The involuntary or coerced sterilisation of people with disabilities in Australia Submission 60 - Supplementary Submission 1

| From: To: | |
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| Subject: | Supplemental information for Senate Inquiry on the involuntary or coerced sterilisation of people with disabilities |
| Date: | Monday, 15 April 2013 12:13:11 PM |

Dear Dr Holland,

I am writing to specify the details of the genital cutting conference to which I alluded in my testimony and to provide supplemental information regarding my comments about Androcur and Dexamethasone.

Genital Cutting Conference

The conference to which I referred was the IV World Congress of the International Society for Hypospadias and DSD (ISHID). An open letter from intersex rights activists to the conference organisers is available here:

http://zwischengeschlecht.org/pages/Open-Letter-ISHID-2011-18-09

Details of the protest against non-consensual, medically unnecessary "live" genital surgery conducted on intersex young people at the 2011 World Congress in London are available here: <u>http://stop.genitalmutilation.org/post/Open-Letter-ISHID-2011</u>

Note that the main website (<u>http://stop.genitalmutilation.org/</u>) contains numerous similar examples of "live" involuntary or coerced unnecessary treatments on intersex people that are performed at international medical conferences organised by professional societies in the fields of endocrinology and various surgical specialties.

Androcur and Dexamethasone

Please also find the unclassified note from the Regulatory Integrity Section of the Medical Specialists Service Branch of the Medical Benefits Division (pasted below). These responses were provided to the National LGBTI Health Alliance based on the Regulatory Integrity Section's consultation with the Pharmaceutical Benefits Division.

As documented below, there is no appropriate item code for intersex women who receive Androcur on the PBS. This has led to these women being listed under item code 1404 below, a code that conflates intersex women with male sex offenders. This listing in intersex women's medical records is stigmatising and discriminatory.

Also documented below is unrestricted listing of Dexamethasone on the PBS. A treating physician in Australia is currently able to prescribe Dexamethasone for the off-label purpose of attempting to prevent intersex births (a major international problem), despite medical evidence that this use can cause cognitive impairment and developmental delays in children and damage to pregnant people.

<u>[Unclassified Note</u> Mon 18/02/2013 11:05 AM Hello Gavi,

I have received responses to your queries on Androcur and Dexamethasone - see below.

1) What are the listed indications/conditions for administration of the steroidal anti-androgen Androcur (also known as cyproterone acetate) under the PBS?

Item code 1230 - Moderate to severe androgenisation in non-pregnant women (acne alone is not a sufficient indication of androgenisation) Item code 1014 - Advanced carcinoma of the prostate Item code 1404 - To reduce drive in sexual deviations in males

Details of these restrictions for this authority required medicine are available on the PBS website at <u>www.pbs.gov.au</u>

2) Is prenatal Dexamethasone available under the PBS and, if so, what are the listed indications/conditions?

Dexamethasone is listed on the PBS in the form of eyedrops and tablets and has an unrestricted listing. The indications for Dexamethasone are on the Australian Register of Therapeutic Goods: https://www.ebs.tga.gov.au/

A patient's treating medical professional would be best placed to advise whether Dexamethasone would be suitable for the treatment of their condition.

3) Could we obtain an electronic copy of the PBS items that mention Androcur or Dexamethasone?

This information is available at <u>www.pbs.gov.au</u>, by searching the schedule's A-Z listing by medicine name.

4) To whom should we direct any concerns about how Androcur and Dexamethasone are administered under the PBS?

Requirements are based on recommendations by the independent Pharmaceutical Benefits and Advisory Committee (PBAC). The PBAC will accept submissions to amend PBS listings, based on evidence of the medicine's clinical effectiveness and cost effectiveness, at any time. Enquiries can be directed to the PBAC Secretariat email <u>PBAC@health.gov.au</u>.

If, alternately, the question refers to approval of PBS prescriptions, the Department of Human Services (Medicare) administers the PBS on behalf of the Australian Government.

I hope this is of assistance.

Kind Regards

Michael Ryan Director Regulatory Integrity Section Medical Specialists Services Branch Medical Benefits Division Australian Government Department of Health and Ageing

Best regards,

Gávi

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