Intersex Genital Mutilations

Human Rights Violations Of Children
With Variations Of Sex Anatomy

HUMAN RIGHTS FOR HERMAPHRODITES TOO!

StopIGM.org

Intersex UK

PROTECT EVERY BODY

UKIA

UK Intersex Association

NGO Report for Session

to the Initial Report of the United Kingdom on the Convention on the Rights of Persons with Disabilities (CRPD)

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Executive Summary

All typical forms of IGM practices are still practised in the United Kingdom today, facilitated and paid for by the State party via the National Health Service (NHS). Parents and children are misinformed, kept in the dark, sworn to secrecy, kept isolated and denied appropriate support.

The United Kingdom is in breach of its obligations under the Convention to **(a)** take the necessary measures, including of legislative nature to **prevent involuntary, non-urgent surgery and other medical treatment** of intersex persons, **(b)** to ensure **access to redress**, and the right to fair and adequate **compensation** and **rehabilitation** for victims, and **(c)** to **provide families with intersex children with adequate counselling and support** (CRPD/C/DEU/CO/1, paras 37-38; CRPD/C/ITA/CO/1, paras 45-46).

This Committee has consistently recognised IGM practices to constitute a serious human rights violation under the Convention in Concluding Observations. In addition, **CRC** has already considered IGM practices in the **UK** as a harmful practice.

Also **CAT**, **CEDAW**, 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 so far issued **26 Concluding Observations on IGM**, typically obliging State parties to enact legislation to **(a)** end the practice and **(b)** ensure redress and compensation, plus **(c)** 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, 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.

IGM practices include **non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other harmful medical procedures based on prejudice** that would not be considered for "normal" children, without evidence of benefit for the children concerned. **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 of artificial hormones, significantly elevated rates of self-harming behaviour and suicidal tendencies, lifelong mental suffering and trauma, increased sexual anxieties, less sexual activity, dissatisfaction with functional and aesthetic results.

This **Thematic NGO Report** has been compiled by intersex NGOs **StopIGM.org / Zwischengeschlecht.org**, **IntersexUK**, **The UK Intersex Association**, and UK intersex advocate **Leslie Jaye**. It contains **Suggested Recommendations** and an Annexe with **10 Case Studies**.

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Table of Contents

A. Introduction

1. Intersex and IGM in the United Kingdom

The United Kingdom of Great Britain and Northern Ireland will be considered for its initial periodic review by the Committee on the Rights of Persons with Disabilities in 2017. Allover the UK, **doctors in public, university and private clinics** are regularly performing **IGM practices**, i.e. non-consensual, medically unnecessary, irreversible cosmetic genital surgeries, sterilising procedures, and other harmful treatments on intersex children, which have been repeatedly **recognised by this Committee** and other **UN bodies** as constituting **violence**, a **violation of the integrity of the person**, a **harmful practice** and **torture or ill-treatment.**

In 2015, **CRC recognised IGM in the UK** as a serious violation. However, to this day the United Kingdom undeviatingly not only does nothing to prevent this abuse, but **continues to directly finance it via the public National Health Service (NHS)** and via funding the public university clinics and paediatric hospitals, thus **violating its duty** to prevent involuntary harmful medical treatment also on intersex children, and to guarantee access to **adequate counselling and consensual needed health care** for intersex people and their families.

To this day the UK Government **refuses to take appropriate legislative, administrative and other measures** to guarantee the full and effective participation of intersex children in society on an equal basis, and **to remove barriers** preventing intersex people and IGM survivors from the full enjoyment of all human rights, including their rights to physical integrity and self-determination, their rights to the best attainable standard of health, and their rights to justice, redress and compensation.

2. About the Rapporteurs

This NGO report has been prepared by the **Intersex NGO Coalition UK:**

- **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 end IGM Practices and other human rights violations perpetrated on intersex people, according to its motto, *"Human Rights for Hermaphrodites, too!"* [1] According to its charter,[2] StopIGM.org works to support persons concerned seeking redress and justice, and regularly reports to UN treaty bodies on IGM practices and has been active in the UK since 2011[3] [4] [5] [6] [7].

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[1] http://Zwischengeschlecht.org/, English pages: http://StopIGM.org/

[2] http://zwischengeschlecht.org/post/Statuten

[3] http://zwischengeschlecht.org/pages/Open-Letter-ISHID-2011-18-09

[4] Margaret Simmonds, "Girls/women in inverted commas – facing 'reality' as an XY-female", PhD Thesis University of Sussex, p. 208 (PDF p. 214), http://sro.sussex.ac.uk/43431/1/Simmonds,_Margaret.pdf

[5] Australian Senate Hearing, 28.03.2013, Testimony G. Ansara, p. 11 (PDF p. 15), http://parlinfo.aph.gov.au/parlInfo/download/committees/commsen/86ba4480-36ef-4e72-b25e-9fa162f9a4ae/toc_pdf/Community%20Affairs%20References%20Committee_2013_03_28_1856_Official.pdf;fileType=application%2Fpdf#search=%22committees/commsen/86ba4480-36ef-4e72-b25e-9fa162f9a4ae/0000%22

[6] http://stop.genitalmutilation.org/public/Open-Letter_I-DSD_2013.pdf

- **IntersexUK (iUK)**, founded in 2011, is an NGO led by UK intersex persons and survivors of IGM practices working to improve the well-being and human rights of intersex persons, and to raise awareness on intersex issues, including in regional and international media. They deliver educational training in universities and political consultancy to public sector bodies, particularly in England and Scotland.[8] [9]
- **The UK Intersex Association (UKIA)**, founded in 2000, is an NGO led by UK intersex persons and survivors of IGM practices working to improve the well-being and human rights of intersex persons, and to raise awareness on intersex issues.[10] [11]
- **Leslie Jaye** is a UK intersex person, survivor of IGM practices and intersex human rights defender working to improve the well-being and human rights of intersex persons, and to raise awareness on intersex issues.[12]

In addition, the Rapporteurs would like to acknowledge the work of the **Androgen Insensitivity Syndrome Support Group UK (AISSG UK)**[13] and **Margaret Simmonds**.[14] We would like to acknowledge the work of **Michel O'Brien**.[15] And we would like to acknowledge the work of **Ellie Magritte**[16] and **dsdfamilies.org**.[17]

3. Methodology

This thematic NGO report is an **update to the PSWG NGO Report** by the same rapporteurs.[18] It includes **10 anonymised personal testimonies of UK survivors of IGM practices** originally compiled for the 2016 CRC UK Thematic Intersex NGO Report by the same Rapporteurs,[19] based on (a) written submissions solicited by the Rapporteurs and ISUK, (b) interviews conducted for this NGO report, and (c) written testimonies available online via AISSG UK[20] and Hypospadias UK[21] (see source given at the end of each testimony). They show in an exemplary manner how different forms IGM are practiced in the UK without informed consent by the persons concerned and/or their parents, and cause **severe physical and mental pain and suffering**.

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[7] http://www.ias.surrey.ac.uk/workshops/intersex/papers/Intersex%20programme%20brochure.pdf

[8] https://www.theguardian.com/world/2016/jul/02/male-and-female-what-is-it-like-to-be-intersex
http://www.independent.co.uk/news/uk/home-news/special-report-intersex-women-speak-out-to-protect-the-next-generation-8974892.html

[9] http://intersexuk.org

[10] https://www.theguardian.com/world/2016/jul/02/male-and-female-what-is-it-like-to-be-intersex
https://www.vice.com/en_uk/read/the-group-campaigning-for-better-intersex-rights

[11] http://ukia.co.uk

[12] http://intersexday.org/en/language-truth-jaye/

[13] http://www.aissg.org/

[14] Margaret Simmonds: 'Girls/women in inverted commas – facing "reality" as an XY-female', University of Sussex 2012, http://sro.sussex.ac.uk/43431/1/Simmonds,_Margaret.pdf

[15] http://oiiinternational.com/653/holistic-for-whom/

[16] http://www.dsdfamilies.org/docs/conf/working_together.pdf

[17] http://www.dsdfamilies.org/

[18] http://intersex.shadowreport.org/public/2017-CRPD-PSWG-UK-NGO-Coalition-Intersex-IGM.doc

[19] http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

[20] http://www.aissg.org/41_STORIES.HTM

[21] http://www.hypospadiasuk.co.uk/life-stories-of-men-with-hypospadias/

B. List of Issues and Replies on Intersex

List of Issues (para 11. (a) + 12.)

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

11. Please provide information on:

(a) How women, children, **intersex people** and elderly persons with disabilities experiencing abuse, ill-treatment, sexual violence and/or exploitation are protected and have access to justice in line with target 16.3 of the Sustainable Development Goals;

[…]

Protecting the integrity of the person (art. 17)

12. Please explain measures to criminalise sterilisation of women and girls with disabilities and **intersex people** by consent of any third party rather than their own free and informed consent.

Replies to LoI (paras 73 + 82-83)

Freedom from exploitation, violence and abuse, Article 16 (issue 11a-c)

73. **(a)** The EA2010 protects people from harassment and victimisations on the basis of gender, age, and gender reassignment. Legal aid supports access to justice, providing legal advice and representation for EA2010 harassment or victimisation cases. Additionally, the Youth Justice and Criminal Evidence Act (1999) states that witnesses considered vulnerable, because they are under 18 years or have a mental or physical disability, are eligible for the assistance of an intermediary. Intermediaries support witnesses to understand the questions asked of them and give their evidence during the police interview and in court.

Protecting the integrity of the person, Article 17 (issue 12)

82. The requirement to obtain valid consent for examination or treatment is a matter of law applicable to all people equally; disability is not sufficient reason to forcibly impose treatment. Consent is central to all forms of healthcare, including treatment leading to sterilisation. For the small minority of people lacking the mental capacity to make their own decisions, UK law allows treatment to be given where it is in their best interests, subject to important safeguards.

83. Scots law does not include a specific criminal offence of forced sterilisation; however, this would amount to an assault under common law (most likely an aggravated assault) and could be prosecuted on that basis.

C. Update on Intersex Genital Mutilations in the UK

1. IGM practices in the UK: Updated Summary of PSWG NGO Report

In the **United Kingdom** (see CRC/C/GBR/CO/5, paras 45-46), same as in *Germany* (CRPD/C/DEU/CO/1, paras 37-38; CAT/C/DEU/CO/5, para 20), *Chile* (CRPD/C/CHL/CO/1, para 41-42), *Italy* (CRPD/C/ITA/CO/1, paras 45-46), *Ireland* (CRC/C/IRL/CO/3-4, paras 39-40), *France* (CEDAW/C/FRA/CO/7-8, paras 17e-f + 18e-f; CRC/C/FRA/CO/5, paras 47-48; CAT/C/FRA/CO/7, paras 32–33**)**, *Switzerland* (CEDAW/C/CHE/CO/4-5, paras 38-39; CRC/C/CHE/CO/2-4, paras 42-43; CAT/C/CHE/CO/7, para 20), and in many more State parties,[22] IGM practices **remain pervasive and unchallenged**. In particular, in the UK there are still

- **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 **UK government** undeviantingly refuses to recognise the human rights violations and suffering caused by IGM practices, let alone to *"take effective legislative, administrative, judicial or other measures"* to protect intersex children.

During the recent **CRC Review** of the UK,[23] Flora Taylor Goldhill (Director for Children, Families and Communities, Department of Health) denied the ongoing practice in the UK constituting a human rights violation (see PSWG NGO Report, p. 10). Also the **(non-)answers to the List of Issues regarding intersex** (see p. 7) underline how the UK government steadfastly **ignores that this is a human rights issue** (see also PSWG NGO Report, p. 13-15).

To this day, as documented in the PSWG NGO Report p. 11-13, in the UK **all forms of IGM practices remain widespread and ongoing**, persistently **advocated, prescribed and perpetrated** by state funded University and public Children's Hospitals, and **advocated and paid for** by the public **National Health Service (NHS)**, despite that CRC criticised IGM in the UK as a serious human rights violation.

2. Additional Recent Evidence of the Ongoing Practice (2016-2017)

a) "Hiding the Clitoris": A new IGM Practice emerging from Britain

"Hiding the Clitoris" is a comparatively new surgical method on the rise in Southern England wherein a cut around an "enlarged" clitoris is made and thereafter the clitoral hood is pulled over the clitoris and sewn close in order to "hide" the "enlarged" clitoris. In clinics where this practice

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[22] See http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations

[23] CRC 72nd Session, 24. May 2016, see transcription: http://stop.genitalmutilation.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-the-Child

is performed, in official statistics it is not listed under clitoral surgery but under "vaginal reconstruction", as doctors argue they would only cut around the clitoris. In fact, in some clinics where doctors distinguish between intersex girls with CAH who had or had not clitoral surgery, all in the group of "no clitoral surgery" still had this new form of "hiding the clitoris" done in infancy.[24] Despite that such a procedure on a "normal" girl would be considered as FGM and illegal in the UK, on "subhuman intersex girls" this practice is not only deemed acceptable but even declared by doctors as mere "vaginal surgery".

b) 2017: Prominent Role of UK NHS Hospitals in International IGM Networks

In 2017, the "European Reference Network" was launched to ensure better treatment for patients with rare diseases within the European Union.[25] 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 Endocrine Conditions" a.k.a. "Endo-ERN"**.[26] Like with earlier international networks led by IGM perpetrators, e.g. "I-DSD",[27] "DSDnet"[28] and "DSD-Life",[29] UK NHS Hospitals are prominently involved.[30]

c) Foreign Intersex Children Sent to UK NHS Hospitals for IGM

According to the "Irish Examiner"[31] paediatricians of the Great Ormond Street Children's Hospital NHS Trust regularly attend "multidisciplinary meetings" at "Our Lady's Crumlin Children's Hospital" in Dublin, Ireland, when "difficult decisions" are made regarding IGM surgery on Irish intersex children, and according to Crumlin paediatrician Dr Colm Costigan, *"for more complicated rare surgeries, 'we send children abroad'"*, arguably to Great Ormond Street. Also Maltese intersex children have traditionally been sent to UK NHS Hospitals for IGM surgery,[32] as was also indirectly confirmed by a Maltese ERN Board of Member States representative highlighting the special Maltese relationship with England and Great Ormond Street.[33]

d) 2017: British Association of Paediatric Urologists (BAPU) and General Medical Council (GMC) admitting to continuing with IGM

On 22.05.2017, BBC Radio 4 aired a moving testimony by IGM survivor Jeanette, who had been submitted to IGM 3 "Gonadectomy" without informed consent, accompanied by interviews and statements of IGM doctors.[34] [35] Regarding Jeanette's testimony, retired paediatric endocrinologist

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[24] Personal communication by UK doctor, June 2017

[25] https://ec.europa.eu/health/sites/health/files/ern/docs/2017_brochure_en.pdf

[26] See http://stop.genitalmutilation.org/post/eUROGEN-EU-funded-Intersex-Genital-Mutilators

[27] See Open Letter to "I-DSD 2013", http://stop.genitalmutilation.org/public/Open-Letter_I-DSD_2013.pdf

[28] See http://stop.genitalmutilation.org/post/DSDnet-Intersex-Genital-Mutilators-European-Union

[29] See http://stop.genitalmutilation.org/post/EU-biggest-funder-of-Intersex-Genital-Mutilation-how-much-longer

[30] The "Open Letter of Concern to 6th I-DSD 2017, DSDnet, eUROGEN, Endo-ERN, DSD-Life and Affiliates" lists 14 NHS Clinics involved in current international IGM projects, see p. 2, http://stop.genitalmutilation.org/public/Open_Letter_I-DSD_Copenhagen_2017.pdf

[31] Irish Examiner, "What happens when a child is born intersex in Ireland?", 04.11.2016, Cover story, p. 7-9

[32] Personal communication by Maltese intersex expert, September 2016

[33] Presentation at 3rd conference on European Reference Networks, 09.03.2017, p. 5+6, https://ec.europa.eu/health/sites/health/files/ern/docs/20170309_rt3_05_dalmas_pres_en.pdf

[34] BBC News: "Intersex patients 'routinely lied to by doctors'", 22.05.2017, video and article, http://www.bbc.com/news/health-39979186

Ieuan Hughes admitted that this was not a singular experience, and further explained:

"These women finding out […] in their early or late adult life, and having been told by the medical profession a pack of lies if you like, and eventually finding out and understandably being incredibly angry with the medical profession and sadly angry with their parents." [36]

"Apparently there had been a couple of examples where patients had been so upset they had taken their own lives – sadly." [37]

Regarding the current practice, **British Association of Paediatric Urologists (BAPU)** president Stuart O'Toole indirectly admitted to the practice still taking place by stating, *"most patients were now managed within a team, with input from specialist surgeons and medics and psychologists. 'The parents of the child are involved at every stage.'"* [38]

And **General Medical Council (GMC)** chief executive Charlie Massey indirectly admitted that doctors would still reserve the right to lie to intersex patients: *"We are clear that doctors should not withhold information from patients, unless they believe that giving it would cause the patient serious harm."* [39]

In addition, current documents on the GMC homepage prove that **all forms of IGM practices continue to be advocated by the General Medical Council**.[40] [41]

e) 2017: Scottish DSD Network (SDSD) admitting to continuing with IGM

In a 2017 video interview[42] also linked to on the Scottish DSD Network (SDSD) homepage under "Useful Links",[43] SDSD lead clinician Dr Miriam Deeny (NHS Scotland) openly admitted to IGM 1 "Masculinising Surgeries" and IGM 2 "Feminising Surgeries" still being regularly perpetrated on Scottish children despite surgery "going wrong" or delivering "poor" results:

"The kids who've got hypospadias, where the little boy has to pee sitting down, they will be operated on. I think because culturally it's very difficult for boys not to pee standing up. That's my understanding. So these cases are all operated on by a handful of surgeons across the UK, including within Scotland, in infancy and prior to the age of two years. It's a two-step operation,

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[35] BBC Radio 4, PM: "How doctors stole my identity", 22.05.2017, http://www.bbc.co.uk/programmes/p053p071

[36] See footnote 35, audio at 2:45

[37] See footnote 34, article

[38] Ibid.

[39] Ibid.

[40] The Intercollegiate Surgical Curriculum, Urology Surgery, ISCP Intercollegiate Surgical Curriculum Programme, approved 06 September 2016: Module 12: Paediatric urology, Topic: Science, hypospadias, p. 110; Topic: Congenital disorders affecting the urinary tract, undescended testes, cryptorchidism, p. 110; Topic: Assessment of children requiring urinary tract reconstruction, Vaginal reconstruction / DSD surgery, p. 113-114; Topic: Assessment and management of boys requiring urethral reconstruction, Hypospadias, repair surgeries, p. 114, http://www.gmc-uk.org/Urology_MASTER_2016.pdf_69511155.pdf

[41] Principles for Blueprinting Assessment to the Curriculum in Surgical Specialties, 03.08.2016, Undescended Testis, p. 2; Disorders of Sex Development (DSD), p. 8; Hypospadias, p. 13, http://www.gmc-uk.org/static/documents/content/Paediatric_Surgery.pdf

[42] Pink Saltire, "Introducing Intersex", 22.03.2017, https://www.youtube.com/watch?v=onRPZEPDoPs **Note:** The Rapporteurs **can NOT endorse this video** as it was made by third party groups without consultation and representation of intersex persons and their organisations, see also below C.4., p. 12

[43] See "Introducing Intersex", http://www.sdsd.scot.nhs.uk/support/

and they’re audited to know that the results are good enough. But I think the intersex people where the surgery has gone wrong, would have a bit of a beef with that, and you can see their point.

The group that we really try not to operate on are the girls with Congenital Adrenal Hyperplasia, so they have a quite male looking external genitalia, but they do much better when they’re big and a bit more tissue and they can buy into themselves than if you operate on them in infancy. And that’s surely been the position within the surgical fraternity in Scotland for all of my working life. But even so, within certain cultural groups they would take the children to a surgeon who would operate on them privately or go to one of the centres in England, and we know from audits of our figures coming through our clinic that the results are really pretty poor, a lot of fistulas, abnormal communications into the bladder and into the rectum, with continence issues. So we really do try hard to counsel the parents against that and we don’t offer the surgery but there’s nothing to stop them from taking the kids out of the country or to another centre.”

f) 2016: University Hospitals Bristol admitting to continuing with IGM

In a 2016 Guardian article, [44] University Hospitals Bristol NHS Foundation Trust paediatric urology surgeons Guy Nicholls and Mark Woodward admit to an defend continuing with involuntary surgeries on intersex children.

Mark Woodward: *“A small group of people who have had surgery and are understandably unhappy will detract from a genuine picture of a whole load of people not being unhappy. It’s tricky to write off surgery on the basis of that.”*

Guy Nicholls: “*Surgery in infancy is more straightforward than later in life, Woodward argues: tissues are easier to operate on and heal better, and the distances to bridge are smaller. Performing an operation before a baby can remember the trauma spares them the distress of going through it as a teenager. Plus, no one has expertise in operating on young people old enough to give informed consent.*”

3. “Inferior”, “Abnormal”, “Deformed”: Intersex Framed as Disability in the UK

Individual doctors, national and international medical bodies, public and private healthcare providers have traditionally been **framing and “treating” intersex variations as a form of disability** in need to be “cured” surgically, often **with racist, eugenic and suprematist undertones**.[45] [46] [47] [48]

Accordingly, also in the UK paediatric doctors frame intersex as “abnormalities”, “problems” and

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[44] The Guardian, “‘We don’t know if your baby’s a boy or a girl’: growing up intersex”, 02.07.2016, https://www.theguardian.com/world/2016/jul/02/male-and-female-what-is-it-like-to-be-intersex

[45] 2014 CRC NGO Report, p. 52, 69, 84

[46] In the WHO “World Atlas of Birth Defects (2nd Edition)”, many intersex diagnoses are listed, including *“indeterminate sex”* and *“hypospadias”:* http://web.archive.org/web/20160305152127/http://prenatal.tv/lecturas/world%20atlas%20of%20birth%20defects.pdf

[47] “The Racist Roots of Intersex Genital Mutilations” http://stop.genitalmutilation.org/post/Racist-Roots-of-Intersex-Genital-Mutilations-IGM

[48] For 500 years of “scientific” prejudice in a nutshell, see 2016 CEDAW France NGO Report, p. 7, http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

"disorders", and by parents as "deformity" and "defect".[49]

What's more, the easier an intersex trait can be tested prenatally, **the higher the (selective) abortion rates**,[50] arguably also in the UK,[51] where in particular most intersex diagnoses are listed as permissible for deselection in State sponsored **Preimplantation Genetic Diagnosis (PGD)** guidelines[52], namely:

- ***46XY Sex Reversal 6***; *Status: approved; OMIM number: 613762*
- ***5 Alpha Reductase Deficiency (5ARD)*** *insofar as that condition affects males, with simultaneous sex determination; Status: approved; OMIM number: 264600*
- ***Androgen Insensitivity Syndrome***; *Status: approved; OMIM number: 300068*
- ***Congenital Adrenal Hyperplasia (21 hydroxylase deficiency)***; *Status: approved; OMIM number: 201910*
- ***Gonadal mosaicism***; *Status: approved; OMIM number: [no number]*
- ***Hypospadias (severe)***; *Status: approved; OMIM number: [no number]*
- ***Partial androgen insensitivity*** *syndrome due to defects in the androgen receptor gene; Status: approved; OMIM number: 312300*
- ***Prader Willi Syndrome***; *Status: approved; OMIM number: 176270*
- ***Smith Lemli Opitz Syndrome (SLO)***; *Status: approved; OMIM number: 270400*
- ***Turner's syndrome (Mosaic)***; *Status: approved; OMIM number: [no number]*

4. Misrepresentation of Intersex as LGBT issue, Misappropriation of Funding

As noted in our PSWG NGO Report (p. 7), intersex persons and their organisations have **spoken out clearly against misrepresenting intersex as an LGBT or SOGI issue**, and in particular **against instrumentalising intersex** as a means to an end by LGBT groups, and **against pinkwashing of IGM** by State parties trying to deflect from criticism of involuntary intersex treatments, 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.**

Nonetheless, the **pervasiveness and persistence** of such harmful misconceptions remains, as illustrated for example in two recent UN press releases misrepresenting IGM as "*sex alignment*

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[49] The Guardian, "'We don't know if your baby's a boy or a girl': growing up intersex", 02.07.2016, https://www.theguardian.com/world/2016/jul/02/male-and-female-what-is-it-like-to-be-intersex

[50] For stats and references, see "Selective Intersex Abortions: XXY 74%, Indeterminate Sex 47%, Hypospadias 2%", http://stop.genitalmutilation.org/post/Selective-Intersex-Abortions-Hypospadias-Intersex-XXY

[51] While there are no statistics available on selective intersex abortions in the UK, it's noteworthy that late term abortion is legal in the UK if "E - there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped: Section 1(1)(d).", see https://www.gpnotebook.co.uk/simplepage.cfm?ID=1449852947

[52] For example in the UK, see https://www.hfea.gov.uk/pgd-conditions/
See also 2014 CRC NGO Report, p. 76, http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

surgeries" (i.e. voluntary procedures on transsexual or transgender persons), and IGM survivors as *"transsexual children"*,[53] and State parties regularly referring to e.g. transgender guidelines[54] or *"Gender Identity Law"* [55] when asked about IGM by e.g. Treaty bodies.

South Africa[56] and **France**[57] are still the only States officially recognising IGM constituting a harmful practice, but so far without enacting legislation accordingly. **Malta**[58] and **Argentina**[59] are still the only countries formally banning IGM, but both without any sanctions or known progress. **Human rights agencies reports regularly fail** to identify the most important applicable human rights frameworks,[60] and only call for legislation regarding *"Gender Identity Registration"* and *"Discrimination"*, but fail to do so in order to end IGM practices and the impunity of the perpetrators and accessories, thus perpetuating the harmful stereotypes, appropriation and colonisation of intersex politics, and erasure of IGM and IGM survivors and their legitimate concerns and demands.[61] [62]

A current UK example of **LGBT groups talking for intersex persons and their organisations without consultation or representation** is the Scottish Pink Saltire Video "Introducing Intersex"[63] also promoted by the Scottish DSD Network,[64] which was financed by the Scottish Lottery Fund,[65] and in which intersex is "introduced" and explained exclusively by non-intersex persons and organisations including Pink Saltire, Equality Network Scotland, and the Scottish DSD Network, while intersex persons and their organisations were neither consulted nor represented.

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[53] For relevant excerpts and references, see http://stop.genitalmutilation.org/post/UN-Press-Release-calls-IGM-survivors-transsexual-children-CATArgentina-UNCAT60

[54] CAT56 Austria, see http://stop.genitalmutilation.org/post/Geneva-UN-Committee-against-Torture-questions-Austria-over-Intersex-Genital-Mutilations

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

[56] CRC74 Constructive dialogue, unofficial transcript: http://stop.genitalmutilation.org/post/LIVE-South-Africa-Questioned-Over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-the-Child
See also Mail & Guardian (27.10.2016), https://mg.co.za/article/2016-10-27-00-sa-joins-the-global-fight-to-stop-unnecessary-genital-surgery-on-intersex-babies/

[57] See http://stop.genitalmutilation.org/post/France-condemns-mutilations-of-intersex-children-proposes-prohibition

[58] See http://stop.genitalmutilation.org/post/Intersex-politics-that-ignore-the-daily-mutilations-PINKWASHING-OF-IGM-PRACTICES

[59] See 2017 CAT Argentina NGO Report, p. 10, 13–14, http://intersex.shadowreport.org/public/2017-CAT-Justicia-Intersex-Zwischengeschlecht-IGM.pdf

[60] See submission to SR-Disability, p. 5-6, http://intersex.shadowreport.org/public/2017-SR-Disability-Submission-Intersex-IGM-V2.doc

[61] 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
See also http://stop.genitalmutilation.org/post/IDAHOT-2015-Let-s-Talk-About-Intersex-Appropriation

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

[63] Pink Saltire, "Introducing Intersex", 22.03.2017, https://www.youtube.com/watch?v=onRPZEPDoPs **Note:** The Rapporteurs **can NOT endorse this video** as it was made by third party groups without consultation and representation of intersex persons and their organisations.

[64] See "Introducing Intersex", http://www.sdsd.scot.nhs.uk/support/

[65] See https://pinksaltire.com/2016/10/08/do-you-know-what-the-i-means/

So far Scotland is the only UK country with a budget for funding **intersex awareness raising** with at least "£135,000 for intersex work", however **paid out exclusively to LGBT organisations**. [66] [67]

So unfortunately while the Scottish Government and the Scottish political parties publicly strive to address *"specific intersex-related equality and human rights concerns"*,[68] in fact they only do so regarding issues marginal to most intersex people like e.g. *"hate crimes against non-binary or intersex people"* [69] and *"update[ing] the Gender Recognition Act 2004 […] to alter the law to make better provisions for […] specifically non-binary and intersex people"*,[70] regarding the main issue of IGM they steadfastly **keep funding and supporting the doctors and clinics responsible for continuing the practice**.

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[66] *"Equality Network funding includes £600,000 for the work of Scottish Trans, representing an increase of 53% on previous funding, and in recognition of the huge increase in demand for trans services, including a Scottish Government gender recognition consultation expected in the Autumn, as well as £135,000 for intersex work."*, see Pink Saltire, "Big Four LGBT Charities in Government Funding Windfall", https://pinksaltire.com/2017/06/28/big-four-lgbt-charities-in-government-funding-windfall/

[67] See also £45,000 for "intersex project" paid out to Equality Network, http://www.gov.scot/Topics/People/Equality/Funding/funding/EqualityFunding

[68] https://beta.gov.scot/policies/equality/lgbti/

[69] https://pinksaltire.com/2017/06/10/scots-lgbt-hate-crime-reaches-new-high/

[70] https://pinksaltire.com/2016/09/01/nhs-under-strain-as-gender-identity-demand-surges/

D. Recommendations

The Rapporteurs respectfully suggest that, with respect to the treatment of intersex persons in the United Kingdom, the Committee includes the following measures in their recommendations to the UK Government (in line with this Committee's previous recommendations on intersex persons, and with CRC's previous recommendations on IGM practices to the UK).

Intersex persons (art. 16, 17)

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, the lack of redress, compensation and rehabilitation in such cases, and the lack of implementation of the 2015 recommendations CRC/C/GBR/CO/5, paras 46-47.

The Committee recommends that the State party take the necessary measures, including of a legislative nature to implement all the recommendations of CRC/C/GBR/CO/5, para 47 relevant to intersex children, to:

(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 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 interdisciplinary working groups established to review these procedures, as well as in all matters concerning them.

Annexe 1 “UK Case Studies”

Case Study No. 1

Source: Written submission, interview.

Born 1963, presenting as male. After adrenal crisis diagnosed with CAH.

1966 initial reduction of clitoris at three.

1967 clitoris completely amputated before fourth birthday at Great Ormond Street Hospital for Children (GOSH).

Remembers being led in to a room, students standing in a row at the wall, staring at their shoes while she is told to stand on a table and undress.

1978 start of several exploratory surgeries to explore the internal reproductive layout.

1980 attempt to create a neo-vagina at 17 led by Sir Jack Dewhurst at Chelsea Westminster Hospital. Announced as „minor correction“ due before 18 to be paid for, the neo-vagina broke down as a consequence of not being sterile, leading to septicemia and 5 days in coma, followed by repair surgery a few weeks later.

Pre 2012, after discovering her GOSH patient number in her GP's notes, files subject access request to obtain medical records. GOSH first denies her ever having been a patient. Then says records are archived in microfilm cabinet. In September 2012, after repeated written complaints, GOSH apologises for not being able to find the records, and officially registers them as lost.

> *“I do not, and never have had a functional vagina, and nor do I have anything that could be described as a clitoris. I do have severe scarring in my groin, which gives me great pain almost every day.”*
>
> *“I have suffered a lifetime with flashbacks and nightmares about my experiences at Great Ormond Street, and the physical mutilations my body has suffered as a consequence of being born intersex. I have a formal diagnosis of PTSD in my GP’s notes, and have struggled with bouts of depression at points in my life.”*

Case Study No. 2

Source: Written submission, interview.

Born 1966 at a private hospital in the UK with abdominal testes and a micropenis with hypospadias. Transferred to a general NHS hospital in Glasgow, and after that to another General Hospital in Manchester. Doctors unsure about sex, further tests revealed male chromosomes. Later diagnosed with 5 Alpha Reductase Deficiency.

Feminising surgery during first months on penis and scrotum, removal of testes.

1976 vaginoplasty at 10. Then refused any further surgery and the prescribed hormones.

In 1997, at age 19, decides to live as man and seeks reconstructive surgery.

Soon after he had a road traffic accident, which he survived severely hurt, but is in a wheelchair since that day.

His medical records contain information about the accident, but all documents concerning intersex treatment are gone.

> *“My family objected [to feminising surgery], but were advised that my life would be a living nightmare if I grew up looking so different. It wasn't possible (or so they were told) to make me look like a ‘normal boy’ so the best thing would be to make me look like a girl (on the outside). I wouldn't remember the operation nor have any idea that I was male, so would grow up a happy, well-adjusted girl. The ‘only’ drawback was that I would be infertile.”*
>
> *“Some surgery was performed in the first months of life to ‘reduce’ my penis to resemble a clitoris and my scrotum split open and sutured to resemble labia. Later, one testicle was found in my groin and surgically removed (and in my case, my fertility). I had ultrasound tests and some abdominal surgery in order to find the second gonad, but this was unsuccessful. Following the surgeries, my health was poor due to what was to be a long legacy of [urethral tract] infections.”*
>
> *“When I first attended school, I had problems due to repeated genital and renal infections. For my first day in school I had to wear incontinence pants, [...].”*
>
> *“Concurrent with attending school I spent years attending hospital being prodded and poked by medics whilst a spotlight was shone on me and being made to feel like a specimen on a slab.”*

Case Study No. 3

Source: Written submission.

Born 1969 in Portsmouth, England, classified and raised as a girl.

1976 referred to Chelsea Hospital for Women in London because of abdominal pain. Professor Sir John Dewhurst diagnosis CAIS, tells parents “ovaries” have to be removed or she would die of cancer. Parents consent to surgery.

Ashamed of body after surgery, sexually abused by teenager at the age of 8.

1981 start of „hormone replacement therapy“. Drinking alcohol at 12, taking drugs from age 14. Mother leaves the family in 1983, two suicide attempts.

1994 discovers truth about gonadectomy. Psychotherapies, in recovery from addiction for 14 years, meets other intersex person in her forties.

Still suffering from trauma, afraid of hospitals, nightmares before going to the doctor. Currently on anti-depressants for anxiety and low mood.

> *“He [Dewhurst] told my parents and I that I am a "special little girl" [...]. He said I was lucky to be diagnosed [...] (implying that other girls died from it).”*
>
> *“Our family saw Dr Dewhurst as a God-like "saviour" figure and my parents went along with whatever he wanted from then on- as he had "saved" their little girl's life. [They] compl[ied] with his wish to see me in London every 6 months, ostensibly to check on my progress, in reality, not medically unnecessary. Although I believed these visits were to make sure the cancer wasn't active. [H]e would have between 8-15 medical students, who would all gather around my bed and examine my body- whilst he talked about me, as an interesting, rare & special specimen.”*
>
> *“[Later] I went to see a male gynaecologist who told me I had a small vagina and no womb and probably wouldn't grow public hair. He sent me home with an NHS kit of dildos- small to large; and told me to insert them every day. I felt so ashamed and embarrassed I threw them in the bin. I stopped doing sport at school as I didn't have periods and no pubic hair growing; and absolutely no support structure.”*

Case Study No. 4

Source: Written submission.

Born 1984 at Edinburgh Western General Hospital, classified and raised as girl.

1987 referred to Edinburgh Sick Kids Hospital for routine hernia operation, where the doctors found abdominal testes and removed them without consulting the parents first.

Diagnosis „Testicular Feminisation“ was later changed to „Partial Androgen Insensitivity Syndrome“, and finally to „Intersex“.

1992 surgery to lengthen the vagina.

1994 (age 10) parents tell her that she cannot have children, but there is no counselling from constultant of Edinburgh Sick Kids Hospital.

1998 (age 14) learns she had been born with testes.

> *“[A]s my Mother awaited me coming out of surgery, the surgeon approached her and told her that whilst they were operating, they had discovered two internal undescended testes, and had removed them due to an alleged cancer risk. This was done with absolutely no consent from anyone, informed or otherwise, from either my parents or (obviously) myself - as I was three. The Surgeon who operated on myself informed my Mother about this in a hospital waiting room with around three or four people sitting nearby, who heard everything. She became rather upset and began crying.”*
>
> *“My parents continued to raise me as a girl, and a later operation were scheduled, without my consent, at the age of eight, to lengthen the vagina. I can remember all of my hospital stays vividly, and the first one in particular was horrendous. To say that I was only three, my memory of it was surprisingly vivid, as I screamed in terror, cried, and retched as the doctors attempted to administer the old-fashioned style of anaesthetic, with a mouth piece. To this day that hideous smell haunts me, the very memory of this incident sickens and upsets me.”*

Case Study No. 5

Source: Written submission.

Born 1988 in Leamington Spa England with a Cloacal Exstrophy, no visible genitalia, sex unknown. Given a boy's name. Later transferred to Birmingham Children's Hospital for first emergency surgery to close abdomen.

At ten months old first appointment with urologist of Great Ormond Street Hospital for Children (GOSH) in London to perform surgery to close abdomen and pelvis. Urologist persuades parents to also perform feminising surgery and to remove reproductive organs to avoid cancer risk.

Around 18 months surgery to close abdomen and pelvis, removal of reproductive organs. No further genital surgeries were performed. Raised as a girl.

1992 mother tells him that he originally was a boy. Growing up confused, always feeling like a boy.

„Hormone replacement therapy“ during teenage years. Depression, suicide attempts, self harm.

Later in life routine chromosome test reveals XY chromosomes. Obtained medical records show that healthy testes were removed during childhood.

> *“[When the consultant urologist at GOSH explained] my parents should raise me as a girl, naturally*

> *they immediately dismissed his idea, they had had a little boy for almost a year, so where was the sense in changing that now. The consultant sat them down and explained that babies born with Cloacal Exstrophy were almost always raised female as being raised male had a massive detrimental effect on the physical and emotional wellbeing of the child."*
>
> *"He went on to explain that as a male I wouldn't have a penis and that the psychological effect would lead to depression and maybe even suicide and that surgically reconstructing a penis wasn't viable. He explained that as a female he could construct a vagina and that with the right hormones I would grow up like any other little girl."*
>
> *"Some soul searching later and my parents decided, that, if my life would be so much more difficult as a boy then raising me as a girl was the only option. They were told to pick a day to make the transition, they chose my first birthday. The night before my birthday they put me to bed then began changing all of my clothes from blue to pink [...]."*
>
> *"Unfortunately there are many cases of Cloacal Exstrophy males who have been castrated and raised female, it was and still is depending on where you are born the standard practice of care."*
>
> *"Though it is too late to fix the damage of the past, it is vital that we protect these children in the future."*

Case Study No. 6

Source: Written submission.

Born 1991 at the Sandwell Hospital, West Midlands, UK, classified and raised as girl.

1996 at the age of five referred to Birmingham Children's Hospital for surgery to fix a hernia. Doctors find an abdominal testis and performed a biopsy. Parents are coerced to make the decision to perform a gonadectomy to avoid high cancer risk. Both testes removed during another surgical procedure shortly after.

2002 at 11 told about her diagnosis, start of „hormone replacement therapy“. Finally also had to deal with a doctor without any knowledge about her condition, which prescribed hormonal medication detrimental to bone health, leading to low bone density. Today on the correct medication, but has to pay up monthly for two separate forms of medication for the rest of her life. Recently been diagnosed with Generalised Anxiety Disorder and moderate to severe depression.

> *"One vivid memory is when I was roughly about 7 or 8 years old, I remember feeling cornered in a room of around 8 adults. I felt on display for some kind of exhibition which I had no idea was about. I was asked questions by doctors, nurses and medical students, but I remember feeling unbelievably anxious and shy and I simply could not speak. At this point, I was asked to leave while the adults talked about my health, something I was kept in the dark about. I knew there was something wrong with me, but I was always told by professionals that it was "just a check-up for your hernia"."*
>
> *"I went for annual check-ups in order for Dr. Kirk to review my progress with regards to pubescent changes, particularly breast growth. [...] [I]t felt wrong that I had to sit there while he examined closely and touched my breasts. When I was around 14, I was referred to Birmingham Women's Hospital. Mrs Blunt, the specialist I was in contact with at this time, was helpful and seemed to know quite a lot about my individual case. However, I remember having to have the length of my vagina examined, which was measured by Mrs Blunt penetrating a finger inside of my vaginal opening. [...] I was prescribed with dilators to stretch my vaginal opening so that I could have sexual intercourse in the future."*

> *“[I] was persuaded not to tell anyone about my condition because nobody would accept me for the way I am. [...] I was never offered any form of psychological support, and [...] my parents found it difficult and uncomfortable to talk about. [...] I used to sit in my room and sometimes self-harm, feeling suicidal.”*

> *“Since reaching out to support networks on social networking sites that I found by myself, I feel so much more accepting of myself and realise that I’m not as abnormal and alone as first believed. In hindsight, I wish that my family and I were provided with more informative, psychological support to allow an autonomous decision with regards to life-changing surgery and other aspects.”*

Case Study No. 7

Source: http://www.aissg.org/stories/sophia.htm

Born 1964, diagnosed with 5-alpha reductase deficiency.

Hypospadias repair at age of 18 months.

Learning about her diagnosis in her forties.

Later in life, after many painful complications, opting for feminising surgery.

Angry about parent's and doctor's mismanagement, and about secrecy.

> *“I describe myself as someone who was the victim of a misinformed medical profession and a conformity obsessed society. The problem is not one of "social interactions" or "sexology". The problem with me was being born with a metabolic condition that has symptoms people were all confused about. I never felt like a "little girl" or a "little boy". It was at an early age I just became numb to such notions. I actually thought the rest of the world was pathologically obsessed. I was sort of living in some nightmare populated by blank eyed zombies who saw nothing other than "sex" and "gender". And let's be honest here, was that the sort of thing a child should have to put up with?”*

> *“My body is still a mess with numerous scars, my mind is also scarred by what happened to me as a child.”*

Case Study No. 8

Source: http://www.aissg.org/stories/sam.htm

Born 1985, diagnosed with PAIS, gonadectomy at 18 months old, vaginoplasty at 1 ½ years old.

Under doctors' care at UCLH (Elizabeth Garrett Anderson Hospital) since about 14 or 15 years old.

In 2004 another surgery is performed to correct the poor results of the vaginal surgery as a toddler, with disastrous outcome: unable to place the vaginal opening where planned, the surgeons proceeded anyway. Complications, urethral problems, severe pain, also in the abdomen due to repeated laparoscopic examinations, followed by a bad infection, and a 4-5 month healing process.

The result is a ring of large scars, dilation doesn't work because of scaring, the vagina shrinks again.

Later another vaginoplasty is performed in Brazil, with better results, but still leaving the traces of the other surgeries on the exterior.

> *“Due to my anatomy downstairs they put the vagina where my perineum [area between labia/vulva and anus] once was, and in my opinion too far back and behind my vulva lips. It literally looked like I had*

> *sat on a metal fence spike and it was an injury!"*

Case Study No. 9

Source: http://www.aissg.org/stories/liam.htm

Born 1986 with hypospadias, hypospadias „repair" surgery during childhood, discovers to have PAIS and hypospadias over the internet at the age of 25. The trigger was a psychotic episode and him starting to think he was a woman, and an admission to a psychiatric hospital. Suffers from psychosocial problems and incontinence.

> *"It was amazing, life changing, life affirming when the truth has finally come out. I've been admitted to a physchiatric hospital for psychosis and I'm now in a theraputic community in Scotland (...). I've never known that I had a defect at birth and not until I had my psychotic episode did I start to think I was a woman. Since then I've asked my dad (a GP) about it and my mum - but it became obvious that they weren't telling me what was going on; it's only till I typed in my symptoms to a google search did I find out about all the information firstly about hypospadias and then about Partial AIS and CAIS - when I did this 4 hours ago everything clicked into place and the relief of the truth came out. I'm writing to you because I fear that I may never get to meet any other sufferers or come to the meeting annual because of the cloak of deceipt that has been around me since my conscience and because of the lack of trust of those around me: and fear too partly because of psychosis."*

> *"None of the medical professionals have been honest about [having hypospadias], and I would also like to get a full copy of my medical records now that I feel I'm in a position so that it will not affect my mental health so that I can see exactly what went on."*

Case Study No. 10

Source: 48 years old in the UK, http://www.hypospadiasuk.co.uk/life-stories-of-men-with-hypospadias/

Three-stage surgery between age 3 and 5 at Great Ormond Street Hospital for Children (GOSH) in London, surgery seemingly successful.

Discharged from aftercare at age 7.

During adolescence problems become more obvious, but unable to talk to parents or doctor about it. Years after the first complications, a diverticulum (sort of pocket our pouch off the urethra, where urine collected) developed, causing frequent pain and tendency to empty urine later, causing embarassement.

Physical problems getting worse in his 30s and 40s, stone in diverticulum, chronic urinary tract infections.

In 2007 finally seeking medical advice, GP's refers him immediately to consultant urologist at Guy's Hospital, which refers him to specialist at UCLH. Two-stage repair surgery followed to remove stone and diverticulum and rebuild urehtra.

> *"I feel much better, both physically and personally. Physically, because I realise that the stone had been causing me a lot of low-level, chronic infections which were making me feel generally unwell. It was also quite uncomfortable during sex. Personally, because I have finally faced up to my "dark secret" and done something about it. It's hard to describe how great this feels – it's like a big weight being taken off my shoulders. Anyone who's gone through similar experiences will understand."*

> *"I've had tremendous support from a couple of other men with HS whom I met through the old Yahoo groups. It was this experience, of meeting "sufferers", that initiated the whole process of being able to*

face up to my HS, tell my partner about it and seek medical advice."

"I've received very little information about what was going to happen to me, and absolutely no counselling whatsoever. I've been badly handled by incompetent hospital administrations who have routinely cocked up appointments, and then don't understand when I get angry or upset. There is absolutely no recognition of the fact that it's hard for a man to deal with issues relating to his genitals; you're expected to breeze through it exactly as you would if you were having your tonsils removed."

"I've been told now that anyone who had HS surgery in infancy is very likely to need a further repair in adulthood – but I had never heard that before. If that was more widely known, I would have consulted a doctor years ago, and saved myself a lot of unhappiness. I also think that any surgery which involves a man's genitals should be accompanied by some form of pre- and post-operative counselling."