

Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Reproductive Anatomy



NGO Report (for Session)
to the 5th and 6th Report of Italy on the
Convention on the Rights of the Child (CRC)

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Introduction

Update: Intersex, IGM and Human Rights in Italy

IGM practices have been raised by the Committee in its **List of Issues** for Italy (CRC/C/ITA/Q/5-6, para 17(e)+(f)) and in the State party's **replies to the LOI** (CRC/C/ITA/Q/5-6/Add.1, paras 105-106; INT/CRC/ARL/ITA/3309/E, Tab 17). This NGO Report addresses **strengths and shortcomings of the statistics on IGM** provided by the State party, and documents recent developments concerning **involvement of Italian university hospitals in international IGM networks**. It contains **Suggested Recommendations** and two Annexes with personal **testimonies of Italian IGM survivors** and an extensive **documentation of IGM practices in Italy**.

IGM practices are known to cause severe, lifelong physical and psychological pain and suffering, and have been repeatedly **recognised by multiple UN treaty bodies¹ including CRC** as constituting a **harmful practice** and violence, and torture or ill-treatment.

About the Rapporteurs

This NGO report has been prepared by Italian intersex person and advocate *Claudia Balsamo* in collaboration with the international intersex NGO *StopIGM.org / Zwischengeschlecht.org*:

- **Claudia Balsamo** is an Italian intersex person and advocate familiar with IGM Practices who has been working to improve the well-being and human rights of intersex people in Italy and Europe, and to raise awareness on intersex issues.^{2 3 4} In 2006 she participated in the first meeting of people with AIS on Lake Como and participated in the formation of the self-help group *AISIA* (Associazione Italiana Sindrome di Insensibilità agli Androgeni),⁵ and served as *AISIA*'s vice president until 2013. In 2015 Claudia Balsamo co-founded the advocacy group *Intersex Esiste*, and presented at the Notes on Rights and Freedom sponsored by the President of the Council of Ministers of Italy.⁶
- **StopIGM.org / Zwischengeschlecht.org**, founded in 2007, is an international intersex human rights NGO based in Switzerland. It is led by intersex persons, their partners, families and friends, and works to eliminate IGM practices and other human rights violations perpetrated on intersex people, according to its motto, "*Human Rights for Hermaphrodites, too!*"⁷ According to its charter,⁸ *Zwischengeschlecht.org* works to support persons concerned seeking redress and justice. *StopIGM.org* has been active in Italy since 2013^{9 10 11 12 13} and regularly reports to UN treaty bodies.¹⁴

1 CAT, CRC, CRPD, SPT, SRT, SRSG VAC, COE, ACHPR, IACHR (2016), "End violence and harmful medical practices on intersex children and adults, UN and regional experts urge",

<http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E>

2 <https://www.interfaceproject.org/claudia-balsamo/> transcript: <https://www.interfaceproject.org/transcript-claudia-balsamo/>

3 <http://www.altrapsicologia.it/wp-content/uploads/2016/04/InterSex-Padova.pdf>

4 <http://www.comunicattive.org/intersex-esiste-nasce-un-approccio-colorato/>

5 <http://www.aisia.org>

6 http://www.unar.it/unar/portal/wp-content/uploads/2015/02/Programma_notedirittieliberta_febbraio2015.pdf

7 <http://Zwischengeschlecht.org/> English pages: <http://stop.genitalmutilation.org>

8 <http://zwischengeschlecht.org/post/Statuten>

9 http://zwischengeschlecht.org/public/Open_Letter_9th-Joint-Meeting_2013.pdf

This report is **endorsed** by Italian advocacy organisations **Intersexioni**¹⁵ and **Intersex Esiste**.¹⁶

In addition, the Rapporteurs would like to acknowledge the work of the self-help groups **AISIA** (Associazione Italiana Sindrome di Insensibilità agli Androgeni),¹⁷ **Nascere Klinefelter**¹⁸ and **Associazione ANIMrkhs**,¹⁹ intersex advocates **Alessandro Comeni**²⁰ and **Sabina Zagari**²¹, and researchers **Michela Balocchi**²² and **Daniela Crocetti**²³.

Methodology

This thematic NGO report is an update to the **2018 CRC Italy Intersex Report (for PSWG)**,²⁴ by the same rapporteurs.

This Report includes an Annexe with **4 anonymised personal testimonies of intersex persons**. The first person narratives have been collected with aid of the peer support group AISIA from submissions and interviews for the 2017 CEDAW Italy Intersex NGO Report (Case No. 1) and from interviews for the doctoral thesis and book of Daniela Crocetti (Cases No. 2-4). Each first-person narrative is preceded by a standardised abstract composed by the Rapporteurs. The identity of all persons concerned is known to AISIA and the Rapporteurs.

The small number of case studies is due to the fact that many patients, their families, and parents find it hard to speak about what happened to them, and do not wish their story to become public, even anonymously. These cases, however, show in an exemplary manner the **severe physical and mental pain and suffering** as a result of IGM practices in Italy.

10 <http://espresso.repubblica.it/attualita/cronaca/2013/09/19/news/noi-intersex-chiediamo-rispetto-1.134087>

11 <http://www.altrapsicologia.it/wp-content/uploads/2016/04/InterSex-Padova.pdf>

12 <http://www.certidiritti.org/x-congresso/>

13 http://www.npwj.org/sites/default/files/ressources/EN_BanFGMProgram_asdelivered_0.pdf

14 <http://intersex.shadowreport.org/>

15 <http://www.intersexioni.it/>

16 <http://www.intersexesiste.com/>

17 <http://www.aisia.org>

18 <http://www.nascereklinefelter.it/>

19 <http://www.animrkhs-onlus.org/>

20 <http://www.intersexioni.it/intervista-ad-alessandro-comeni/>

<http://www.pagina99.it/2016/11/05/storia-alessandro-comeni-interessuale-intersex-no-gender/>

21 <http://www.barinedita.it/storie-e-curiosita/n2865---intersex---nascere-sia-maschi-che-femmine--%C2%ABcostretti-a-mutilazioni-genitali%C2%BB>

<http://intersexday.org/en/discussion-evening-varese-italy/>

22 “Intersexions”, a wide three-year sociological research project by Dr. Michela Balocchi, funded by the Seventh Framework Program FP7-PEOPLE-2013 IOF of the European Union Marie Curie Actions n. 627162, <https://www.intersexionsproject.eu/en/info-map/>

23 Crocetti, Daniela (2011), Medicalizing gender: from intersex to DSD, from the laboratory to patient groups, [Dissertation thesis], Alma Mater Studiorum Università di Bologna. Dottorato di ricerca in Science, technology, and humanities, 23 Ciclo, http://amsdottorato.unibo.it/3282/1/Crocetti_Daniela_tesi.pdf

Crocetti D, 2013 L’Invisibile Intersex: Storie di Corpi Medicalizzati [Invisible Intersex: Histories of Medicalized Bodies], Pisa: Edizioni ETS, pp. 192, <http://www.edizioniets.com/scheda.asp?n=9788846737328>

24 <http://intersex.shadowreport.org/public/2018-CRC-PSWG-Italy-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

A. List of issues on Intersex (CRC/C/ITA/Q/5-6, para 17(e)+(f))

Data, statistics and other information, if available

[...]

17. Please provide, if available, updated statistical data disaggregated by age, sex, ethnic origin, national origin, geographic location and socioeconomic status, for the past three years, on:

[...]

(e) Children who are born intersex;

(f) The number of non-urgent, irreversible surgical and other procedures that have been undertaken on intersex children before an age at which they are able to provide informed consent;

B. Reply to the List of issues on Intersex (CRC/C/ITA/Q/5-6/Add.1, paras 105-106)

Question 17

[...]

(e)

105. No data is available in this area, as the Italian legislation does not allow for the registration of children at birth as intersex.

(f)

106. Data on this point is available in Annex I (Tab 17). [See next page]

C. Annex I to Reply to the List of issues on Intersex (INT/CRC/ARL/ITA/3309/E, Tab 17)

17. Please provide, if available, updated statistical data disaggregated by age, sex, ethnic origin, national origin, geographic location and socioeconomic status, for the past three years, on:

f) The number of non-urgent, irreversible surgical and other procedures that have been undertaken on intersex children before an age at which they are able to provide informed consent;

1. *[Unofficial English] Selection of codes for pathologies of sexual differentiation according to the International Classification of DSD (Disorders of Sex Development) established by the Chicago Consensus Conference of 2006, which identifies and classifies a series of pathologies that can determine DSD of various degrees, as indicated in the following table:*

Codice ICD9-CM	Descrizione diagnosi
758:07:00	Sindrome di Klinefelter
758:06:00	Disgenesia gonadica
752:07:00	Sesso indeterminato e pseudoermafroditismo
758.81	Altre manifestazioni dovute ad anomalie dei cromosomi sessuali
257:02:00	Altre ipofunzioni testicolari
259:05:00	Sindrome da resistenza androgenica
255:02:00	Sindromi adrenogenitali

2. *[Unofficial English] Selection of surgical interventions and procedures of interest to the urogenital apparatus, as indicated in the following table:*

Codice ICD9-CM	Descrizione intervento chirurgico-procedura
58:45:00	Riparazione di ipospadia o epispadia
71:04:00	Interventi sul clitoride
70:06:00	Interventi sulla vagina
62:41:00	Orchiectomia bilaterale
63:04:00	Epididimectomia
63:07:00	Vasectomia e legatura dei vasi deferenti
65:05:00	Ovariectomia bilaterale
66:02:00	Demolizione od occlusione endoscopica bilaterale delle tube
66:03:00	Altra demolizione od occlusione bilaterale delle tube
66:05:00	Salpingectomia totale bilaterale
68:04:00	Isterectomia addominale totale
68:05:00	Isterectomia vaginale
68:06:00	Isterectomia addominale radicale
68:07:00	Isterectomia vaginale radicale
68:08:00	Eviscerazione pelvica

[Unofficial English] Source: Ministry of Health

[Unofficial English] The attached tables illustrate, for each of the years under examination, the total cases of hospital discharge for pathologies related to DSD, and with surgery, disaggregated by age, gender and citizenship. Cases with surgery represent respectively 0.8% of the total in 2015, 0.9% in 2016 and 0.2% in 2017.

[Note: The following tables only present the summaries of total numbers, for the full tables, see: http://intersex.shadowreport.org/public/CRC80-Italy-Annexe-I-Tab17-Intersex_INT_CRC_ARL_ITA_33009_E.xls]

Year 2015. Non-urgent hospital discharges for DSD with and without surgical procedures. Age 0-17					
		SEX			
AGE	CITIZENSHIP	O	F	M	TOTAL
Totale complessivo		3	861	554	1418

[Unofficial English] Source: Ministry of Health

Year 2015. Non-urgent hospital discharges for DSD with surgical procedures. Age 0-17				
		SEX		
AGE	CITIZENSHIP	F	M	TOTAL
Total		7	5	12

[Unofficial English] Source: Ministry of Health

Year 2016. Non-urgent hospital discharges for DSD with and without surgical procedures. Age 0-17				
		SEX		
AGE	CITIZENSHIP	F	M	TOTAL
TOTAL		777	602	1'379

[Unofficial English] Source: Ministry of Health

Year 2016. Non-urgent hospital discharges for DSD with surgical procedures. Age 0-17				
		SEX		
AGE	CITIZENSHIP	F	M	TOTAL
Total		6	7	13

[Unofficial English] Source: Ministry of Health

Year 2017. Non-urgent hospital discharges for DSD with and without surgical procedures. Age 0-17				
		SEX		
AGE	CITIZENSHIP	F	M	TOTAL
Total		695	555	1'252

[Unofficial English] Source: Ministry of Health

Year 2017. Non-urgent hospital discharges for DSD with surgical procedures. Age 0-17				
		SEX		
AGE	CITIZENSHIP	F	M	TOTAL
Total		2	1	3

[Unofficial English] Source: Ministry of Health

D. Recent Developments not mentioned in Replies to the LOI

1. Italian University Hospitals involved in International IGM Networks

In 2017, the “European Reference Network” was launched to ensure better treatment for patients with rare diseases within the European Union.²⁵ Unfortunately, **2 of the newly created “ERNs” also specialise in the proliferation and practice of IGM**, namely the “**Network Urogenital Diseases**” a.k.a. “**eUROGEN**” and the “**Network on Endocrine Conditions**” a.k.a. “**Endo-ERN**”.²⁶ Like with earlier international networks led by IGM perpetrators, e.g. “I-DSD”²⁷ and “DSDnet”,²⁸ Italian Hospitals are again involved.²⁹

Italian “**eUROGEN**” members specialising in IGM practices³⁰ (e.g. “*Posterior hypospadias*”, “*Non-syndromical urogenital malformations*”, “*Urethral reconstruction in rare diseases/conditions*”, “*Urorectal/anorectal malformations*”, “*Complex genital reconstructions (DSDs)*”) include the **Azienda Ospedaliera Padua**, the **Fondazione Policlinico Universitario Agostino Gemelli Roma**, the **Fondazione IRCCS Ca’ Granda Ospedale Maggiore Policlinico Milano**, and the **Ospedale Pediatrico Bambino Gesù Roma** (see also Annexe 2: IGM Practices in Italy, p. 20-25).

Italian “**Endo-ERN**” members³¹ participating in the IGM-related Main Thematic Group “**MTG7: Sex Development & Maturation**” include the **Azienda Ospedaliera Sant’Orsola Malpighi Bologna**, the **Azienda Ospedaliera Universitaria Careggi Firenze**, the **Ospedale San Raffaele Milano**, the **Istituto Auxologico Italiano – Istituto di Ricovero e Cura a Carattere Scientifico Milano**, the **Azienda Ospedaliera Universitaria “Federico II” Napoli**, and the **Azienda Ospedaliera di Padova** (see also Annexe 2: IGM Practices in Italy, p. 20-25).

25 https://ec.europa.eu/health/sites/health/files/ern/docs/2017_brochure_en.pdf

26 See <http://stop.genitalmutilation.org/post/eUROGEN-EU-funded-Intersex-Genital-Mutilators>

27 See Open Letter to “I-DSD 2017”, http://stop.genitalmutilation.org/public/Open_Letter_I-DSD_Copenhagen_2017.pdf

28 See <http://stop.genitalmutilation.org/post/DSDnet-Intersex-Genital-Mutilators-European-Union>

29 The Open Letter to “I-DSD 2017” lists Italian University Clinics involved in current international IGM projects, see p. 1, http://stop.genitalmutilation.org/public/Open_Letter_I-DSD_Copenhagen_2017.pdf

30 <http://eurogen-ern.eu/healthcare-providers/our-members/>

31 <https://endo-ern.eu/about/reference-centers/>

E. Claims of the Italian Government in its Replies to the LOI

In the List of Issues (CRC/C/ITA/Q/5-6, para 17(e)+(f)) the Italian government was asked to “provide, if available, updated statistical data disaggregated by age, sex, ethnic origin, national origin, geographic location and socioeconomic status, for the past three years, on: [...] (e) Children who are born intersex; (f) The number of non-urgent, irreversible surgical and other procedures that have been undertaken on intersex children before an age at which they are able to provide informed consent”.

In its replies to the List of Issues (CRC/C/ITA/Q/5-6/Add.1, paras 105-106), and in the Annex I (INT/CRC/ARL/ITA/3309/E, Tab 17) the Italian government makes a series of **claims, on which the Rapporteurs would like to comment:**

1. Claim “No Data available because no Registration at Birth as Intersex”

105. *No data is available in this area, as the Italian legislation does not allow for the registration of children at birth as intersex.*

Intersex is not a 3rd gender or sex, but a physical variation of reproductive anatomy, see 2014 CRC Switzerland NGO Report, p. 8-11.³² Intersex variations are medically subsumed under a list of relevant medical diagnoses (see also below 2.). In order to collect data on intersex births, one would simply need to collect data of births of children with associated diagnoses.

2. Claim “Selection of ICD9-CM Codes for Variations of Sexual Differentiation”

Annex I, Tab 17: 1. *Selection of codes for pathologies of sexual differentiation according to the International Classification of DSD (Disorders of Sex Development) established by the Chicago Consensus Conference of 2006, which identifies and classifies a series of pathologies that can determine DSD of various degrees, as indicated in the following table:*

The listed 7 diagnoses are only a selection indeed, with the most frequent diagnosis (hypospadias) and others **missing**, including:

752.61 Hypospadias

752.45 Vaginal agenesis

752.51 Undescended testis

3. Claim “Selection of ICD9-CM Codes for Surgical Interventions”

Annex I, Tab 17: 2. *Selection of surgical interventions and procedures of interest to the urogenital apparatus, as indicated in the following table:*

While this selection of procedures is **more comprehensive** than above selection of diagnoses, **missing** interventions often associated with intersex variations include:

65.3 Unilateral oophorectomy

62.3 Unilateral orchiectomy

62.5 Orchiopexy

32 http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

4. Claim “Total Numbers DSD-related Discharges Age 0-17”

Annex I, Tab 17: *The attached tables illustrate, for each of the years under examination, the total cases of hospital discharge for pathologies related to DSD [with and without] surgery, disaggregated by age, gender and citizenship. [...]*

The tables list **total numbers of DSD-related non-urgent hospital discharges age 0-17** with and without surgery:

2015: 1418

2016: 1379

2017: 1252

We commend the State party on these extensive statistics, which seem fairly exhaustive and accurate, considering approximately 480’000 annual live births on average in Italy 2015-2017 and an incidence of about 0.2% intersex births,³³ and further considering that intersex children may stay in and be discharged from hospitals not only after birth, but also in following years.

5. Claim “Total Numbers DSD-related Discharges Age 0-17 with Surgery”

Annex I, Tab 17: *The attached tables illustrate, for each of the years under examination, the total cases of hospital discharge for pathologies related to DSD [...] with surgery, disaggregated by age, gender and citizenship. Cases with surgery represent respectively 0.8% of the total in 2015, 0.9% in 2016 and 0.2% in 2017.*

The tables list **total numbers of DSD-related non-urgent hospital discharges with surgery**:

2015: 12

2016: 13

2017: 3

We commend the State party for openly admitting that IGM practices continue to be performed in Italian children’s clinics, and that the majority of IGM related surgeries continue to be performed in the **first 2 years of life**, which correlates with medical recommendations on the timing of IGM surgery.

We note with concern, however, that these statistics on surgery seem far from exhaustive, but in fact appear to be **unrealistically low**. In particular they fly in the face of **case numbers published by Italian doctors and clinics**:

33 See 2014 CRC Switzerland NGO Report, p. 10-11,

http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

For example the Italian “**It-DSD Study Group**”, a consortium of specialised IGM doctors and clinics in Milano, Torino, Padova, Bologna, Pisa, Roma, Napoli and Palermo, prominently publishes the following figures on their homepage (scroll down):³⁴



5600 diagnoses annually, **456 interventions**, 67% male incidence, 33% female

Or a 2013 study from the paediatric urology department of the **Ospedale Maggiore-Policlinico** in Milano lists 770 primary hypospadias surgeries in 1991-2004, i.e. **over 50 hypospadias surgeries annually** in one clinic alone.³⁵

And a 2004 study from the “Paediatric Surgery Unit” of the **Azienda Ospedaliera San Camillo-Forlanini, Rome**³⁶ reports 693 children submitted to “hypospadias repair” in 10 years, i.e. **69 patients operated annually**, all by one single surgeon, Giacinto Marrocco (see also Annexe 2: IGM Practices in Italy, p. 20-25).

And a 2004 publication on hypospadias by **4 eminent, mostly Italian surgeons** states:³⁷

*“The **surgeon** of whichever speciality should have a dedicated interest in this challenging work, ideally having an **annual volume of at least 40-50 cases**. The ideal time for primary repair is at 6-12 months old [...].”*

Considering that **more than 8 specialised IGM clinics** are members in the **It-DSD Study Group** alone, with each clinic generally employing more than one specialised paediatric urology surgeon, the **alleged total numbers of IGM surgeries** claimed in the replies to the LOI by the Italian Ministry of Health are **obviously far from the truth**.

However, **without statistics disaggregated** not only by age during surgery, but **also by type of intervention**, it’s impossible to determine **where exactly the fault lies** with the alleged numbers given by the Italian Ministry of Health.

34 <http://www.dsd-it.it/>

35 Vallasciani S, Berrettini A, Nanni L, Manzoni G, Marrocco G (2013), Observational retrospective study on acquired megalourethra after primary proximal hypospadias repair and its recurrence after tapering, J Pediatr Urol. 2013 Jun;9(3):364-7, <https://www.ncbi.nlm.nih.gov/pubmed/22658746>

36 G. Marrocco, S. Vallasciani, G. Fiocca, A. Calisti (2004), Hypospadias surgery: a 10-year review. Pediatric surgery international, 20:200–203, at 202, https://www.researchgate.net/publication/8620545_Hypospadias_surgery_A_10-year_review

37 Manzoni G, Bracka A, Palminteri E, Marrocco G (2004): Hypospadias surgery: when, what and by whom? 2004 BJU International No. 94, 1188–1195, at 1188, <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.562.7831&rep=rep1&type=pdf>

F. Suggested Recommendations

The Rapporteurs respectfully suggest that, with respect to the treatment of intersex persons in Italy, the Committee includes the following measures in their recommendations to the Italian Government (in line with CRC's previous recommendations e.g. to 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, 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 intersex genital mutilation, by criminalising or adequately sanctioning unnecessary medical or surgical treatment during infancy or childhood, to guarantee bodily integrity, autonomy and self-determination to children concerned, 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.**

G. Annexe 1 – “Case Studies”

The first person narratives have been collected with aid of the peer support group AISIA. The abstracts were composed by the Rapporteurs. The identity of all persons concerned is known to AISIA and the Rapporteurs.

Case Study No. 1

The person concerned was born 1960 in Termini Imerese and raised as a girl. Later the mother noticed that the labia majora were swollen. In 1962 the person concerned underwent an exploratory laparotomy at the Children's Hospital Bambino Gesù in Rome which revealed testes in the abdomen. After showing more and more signs of virilisation during puberty, in 1971 the person concerned was taken to the private clinic Paideia in Rome, where the testes were removed and the enlarged clitoris was shortened.

When turning 25, the person concerned found out that sexual intercourse was not possible, due to a short vaginal depth, something the doctors hadn't told her. With the help of a gynaecologist and a psychologist she then tried to get information from her former doctors, but was denied them because of “professional secrecy”.

The person concerned was finally diagnosed with 5-alpha-reductase deficiency.

The person concerned tells their story:

I was born in 1960 in Termini Imerese in the province of Palermo, in a Catholic family. My father was a lawyer, my mother a teacher. When I was born the pediatrician and the midwife said I was a female, but after a year my mother noticed that my labia majora were swollen.

In 1962, after a consultation, Dr Musumeci from Catania made a hypothesis: vulviforme hypospadias (perineal hypospadias with a bifid (unfused) scrotum resembling labia majora). After consulting another paediatrician, Dr Piero Vignetti, in 1964 my father took me to a private clinic and paid for the treatment himself. Accompanied by my maternal grandmother I was submitted to a large exploratory laparotomy at the Children's Hospital Bambino Gesù in Rome by Professor Romualdi, from whom my father received yet another diagnosis: male pseudo-hermaphroditism with normal testes, which the Professor wanted to remove immediately. My father objected, accepting instead Dr Vignetti's advice to wait for my development, and only to remove my testes if I would develop male characteristics. My mother only received generic information.

For a short time I had a relatively carefree childhood, protected by my mother a little bit, not by my grandmother or my father. But then I developed a more and more masculine appearance, so much that I was considered strange: boys rejected me because I was girl; girls and my sister rejected me because I was not as feminine as they were.

So in 1971, I was promised a nice trip to Rome with my mother, where I was submitted to gonadectomy and clitorrectomy at the private clinic Paideia, performed by the surgeon Francesco Minervini and advised by the paediatrician Dr Vignetti, again paid for by my father. My mother was present, convinced that it was my ovaries that would be removed because they had "malignant cysts"; lies always repeated to me and her again and again.

I saw that my body was no longer what it had been before. I remembered my clitoris before the

surgery. After the surgery I saw immediately, that my clitoris was gone. My mother said that it was better this way because it wasn't a good thing.

Due to the removal of parts of my clitoris and scarring, it is really hard for me to achieve orgasm.

I had to start oestrogen hormone therapy immediately. Only when I was 26 I found out with the help of an endocrinologist that the dose was much too high, which explained the liver pain and rheumatism I suffered from. The other doctors had never asked how I felt with the hormone therapy. I also had oscillating anxious, hyperactive and/or depressed states, but they were considered manifestations of my character and growth.

After the surgery and the start of the hormonal treatment, I was subjected to follow-up medical exams for four years. Every time they took photos of my genitals. After four years the visits were suspended.

Even though the surgery was "successful" I was neglected and ignored at home and in the family because I was "strange and stupid", unlike my sister who was considered to be perfect. At school I was teased and marginalised because my body was not feminine enough.

As I learned later, Dr Vignetti had advised I should receive psychological assistance, but my family refused because that was considered as a sign of imbalance. Not being able to know what really happened and not having anybody to talk to kept me in a state of constant solitude and agitation.

At university, meeting many different kinds of people made me feel a little better and more independent. But I couldn't talk to anybody about my "issues," not even with my sister. I felt alone. I was always considered strange and to keep under control. I was the family secret. Only my father's brother knew my history, and he mocked me until the last day of his life.

In 1985, when I was 25, I tried to make love, but it was impossible to penetrate me even with a finger: I was shocked and frightened, but my parents gave me the usual answers, that they had to remove the ovaries because of "malignant cysts".

A visit with the gynaecologist Dr Vaccario helped me discover the truth: a blood test revealed that I had "partial androgen insensitivity" and a pseudo vagina of 1 cm.

I trustingly turned to the doctors Vignetti and Minervini who had cared for me to receive more in-depth explanations and detailed medical charts for myself and my gynaecologist Dr Vaccario, but received vague and poorly documented information: I was not heard or respected when I asked for information about my surgery in 1971, because of "professional secrecy". Also my gynaecologist did not receive any more information.

In 1986, I started a vaginal dilation therapy, but it was very painful and on top my father used to pass through my room indiscriminately.

I went to see a psychologist, Tiziana Montan, to help me deal with what had been done to me up to that point. To better understand the situation, she met both my parents, but without receiving any useful information.

From then on I paid for everything out of my own pocket (consultations, examinations, medical and psychological treatments).

In 1998, due to an inguinal neoplasm (later revealed to be benign), I requested another meeting with the doctors Piero Vignettia (then Professore ordinario Clinica Pediatrica, Università degli Studi “La Sapienza” di Roma) and Minervini to obtain information about any findings regarding my internal anatomy, but I received only disinterested replies and "I do not remember". On that occasion I also asked if I could meet other people like me, but the two doctors just joked and changed topic. The psychologist Montan was there and also witnessed this.

In 2007 I had a chromosomal analysis that finally revealed my definitive diagnosis of "5-alpha-reductase deficiency". In the same year I came into possession of some of my father's documents after he had died, which revealed, that in 1964 Dr Vignetti had diagnosed me with male pseudo hermaphroditism and indicated to continue to raise me as a girl, and in case I developed a male appearance to remove my gonads, to widen my vagina first with a nasal speculum and then with a gynaecological one, to provide me with psychological support, and to have a surgical vaginoplasty in adolescence. The documents also revealed that in 1986 my father still asked Vignetti and Minervini to continue to lie to me and to my gynaecologist, when the doctors told my father that my right to know the truth should be respected – although in the end they denied me any information.

Today, I am still seeing the psychologist Tiziana Montan. She helps me to deal with the consequences of those traumas, the coercion, abuses, and lies. Since 1971 not a day passes when I do not wonder if I became who I am because of myself or as a consequence of surgery, hormones and neglect. And I wonder how long this practice will continue, so as not to disturb the peace and beliefs of men like my father.

Case Study No. 2

The person concerned was born in a small town outside of Rome in 1972. As a small child she was diagnosed with a heart condition, and an inguinal hernia at the Hospital Bambino Gesù in Rome. At 17 she again had an inguinal hernia and the doctors then decided to remove her testes, but did not inform her about the surgery, her diagnosis or the hormones she would need to take for the rest of her life. The parents weren't informed completely either, and so she did not take hormones for the ten years after the gonadectomy until she learned about her diagnosis CAIS by accident from a textbook, and thereafter was prescribed oestrogens.

She suffered osteoporosis, depression and other health problems due to the lack of hormones.

When she eventually learned about her diagnosis and asked doctors for information, she was told she shouldn't have sex because her body wasn't fully formed, making her feel ashamed of her body and afraid to have relationships.

Once she learned of her medical history she confronted her parents and felt betrayed by them for many years.

She was monitored once a year for her heart condition, but didn't get any care regarding the hormone therapy, and continued to have health problems. At 37 years old she learned of other persons with CAIS who also had their testes removed but used androgens instead of estrogens with positive results. Seeing as there were no doctors who would try this in Italy, she had androgens prescribed to her father and began taking them without any medical support. She died

of a heart attack 6 months later.

The person concerned tells their story:

I don't think of it as a disease, because I didn't have anything at all until I was 17 years old. Then at 17 they operated on me and I still didn't know anything because my parents didn't tell me anything. Now I've begun to learn something on the internet.

At 17, when I went in for a hernia but they removed my gonads, and then my parents refused to follow any therapy, I never took any hormone therapy. Later by myself I got a DNA test, to see my chromosomes, and I found out I had this syndrome.

I used to be skinny, but after the operation I got fat.

I didn't choose it [the gonadectomy], my parents told me it was a hernia, they didn't tell me anything. My dad is very impatient, tends to remove things, to hurry up. He wants problems to be resolved quickly.

I wouldn't have ever had the surgery, because now I have osteoporosis.

The doctors were the ones who really gave me hang-ups, because they told me "you can't have sex, got it?" I froze up, I was even engaged, so now I have left him, because they told me that my vagina was too small, so I froze up.

But maybe it would have worked, because my aunts [who also had CAIS] didn't do anything [didn't have any surgery], they are married and have normal sexual intercourse.

Doctors ruin you, some doctors ruin patients. Before the operation I was fine. After the operation without hormones, for a long time I had no hormones, I had the classic menopause, so heat flashes, depression.

If I could talk to the doctor who did this to me, I would be very angry, I would say that he was superficial, that he didn't inform my parents, but above all he didn't inform me, because I also had rights that were not respected. He only thought about removing my gonads and didn't give me any hormone therapy.

Case Study No. 3

The person concerned was born in a small town outside of Milano in 1979. She was first diagnosed with AIS and later with Leydig Cell Hypoplasia. At 15 her abdominal testes were removed and she was prescribed oestrogens, but was not informed about her medical history or the purpose of the surgery. She was told she had cancer and her uterus removed, and for ten years lived in fear of the cancer coming back. She suffered severe depression and other negative health repercussions due to the unmonitored hormone therapy. Only at 25 she learned about her diagnosis and the removal of the testes, which she says she would not have chosen.

She also felt hurt by the numerous medical exams she was subjected to without any explanation.

The person concerned tells their story:

I went to the hospital thinking I was being operated on for an inguinal hernia and instead they

gave me a gonadectomy, and I was not told. My parents knew but the doctors told them not to tell me anything, because I would not understand, to say nothing to anyone because it wasn't a normal thing, it was something that would make me feel ashamed, that I couldn't accept, and that no one could accept.

I tried many times to ask why, but they never gave me an answer. I had problems when I got a serious boyfriend. We went together to Professor Chinello who operated on me, and he explained that I had had a tumor and they had removed my uterus, therefore I could not have children. I was always afraid that the cancer cells would re-grow and that they could destroy my future.

[Later] I saw a[nother] doctor and told him that I had been operated on at 15 years, that I had had uterine cancer. He looked at the medical records and asked me why had they told me that I had had a tumour? I told him that they had only told me at 19 years old because they thought it was too strong a blow for me at 15. The doctor wanted to know how old I was then and I told him 24, 25. And he said "old enough to know you didn't have a tumour, you are a pseudo-hermaphrodite." Just like that, abruptly, I knew the truth. I laughed in his face, because I had already seen a documentary, I already knew something.

Nobody explained anything to me, the internet and the documentary explained something to me. I got no explanation from the doctors. I'm angry with the doctors, very angry. I would have liked them to leave me the chance to decide later, when I would have had the maturity to do so. I would have liked to choose myself whether to operate or not. And honestly I wouldn't have had the operation, I would have kept the testes. Absolutely.

I would like to sue. To be examined continuously, medical visits without explanation. All those exams hurt me and I didn't even know anything yet. I didn't know, it was traumatic.

Case Study No. 4

The person concerned was born in small town outside of Milano in 1987 but was treated in Bologna at Sant'Orsola University Hospital. The lead pediatric surgeon advised her parents to subject her to a vaginal lengthening surgery, which they initially declined. The hospital sent numerous letters to her parents insisting that this was an essential operation that needed to be performed in childhood, until her parents folded to the medical pressure when she was ten years old.

She received a vaginal lengthening surgery that entails taking a piece of the intestine and attaching it to the end of the existent short vaginal entrance. This procedure often leads to tight scar tissue at the point where the intestinal tissue has been attached, must be maintained through dilation, and the intestinal tissue often produces malodorous fluids as it would in the intestine.

The person concerned remembers the period in the hospital as intensely traumatic, fully of invasive examinations, but without any explanations as her parents were instructed to tell her nothing.

Her first attempts at sexual intercourse as an adult were traumatic and painful, involving tearing and bleeding due to the scar tissues that had developed at the joint of the tissues. Instead of being pliable as her short vaginal entrance would have been, the operation created rigid tissue prone to

tearing. It took her more than ten years to be able to have remotely comfortable or pleasurable intercourse or sexual intimacy.

The person concerned expressed interest in suing the doctors who had forced her parents to agree to the surgery, but Italian law was too ambiguous regarding consent laws and statutes of limitations for her to be able to find a lawyer who would take the case and she eventually lost interest in pursuing the case.

H. Annexe 2 – IGM Practices in Italy: Most Common Forms

a) IGM 3 – Sterilising Procedures:

**Castration / “Gonadectomy” / Hysterectomy /
Removal of “Discordant Reproductive Structures” / (Secondary) Sterilisation
Plus arbitrary imposition of hormones**³⁸

“I wouldn’t have ever had the surgery [gonadectomy], because now I have osteoporosis.”

(Case No. 2, see also Cases No. 1, 3, 4)

As advocated in the “**2016 Global Disorders of Sex Development Consensus Statement**”,³⁹ with Italian contributors Massimo Di Grazia (Department of Paediatric Surgery, **IRCCS Ospedale Infantile Burlo Garofolo**, Trieste), Arianna Lesma (Director Urology, **IRCCS San Raffaele**, Milan), Gianantonio Manzoni (Director of Paediatric Urology, **Fondazione IRCCS Cà Granda dell'Ospedale Maggiore Policlinico**, Milan), Giacinto Marrocco (Director Paediatric Surgery and Urology, **Azienda Ospedaliera San Camillo-Forlanini**, Rome, currently Centre of Paediatric Surgery, **Salvator Mundi international Hospital**), Emilio Merlini (Director Paediatric Urology, **Azienda Ospedaliero Universitaria Torino**, Turin), Waifro Rigamonti (currently Professor of Paediatric Surgery, **Università degli studi di Trieste**, former Director Paediatric Urology, **Ospedale Infantile Burlo Garofolo**, Trieste) – even when admitting “*low*” cancer risk (“*GCC risk*”) e.g. for CAIS (and despite explicitly acknowledging CRC/C/CHE/CO/2-4)⁴⁰:

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 (see fn 43)

Similarly in a 2013 publication by paediatricians of the **University of Messina** and the **Campus Bio-Medico in Rome** describe **practicing gonadectomy** on a person with CAIS, justified by an alleged “*high*” cancer risk, without even telling the person concerned⁴¹:

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

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

39 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>

40 *ibid*, at 180 (fn 111)

41 Pizzo A, Laganà AS, Borrielli I, Dugo N. Complete androgen insensitivity syndrome: a rare case of disorder of sex development. *Case Reports in Obstetrics and Gynecology*. 2013,

“After communicating the results to the parents (who preferred not to inform the patient), we decide to perform laparoscopy [...] [C]onsidering the high incidence of malignant degeneration of the gonads held in the abdominal cavity, we addressed the patient to a bilateral gonadectomy. [...] Parents preferred not to disclose the diagnosis to the daughter, to whom it was explained that, due to the absence of the uterus and ovaries, hormone therapy was needed but could not resolve nor amenorrhea nor infertility. This news was so devastating for a young psychologically female, who hoped to solve her problems in other ways.”

In addition, after public criticism by colleagues,⁴² above paediatricians defended the involuntary unnecessary gonadectomy as having just followed “Italian law”:⁴³ (see also **Cases No. 3, 4**).

*“Moreover, all the authors of the paper “Complete androgen insensitivity syndrome: a rare case of disorder of sex development” [2] currently **work in Italy and operate under the Italian law**, as Balsamo et al. [1] do. According to the Italian law, the decision regarding disclosure of the diagnosis and medical/surgical treatment in minor patients must be demanded from their parents, unless there is a different decision from a judge. **So we just followed the law of the country in which we live and operate as MD, without applying any personal opinion about it.**”*

Also the **IRCCS San Raffaele**, Milan, openly advocates removal of “Eventual removal of altered gonads” on its homepage under “ambiguous genitalia”.⁴⁴

b) IGM 2 – “Feminising Procedures”: Clitoris Amputation/“Reduction”, “Vaginoplasty”, “Labioplasty”, Dilatation⁴⁵

“Due to the removal of parts of my clitoris and scarring, it is really hard for me to achieve orgasm.” (Case No. 1)

As advocated by the **Ministry of Health** in their guidelines regarding “Promotion and care for the health of the child and the adolescent” (p. 153, own translation):⁴⁶

*“Feminizing surgery has three main goals: **reduce the size of the protruding masculinized clitoris**, reconstruct the large and small labia, increase the opening and, if possible, the length of the vagina. **Early surgery should only be considered in cases of severe virilisation and, whenever possible, should be performed at the same time as the repair of the urogenital sinus.**”*

<https://www.hindawi.com/journals/criog/2013/232696/>

42 Balsamo, Antonio et al. “Comment on ‘Complete Androgen Insensitivity Syndrome: Optimizing Diagnosis and Management.’” *Case Reports in Obstetrics and Gynecology* 2014,

<https://www.hindawi.com/journals/criog/2014/285715/>

43 Laganà Antonio Simone and Pizzo Alfonsa: Response to: Comment on “Complete Androgen Insensitivity Syndrome: Optimizing Diagnosis and Management”. *Case Reports in Obstetrics and Gynecology*, Volume 2014, <https://www.hindawi.com/journals/criog/2014/808270/>

44 <http://www.hsr.it/clinica/specialita-cliniche/urologia/urologia-san-raffaele/patologie-e-trattamenti/ambiguita-genitali/>

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

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

46 Ministry of Health (2012), Promotion and care for the health of the child and the adolescent: clinical, technological and structural criteria of appropriateness (Promozione e tutela della salute del bambino e dell’adolescente: criteri di appropriatezza clinica, tecnologica e strutturale). Quaderni del Ministero della Salute, n. 16, luglio-agosto 2012, http://www.salute.gov.it/imgs/C_17_pubblicazioni_2573_allegato.pdf

As advocated in a brochure published by the **IRCCS Ospedale San Raffaele Milano** and **Università degli Studi di Padova, Dipartimenti di Salute della Donna e del Bambino**,⁴⁷ and online by the doctor-supported parent's association “**Associazione Interregionale Iperplasia Surrenalica Congenita ONLUS (AIRISC)**”⁴⁸ and “**Associazione I.S.C. ONLUS Lombardia**”⁴⁹ promoting early surgery:

“Surgical Therapy

Hormonal therapy is not enough to correct the external genital anomalies caused in the female by excess of androgens in utero. It is therefore necessary to intervene surgically to reduce the excessive size of the clitoris and to correct the appearance of the vagina, separating the outlet of the urinary tract from the vaginal opening. Generally, surgery is done early in the first year of life to prevent the baby from being psychologically disturbed by the genital alteration. Most often the interventions are performed as a single surgery, with a possible revision during puberty. The purpose is twofold: correct the anatomical alteration (aesthetic aspect) and allow for normal and satisfying adult sexual relations (functional aspect).”

Accordingly, a publication out of the **IRCCS Ospedale San Raffaele Milano** and **Università Vita-Salute San Raffaele** reports eighty-two patients being submitted to “clitoral reduction surgery” between 1998 and 2005 performed by a single surgeon, **Arianna Lesma**.⁵⁰ From the same clinic, a later study reports **95 patients** with CAH having been submitted to clitoral reduction surgery between 1980 and 2010, concluding:⁵¹

“Although clitoral sensitivity in sexually active patients with congenital adrenal hyperplasia treated with Passerini-Glazel feminizing genitoplasty is significantly reduced compared to controls, sexual function in those patients is not statistically or clinically significantly different from their healthy counterparts. Finally, 1-stage Passerini-Glazel feminizing genitoplasty seems to allow normal adult sexual function.”

Similarly, a 2016 publication out of the **Università degli Studi di Bologna** and **Unità Operative di Chirurgia Pediatrica del Policlinico S. Orsola-Malpighi Bologna**⁵² lists “99 patients with type III vaginal malformations were treated from 1980 to 2014”, and promotes vaginal dilation during the first years of life:

47 Gianni Russo, Maria Pia Guarneri, Paola Peroni, Paola Sgaramella (IRCCS Ospedale San Raffaele Milano), Nella Augusta Greggio (Università degli Studi di Padova, Dipartimenti di Salute della Donna e del Bambino) (2014), opuscolo “Iperplasia Surrenale Congenita”.

48 http://airisc.it/iperplasia_terapia.html

49 <http://manuel241069.wixsite.com/adrenogenital/iperplasia> → “LA TERAPIA CHIRURGICA”

50 Arianna Lesma, Aldo Bocciardi, Francesco Montorsi, Patrizio Rigatti, Passerini-Glazel Feminizing Genitoplasty: Modifications in 17 Years of Experience with 82 Cases, *European Urology* 52 (2007) 1638–1644, [http://www.europeanurology.com/article/S0302-2838\(07\)00346-6/pdf](http://www.europeanurology.com/article/S0302-2838(07)00346-6/pdf)

51 Arianna Lesma, Aldo Bocciardi, Stefano Corti, Giuseppe Chiumello, Patrizio Rigatti, Francesco Montorsi, Sexual Function in Adult Life Following Passerini-Glazel Feminizing Genitoplasty in Patients with Congenital Adrenal Hyperplasia, *THE JOURNAL OF UROLOGY* Vol. 191, 211, 2013, [http://www.jurology.com/article/S0022-5347\(13\)05090-8/fulltext](http://www.jurology.com/article/S0022-5347(13)05090-8/fulltext)

52 Lima, M., Destro, F., Cantone, N., Shalaby, M. M. A. E.-A., & Ruggeri, G. (2016). Anterior Sagittal Approach and Total Urogenital Mobilization for the Treatment of Persistent Urogenital Sinus in a 2-Year-Old Girl. *European Journal of Pediatric Surgery Reports*, 4(1), 13–16, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5177548/>

*“Persistent urogenital sinus (UGS) is a **complex, challenging, and controversial pathology for the pediatric surgeon.** [...] Two-step surgery was recently introduced in our center for young patients to avoid lengthy operations in the case of long UGS (**genital reconstruction in the first months of life and delayed urogenital mobilization within the 1st year**). [...] After 2 weeks of the surgery, **vaginal dilatations were initiated by the patient's mother once a day for the 1st week and then twice a week for a total of 3 months**, increasing the size of the dilator to avoid postoperative vaginal stenosis [...] **[T]he mother was satisfied with the cosmetic results.** [...] In all cases, surgery has three main goals: (1) to separate the urinary and genital tract, (2) to correct urinary continence, and (3) to **prepare for normal reproductive and sexual life through reconstruction of the vagina and external genitalia.** [...]”*

Also the **IRCCS San Raffaele**, Milan, openly advocates “*Genitoplasty is a surgical procedure performed to correct the external genitals in a female way*” including “clitoral reduction”, “vaginoplasty” and “labioplasty” “*with a single intervention, performed at the age of about 6 months*” on its homepage under “*ambiguous genitalia*”.⁵³

c) IGM 1 – “Masculinising Surgery”: Hypospadias “Repair”⁵⁴

As advocated by the **Ministry of Health** in their guidelines regarding “Promotion and care for the health of the child and the adolescent” (p. 153, own translation):⁵⁵

*“In children with male gonadal sex, **hypospadias, if present, requires early surgical correction.**”*

As advocated by doctors of the “Paediatric Surgery Unit” of the **Azienda Ospedaliera San Camillo-Forlanini, Rome**⁵⁶, while at the same time admitting to having performed “hypospadias repair” on 693 children over 10 years, all operated by the same surgeon, Giacinto Marrocco:

*“Our experience shows that the **ideal age for surgery is 8–12 months.** Several considerations support our choice: the penile growth curve [6], **minor impact on the child psychologically** (genital area knowledge and stranger anxiety begin after 12 months of age) and **easier management when the patient is still in diapers.**”*

As currently advocated by the **IRCCS Ospedale Pediatrico Bambino Gesù** in Rome on its homepage (own translation):⁵⁷

*“Current guidelines agree to **correct all forms of hypospadias, including atypical forms, within the second year of life, preferably in a single procedure.** This replaces all the recommendations only to correct the most severe forms, which underestimated the psychological impact of the*

53 <http://www.hsr.it/clinica/specialita-cliniche/urologia/urologia-san-raffaele/patologie-e-trattamenti/ambigua-genitali/>

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

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

55 Ministry of Health (2012), Promotion and care for the health of the child and the adolescent: clinical, technological and structural criteria of appropriateness (Promozione e tutela della salute del bambino e dell'adolescente: criteri di appropriatezza clinica, tecnologica e strutturale). Quaderni del Ministero della Salute, n. 16, luglio-agosto 2012, http://www.salute.gov.it/imgs/C_17_pubblicazioni_2573_allegato.pdf

56 G. Marrocco, S. Vallasciani, G. Fiocca, A. Calisti (2004), Hypospadias surgery: a 10-year review. *Pediatric surgery international*, 20:200–203, at 202, https://www.researchgate.net/publication/8620545_Hypospadias_surgery_A_10-year_review

57 <http://www.ospedalebambinogesù.it/ipospadia?inheritRedirect=true>

*aesthetic problem. Reconstruction should also provide an aesthetic appearance as normal as possible, in order to **prevent psychological problems.***”

d) Prenatal “Therapy”

As advocated by the **Ministry of Health** (p. 149, own translation):⁵⁸

*“The consequences of the enzymatic deficit due to fetal hyperandrogenization **may be prevented by administering, precociously, dexamethasone to the mother.**”*

As advocated by the Italian **Associazione Culturale Pediatri** and several Italian paediatricians of the **Università di Bologna, Policlinico S. Orsola-Malpighi**:⁵⁹

*“Prenatal diagnosis and treatment **should be performed** in families at risk for classical form, underlining them that long term results in dexamethasone treated subjects have however lacking.”*

As in 2016 again advocated **despite known risks** by Italian paediatricians of **IRCCS Ospedale San Raffaele** and **Università Vita-Salute San Raffaele, Milan** (own translation):⁶⁰

*“In families with a child affected by the classic form, and in which were identified two pathogenic variants, one can **offer prenatal diagnosis and dexamethasone therapy** [...] More recently, some studies on the long-term effects on children treated with dexamethasone do not indicate general **problems** except for **long-term cognitive effects** [...]. The authors conclude that these data **should be verified by further studies.**”*

58 Ministry of Health (2012), Promotion and care for the health of the child and the adolescent: clinical, technological and structural criteria of appropriateness (Promozione e tutela della salute del bambino e dell'adolescente: criteri di appropriatezza clinica, tecnologica e strutturale). Quaderni del Ministero della Salute, n. 16, luglio-agosto 2012, http://www.salute.gov.it/imgs/C_17_pubblicazioni_2573_allegato.pdf

59 A. Balsamo, A. Cicognani. SINDROME ADRENO-GENITALE CONGENITA DA DEFICIT DI 21-IDROSSILASI. *Medico e Bambino* 2005;24:293-301, https://www.medicoebambino.com/?id=0505_293.pdf

60 Carrera, Paola, Chiara Di Resta, and Maurizio Ferrari. 2016 "Sindrome adrenogenitale: più comune di quanto si pensi." *Prospettive in Pediatria Società Italiana di Pedatria* • Vol. 46 • N. 181 • Pp. 83-84.