

Intersex Genital Mutilation in Ukraine: Update to LOI Report

Dear Committee on the Rights of the Child

All typical forms of Intersex Genital Mutilation are still practised in Ukraine, both in public University hospitals and in private clinics, facilitated and paid for by the State party via the public health system. Parents and children are misinformed, kept in the dark, sworn to secrecy, kept isolated and denied appropriate support.

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1. Ukraine's commitment to "protect intersex children from violence and harmful practices", "ensure accountability" and "access to remedy"

UNHRC48 Statement, 04.10.2021

On occasion of the 48th Session of the Human Rights Council the State party supported a public follow-up statement reiterating the call to end harmful practices and ensure access to justice:

*"Intersex persons also need to be protected from **violence** and States must **ensure accountability** for these acts. [...]"*

*Furthermore, there is also a need to take measures to protect the **autonomy** of intersex children and adults and their rights to health and to **physical and mental integrity** so that they live **free from violence and harmful practices**. Medically unnecessary surgeries, hormonal treatments and other invasive or irreversible non-vital medical procedures without their free, prior, full and informed consent are **harmful to the full enjoyment of the human rights** of intersex persons.*

*We call on all member states to take measures to combat violence and discrimination against intersex persons, develop policies in close consultations with those affected, ensure accountability, reverse discriminatory laws and provide victims with access to remedy.”*¹

2. IGM practices persist, insufficient protections, Government fails to act

To this day, in Ukraine all forms of IGM practices remain widespread and ongoing, persistently advocated, prescribed and perpetrated in the state funded University hospitals and in private clinics.

a) IGM 3 – Sterilising Procedures:

**Castration / “Gonadectomy” / Hysterectomy /
Removal of “Discordant Reproductive Structures” / (Secondary) Sterilisation
Plus arbitrary imposition of hormones**²

The **Ukrainian Association of Urology (Асоціація Урологів України)** still endorses the unchanged, current **2022 Guidelines of the European Association of Urology (EAU)**,³ which include the current **ESPU/EAU “Paediatric Urology” Guidelines 2022**⁴ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU) which stress:⁵

“Individuals with DSD have an increased risk of developing cancers of the germ cell lineage, malignant germ cell tumours or germ cell cancer in comparison with to the general population.”

Further, regarding *“whether and when to pursue gonadal or genital surgery”*,⁶ the Guidelines refer to the *“ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)”*,⁷ which advocates “gonadectomies”:

“Testes are either brought down in boys or removed if dysgenetic with tumour risk or in complete androgen insensitivity syndrome or 5 alpha reductase deficiency. Testicular prostheses can be inserted at puberty at the patient’s request.”

Also, the **“2016 Global Disorders of Sex Development Consensus Statement”**⁸ refers to the *“ESPU/SPU standpoint”*, advocates *“gonadectomy”* – even when admitting *“low”* cancer risk for CAIS (and despite explicitly acknowledging CRC/C/CHE/CO/2-4)⁹:

1 Statement supported by Ukraine (and 52 other States) during the 48th Session of the Human Rights Council on 4 October 2021, <https://www.bmeia.gv.at/oev-genf/speeches/alle/2021/10/united-nations-human-rights-council-48th-session-joint-statement-on-the-human-rights-of-intersex-persons/>

2 For general information, see 2016 CEDAW NGO Report France, p. 47, <http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

3 <https://uroweb.org/guidelines/endorsement/>

4 <https://d56bochluxqz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2022.pdf>

5 Ibid., p. 89

6 Ibid., p. 88

7 P. Mouriquand, A. Caldamone, P. Malone, J.D. Frank, P. Hoebeke, “The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)”, *Journal of Pediatric Urology* vol. 10, no. 1 (2014), p. 8-10, [http://www.jpurology.com/article/S1477-5131\(13\)00313-6/pdf](http://www.jpurology.com/article/S1477-5131(13)00313-6/pdf)

8 Lee et al., “Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care”, *Horm Res Paediatr* 2016;85:158–180, <https://www.karger.com/Article/Pdf/442975>

9 Ibid., at 180 (fn 111)

Table 2. GCC risk: clinical management

| | Male | Female | Unclear gender |
|--|--|--|---|
| Gonadal dysgenesis (45,X/46,XY and 46,XY) | Undescended testes – Orchiopexy with biopsy – Self-examination – Annual ultrasound (post-puberty) Post-pubertal biopsy – Based on ultrasound and results of first biopsy – If CIS becomes GB → gonadectomy Low threshold for gonadectomy if ambiguous genitalia | Bilateral gonadectomy at diagnosis | Low threshold for gonadectomy if ambiguous genitalia If intact, gonadectomy depends on gender identity |
| Undervirilization (46,XY: partial AIS, complete AIS, testosterone synthesis disorders) | Undescended testes – Orchiopexy with biopsy – Self-examination – Annual ultrasound (post-puberty) Post-pubertal biopsy – Bilateral, CIS → gonadectomy/irradiation Repeat biopsy at 10 years of age – Consider gonadectomy to avoid gynecomastia or if on testosterone supplementation | Partial AIS and testosterone synthesis disorders – Prepubertal gonadectomy Complete AIS – Postpubertal gonadectomy or follow-up – GCC risk low, allow spontaneous puberty | Partial AIS and testosterone synthesis disorders – Bilateral biopsy – Low threshold for gonadectomy Intensive psychological counseling and follow-up |
| No data are available on the value of cryopreservation or safety if a precursor lesion for GCC is present. | | | |

Source: Lee et al., in: Horm Res Paediatr 2016;85:158-180, at 174

Accordingly, a **2022 medical publication** of doctors amongst others from the **Ukrainian Scientific and Practical Center of Endocrine Surgery, Transplantation of Endocrine Organs and Tissues of the Ministry of Health of Ukraine** in Kiev, and the **National Children’s Specialized Hospital OHMATDYT of the Ministry of Health of Ukraine** in Kiev reports **multiple cases** of intersex children submitted to “*gonadectomy*”.¹⁰

b) IGM 2 – “Feminising Procedures”: Clitoris Amputation/“Reduction”, “Vaginoplasty”, “Labiaplasty”, Dilatation¹¹

The **Ukrainian Association of Urology (Асоціація Урологів України)** still endorses the unchanged, current **2022 Guidelines of the European Association of Urology (EAU)**,¹² which include the current **ESPU/EAU “Paediatric Urology” Guidelines 2022**¹³ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In **chapter 3.17 “Disorders of sex development”**,¹⁴ despite admitting that “*Surgery that alters appearance is not urgent*”¹⁵ and that “*adverse outcomes have led to recommendations to delay unnecessary [clitoral] surgery to an age when the patient can give inform consent*”,¹⁶ the ESPU/EAU Guidelines nonetheless explicitly **refuse to postpone non-emergency surgery**, but in contrary **insist to continue with non-emergency genital surgery** (including partial clitoris amputation) on young children based on “*social and emotional conditions*” and **substituted decision-making by “parents and caregivers implicitly act[ing] in the best interest of their children**” and making “*well-informed decisions [...] on their behalf*”, and further **explicitly refusing “prohibition**

10 Evgenia Globa, Natalia Zelinska, Yulia Shcherbak, Joelle Bignon-Topalovic, Anu Bashamboo, Ken McElreavey, “Disorders of Sex Development in a Large Ukrainian Cohort: Clinical Diversity and Genetic Findings”, *Frontiers in Endocrinology*, 1 March 2022, Volume 13, Article 810782, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9012099/pdf/fendo-13-810782.pdf>

11 For general information, see 2016 CEDAW NGO Report France, p. 48, <https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

12 <https://uroweb.org/guidelines/endorsement/>

13 <https://d56bochluzqnx.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2022.pdf>

14 *Ibid.*, p. 86

15 *Ibid.*, p. 88

16 *Ibid.*, p. 88

regulations” of unnecessary early surgery,¹⁷ referring to the 2018 ESPU Open Letter to the Council of Europe (COE),¹⁸ which further invokes **parents’ “social, and cultural considerations”** as justifications for early surgery (p. 2).

Accordingly, news articles from 2017 describe how a **regional hospital in Lviv** performed surgery on a 3-year-old intersex child who first had been raised as a boy, but after thorough examination, it was decided that it would be better to raise the child as a girl, and **genitoplasty** was performed to make the child’s genitalia appear more female¹⁹. One of the articles states: *“Doctors introduced parents to the findings of geneticists and revealed to them all the complexities of surgery. If you shape a boy, then the operation will have to be done in several stages, it will be quite traumatic, but the main thing - the boy, when he grows up, will not be a full-fledged man, he will only resemble him on external grounds. It will be a great psychological trauma for him, and it is unknown how he will react to it. Nature ordered that the anatomical structure of the child’s body leaned more towards the girl. But the last word was for the parents. They, weighing all the pros and cons, decided to form a girl.”*²⁰

Also, a **2022 medical publication** of doctors amongst others from the **Ukrainian Scientific and Practical Center of Endocrine Surgery, Transplantation of Endocrine Organs and Tissues of the Ministry of Health of Ukraine** in Kiev, and the **National Children’s Specialized Hospital OHMATDYT of the Ministry of Health of Ukraine** in Kiev reports **multiple cases** of intersex children submitted to *“clitorectomy”, “vaginoplasty”* and *“reconstruction of the urogenital sinus”*.²¹

17 Ibid., p. 89

18 https://www.espu.org/images/documents/ESPU_Open_Letter_to_COE_2018-01-26.pdf

19 Quoted from: Egalite Intersex Ukraine, Organisation Intersex International Europe, NNID Foundation (2020), “The Rights of Intersex People in Ukraine. Parallel Report for the 67th session of the Committee on Economic, Social and Cultural Rights”, INT/CESCR/CSS/UKR/41269, para 10, Original sources:

Mishishin A. Вперше в Україні львівські медики прооперували ребенка с гермафродитизмом (For the first time in Ukraine, Lviv doctors operated on a child with hermaphroditism). KP. 6 April 2017.

https://zaxid.net/lvivski_hirurgi_sformuvali_stat_ditini_vzhe_pislya_yiyi_narodzhennya_n1422323

Druzhblyak N. Як Віктор став Вікторією (How Victor Became Victoria). High Castle Online. 07 April 2017.

<https://wz.lviv.ua/life/196616-yak-viktor-stav-viktoriei>

Balandyuh O. Львівські хірурги сформувавши стать дитини ... вже після її народження: Маля народилося істинним гермафродитом (Lviv surgeons formed the sex of the baby ... even after she was born: The baby was born a true hermaphrodite). Zaxit.net. 3 April 2017.

https://zaxid.net/lvivski_hirurgi_sformuvali_stat_ditini_vzhe_pislya_yiyi_narodzhennya_n1422323 .

Українські хірурги вперше провели ребенку операцію по смене пола (Ukrainian surgeons first performed a child sex change operation). InfoResist. 3 April 2019. <https://inforesist.org/ukrainskie-hirurgi-vervyie-proveli-rebenku-operatsiyu-po-smene-pola/>

20 Ibid., Original sources: **Balandyuh O.** Львівські хірурги сформувавши стать дитини ... вже після її народження: Маля народилося істинним гермафродитом (Lviv surgeons formed the sex of the baby ... even after she was born: The baby was born a true hermaphrodite). Zaxit.net. 3 April 2017.

https://zaxid.net/lvivski_hirurgi_sformuvali_stat_ditini_vzhe_pislya_yiyi_narodzhennya_n1422323

21 Evgenia Globa, Natalia Zelinska, Yulia Shcherbak, Joelle Bignon-Topalovic, Anu Bashamboo, Ken McElreavey, “Disorders of Sex Development in a Large Ukrainian Cohort: Clinical Diversity and Genetic Findings”, *Frontiers in Endocrinology*, 1 March 2022, Volume 13, Article 810782,

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9012099/pdf/fendo-13-810782.pdf>

c) IGM 1 – “Masculinising Surgery”: Hypospadias “Repair”²²

The **Ukrainian Association of Urology (Асоціація Урологів України)** still endorses the unchanged, current **2022 Guidelines of the European Association of Urology (EAU)**,²³ which include the current **ESPU/EAU “Paediatric Urology” Guidelines 2022**²⁴ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In **chapter 3.6 “Hypospadias”**,²⁵ the ESPU/EAU Guidelines’ **section 3.6.5.3 “Age at surgery”** nonetheless explicitly promotes, **“The age at surgery for primary hypospadias repair is usually 6-18 (24) months.”**²⁶ – despite admitting to the **“risk of complications”**²⁷ and **“aesthetic[...]**” and **“cosmetic”** justifications.²⁸

Multiple hospitals in Ukraine, including the **Oberig Clinic** in Kiew, the **Dobrobut Hospital** in Kiew, and the **Babykrok Clinic** associated with the **Zaporizhia State Medical University** continue to offer early **“surgical treatment of hypospadias”** (see our 2020 NGO Report for LOI, p. 9).

3. Replies to LOI fail to answer on intersex children and IGM

Intersex and IGM were not mentioned in the 5th and 6th Ukrainian State report, but were included in the List of Issues (para 5(e)). However, the Replies to the LOI failed to answer this question.

4. Lack of independent data collection and monitoring

In Ukraine, there are still no official statistics on intersex birth and on IGM practices available. Nonetheless, a **2022 medical publication** of doctors amongst others from the **Ukrainian Scientific and Practical Center of Endocrine Surgery, Transplantation of Endocrine Organs and Tissues of the Ministry of Health of Ukraine** in Kiew, and the **National Children’s Specialized Hospital OHMATDYT of the Ministry of Health of Ukraine** in Kiew reports **“682 DSD patients”** listed in the **“Ukrainian DSD Register”**, many of them submitted to IGM practices.²⁹

5. Public criticism of IGM and calls for a legal prohibition and access to redress

Local NGO **Egalite Intersex Ukraine** states on its homepage, **“the decision on surgical intervention can only be taken by the intersex person himself, reaching the mature age”**.³⁰ And under **“What are the human rights violations the most typically happen concerning intersex people?”**, it lists first, **“The right to life, liberty and personal integrity.”**³¹

22 For general information, see 2016 CEDAW NGO Report France, p. 48-49,

<https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

23 <https://uroweb.org/guidelines/endorsement/>

24 <https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2022.pdf>

25 Ibid., p. 26

26 Ibid., p. 27

27 Ibid., p. 27

28 Ibid., p. 27

29 Evgenia Globa, Natalia Zelinska, Yulia Shcherbak, Joelle Bignon-Topalovic, Anu Bashamboo, Ken McElreavey, “Disorders of Sex Development in a Large Ukrainian Cohort: Clinical Diversity and Genetic Findings”, *Frontiers in Endocrinology*, 1 March 2022, Volume 13, Article 810782, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9012099/pdf/fendo-13-810782.pdf>

30 <https://intersexukraine.org/en/answers-and-questions/#1553862340657-fab27839-c05c>

31 <https://intersexukraine.org/en/answers-and-questions/#1553862459595-5ece86e9-c463>

Already in a **2017 news article** a concerned intersex person spoke out against IGM practices:

*“Intersex children are the same children as everyone else. Their genetic and biological characteristics do not make them any different. **If these features do not endanger their health, intervention is not necessary. When becoming an adult, they will decide by themselves.**”*³²

Last but not least, in 2020 Egalite Intersex Ukraine recommended that Ukraine should “[a]dopt **clear legislative provisions explicitly prohibiting the performance of unnecessary surgical or other medical treatment on intersex children until they reach an age when they can give their free, prior and fully informed consent; provide families with intersex children with adequate counselling and support; provide redress for intersex persons who have undergone such unnecessary procedures, without fear of retribution or stigmatization, access to effective remedies and victim support, such as legal, social, medical and psychological assistance and consider establishing a state compensation fund.**”³³

32 Quoted from: Egalite Intersex Ukraine, Organisation Intersex International Europe, NNID Foundation (2020), “The Rights of Intersex People in Ukraine. Parallel Report for the 67th session of the Committee on Economic, Social and Cultural Rights”, INT/CESCR/CSS/UKR/41269, para 11, Original source:

Druzhblyak N. Як Віктор став Вікторією (How Victor Became Victoria). High Castle Online. 07 April 2017. <https://wz.lviv.ua/life/196616-yak-viktor-stav-viktoriei>

33 Egalite Intersex Ukraine, Organisation Intersex International Europe, NNID Foundation (2020), “The Rights of Intersex People in Ukraine. Parallel Report for the 67th session of the Committee on Economic, Social and Cultural Rights”, INT/CESCR/CSS/UKR/41269, Suggested Recommendations

6. Suggested Questions for the dialogue

Harmful practices on intersex children: We are concerned about reports of unnecessary genital surgery and other procedures on intersex children without their informed consent. These treatments can cause severe physical and psychological suffering, and can be considered as genital mutilation. We are also concerned about the lack of access to justice and redress in such cases.

My questions:

- **Please provide data on irreversible medical or surgical treatment of intersex children, disaggregated by type of intervention and age at intervention, including on hypospadias surgery.**
- **Which criminal or civil remedies are available for intersex people who have undergone involuntary irreversible medical or surgical treatment as children, and are these remedies subject to any statute of limitations?**

7. Suggested Recommendations

The Rapporteurs respectfully suggest that, with respect to the treatment of intersex persons in Ukraine, the Committee includes the following measures in their recommendations to the Ukrainian Government (in line with this Committee's previous recommendations on IGM practices).

Harmful practices: Intersex genital mutilation

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

With reference to the joint general recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/general comment No. 18 of the Committee on the Rights of the Child (2019) on harmful practices, and taking note of target 5.3 of the Sustainable Development Goals, the Committee urges the State party to:

- **Ensure that the State party's legislation explicitly prohibits the performance of unnecessary medical or surgical treatment on intersex children where those procedures may be safely deferred until children are able to provide their informed consent, and provide reparations for children who received unnecessary treatment, including by extending the statute of limitations.**
- **Provide families with intersex children with adequate counselling and support.**
- **Systematically collect data with a view to understanding the extent of these harmful practices so that children at risk can be more easily identified and their abuse prevented.**

Thank you for your consideration and kind regards,

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