Open Letter of Concern to the 9th Joint Meeting
by Persons Concerned, Partners, Families, Friends and Allies

9th Joint Meeting of Paediatric Endocrinology
c/o Milano Congressi
Piazzale Carlo Magno, 1
I-20149 Milano

European Society for Paediatric Endocrinology (ESPE)
Pediatric Endocrine Society (PES)
Australasian Paediatric Endocrine Group (APEG)
Asia Pacific Endocrine Society (APPES)
African Society for Pediatric and Adolescent Endocrinology (ASPAE)
Japanese Society for Pediatric Endocrinology (JSPE)
Sociedad Latinoamericana de Endocrinologia Pediatrica (SLEP)
Società Italiana di Endocrinologia e Diabetologia Pediatrica (SIEDP)
c/o 9th Joint Meeting of Paediatric Endocrinology
Milano Congressi
Piazzale Carlo Magno, 1
I-20149 Milano

Ospedale San Raffaele
Prof. Gabriele Pelissero, Presidente
Via Olgettina, 60
I-20132 Milano

Università Vita-Salute San Raffaele
Dott.ssa Raffaella Voltolini, Direttore Generale
Via Olgettina, 58
I-20132 Milano

Università degli Studi di Milano
Direzione
Via Festa del Perdono, 7
I-20122 Milano

Ospedale San Camillo-Forlanini
Aldo Morrone, Direttore Generale
Piazza Carlo Forlanini, 1
I-00151 Roma

Ospedale Maggiore Policlinico di Milano
Luigi Macchi, Direttore Generale
Via Francesco Sforza, 28
I-20122 Milano

Ospedale Maggiore Policlinico di Milano
Neonatologia Mangiagalli
Prof. Fabio Mosca, Direttore
Via della Commenda, 12
I-20122 Milano

Ospedale Regina Margherita
Dr. Angelo Del Favero, Direttore Generale
Corso Bramante, 88
I-10126 Torino
Dear Speakers, Chairpersons, and Participants of the 9\textsuperscript{th} Joint Meeting of Paediatric Endocrinology  
Dear Board, Scientific Committee and Members of ESPE, PES, APEG, APPES, ASPAE, JSPE, SLEP, and SIEPD  
Dear Directors of Paediatric DSD-Clinics in Italy  
Dear Directors of Milan Paediatric Clinic and University  

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 9\textsuperscript{th} Joint Meeting, as well as Italian 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 global dissemination of systematic cosmetic genital surgeries on children, including amputations or excisions of children’s clitorises and ‘prophylactic’ castrations, is inextricably linked to a.o. both PES and ESPE as professional societies, as well as to prominent individuals, e.g.:

- Lawson Wilkins, name patron of [LW]PES, ‘inventor’ of systematic cosmetic genital ‘corrections’ on children with ‘atypical’ sex anatomies\textsuperscript{1}, and forerunner of countless endocrinologists worldwide advocating cosmetic clitoris amputations on children under the pretext that ‘removal of the clitoris does not interfere with the ability to achieve orgasm.’\textsuperscript{2}

- Andrea Prader, founding member and president of ESPE, name patron of ESPE’s annual ‘Andrea Prader Prize’ also given out during the 9\textsuperscript{th} Joint Meeting, and inventor of the ‘Prader Scale’ still used to classify ‘too big’ clitorises in need of surgical ‘reduction’ until today.\textsuperscript{3}

We deeply regret that until today ESPE, PES, and the other societies participating at the 9\textsuperscript{th} Joint Meeting, refuse coming to terms with the past as a first step towards reconciliation. While we recognise the medical achievements of the societies participating at the 9\textsuperscript{th} Joint Meeting, 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.

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\textsuperscript{3} A Hughes, C Houk, S F Ahmed, P A Lee, LWPES/ESPE Consensus Group: ‘Consensus statement on management of intersex disorders’, see ‘Surgical management’, Arch Dis Child 2006;000:1–10
cerned. We feel, especially for the societies concerned it is long overdue to finally start a process of coming to terms with the past as a necessary first step towards reconciliation.

We are also very saddened that PES and ESPE were the driving forces behind the highly stigmatising new 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 9th Joint Meeting up to now refuse to consider more suitable suggestions, namely ‘Variations of Sex Development’.

In addition, we note that all current major government-funded DSD research projects are lead by paediatric endocrinologists advocating medically not necessary genital surgeries on children, and are offered a platform at the 9th Joint Meeting: I-DSD (WG6-117), DSD-Life (WG6-118), DSDnet (WG6-119). We are deeply saddened and concerned, that, despite some progress, persons concerned and their organisations are still far from being consulted properly, if at all.

Last but not least, we are deeply saddened and concerned that until today, paediatric endocrinologists are the medical profession mostly responsible for telling parents that it is suitable to ‘consent’ to medically not necessary, cosmetic genital surgeries on their children, as acknowledged within the 9th Joint Meeting itself, see abstract WG6-114: ‘The paediatric endocrinologist is often situated at the centre of the DSD team and acts as a conduit for communication’, while referring to the ‘UK DSD guidance document 2011’ that explicitly endorses medically not necessary, cosmetic surgeries: ‘Some parents may consider early genital surgery as a mechanism that could possibly protect their child from the risk of future stigma’.

A few additional random examples of societies, institutions and speakers featuring at the 9th Joint Meeting advocating medically not necessary, cosmetic genital surgeries, gonadectomies and imposition of hormones on children with ‘atypical’ sex anatomies:

- The 2011 APEG brochure ‘Hormones and Me: Congenital Adrenal Hyperplasia (CAH)” openly advocates cosmetic genital surgeries: ‘Some girls with CAH will have corrective surgery to their genitalia. Surgery is usually performed in infancy but it may be necessary to have further procedures later in life. Surgery normally involves reducing the size of the clitoris (while preserving sensation), separating the fused labia and enlarging the vaginal opening’ (p 17) – despite acknowledging at least some of the detrimental effects of the surgeries: ‘Some women with CAH who have had surgery may have difficulties with sexual intercourse, such as vaginal dryness or tightness’ (p 18).

- Olaf Hiort, Paediatric University Hospital Lübeck, Germany, team leader EuroDSD and DSDnet, in 2013 still advocates cosmetic ‘clitoral reductions’ on children.7

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4 S. Faisal Ahmed, Glasgow, UK: Abstract WG6-114 ‘Communication around the DSD patient in the clinical setting’
6 http://www.apeg.org.au/Portals/0/resources/Hormones_and_Me_8_CAH.pdf
• Berenice B. Mendonca, University Hospital of the Medical Faculty of São Paulo, Brazil, contributing to no less than 8 presentations within the programme of the 9th Joint Meeting, mostly related to DSD, and including the ‘SLEEP “Cesar Bergadà Lecture’’ (PL6-7), advocates cosmetic genital surgeries on children ‘preferably before 2 years of age’\(^8\) as well as ‘prepubertal gonadectomy’ in ‘CAIS patients’—despite acknowledging that ‘a recent study [2005] showed that tumor risk is low […] before and during puberty’ (but conveniently ignoring newer reviews indicating generally low cancer risks in CAIS patients).\(^9\)

• Mariacarolina Salerno, Federico II University of Naples, Italy, contributing to 5 poster presentations at the 9th Joint Meeting, incl. Sex Differentiation 2 (P1-d2-588), advocates both cosmetic genital surgeries on children and gonadectomies in an August 2013 newspaper article: ‘In the first case [PAIS] it’s often possible to assign the male gender, to correct the atypical genitalia surgically and prescribe a hormone therapy. In the second case [CAIS] it’s necessary to assign the female gender and in puberty we recommend removing the gonads.’\(^10\)

• In Italy, there’s a veritable ‘boom’ of cosmetic surgeries on ‘children of “uncertain” sex’, with ‘50 % growth rate’, and ‘during the last five years, over 350 sex change surgeries on children under 6 years’ at the Hospital San Camillo-Forlanini in Rome alone, but due to budgeting problems no qualified psychosocial support, according to director general Aldo Morrone in a June 2013 article.\(^11\)

While we are pleased to note that a member of a parent support group was invited to speak at the 9th Joint Meeting, and recognise this as a small step in the right direction, we deeply regret that persons concerned and their organisations are once again left out completely.

We also deeply regret that the 9th Joint Meeting 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.

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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’\textsuperscript{12, 13}, ‘traumatizing’\textsuperscript{14}, ‘immensely destructive of sexual sensation and of the sense of bodily integrity’\textsuperscript{15, 16}, and have compared the surgeries and their effects to female genital mutilation\textsuperscript{17} (which has been corroborated by international experts\textsuperscript{18}), and to child sexual abuse\textsuperscript{19} (which also has been corroborated by studies\textsuperscript{20}). 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\textsuperscript{21}, ‘essentially impervious to data’\textsuperscript{22}. 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\textsuperscript{23}, San Francisco Human Rights Commission 2005\textsuperscript{24}, CEDAW 2009\textsuperscript{25}, Amnesty Switzerland 2010\textsuperscript{26}, Amnesty Germany 2010\textsuperscript{27}), as well as further publications by experts in these fields (such as Hanny Lightfoot-Klein 2003/2008\textsuperscript{28}, Fana Asefaw 2005\textsuperscript{29}, Nancy Ehrenreich/Mark Barr 2005\textsuperscript{30}), all of them concluding that non-consensual cosmetic surgeries on children with ‘atypical’ sex anatomies

14 Emi Koyama: ‘Intersex Medical Treatment and Sexual Trauma’
17 ISNA’s Amicus Brief on Intersex Genital Surgery (1998) http://www.isna.org/node/97
26 http://blog.zwischengeschlecht.info/post/2010/04/26/Amnesty-Schweiz%C3%A9-Historischer-Entscheid-f%C3%Bcr-%C2%20Menschenrechte-auch-f%C3%Bcr-Zwitter%C2%20
27 http://blog.zwischengeschlecht.info/post/2010/05/26/Amnesty-Deutschland%C3%A9-Ebenfalls-historischer-Entscheid-f%C3%Bcr-%C2%20Menschenrechte-auch-f%C3%Bcr-Zwitter
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.

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’\(^{31}\), on the basis of the concluding observations of the Committee on the Elimination of Discrimination against Women (CEDAW) on Costa Rica\(^{32}\), as a response to a shadow report by persons concerned.\(^{33}\)

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.\(^{34}\)

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\(^{35}\), stressed their Right to Physical Integrity and the limits of the parent's rights to consent to cosmetic procedures for their children\(^{36}\), and recommended reparations for survivors\(^{37}\) as well as the suspension of the statutes of limitation until adulthood regarding lawsuits by survivors of non-consensual cosmetic genital surgeries on children.\(^{38}\)

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.\(^{39}\)

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

\(^{31}\) http://www2.ohchr.org/english/bodies/hrcouncil/docs/19session/A.HRC.19.41_English.pdf
\(^{32}\) http://www2.ohchr.org/english/bodies/cedaw/docs/co/CEDAW-C-cri-CO-5-6.pdf
\(^{34}\) http://www2.ohchr.org/english/bodies/cat/docs/co/CAT.C.DEU.CO.5_en.pdf
\(^{36}\) "Eine erste Einschätzung", http://diskurs.ethikrat.org/2011/06/eine-erste-einschatzung/
\(^{39}\) 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=NHzLpZeg7tInp6l0NTU04212Z6ln1ad1IIZn4Z2qZpmO2Yuq2Z6gpJCKfX96f2ym162epYbg2c_JjKbNoKSn6A--
causing severe mental suffering.’ The report also states, ‘These procedures [genital-normalising 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.\textsuperscript{40}

\begin{itemize}
\item[f)] 2013 the Australian Senate initiated hearings on involuntary and coerced sterilisations, which explicitly include medically not necessary treatments on intersex people\textsuperscript{41}. 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.\textsuperscript{42}
\item[g)] 2013 in Germany a lawsuit by a person concerned against the University Hospital Erlangen and individual employees for performing an irreversible and medically unnecessary surgery on the person concerned has been greenlit for trial.
\item[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\textsuperscript{43}. Contrary to a motion by the defendants to dismiss the federal case, it has now been officially greenlit by a federal court.\textsuperscript{44}
\item[i)] 2013 the German Federal Parliament unanimously referred three proposals to legislate against cosmetic genital surgeries on children with ‘atypical' sex anatomies\textsuperscript{45}. All political parties now released statements approving legislation against cosmetic genital surgeries on children with ‘atypical’ sex anatomies.\textsuperscript{46}
\item[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’.\textsuperscript{47}
\end{itemize}

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.

\textsuperscript{40} http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf
\textsuperscript{41} http://oii.org.au/21727/involuntary-sterilisation/
\textsuperscript{42} http://oii.org.au/22861/senate-inquiry-sterilisation-update-fgm/
\textsuperscript{44} http://aiclegal.org/wordpress/wp-content/uploads/2012/10/050714_Crawford_Complaint_Release_FINAL_FINAL.pdf
\textsuperscript{45} http://oii.org.au/aic-announces-important-first-victory-in-mc-case/
\textsuperscript{46} http://zwischengeschlecht.org/public/Bundestag_17240_TOP-19_Intersex_Protokoll_Reden.pdf
\textsuperscript{47} 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

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 9th Joint Meeting 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 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.

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

Ruby Almeida, Chair, Quest – Group for Lesbian and Gay Catholics, London, UK
Claudia Astorino, Assistant Director, OII USA
Michela Balocchi, PhD, Centro di Ricerca Politesse Università di Verona, intersexioni.it
Sophie Barbut, Luxembourg

Michael Bennett, Deputy Chair, Quest – Group for Lesbian and Gay Catholics, London, UK
Adriane Borger, Teacher, Zurich, Switzerland
Ben Böttger, NoNo Verlag, Berlin, Germany

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

Imy Callaway, Youth and Social Networker Outreach, Intersexuk, UK
Anne Carter, South Warwickshire Transgender and Intersex Group (SWTIG), UK
Susan ‘Charlie’ Chapler, M.D., Gualala, USA
Philippe Chételat, Switzerland
Hiker Chiu, Founder, OII Chinese, Taiwan
Carlotta Cossutta, PhD Student in Philosophy, University of Verona, Italy
Julia Dittmann, Filmmaker, Berlin, Germany
Richard Duncker, Men Do Complain, London, UK
Ditte Dyreborg, affiliated with Pangea International, Copenhagen, Denmark
Karin Erni, Langonnet, France
Frauenambulatorium, Switzerland
Julian Fischer, Autonomes AStA-Schwulenreferat, Frankfurt a.M., Germany
Do. Gerbig, Professional Academic and Captioner (Speech-to-Text), Hamburg, Germany
Holly Greenberry, Co Founder, Director & Public Relations, Intersexuk, UK
Claudia Griesser, Waltalingen, Switzerland
Eda Gross, Zurich, Switzerland
Vincent Guillot, Landelau, France
Kris Günther, OII Belgium and co-administrator Genres Pluriels
Phoebe Hart, Filmmaker, Australia
Diana Hartmann, Hamburg, Germany
International Alliance of Women (IAW)
Intersex & Transgender Luxembourg a.s.b.l.
Alex Jürgen, Intersex Austria
Claudia Kasper, München, Germany
Michaela Katzer, Consultant Urologist, Halle, Germany
Uli Kern, Social Anthropologist, Zurich, Switzerland
Claudia Koltzenburg, Nürtingen, Germany
J.G. Kuil, Netherlands
Lesbian and Gay Christian Movement (LGCM), London, UK
Dr. Heinz Markwalder, Scientist, Zurich, Switzerland
Mischa Müller, Artist, Zurich, Switzerland
Dr Tanya Ni Mhuirthile, Legal Specialist: Gender & Sex within Human Rights Law, Intersexuk, UK
OII Australia
Pidgeon Pagonis, Youth Leadership Intern, Advocates for Informed Choice, USA
(Personal capacity, affiliation given for identification purposes only)
Massimo Prearo, Marie Curie Fellow - Politesse / Politics and theory of sexuality - University of Verona, Italy

Dr. Tove Soiland, Lecturer, Universities of Zurich and Hamburg

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

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

Dawn Vago, P.R. & Outreach Educator, Intersexuk, UK

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

Hida Viloria, Chair, Organisation Intersex International / Director, OII USA
(Organisation Intersex International: Personal capacity, affiliation given for identification purposes only)

Anne Käthi Wehrli, Zurich, Switzerland

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