



NGO Report (for Session)

to the 5th and 6th Report of Austria on the Convention on the Rights of the Child (CRC)

Dear Committee on the Rights of the Child

1. Scope of this Submission

This Report is an update to the **Thematic Intersex NGO Report (for PSWG)**¹ by the same Rapporteurs² (henceforth PSWG Report). It documents new evidence and developments in Austria since the PSWG, namely of Austrian doctors and University hospitals advocating and perpetrating **IGM 1 “masculinising” surgery** (see p. 1), **IGM 2 “feminising” surgery** (p. 3) and discusses the recent **Ministerial “DSD Guidelines”** allowing IGM doctors to continue the practice with **impunity** (p. 4). It contains **Suggested Recommendations** (p. 6).

Further, we would like to express our **concern regarding the Committee’s decision not to mention the non-consensual, irreversible, medically unnecessary, cosmetic genital surgeries on intersex children justified by psychosocial indications** in the List of Issues for Austria (LOI) (CRC/C/AUT/Q/5-6). The Committee thus misses a window of opportunity to change the fate of intersex children in Austria.

What is more, since doctors specialising in IGM practices and Government bodies enabling them are known to monitor and consider relevant UN proceedings, there is reasonable cause for concern that both **Austrian and international IGM doctors and Government bodies in charge will construe further silence by the Committee about the ongoing practice in Austria as justification and encouragement** to continue, directly resulting in more **harm**.³

2. IGM 1 “Masculinising” Surgery

As documented in our **PSWG Report** (p. 12), the current **2018 ESPE/EAU “Paediatric Urology” Guidelines** chaired by Innsbruck paediatric urology head surgeon Prof Dr Christian Radmayr promote IGM 1 **“usually [at] 6-18 (24) months”**, and also other University Clinics promote **“early surgical correction” “around the 1st year of life”** (p. 12-13).

1 <http://intersex.shadowreport.org/public/2019-CRC-PSWG-Austria-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

2 Ibid., p. 5

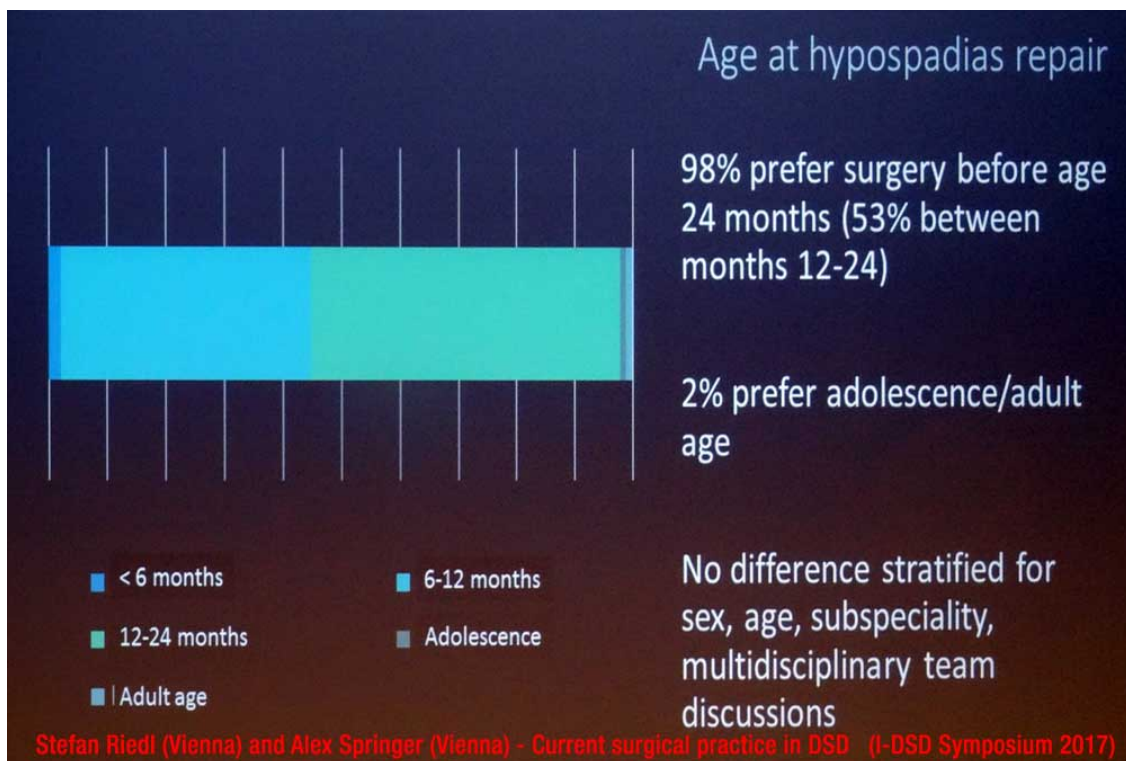
3 See personal **testimony** of Austrian IGM survivors, **2015 CAT Austria Intersex NGO Report**, p. 13-18, <http://intersex.shadowreport.org/public/2015-CAT-Austria-VIMOE-Zwischengeschlecht-Intersex-IGM.pdf>

In addition, a medical article by IGM doctors from the Departments of Pediatric Surgery and Urology of the **Medical University Vienna** published shortly after the PSWG deadline **promotes even more experimental “surgical techniques”**, and further offers revealing insights on the **frequency of IGM 1 and the harmful consequences**:

*“Materials and Methods: This is a **consecutive single team (2 surgeons)** retrospective series. **Between 2014 and 2017, 250 patients underwent hypospadias repair [...]. Median age at first stage was 1.5 (0.5–22.1) years [...].***

*Results: The total **complication rate was 22.9%. [...]**”⁴*

This continued preference for “*early surgical correction*” is also in line with a previous **survey** presented by partly the same **Vienna IGM doctors**:⁵



And it is further confirmed in an **October 2019** news report based on an interview again with **Vienna IGM doctor Stefan Riedl**:⁶

*“certain cases are **treated early** – in addition to medically necessary hormone treatment, these include **hypospadias repair** or the removal of functionless gonads”*

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- 4 Ursula Tonnhofer, Manuela Hiess, Martin Metzelder, Doris Hebenstreit, and Alexander Springer (2019), Midline Incision of a Graft in Staged Hypospadias Repair–Feasible and Durable?, *Frontiers in Pediatrics*, 2019; 7: 60, p. 1, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6423900/pdf/fped-07-00060.pdf>
- 5 Photo of presentation slide: Stefan Riedl (Vienna) and Alex[ander] Springer (Vienna) -Current surgical practice in DSD: results of the COST/DSDnet surgery survey, presentation at 6th I-DSD Symposium Copenhagen, 29.06.2017, see programme p. 5, https://www.gla.ac.uk/media/Media_533778_smxx.pdf
- 6 Der Standard (21.09.2019), “Geschlechterentwicklung: Was Ärzte tun, wenn ein Neugeborenes weder Mädchen noch Bub ist” [“*Sex development: What doctors do when a newborn is neither a girl nor a boy*”], <https://www.derstandard.at/story/2000108887801/was-aerzte-tun-wenn-ein-neugeborenes-weder-maedchen-noch-bub>

3. IGM 2 “Feminising” Surgery

As documented in our **PSWG Report** (p. 12), Austrian IGM doctors promote “*One-stage feminizing genitoplasty is recommended in young infants*” (p. 12)

In the meantime, some Austrian IGM doctors publicly **claim to have abandoned IGM 2** (however, they conveniently continue to **refuse to disclose relevant statistics**), for example again **Vienna IGM doctor** Stefan Riedl in the already mentioned **October 2019** news report:⁷

“In the past, interventions were carried out as soon as possible, today a reconsideration has taken place in medicine and irreversible interventions are avoided as far as possible, according to medical experts last week at the European Congress for Paediatric Endocrinology in Vienna. [...]

‘In all other cases [i.e. IGM 2] – based on the right to physical integrity – the patient is allowed as much time as possible until puberty or later,’ explains Riedl. If the prospective teenager is not yet sure of his or her gender identity when puberty sets in, it is also possible to delay puberty by administering hormone blockers.”

However, such **unsubstantiated claims** fly in the face of **current statistics** presented by another **Vienna IGM doctor** at the **September 2019** “*European Congress for Paediatric Endocrinology*” in Vienna mentioned in above quote (i.e. the **58th Annual Meeting of the European Society for Paediatric Endocrinology ESPE**):⁸

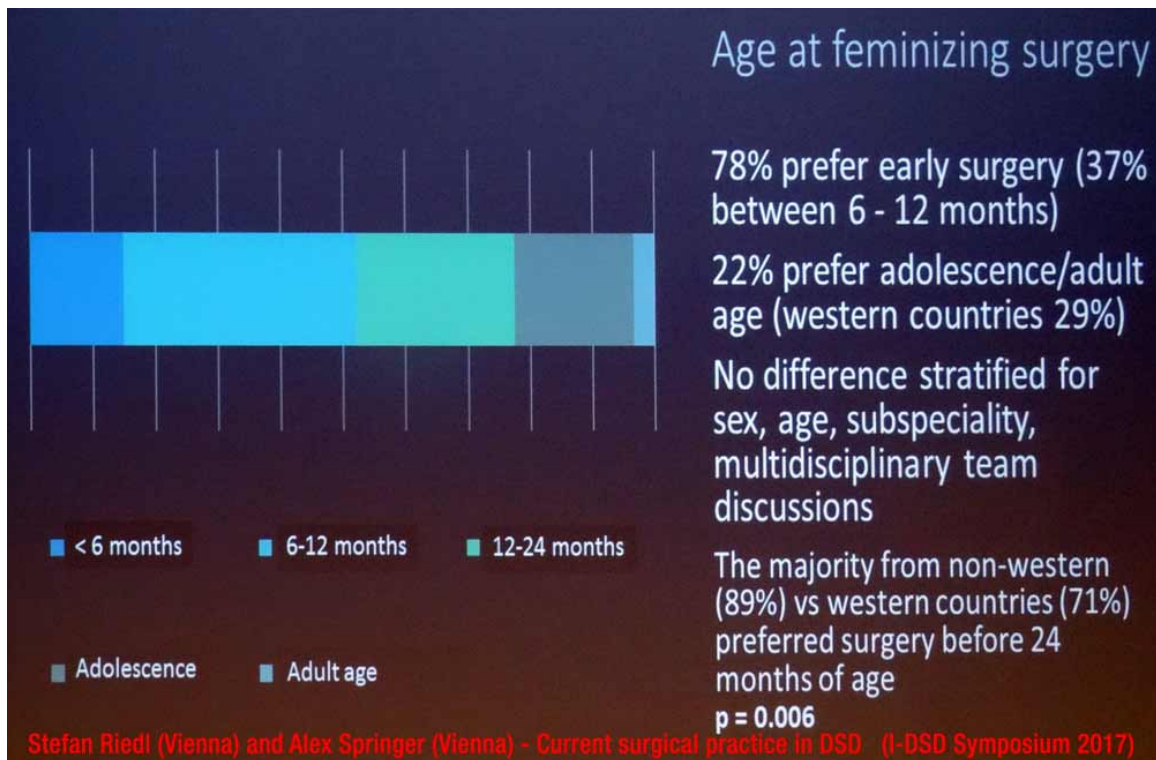
“Genital surgery has been performed in 251 (76%). Clitoral surgery been performed in 231 (92%), vaginal surgery in 204 (81%) and a combination of clitoral and vaginal surgery had been performed in 186 (74%). Of the 251 who had surgery, 18 (7%) had vaginal but no clitoral surgery whilst 42 (17%) had clitoral but no vaginal surgery. Mean age at first surgery was 2.5 years (0-15), with clitoral surgery and vaginal surgery at 2.6 years (range) and 3.2 years (range), respectively. [...] The Chicago Consensus Statement on DSD (comparison of data before and after 2006) did not have any significant influence on the timing or probability of surgery.”

What’s more, Riedl’s **unsubstantiated claims** fly in the face of the previously mentioned **survey** presented by Riedl **himself** and fellow **Vienna IGM doctor** Alexander Springer,⁹ documenting **preference for early “clitoral surgery” by IGM doctors** much in line with above ESPE statistics:

7 Ibid.

8 Doris Hebenstreit (Department of Urology, Hanusch Krankenhaus, **Vienna**), Faisal Ahmed, on behalf of the contributing centres within the I-DSD registry and I-CAH registry, Alexander Springer (Medical University **Vienna**), Christoph Krall, Nils Krone, Niels Birkebaek, Tatjana Milenkovic, Birgit Koehler, Christa Flueck, Ruth Krone, Antonio Balsamo, Rodolfo Rey, Carlo Acerini, Alya Guven, Tulay Guran, Feyza Darendeliler, Sabah Alvi, Marta Korbonits, Walter Bonfig, Eduardo Correa Costa, Richard Ross, Violeta Iotova, Daniel Konrad, Jillian Bryce, Hedi Claahsen van der Grinten, Liat de Vries, **Contemporary surgical approach in CAH 46XX – Results from the I-DSD/I-CAH Registries**, presentation at ESPE 2019, see Abstract Book, p. 96, <https://www.karger.com/Article/Pdf/501868>

9 Photo of presentation slide: Stefan Riedl (Vienna) and Alex[ander] Springer (Vienna) -Current surgical practice in DSD: results of the COST/DSDnet surgery survey, presentation at 6th I-DSD Symposium Copenhagen, 29.06.2017, see programme p. 5, https://www.gla.ac.uk/media/Media_533778_smxx.pdf



4. Ministerial “DSD Guidelines” allowing IGM doctors to continue with impunity

As documented in our **PSWG Report** (p. 9), an alarming new trend is the **increasing misrepresentation of IGM as “health-care issue”** instead of a serious violation of non-derogable human rights, and the **promotion of “self-regulation” of IGM by the current perpetrators** (i.e. IGM doctors, Health Ministries and other related actors and bodies) – instead of effective measures to finally end the **harmful practice** (as repeatedly stipulated also by this Committee).

Unfortunately, this has now also been the case in Austria:

Without public announcement, in **September 2019** the **Ministry of Health** published on its homepage a longwinded, 95-page **“Medical DSD Guideline”**.¹⁰ While its title *“Recommendations on variations of sex development”* clearly **alludes** to the vastly superior (and much more to the point) 2012 Swiss Bioethic Recommendations¹¹ which support prohibition of IGM under criminal law and to address obstacles to access to justice, namely the statutes of limitations,¹² and further the Ministry has to be commended to have also **consulted with Austrian intersex advocates**, unfortunately, it has to be clearly said that **in the end the Ministry sided with the IGM doctors and failed** to support the demands of intersex people.

10 Federal Ministry of Labour, Social Affairs, Health and Consumer Protection (2019), “Empfehlungen zu Varianten der Geschlechtsentwicklung” [*“Recommendations on variations of sex development”*], https://www.sozialministerium.at/dam/jcr:3e0dc44d-0464-42ed-ad1d-c3562ec8c873/empfehlungen_varianten_der_geschlechtsentwicklung.pdf

11 Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE) (2012), Zum Umgang mit Varianten der Geschlechtsentwicklung. Ethische Fragen zur “Intersexualität” [*“On the management of variations of sex development. Ethical issues relating to “intersex”*], English version see https://www.nek-cne.admin.ch/inhalte/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf

12 Ibid., see Recommendation 12, p. 19

Tellingly, while the “Guideline” contains a 9-page section “5 *Legal basis for variations of sex development*” (p. 20-28) which even mentions the “*prohibition of torture (Art. 3 ECHR)*” (p. 20) and “*the possible [!] right to redress after interventions that have subsequently turned out to be severely traumatising and restricting the quality of life*” (p. 19), it conveniently **fails to refer to the 2015 CAT Concluding Observations** to Austria on intersex and IGM (CAT/C/AUT/CO/6, paras 44-45), let alone to the **Convention on the Rights of the Child**, and/or protection from **harmful practices**.

What’s more, the “Guideline” again repeats the already above mentioned, **unsubstantiated claims of “considerable change” in the medical practice “in recent decades”** (p. 23).¹³

Accordingly, **Austrian intersex advocates have clearly and officially “criticise[d] double standards” of the “Guideline”**:¹⁴

“A definite refusal of non-consensual and medically unnecessary treatments is missing here [i.e. within the “Guideline”] and there [i.e. in recent unsubstantiated public claims of “change” by IGM doctors, see above], and so these continue to be carried out.”

Namely, **Platform Intersex Austria (PIÖ)** legal expert Eva Matt further observed:¹⁵

“The problem is that the various contributions in the paper partly contradict each other strongly. In everyday medical practice, very different therapy plans can be justified by this paper. There is no legal security for the physical autonomy of intersex people.”

And **Association of intersex people Austria (VIMÖ)** member Tinou Ponzer stated:¹⁶

“For twenty years, medical guidelines have spoken of a restrictive approach to surgery and of involving self-help groups. Unfortunately, in the peer support we have to find out again and again that this is not yet the case in practice in 2019.”

Nonetheless, it has to be expected that **Austrian Government representatives will still claim “we have now this wonderful new Guideline and everything is well”** – while at the same time **refusing to disclose data on the actual current practice** in Austria, let alone to finally **take effective measures against harmful practices on intersex children**, namely by **criminalising** the practice and to address obstacles to **access to justice and redress**, namely the **statutes of limitations**.

There we would like to again **urge the Committee to address IGM practices in Austria** in the forthcoming 83rd Session, and to **sternly remind Austria of its obligations under the Convention** to adequately protect intersex children against **harmful practices** (see next page).

Thank you for your consideration and kind regards,

Daniela Truffer & Markus Bauer (StopIGM.org / Zwischengeschlecht.org)

13 *“In recent decades, opinions about what is medically indicated in the case of a Variation of sex development and what is in the best interest of the child have changed considerably.”*

14 Association of intersex people Austria (VIMÖ) (07.10.2019), Press release: “Gesundheitsministerium veröffentlicht Empfehlungen zu Varianten der Geschlechtsentwicklung” [“Ministry of Health publishes recommendations on variations of sex development”], https://www.ots.at/presseaussendung/OTS_20191007_OTS0140/gesundheitsministerium-veroeffentlicht-empfehlungen-zu-varianten-der-geschlechtsentwicklung

15 Ibid.

16 Ibid.

5. Suggested Recommendations

The Rapporteurs respectfully suggest that, with respect to the treatment of intersex children in Austria, the Committee includes the following measures in their recommendations to the Austrian Government (in line with CRC's previous recommendations e.g. to Portugal, Malta, Belgium, South Africa, Denmark and Switzerland):

Harmful practices: Intersex genital mutilation

The Committee remains seriously concerned about cases of medically unnecessary and irreversible surgery and other treatment on intersex children both domestic and overseas, without their informed consent, which can cause severe suffering, and the lack of redress and compensation in such cases.

In the light of its joint general comment No. 18 (2014) and No. 31 of the Committee on the Elimination of Discrimination against Women on harmful practices, the Committee recommends that the State party:

- (a) Ensure that the State party's legislation explicitly prohibits all forms of intersex genital mutilation, by criminalising or adequately sanctioning unnecessary medical or surgical treatment during infancy or childhood, including extraterritorial protections, and provide families with intersex children with adequate counselling and support;**
- (b) Adopt legal provisions and repeal time-limits in order to provide redress to the victims of such treatment, including adequate compensation and as full rehabilitation as possible, and undertake investigation of incidents of surgical and other medical treatment of intersex children without their informed consent;**
- (c) Systematically collect disaggregated data on harmful practices in the State party and make information on the ways to combat these practices widely available;**
- (d) Educate and train medical, psychological and education professionals on intersex as a natural bodily variation and on the consequences of unnecessary surgical and other medical interventions for intersex children.**