

Open Letter of Concern to the 4th World Congress of Pediatric Surgery WOFAPS 2013 by Persons Concerned, Partners, Families, Friends and Allies

4th World Congress of the World Federation
of Associations of Pediatric Surgeons (WOFAPS 2013)
c/o bcc Berliner Congress Center
Alexanderstraße 11
10178 Berlin

Otto-Heubner-Centrum für Kinder- und Jugendmedizin
Charité Universitätsmedizin Berlin
Augustenburger Platz 1
13353 Berlin

Berlin, October 14, 2013

Dear Board, Scientific Committee and Members of WOFAPS and its member associations
Dear Speakers, Chairpersons, and Participants of the 4th World Congress
Dear Charité Universitätsmedizin Berlin

As survivors of non-consensual genital surgeries on children with variations of sex anatomy, 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 professional associations at the 4th World Conference, as well as participating Paediatric DSD Clinics, seem to refuse to listen to their former patients, and instead continue to advocate, justify and recommend medically not necessary, irreversible, non-consensual, cosmetic genital surgeries, 'prophylactic' gonadectomies and imposition of hormones on children with 'atypical' sex anatomies, no matter what the consequences for these children, as well as offering selective late-term-abortions.

Furthermore, we are deeply saddened and concerned that the introduction and **global dissemination** of cosmetic genital surgeries on children concerned, including a.o. **amputations or excisions of children's clitorises** and **'prophylactic' castrations**, is inextricably linked to the emergence of paediatric surgery as a specialty, and of local and regional professional associations, as well as to pioneering individual surgeons, e.g.:

- Carlos Lagos García (Buenos Aires, Argentine), 'pioneering character' and contributor to the 'national scientific and technological heritage' of 'most outstanding Argentinean medical contributions in the last century'¹. Lagos García's 'Las deformid-

¹ Abel L. Agüero, Alfredo G. Kohn Loncarica (†), Norma I. Sánchez, José M. Trujillo: 'Contribuciones originales de la medicina argentina a la medicina universal', Revista de Historia & Humanidades Médicas, Vol. 3 No 1, Julio 2007, http://www.fmv-uba.org.ar/histomedicina_old/Articulo%20-%20Aportes%20originales%20de%20la

ades de la sexualidad humana' (1925), arguably the first modern textbook on the subject, pioneered early cosmetic clitoris amputations, hypospadias surgery, and gonadectomies, as well as forced medical display.

- Hugh Hampton Young (Baltimore, USA), 'pioneer in pediatric urology'². Young's influential textbook 'Genital Abnormalities, Hermaphroditism, and Related Adrenal Diseases' (1937) advocated early cosmetic clitoris amputations, hypospadias surgery, and gonadectomies, as well as forced medical display. As did the revised later editions published by Howard W. Jones and William Wallace Scott in 1958³ and 1971⁴.
- Marcel Bettex (Berne, Switzerland), WOFAPS president 1984-1986, and co-contributor to Max Grob's (Zurich, Switzerland) influential textbook 'Lehrbuch der Kinderchirurgie' (1957), translated in six languages⁵, advocating early cosmetic clitoris amputations for psycho-social reasons as 'surely justified'⁶, as well as early cosmetic hypospadias surgery and gonadectomies, and forced medical display. Bettex's own textbook 'Wesentliches über Kinderchirurgie' (1975) still advocated early cosmetic clitoris amputations, as well as early cosmetic hypospadias surgery and gonadectomies, and forced medical display.

We deeply regret that until today WOFAPS, its member societies, as well as DSD Clinics and individual doctors represented at the 4th World Congress, refuse **coming to terms with the past** as a first step towards reconciliation. While we recognise the medical achievements of the participating societies, and of their past and present members, we feel it is intolerable to not also acknowledge their errors and the lifelong suffering they caused to the people concerned. We feel, especially for the societies and paediatric DSD clinics concerned it is long overdue to finally start a process of coming to terms with the past as a necessary first step towards **reconciliation**.

In addition, we are very saddened that WOFAPS, its member associations and individual surgeons still support the highly **stigmatising nomenclature 'Disorders of Sex Development (DSD)'**, and we deeply regret that, despite unequivocal criticism by most organisations of persons concerned, the societies represented at the 4th World Congress up to now refuse to consider more suitable suggestions, namely 'Variations of Sex Development'.

Last but not least, we are deeply saddened and concerned that until today, WOFAPS, its member associations and individual paediatric surgeons keep **endorsing and practicing medically not necessary cosmetic genital surgeries**, as well telling parents that it is suitable to 'consent' to medically not necessary, cosmetic genital surgeries on their children.

[%20medicina%20argentina.pdf](#)

2 Meldrum KK, Mathews R, Gearhart JP: 'Hugh Hampton Young: a pioneer in pediatric urology', J Urol. 2001 Oct;166(4):1415-7

3 Howard W. Jones, William Wallace Scott: 'Hermaphroditism, Genital Anomalies and Related Endocrine Disorders', Baltimore 1958.

4 Howard W. Jones, William Wallace Scott: 'Hermaphroditism, Genital Anomalies and Related Endocrine Disorders. Second Edition', Baltimore 1971.

5 'Forschungsmagazin Nr. 3 / 2009', Kinderspital Zürich (p 19), <http://www.kispi.uzh.ch/Kinderspital/Forschungsmagazin09.pdf>

6 Max Grob, Margrit Stockmann, Marcel Bettex: 'Lehrbuch der Kinderchirurgie', Stuttgart 1957, p 587.

A few selected examples of individuals and institutions represented at the 4th World Congress advocating medically not necessary, cosmetic genital surgeries, gonadectomies, imposition of hormones and other controversial treatments on children with ‘atypical’ sex anatomies:

- John Gearhart (Johns Hopkins School of Medicine, Baltimore, USA) became globally known (and criticised) mainly for the now classic quote attributed to him, ‘You can make a hole, but you can’t build a pole’⁷, as well as for his comment that men with small penises ‘sometimes try to kill themselves’⁸, for deliberately confusing orgasmic function with ‘successful vaginal penetration’⁹, and for not always diplomatic reactions in answer to well-founded criticism by persons concerned.¹⁰
- Peter Cuckow (Great Ormond Street Hospital for Children, The Paediatric Urology Partnership, London, UK), admits atypical sex anatomies to be ‘very distressing to the family, and surgery is available to make that appearance more acceptable’¹¹. The ‘live genital surgery’ event during the IV World Congress on Hypospadias and Disorders of Sex Development in London in 2011, in which Cuckow played an instrumental role, has been criticised in a recent thesis as not only causing ‘disquiet in European patient advocacy/activism circles’, but also deeply upsetting at least one participating clinician¹², and also attracted criticism during a hearing of the Australian Senate during of the ongoing Inquiry on involuntary or coerced sterilisation¹³.

7 Melissa Hendricks: ‘Is It a Boy or a Girl?’, Johns Hopkins Magazine, November 1993, 10-16, for criticism by persons concerned see e.g. Morgan Holmes: ‘remembering a Queer Body’, Undercurrents (May 1994: 11-13), <http://www.aissg.org/articles/HOLMES.HTM>; Cheryl Chase: ‘Hermaphrodites with attitude: Mapping the emergence of intersex political activism.’ GLQ 4(2):189–211 (1998), Michel Reiter: ‘Genitale Korrekturen an intersexuellen Menschen. “It’s easier to make a hole than to build a pole”’, Kassiber 34 (1998), http://www.nadir.org/nadir/initiativ/kombo/k_34isar.htm

8 Melissa Hendricks: ‘Is It a Boy or a Girl?’, Johns Hopkins Magazine, November 1993, p 10-16, for criticism by persons concerned see e.g. Iain Morland: ‘Thinking with the Phallus’, The Psychologist Vol 17 No 8 (2004), 448-450, http://www.thepsychologist.org.uk/archive/archive_home.cfm/volumeID_17-editionID_109-ArticleID_734-getfile_getPDF/thepsychologist%5C0804intersex.pdf

9 Bailez MM, Gearhart JP, Migeon C, Rock J, 1992: Vaginal reconstruction after initial construction of the external genitalia in girls with salt-wasting adrenal hyperplasia. J Urol 148: 680-682, for criticism by persons concerned see e.g. Cheryl Chase: ‘Affronting Reason’, in: Dawn Atkins (ed): Looking Queer (1998), 205-219

10 Cf. e.g. Natalie Angier: ‘Intersexual Healing: An Anomaly Finds a Group’, New York Times, Sunday 4 February 1996, Week in Review Section, p.14, <http://www.nytimes.com/1996/02/04/weekinreview/ideas-trends-intersexual-healing-an-anomaly-finds-a-group.html>; Martha Coventry: ‘The Tyranny of the Esthetic. Surgery’s Most Intimate Violation’, On The Issues Magazine, Vol 7, Summer 1998, <http://www.ontheissuesmagazine.com/1998summer/su98coventry.php>; Cheryl Chase: ‘What is the agenda of the intersex patient advocacy movement?’, Endocrinologist. 13(3):240-242, May/June 2003, <http://www.isna.org/agenda>

11 Murray, J., ‘Intersex conditions’, in: Woman’s Hour. 2001, BBC: London, http://www.bbc.co.uk/radio4/womanshour/10_12_01/tuesday/info1.shtml, for criticism see Cheryl Chase: ‘What is the agenda of the intersex patient advocacy movement?’, Endocrinologist. 13(3):240-242, May/June 2003, <http://www.isna.org/agenda>

12 Margaret Simmonds: ‘Girls/women in inverted commas – facing “reality” as an XY-female’, University of Sussex 2012, p 208, http://sro.sussex.ac.uk/43431/1/Simmonds,_Margaret.pdf

13 Parliament of Australia, Community Affairs References Committee, Senate committee, Thursday, 28 March 2013, ‘Involuntary or coerced sterilisation of people with disabilities in Australia’, Official Committee Hansard, Testimony by Y Gavriel Ansara, p 11, <http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id:%22committees/commsen/86ba4480-36ef-4e72-b25e-9fa162f9a4ae/0000%22>, 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

- Prem Puri (Our Ladies Children's Hospital, Dublin, Ireland) and Michael Höllwarth (Medical University, Graz, Austria), editors of the 2009 textbook 'Pediatric Surgery. Diagnosis and Management' which unimprovedly promotes a.o. cosmetic genital surgeries and castrations on children with 'Intersex Disorders' (Chapter 91, by Maria Marcela Bailez, J.P. Garrahan Children's University Hospital, Buenos Aires, Argentine), and cosmetic genital surgeries on children with 'Hypospadias' (Chapter 94, by Göran Läckgreny, University Children's Hospital, Uppsala, Sweden, and Agneta Nordenskjöld, Karolinska University Hospital, Stockholm, Sweden).
- Dix Poppas (American College of Surgeons, Children's Hospital of New York Presbyterian - Weill Medical College of Cornell University, New York City, USA), advocates early cosmetic genital surgeries e.g. for Congenital Adrenal Hyperplasia (CAH)¹⁴ and Hypospadias¹⁵, and attracted considerable public criticism after a bioethics examination¹⁶ of some of his methods went viral.
- Gabriele Jergl-Corkin, Clothilde Leriche (University Hospital, Ulm, Germany): According to a similar presentation given at the '4th International Symposium on Disorders of Sex Development' in June 2013 in Glasgow, Leriche 'has operated over 600 children with CAH, performing clitoris reductions, vaginoplasties and reconstructions of the labia.'¹⁷ (In 2012, Leriche claimed to have operated on '500 CAH-girls', as well as on '170 other children'.¹⁸)
- John M. Hutson (Royal Children's Hospital, Melbourne, Australia): According to a submission to the Australian Senate dated July 10, 2013, at RCH cosmetic genital surgery on DSD patients 'is most commonly performed in infancy', relying on 'highly skilled paediatric urologists with extensive experience in this area', but admitting 'that outcomes related to current approaches remain to be established'.¹⁹
- Ricardo González (Charité Universitätsmedizin, Berlin, Germany, Medizinische Hochschule Hannover (MHH), Germany, University Children's Hospital, Zurich, Switzerland, and Hospital Italiano, Buenos Aires, Argentine): E.g. in his 2006 publication 'Ambiguous Genitalia'²⁰, despite acknowledging 'considerable controversy [...] on how and when to surgically intervene in patients with female pseudohermaphroditism', González concludes unfazed: 'Although results for surgery for congenital adrenal hyperplasia have been less than satisfactory when adults who had surgery in childhood are evaluated, [...] we favor the continued development of more refined surgical techniques that may yield better results in the future.'

14 Weill Cornell Medical College: 'Surgical Management of Congenital Adrenal Hyperplasia', <https://www.cornellurology.com/clinical-conditions/pediatric-urology/genitoplasty-surgery>

15 Weill Cornell Medical College: 'Pediatric Urology / Hypospadias', <https://www.cornellurology.com/clinical-conditions/pediatric-urology/hypospadias/>

16 Alice Dreger and Ellen K. Feder: 'Bad Vibrations', Bioethics Forum, The Hastings Center Report, <http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=4730&blogid=140>

17 4th I-DSD Symposium 2013: 'Proceedings of the 4th International Symposium on Disorders of Sex Development', p 24-25, http://www.gla.ac.uk/media/media_279274_en.pdf

18 Clothilde Leriche: Presentation Fall 2012, <http://blog.zwischengeschlecht.info/post/2012/12/07/Intersex-Genitalverstümmelungen-Uniklinik-Ulm-DSD-Symposium>

19 Royal Children's Hospital, Melbourne: 'Modified terms of reference for the Senate Inquiry: The involuntary or coerced sterilisation of people with disabilities in Australia: People with intersex conditions', <http://www.aph.gov.au/DocumentStore.ashx?id=84e279b0-e824-4d4a-9aba-080b11077117&subId=16195>

20 Ricardo González, Lisandro A. Piaggio: 'Ambiguous Genitalia', *Curr Opin Urol* 16:273-296, 2006

One of the main concerns of persons concerned is that, instead of engaging in a dialogue with their (former) patients, clinicians prefer talking about them, but never with them. We therefore deeply regret that **persons concerned and their organisations are once again left out** completely at the 4th World Conference, as well as parents of persons concerned.

Furthermore, we deeply regret that the 4th World Conference still fails to adequately address at all the grave **ethical and legal implications** of non-consensual cosmetic genital surgeries on children with ‘atypical’ sex anatomies (including hypospadias repair), as well as non-consensual imposition of hormones (including 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, 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’^{21 22}, ‘traumatizing’²³, ‘immensely destructive of sexual sensation and of the sense of bodily integrity’^{24 25}, and have compared the surgeries and their effects to female genital mutilation²⁶ (which has been corroborated by international experts²⁷), and to child sexual abuse²⁸ (which also has been corroborated by studies²⁹). 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 excuses³⁰, ‘essentially impervious to data’³¹. In addition, until today there has been no reckoning at all regarding cosmetic clitoris amputations or any other earlier cosmetic practices.

21 ISNA: ‘Hypospadias: Parent’s Guide to Surgery’ <http://www.isna.org/node/81>

22 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>

23 Emi Koyama: ‘Intersex Medical Treatment and Sexual Trauma’

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

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

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

27 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

28 Tamara Alexander: ‘The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse’, <http://www.isna.org/articles/analog>

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

30 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

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

In the past decade, many reports and statements by Human Rights Advocacy Groups emerged (for example, Terre des Femmes 2004³², San Francisco Human Rights Commission 2005³³, CEDAW 2009³⁴, Amnesty Switzerland 2010³⁵, Amnesty Germany 2010³⁶), as well as further publications by experts in these fields (such as Hanny Lightfoot-Klein 2003/2008³⁷, Fana Asefaw 2005³⁸, Nancy Ehrenreich/Mark Barr 2005³⁹), 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 emphasise the similarities and **parallels** between such surgeries and the generally condemned practice of **female genital mutilations (FGM)**.

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'⁴⁰, on the basis of the concluding observations of the Committee on the Elimination of Discrimination against Women (CEDAW) on Costa Rica⁴¹, as a response to a shadow report by persons concerned⁴²
- 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 reparations⁴³
- 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 children⁴⁴, stressed their Right to Physical Integrity and the limits of the parent's rights to consent to cosmetic procedures for their children⁴⁵, and recommended reparations for survivors⁴⁶ as well as the suspension of the statutes of limitation until adulthood

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

33 http://www.isna.org/files/SFHRC_Intersex_Report.pdf

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

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

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

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

38 http://kastrationsspital.ch/public/FGC-intersex_2artikel_asefaw_hrzan.pdf

39 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

40 http://www2.ohchr.org/english/bodies/hrcouncil/docs/19session/A.HRC.19.41_English.pdf

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

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

43 http://www2.ohchr.org/english/bodies/cat/docs/co/CAT.C.DEU.CO.5_en.pdf

44 German Ethics Council: Empfehlungen 6 und 7 zur medizinischen Behandlung, Stellungnahme "Intersexualität", p. 174, <http://www.ethikrat.org/dateien/pdf/stellungnahme-intersexualitaet.pdf>

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

46 German Ethics Council: 8.3.8.1. "Entschädigungsfonds", Stellungnahme "Intersexualität", p. 164-166, <http://www.ethikrat.org/dateien/pdf/stellungnahme-intersexualitaet.pdf>

regarding lawsuits by survivors of non-consensual cosmetic genital surgeries on children.⁴⁷

- 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 this⁴⁸
- 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 legislation⁴⁹
- f) 2013 the Australian Senate initiated hearings on involuntary and coerced sterilisations, which explicitly include medically not necessary treatments on intersex people⁵⁰. Acknowledging the grave concerns, the Senate Committee decided to publish an individual report exclusively addressing human rights violations and non-consented medical treatments of children with 'atypical' sex anatomies.⁵¹
- g) 2013 in Germany a lawsuit by a person concerned against the University Hospital Erlangen and the surgeon 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 care⁵². Contrary to a motion by the defendants to dismiss the federal case, it has now been officially greenlit by a federal court.⁵³

47 German Ethics Council: Empfehlung 14 zur medizinischen Behandlung, Stellungnahme "Intersexualität", p. 176, <http://www.ethikrat.org/dateien/pdf/stellungnahme-intersexualitaet.pdf>

48 Swiss National Advisory Commission on Biomedical Ethics: 'On the management of differences of sex development', http://www.bag.admin.ch/nek-cne/04229/04232/index.html?lang=en&download=NHZLpZeg7t,lnp6l0NTU042l2Z6ln1ad1lZn4Z2qZpnO2Yuq2Z6gpJCKfX96f2ym162epYbg2c_JjKbNoKSn6A--

49 http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

50 <http://oii.org.au/21727/involuntary-sterilisation/>
<http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id:%22committees/commsen/86ba4480-36ef-4e72-b25e-9fa162f9a4ae/0000%22>

51 <http://oii.org.au/22861/senate-inquiry-sterilisation-update-fgm/>
<https://senate.aph.gov.au/submissions/committees/viewdocument.aspx?id=11a2158b-a218-46af-974d-3a900a430945>

52 http://aiclegal.org/wordpress/wp-content/uploads/2012/10/050714_Crawford_Complaint_Release_FINAL_FINAL.pdf

53 <http://aiclegal.org/aic-announces-important-first-victory-in-mc-case/>

- i) 2013 the German Federal Parliament unanimously referred three proposals to legislate against cosmetic genital surgeries on children with ‘atypical’ sex anatomies⁵⁴. All political parties now released statements approving legislation against cosmetic genital surgeries on children with ‘atypical’ sex anatomies.⁵⁵
- j) 2013 the Council of the European Union adopted Human Rights Guidelines explicitly criticising ‘medically unnecessary surgery, performed without their informed consent, or that of their parents, in an attempt to “fix” their sex’.⁵⁶
- k) 2013 the Council of Europe (COE) adopted the Resolution 1952 (2013) ‘Children’s right to physical integrity’, unmistakably criticising ‘the specific situation of intersex people [...] subjected to unnecessary medical or surgical treatment that is cosmetic rather than vital for health during infancy or childhood’, and calling for legislation.⁵⁷

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 getting 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.

And we are confident you also noticed the **recent increase in litigation** by or on behalf of former DSD patients, as well as the emerging pattern that it’s **mostly surgeons getting sued** for damages (e.g. € 100’000.– in the first successful German case in 2009⁵⁸, as compared to € 250’000.– in the current ongoing suit⁵⁹), while e.g. paediatric endocrinologists, who as a profession are often in charge of guidelines as well as individual treatments, up to now only appeared as expert witnesses, delivering statements used for sentencing while at the same time claiming they are not involved in the surgeries at all.

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, and that the 4th World Congress also mostly 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 grateful for your services, but on the other hand abandon unethical, inhumane and illegal practices like non-consensual cosmetic surgeries, gonadectomies, and imposition of hormones 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 as a step towards reconciliation**.

54 http://zwischenengeschlecht.org/public/Bundestag_17240_TOP-19_Intersex_Protokoll_Reden.pdf

55 See statements by party representatives of CDU/CSU, FDP and Greens collected here: <http://blog.zwischengeschlecht.info/post/2013/05/06/Do-16-5-2013-Bundestag-Antrage-Intersex-Genitalverstummelungen>

See also election touchstones 2013: http://blog.zwischengeschlecht.info/public/lsvd_wahl-2013_intersex.png

56 Council of the European Union, ‘Guidelines to Promote and Protect the Enjoyment of All Human Rights by Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Persons’ document number 11492/13, <http://register.consilium.europa.eu/pdf/en/13/st11/st11492.en13.pdf>

57 Assembly of the Council of Europe: Resolution 1952 (2013) ‘Children’s right to physical integrity’, <http://www.assembly.coe.int/nw/xml/XRef/X2H-Xref-ViewPDF.asp?FileID=20174&lang=en>

58 Landgericht Köln, 25 O 179/07 (06.02.2008), Oberlandesgericht Köln, 5 U 51/08 (03.09.2008), Landgericht Köln, 25 O 179/07 (12.08.2009)

59 Landgericht Nürnberg-Fürth, 4 O 7000/11 (ongoing)

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_at_zwischengeschlecht.org

AG Queer Studies, Hamburg, Germany

Beat Alig, Chur, Switzerland

Y Gavriel Ansara, School of Psychology, University of Surrey, UK

Karen Barouski, Wisconsin, USA

Councillor Tony Briffa JP, Vice-President OII Australia, Vice-President AIS Support Group Australia

Beatrice Busi, PhD in Philosophy of science, Research Fellow Verona University, Research Centre POLITESSE, Italy

Mauro Cabral, Argentina

Regula Cathomas, Chur, Switzerland

Fiorella Cerchiara, Italy

Susan 'Charlie' Chapler, M.D., Gualala, USA

Philippe Chételat, Switzerland

Milena Coccalotto, Turin, Italy

Carlotta Cossutta, PhD Student in Philosophy, University of Verona, Italy

Urs Dändliker, Männerdorf, Zurich

Milton Diamond, Professor, University of Hawaii, USA

Richard Duncker, Men Do Complain, London, UK

Ditte Dyreborg, Denmark, Intersex (Interkøn) individual, affiliated with Pangea International, and Co-founder of a Danish Intersex Organisation under development, Copenhagen, Denmark

Julian Fischer, Autonomes AStA-Schwulenreferat, Frankfurt a.M., Germany

Stefanie Föhring, Cologne, Germany

Yuri Guaiana, National Secretary of Associazione Radicale Certi Diritti, Italy

Do. Gerbig, Professional Academic and Captioner (Speech-to-Text), Hamburg, Germany

Kris Günther, OII Belgium and co-administrator Genres Pluriels

Bonnie Hart, President, AIS Support Group Australia

Phoebe Hart, Filmmaker, Australia

Diana Hartmann, Hamburg, Germany

Tino Hofmann, Berlin, Germany

Natasha Jiménez Mata, General Coordinator Mulabi/Latin American Space for Sexualities and Rights, Costa Rica

Karin Joss, Dällikon, Switzerland

Alex Jürgen, Neumarkt, Intersex Austria

Claudia Kasper, Munich, Germany

Michaela Katzer, Consultant Urologist, Halle, Germany

Jason Kirkpatrick, Filmmaker, Berlin, Germany

Michaela Koch, Carl von Ossietzky University Oldenburg, Hamburg, Germany
(Personal Capacity, Affiliation given for identification purposes only)

Claudia Koltzenburg, Nürtingen, Germany

Bianca Miglioretto, Zurich, Switzerland

J.G. Kuil, Netherlands

Camille Lamarre, intersexed, Nîmes, France

Dr Heinz Markwalder, Scientist, Zurich, Switzerland

Mischa Müller, Artist, Porquénao Society, Zurich, Switzerland

Pol Naidenov, Intersex person from Bulgaria

Tom Odegard/Ms.G, USA

Vincenza Perilli, Italy

Susanne Rohrer, Männedorf, Zurich

Victor Schiering, Facharbeitskreis Beschneidungsbetroffener im MOGiS e.V., Germany

Dr Tove Soiland, Lecturer, Universities of Zurich and Hamburg

Chris Somers xxy, Internationally known Intersex Activist since 1995, Australia

Pauline Sometimes, Committee member of organisations Manchester TransForum and Manchester Concord, UK
(Personal Capacity, Affiliation given for identification purposes only)

Dr Jemma Tosh, University of Chester, UK
(Personal Capacity, Affiliation given for identification purposes only)

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

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