

# **Open Letter of Concern to the 4<sup>th</sup> I-DSD Symposium by Persons Concerned, Partners, Families, Friends and Allies**

I-DSD  
Dr Jillian Bryce  
Section of Child Health  
University of Glasgow  
Royal Hospital for Sick Children – Yorkhill  
Glasgow, G3 8SJ

4th International Symposium on Disorders  
of Sex Development  
Sir Charles Wilson Building  
Kelvin Way  
Glasgow, G12 8QQ

SDSD Office  
9<sup>th</sup> Floor QM Tower  
Yorkhill Hospital  
Dalnair Street  
Glasgow, G3 8SJ

Royal Hospital for Sick Children – Yorkhill  
Dalnair Street  
Glasgow, G3 8SJ

University of Glasgow  
University Avenue  
Glasgow, G12 8QQ

Glasgow, June 7 2013

Dear Board, Scientific Committee and Members of I-DSD  
Dear Speakers, Chairpersons and Participants of the 4<sup>th</sup> International DSD Symposium  
Dear Scottish Disorder of Sex Development Managed Clinical Network (SDSD)  
Dear Royal Hospital for Sick Children Yorkhill  
Dear University of Glasgow

As survivors of non-consensual childhood genital surgeries, as well as persons concerned grateful for having escaped such surgeries, as partners, family members and friends of persons concerned, and as allies, we are deeply saddened and concerned that an apparently overwhelming majority of the speakers, chairpersons and involved institutions at the 4<sup>th</sup> International DSD Symposium seems to refuse to listen to their former patients, and in-

stead continue to advocate, justify and/or perform medically not necessary, irreversible cosmetic genital surgeries on children with 'atypical' sex anatomies, no matter what the consequences for these children.

A few representative examples:

- Faisal Ahmed, John Achermann, Gerry Conway, Nils Krone, et. al.: *Clin Endocrinol (Oxf)*. (2011) July; 75(1): 12–26.<sup>1</sup> (Note how the ethics paper by Wiesemann, Ude-Koeller et. al. (2010)<sup>2</sup> is mentioned just once: as a rationale for allowing cosmetic genital surgeries on children.)
- Olaf Hiort, et. al.: *Monatsschr Kinderheilkd* (2013) 161:145–152.<sup>3</sup> (Advocates cosmetic 'clitoral reductions' on children)
- Berenice B. Mendonca: *Semin Reprod Med*. (2012); 30(5):339-350.<sup>4</sup> (Advocates cosmetic genital surgeries on children 'preferably before 2 years of age'.)
- Pierre Mouriquand, et. al.: *Best Practice & Research Clinical Endocrinology & Metabolism* 24 (2010) 311–324<sup>5</sup>; *Arch. Esp. Urol.* 2010; 63 (7): 495-504.<sup>6</sup> (Both papers promote cosmetic 'masculinising' and 'feminizing' genital surgeries as well as cosmetic gonadectomies on children 'between 6 and 24 months of age'.)
- David Sandberg, et. al.: *International Journal of Pediatric Endocrinology* (2011), 2011:10.<sup>7</sup> (While not directly promoting cosmetic genital surgeries on children, it is noteworthy that all 28 children aged 0-6 years mentioned in this study were submitted to such surgeries without exception.)
- The Scottish Disorder of Sex Development Managed Clinical Network (SDSD), of which the University of Glasgow's Royal Hospital for Sick Children Yorkhill is a member, supports the guidelines by Faisal Ahmed, John Achermann, Gerry Conway, Nils Krone, et. al. (see above)<sup>8</sup>, and in addition recommends cosmetic hypospadias surgeries on small children for 'social' reasons.<sup>9</sup>

While we are pleased to note that there will be a 'Parallel Support Group Session' as a late addition to the programme, and recognise this as an appropriate step in the right direction, we deeply regret that only very few support groups and organisations of people concerned were invited, and that all others were factually barred, and as well that there's only a parallel session, but no opportunity for persons concerned to address the actual symposium.

We also deeply regret that the 4<sup>th</sup> I-DSD Symposium still fails to address at all the grave ethical and legal implications of non-consensual cosmetic genital surgeries on children

---

1 <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3132446/>

2 <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2859219/>

3 <http://link.springer.com/content/pdf/10.1007%2Fs00112-012-2828-9.pdf>

4 [http://www.medscape.com/viewarticle/772502\\_7](http://www.medscape.com/viewarticle/772502_7)

5 <http://sites.harvard.edu/fs/docs/icb.topic1053306.files/Vidal%2010.pdf>

6 <http://ts-si.org/files/GorduzaEtAlSurgicalChallengesDSD63075.pdf>

7 <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3223129/>

8 <http://www.sdsd.scot.nhs.uk/Information.html>

9 <http://www.sdsd.scot.nhs.uk/Information%20leaflets/New%20hypospadias%20leaflet%20for%20parents291211.pdf>

with 'atypical' sex anatomies, as well as non-consensual imposition of hormones (e.g. prenatal dexamethasone), despite the ongoing scholarly and public debate. There are many distinguished experts in the field of Ethics and DSD, e.g. Alice Dreger, Katrina Karkazis or Ellen Feder, as well as legal experts, like e.g. Anne Tamar-Mattis. Unfortunately, none of these were invited.

In our opinion, this demonstrates a regrettable lack of willingness to listen to critical voices, let alone to enter into a real debate.

For 60 years now, the practice of systematic cosmetic genital surgeries on children with 'atypical genitals' persists. In all these years and decades, the clinicians responsible weren't able to produce any evidence for the alleged benefits for the children concerned, not even adequate follow-ups, or even just to disclose bare statistics, but instead insist on continuing to operate on the basis of mere anecdotal evidence. In addition, until the 1980s, one of the most common procedures was cosmetic amputation of 'too big' clitorises resp. 'too small' penises, also in the UK<sup>10</sup>, and with psycho-social rationale similar to such used today to justify the more 'modern' procedures.

For 20 years now, survivors of these surgeries have protested them publicly, describing them consistently as 'very harmful'<sup>11 12</sup>, 'traumatizing'<sup>13</sup>, 'immensely destructive of sexual sensation and of the sense of bodily integrity'<sup>14 15</sup>, and have compared the surgeries and their effects to female genital mutilation<sup>16</sup> (which has been corroborated by international experts<sup>17</sup>), and to child sexual abuse<sup>18</sup> (which also has been corroborated by studies<sup>19</sup>). For 20 years now, the clinicians concerned have mainly refused to heed, let alone acknowledge these serious concerns, but instead keep on repeating the same old excuses<sup>20</sup>, 'essentially impervious to data'<sup>21</sup>. In addition, until today there has been no reckoning at all regarding cosmetic clitoris amputations or any other earlier cosmetic practices.

In the past decade, many reports and statements by Human Rights Advocacy Groups emerged (for example, Terre des Femmes 2004<sup>22</sup>, San Francisco Human Rights Commis-

---

10 Cf. e.g. Christopher Dewhurst / Ronald Gordon: 'The Intersexual Disorders' (1969), pp. 39-41

11 ISNA: 'Hypospadias: Parent's Guide to Surgery' <http://www.isna.org/node/81>

12 Tiger Howard Devore: 'Endless Calls for "More Research" as Harmful Interventions Continue' (1995), Hermaphrodites with Attitude, Fall/Winter 1995-96, <http://www.isna.org/files/hwa/winter1996.pdf>

13 Emi Koyama: 'Intersex Medical Treatment and Sexual Trauma'

14 Cheryl Chase: Letters from Readers. 1993, The Sciences, July/August, 3, <http://www.isna.org/articles/chase1995a>

15 Mauro Cabral: UN 2004 – NGO statement: Intersexuality, <http://ilga.org/ilga/en/article/61>

16 ISNA's Amicus Brief on Intersex Genital Surgery (1998) <http://www.isna.org/node/97>

17 e.g. Hanny Lightfoot-Klein: 'Children's Genitals Under the Knife: Cultural Imperatives, Secrecy, and Shame' (2007), Chapter Nine: Intersex Surgery: For the Good of Whom?, p 167-176

18 Tamara Alexander: 'The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse', <http://www.isna.org/articles/analogue>

19 Arch Sex Behav. (2009) Feb;38(1):16-33, <http://www.ncbi.nlm.nih.gov/pubmed/17943433>

20 Alice Dreger: "'Ambiguous Sex"—or Ambivalent Medicine?', The Hastings Center Report May/ Jun 1998, Volume 28, Issue 3 Pages 24-35, [http://www.isna.org/articles/ambivalent\\_medicine](http://www.isna.org/articles/ambivalent_medicine)

21 Cheryl Chase: 'What is the agenda of the intersex patient advocacy movement?' (2002) <http://www.isna.org/agenda>

22 <http://blog.zwischengeschlecht.info/post/2010/07/01/Genitalverstuemmelungen-an-Zwittern-Terre-des-Femmes-%2C-2004>

sion 2005<sup>23</sup>, CEDAW 2009<sup>24</sup>, Amnesty Switzerland 2010<sup>25</sup>, Amnesty Germany 2010<sup>26</sup>), as well as further publications by experts in these fields (such as Hanny Lightfoot-Klein 2003/2008<sup>27</sup>, Fana Asefaw 2005<sup>28</sup>, Nancy Ehrenreich/Mark Barr 2005<sup>29</sup>), all of them concluding that non-consensual cosmetic surgeries on children with 'atypical' sex anatomies constitute a grave violation of their human rights, particularly the children's right to physical integrity, and who underline the similarities and parallels between these surgeries and the generally condemned practice of female genital mutilations.

In the last two years alone,

- a) 2011 the United Nations High Commissioner for Human Rights (UNHCHR) criticised that 'intersex children, who are born with atypical sex characteristics' are submitted to 'medically unnecessary surgery, performed without their informed consent, or that of their parents'<sup>30</sup>, on the basis of the concluding observations of the Committee on the Elimination of Discrimination against Women (CEDAW) on Costa Rica<sup>31</sup>, as a response to a shadow report by persons concerned<sup>32</sup>
- b) 2012 the United Nations Committee against Torture (CAT) found non-consensual cosmetic genital surgeries on children in violation of the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment and recommended reparations<sup>33</sup>
- c) 2012 on behalf of the German Federal Government, the German Ethics Council issued a statement that explicitly acknowledged the physical and psychological suffering of survivors of non-consensual cosmetic genital surgeries on children<sup>34</sup>, stressed their Right to Physical Integrity and the limits of the parent's rights to consent to cosmetic procedures for their children<sup>35</sup>, and recommended reparations for survivors<sup>36</sup> as well as the suspension of the statutes of limitation until adulthood regarding lawsuits by survivors of non-consensual cosmetic genital surgeries on children<sup>37</sup>

---

23 [http://www.isna.org/files/SFHRC\\_Intersex\\_Report.pdf](http://www.isna.org/files/SFHRC_Intersex_Report.pdf)

24 <http://www2.ohchr.org/english/bodies/cedaw/docs/co/CEDAW-C-DEU-CO6.pdf>

25 <http://blog.zwischengeschlecht.info/post/2010/04/26/Amnesty-Schweiz%3A-Historischer-Entscheid-f%C3%BCr-%22Menschenrechte-auch-f%C3%BCr-Zwitter%21%22>

26 <http://blog.zwischengeschlecht.info/post/2010/05/26/Amnesty-Deutschland%3A-Ebenfalls-historischer-Entscheid-f%C3%BCr-%22Menschenrechte-auch-f%C3%BCr-Zwitter%21%22>

27 Hanny Lightfoot-Klein: Children's Genitals Under the Knife (2008)

28 [http://kastrationsspital.ch/public/FGC-intersex\\_2artikel\\_asefaw\\_hrzan.pdf](http://kastrationsspital.ch/public/FGC-intersex_2artikel_asefaw_hrzan.pdf)

29 Nancy Ehrenreich/Mark Barr: 'Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of "Cultural Practices"'; [http://www.intact-network.net/intact/cp/files/1284898535\\_66-%20Intersex%20Surgery,%20Female%20Genital%20Cutting,%20and%20the%20Selective%20Condemnation%20of%20%E2%80%9CCultural%20Practices%E2%80%9D%20Report%20%282005%29.pdf](http://www.intact-network.net/intact/cp/files/1284898535_66-%20Intersex%20Surgery,%20Female%20Genital%20Cutting,%20and%20the%20Selective%20Condemnation%20of%20%E2%80%9CCultural%20Practices%E2%80%9D%20Report%20%282005%29.pdf)

30 [http://www2.ohchr.org/english/bodies/hrcouncil/docs/19session/A.HRC.19.41\\_English.pdf](http://www2.ohchr.org/english/bodies/hrcouncil/docs/19session/A.HRC.19.41_English.pdf)

31 <http://www2.ohchr.org/english/bodies/cedaw/docs/co/CEDAW-C-CRI-CO-5-6.pdf>

32 <http://intersex.shadowreport.org/post/2012/10/26/Shadow-Report-CEDAW-2011>

33 [http://www2.ohchr.org/english/bodies/cat/docs/co/CAT.C.DEU.CO.5\\_en.pdf](http://www2.ohchr.org/english/bodies/cat/docs/co/CAT.C.DEU.CO.5_en.pdf)

34 German Ethics Council: Empfehlungen 6 und 7 zur medizinischen Behandlung, Stellungnahme "Intersexualität", p. 174

35 "Eine erste Einschätzung", <http://diskurs.ethikrat.org/2011/06/eine-erste-einschätzung/>

36 8.3.8.1. "Entschädigungsfonds", Stellungnahme "Intersexualität", p. 164-166.

37 Empfehlung 14 zur medizinischen Behandlung, Stellungnahme "Intersexualität", p. 176.

- d) 2012 on behalf of the Swiss Federal Government, the Swiss National Commission on Biomedical Ethics (NEK-CNE) issued a statement recommending to stop non-consensual cosmetic genital surgeries on children for psycho-social reasons, and legislation to achieve this<sup>38</sup>
- e) 2013 the United Nations Special Rapporteur on Torture (SRT) criticised in a report, 'Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, "in an attempt to fix their sex", leaving them with permanent, irreversible infertility and causing severe mental suffering.' The report also states, 'These procedures [genital-normalizing surgeries] are rarely medically necessary, can cause scarring, loss of sexual sensation, pain, incontinence and lifelong depression and have also been criticized as being unscientific, potentially harmful and contributing to stigma,' and called for legislation<sup>39</sup>
- f) 2013 the Australian Senate initiated hearings on involuntary and coerced sterilisations, which explicitly include medically not necessary treatments on intersex people<sup>40</sup>
- g) 2013 in Erlangen, Germany a lawsuit by a person concerned against the University Hospital and individual employees for performing an irreversible and medically unnecessary surgery on the person concerned has been greenlit for trial
- h) 2013 in the U.S.A. a lawsuit has been filed both in federal and state courts against the South Carolina Department of Social Services, Greenville Hospital System, Medical University of South Carolina and individual employees for performing an irreversible and medically unnecessary surgery on an infant in the state's care<sup>41</sup>
- i) 2013 the German Federal Parliament unanimously referred three proposals to legislate against cosmetic genital surgeries on children with 'atypical' sex anatomies<sup>42</sup>

We are sure, as professionals you are aware of the growing controversy about non-consensual cosmetic genital surgeries on children with 'atypical' sex anatomy also becoming better known to the general public, as well as of the leaning of the general public regarding genital mutilation, unethical medical experiments and forced surgeries and sterilisations.

It is our understanding, that in your capacity as clinicians you have plenty of patients with actual medical needs who depend on your professional help, as well as that the 4<sup>th</sup> I-DSD Symposium also addresses real medical issues.

Therefore, we would like to suggest respectfully that you consider focusing your efforts on helping those patients with real medical issues, of whom we are sure that they are deeply

38 [http://www.bag.admin.ch/nek-cne/04229/04232/index.html?lang=en&download=NHZLpZeg7t,lnp6I0NTU042l2Z6ln1ad1IZn4Z2qZpnO2Yuq2Z6gpJCKfX96f2ym162epYbg2c\\_JjKbNoKSn6A--](http://www.bag.admin.ch/nek-cne/04229/04232/index.html?lang=en&download=NHZLpZeg7t,lnp6I0NTU042l2Z6ln1ad1IZn4Z2qZpnO2Yuq2Z6gpJCKfX96f2ym162epYbg2c_JjKbNoKSn6A--)

39 [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf)

40 <http://oii.org.au/21962/opening-statement-at-the-senate-hearing-on-involuntary-sterilisation/>

41 [http://aiclegal.org/wordpress/wp-content/uploads/2012/10/050714\\_Crawford\\_Complaint\\_Release\\_FINAL\\_FINAL.pdf](http://aiclegal.org/wordpress/wp-content/uploads/2012/10/050714_Crawford_Complaint_Release_FINAL_FINAL.pdf)

42 [http://zwischenegeschlecht.org/public/Bundestag\\_17240\\_TOP-19\\_Intersex\\_Protokoll\\_Reden.pdf](http://zwischenegeschlecht.org/public/Bundestag_17240_TOP-19_Intersex_Protokoll_Reden.pdf)

grateful for your services, but on the other hand abandon unethical, inhumane and illegal practices like non-consensual cosmetic surgeries on children with 'atypical' sex anatomies, while you still can do so on your own terms. And at the same time start a process of coming to terms with the past of these practices.

Thank you for your consideration.

Kind regards

Daniela Truffer, Markus Bauer (corresponding authors)  
Founding Members, Human Rights Group Zwischengeschlecht.org  
P.O.Box 2122, CH-8031 Zurich, Switzerland  
info@zwischen-geschlecht.org

AG Queer Studies, Hamburg, Germany

Ruby Almeida, Chair, Quest – Group for Lesbian and Gay Catholics, London, UK

Claudia Astorino, OII USA

Sophie Barbut, Luxembourg

Alexandre Baril, Ph.D. Student and Part-Time Professor, Institute of Women's Studies,  
University of Ottawa, Canada

Blandine Bussery, France

Gabrielle Bouchard, Peer support and Trans' advocacy Coordinator, Centre de lutte contre  
l'oppression des genres, Canada

Marie-Hélène Bourcier, Sociologist, Université de Lille, France

Alkaios Boussoulas, Berlin, Germany

Anne Carter, South Warwickshire Transgender and Intersex Group (SWTIG), UK

Hiker Chiu, Founder, OII Chinese, Taiwan

Dr. Milton Diamond, Professor, University of Hawaii, USA

Ditte Dyreborg, affiliated with Pangea International, Copenhagen, Denmark

Richard Duncker, Men Do Complain, London, UK

Gilbert Emond, Ph.D., Associate Professor, Concordia University, Montréal, Canada

Facharbeitskreis Beschneidungsbetroffener im MOGiS e.V. und Freunde, Germany

Jules Falquet, Sociologist, Université Paris Diderot, France

Elsa Galerand, Canada

Eleni Giannakou, Hamburg, Germany

Glasgow University Feminist Society, UK

Lucie Gosselin, Anthropologist, Canada

Mona Greenbaum, Executive Director, Coalition des familles homoparentales, Montréal, Canada

Claudia Griesser, Waltalingen, Switzerland

Sally Gross, Founder and Director, Intersex South Africa

Vincent Guillot, Landelau, France

Kris Günther, Co-Administrator, Genres Pluriels, OII Belgium

Phoebe Hart, Filmmaker, Australia

Diana Hartmann, Hamburg, Germany

Diba Hashemi, Germany

Joke Jansen, Hamburg, Germany

Alex Jürgen, Intersex Austria

Julius Kaggwa, Support Initiative for People with atypical sex Development (SIPD), Uganda

Claudia Kasper, Munich, Germany

Michaela Katzer, Consultant Urologist, Halle, Germany

Michaela Koch, Universität Oldenburg, Germany

Claudia Koltzenburg, Nürtingen, Germany

Deborah Lambillotte, Coordinatrice, Casa Rosa vzw, Gent, Belgium

Julia Mac Gowan, Vienna, Austria

Paul Maheke Ngamaha, France

Dr. Heinz Markwalder, Scientist, Zurich, Switzerland

Anne Tamar-Mattis, JD, Executive Director, Advocates for Informed Choice, USA  
(Personal capacity, affiliation given for identification purposes only)

MOGiS e.V. - Eine Stimme für Betroffene, Rostock, Germany

Benjamin Moron-Puech, Ph.D. student in law, University Panthéon-Assas, Paris, France

Michelle O'Brien, OII New Zealand

Pidgeon Pagonis, Youth Leadership Intern, Advocates for Informed Choice, USA  
(Personal capacity, affiliation given for identification purposes only)

PolitiQ: Queers Solidaires, Montréal, Canada

PinkBloc, Montréal, Canada

Christina Schäfer, Hamburg, Germany

Dr. Tove Soiland, Historian, Zurich, Switzerland

Wal Torres, MSc., Ph.D., Gendercare.com, OII Brasil

Intersex & Transgender Luxembourg

Hida Vilorio, Chair, Organisation Intersex International / Director, OII USA

J. Vreer Verkerke, Vreerwerk Gender education Trans rights, TGEU, Netherlands

Eve Waterside, UK

Gina Wilson, President, OII Australia

Simon Zobel, Amnesty International, Berlin, Germany  
(Personal capacity, affiliation given for identification purposes only)