Open Letter of Concern

to 55th ESPE 2016 and French DSD Universities and Clinics

by Persons Concerned, Partners, Families, Friends and Allies

55th Annual Meeting of European Society for Paediatric Endocrinology (ESPE)
c/o Le Palais des Congrès 2 Place de la Porte Maillot 75017 Paris

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DSD Reference Clinics (Centres de Référence Médico-Chirurgical des Maladies Rares des Anomalies du Développement Sexuel (ADS))
- Hôpital Universitaire Robert-Debré, Paris
- Hôpital Necker-Enfants Malades, Paris
- Hôpital Armand-Trousseau, Paris
- Hôpital Bicêtre, Paris

DSD Competence Clinics (Centres de Compétence des Maladies rares du développement sexuel)
- CHU Amiens-Picardie
- CHU Angers
- CHRU Besançon
- CHU Bordeaux
- CHRU Brest
- CHU Caen
- CHU Clermont-Ferrand
- CHU Dijon Bourgogne
- CHU Grenoble-Álpes
- CHRU Lille, Hôpital Jeanne de Flandre
- CHU Limoges
- Centre Hospitalier Bretagne Sud, Lorient
- CHU Sud-Est, Marseille
- CHRU Montpellier
- CHRU Nancy
- CHU Nantes
- CHU Nice
- CHU d’Île-de-France, Paris
- CHI Poissy Saint-Germain-en-Laye
- CHU Reims
- CHU Rennes
- CHU Rouen
- Clinique Mathilde, Rouen
- Centre Hospitalier Saint-Brieuc
- CHU Saint-Etienne
- CHU Strasbourg
- CHRU Tours

Other DSD Clinics
- CHU Guadeloupe, Pointe-à-Pitre
- CHU Martinique, Fort de France
- CHU Nîmes
- CHU Poitiers
- CHU la Réunion, Saint Paul
- Clinique St Michel et Ste Anne, Quimper
- CHU Toulouse

DSD Universities
- Université de Picardie Jules Verne, Amiens
- Université d’Angers
- Université de Franche-Comté, Besançon
- Université de Bordeaux
- Université de Bretagne Occidentale, Brest
- Université de Caen Normandie
- Université d’Auvergne, Clermont-Ferrand
- Université de Bourgogne, Dijon
- UFR des Sciences de Santé, Dijon
- Université de Lille 2 - Droit et Santé
- Université de Limoges
- Université de Bretagne-Sud, Lorient
- Université de Lyon
- Aix-Marseille Université
- Université de Montpellier
- Université de Lorraine, Nancy
- Université de Nantes
- Université Nice Sophia-Antipolis
- Université Paris 13
- Université Pierre et Marie Curie, Paris
- Université Paris Descartes
- Université Denis-Diderot Paris 7
- Université Paris-Est
- Université Paris-Sud
- Université de Versailles, Paris
- Université de Reims
- Université de Rennes 1
- Université de Rouen, Mont-Saint-Aignan
- Université de Strasbourg
- Université François-Rabelais de Tours
Dear Speakers, Chairpersons, and Participants of the 55th Annual Meeting of the European Society for Paediatric Endocrinology

Dear Board, Scientific Committee and Members of ESPE and SFEDP

Dear Directors of Paediatric DSD Clinics in France

Dear Directors of Universities training DSD Doctors in France

In 2016, France has been reprimanded 3 times by the UN for allowing non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, sterilising procedures and imposition of hormones on children with variations of sex anatomy to continue with impunity, with the

- UN Committee on the Rights of the Child (CRC)\(^1\)
- UN Committee against Torture (CAT)\(^2\)
- UN Committee on the Elimination of Discrimination against Women (CEDAW)\(^3\)

unmistakably condemning involuntary non-urgent procedures on intersex children in France (and elsewhere) as

- “harmful practice” like FGM: CRC art. 22(3), CEDAW art. 5(a)
- “inhuman treatment” falling under the prohibition of torture: CAT arts. 2, 12, 14, 16.

So far, in total 16 UN reprimands for involuntary non-urgent treatments on intersex children have been issued to 11 State parties in

- Europe: Germany\(^4\), Switzerland\(^5\), Austria\(^6\), Denmark\(^7\), France\(^8\), Ireland\(^9\), UK\(^10\), Italy\(^11\)
- Asia: Hong Kong\(^12\), Nepal\(^13\)
- South America: Chile\(^14\)

In addition to the above UN treaty bodies, also the UN Committee on the Rights of Persons with Disabilities (CRPD) condemned involuntary non-urgent DSD treatments as a violation of the “integrity of the person” (CRPD art. 17); and the UN Human Rights Committee (HRCttee) is currently investigating them as torture and unlawful human experimentation (CCPR art. 7).

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1 CRC/C/FRA/CO/5, paras 47-48
2 CAT/C/FRA/CO/7, paras 32–33
3 CEDAW/C/FRA/CO/7-8, paras 17e-f, 18e-f
4 CAT/C/DEU/CO/5, para 20; CRPD/C/DEU/CO/1, paras 37-38
5 CRC/C/CHE/CO/2-4, paras 42-43; CAT/C/CHE/CO/7, para 20
6 CAT/C/AUT/CO/6, paras 44-45
7 CAT/C/DNK/CO/6-7, paras 42-43
8 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
9 CRC/C/IRL/CO/3-4, paras 39-40
10 CRC/C/GBR/CO/5, paras 45–46
11 CRPD/C/ITA/CO/1, paras 45-46
12 CAT/C/CHN-HKG/CO/5, paras 28-29
13 CRC/C/NPL/CO/3-5, paras 41-42
14 CRC/C/CHL/CO/4-5, paras 48-49; CRPD/C/CHL/CO/1, paras 41-42
A 2016 verdict by the Nuremberg district court marks 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.\textsuperscript{15} This and two more lawsuits against DSD university clinics, individual clinicians including paediatric endocrinologists, public bodies and civil servants in Munich\textsuperscript{16} and South Carolina (USA)\textsuperscript{17} 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.

As survivors of non-consensual childhood genital surgeries and other involuntary procedures, 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 this year’s ESPE annual congress broadens the discussion by including an ethicist's viewpoint and even touching upon human rights and the necessity to develop and introduce non-surgical approaches.

We remain deeply concerned, however, that members of ESPE and SFEDP, as well as French DSD Universities and Children’s Clinics still continue to advocate, justify, arrange and perform involuntary non-urgent procedures on children and adolescents with variations of sex anatomy.

We therefore would like to reiterate our pleas to ESPE and its affiliates\textsuperscript{18}, including SFEDP and French Universities and Children’s Clinics,

- to kindly reconsider non-consensual cosmetic treatments of children and adolescents with intersex variations (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 intersex variations (including hypospadias and CAH)
- to initiate a process of coming to terms with the past as a necessary first step towards reconciliation.

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

\textsuperscript{15} http://stop.genitalmutilation.org/post/Nuremberg-Hermaphrodite-Lawsuit-Damages-and-Compensation-for-Intersex-Genital-Mutilations
\textsuperscript{16} ibid.
\textsuperscript{17} http://interactadvocates.org/category/m-c/
Thank you again for your consideration.

Kind regards

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