

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



NGO Report (for Session)
to the 8th Report of the United Kingdom
on the Convention on the Elimination of
All Forms of Discrimination against Women (CEDAW)

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Executive Summary

All typical forms of IGM practices are still widespread in the United Kingdom today, facilitated and paid for by the State party via the National Health Service (NHS), with statistics indicating about 2,900 involuntary, non-urgent interventions practiced annually.

The United Kingdom is in breach of its obligations under the Convention on the Elimination of All Forms of Discrimination against Women to (a) take effective legislative, administrative, judicial or other measures to prevent involuntary, non-urgent surgery and other medical treatment and harmful practices of intersex persons based on prejudice, and (b) to ensure access to redress, and the right to fair and adequate compensation and rehabilitation for victims (CEDAW Arts. 1 and 5(a), General Recommendations No. 19 and 31).

This Committee has repeatedly recognised IGM practices to constitute a harmful practice, and called for legislation to (a) end the practice, (b) ensure redress and compensation, and (c) to provide access to free counselling (e.g. CEDAW/C/FRA/CO/7-8, paras 18e-f+19e-f; CEDAW/C/CHE/CO/4-5, paras 24-25, 38-39; CEDAW/C/DEU/CO/7-8, paras 23-24; CEDAW/C/MEX/CO/9, para 21-22; CEDAW/C/NPL/CO/6, paras 18(c)-19(c)).

In addition, CRC has already considered IGM in the UK as a harmful practice, referring to the CEDAW-CRC Joint General Comment/Recommendation No. 31/18 (CRC/C/GBR/CO/5, paras 46-47) and CRPD as a violation of the integrity (CRPD/C/GBR/CO/1, paras 10(a)-11(a), 38-41). Also CAT, CCPR, SR Torture, SR Violence against Women, SRSV Violence against Children, UNHCHR, the Council of Europe (COE), the Inter-American Commission on Human Rights (IACHR), the African Commission on Human and Peoples' Rights (ACHPR) and the World Health Organisation (WHO) recognise IGM practices as a serious violation of non-derogable human rights, calling for legislative remedy and access to redress and justice.

Intersex people are born with Variations of Reproductive 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 treatments that would not be considered for “normal” children, without evidence of benefit for the children concerned, but justified by societal and cultural norms and beliefs. 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 IntersexUK, The UK Intersex Association and StopIGM.org. It contains Suggested Recommendations (p. 20).

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A. Introduction

1. Intersex and IGM in the United Kingdom

The United Kingdom has been reviewed by **CRC** (2016), and **CRPD** (2017), with both Committees **recognising** IGM in the UK as constituting a **harmful practice, cruel, inhuman or degrading treatment**, and a **violation of integrity**.

In countries all over the world, **UN treaty bodies including CEDAW** are regularly denouncing IGM as a **harmful practice** and a **serious violation of non-derogable human rights**.^{1 2}

Nonetheless, the **UK fails to recognise the serious nature** of the violations constituted by IGM practices, and **fails to undertake effective measures**, including legislation, to protect intersex children from the daily mutilations.

To this day the United Kingdom 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 non-derogable duty** to prevent inhuman treatment of intersex children, to guarantee access to **justice, redress and compensation** to IGM survivors, as well as access to **adequate counselling and consensual needed health care** for intersex people and their families.

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!”*³ According to its charter,⁴ StopIGM.org works to support persons concerned seeking redress and justice, and regularly reports to UN treaty bodies on IGM practices. StopIGM.org has been active in the UK since 2011^{5 6 7 8 9}.

1 Currently there are **38 UN Treaty body Concluding Observations** explicitly condemning IGM practices as a **serious violation of non-derogable human rights**, see:

<http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations>

2 **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>

3 <http://Zwischengeschlecht.org/>, English pages: <http://stop.genitalmutilation.org/>

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

5 <http://zwischengeschlecht.org/pages/Open-Letter-ISHID-2011-18-09>

6 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

7 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

8 http://stop.genitalmutilation.org/public/Open-Letter_I-DSD_2013.pdf

9 <http://www.ias.surrey.ac.uk/workshops/intersex/papers/Intersex%20programme%20brochure.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.^{10 11}
- **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.^{12 13}

In addition, the Rapporteurs would like to acknowledge the work of the **Androgen Insensitivity Syndrome Support Group UK (AISSG UK)**¹⁴ and **Margaret Simmonds**.¹⁵ We would like to acknowledge the work of **Leslie Jaye**¹⁶ and of **Michel O’Brien**.¹⁷ We would like to acknowledge the work of **Ellie Magritte**¹⁸ and **d sdfamilies.org**.¹⁹ And we would like to acknowledge the work of Daniela Crocetti, Surya Monro, and Tray Yeadon-Lee with Fae Garland and Mitch Travis at the University of Huddersfield’s **Intersex/DSD Human Rights, Citizenship and Democracy [EUCIT] Project**.²⁰

10 <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>

11 <http://intersexuk.org>

12 <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

13 <http://ukia.co.uk>

14 <http://www.aissg.org/>

15 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

16 <https://intersexday.org/en/language-truth-jaye/>

17 <http://oiiinternational.com/653/holistic-for-whom/>

18 http://www.dsdfamilies.org/docs/conf/working_together.pdf

19 <http://www.dsdfamilies.org/>

20 https://research.hud.ac.uk/institutes-centres/ccid/projects/intersex-dsd_human_rights/

3. Methodology

This thematic NGO report is an update to the **2018 CEDAW UK PSWG NGO Report**.²¹ It is in part based on the **2016 CRC UK NGO Report**,²² the **2017 CRPD UK PSWG NGO Report**,²³ and the **2017 CRPD UK NGO Report**²⁴ the by the same rapporteurs.

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,²⁵ based on (a) written submissions solicited by the Rapporteurs and IntersexUK, (b) interviews conducted for this NGO report, and (c) written testimonies available online via AISSG UK²⁶ and Hypospadias UK²⁷ (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**.

21 <http://intersex.shadowreport.org/public/2018-CEDAW-PSWG-UK-NGO-Coalition-Intersex-IGM.pdf>

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

23 <http://intersex.shadowreport.org/public/2017-CRPD-PSWG-UK-NGO-Coalition-Intersex-IGM.pdf>

24 <http://intersex.shadowreport.org/public/2017-CRPD-UK-NGO-Coalition-Intersex-IGM.pdf>

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

26 http://www.aissg.org/41_STORIES.HTM

27 <http://www.hypospadiasuk.co.uk/life-stories-of-men-with-hypospadias/>

B. Precedents

1. List of issues on Intersex (CEDAW/C/GBR/Q/8, 8)

Discriminatory gender stereotypes and harmful practices

[...]

8. *The report indicates that in 2015 the State party introduced a number of provisions to strengthen the Female Genital Mutilation Act in order to help break down barriers to prosecution (para. 183). Please provide information on the extent to which these changes to the law have facilitated the prosecution of female genital mutilation cases in the State party. What progress has been made following the introduction of a mandatory reporting duty, which requires regulated health-care and social-care professionals, as well as teachers, to report to the police all “known” cases of female genital mutilation in girls under the age of 18 years? Please provide information on the progress made to provide medical and psychosocial support to women and girls who are victims of female genital mutilation. **Please provide data on the number of surgical and other procedures that have been undertaken on intersex children under the age of 18 years in the State party.***

2. Reply to the List of issues on Intersex (CEDAW/C/GBR/Q/8/Add.1, para 46)

Discriminatory gender stereotypes and harmful practices

[...]

46. *Issues faced by people who are living with variant sex characteristics is an emerging policy area for Government. UK Government has announced its intention to publish a call for evidence on these issues. The evidence gathered from this exercise will inform the Government’s next steps in this area. UK Government is aware of some calls from the sector to ban the practice of medical interventions on minor’s sex characteristics.*

C. Non-derogable Protections denied: The Misrepresentation of IGM as “LGBT” or “Health Care” Issue

1. Intersex is NOT THE SAME as LGBT or SOGI

Unfortunately, there are often interrelated **harmful misconceptions about intersex** still prevailing in public, with often **serious legal consequences**, notably if intersex is falsely labelled as being the same as or a subset of LGBT or SOGI, e.g. if intersex and/or intersex status are **misrepresented as a sexual orientation** (like gay or lesbian), and/or as a **gender identity**, as a subset of **transgender**, as the same as **transsexuality**.

The underlying reasons for such harmful misconceptions include **lack of awareness**, third party groups **instrumentalising intersex as a means to an end**^{28 29} 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 or misrepresenting intersex issues,³⁰ 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**.

Also **human rights experts** are increasingly warning of the **harmful conflation** of intersex and LGBT.³¹

Particularly **State parties** are constantly **misrepresenting intersex and IGM as sexual orientation or gender identity issues** in an attempt to **deflect from criticism** of the serious human rights violations resulting from IGM practices, instead referring to e.g. “*gender reassignment surgery*” (i.e. voluntary procedures on transsexual or transgender persons) and “*gender assignment surgery for children*”,³² “*a special provision on sexual orientation and gender identity*”, “*civil registry*” and “*sexual reassignment surgery*”³³, transgender guidelines³⁴ or “*Gender Identity*”^{35 36} when asked about IGM by e.g. Treaty bodies.

Regrettably, **these 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),

28 CRC67 Denmark, <http://stop.genitalmutilation.org/post/CRC67-Intersex-children-used-as-cannon-fodder-LGBT-Denmark>

29 CEDAW66 Ukraine, <http://stop.genitalmutilation.org/post/Ukraine-Instrumentalising-Intersex-and-IGM-for-LGBT-and-Gender-Politics>

30 For references, see 2016 CEDAW France NGO Report, p. 45. <http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

31 For example ACHPR Commissioner Lawrence Murugu Mute (Kenya), see <http://stop.genitalmutilation.org/post/ACHPR-African-Commissioner-warns-Stop-conflating-intersex-and-LGBT>

32 CRC73 New Zealand, <http://stop.genitalmutilation.org/post/NZ-to-be-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-the-Child>

33 CCPR120 Switzerland, <http://stop.genitalmutilation.org/post/Pinkwashing-of-Intersex-Genital-Mutilations-at-the-UN-CCPR120>

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

35 CAT60 Argentina, <http://stop.genitalmutilation.org/post/CAT60-Argentina-to-be-Questioned-on-Intersex-Genital-Mutilation-by-UN-Committee-against-Torture>

36 CRPD18 UK, <http://stop.genitalmutilation.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD>

IGM survivors as “*transsexual children*”, and intersex NGOs as “*a group of lesbians, gays, bisexuals, transgender and intersex victims of discrimination*”,³⁷ and again IGM survivors as “*transgender children*”,³⁸ “*transsexual children who underwent difficult treatments and surgeries*”, and IGM as a form of “*discrimination against transgender and intersex children*”³⁹ and as “*sex assignment surgery*” while referring to “*access to gender reassignment-related treatments*”.⁴⁰

What’s more, **LGBT organisations** (including “LGBTI” organisations without actual intersex representation or advocacy) are using the ubiquitous misrepresentation of intersex = LGBT to **misappropriate intersex funding**, thus depriving actual intersex organisations (which mostly have no significant funding or public representation, if any) of much needed resources.⁴¹

On a **legislative level**, the wilful misrepresentation of intersex as a LGBT or gender issue inevitably perpetuates the **denial of intersex children’s non-derogable rights**, including the right to **protection from inhuman treatment**, genital mutilation or involuntary sterilising procedures, and the **right to justice, redress and compensation** of those submitted to such harmful medical practices.

2. 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**^{42 43 44} – instead of effective measures to finally end the practice (as repeatedly stipulated also by this Committee).

Even worse, **Health** ministries construe UN Treaty body Concluding Observations falling short of explicitly recommending legislation to criminalise or adequately sanction IGM as an **excuse for “self-regulation” promoting state-sponsored IGM practices to continue with impunity**.⁴⁵

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

38 CRC77 Spain, <http://stop.genitalmutilation.org/post/UN-Press-Release-mentions-genital-mutilation-of-intersex-children>

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

40 CAT/C/DNK/QPR/8, para 32

41 For example in Scotland (UK), LGBT organisations have so far collected at least £ 135,000.– public intersex funding, while actual intersex organisations received ZERO public funding, see 2017 CRPD UK NGO Report, p. 14, <http://intersex.shadowreport.org/public/2017-CRPD-UK-NGO-Coalition-Intersex-IGM.pdf>

Typically, during the interactive dialogue with CRPD, the UK delegation nonetheless tried to sell this glaring misappropriation as “supporting intersex people”, but fortunately got called out on this by the Committee, see transcript (Session 2, 10:53h + 11:47h), <http://stop.genitalmutilation.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD>

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

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

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

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

D. 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, CRPD/C/GBR/CO/1, paras 10(a)-11(a), 38-41), same as in *Germany* (CEDAW/C/DEU/CO/7-8, paras 23-24; CAT/C/DEU/CO/5, para 20; CRPD/C/DEU/CO/1, paras 37-38), *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**,⁴⁶ 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**
- **no measures** in place to ensure **systematic data collection and monitoring** of IGM
- **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 fails to recognise the serious human rights violations**⁴⁷ and the lifelong, severe suffering caused by IGM practices, let alone to *“take effective legislative, administrative, judicial or other measures”* to protect intersex children.

What’s worse, this continues **after the State party has already been reprimanded by CRC in 2016**, and by **CRPD in 2017** for IGM practices, with both Committees calling for **legislative measures** including to ensure access to **redress**, and to provide **adequate support**.

UK doctors are very outspoken about their determination to continue with involuntary surgeries etc. on intersex children *“[u]ntil such time as there is a change in law”* (see **2018 PSWG NGO Report**, p. 15).

To this day, as further documented in our **2018 PSWG NGO Report** (p. 11-17), 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)**.

Last but not least, **it should be duly noted** that the **State party’s reply** to the List of Issues **conveniently ignored** the Committee’s question about *“data on the number of surgical and other procedures that have been undertaken on intersex children under the age of 18 years in the State party.”* However, the Rapporteurs would like to recall the **statistics provided in our 2018 PSWG NGO Report** (p. 11-17), which are **based on NHS England Hospital Episode Statistics (HES)** and were originally published in a research report of the University of Huddersfield, indicating **annually up to 2,900** non-urgent genital surgeries on intersex children in England alone.

46 See <http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations>

47 **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. Additional Evidence of the Ongoing Practice in the UK

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 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.⁴⁸ 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) 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.⁴⁹ 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**”.⁵⁰ Like with earlier international networks led by IGM perpetrators, e.g. “I-DSD”,⁵¹ “DSDnet”⁵² and “DSD-Life”,⁵³ UK NHS Hospitals are prominently involved.⁵⁴

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

According to the “Irish Examiner”⁵⁵ 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,⁵⁶ 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.⁵⁷

48 Personal communication by UK doctor, June 2017

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

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

51 See Open Letter to “I-DSD 2013”, http://stop.genitalmutilation.org/public/Open-Letter_I-DSD_2013.pdf

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

53 See <http://stop.genitalmutilation.org/post/EU-biggest-funder-of-Intersex-Genital-Mutilation-how-much-longer>

54 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

55 Irish Examiner, “What happens when a child is born intersex in Ireland?”, 04.11.2016, Cover story, p. 7-9

56 Personal communication by Maltese intersex expert, September 2016

57 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

d) 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.^{58 59} Regarding Jeanette’s testimony, retired paediatric endocrinologist 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.”*⁶⁰

*“Apparently there had been a couple of examples where patients had been so upset they had taken their own lives – sadly.”*⁶¹

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.’”*⁶²

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.”*⁶³

In addition, current documents on the GMC homepage prove that **all forms of IGM practices continue to be advocated by the General Medical Council.**^{64 65}

58 BBC News: “Intersex patients ‘routinely lied to by doctors’”, 22.05.2017, video and article, <http://www.bbc.com/news/health-39979186>

59 BBC Radio 4, PM: “How doctors stole my identity”, 22.05.2017, <http://www.bbc.co.uk/programmes/p053p071>

60 See footnote 35, audio at 2:45

61 See footnote 34, article

62 Ibid.

63 Ibid.

64 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, https://www.gmc-uk.org/-/media/documents/Urology_MASTER_2016.pdf_69511155.pdf_71618311.pdf

65 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

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

In a 2017 video interview⁶⁶ also linked to on the Scottish DSD Network (SDSD) homepage under “Useful Links”,⁶⁷ 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, 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) University Hospitals Bristol admitting to continuing with IGM

In a 2016 Guardian article,⁶⁸ 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.”*

66 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

67 See “Introducing Intersex”, <http://www.sdsd.scot.nhs.uk/support/>

68 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>

g) “Inferior”, “Abnormal”, “Deformed”: Selective Intersex Abortions 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 supremacist undertones**.^{69 70 71 72}

Accordingly, also in the UK paediatric doctors frame intersex as “abnormalities”, “problems” and “disorders”, and by parents as “deformity” and “defect”.⁷³

What’s more, the easier an intersex trait can be tested prenatally, **the higher the (selective) abortion rates**,⁷⁴ arguably also in the UK,⁷⁵ where in particular most intersex diagnoses are listed as permissible for deselection in State sponsored **Preimplantation Genetic Diagnosis (PGD)** guidelines⁷⁶, 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]

69 2014 CRC NGO Report, p. 52, 69, 84

70 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>

71 “The Racist Roots of Intersex Genital Mutilations” <http://stop.genitalmutilation.org/post/Racist-Roots-of-Intersex-Genital-Mutilations-IGM>

72 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>

73 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>

74 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>

75 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>

76 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

h) Misrepresentation of Intersex as LGBT issue, Misappropriation of Funding

As elaborated above (p. 9-10), 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**.

South Africa⁷⁷ and **France**⁷⁸ are still the only States officially recognising IGM constituting a harmful practice, but so far without enacting legislation accordingly. **Malta**⁷⁹ and **Argentina**⁸⁰ 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,⁸¹ 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.^{82 83}

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”⁸⁴ originally also promoted by the Scottish DSD Network,⁸⁵ which was financed by the Scottish Lottery Fund,⁸⁶ 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.

77 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/>

78 See <http://stop.genitalmutilation.org/post/France-condemns-mutilations-of-intersex-children-proposes-prohibition>

79 See <http://stop.genitalmutilation.org/post/Intersex-politics-that-ignore-the-daily-mutilations-PINKWASHING-OF-IGM-PRACTICES>

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

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

82 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>

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

84 Pink Saltire, “Introducing Intersex”, video 22.03.2017. **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. (Video removed after CRPD18: <https://www.youtube.com/watch?v=onRPZEPDoPs>)

85 See “Introducing Intersex”, <http://www.sdsd.scot.nhs.uk/support/> (link removed after CRPD18)

86 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**.⁸⁷ In total, 2016-2020 a staggering **£180,000 will be paid out to LGBT organisations for “intersex work”**,^{88 89} while intersex NGOs continue to receive ZERO.

So unfortunately while the Scottish Government and the Scottish political parties publicly strive to “*include[...] intersex as part of our equality approach since 2014*”,⁹⁰ in fact they only do so regarding issues marginal to most intersex people like e.g. “*hate crimes against non-binary or intersex people*”⁹¹ and “*update[ing] the Gender Recognition Act 2004 [...] to alter the law to make better provisions for [...] specifically non-binary and intersex people*”,⁹² however, regarding the main issue of intersex children being submitted to IGM they steadfastly **keep funding and supporting the doctors and clinics responsible for continuing the practice**.

87 “*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/>

88 See also £45,000 for “intersex project” paid out to Equality Network in 2016,

<https://www.gov.scot/publications/equality-funding-2016-2017/>

89 See also annually £45,000 for “intersex project” paid out to Equality Network in 2017, 2018, 2019.

<https://www.gov.scot/publications/equality-national-intermediary-bodies-funding-2017-2020/>

90 <https://www.gov.scot/policies/lgbti/>

91 <https://pinksaltire.com/2017/06/10/scots-lgbt-hate-crime-reaches-new-high/>

92 <https://pinksaltire.com/2016/09/01/nhs-under-strain-as-gender-identity-demand-surges/>

E. Conclusion: UK must “take effective measures” to end IGM

For many years, the **UK government has been called upon to**

- undertake **legislation to prohibit** IGM practices
- guarantee **access to justice and redress** for IGM survivors
- ensure **adequate support** for intersex children and their families
- systematically **collect disaggregated data**,

including by UN Treaty bodies **CRC** and **CRPD**, which have expressed **concern** about

“[c]ases of medically unnecessary surgeries and other procedures on intersex children before they are able to provide their informed consent, which often entail irreversible consequences and can cause severe physical and psychological suffering, and the lack of redress and compensation in such cases”,

and have **urged the UK**, inter alia, to

- *“[e]nsure that no one is subjected to unnecessary medical or surgical treatment during infancy or childhood”*
- *“[provide] protection and care to the child victims and the prosecut[e] those found guilty of perpetrating such acts”*
- *“[e]stablish measures to ensure equal access to justice”*
- *“[p]rovide redress to the victims of such treatment”*
- *“[e]ducate medical and psychological professionals [...] on the consequences of unnecessary interventions for intersex children”*

Since then, on the positive side the **current UK Government** has to be commended for being the **very first** to

- publicly **acknowledge the call for legislative measures** to prevent IGM practices (CEDAW/C/GBR/Q/8/Add.1, para 46)
- publicly **admit that it is wrong to conflate intersex with transgender**,^{93 94}
- undertake a **Call for Evidence on Variations in Sex Characteristics** in consultation with intersex advocates.⁹⁵

93 *“I draw the committee’s attention to a couple of drafting points in relation to the policy memorandum. The first is that it **incorrectly includes intersex people under the umbrella term “trans”**. That was an unfortunate action during drafting in relation to an area that is constantly developing. We recognise that the needs of trans people and of **intersex people are different**. We will ensure that any future documentation does **not include intersex people under the trans umbrella**.”* Fiona Hyslop, Cabinet Secretary for Culture, Tourism and External Affairs, Scottish Government, at the 34th Meeting of the Culture, Tourism, Europe and External Affairs Committee, 20.12.2018, column 28, <http://www.parliament.scot/parliamentarybusiness/report.aspx?r=11864&mode=pdf>

94 *“The sex characteristics of focus here are **naturally occurring genetic, chromosomal, gonadal, anatomical and hormonal variations**. It includes diagnoses such as Congenital Adrenal Hyperplasia (or CAH), Hypospadias, Androgen Insensitivity Syndrome (AIS), Klinefelter syndrome and Turner syndrome, as well as many others. **This is distinct from being transgender or non-binary**, which are to do with a person’s gender identity.”* Government Equalities Office (2019), Variations in Sex Characteristics. A Call for Evidence, p. 3, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/771459/VSC_call_for_evidence_Web_Accessible.pdf

95 <https://www.gov.uk/government/news/government-calls-for-evidence-on-people-who-have-variations-in-sex-characteristics>

Unfortunately, there are also still serious **shortcomings, gaps, concerns and challenges**.

To this day, UK doctors, hospitals, the NHS and still far too many Government officials **fail to recognise the serious human rights violations**⁹⁶ and the lifelong, severe suffering caused by IGM practices.

To this day, the **United Kingdom is categorically failing to meet its non-derogable obligations under the Convention** towards intersex people, and in particular towards intersex children, including to take **effective legislative, administrative, judicial or other measures** to prevent **harmful practices** (art. 5(a) in conjunction with CEDAW-CRC Joint General Comment No. 31/18 “on harmful practices”).

Adult victims of IGM practices unchangedly encounter **severe obstacles** in the pursuit of their right to an **impartial investigation**, and to **redress** and fair and adequate **compensation**, including the means for as **full rehabilitation** as possible (art. 5(a) in conjunction with CEDAW-CRC Joint General Comment No. 31/18 “on harmful practices”).

Also the United Kingdom’s efforts on **education and information regarding the prohibition against torture in the training of medical personnel** remain grossly insufficient with respect to the treatment of intersex people, as evidenced by the fact that **involuntary, non-urgent interventions continue**, paid for by the National Health Service (NHS) (see above p. 11-15 and 2018 CEDAW UK PSWG NGO Report,⁹⁷ p. 11-17).

The UK must finally “take effective legislative, administrative, judicial or other measures” to protect intersex children from harmful practices – in line with its obligations under CEDAW, CRC, CRPD, CAT and CCPR.

96 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>

97 <http://intersex.shadowreport.org/public/2018-CEDAW-PSWG-UK-NGO-Coalition-Intersex-IGM.pdf>

F. Suggested Recommendations

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

Harmful Practices: Intersex Genital Mutilation (art. 5)

The Committee remains concerned about reports that unnecessary and irreversible surgery and other medical treatments are performed on intersex children without their informed consent and impartial counselling. It is concerned that such procedures, which cause long-term physical and psychological suffering, have not been the object of any inquiry, sanction or reparation and that there are no specific legal provisions providing redress and rehabilitation to the victims (art. 5).

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

- (a) Adopt clear legislative provisions explicitly prohibiting the performance of unnecessary surgical or other medical treatment on intersex children before they reach the legal age of consent, provide families with intersex children with adequate counselling and support, and provide redress to intersex persons having undergone such treatment, including adequate compensation.**

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[ie]d 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 consultant 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 scarring, 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 psychiatric hospital for psychosis and I'm now in a therapeutic 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 deceit 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 embarrassment.

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 urethra.

“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.”