/kispisg/pdf_Dateien/kliniken_und_fachbereiche/fachbereiche_a-z/endokrinologie/Flyer_Sprechstunde_ENG_DEF.pdf)

23 <https://www.kispi.uzh.ch/de/patienten-und-angehoerige/fachbereiche/urologie/Documents/Diagnosen%20Urologie.pdf>

24 Personal communication 23.09.2015

25 <http://www.kinderspital-luzern.ch/de/kinder-und-eltern/medizinisches-angebot/kinderchirurgie/urologie/>

26 <https://web.archive.org/web/20161015030845/www.akic2016.de/programm/programmuebersicht/>

27 Presentation at 110. Jahrestagung der Deutschen Gesellschaft für Kinder- und Jugendmedizin e.V. (DGKJ), 13.09.2014, <http://www.springermedizin.de/dgkj-operation-klare-sache-beim-adrenogenitalen-syndrom/5327262.html>

Book chapter “Timing of Surgery for feminising Genitoplasty in Patients suffering from Congenital Adrenal Hyperplasia”, in: Olaf Hiort, S. Faisal Ahmed (eds), *Understanding Differences and Disorders of Sex Development (DSD)*, Basel: Karger, 2014.

#### d) IGM 1 – “Masculinising Surgery”: Hypospadias “Repair”<sup>28</sup>

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

To this day, the **Swiss federal Disability Insurance** (Invalidenversicherung IV) covers masculinising procedures on intersex children until the age of 20 – but not for consenting adults! – according to its **List of Birth Defects** (Liste der Geburtsgebrechen) under **No.s 352, 359, 466**.<sup>29</sup>

The **Bern University Children’s Clinic “Inselspital”**’s “Department of Paediatric Surgery” advocates on its list “Timing of Elective Surgery” “hypospadias repair” at the age of “6-12 months (before the 3rd year)”.<sup>30</sup>

The **Zurich University Children’s Hospital**’s surgical “Department for Paediatric Urology” lists as “typical treated diagnoses”: “Hypospadias”.<sup>31</sup> On occasion of a 2015 presentation at the Hospital, the head surgeon openly admitted to regularly performing “hypospadias repair”.<sup>32</sup> According to nurses working at the Zurich University Children’s Hospital, 1-2 children per week are submitted to “hypospadias repair”.<sup>33</sup>

The **Basel University Children’s Hospital**’s “Department of Paediatric Surgery / Urology” lists under “Typical Urology Diseases and Malformations” treated by its paediatric surgeons “Hypo-/Epispadias”.<sup>34</sup>

In addition, also the **Eastern Switzerland Children’s University Hospital St. Gallen**,<sup>35</sup> the **Luzern Cantonal Children’s Clinic**,<sup>36 37</sup> the **Geneva University Children’s Clinic**,<sup>38</sup> the **Aarau Cantonal Children’s Hospital**,<sup>39</sup> and the **Thurgau Cantonal Children’s Hospital**<sup>40</sup> offer and perform “hypospadias repair”.

#### e) Prenatal “Therapy”<sup>41</sup>

Also prenatal “Therapy” with Dexamethasone is still advocated and practiced in Switzerland, for example in the **Bern University Children’s Clinic “Inselspital”**.<sup>42</sup>

28 For general information, see 2016 CEDAW NGO Report France, p. 48-49. <http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

29 see <http://blog.zwischengeschlecht.info/pages/Kosmetische-Genitaloperationen-Ziffern-Liste-der-Geburtsgebrechen>

30 <http://www.kinderkliniken.insel.ch/de/zuweiser/kinderchirurgie/zeitpunkt-elektiver-eingriff/>

31 <https://www.kispi.uzh.ch/de/patienten-und-angehoerige/fachbereiche/urologie/Documents/Diagnosen%20Urologie.pdf>

32 Personal communication 23.09.2015

33 See 2014 CRC NGO Report, p. 43, fn 96, [http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)

34 [http://www.ukbb.ch/de/ukbb/abteilungen-dienste/chirurgie.php#anchor\\_9a0a567a\\_Accordion-Urologie](http://www.ukbb.ch/de/ukbb/abteilungen-dienste/chirurgie.php#anchor_9a0a567a_Accordion-Urologie)

35 [http://www.kispisg.ch/images/kispisg/pdf\\_Dateien/kliniken\\_und\\_fachbereiche/fachbereiche\\_a-z/endokrinologie/Flyer\\_Sprechstunde\\_ENG\\_DEF.pdf](http://www.kispisg.ch/images/kispisg/pdf_Dateien/kliniken_und_fachbereiche/fachbereiche_a-z/endokrinologie/Flyer_Sprechstunde_ENG_DEF.pdf)

36 <http://www.kinderspital-luzern.ch/de/kinder-und-eltern/medizinisches-angebot/kinderchirurgie/urologie/>

37 <https://web.archive.org/web/20161015030845/www.akic2016.de/programm/programmuebersicht/>

38 <http://www.hug-ge.ch/chirurgie-pediatrique/malformation-de-la-verge>

39 <https://www.ksa.ch/zentren-kliniken/kinderchirurgie/leistungsangebot#genitalchirurgie>

40 see p. 23, [http://www.stgag.ch/uploads/media/ksm\\_gb\\_2011.pdf](http://www.stgag.ch/uploads/media/ksm_gb_2011.pdf)

41 For general information, see 2014 CRC NGO Report Switzerland, p.75-76, [http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)

42 [http://www.kinderkliniken.insel.ch/fileadmin/kinderheilkunde/kinderheilkunde\\_users/Endokrinologie/Unterlagen/Endokrinologie/skript\\_praenatale\\_diagnostik.pdf](http://www.kinderkliniken.insel.ch/fileadmin/kinderheilkunde/kinderheilkunde_users/Endokrinologie/Unterlagen/Endokrinologie/skript_praenatale_diagnostik.pdf)

## f) 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**):<sup>43</sup>

- **Forced Mastectomy** (p. 70)
- **Misinformation and Directive Counselling for Parents** (p. 70)
- **Systematic Lies and Imposition of “Code of Silence” on Children** (p. 72)
- **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. 1–6.**)

## 4. IGM Practices in Switzerland as a Violation of the Covenant

### a) Torture or Ill-Treatment (Article 7)

The **Committee against Torture** already recognised IGM practices in **Switzerland** to constitute at least **ill-treatment** in breach of the Convention with CAT articles 2, 12, 14, 16 as applicable, and – referring to the **Swiss National Ethics Commission (NEK-CNE)** and **CRC** – obliged the State party (CAT/C/CHE/CO/7, para 20):

- a) to undertake legislative, administrative and other necessary measures to ensure the bodily integrity of intersex people, and that no-one is submitted to medical or surgical sex assignment treatments during childhood, which do not constitute a medical emergency, as recommended by the Swiss National Advisory Commission on Biomedical Ethics and by the Committee on the Rights of the Child (CRC/C/CHE/CO/2-4, par. 43 b));*
- b) to ensure access to psychosocial counselling and support for persons concerned and parents free of charge, and to inform them on the possibility to postpone any decision regarding unnecessary treatments until the person concerned can decide themselves;*
- c) to investigate cases of medical or surgical treatments of intersex persons without their informed consent, and to undertake legislative measures to ensure redress for victims, including adequate compensation.*

Also this Committee’s **General comment No. 20: Article 7** (Prohibition of torture, or other cruel, inhuman or degrading treatment or punishment) obliges State parties to

- *“afford everyone **protection through legislative and other measures as may be necessary** against the acts prohibited by article 7, whether inflicted by people acting in their official capacity, outside their official capacity or in a private capacity.”* (para 2)
- *“inform the Committee of the **legislative, administrative, judicial and other measures** they take **to prevent and punish** acts of torture and cruel, inhuman and degrading treatment in any territory under their jurisdiction.”* (para 8)
- *“indicate how their legal system effectively guarantees the **immediate termination** of all the acts prohibited by article 7 as well as **appropriate redress**. The **right to lodge complaints** against maltreatment prohibited by article 7 must be recognized in the domestic law. **Complaints must be investigated promptly and impartially by competent authorities so as to make the remedy effective**. The reports of States parties should provide specific information on the remedies*

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43 [http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)

available to victims of maltreatment and the procedure that complainants must follow, and **statistics on the number of complaints and how they have been dealt with.**” (para 14)

- “**guarantee freedom from such acts within their jurisdiction; and to ensure that they do not occur in the future.** States may not deprive individuals of the **right to an effective remedy, including compensation and such full rehabilitation as may be possible.**” (para 15)

Thus, in contrary to the evasive answers by the State party, IGM practices in Switzerland surely constitute **torture or ill-treatment in breach of article 7.**

## **b) Involuntary Medical or Scientific Experimentation (Article 7)**

As generally there is **no evidence** of any benefit for the children submitted IGM practices, any such treatments are **experimental**. While due to the general avoidance of follow-up by doctors (including the wilful destruction of evidence in the form of medical records in **Switzerland**, see below), IGM practices are mostly done as **uncontrolled field experiments** and so in many cases may not be considered as involuntary medical or scientific experimentation in a more strict definition. However, internationally there are **many examples proving also a strict definition to apply.**<sup>44</sup> For decades, intersex children have been regularly described and exploited by scientists as an “*experiment of nature*”.<sup>45 46 47</sup> Often **twins, siblings, mothers or other family members or relatives** of intersex children are used as controls.<sup>48 49</sup> Generally, intersex children are often used as **subjects in scientific research**, also in **Switzerland**,<sup>50</sup> and the **Swiss Federal Human Research Act** enacted in 2014 is

44 see e.g. Case Study No. 1 in 2015 CAT Austria NGO Report (p. 13-15), explaining how of **two intersex cousins, one was castrated at age 5 or 6 and the other only at age 10 “to document the difference”**, <http://intersex.shadowreport.org/public/2015-CAT-Austria-VIMOE-Zwischengeschlecht-Intersex-IGM.pdf>

45 see e.g. Kang H-J, Imperato-McGinley J, Zhu Y-S, Rosenwaks Z. 5alpha-reductase-2 Deficiency’s Effect on Human Fertility. *Fertility and sterility*. 2014;101(2):310-316, at p. 5, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4031759/pdf/nihms578345.pdf>

46 Clarnette, T.D; Sugita, Y.; Hutson, J.M.: Genital anomalies in human and animal models reveal the mechanisms and hormones governing testicular descent, *British Journal of Urology* (1997), 79, 99–112, at 99, <http://onlinelibrary.wiley.com/doi/10.1046/j.1464-410X.1997.25622.x/pdf>

47 U. Kuhnle; W. Kral; Geschlechtsentwicklung zwischen Genen und Hormonen. Worin liegt der Unterschied zwischen Mädchen und Jungen, Männern und Frauen?, *Monatsschr Kinderheilkd* 2003 · 151:586–593, at 591

see also: Lang C.; · Kuhnle U.: Intersexuality and Alternative Gender Categories in Non-Western Cultures, *Horm Res* 2008;69:240–250

48 see e.g. Dittmann, R. W., Kappes, M. H., Kappes, M. E., Borger, D., Stegner, H., Willig, R. H., Wallis, H. (1990). “Congenital adrenal hyperplasia. I: Gender-related behavior and attitudes in female patients and sisters.” *Psychoneuroendocrinology* 15(5-6): 401-420

see also: Ralf W. Dittmann, “Pränatal wirksame Hormone und Verhaltensmerkmale von Patientinnen mit den beiden klassischen Varianten des 21-Hydroxylase-Defektes. Ein Beitrag zur Psychoendokrinologie des Adrenogenitalen Syndroms”, *European University Studies*, Bern: 1989

49 for an example of studies on intersex twins by German gynaecologist Ernst Philipp in collaboration with **Andrea Prader (Zurich University Children’s Clinic)**, see Marion Hulverscheidt (2016), Begriffsdefinitionen „Intersexualität“ VII: Eine einheitliche Betrachtung des Zwittertums – der Kieler Gynäkologe Ernst, <http://intersex.hypotheses.org/3976>

50 for e.g. the development of the world-renowned “Prader Scale” from research on intersex children at the **Zurich University Children’s Clinic** by **Andrea von Prader** in the 1950s, see 2014 CRC NGO Report, at 56, [http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)



known to contain **loopholes** allowing for non-consensual experimentation particularly in cases of **experimental and/or off-label treatments**,<sup>51</sup> which applies to virtually all involuntary intersex treatments. In addition, parents of an intersex infant being treated at the **Eastern Switzerland Children’s University Hospital St. Gallen**, then research partner<sup>52</sup> of the Lübeck-led international research project “**EuroDSD**”,<sup>53</sup> reported the hospital repeatedly **sending blood samples to Germany for “genetic and hormonal analysis”**, which only stopped after they refused to go to this hospital temporarily.<sup>54</sup>

Thus, intersex children surely also fall under “*persons not capable of giving valid consent*” deserving “*special protection in regard to such experiments*” according to **General comment No. 20** (para 7), and involuntary experimental intersex treatments in **Switzerland** and associated research projects with **Swiss participation** including “**EuroDSD**”, “**DSDnet**” and “**DSD-Life**”,<sup>55</sup> surely also constitute **involuntary medical or scientific experimentation in breach of article 7**.

### **c) Harmful Practice and Violence against Children (Article 24)**

The **Committee on the Rights of the Child** already recognised IGM practices in **Switzerland** to constitute a **harmful practice** and **violence against children** in breach of the Convention, and – referring to the **CEDAW/CRC Joint General Recommendation/Comment 31/18** “on harmful practices” and the **Swiss National Ethics Commission (NEK-CNE)** – obliged Switzerland (CRC/C/CHE/CO/2-4, paras 42-43):

*(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.*

Also the **Committee on the Elimination of Discrimination against Women** already recognised “**intersex genital mutilation**” in **Switzerland** to constitute a **harmful practice** in breach of the Convention, and – referring to the **CEDAW/CRC Joint General Recommendation/Comment 31/18** “on harmful practices” and the **Swiss National Ethics Commission (NEK-CNE)** – obliged Switzerland (CEDAW/C/CHE/CO/4-5, paras 24-25, 38-39) to:

*(c) Ensure that, in line with recommendations by the Swiss National Advisory Commission on Biomedical Ethics, no child is subjected to unnecessary medical or surgical treatment during infancy or childhood, adopt legislation to protect the bodily integrity, autonomy and self-determination of intersex persons and provide families with intersex children with adequate counselling and support;*

*(d) Adopt legal provisions, under the guidance of the courts, in order to provide redress to intersex persons affected by cases of surgical or other medical treatment without their free, prior and informed consent by or that of their parents;*

*(e) Educate and train medical professionals on the harmful impact of unnecessary surgical or other medical interventions for intersex children and ensure that the views of intersex persons are fully considered by the interdis-*

51 e.g. Margrit Kessler, president of the **Swiss Patient Organisation** (Schweizerische Patientenorganisation SPO), criticised the lack of independent oversight in experimental treatments, see: Otto Hostettler, “Heimliche Versuche am Menschen” (“**Secret Human Experimentation**”), in: Der Beobachter, <https://www.beobachter.ch/gesetze-recht/forschung-heimliche-versuche-am-menschen>

52 see <http://www.kispisg.ch/kliniken-fachbereiche/fachbereiche-a-z/endokrinologie/forschung-ausbildung#forschung>

53 see 2015 CCPR LoIPR NGO Report by the same Rapporteurs, p. 15-16, [http://intersex.shadow-report.org/public/2014-CCPR-LoIPR-Swiss\\_NGO-Report\\_Zwischengeschlecht\\_Intersex-IGM.pdf](http://intersex.shadow-report.org/public/2014-CCPR-LoIPR-Swiss_NGO-Report_Zwischengeschlecht_Intersex-IGM.pdf)

54 Personal communication 04.06.2017, see also Case Study No. 5

55 see 2014 CCPR LoIPR NGO Report by the same Rapporteurs, p. 15-16, [http://intersex.shadow-report.org/public/2014-CCPR-LoIPR-Swiss\\_NGO-Report\\_Zwischengeschlecht\\_Intersex-IGM.pdf](http://intersex.shadow-report.org/public/2014-CCPR-LoIPR-Swiss_NGO-Report_Zwischengeschlecht_Intersex-IGM.pdf)

*ciplinary working groups established to review these procedures.*

In addition, also this Committee, referring to articles 7 and 24, is consistently advocating to “[a]dopt and enforce the necessary legislative measures” in order to prevent and criminalise **harmful practices** and **genital mutilation**, including its **medicalised forms**.<sup>56</sup>

Thus, in contrary to the evasive answers by the State party, IGM practices in Switzerland surely constitute a **harmful practice** also **in breach of article 24**.

## 5. Lack of Legislative Provisions, Impunity of the Perpetrators

As established above under 4. a–c), the Covenant, related General comments and previous Committee jurisprudence clearly oblige State parties to undertake “**legislative, administrative, judicial and other measures [...] to prevent and punish**” acts of **torture or ill-treatment, involuntary medical or scientific experimentation** and **harmful practices** or **genital mutilation**.

Also the Swiss National Ethics Commission explicitly stipulated, “*There should be a legal review of the liability implications of unlawful interventions in childhood, and of the associated **limitation periods**. Questions of **criminal law**, such as the applicability of offences of assault (Art. 122 and 123, StGB) and the prohibition on genital mutilation (Art. 124, StGB), should also be investigated.*”<sup>57</sup>

Also the **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.*”<sup>58</sup> And in 2015, on occasion of the 55th Session of the Committee against Torture, Meyrat added, “*Only the fear of the judge will make things change. We need statutes of limitation long enough so that victims may sue as adults.*”<sup>59</sup>

However, the **Swiss State party**, despite now admitting that IGM practices have been “*denounced at the political level by the Federal Parliament and Council as well as by the National Ethics Commission*” (State report, para 188) and can cause “*considerable consequential damage and severe suffering of persons concerned*”,<sup>60</sup> so far **undeviatingly refuses** to “*take effective legislative, administrative, judicial or other measures*” to protect intersex children, or even to formally acknowledge that IGM practices constitute torture or ill-treatment, genital mutilation or a harmful practice, but instead, in its 2016 “*answer*” to the National Ethics Commission (NEK-CNE) already announced in the State report (para 188), **counterfactually claims** IGM practices would be **strictly a thing of the “past”**, and the recommendations of the Swiss National Ethics Commission

56 see e.g. CCPR/C/SDN/CO/3, para. 15 ; CCPR/C/SDN/CO/4, para 13; CCPR/CO/84/YEM, paras. 11 and 12; CCPR/C/YEM/CO/5, para 9; CCPR/C/DJI/CO/1, para 8; CCPR/C/IDN/CO/1, para 12

57 Recommendation 12, p. 19, 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, [http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK\\_Intersexualitaet\\_En.pdf](http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf)

58 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](http://www.swissinfo.ch/eng/swiss_news/Third_gender_fights_for_recognition.html?cid=34791620)

59 Tribune de Genève / 24 heures, 03.08.2016, p. 5 respectively 6. English translation: <http://stop.genitalmutilation.org/post/IGM-Only-Fear-of-the-Judge-Will-Make-Surgeons-Change>

60 Swiss Federal Government, press release 06.07.2016, *Personnes aux caractéristiques sexuelles ambiguës : sensibiliser davantage*, <https://www.admin.ch/gov/fr/accueil/documentation/communiqués.msg-id-62507.html>



(NEK-CNE) concerning the Federal Government all to be **“already implemented or in the process of being implemented”** with the only exception of the *“free psychosocial support”* for persons and families concerned which the government considered *“impossible”*.<sup>61</sup>

What’s worse, this comes after the **Swiss State party** has already been reprimanded by no less than **CRC, CAT and CEDAW** for IGM practices, and, referring to the **National Ethics Commission (NEK-CNE)** recommendations, explicitly obliged **Switzerland** to **“take effective legislative, administrative, judicial or other measures”**.

## 6. Obstacles to Redress, Fair and Adequate Compensation

As established above under 4. a–c), the Covenant, related General comments and previous Committee jurisprudence also oblige State parties to guarantee **“right to an effective remedy, including compensation and such full rehabilitation as may be possible”** to victims of **torture, ill-treatment, harmful practices or genital mutilation**.

Also the Swiss National Ethics Commission explicitly stipulated, *“There should be a legal review of the liability implications of unlawful interventions in childhood, and of the associated limitation periods.”*<sup>62</sup>

However, the **statutes of limitation** prevent survivors of early childhood IGM practices to call a court because persons concerned often **do not find out** about their medical history until much later in life, which in combination with severe trauma caused by IGM Practices often proves to amount to a severe obstacle.<sup>63</sup> Also in **Switzerland** the statutes of limitations effectively **prohibit survivors of early childhood IGM practices to call a court**, as also noted by **Swiss paediatric surgeon Blaise Meyrat** (see above under 5.). So far in Switzerland no victim of IGM practices succeeded in going to court ever.

Nonetheless, as also established above under 5., to this day, the **Swiss government undeviatingly refuses** to act accordingly, but instead simply **denies** the problem, or **counterfactually claims** the issue to be already resolved – despite that also **CRC, CAT and CEDAW**, all referring to the **National Ethics Commission (NEK-CNE)** recommendations, explicitly obliged the State party to ensure **access to redress and justice** for IGM survivors.

## 7. Lack of Independent Data Collection and Monitoring

With no statistics available on intersex births, let alone surgeries and costs, and **Swiss perpetrators, government and health departments 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 scrutiny and debate, perpetrators of IGM practices respond by suppressing complication rates, as well as refusing to talk to journalists *“on record”*.<sup>64</sup>

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61 *ibid.*

62 Recommendation 12, p. 19, 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, [http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK\\_Intersexualitaet\\_En.pdf](http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf)

63 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.

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

Similarly, in the past years Swiss cantonal and federal bodies issued **only fragmentary and conflicting numbers** of involuntary intersex treatments in Switzerland.<sup>65</sup> And while during the 2015 CRC review of Switzerland, the Swiss delegation promised that *“the government wishes to collect information on surgery on intersex grounds. For the time being we have no clear data, **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**, and the information on such surgery will allow us to gain a better appraisal of the situation”*,<sup>66</sup> in 2016 the State party nonetheless just reiterated its **old incomplete 2011 figure** of *“1-3 treatments per age group”* (**State report**, para 188, fn 97).

In addition, the State party **refuses to initiate impartial investigations**, as well as **data collection, monitoring, and disinterested research**, and **Swiss hospitals are often unwilling to provide full access to patient’s records**.

## 8. Destruction of Evidence of Past IGM Practices

What’s worse, in 2016 the **Zurich University Hospital** was enabled to **destroy about 80% of its relevant historic medical files documenting IGM practices**<sup>67</sup> – ironically as part of a *“[historical] scientific review of the treatment of children with differences of sex development (DSD children)”* funded by the **Swiss National Science Foundation (SNSF)** with Sfr 500’000.–,<sup>68</sup> a “science project” led by the perpetrator institutions **Zurich University Hospital** and **Zurich University** themselves, but **without adequate consultation of intersex persons and their organisations**. As a result, for example a **member of the self-help group Intersex.ch** (see **Case No. 1**) who wanted to access his files, was told that while at the **Zurich State Archives** there was still a note in the register confirming in 1945 and 1946 he was in treatment at the **Department of Surgery of the Zurich University Children’s Hospital**, the **actual files were no longer available**.<sup>69</sup>

**Conclusion**, this situation is clearly not in line with **Switzerland’s** obligations under the Covenant.

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65 See 2014 CRC NGO Report Switzerland, p.43-47, [http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)

66 Transcript, <http://stop.genitalmutilation.org/post/Transcript-Intersex-QA-CRC-Geneva-2015>

67 i.e. 90% of all cases of IGM 1 “masculinising surgeries (hypospadias corrections)”. Personal communication and e-mails with doctor and historian of the Zurich University Children’s Hospital, April 2016; Personal communication with Zurich State Archives, June 2016

68 see Press Release SFNF 10.10.2016, <http://www.snf.ch/en/researchinFocus/newsroom/Pages/news-161010-press-release-reviewing-the-treatment-of-differences-of-sex-development.aspx>

69 E-mails Zurich State Archives, 19.01.2017 and 21.03.2017

## C. Recommendations

*The Rapporteurs respectfully suggest that, with respect to the treatment of intersex persons in Switzerland, the Committee includes the following measures in their recommendations to the Swiss Government (in line with CRC's, CAT's and CEDAW's previous recommendations to Switzerland):*

### **Intersex persons**

The Committee remains seriously concerned about cases of medically unnecessary and irreversible surgery and other treatment of intersex children and adults without their informed consent, which can cause severe suffering, and the lack of redress and compensation in such cases (arts. 7 and 24).

**In the light of its general comment No. 20 (1992) and in line with the recommendations by the National Advisory Commission on Biomedical Ethics, the Committee recommends that the State party:**

- (a) Ensure that no-one is subjected to unnecessary medical or surgical treatment during infancy or childhood, adopt legislation with a view to guarantee bodily integrity, autonomy and self-determination to persons concerned, and provide families with intersex children with adequate counselling and support;**
- (b) Undertake investigation of incidents of surgical and other medical treatment of intersex persons without informed consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation;**
- (c) Systematically collect disaggregated data on harmful practices in the State party and make information on the ways to combat these practices widely available;**
- (d) Educate and train medical and psychological professionals on the consequences of unnecessary surgical and other medical interventions for intersex children, including of "blind" prenatal hormonal interventions on pregnant women and their children.**

## D. Annexe “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.



**[StopIGM.org](http://StopIGM.org) / [Zwischengeschlecht.org](http://Zwischengeschlecht.org),  
[Intersex.ch](http://Intersex.ch), [SI](http://SI) Selbsthilfe Intersexualität**