

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



**HUMAN
RIGHTS FOR
HERM
APHRODITES
T O O !**

**NGO Report
to the 5th and 6th Periodic Report of Spain
on the Convention on the Rights of the Child (CRC)**

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Executive Summary

All typical forms of IGM practices are still practiced in Spain today, facilitated and paid for by the State party via the public National Health System (SNS). Parents and children are misinformed, kept in the dark, sworn to secrecy, kept isolated and denied appropriate support.

Spain is thus in breach of its **obligations** under the Convention on the Rights of the Child to **(a)** take effective legislative, administrative, judicial or other measures to **prevent harmful practices on intersex children** causing severe mental and physical pain and suffering of the persons concerned, and **(b) ensure access to redress and justice**, including fair and adequate **compensation** and as full as possible **rehabilitation** for victims, as stipulated in **CRC art. 24 para. 3** of the Convention in conjunction with the **CRC/CEDAW Joint general comment No. 18/31** “on harmful practices”).

CRC, CEDAW, CAT, CRPD, the HRCttee, 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.

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, and/or 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.

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.

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.

For 25 years, intersex people have publicly denounced 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** was prepared by the international intersex NGOs **StopIGM.org / Zwischengeschlecht.org** and **Brújula Intersexual** in collaboration with intersex children, adults and parents of intersex children from Spain.

It contains **Suggested Recommendations** and an Annexe with **4 Case Studies**.

**NGO Report
to the 4th and 5th Periodic Report of Spain
on the Convention on the Rights of the Child (CRC)**

Table of Contents

IGM Practices in Spain

Executive Summary	3
Introduction	5
1. Intersex, IGM Practices and Human Rights in Spain	5
2. About the Rapporteurs	5
3. Methodology	5
A. Background: Intersex, IGM and Misrepresentations	6
1. IGM Practices – Involuntary, unnecessary medical interventions	6
2. Intersex is NOT THE SAME as LGBT or SOGI	7
3. Misrepresenting Genital Mutilation as “Health Care”	7
B. IGM Practices in Spain: State-Sponsored and Pervasive	8
1. IGM Practices in Spain: Pervasive and Unchallenged	8
a) Overview: Lack of Protection for Intersex Persons in Spain	8
b) IGM 3 – Sterilising Procedures	9
c) IGM 2 – “Feminising Procedures”	9
d) IGM 1 – “Masculinising Surgery”	10
e) Other Unnecessary and Harmful Medical Interventions and Treatments	11
f) Spanish Public University Hospitals involved in International IGM Networks ...	11
2. IGM Practices in Spain as a Violation of CRC	12
a) Harmful Practice (art. 24(3) and JGC No. 18)	12
b) Violence against Children (art. 19 and GC No. 13)	13
3. Lack of Legislative Provisions, Impunity of the Perpetrators	13
4. Obstacles to Redress and Compensation	14
C. Conclusion: Spain is Failing its Obligations under CRC	15
D. Suggested Recommendations	16
E. Annexe “Case Studies”	17
Case No. 1	17
Case No. 2	18
Case No. 3	10
Case No. 4	20

Introduction

1. Intersex, IGM Practices and Human Rights in Spain

Spain will be considered for its combined 5th and 6th periodic review by CRC. Unfortunately, **intersex children were not mentioned in the State Report.**

This NGO Report demonstrates doctors in **Spanish public university clinics** are regularly performing **IGM practices**, including non-consensual, medically unnecessary, irreversible cosmetic genital surgeries, sterilising procedures, and other harmful treatments on intersex children and adolescents, have been **described by survivors as genital mutilation and torture.** IGM practices are known to cause severe, lifelong physical and psychological pain and suffering, and have been **repeatedly recognised by this Committee and other UN treaty bodies as constituting a harmful practice** as well as torture or ill-treatment.

Despite ongoing public criticism of the practice in Spain by IGM survivors and legal experts, to this day the **State party** not only **fails to take effective legislative, administrative or other action to prevent the practice**, but in fact **directly finances it** via the public National Health System (SNS) and via funding the public university clinics and paediatric hospitals that practice IGM, thus **violating its duty to prevent harmful practices** (Art. 24(3) in conjunction with the CRC/CEDAW Joint general comment 18/31).

2. About the Rapporteurs

This thematic NGO report has been prepared by the international intersex NGOs *Brújula Intersexual* and *StopIGM.org / Zwischenengeschlecht.org* in collaboration with Spanish intersex children, adults and their parents.

- **Brújula Intersexual** (english translation: Intersex Compass) is a Mexican-based NGO founded by Laura Inter in 2013. Its main objectives are to inform, disseminate and make visible everything related to intersex, mainly for Spanish-speaking people. We give priority to the opinion of intersex people over medical opinion. It is also a space that offers help and guidance to Spanish-speaking intersex people and their families, from countries such as Mexico, Spain, Argentina, Chile, among others.¹
- **StopIGM.org / Zwischenengeschlecht.org**, founded in 2007, is an international Human Rights NGO based in Switzerland, led by intersex persons, their partners, families and friends. It 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!*”² According to its charter,³ *Zwischenengeschlecht.org* works to support persons concerned seeking redress and justice. *StopIGM.org* regularly reports to UN treaty bodies.⁴

In addition, the Rapporteurs would like to acknowledge the work of the Spanish Androgen Insensitivity Syndrome Support Group, **Asociación y grupo de Apoyo a favor de las personas afectadas por el Síndrome de Insensibilidad a los Andrógenos y condiciones relacionadas (GrApSIA).**⁵ And we would like to acknowledge the work of Professor of Philosophy of Law **Daniel J. García López.**⁶

1 <https://brujulaintersexual.org/>

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

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

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

5 <https://grapsia.org/>

6 <https://brujulaintersexual.files.wordpress.com/2017/10/intersex-manifesto-english.pdf>

3. Methodology

This thematic NGO report is a localised update to previous reports to CRC by StopIGM.org in collaboration with fellow intersex advocates and organisations, most recently for *Denmark, South Africa, New Zealand, the United Kingdom of Great Britain and Northern Ireland, and Nepal*.⁷

This Report includes **4 anonymised personal testimonies of Spanish survivors of IGM practices**. The stories were obtained from (a) written submissions solicited by the Rapporteurs, (b) interviews conducted for this NGO report, and (c) written testimonies available from publicly available publications, or a combination thereof (see source given for each testimony). 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 testimonies, however, show in an exemplary manner how different forms IGM are practiced in the Spain without informed consent by the persons concerned and/or their parents, and cause **severe physical and mental pain and suffering**.

A. Background: Intersex, IGM and Harmful Misrepresentations

1. 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**,⁸ 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*”.⁹

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**,¹⁰ 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.¹¹

7 <http://intersex.shadowreport.org/category/CRC-2016>

8 See “What is Intersex?”, 2015 CRC Ireland NGO Report, p. 23–25, <http://intersex.shadowreport.org/public/2015-CRC-Ireland-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

9 For references, see “What are Intersex Genital Mutilations (IGM)?”, 2015 CRC Ireland Report, p. 29

10 See “IGM Practices – Non-Consensual, Unnecessary Medical Interventions”, 2015 CRC Ireland NGO Report, p. 29–34

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, 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,¹² 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**.

Regrettably, **such harmful misrepresentations seem to be on the rise also at the UN**, for example in recent **UN press releases** and **Summary records** misrepresenting IGM as “*sex alignment surgeries*” (i.e. voluntary procedures on transsexual or transgender persons), IGM survivors as “*transsexual children*”, and intersex NGOs as “*a group of lesbians, gays, bisexuals, transgender and intersex victims of discrimination*”,¹³ and again IGM survivors as “*transsexual children who underwent difficult treatments and surgeries*”, and IGM as a form of “*discrimination against transgender and intersex children*”,¹⁴ and **State parties** are frequently referring to e.g. transgender guidelines¹⁵ or “*Gender Identity Law*”¹⁶ when asked about IGM by e.g. Treaty bodies.

3. Misrepresenting Genital Mutilation as “Health Care”

An interrelated, alarming new trend is the **increasing misrepresentation of IGM as “health-care issue”** instead of a serious human rights violation, and the **promotion of “self-regulation” of IGM by the current perpetrators**^{17 18 19} – instead of effective measures to finally end the practice (as unmistakably stipulated by CRC art. 24 (3) in conjunction with the CRC/CEDAW Joint General Comment No. 18/31 “*on harmful practices*”). Even worse, **Health ministries construe CRC Concluding observations falling short of explicitly recommending to criminalise IGM as an excuse for promoting state-sponsored IGM practices to continue with impunity**.²⁰

12 For references, see 2015 CRC France NGO Report, p. 32, fn 30, [online \(PDF\)](#)

13 CAT60 Argentina, <http://stop.genitalmutilation.org/post/UN-Press-Release-calls-IGM-survivors-transsexual-children-CATArgentina-UNCAT60>

14 CRC76 Denmark, <http://stop.genitalmutilation.org/post/UN-Press-Release-calls-IGM-survivors-transsexual-children-CRC-Denmark-UNCRC67>

15 CAT56 Austria, see <http://stop.genitalmutilation.org/post/Geneva-UN-Committee-against-Torture-questions-Austria-over-Intersex-Genital-Mutilations>

16 CAT 60 Argentina, unofficial transcript see <http://stop.genitalmutilation.org/post/CAT60-Arentina-to-be-Questioned-on-Intersex-Genital-Mutilation-by-UN-Committee-against-Torture>

17 For example Amnesty (2017), see <http://stop.genitalmutilation.org/post/Amnesty-Report-fails-Intersex-Children-and-IGM-Survivors>

18 For example FRA (2015), see Presentation OHCHR Expert Meeting (2015), slide 8, http://stop.genitalmutilation.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf

19 For example CEDAW (2017), see, <http://stop.genitalmutilation.org/post/Major-Setback-for-Intersex-Human-Rights-at-the-UN>

20 See for example Ministry of Health Chile (2016), <http://stop.genitalmutilation.org/post/Circular-7-step-back-for-intersex-human-rights-in-Chile>

B. IGM in Spain: State-sponsored and pervasive, Gov fails to act

1. IGM practices in Spain: Pervasive and unchallenged

a) Overview: Lack of Protection for Intersex Persons in Spain, IGM state-sponsored

Allover Spain, all forms of **IGM practices remain widespread and ongoing**, persistently **advocated, prescribed and perpetrated** by state funded University and Public Children's Clinics, and **paid for** by the **Spanish National Health System (SNS)** – as the actors themselves publicly admit, as well as to the psycho-social justification of the surgeries, and to knowledge of the human rights implications:

The endocrinologist of Vall'd Hebron, Laura Audi, [...] is opposing legislation [to ban IGM]. "Any radical stance is bad, it doesn't serve to say that we should never operate, nor does it serve to say that we should not change any of the protocols," says the doctor who asserts that in Spain "it has been years since there has been any surgical intervention or open exploration in intersex minors without the informed knowledge of parents." (20 Minutos 11.08.2016)²¹

"Ablations [of the clitoris] like Olga's are no longer practiced," the president of the Spanish Society of Pediatric Surgery, Iñaki Eizaguirre, assures EL MUNDO. However, the expert admits that genital standardisation surgeries in children do continue to be performed in hospitals. Surgeries that are not necessary because the child's health is at risk, but rather "are convenient for coexistence, social-family relations and to avoid problems." (El Mundo 11.12.2016)²²

On the side of protections, in **Spain**, same as in the states of *Switzerland* (CRC/C/CHE/CO/2-4, paras 42-43), *Ireland* (CRC/C/IRL/CO/3-4, paras 39-40), *France* (CRC/C/FRA/CO/5, paras 47-48), the *United Kingdom* (CRC/C/GBR/CO/5, paras 45–46), *Chile* (CRC/C/CHL/CO/4-5, paras 48–49), *Nepal* (CRC/C/NPL/CO/3-5, paras 41–42), *South Africa* (CRC/C/ZAF/CO/2, paras 39–40), *New Zealand* (CRC/C/NZL/CO/5, paras 25 + 15) and *Denmark* (CRC/C/DNK/CO/5, para 24), **there are**

- **no effective 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 IGM practices, including non-consensual, medically unnecessary, irreversible surgery and other harmful treatments
- **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 survivors of childhood IGM practices
- **no legal or other measures** in place to ensure **data collection and monitoring** of IGM practices
- **no legal or other measures** in place to ensure **education and training of medical professionals** on the consequences of IGM practices

21 <http://www.20minutos.es/noticia/3055849/0/padres-espanoles-cuestionan-cirugia-genital-bebes-intersexuales/>

22 <http://www.elmundo.es/sociedad/2016/12/11/584b00db22601d53428b4646.html>

Out of the 17 autonomous Communities, the **Community of Madrid** has to be commended for having enacted legislation aimed at preventing IGM practices. **Law 2/2016 of the Community of Madrid**²³ states in art. 4 (3), “[...] genital surgeries of intersex persons without the informed consent of the person concerned or the need to ensure biological functionality for health reasons, are **prohibited in the health services of the Community of Madrid.**” Art. 15 titled “**Health care for intersex people**” further affirms, “**1. The public health system in Madrid will ensure the eradication of genital modification practices in newborn babies [...] with the exception of medical criteria based on the protection of the newborn’s health and with legal authorization.**”

While Madrid’s **Law 2/2016 art. 53 “Penalties”** has to be lauded to at least include some sanctions – ranging from a warning or fines of 200 to 3,000 Euros for “minor infringements” and up to 20,001 to 45,000 Euros plus possible temporary suspension for “very serious infringements” –, in practice the Law 2/2016 **isn’t enforced (nor its implementation monitored)**, as also in the **Community of Madrid** both public and private **children’s hospitals openly flaunt the law by continuing to publicly advertise, perform and promote IGM practices** – just the same as in the other autonomous Communities without such a law:

b) IGM 3 – Sterilising Procedures:

Castration / “Gonadectomy” / Hysterectomy /

Removal of “Discordant Reproductive Structures” / (Secondary) Sterilisation²⁴

“Two years old, they took my testes.” (Case No. 4)

The brandnew **2017 DSD Guidelines** authored by the “DSD Working Group” of the **Spanish Society of Paediatric Endocrinology (SEEP)**²⁵ unchangingly promote “prophylactic gonadectomy” (p. 44–46):

“In Complete Androgen Insensitivity (CAIS) without residual receptor activity, the rate of malignant tumors is low. [...] [T]he general recommendation is prophylactic gonadectomy in late puberty. [...] Having decided to perform a gonadectomy in these patients, the need for hormone replacement treatment should be discussed with the family and patient. In general, the doses of estrogen needed to maintain bone mass and prevent symptoms of estrogen deficiency are higher than those used in menopause, and should be adapted to each patient.”

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

“I’m sure that if they had respected my body as it was, the sensations would be much better.” (Case No. 2)

The **Madrid University Children’s Hospital La Paz’s** current “**Formative Itinary Paediatric Surgery**”²⁶ lists under fields under mandatory procedures of which a trained paediatric surgeon must have “at least solid knowledge” (p. 9):

23 Ley 2/2016, de 29 de marzo, de Identidad y Expresión de Género e Igualdad Social y no Discriminación de la Comunidad de Madrid, http://noticias.juridicas.com/base_datos/CCAA/573598-1-2-2016-de-29-mar-ca-madrid-identidad-y-expresion-de-genero-e-igualdad.html

24 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>

25 available at http://www.seep.es/privado/gads/GUIA_MANEJO_ADS_DSD_SEEP.PDF

26 <http://www.madrid.org/cs/Satellite?blobcol=urldata&blobheader=application%2Fpdf&blobheadername1=Content-disposition&blobheadername2=cadena&blobheadervalue1=filename%3DGIFT+Cirug%3%ADa+Pedi%3%Altrica.pdf&blobheadervalue2=language%3Des%26site%3DHospitalLaPaz&blobkey=id&blobtable=MungoBlobs&blobwhere=1352905205919&ssbinary=true>

GENITAL PATHOLOGY

73. *Testicular descent abnormalities. Cryptorchidism. Ectopies. Testicular retention.*

74. *Acute scrotum. Testicular torsion and hydatid torsion. Orchitis and epididymitis. Ovarian torsion. Ovarian cysts.*

75. **Intersex states.**

76. *Hypospadias and epispadias.*

77. **Female external genital abnormalities. Vaginal agenesis and duplication. Hydro and hematocolps. Fused Labia.**

In 2017, the Barcelona University Children's Hospital Vall d'Hebron in collaboration with the **Catalan Health Department** and the *Institut Català de la Salut* co-organised a "masterclass" titled "**Pediatric Urogenital Reconstructive Surgery: Disorders of Sex Development DSD XX**", specialising in "feminising" "Surgery in children with atypical genital development (AGD)" and including no less than **3 sessions of "Live surgery"**.²⁷

d) IGM 1 – "Masculinising Surgery": Hypospadias "Repair"²⁸

The **Madrid University Children's Hospital La Paz's** current "**Formative Itinary Paediatric Surgery**"²⁹ lists under fields under mandatory procedures of which a trained paediatric surgeon must have "*at least solid knowledge*" (p. 9):

GENITAL PATHOLOGY

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75. **Intersex states.**

76. **Hypospadias and epispadias.**

77. **Female external genital abnormalities. Vaginal agenesis and duplication. Hydro and hematocolps. Fused Labia.**

Madrid University Children's Hospital La Paz's Chief of Paediatric Urology Section, Dr. Pedro López Pereira, is also a board member of the **European Society for Paediatric Urology (ESPU)**, whose current **2017 Guidelines "Paediatric Urology"** promote "*cosmetic indications*" as justification for early surgeries: "**The age at surgery for primary hypospadias repair is usually 6-18 (24) months.**"³⁰

The **2017 ESPU Annual Meeting** was held in **Barcelona**, where multiple presentations promoted IGM practices, for example in a presentation by 8 paediatric surgeons from

27 see programme available both at Vall'Hebron, <http://www.aulavhebron.net/aula/documentos/URO.pdf> and the **Spanish Society for Paediatric Surgery (SECIPE)**, <https://www.secipe.org/coldata/upload/noticias/DSDVHEBRONDEF.pdf>

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 <http://www.madrid.org/cs/Satellite?blobcol=urldata&blobheader=application%2Fpdf&blobheadername1=Content-disposition&blobheadername2=cadena&blobheadervalue1=filename%3DGIFT+Cirug%C3%ADa+Pedi%C3%A1trica.pdf&blobheadervalue2=language%3Des%26site%3DHospitalLaPaz&blobkey=id&blobtable=MungoBlobs&blobwhere=1352905205919&ssbinary=true>

30 available at <http://uroweb.org/guideline/paediatric-urology/>

the **Madrid University Children’s Hospital La Paz** reporting “*60 patients*” with “*primary [hypospadias] repair at 36±8 months of age*”.³¹

In February 2018 the **Madrid University Children’s Hospital Fundación Alcorcón** and the **Madrid Urological Society** will co-host the “*VII International Course of Urethral Reconstructive Surgery*”, where multiple presentations will promote IGM 1, including a video-presentation on “*surgery of distal hypospadias*” moderated by **Madrid University Children’s Hospital La Paz’s** Chief of Paediatric Urology Section, Dr. Pedro López Pereira.³²

In 2016–2017, the **Málaga Escuela de Urología Pediátrica y Fetal del Colegio de Médicos** and the **Colegio Oficial de Médicos de la Provincia de Málaga** co-organised at least 2 similar courses promoting early hypospadias surgery, one in collaboration with the **Universidad Internacional de Andalucía (UNIA)**³³ and another at the **Clínica Santa Elena (Los Álamos, Torremolinos)**.³⁴ And in 2015 a similar course took place at the **Complejo Hospitalario Universitario de Albacete**.³⁵

e) IGM 4: Other Unnecessary and Harmful Medical Interventions and Treatments

Other common harmful treatments include (as detailed in the **2014 CRC NGO Report**):³⁶

- **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. 1–4**.)

f) Spanish Public University Hospitals involved in International IGM Networks

In 2017, the “European Reference Network (ERN)” was launched to ensure better treatment for patients with rare diseases within the European Union.³⁷ Unfortunately, **2 of the newly created “ERNs” also specialise in the proliferation and practice of IGM**, namely the “**Network Urogenital Diseases**” a.k.a. “**eUROGEN**” and the “**Network on En-**

31 28th ESPU, 21.04.2017, Session 14: Hypospadias 2. Mariela DORE , Paloma TRIANA, Virginia AMESTY, Vanessa NÚÑEZ (Children’s Hospital La Paz, Pediatric Surgery); Roberto LOBATO, Susana RIVAS, Pedro LOPEZ PEREIRA and Maria Jose MARTÍNEZ-URRUTIA (Children’s Hospital La Paz, Pediatric Urology): “THE EFFECT OF PREOPERATIVE HORMONAL STIMULATION ON OPERATIVE OUTCOMES AFTER PROXIMAL HYPOSPADIAS REPAIR”

32 see programme, <https://www.bcongresos.com/congresos/gestor/ckfinder/userfiles/files/VII%20Curso%20Cirugia%20Uretra.pdf>

33 “I Experto Universitario en Hipospadias” <https://www.secipe.org/coldata/upload/noticias/ExptpHiposp%20UNIA.pdf>

34 “14º Curso Internacional Práctico de Hipospadias de Málaga”, <https://www.secipe.org/coldata/upload/noticias/hipospadiasmalaga2016.pdf>

35 see programme, http://www.chospab.es/cursos_jornadas/2015/hipospadias/intro.htm

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

37 https://ec.europa.eu/health/sites/health/files/ern/docs/2017_brochure_en.pdf

doctrine Conditions” a.k.a. “Endo-ERN”.³⁸ Like with earlier international networks led by IGM perpetrators, e.g. “EuroDSD”/“I-DSD”³⁹ and “DSDnet”,⁴⁰ **Spanish University Hospitals** are again involved.⁴¹

2. The Treatment of Intersex Children in Spain as a Harmful Practice and Violence

a) Harmful Practice (art. 24(3) and JGC No. 18)⁴²

Article 24 para 3 CRC calls on states to abolish harmful “traditional practices prejudicial to the health of children”. While the initial point of reference for the term was the example of Female Genital Mutilation/Cutting (FGM/C), the term consciously wasn’t limited to FGM/C, but meant to include all forms of harmful, violent, and/or invasive traditional or customary practices.⁴³

The Committee has repeatedly considered IGM as a harmful practice, and the CRC/CEDAW Joint General Comment No. 18/31 on harmful practices as applicable.⁴⁴

Harmful practices (and inhuman treatment) have been identified by intersex advocates as the **most effective, well established and applicable human rights frameworks** to eliminate IGM practices and to end the impunity of the perpetrators.⁴⁵

The **Joint General Comment No. 18 “on harmful practices”** “*call[s] upon States parties to explicitly prohibit by law and adequately sanction or criminalize harmful practices, in accordance with the gravity of the offence and harm caused, provide for means of prevention, protection, recovery, reintegration and redress for victims and combat impunity for harmful practices*” (para 13).

Particularly, the Joint General Comment further underlines the need for a “**Holistic framework for addressing harmful practices**” (paras 31–36), including “**legislative, policy and other appropriate measures that must be taken to ensure full compliance with [state parties’] obligations under the Conventions to eliminate harmful practices**” (para 2), as well as

- “Data collection and monitoring” (paras 37–39)
- “Legislation and its enforcement” (paras 40–55), particularly:

38 See <http://stop.genitalmutilation.org/post/eUROGEN-EU-funded-Intersex-Genital-Mutilators>

39 See Open Letter to “I-DSD 2017”, http://stop.genitalmutilation.org/public/Open_Letter_I-DSD_Copenhagen_2017.pdf

40 See <http://stop.genitalmutilation.org/post/DSDnet-Intersex-Genital-Mutilators-European-Union>

41 The Open Letter to “I-DSD 2017” lists Spanish University Clinics involved in current international IGM projects, see p. 2, http://stop.genitalmutilation.org/public/Open_Letter_I-DSD_Copenhagen_2017.pdf

42 For a more extensive version, see *2016 CRC UK Thematic NGO Report*, p. 55–56, http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

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

44 CRC/C/CHE/CO/2-4, paras 42-43; CRC/C/IRL/CO/3-4, paras 39-40; CRC/C/FRA/CO/5, paras 47-48; CRC/C/CHL/CO/4-5, paras 48–49; CRC/C/GBR/CO/5, paras 45–46; CRC/C/NPL/CO/3-5, paras 41–42; CRC/C/ZAF/CO/2, paras 39–40; CRC/C/NZL/CO/5, paras 25 + 15; CRC/C/DNK/CO/5, para 24

45 Daniela Truffer, Markus Bauer / Zwischengeschlecht.org: “Ending the Impunity of the Perpetrators!” Input for Session 3: “Human Rights Standards and Intersex People – Progress and Challenges - Part 2” at “Ending Human Rights Violations Against Intersex Persons.” OHCHR Expert Meeting, Geneva 16–17.09.2015, online: http://StopIGM.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf

- “**adequate civil and/or administrative legislative provisions**” (para 55 (d))
- “provisions on **regular evaluation and monitoring**, including in relation to implementation, enforcement and follow-up” (para 55 (n))
- “**equal access to justice**, including by **addressing legal and practical barriers to initiating legal proceedings, such as the limitation period**, and that the **perpetrators and those who aid or condone such practices are held accountable**” (para 55 (o))
- “equal access to **legal remedies and appropriate reparations in practice**” (para 55 (q)).

Last but not least, the Joint General Comment explicitly stipulates: “Where **medical professionals or government employees or civil servants are involved or complicit in carrying out harmful practices**, their status and responsibility, including to report, should be seen as an **aggravating circumstance in the determination of criminal sanctions or administrative sanctions such as loss of a professional licence or termination of contract**, which should be preceded by the issuance of warnings. **Systematic training** for relevant professionals is considered to be an effective preventive measure in this regard.” (para 50)

Thus, **IGM practices in Spain** – as well as the **failure of the state party to enact effective legislative, administrative, social and educational measures** to eliminate them and to ensure effective access to remedies and redress – clearly violate Article 24 CRC, as well as the CRC/CEDAW Joint General Comment No. 18/31 on harmful practices.

b) Violence against Children (art. 19 and GC No. 13) ⁴⁶

Similarly, the Committee has also considered IGM practices as violence against children, and Art. 19 and the General Comment No. 13 also offer strong provisions to combat IGM practices.

3. Lack of Legislative Provisions to Ensure Protection from IGM Practices, Impunity of the Perpetrators (art. 24(3) and JGC No. 18; art. 19 and GC No. 13)

Article 24 para. 3 of the Convention in conjunction with the CRC/CEDAW Joint General Comment No. 18/31 “on harmful practices” (2014) underline state parties’ obligations to “**explicitly prohibit by law and adequately sanction or criminalize harmful practices**” (JGC 18/31, para 13), as well as to “**adopt or amend legislation with a view to effectively addressing and eliminating harmful practices**” (JGC 18/31, para 55), and specifically to ensure “**that the perpetrators and those who aid or condone such practices are held accountable**” (JGC 18/31, para 55 (o)).

Also Article 19 of the Convention calls upon states to “**take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence**”, and the General Comment No. 13 “The right of the child to freedom from all forms of violence” (2011) stipulates that state parties “**ensur[e] absolute prohibition of all forms of violence against children in all settings and effective and appropriate sanctions against perpetrators**” (GC 13, para 41 (d)).

Accordingly, with regards to IGM practices, and referring to Article 24 para 3 and the CRC/CEDAW Joint General Comment No. 18/31, this Committee already explicitly recognised the obligation for State parties to “**[e]nsure that the State party’s legislation prohibits**

46 For a more extensive version, see 2016 CRC UK Thematic NGO Report, p. 57, http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

all forms of harmful practices [including intersex genital mutilation]”,⁴⁷ as well as 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*”,⁴⁸ and to “[u]ndertake investigation of incidents of surgical and other medical treatment of intersex children without informed consent and **adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation**”.⁴⁹

However, to this day and **against better knowledge** the **Spanish government refuses to even discuss, let alone enact appropriate legislative measures** to effectively eliminate IGM practices, nor to **address the factual impunity of IGM perpetrators, but simply ignores the practice.**

Worse, **Spanish government bodies**, while repeatedly having been made aware of the harm done by the practice, are **actively shielding IGM perpetrators** by refusing to take action to outlaw and adequately sanction the practice.

This situation with the **Spanish government** ignoring the ongoing practice while continuing to **protect and fund the perpetrators** is clearly not in line with **Spain’s obligations** under the Convention and CRC/CEDAW Joint General Comment No. 18/31.

4. Obstacles to Redress, Fair and Adequate Compensation, and Rehabilitation (art. 24(3) and JGC No. 18; art. 19 and GC No. 13)

Article 24 para. 3 of the Convention in conjunction with the CRC/CEDAW Joint General Comment No. 18/31 “on harmful practices” clearly stipulate the right of victims of IGM practices to “*equal access to legal remedies and appropriate reparations*” (JGC 18/31, para 55 (q)), and specifically to ensure that “*children subjected to harmful practices have equal access to justice, including by addressing legal and practical barriers to initiating legal proceedings, such as the limitation period*” (JGC 18/31, para 55 (o)).

Article 19 of the Convention and the General Comment No. 13 “The right of the child to freedom from all forms of violence” also stipulate the right of victims to “*effective access to redress and reparation*” (GC 13, para 41 (f)), “*including compensation to victims*” (GC 13, para 56).

However, also in **Spain** the **statutes of limitation** prohibit 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, and **severe trauma** caused by IGM practices often prohibits them to act in time even once they do.⁵⁰ So far there was no case of a victim of IGM practices succeeding in going to a Spanish court.

The **Spanish government** so far refuses to ensure that non-consensual unnecessary IGM surgeries on minors are recognised as a form of **genital mutilation**, which would formally prohibit parents from giving “consent”. In addition, the state party **refuses to initiate impartial investigations**, as well as data collection, monitoring, and disinterested research.

47 CRC/C/ZAF/CO/2, 27 October 2016 paras 39–40

48 CRC/C/CHE/CO/2-4, 26 February 2015, para 43

49 CRC/C/DNK/CO5, 26 October 2017, para 24

50 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.

C. Conclusion: Spain is Failing its Obligations towards Intersex Children under the Convention on the Rights of the Child

The surgeries and other harmful treatments intersex people endure cause severe physical and mental pain and suffering. 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 of the suffering this causes. The State party is responsible for these violations constituting a harmful practice, violence against children, and torture or at least ill-treatment, perpetrated by publicly funded doctors, clinics, and universities, as well as in private clinics, all relying on money from the public National Health System (SNS), and public grants. Although in the meantime the pervasiveness of IGM practices and the harm caused is common knowledge and criticised in public by survivors and legal experts, Spain nonetheless fails to prevent these grave violations, but allows the human rights violations of intersex children to continue unhindered.

Thus **Spain is in breach of its obligation to “take effective legislative, administrative, judicial or other measures” to prevent harmful practices** (Art. 24 para. 3 in conjunction with CRC/CEDAW Joint General Comment No. 18/31 “on harmful practices”), as well as of its obligations under Articles 2, 3, 6, 8, 12, 16, 19, 23, 24.1, 34, 36, and 37 of the Convention on the Rights of the Child.⁵¹

Also in Spain, victims of IGM practices encounter severe obstacles in the pursuit of their **right to access to redress and justice**, including **fair and adequate compensation**, and the means for **as full rehabilitation as possible**.

Further the state party’s efforts on **education and information regarding the human rights aspects of IGM practices in the training and education of medical personnel** are grossly insufficient with respect to the treatment of intersex people.

The Rapporteurs would therefore like to urge the Committee to raise and **adequately address intersex genital mutilation** during the forthcoming 77th Session, and to **sternly remind Spain of its obligations** under the **Convention art. 24 (3)** and **Joint General Comment No. 18** “on harmful practices”, in line with the Committee’s previous recommendations (see next page “**Suggested Recommendations**”).

51 See *2016 CRC UK Thematic NGO Report*, p. 53–58, http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

D. Suggested Recommendations

The Rapporteurs respectfully suggest that, with respect to the treatment of intersex persons in Spain, the Committee includes the following measures in their recommendations to the Spanish Government (in line with CRC's previous recommendations e.g. to South Africa, Denmark and Switzerland):

Harmful practices: Intersex genital mutilation

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

In the light of its joint general comment No. 18 (2014) and No. 31 of the Committee on the Elimination of Discrimination against Women on harmful practices, the Committee recommends that the State party:

- (a) Ensure that the State party's legislation prohibits all forms of harmful practices, including intersex genital mutilation**
- (b) Explicitly prohibit unnecessary medical or surgical treatment during infancy or childhood to guarantee bodily integrity, autonomy and self-determination to children concerned, and provide families with intersex children with adequate counselling and support;**
- (c) Adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation and as full rehabilitation as possible, and undertake investigation of incidents of surgical and other medical treatment of intersex children without informed consent;**
- (d) Systematically collect disaggregated data on harmful practices in the State party and make information on the ways to combat these practices widely available;**
- (e) Educate and train medical, psychological and education professionals on intersex as a natural bodily variation and on the consequences of unnecessary surgical and other medical interventions for intersex children.**

E. Annexe “Case Studies”

The first-person narratives have been compiled from written submissions and personal interviews solicited and conducted by the Rapporteurs, and from publicly available testimonies (see source given for each testimony). The abstracts were composed by the Rapporteurs.

Case Study No. 1

Source: Written submission and interview

Born in 2001 with ambiguous genitalia, a salt-losing Congenital Adrenal Hyperplasia (CAH) was diagnosed

Age 17 months clitoral reduction, vaginoplasty and labioplasty

Age 24 months redo-labioplasty

Age 2-12 years vaginal dilation under anaesthesia

Cushing Syndrome from high dosages of hydrocortisone

At the age of 12 the child refused any further treatment and is seeing a psychologist since then.

The mother of the person concerned tells their story:

We are from Tenerife, Canarias. 16 years ago my child was born, who was later diagnosed with Congenital Adrenal Hyperplasia (CAH). At first everything seemed “normal”, but in the pediatric review, from the first days, they noticed that my baby had ambiguous genitalia and we were referred to endocrinology.

They sent us to the Hospital Universitario Nuestra Señora de la Candelaria, and the endocrinologist was Idelfonso Gonzáles.

It took approximately 30 days to give us an appointment with him, and 3 days before this, my child became very sick and had to be admitted to the hospital as an emergency. I presented myself with the endocrinologist Idelfonso Gonzáles. I told him that my child is in the emergency room and was seriously ill, and that I need him to see my child, because the pediatrician suspects he has CAH, so he went to the emergency room to see my child. When he sees him, the first thing he says to me is: “I’m sure she has CAH, but we have to run some tests, and she is ill because she probably is a salt wasting”.

Then they began to do the tests, including the karyotype, but nobody explained to me what was really happening.

When all the results of the tests arrived, they told me:

“Your daughter has ambiguous genitalia and is sick, because she has CAH 21 hydroxylase, salt wasting. Her clitoris is malformed and we have to operate immediately, otherwise she will develop poorly, with a deformity, and may even suffer from carcinogenic diseases.”

Hearing that, I went crazy, back then I was only 21 years old and I wanted the best for my child.

3 days later they gave us an appointment to schedule the surgery. The surgeon was José Antón. We went to the appointment, and after all the bad things that he told us could happen if my child didn’t get the surgery, we decided to agree to genital surgery.

At 17 months old he was operated for the first time, the doctors performed a clitoral reduction, vaginoplasty and labioplasty.

After 24 months a second intervention followed to redo the labia.

From 2 years old to 12 years old, doctors performed vaginal dilation in the operating room under anesthesia. At first this happened every 6 months, and then every year, with dilators number 20.

All the surgeries were paid in full by the public health care service without further ado.

Not only he was submitted to surgeries, but he was given very high doses of hydrocortisone, that resulted in him developing Cushing Syndrome.

At age 12 he told me: “Mom, I do not want them to touch me anymore, I am a boy”.

When I listened to him, I realized the great madness I had done.

At that time I searched for information and found a psychologist, the best psychologist I could ever find.

We went to the appointment, and from that moment, my son was a boy for me and for the whole world.

At age 14 a mastectomy was performed, that was done because my son asked for it, and was paid only after some struggle by social security.

Now my son is 16 years old. He lost his childhood and part of his adolescence, suffers from psychological problems resulting from the unwanted surgeries, and continues to see the psychologist.

As I type this, my son sits next to me, and we both hope that telling our story will help to ensure that future intersex children and their parents will be protected from having to suffer the same or a similar ordeal as we and particularly he did.

Case Study No. 2

Source: Personal communication and written testimony at <https://brujulaintersexual.org/2015/10/28/como-descubri-que-soy-intersexual-por-olga-mujer-intersexual-espanola-hsc/>

1991 born with ambiguous genitalia, diagnosed with salt-losing Congenital Adrenal Hyperplasia (CAH)

Age 3 partial clitoris amputation

Age 16 vaginoplasty and dilations

Age 21 second vaginal surgery

All surgeries were done at Children's Hospital La Paz, Madrid

The person concerned tells her story:

“At the age of 3 I had to undergo a hernia operation, and the doctors took advantage of it to perform a clitorrectomy. My parents consented, assured them that I would not lose sensitivity, and that it would be in my best interest in the future.”

“And I grew up naive to all this.”

“[My parents] have always worked hard, and although I love them very much and I have a very good relationship with both of them, we never had much communication. [...] I never asked them anything about my “problem”, although every year we went to Madrid to get tested, [...]”

“[The doctor] told me about the vaginoplasty, which I consented to. Since my breasts weren't growing, we agreed to do a mammoplasty as well. So I went into the O. R. for a second time.”

“[The] problem came at the time of the dilations. It hurt a lot, I wasn’t prepared for it, so the doctor said it was best if I didn’t do anything. I came home with my chest, but without a “functional” vagina. I started college, forgetting a little bit about this whole thing.”

“I underwent surgery for the third time, this time doing the appropriate dilations. At first they were painful, I got used to it over time, but they have never, ever been pleasant. Neither was sex. That’s where I started worrying, it had happened so much, for that? And from this I also became more interested in Congenital Adrenal Hyperplasia (CAH), and in short, myself. I started looking for information on the Internet, [...]

“I still don’t see sex as the greatest pleasure of all. I don’t know if it’s the lack of sensitivity due to surgeries, if it’s a psychological problem, or a little of each one. That’s why my search began again, now that I know English, a new world of information has opened up before me. I discovered what it’s like to be intersex (ironic, right? To be something and not know that you are until you’re over 20 years old), I discovered that I wasn’t alone and that there are a lot of people like me, much more than I thought. I discovered that there are people who haven’t been through the surgeries and yet they’re happy, and that made me wonder what it would have been like if I’d never had surgery. Maybe if I had had psychological support, someone explaining what was happening to me, or maybe if I had asked, now it wouldn’t be the way I am now. Maybe I would have decided to be a man, or maybe a woman, or maybe none of that. But I’ll never know. That’s why I ask that babies stop having surgeries, and that they be the ones to choose. I don’t blame my parents for anything, they did what they thought was best and they’ve always been great to me, I love them a lot.”

“I’m sure that if they had respected my body as it was, the sensations would be much better, but it’s still a partial ablation. And I don’t think that having ambiguous genitalia causes problems, as long as the parents know how to carry it as something normal and transmit it to the child and society.”

“Disinformation is a problem, and we have to remedy it!”

Case Study No. 3

Source: Media Interview “Pikara online magazine”
available at <https://brujulaintersexual.org/2017/10/13/soy-lola-y-soy-intersexual/>

*At birth nothing was detected at first, raised as a girl
During adolescence diagnosed with Complete Androgen Insensitivity Syndrome (CAIS)
Removal of testes, hormonal treatment, vaginoplasty*

The person concerned tells her story:

“I grew up being a normal kid, like any other girl. But the conflict came in adolescence. When I turned fourteen I was very worried, all my friends already menstruated and they were totally developed, but I did not. My breasts were small, I was taller than the others, and I had hardly any hair on my armpits or vulva. That’s when Mom took me to the endocrine and the tests started. A few days later we were told that I, who until then had been socialized like any other normal girl, had XY chromosomes, just like a boy.”

“According to doctors I had a syndrome (that of a certain Morris), it is also known as androgen insensitivity (AIS). They told me that there were very few people like me and they gave me an example of a beautiful movie actress, I guess to make me feel better. In short, we didn’t have to worry. According to them, these were the steps that had to be taken: remove the gonads as soon as possible because it is likely that in the future they will develop a tumour,

enlarge the vagina to have normal and pleasant sexual relations, and start to medicate with estrogen (female hormones) for life.”

“It was then when my family and I, totally lost, because of something we had never heard before, found ourselves without more information than what the doctors gave us, and we followed in his footsteps because the word tumour frightened us and we had no other points of view or other families. And just like that, with a few “simple” operations, the problem was solved. But that is, just in case it’s better to keep it secret, don’t let the people around me start to think that I wasn’t a normal girl anymore. It didn’t matter how I felt. You know what the hardest part is, silence. That damn silence that made us live all this as a drama: with anguish, with pain, and the saddest, in loneliness.”

“And so it was, from my adolescence until today. And it turns out that a few years later I began to meet more people like me, with stories similar to mine and with very diverse experiences. People like Mary, who lived sixty years in silence, without saying anything to anyone. Others like Angela, who when she reached adolescence her clitoris grew larger and with the excuse that she had ovarian cancer (it was a lie) she was operated on several times. I also met people like Laia, who was born with fused lips and will have a choice about her body when she grows up. For some, like Gaby, surgery helped them feel better and lead a happy life, but for Leo, who was born with the urethra hole in a different place from the normative one, surgery left multiple scars and eliminated their ability to feel sexual pleasure.”

Case Study No. 4

Source: Interview at <http://20minutos.es/noticia/3066217/0/sara-testimonio-intersexuales/>

Born with ambiguous genitalia

Diagnosed with Partial Androgen Insensitivity Syndrome (PAIS)

Age 2 removal of abdominal testes

Age 4 genital surgery

In her twenties two failed interventions to create a vagina

The person concerned tells her story:

“My parents kept me a secret. So secretly they took it along that years later I realized that my parents erased from their memory the surgical procedures that I underwent as a child. Two years old, they took my testes. When I was four years old I had a second aesthetic intervention.”

“Now I know that there are parents who refuse, but before it was unthinkable not to operate. I wish they hadn’t intervened. It was dramatic and painful. The biggest trauma in my life. Thirty years ago the hospital protocol said that parents could not enter after the intervention to stay with their daughter. And so, when I was two years old, I spent ten days in the hospital, tied to the bed so that it wouldn’t touch me and with my parents on the other side of a glass. Tremendous loneliness.”

“I blame my parents for not defending me enough. Parents of today should know that anaesthetics are more risky if applied to children under five years of age, they should know the pros and cons of these operations and thus assume the risks they take. It is true that before doctors used to scare the parents and told them that it was always necessary to remove the gonads that did not coincide with the assigned sex because there was a high risk of tumorization. It’s as if breast cancer is a risk that all women’s breasts are removed without contemplation.”

“I didn’t know exactly what was happening to me until I was 20. Well, at puberty I was already suspicious, because my period didn’t come and that was something I had to keep in the most absolute of secrets. My body complexed me and I was silent. My first idea was that no one had to know about this. It was during a routine doctor’s visit, at age 20, when the doctor mentioned Androgen Insensitivity Syndrome (AIS) and I went to the vademecum [medical textbook] of my roommate, who was studying medicine, to learn who I was.”

“Then I’d go to Grapsia, to the support group. I had panic at first, but it was a blast... what a feeling of having found a real family, the relief of being able to speak calmly, unmask myself. It is a very special connection that is created with others affected, even more so than with people with whom you have lived a lifetime.”

“When I was in my twenties I voluntarily decided to go through two interventions to build my vagina. [...] But it was a real failure. I don’t even think about it anymore. I don’t want to know anything. [...] Intimate relationships are my workhorse [...].”

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



**HUMAN
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**NGO Report
to the 5th and 6th Periodic Report of Spain
on the Convention on the Rights of the Child (CRC)**