

Intersex Genital Mutilation in Bulgaria: Update to LOIPR Report

Dear Committee on the Rights of the Child

All typical forms of Intersex Genital Mutilation are still practised in Bulgaria, 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. Despite repeated calls by intersex persons, NGOs and human rights agencies to protect intersex children, Bulgaria fails to act.

1. Updated summary	1
a) Lack of protections persists, Government fails to act	1
b) IGM practices persist	2
2. State Report confirms IGM practices continue, fails to provide data.....	2
a) LOIPR: CRC/C/BGR/QPR/6-7, paras 17(b)+36(b).....	2
b) State Report	3
3. Recent other reports corroborating IGM and public criticism	3
a) U.S. Department of State: Bulgaria 2021 Human Rights Report	3
b) ECRI Report on Bulgaria (2022)	3
4. Endorsed current guidelines, upcoming ESPU Course 2023 in Sofia.....	4
a) IGM 3 – Sterilising Procedures: Castration / “Gonadectomy” / Hysterectomy	4
b) IGM 2 – “Feminising Procedures”: Clitoris Amputation/“Reduction”, “Vaginoplasty”	5
c) IGM 1 – “Masculinising Surgery”: Hypospadias “Repair”	6
d) 2023 ESPU Paediatric Urology Course in Sofia	6
5. Suggested Questions for the dialogue.....	7
6. Suggested Recommendations	8

1. Updated summary

a) Lack of protections persists, Government fails to act

In **Bulgaria**, on the side of protections of intersex children from harmful practices, there are still

- **no legal or other protections** in place to **prevent all IGM practices** as stipulated in art. 24(3) and the CRC-CEDAW Joint General Comment No. 18/31,
- **no legal measures** in place to ensure **access to redress and justice** for adult IGM survivors,
- **no legal measures** in place to ensure the **accountability** of all IGM perpetrators and accessories,
- **no measures** in place to ensure **data collection** and **monitoring** of IGM practices.

Despite that the persistence of IGM practices in Bulgaria is a **matter of public record**, same as the **criticism and appeals by intersex persons, NGOs and human rights agencies**, to this day the Bulgarian Government fails to **recognise** the serious human rights violations and the severe pain and suffering caused by IGM practices, let alone to *“take effective legislative, administrative, judicial or other measures”* to protect intersex children from harmful practices.

b) IGM practices persist

To this day, in Bulgaria all forms of IGM practices remain widespread and ongoing, persistently **advocated, prescribed and perpetrated** by the state funded **University Hospitals**, as well as **private contractual hospitals**, and **paid for by the State** via the **public health system** financed by the compulsory **National Health Insurance Fund (NHIF)** for employees and self-employed persons, and for **children aged 0-18 directly by the State** (see also below, p. 3-6).

The best known hospitals practising IGM in Bulgaria remain the **Sofia University Hospital** and the **Varna University Hospital “St. Marina”** (see our NGO Report for LOIPR, p. 9-10), which are also involved in **international IGM networks**,¹ namely **“DSDnet”**,² the IGM-related Main Thematic Group **“MTG7: Sex Development & Maturation”** of **“Endo-ERN”**^{3 4} and the **“I-DSD/I-CAH Registry”**.⁵

However, besides the Sofia and Varna University Hospitals also various other **public University Hospitals** as well as **private clinics** practice IGM in Bulgaria (see our NGO Report for LOIPR, p. 10-12).

2. State Report confirms IGM practices continue, fails to provide data

a) LOIPR: CRC/C/BGR/QPR/6-7, paras 17(b)+36(b)

Harmful practices

17. Please explain the measures taken: [...]

(b) To prevent the unnecessary medical or surgical treatment of intersex children and provide adequate counselling, support and access to effective remedies for children subjected to such treatment during childhood, including by eliminating the statute of limitations for raising a claim against such treatment. [...]

D. Violence against children (arts. 19, 24 (3), 28 (2), 34, 37 (a) and 39)

36. Please provide data, disaggregated as described in paragraph 31 above, on: [...]

(b) The number of intersex children who have been subjected to irreversible medical or surgical procedures;

1 The Open Letter to “I-DSD 2017” lists Bulgarian University Clinics involved in international IGM projects, see p. 1, https://stopigm.org/public/Open_Letter_I-DSD_Copenhagen_2017.pdf

2 <http://www.dsdnet.eu/management-committee.html#Bulgaria>

3 UMHAT “Sveta Marina” (Varna), <https://endo-ern.eu/reference-centre/mhat-sveta-marina/>

4 UHOG “Maichin dom” (Sofia), see: Luca Persani, **Silvia Andonova**, et al. (2022), “The genetic diagnosis of rare endocrine disorders of sex development and maturation: a survey among Endo-ERN centres”, <https://ec.bioscientifica.com/view/journals/ec/11/12/EC-22-0367.xml>

5 See for example participation in poster “Contemporary Surgical Approach in CAH 46XX – Results from the I-DSD/I-CAH Registries”, https://abstracts.eurospe.org/hrp/0092/eposters/hrp0092rfc10.1_eposter.pdf

b) State Report

Regarding the **question 17(b) LOIPR** on measures taken to prevent IGM, the **State Report fails to give a specific answer**, but only generally mentions “*surgical interventions*” and risky “*invasive and other diagnostic and therapeutic methods*”. However, the answer given seems to **confirm that IGM practices** on “*minors and underage patients*” **continue** with substitute “*consent*” given by “*parent/guardian or guardian*”:

Harmful practices

Reply to paragraph 17 of the list of issues

[...]

115. In the case of surgical interventions, general anaesthesia, invasive and other diagnostic and therapeutic methods that lead to an increased risk to the patient’s life and health or to a temporary change in his/her consciousness, medical information and informed consent is provided in writing. Article 87 of the Health Act provides for the cases in which informed consent is expressed by legal representatives of the patient – parent/guardian or guardian, for minors and underage patients.

Regarding the **question 36(b) LOIPR** on numbers of IGM practices, the **State Report fails to provide any answers**: “1.0. Annex I” only covers question 36(a), and “1.1. Sub-annex I Data Para. 36” again only covers question 36(a).

3. Recent other reports corroborating IGM and public criticism

a) U.S. Department of State: Bulgaria 2021 Human Rights Report

“Acts of Violence, Criminalization, and Other Abuses Based on Sexual Orientation and Gender Identity

[...]

NGOs urged the government to discontinue normalization therapies on intersex children, which were funded by the National Health Insurance Fund with consent from their parents.” (p. 35-36)⁶

b) ECRI Report on Bulgaria (2022)

“20. In this monitoring cycle, ECRI also covers the situation of intersex persons. According to NGOs met by ECRI, intersex issues are often pathologised by healthcare professionals in Bulgaria and are frequently considered to necessitate a medical response. Most ‘sex-normalising’ treatments/surgery take place in early childhood with the consent of the parents. There are two specialised departments in the University hospitals in Sofia and in Varna. An LGBTI-NGO established contact with the heads of these departments and held meetings to raise awareness about intersex persons and their specific needs and problems from a rights-based perspective. ECRI strongly encourages the Bulgarian authorities to support such dialogue and to take inspiration from available international guidance on the topic.” (p. 10)⁷

⁶ https://www.state.gov/wp-content/uploads/2022/03/313615_BULGARIA-2021-HUMAN-RIGHTS-REPORT.pdf

⁷ European Commission against Racism and Intolerance ECRI (CoE) (2022), “ECRI REPORT ON BULGARIA (sixth monitoring cycle)”, <https://rm.coe.int/ecri-sixth-report-on-bulgaria/1680a83581>

4. Endorsed current guidelines, upcoming ESPU Course 2023 in Sofia

In 2023, Bulgarian medical bodies continue to endorse the current international ESPU/EAU medical guidelines prescribing all forms of IGM practices:

a) IGM 3 – Sterilising Procedures:

**Castration / “Gonadectomy” / Hysterectomy /
Removal of “Discordant Reproductive Structures” / (Secondary) Sterilisation
Plus arbitrary imposition of hormones**⁸

The **Bulgarian Association of Urology (Българско Урологично Дружество)** still endorses the unchanged, current **2022 Guidelines of the European Association of Urology (EAU)**,⁹ which include the current **ESPU/EAU “Paediatric Urology” Guidelines 2022**¹⁰ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU) which stress:¹¹

“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*”,¹² the Guidelines refer to the “*ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)*”,¹³ 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**”¹⁴ 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)¹⁵:

8 For general information, see 2016 CEDAW NGO Report France, p. 47,

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

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

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

11 Ibid., p. 89

12 Ibid., p. 88

13 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)

14 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>

15 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

b) IGM 2 – “Feminising Procedures”: Clitoris Amputation/“Reduction”, “Vaginoplasty”, “Labiaplasty”, Dilation¹⁶

The **Bulgarian Association of Urology (Българско Урологично Дружество)** still endorses the unchanged, current **2022 Guidelines of the European Association of Urology (EAU)**,¹⁷ which include the current **ESPU/EAU “Paediatric Urology” Guidelines 2022**¹⁸ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In **chapter 3.17 “Disorders of sex development”**,¹⁹ despite admitting that “*Surgery that alters appearance is not urgent*”²⁰ and that “*adverse outcomes have led to recommendations to delay unnecessary [clitoral] surgery to an age when the patient can give inform consent*”,²¹ 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 regulations”** of unnecessary early surgery,²² referring to the 2018 ESPU Open Letter to the Council of Europe (COE),²³ which further invokes **parents’ “social, and cultural considerations”** as justifications for early surgery (p. 2).

16 For general information, see 2016 CEDAW NGO Report France, p. 48,

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

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

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

19 Ibid., p. 86

20 Ibid., p. 88

21 Ibid., p. 88

22 Ibid., p. 89

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

c) IGM 1 – “Masculinising Surgery”: Hypospadias “Repair”²⁴

The **Bulgarian Association of Urology (Българско Урологично Дружество)** still endorses the unchanged, current **2022 Guidelines of the European Association of Urology (EAU)**,²⁵ which include the current **ESPU/EAU “Paediatric Urology” Guidelines 2022**²⁶ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In **chapter 3.6 “Hypospadias”**,²⁷ 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.”*²⁸ – despite admitting to the *“risk of complications”*²⁹ and *“aesthetic[...]”* and *“cosmetic”* justifications.³⁰

d) 2023 ESPU Paediatric Urology Course in Sofia

On 20-21 October 2023, the **“XIX ESPU Educational Course in Paediatric Urology”** co-organised by the **Bulgarian Society of Paediatric Urology and Nephrology** and the **Bulgarian Association of Urology** will take place in Sofia.³¹ While there is no programme available yet, the ESPU Educational Courses are known to regularly feature all forms of IGM practices.^{32 33}

24 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>

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

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

27 Ibid., p. 26

28 Ibid., p. 27

29 Ibid., p. 27

30 Ibid., p. 27

31 <https://www.espu.org/events/calendar/eventdetail/180/-/xix-espu-educational-course-in-paediatric-urology>

32 E.g. programme of “XVIII Educational Course” 2022, see “Genitalia I” and “Genitalia II”, p. 4-5,

https://www.espu.org/images/events/ESPU_18th_Educational_Committee_Course_2022_programme.pdf

33 E.g. programme of “XVII Educational Course” 2019, see “Live Surgery” and “Genitalia”, p. 2,

https://www.espu.org/images/events/XVII_ESPU_Educational_Course_2019_program.pdf

5. 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?**

6. Suggested Recommendations

The Rapporteurs respectfully suggest that, with respect to the treatment of intersex persons in Bulgaria, the Committee includes the following measures in their recommendations to the Bulgarian 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)