## Zwischengeschlecht.org

Human Rights for Hermaphrodites too! P.O.B. 2122 CH-8031 Zurich info\_at\_zwischengeschlecht.org

> 1st ESFFU-ESGURS Joint Meeting c/o Eberhard Karls Universität Tübingen Kupferbau Hölderlinstraße 5 72074 Tübingen

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Universitätsklinikum Tübingen (UKT) Geschäftsstelle Aufsichtsrat und Klinikumsvorstand Geissweg 3 72076 Tübingen

European Association of Urology (EAU) PO Box 30016 NL-6803 AA ARNHEM The Netherlands

Tübingen, October 6th 2011

## **Open Letter of Concern**

Dear Mr Karl-Dietrich Sievert

Dear Mr John Heesakkers

Dear Mr Serdar Deger

Dear Speakers, Chairpersons and Participants of the 1st ESFFU-ESGURS Joint Meeting

Dear Eberhard Karls Universität Tübingen

Dear Universitätsklinikum Tübingen (UKT)

Dear European Association of Urology (EAU)

As members of a human rights advocacy group, and as survivors of non-consensual childhood surgeries as well as persons concerned grateful for having escaped such surgeries, we are very saddened and concerned about how, as far as we can see, an overwhelming majority of the speakers and chairpersons at the '1st Joint Meeting of the EAU Section of Female and Functional Urology (ESFFU) and the EAU Section of Genito-Urinary Surgeons (ESGURS)' dealing with such surgeries seems to refuse to listen to their former patients, and instead continue to advocate and perform medically unnecessary cosmetic genital surgeries on children no matter what the consequences for these children. We deeply regret that the Eberhard Karls Universität Tübingen, renowned for its Internationales Zentrum für Ethik in den Wissenschaften (IZEW), the Universitätsklinikum Tübingen (UKT) and the European Association of Urology (EAU) take part in such a

questionable endeavour, including the infamous 'live surgeries', which also regularly have been taking place during the I-IV Symposium für Rekonstruktive Urologie held in Tübingen earlier.

For 50 years now, the practice of systematic cosmetic genital surgeries on little children with 'atypical' genitals persists. In all these years and decades, the clinicians responsible weren't able to produce any evidence for the alleged benefit to the children concerned, not even adequate follow-ups, or even just to disclose bare statistics, but insist on continuing to operate on the basis of mere anecdotal evidence.

For 20 years now, survivors of these surgeries have protested them, describing them consistently as 'very harmful' [1] [2], 'traumatizing' [3], as 'immensely destructive of sexual sensation and of the sense of bodily integrity' [4], and have compared the surgeries and their effects to female genital mutilation [5] and child sexual abuse [6]. For 20 years now, the clinicians concerned have refused to heed, let alone acknowledge these grave concerns, but instead continue repeating the same old excuses [7], 'essentially impervious to data' [8].

During the last decade, these accusations have been backed again and again by human rights experts [9] and honest clinicians alike [10].

However, as far as we know the vast majority just keeps on turning a blind eye to these criticisms of the surgeries. Examples from the roster of the 1st ESFFU-ESGURS Joint Meeting include:

Daniela Andrich (London): European Urology 54 (2008) 1031-1041 Anthony Mundy (London): European Urology 49 (2006) 774-776 Enzo Palminteri (Arezzo): European Urology 49 (2006) 887-895 Jörg Seibold (Tübingen): Der Urologe A 44 (2005) 768-773

Karl-Dietrich Sievert (Tübingen): Der Urologe A 44 (2005) 768-773

Arnulf Stenzl (Tübingen): Der Urologe A 44 (2005) 768-773

Considering this, it comes as no surprise that the 1st ESFFU-ESGURS Joint Meeting includes several unethical and inhumane cosmetic 'live surgeries', which also regularly have been taking place during the I-IV Symposium für Rekonstruktive Urologie in Tübingen earlier.

Something we find especially repugnant are the repeated statements, amongst others, by aforementioned clinicians relishing the 'surgical challenges', and stubbornly continuing with their 'experiments' in the hope that 'in 20 years surgery will be much better', obviously without any care, pity or compassion with their unfortunate past, present and future 'subjects'.

The same applies to the continuing scorn for, and intolerably paternalistic approaches towards, adult survivors of such surgeries who speak out about their suffering and demand an end of non-consensual cosmetic genital surgeries on children and minors, to the endeavours to marginalise their experiences, to deride them publicly and to deny their right to voice their experiences and opinions. Same as the claims of clinicians, actually to be the ones who are victimized, the alleged victimizers being survivors of their surgical experiments and human rights advocates.

We also note that the 1st ESFFU-ESGURS Joint Meeting utterly fails to address the ethical and legal implications of non-consensual cosmetic genital surgeries on children, despite the ongoing scholarly and public debate. There are many distinguished experts in the field of Ethics and 'DSD', such as Alice Dreger, Katrina Karkazis and Ellen Feder, who engage with these ethical issues. Unfortunately, none of these were invited, but in contrary, within the 1st ESFFU-ESGURS Joint Meeting, ethics and human rights of non-consensual cosmetic genital surgeries

on children are not even being considered at all. In our opinion, this demonstrates an obvious lack of willingness to listen to former patients, let alone to enter into a real debate in general and to answer to any critical questions in particular.

There are also many reports and statements by Human Rights Advocacy Groups (for example, Terre des Femmes 2004, San Francisco Human Rights Commission 2005, CEDAW 2009, Amnesty Switzerland 2010, Amnesty Germany 2010) and publications by experts in these fields (such as Hanny Lightfoot-Klein 2003/2008, Fana Asefaw 2005, Nancy Ehrenreich/Mark Barr 2005) clearly stating that non-consensual cosmetic surgeries on children gravely violate human rights, particularly the right to physical integrity, and who underline the similarities and parallels between these surgeries and the practice of female genital mutilations. Again, we feel an obvious lack of willingness by the 1st ESFFU-ESGURS Joint Meeting to acknowledge the facts, let alone to enter into a real debate in general and to answer any critical questions in particular.

Frankly, we are sick and tired of being lied to and being fobbed off with the same old denials, excuses and cheap promises.

We are sure you are aware of the controversy about cosmetic genital surgeries becoming better known in the general public every month, as well as of of the leaning of the general public with regards to genital mutilation, unethical medical experiments and unwanted surgeries.

It is our understanding, that in your capacity as clinicians you have plenty of patients with real medical needs who depend on your professional help, as well as the 1st ESFFU-ESGURS Joint Meeting partly also addresses real medical issues with bladder or urethral function.

Therefore, we would like to suggest respectfully that you focus your efforts on helping those patients, 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 on children, for which, as you are surely well aware, many, many of your former patients loathe and despise you from the bottom of their hearts, and wish you things, which our sense of politeness forbids us to repeat in this letter.

And we humbly suggest that you do so while you still can on your own terms.

Thank you for your consideration.

Kind regards

for Zwischengeschlecht.org

Daniela Truffer (President)

The human rights advocacy group Zwischengeschlecht.org demands the prohibition of cosmetic genital surgeries on children and minors and 'Human Rights for Hermaphrodites too!'

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## **Notes**

- [1] ISNA: 'Hypospadias: Parent's Guide to Surgery' http://www.isna.org/node/81
- [2] 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
- [3] Emi Koyama: 'Intersex Medical Treatment and Sexual Trauma'
- [4] Cheryl Chase: Letters from Readers. 1993, The Sciences, July/August, 3, http://www.isna.org/articles/chase1995a
- [5] ISNA's Amicus Brief on Intersex Genital Surgery (1998) http://www.isna.org/node/97
- [6] Tamara Alexander: 'The Medical Management of Intersexed Children: An Analogue for Child hood Sexual Abuse', http://www.isna.org/articles/analog
- [7] 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
- [8] Cheryl Chase: 'What is the agenda of the intersex patient advocacy movement?' (2002) http://www.isna.org/agenda
- [9] 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
- [10] cf. e.g. Emi Koyama: Catherine Minto & Sarah Creighton Fan Page http://www.ipdx.org/articles/minto-creighton.html