

Open Letter of Concern to 6th I-DSD 2017, DSDnet, eUROGEN, Endo-ERN, DSD-Life and Affiliates by Persons Concerned, Partners, Families, Friends and Allies

6th I-DSD 2017
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Governing and Affiliated Bodies of eUROGEN, Endo-ERN, DSDnet, DSD-Life

- European Commission
- EU Cooperation in Science & Technology (COST)
- European Society of Paediatric Urology (ESPU)
- European Society of Paediatric Endocrinology (ESPE)
- ERN Board of Member States (ERN BoMS)
- European Association of Urology (EAU)
- European Society of Endocrinology (ESE)
- Medical Research Council (MRC)

Danish DSD Clinics and Universities

- Copenhagen University Hospital (Rigshospitalet)
- Aarhus University Hospital
- Odense University Hospital (OUH)
- University of Copenhagen
- University of Aarhus
- University of Odense

DSD Clinics affiliated with eUROGEN, Endo-ERN, DSDnet, DSD-Life

Austria

- St Anna Children's Hospital, Vienna
- Medical University Vienna

Belgium

- Centre Hospitalier Universitaire de Liège
- Cliniques universitaires Saint-Luc
- Cliniques universitaires de Bruxelles, Hôpital Erasme
- Ghent University and Ghent University Hospital
- Hôpital Universitaire des Enfants Reine Fabiola, Brussels
- UZ University Hospital Brussels
- UZ University Hospital Leuven

Bulgaria

- Medical University of Varna (MUV)
- University Hospital Sofia
- UMHAT University Hospital St. Marina, Varna
- USHATE 'Acad. Ivan Penchev', Sofia

Croatia

- University Hospital Rijeka

Cyprus

- The Cyprus Institute of Neurology and Genetics, Nicosia

Czech Republic

- Královské Vinohrady University Hospital Prague
- University Hospital Motol Prague

Denmark

- Aarhus University Hospital
- Copenhagen University Hospital (Rigshospitalet)

Estonia

- University Hospital Tartu

Finland

- University of Eastern Finland, Kuopio
- University of Helsinki
- University of Turku
- University of Oulu

France

- Assistance Publique – Hôpitaux de Marseille
- Assistance Publique – Hôpitaux de Paris
Robert Debré, Necker, St Antoine,
La Pitié Salpêtrière, Bicêtre, Trousseau
- Centre Hospitalier Universitaire Angers
- Centre Hospitalier Universitaire de Toulouse
- Centre Hospitalier Universitaire Montpellier
- Institut Pasteur, Paris
- Hospices Civils de Lyon, Université Claude Bernard
- Université Claude Bernard Lyon 1, Hôpital Mère-Enfant de Lyon

Germany

- Charité - Universitätsmedizin Berlin
- Hannoversche Kinderheilstalt
- Justus Liebig Universität Giessen

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DSD Clinics affiliated with eUROGEN, Endo-ERN, DSDnet, DSD-Life (continued)

Germany (continued)

- Klinikum Bremen-Mitte
- Ludwig-Maximilians-Universität München
- Otto-von-Guericke Universität Magdeburg
- Universitätsklinikum Aachen
- Universitätsklinikum Essen
- Universitätsklinikum Hamburg-Eppendorf
- Universitätsklinikum Leipzig
- Universitätsklinikum Mainz
- Universitätsklinikum Marburg
- Universitätsklinikum Regensburg
- Universitätsklinikum Schleswig-Holstein, Kiel
- Universitätsklinikum Schleswig-Holstein Lübeck
- Universitätsklinikum Würzburg
- Universitätsmedizin Göttingen
- Westfälische Wilhelms-Universität Münster

Hungary

- Csolnoky Ferenc County Hospital, Veszprem
- Semmelweis University Budapest

Israel

- Ben-Gurion University of the Negev

Italy

- Azienda Ospedaliero-Universitaria Bologna S. Orsola-Malpighi
- Azienda Ospedaliero Universitaria Città della Salute e della Scienza di Torino
- Azienda Ospedaliera Universitaria Meyer Firenze
- Azienda Ospedaliera di Padova
- Azienda Ospedaliera Universitaria Pisana
- Azienda Ospedaliera Universitaria "Federico II" Napoli
- Fondazione Policlinico Universitario A. Gemelli Roma
- Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico Milano
- IRCCS A.O.U San Martino Genova
- Ospedale Pediatrico Bambino Gesù Roma
- Ospedale San Raffaele Milano
- Ospedale Universitario Firenze

Lithuania

- University Hospital Kauno Klinikos, Kaunas
- Vilnius University Hospital Santariškių Klinikos

Luxembourg

- Centre Hospitalier de Luxembourg

Macedonia

- Macedonian Academy of Sciences and Arts

Netherlands

- Academic Medical Center Amsterdam
- Erasmus Medical Center Rotterdam
- Leiden University Medical Center
- Maastricht University Medical Center
- Máxima Medisch Centrum, Veldhoven
- Radboud University Medical Center, Nijmegen
- University Medical Centre Groningen
- VU University Medical Center, Amsterdam

Norway

- Oslo University Hospital-Rikshospitalet

Poland

- Children's Memorial Health Institute, Warsaw
- Medical University of Lodz
- Medical University of Gdansk
- Poznan University of Medical Sciences
- Public Pediatric Teaching Hospital, Warsaw

Romania

- Clinical Children's Emergency Hospital Louis Turcanu, Timisoara
- University of Medicine and Pharmacy Victor Babes Timisoara

Slovenia

- UMC University Hospital Ljubljana

Spain

- Hospital Sant Joan de Déu Barcelona
- Hospital Universitario Cruces, Bilbao
- Hospital Vall d'Hebron, Barcelona
- UPV-EHU University Hospital of Vasco Country, Barakaldo

Sweden

- Karolinska Institutet, Stockholm
- Sahlgrenska University Hospital

Switzerland

- University Hospital Insel Bern
- University of Fribourg

United Kingdom

- Alder Hey Children's Hospital NHS Foundation Trust, Liverpool
- Central Manchester University Hospitals NHS Foundation Trust
- Great Ormond Street Hospital NHS Foundation Trust, London
- Guy's and St Thomas' NHS Foundation Trust
- King's College Hospital NHS Foundation Trust
- NHS Greater Glasgow and Clyde Board
- Sheffield Teaching Hospitals NHS Foundation Trust
- St George's University Hospitals NHS Foundation Trust
- The Christie NHS Foundation Trust
- University College London Hospitals NHS Foundation Trust
- University of Glasgow
- University Hospitals Birmingham NHS Foundation Trust
- University Hospitals Bristol – NHS Foundation Trust
- University Hospital Southampton – NHS Foundation Trust

Copenhagen, June 2017

Dear Speakers, Chairpersons, and Participants of the 6th International DSD Symposium

Dear DSDnet, eUROGEN, Endo-ERN, DSD-Life

Dear European Commission, ERN Board of Member States (ERN BoMS)

Dear European Cooperation in Science & Technology (COST)

Dear EAU, ESPU, ESE, ESPE

Dear Medical Research Council (MRC)

Dear Directors of Paediatric DSD Clinics in Denmark

Dear Directors of Universities training DSD Doctors in Denmark

As survivors of non-consensual childhood genital surgeries and other involuntary procedures related to variations of sex anatomy, as persons concerned grateful for having escaped such treatments, as partners, family members and friends of persons concerned, and as allies, we acknowledge and welcome that the 6th I-DSD Symposium broadens the discussion by again including contributions by persons concerned, and even touching upon human rights and the necessity to develop and introduce non-surgical approaches.

We remain deeply saddened and concerned, however, that I-DSD, I-CAH, DSDnet, eUROGEN, Endo-ERN and DSD-Life, as well as affiliated DSD Clinics, Universities, Government and other public bodies nonetheless continue to **advocate, justify, arrange, perform, facilitate and/or acquiesce in** involuntary non-urgent procedures on children and adolescents with variations of sex anatomy, while at the same time denying the **serious human rights violations** caused by such practices.

We therefore would like to **kindly remind you** of the following:

In 2016, **Denmark** has been reprimanded by the **UN Committee against Torture (CAT)** for allowing non-consensual, non-urgent, irreversible procedures on children with variations of sex anatomy to continue with impunity, and obliged Denmark to *“[t]ake the necessary legislative, administrative and other measures to guarantee the respect for the physical integrity and autonomy of intersex persons”*.¹

In total, so far the

- **UN Committee on the Rights of the Child (CRC)**
- **UN Committee against Torture (CAT)**
- **UN Committee on the Elimination of Discrimination against Women (CEDAW)**
- **UN Committee on the Rights of Persons with Disabilities (CRPD)**
- **UN Committee on Economic, Social and Cultural Rights (CESCR)**

have issued **25 reprimands** for involuntary non-urgent treatments on intersex children to **16 State parties** in

¹ CAT/C/DNK/CO/6-7, paras 42-43

- Europe: Germany², Switzerland³, Austria⁴, Denmark⁵, France⁶, Ireland⁷, UK⁸, Italy,⁹ Netherlands¹⁰
- Asia: Hong Kong¹¹, Nepal¹²
- South America: Chile,¹³ Uruguay¹⁴
- Africa: South Africa¹⁵
- Oceania: New Zealand,¹⁶ Australia¹⁷

each time unmistakably condemning the involuntary non-urgent procedures as

- **“harmful cultural practice”** and **“intersex genital mutilation”** CRC art. 24(3), CEDAW art. 5(a) and CEDAW-CRC Joint general recommendation No. 31/18
- **“inhuman treatment”** falling under the prohibition of torture: CAT arts. 2, 12, 14, 16
- **“violation of the integrity of the person”**: CRPD art. 17 and General comment No. 3 (2016) on women and girls with disabilities
- **“violation of the right to physical & mental health”**: CESCR art. 12, GC No. 22

and obliging state parties to take effective measures, including legislation, to end the practice and ensure the human rights of intersex children, adolescents and adults.

In addition to the above stated UN treaty bodies and human rights violations, also the

- **UN Human Rights Committee (HRCtee)** is investigating involuntary, non-urgent treatments as torture, violence against children and unlawful human experimentation (CCPR arts. 7, 24) during its 120th session starting next week,
- **UN Committee on Economic, Social and Cultural Rights (CESCR)** further states in its General comment No. 22 (2016) on the right to sexual and reproductive health, para 59: *“Violations of the obligation to protect occur when a State fails to take effective steps to prevent third parties from undermining the enjoyment of the right to sexual and reproductive health. This includes the failure to prohibit and take measures to prevent [...] medically unnecessary, irreversible and involuntary surgery and treatment performed on intersex infants or children.”*
- regional human rights bodies including the **Inter-American Commission on Human Rights (IACHR)**, the **African Commission on Human and Peoples’ Rights (ACHPR)** and the **Council of Europe (COE)** condemned the involuntary non-urgent procedures as a *“harmful medical practice”*,¹⁸
- as well as the **World Health Organisation (WHO)**, twice.¹⁹

2 CAT/C/DEU/CO/5, para 20; CRPD/C/DEU/CO/1, paras 37-38; CEDAW/C/DEU/CO/7-8, paras. 23–24

3 CRC/C/CHE/CO/2-4, paras 42-43; CAT/C/CHE/CO/7, para 20; CEDAW/C/CHE/CO/4-5, paras 24–25, 38–39

4 CAT/C/AUT/CO/6, paras 44-45

5 CAT/C/DNK/CO/6-7, paras 42-43

6 CRC/C/FRA/CO/5, paras 47-48; CAT/C/FRA/CO/7, paras 32–33; CEDAW/C/FRA/CO/7-8, paras 17e-f, 18e-f

7 CRC/C/IRL/CO/3-4, paras 39-40

8 CRC/C/GBR/CO/5, paras 45–46

9 CRPD/C/ITA/CO/1, paras 45-46

10 CEDAW/C/NLD/CO/6, paras 21-22, 23-24; E/C.12/NLD/CO/6, paras 46-47, 18

11 CAT/C/CHN-HKG/CO/5, paras 28-29

12 CRC/C/NPL/CO/3-5, paras 41-42

13 CRC/C/CHL/CO/4-5, paras 48-49; CRPD/C/CHL/CO/1, paras 41-42

14 CRPD/C/URY/CO/1, paras 43-44

15 CRC/C/ZAF/CO/2 paras 37-38

16 CRC/C/NZL/CO/5, para 25

17 E/C.12/AUS/CO/5, paras 49-50

18 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>

19 WHO, OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF, Eliminating forced, coercive and otherwise

A 2016 **verdict by the Nuremberg district court** marked the first time that a DSD university clinic has been sentenced to pay damages for non-consensual genital surgery, gonadectomy and imposition of hormones to an intersex person.²⁰ This and two more lawsuits against DSD university clinics, individual clinicians including paediatric endocrinologists, public bodies and civil servants in **Munich**²¹ and **South Carolina (USA)**²² are ongoing. What's more, the non-applicability of statutes of limitation in cases of DSD treatments constituting harmful practices or inhuman treatment is enshrined in international law and has been recognised by above UN treaty bodies.

On 14 February 2017 the **European Parliament** adopted a resolution on promoting gender equality in mental health and clinical research which explicitly “[c]alls on the Member States to prevent, ban and prosecute female genital mutilation and genital mutilation affecting intersex persons, and to provide mental health support, in conjunction with physical care, to victims and to those individuals likely to be targeted.”²³

And on 14 April 2017 the **Senate of Nevada (USA)** passed a bill that prohibits any non-consensual “surgical procedure to assign anatomical sex, including, without limitation, surgery to relocate the urethral meatus, of a child under 18 years of age” unless “delaying the procedure is likely to endanger the life of the child”, with violations resulting in disciplinary action or suspension or revocation of medical license,²⁴ and also other states are undertaking legislative efforts.

We therefore would like to reiterate²⁵ our pleas to I-DSD, I-CAH, DSDnet, eUROGEN, Endo-ERN, DSD-Life, as well as affiliated DSD Clinics, Universities, Government and other public bodies,

- **to kindly reconsider non-consensual cosmetic treatments of children and adolescents with variations of sex anatomy (including hypospadias and CAH)**
- **to kindly reconsider the stigmatising nomenclature ‘Disorders of Sex Development’**
- **to do so in consultation with intersex people and the organisations that represent them**
- **to acknowledge the harm and suffering inadvertently caused by non-consensual treatments of children and adolescents with variations of sex anatomy (including hypospadias and CAH)**
- **to initiate a process of coming to terms with the past as a necessary first step towards reconciliation.**

involuntary sterilization. An interagency statement, May 2014, paras 2, 6, 7:

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

World Health Organization, Sexual health, human rights and the law [Internet], 2015, p. 26,

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

20 <http://stop.genitalmutilation.org/post/Nuremberg-Hermaphrodite-Lawsuit-Damages-and-Compensation-for-Intersex-Genital-Mutilations>

21 ibd.

22 <http://interactadvocates.org/category/m-c/>

23 <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P8-TA-2017-0028+0+DOC+XML+V0//EN>

24 AN ACT relating to health care; establishing conditions for the performance on a child of any surgical procedure to assign anatomical sex; providing for disciplinary action against certain providers of health care for any violation of those conditions, <https://www.leg.state.nv.us/Session/79th2017/Bills/SB/SB408.pdf>

25 See Open Letter of Concern to ‘3rd EuroDSD Symposium 2011’, http://zwischenengeschlecht.org/public/3rd-EuroDSD_Open-Letter.pdf; Open Letter of Concern to ‘4th I-DSD Symposium 2013’, http://stop.genitalmutilation.org/public/Open-Letter_I-DSD_2013.pdf

And we respectfully maintain it would be in the best interest of all parties if such a process could be initiated before legislators will take over eventually.

Thank you again for your consideration.

Kind regards

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