

Message from the President..... 1
 New AISSGA URL 2
 Third International Intersex Forum 2
 AISSGA Response to the Senate Community Affairs Committee report - “*Involuntary or Coerced Sterilisation of Intersex People in Australia*” 3
 Follow up from 2013 National Conference 6
 Third Gender: A Step Toward Ending Intersex Discrimination..... 7
 Open birth sex assignments do not reduce surgical interventions 9
 Intersex women speak out to protect next generation..... 10
 When is marriage equality not marriage equality?..... 13
 Surfing the Internet..... 14
 Book: Golden Boy 15
 Become a Member 16
 The next dAISy 16

Message from the President

Welcome to the first dAISy newsletter for 2014!

2013 was a bumper intersex year with much movement station in terms of advocacy, awareness and community building.

In October of 2013 I had the great privilege of attending the *Health Care Pathways for Intersex Trans and Gender Diverse Young Peoples’ Forum* hosted by the City of Greater Geelong. This was a landmark events where healthcare service providers, teachers and healthcare workers from all states and territories gathered together to hear first-hand accounts of the needs of our communities. Many people were shocked that this had never occurred before and lack of awareness about intersex issues. It was a spectaclar networking and knowledge building event, the positive benefits of which are still flowing on to this day.

Since then I have returned to Melbourne to conduct several intersex, trans and gender diversity awareness workshops for local service providers with my new friends at Zoe Belle Gender Clinic and Ygender, a trans support group for young people. I was even a guest mentor at Peninsula Pride's annual youth camp! What fun!

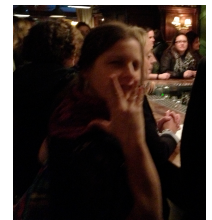
2013 also saw the release of the Senate Inquiry report into the *Involuntary or Coerced Sterilisation of Intersex People in Australia*. This document was informed by the voices from the peak intersex organisations and activists alongside professional medical associations and practitioners. The report was in many areas damning of the historical and current medical treatment of intersex people and the Senate Committee made many recommendations about what is need to ameliorate policy in this area. I've written more on this later in this issue of dAISy.

I am eternally grateful for the support and tireless efforts to Tony Briffa and our friends from OII Australia and the National LGBTI Health Alliance in effecting great change and helping to create a better future for intersex folk in Australia.

2014 is shaping up to be a wonderful year with much advocacy work still to be done, new AISSGA members and rumours of a national conference in Adelaide!

Thanks everyone for your continued excellence in the open waters of life! I look forward to seeing you all soon.

xx Bonnie



New AISSGA URL

After many years, the community portal Vicnet is no longer able to host our extensive website.

Therefore, it is with great pleasure we announced our brand spanking new URL:

www.aissga.org.au

Although our online communication activities have diversified to recently include a secret Facebook group (let us know if you would like to join!) the website continues to be an important repository of information for our community and beyond.

In the process of transferring the website over to the new web address, we're trying to weed out some of the old, broken links and update our information so that we're 100% shiny and new.

Please check us out again and let us know what you think – if there's anything you'd like us to change, improve or delete.... ☺

Third International Intersex Forum

By Tony Briffa, 30 January 2014



Forum Participants

I was very honoured to have participated in the Third International Intersex Forum in Malta with Morgan Carpenter between 29 November and 1

December 2013, which brought together 34 intersex human rights activists from around the globe. The forum was organised and sponsored by ILGA-Europe. Working with such passionate and capable intersex people from around the world for a common purpose, learning about the experiences of intersex people in their countries, meeting friends I have known online for years but never met in person, and developing an agreed position for our ongoing work was an inspiring and often emotional experience.

I was surprised how easy it was for us to put together a consensus statement that articulated our goals. I am humbled to have been a part of it, and the experience has renewed my passion for working with activists around the world for our common good.

The statement we developed is as follows:

Preamble

We affirm that intersex people are real, and we exist in all regions and all countries around the world. Thus, intersex people must be supported to be the drivers of social, political and legislative changes that concern them.

We reaffirm the principles of the First and Second International Intersex Fora and extend the demands aiming to end discrimination against intersex people and to ensure the right of bodily integrity, physical autonomy and self-determination.

Demands

- To put an end to mutilating and 'normalising' practices such as genital surgeries, psychological and other medical treatments through legislative and other means. Intersex people must be empowered to make their own decisions affecting own bodily integrity, physical autonomy and self-determination.
- To put an end to preimplantation genetic diagnosis, pre-natal screening and treatment, and selective abortion of intersex fetuses.
- To put an end to infanticide and killings of

intersex people.

- To put an end to non-consensual sterilisation of intersex people.
- To depathologise variations in sex characteristics in medical guidelines, protocols and classifications, such as the World Health Organization's International Classification of Diseases.
- To register intersex children as females or males, with the awareness that, like all people, they may grow up to identify with a different sex or gender.
- To ensure that sex or gender classifications are amendable through a simple administrative procedure at the request of the individuals concerned. All adults and capable minors should be able to choose between female (F), male (M), non-binary or multiple options. In the future, as with race or religion, sex or gender should not be a category on birth certificates or identification documents for anybody.
- To raise awareness around intersex issues and the rights of intersex people in society at large.
- To create and facilitate supportive, safe and celebratory environments for intersex people, their families and surroundings.
- To ensure that intersex people have the right to full information and access to their own medical records and history.
- To ensure that all professionals and healthcare providers that have a specific role to play in intersex people's wellbeing are adequately trained to provide quality services.
- To provide adequate acknowledgement of the suffering and injustice caused to intersex people in the past, and provide adequate redress, reparation, access to justice and the right to truth.
- To build intersex anti-discrimination legislation in addition to other grounds, and to ensure protection against intersectional discrimination.
- To ensure the provision of all human rights and citizenship rights to intersex people, including the right to marry and form a family.
- To ensure that intersex people are able to participate in competitive sport, at all levels, in accordance with their legal sex. Intersex athletes who have been humiliated or stripped of their titles should receive reparation and reinstatement.

- Recognition that medicalization and stigmatisation of intersex people result in significant trauma and mental health concerns.
- In view of ensuring the bodily integrity and well-being of intersex people, autonomous non-pathologising psycho-social and peer support be available to intersex people throughout their life (as self-required), as well as to parents and/or care providers.

In view of the above the Forum calls on:

- International, regional and national human rights institutions to take on board, and provide visibility to intersex issues in their work.
- National governments to address the concerns raised by the Intersex Forum and draw adequate solutions in direct collaboration with intersex representatives and organisations.
- Media agencies and sources to ensure intersex people's right to privacy, dignity, accurate and ethical representation.
- Funders to engage with intersex organisations and support them in the struggle for visibility, increase their capacity, the building of knowledge and the affirmation of their human rights.
- Human rights organisations to contribute to build bridges with intersex organisations and build a basis for mutual support. This should be done in a spirit of collaboration and no-one should instrumentalise intersex issues as a means for other ends.

AISSGA Response to the Senate Community

Affairs Committee report - "*Involuntary or Coerced Sterilisation of Intersex People in Australia*"

By Bonnie Hart, 27 October 2013

In October of 2013 the [Senate Standing Committee on Community Affairs released its report into Involuntary or coerced sterilisation of](#)

[intersex people in Australia](#), a highly anticipated document by the many individuals and organisations who made submissions throughout the Inquiry process.

After viewing the submissions provided by the various parties, inviting individuals to provide vocal evidence and conducting their own research the Senate Committee made the following fifteen recommendations:

Recommendation 1

The committee recommends that governments and other organisations use the term 'intersex' and not use the term 'disorders of sexual development'.

Recommendation 2

The committee recommends that health professionals and health organisations review their use of the term 'disorders of sexual development', seeking to confine it to appropriate clinical contexts, and should use the terms 'intersex' or 'differences of sexual development' where it is intended to encompass genetic or phenotypic variations that do not necessarily require medical intervention in order to prevent harm to physical health.

Recommendation 3

The committee recommends that all medical treatment of intersex people take place under guidelines that ensure treatment is managed by multidisciplinary teams within a human rights framework. The guidelines should favour deferral of normalising treatment until the person can give fully informed consent, and seek to minimise surgical intervention on infants undertaken for primarily psychosocial reasons.

Recommendation 4

The committee recommends that the Commonwealth government provide funding to ensure that multidisciplinary teams are established for intersex medical care that have dedicated coordination, record-keeping and research support capacity, and comprehensive membership from the various medical and non-medical specialisms. All

intersex people should have access to a multidisciplinary team.

Recommendation 5

In light of the complex and contentious nature of the medical treatment of intersex people who are unable to make decisions for their own treatment, the committee recommends that oversight of these decisions is required.

Recommendation 6

The committee recommends that all proposed intersex medical interventions for children and adults without the capacity to consent require authorisation from a civil and administrative tribunal or the Family Court.

Recommendation 7

The committee recommends that the Standing Committee on Law and Justice consider the most expedient way to give all civil and administrative tribunals in all States and Territories concurrent jurisdiction with the Family Court to determine authorisation for intersex medical interventions proposed for a child.

Recommendation 8

The committee recommends that civil and administrative tribunals be adequately funded and resourced to consider every intersex medical intervention proposed for a child.

Recommendation 9

The committee recommends that the special medical procedures advisory committee draft guidelines for the treatment of common intersex conditions based on medical management, ethical, human rights and legal principles. These guidelines should be reviewed on an annual basis.

Recommendation 10

The committee recommends that complex intersex medical interventions be referred to the special medical procedures advisory committee for consideration and report to whichever body is considering the case.

Recommendation 11

The committee recommends that the provision of information about intersex support groups to both parents/families and the patient be a mandatory part of the health care management of intersex cases.

Recommendation 12

The committee recommends that intersex support groups be core funded to provide support and information to patients, parents, families and health professionals in all intersex cases.

Recommendation 13

The committee recommends that the Commonwealth Government support the establishment of an intersex patient registry and directly fund research that includes a long-term prospective study of clinical outcomes for intersex patients.

Recommendation 14

The committee recommends that the Commonwealth government investigate the appropriate regulation of the use of dexamethasone for prenatal treatment of CAH.

Recommendation 15

The committee recommends that, effective immediately, the administration of dexamethasone for prenatal treatment of CAH only take place as part of research projects that have ethics approval and patient follow-up protocols.

The AIS Support Group Australia welcomes the Senate Committee Report into the involuntary or coerced sterilisation of intersex people in Australia as a timely and well researched document addressing the current and historical treatment of intersex people in Australia”, Ms Bonnie Hart, President of the AIS Support Group Australia said. “We are grateful to senators on the committee and all of the parties who were involved in supplying information to this enquiry so that a balanced and independent overview of the issues affecting intersex people and their families, clinicians and policy makers could be presented.”

The AIS Support Group Australia is happy that the committee has identified ‘intersex’ as the most acceptable term to describe our state of being within social and political landscapes and that the term 'differences of sexual development' be implemented within health environments. The committee has seen fit to state in conclusion “that genetic diversity is not a problem in itself” mirroring our view that there is no inherent ‘disorder’ associated with being intersex.”

The recommendation towards clear national guidelines to oversee the treatment of intersex people with the medical system is encouraging and welcomed. Such frameworks may have the potential to provide clinicians and parents the confidence in their actions to provide the best possible care of intersex infants and ensure adequate access to grievance processes, if needed, for all parties involved. The AIS Support Group Australia promotes a human rights based, patient centred approach when medical interventions are necessary to preserve life and would support guidelines that mirror this in the highest regard. In establishing these guidelines, and throughout any review process, we would like to see mandatory representation from the intersex community including peer-based support groups.

As the **AISSGA calls for moratorium on non-urgent medical intervention to intersex bodies**, we welcome the recommendations made by the committee for legal oversight of surgical treatments of intersex people who are unable to fully consent. We are however concerned that with the stated lack of coherent long-term research in this field and the absence of “evidence to show that there are poor clinical or social outcomes from *not* assigning a sex to intersex infants”, that tribunals and courts may continue to permit irreversible medical interventions on intersex infants based on perceived psychosocial rationales. For this reason any court involvement in the decision making process would need to adhere to strict guidelines established with the maintenance of the intersex person’s human rights as it

cornerstone.

We are grateful for the acknowledgement the committee made of the contributions made peer-based intersex organisations in this report and welcome their recommendations to allocate greater resources and core funding to our groups so that we can continue to provide support and information to our community and health care professionals. As a wholly volunteer run organisation, the AIS Support Group welcomes any support to help us adequately contribute to all of the recommendation processes and manage the vast amount of work still needed to be done to ensure intersex people are happy, healthy and protected under law.

The committee has found that “overall, there are very limited studies of the long-term outcomes of surgery, and some of the results should be of serious concern”. For this reason we support their recommendation that federal funding be allocated to conduct additional research in this area.

The AIS Support Group looks forward to collaboratively working with the government, medical and human rights experts, the Family court and other intersex groups to ensure the recommendations of the Senate Inquiry are implemented into law and professional practice as quickly as possible.

Follow up from 2013 National Conference

It's been some months since our last national conference in Melbourne, but we enjoyed another great weekend of learning, sharing and celebrating. 2013 was a terrific year for us with the group's involvement in the involuntary or coerced sterilization of people with disabilities in Australia and Vic Health's paper on decision making principals for the care of infants, children and adolescents with intersex conditions.

We were treated to a number of moving, provocative and entertaining presentations during

the weekend. Professor Garry Warne, who has had a marked impact on the field of understanding and treatment of intersex in his many years as a leading pediatric endocrinologist at the RCH in Melbourne gave a thoughtful presentation on his career and the “getting of wisdom”.

His colleague Sonia Grover also came to speak anecdotally about her relevant research and clinical practice in gynecology at RCH Melbourne. Her discussion about what a ‘normal’ vagina / labia looks like was particularly enlightening (hint: there is no ‘normal’). She also attended the 4th I-DSD Symposium 2013 in Glasgow, which features the most up-to-date medical research. The proceedings of this symposium can be found here http://www.gla.ac.uk/media/media_279274_en.pdf

Of particular interest to many of the attendees was a workshop given (via Skype) by legendary American jazz impresario and activist Eden Atwood's entitled *Sexual Healing*. Eden has developed this workshop in order to help people with AIS and intersex to overcome psychological barriers to intimacy. Eden recently graduated with Masters of Social Work from Walla Walla University <http://www.interfaceproject.org/eden-atwood/>



Eden Atwood

Many of these presentations included powerpoints, which many of our speakers are happy for us to share with you post-conference. If you would like any of these, please let us know by emailing us at aissgaustralia@gmail.com

At the conference, we were pleased receive funding from our key sponsor, the National LGBTI Health Alliance. Their ongoing support allowed us to offer travel bursaries, conference packs and some amazing conference catering. Yum! We'd also like to acknowledge the backing of the VAC/GMHC (who provided the venue), Jurlique and Genetic Support Network Victoria.

Third Gender: A Step Toward Ending Intersex Discrimination

A Commentary By Silvan Agius



Mauro Cabral

Intersex rights activists including Mauro Cabral (pictured) are campaigning to raise awareness of their plight. Photo by Del LaGrace Volcano

Hailed as a sign of the times by some and the end of Western civilization by others, a German law introducing an "indeterminate" gender option on birth certificates has sparked a wave of media interest. But the change is only a small victory in the fight for intersex recognition.

Intersex people, that is, those who are born neither exclusively male nor exclusively female, form one of the most invisible groups in our society. Contrary to popular belief, this has little to do with their supposed rarity and more to do with the

violence our society inflicts upon those who don't conform to binary and mutually exclusive "male" and "female" categories.

Reductively, when we were born, the first question asked about each of us was, in all likelihood, were we a boy or a girl? Questions about our health and well-being trailed behind, if asked at all. As we grew older, we were all instilled with gender roles based on the sex assigned to us at birth. We were taught how to perform our gender in ways that meet social expectations. Any divergence was punished, while affirmations of our socially accepted gender were rewarded.

Such a setting leaves no space for the expression of variance or ambiguity, no matter how small. In turn, most of us internalized a sense of disgust when presented with sex and gender ambiguity.

Relatively few people are aware that the bodies of infants detected as intersex are medicalized, and their genitalia routinely modified to fit a surgeon's expectations of female or male standards without their consent. The first surgeries and treatments are often performed on newborns or toddlers, with the proxy consent of their often puzzled and inadequately informed parents. These medical procedures are typically cosmetic, and rarely necessary for the well-being of intersex people.

The Australian Example

On the contrary, the predominant rationale for such surgeries continues to be stigma and the maintenance of our skewed understandings of binary sex that are maintained through the erasure of intersex differences. It is a vicious cycle that comes with a hefty price for intersex people, often paid in silence and solitude while trying to make sense of why their bodies were violated and their lives so deeply scarred.

There is light at the end of the tunnel, though. Awareness of these human rights breaches is growing and more attention is being paid to the needs of intersex people than ever before.

The Swiss National Advisory Commission on Biomedical Ethics apologized in November 2012 for past treatment, calling for "an end to surgery for psychosocial reasons." The Commission also called for the deferral of non-trivial treatment until a child can consent, a policy enforced with criminal sanctions. They say that "there is no guarantee that a decision which is good for the child" will also be best for the future adolescent or adult.

This year, Australia has made great strides through the adoption of an anti-discrimination law that protects "intersex status" alongside established grounds such as "sex" and "race." The government has also adopted new guidelines on the recognition of sex and gender, which are currently being implemented. The Australian healthcare system is removing gendered references in its services, focusing on the specific biological needs of patients instead of their legal sex or gender.

Additionally, the Australian Senate is engaged in a formal inquiry into the involuntary or coerced sterilization of intersex people. An earlier Senate report on the sterilization of people with disabilities recommended the replacement of a flawed "best interests of the child" test with a new "best protection of rights" test. It also flagged concerns about the scope of "therapeutic" surgery.

Increasing Awareness

The new German law that will enter into force on November 1 has sparked a wave of interest in the media, mainly due to the creation of an "indeterminate gender" option on birth certificates. While hailed as the sign of the times by some and the end of Western civilization by others, no reporter has yet asked how this will effectively improve quality of life for intersex people, particularly when cosmetic genital surgeries on infants are set to continue.

In short, while there may be some limited benefits from the new German law, real progress for

intersex people is not measured through the number of available labels but through an end to the human rights breaches currently being inflicted. Surgical or hormonal treatment for cosmetic, non-medically necessary reasons must be deferred to an age when intersex people are able to provide their own free, prior and fully informed consent.

Intersex issues should cease to be understood as medical and instead be addressed more prominently by human rights institutions. The right to bodily integrity and self-determination should be ensured and past abuses acknowledged. Governments should learn from Australia and follow its lead by addressing human rights concerns in partnership with intersex people themselves.

The new German law has raised awareness. Now we need the solutions.

Silvan Agius is the policy director at ILGA Europe -- the European chapter of the International Lesbian, Gay, Bisexual, Trans and Intersex Association. The article was co-authored by Morgan Carpenter and Dan Christian Ghattas of OII -- the world's largest network of intersex people.

<http://www.spiegel.de/international/europe/third-gender-option-in-germany-a-small-step-for-intersex-recognition-a-917650.html#spRedirectedFrom=www&referrer=https://m.facebook.com>



Open birth sex assignments do not reduce surgical interventions

By Morgan Carpenter, 4 November 2013

Blank or indeterminate classifications on infant's birth certificates do not, alone, reduce the likelihood of surgical interventions.

This might seem like a non sequitur, but it turns out to be fundamentally important because many people do argue that moves in Germany to establish similarly open sex assignment policies for some intersex infants at birth will lead to improved circumstances for intersex infants, and [less pressure to undergo surgical intervention](#). The new policy on birth certificates has, to our understanding, not been accompanied by any measures to directly tackle surgical interventions on infants, or to tackle discrimination against affected infants.

[ABC News in the US](#), for example, says:

The aim of the law was to take the pressure off parents who might make hasty decisions on sex-assignment surgery for newborns, and to fight discrimination against those who are intersex.

[Sydney Morning Herald](#) says:

The new law, which stems from a study by the German Ethics Council into intersexuality, will alleviate the pressures on new parents, providing an alternative to the medical procedure.

The situation in NZ shows that this is simply not true.

Birth certificates in NZ and Australia

Advice from the NZ Department of Internal Affairs [states that](#):

Recording sex as "indeterminate"

...A person's sex can be recorded as indeterminate at the time of birth if it cannot be ascertained that the person is either male or female, and there are a number of people so recorded.

Correspondence with directors of the [Intersex Trust Aotearoa NZ](#) and [OII Aotearoa/NZ](#) shows that "indeterminate" birth certificates have been available at least since the 1950s.

In contrast, Australian birth certificates with no sex data have been available for at least a decade – but only in the State of Victoria, and only to adults who request this, if they have documentary evidence of their intersex status. [Attempts by non-intersex people to obtain non-binary birth certificates in Australia have resulted in legal appeals with no conclusion](#).

Decision making on infant surgical interventions

Australia and NZ share a number of common institutions, including clinician institutions such as the Australasian Paediatric Endocrine Group (APEG) that share a common approach to the clinical management of intersex infants and children. Information presented by this clinical organisation to an [Australian Senate inquiry that reported in October 2013](#) shows that the same clinical practices take place in both countries – and that NZ is an outlier with early surgery recommended in cases of CAH (there is no data on other intersex variations):

(3.49) In 2013, presenting information about the treatment of congenital adrenal hyperplasia, Hewitt reported research that indicated almost all Australian and New Zealand respondents to an Australasian Paediatric Endocrine Group recommended genital surgery in cases of virilised genitals, though not all supported this surgery being timed to occur in infancy...

(3.106) Amongst those who supported early genital surgery, most favoured doing it between 6 and 12 months of age. But when the researchers analysed outliers, they found very strong regional variations. Those favouring surgery at less than 6 months were all from New Zealand, Queensland or outside the region...

According to this data, the availability of blank or indeterminate sex assignments at birth has no ameliorating impact on surgical interventions. Indeed, NZ may be an outlier in the region, with more hasty decision-making.

This is not surprising: the problem these laws seek to define and manage is the physical body of intersex infants.

The Australian Senate inquiry has found that current clinical practices raised significant, even "disturbing" ethical concerns:

3.109 As OII commented, normalisation surgery is more than physical reconstruction. The surgery is intended to deconstruct an intersex physiology and, in turn, construct an identity that conforms with stereotypical male and female gender categories"

This is what needs fixing. We need legislation to stop early medical intervention; legislation to define and manage the societal and clinical response to intersex bodies.

Australian anti-discrimination legislation

Finally, we have argued that the new legislation in Germany will likely make discrimination worse, given the importance of sex assignments to practices at kindergartens, schools and other public services. Australia has anti-discrimination legislation, passed in 2013, that explicitly protects people according to our "intersex status".

Germany has not moved to adopt similar legislation. [NZ has no significant data to offer on this issue.](#)

OII Australia does not support the assignment of intersex infants to an indeterminate or "third" sex category at birth due to risk and fear of discrimination which may increase surgical intervention. We support easily mutable sex assignments, and adults' rights to choose.

<http://oii.org.au/24097/flexible-or-open-birth-sex-assignments-have-no-impact-on-surgical-interventions/>

Intersex women speak out to protect next generation

Ed – a great article about some of our British orchid sisters

Sarah Morrison, 2nd Dec 2013



Jo, Sarah, Dawn and Holly, from Intersex UK.

They were born to typical families in typical areas of Britain, but none of them developed into typical male or females. They are intersex.

An estimated one in 2000 babies is born with an intersex condition or a (controversially named) disorder of sex development (DSD), which means that they are born with a reproductive or sexual anatomy that does not fit the typical definitions of female or male. This can include atypical genitalia, chromosomes or internal sex organs.

The women argue that their very existence has been "eradicated" by British society. Generations of children have been operated upon to "normalise" their genitals or sexual anatomy, while official documentation, from birth certificates to passports, requires a male or female box to be ticked.

The women have a type of androgen insensitivity syndrome (AIS), which means they have XY chromosomes, but are partially or completely insensitive to testosterone.

The group has come together to launch a campaign, calling for the Government to urgently review the way intersex people are treated. Following on from Germany's decision to allow newborn babies to be registered as neither male nor female, their recommendations include the option to leave the sex on British birth certificates blank, measures to protect babies or young people from irreversible and non-consensual treatment and surgery, better emotional support and increased education about intersex conditions.

"We are at a tipping point," said Greenberry, co-founder of Intersex UK. "Most intelligent human beings would be completely surprised and utterly dismayed at the civil inequality and human rights abuses that healthy intersex children and young adults are facing."

She added: "We need to sit around the table with the Government because we have lived through it. We are positive role models, and professional and intelligent women, who want to represent the needs of children so that the problems we

experienced aren't replicated."

In the 1960s, it became the norm to operate on children with atypical sexual anatomy at a young age. Doctors assigned the child's gender and operated to reinforce it. Although attitudes started to change around the turn of the millennium, and clinicians say they have moved to a more "multi-disciplinary" approach, there is still no record of the number of operations carried out, according to Professor Sarah Creighton, consultant gynaecologist at University College London Hospitals.

This year, the UN Special Rapporteur on Torture issued a statement condemning non-consensual surgery on children to "fix their sex", highlighting that it could cause "permanent, irreversible infertility and severe mental suffering".

XXXora, a 33-year-old intersex artist from London, who supports the women's campaign, refused an operation. She was born with ambiguous sex organs and raised as a boy, but describes herself as "super-feminised from the beginning". She said: "I never had surgery or hormones. We talked about it, but then I wouldn't be me. I don't want to morph into a blue or pink box; I want to stay in my silver box."

But the campaign is not all about surgery. Certain intersex people, such as Greenberry, are struggling to correct the sex marked on their birth certificates, which makes it impossible to marry and more difficult to adopt children.

Lord Wilf Stevenson, opposition whip and former special adviser to Gordon Brown - who has a more common DSD called hypospadias - supports the campaign and has raised concerns with ministers. "The issue is that the current law has been overtaken by medical technology," he said.

There is also a need to provide long-term emotional support for intersex people. Ellie Magritte (not her real name), the mother of a girl with AIS and a member of the support group DSD Families, said adults "need and deserve much greater investment in adult DSD care, focusing not on gender, genitals and genetics, but on health, wellbeing and happiness". She said not all people

with a DSD define themselves as intersex, but added: "The main challenges for families and kids is the social context in which we live with these conditions."

Pia Clinton-Tarestad, head of specialised commissioning at NHS England, said that the NHS is "working to assess the services we commission for intersex people", and that it understood that "issues surrounding the timing of, and consent to surgery, are controversial". She added that best practice involves "co-operation and agreement" between child, parents and a multidisciplinary clinical team.

HOLLY GREENBERRY

When Holly Greenberry was born, almost four decades ago, doctors spotted a degree of sexual ambiguity. She has XY chromosomes, but also partial androgen insensitivity syndrome, leaving her partly insensitive to testosterone.

She was assigned a male sex on her birth certificate, but she did not develop secondary male characteristics during puberty.

She knew her gender was female and underwent treatment and surgery throughout her teens. Now, the businesswoman, from south-west England, is in the process of adopting a child. Because she is unable to change her name or sex on her birth certificate, adoption is harder and marriage impossible.

"I've never been completely male nor completely female in my genetics. I didn't masculinise the way a male was expected to, and my body feminised in certain areas. I didn't have the words to express myself; I didn't know how I fitted in. It left me feeling really isolated and, while I tried to identify as male, I couldn't do it. It was like having a series of repetitive panic attacks.

Surgery was horrifically damaging and led to huge number of follow-up surgeries. It all could have been prevented if there had been more medical understanding and if there had been less haste in trying to guess which label best fitted. I should have been allowed to be an ambiguous teenager

with the freedom to express my natural gender."

DAWN VAGO

Thirty-three years ago, when Dawn Vago was born, she looked like a typical baby girl. But when she was a young child, doctors told her parents that she had testes which would have to be removed.

Now a married singer and programme director from Warrington, Cheshire, she is genetically XY and has complete androgen insensitivity syndrome. She has been on oestrogen replacement therapy since she was 11.

"The doctors told my parents there was no one else in the UK with this condition. I felt alienated from all of my classmates. I always identified very much as female, but had issues accepting myself. When I first read my file and saw my diagnosis, my world completely exploded. I found a support group and all of a sudden, felt like I wasn't alone. The moment of joy turned into anger. I was in my early twenties and had spent my whole life and childhood feeling alienated. I realised that it doesn't have to be this way.

"The doctors told my parents that they should push me into a career and make me become a busy woman, so maybe I wouldn't have time to settle down and have a family. They said I would find it very difficult to find a partner. Two and half years ago, when I walked down the aisle to my incredibly handsome husband, deep inside I was sticking a middle finger up to the entire medical establishment. I am very proud of who I am and I love my body, but I hate the journey that I've been on."

ELIZABETH JO ROBERTS

Elizabeth Jo, a 29-year-old freelance journalist from Edinburgh, was brought up as a girl. At three years old, when doctors discovered undescended testes, they removed them without her parents' consent.

She was told at the age of 10 that she was infertile and, in her mid-teens, that she had androgen

insensitivity syndrome, having been born with XY chromosomes. She met other people with intersex conditions for the first time only a few weeks ago.

"My parents told me I couldn't have children at 10 years old. I took it pretty badly. It's like when you're winded and all the air is sucked out of you. It destroyed my adolescence. I got bullied quite a lot. When I was 10 or 11, I was first given oestrogen pills, but I used to forget to take them, so I never really developed significantly.

"I struggled with identity issues throughout my adolescence and even in my twenties. I've left it late on in life to meet others like myself. It has been one of the best things I've done; emotionally cathartic. I suffered quite heavily from depression. I want to help others to not feel the same way. They don't have to feel bad about themselves.

Social change takes years to happen, but we should be living in a society where people don't feel bad about their identity because they have chromosomes that are variations on the norm. They should have freedom to express themselves."

SARAH GRAHAM

Sarah, 44, did not find out the truth about her diagnosis until her early twenties. The counsellor from Surrey has complete androgen insensitivity syndrome. She presented at birth as a baby girl and was raised as one, but she has XY chromosomes and was born with internal testes, instead of ovaries. When doctors removed them, at the age of eight, they told her they were removing her ovaries to protect her from cancer and imminent death.

"They should have told my parents the truth about my diagnosis. The lies were enormously damaging to me and affected my life. They put me on oestrogen replacement therapy when I was 12 years old but, if they had left my body intact, I would have produced hormones naturally. Every six months, I was prodded and poked by an army of medical students.

"Once I saw my diagnosis, I felt like a total freak, like I didn't belong, and was offered no support. I felt like the only person in the world with the

condition and that no one would love me. I went into a massive period of self-hatred and self-destruction, which fuelled a drug and alcohol addiction. Children need to be able to grow up intersex if they want and parents shouldn't be so pressured to make a decision. We must be given the space to exist."

<http://www.news-mail.com.au/news/intersex-women-speak-out-protect-next-generation/2101517/>

When is marriage equality not marriage equality?

By Tony Briffa, 19 October 2013

I support marriage equality and acknowledge the great work done by [Australian Marriage Equality \(AME\)](#) over the years. I am disappointed however, that they are now pushing legislation in NSW and Tasmania that will **exclude** some intersex and trans people from marriage. This clearly is not "marriage equality" which is why I am calling on AME to either support amended Bills that are inclusive of all GLBTI people or change their organisation's name. Equality is equality. We are a community and should not leave anyone behind.

The ACT Legislative Assembly is set to adopt legislation this week that will introduce true marriage equality. This is the kind of legislation we need to push.

My wife and I were married in New Zealand three weeks ago where true marriage equality exists. My sex did not matter for the purpose of marriage because in New Zealand marriage is about a commitment made by two people irrespective of sex. As an intersex person who is open about being born biologically both male and female, this is very important. The current marriage laws in Australia only allow marriage to be between a man and a woman to the exclusion of all others. This means people like me are unable to marry anyone unless we deny our true biological selves and

pretend to be one sex and in a heterosexual relationship.

Just as Civil Unions were rejected by the GLBTI community because they would not have provide legal equality to same sex relationships, we should not go down the path of state based laws that exclude sections of our community. Let's work as a cohesive community to ensure we are all equal and that we can all marry irrespective of sex, sexual orientation, gender identity and intersex status. Nothing more, nothing less.

With about 64% of the Australian public supporting marriage equality, and countries like the UK, Spain, France, New Zealand, the Netherlands, and others already introducing marriage equality, this is not too much to ask.

As my wife tweeted yesterday, supporting the current NSW and Tasmanian Bills in their current form are reminiscent of George Orwell's quote from "Animal Farm" - *ALL ANIMALS ARE EQUAL BUT SOME ANIMALS ARE MORE EQUAL THAN OTHERS.*

I look forward to working with AME to achieve true marriage equality in Australia.

Cr Tony Briffa JP
Vice-President, Organisation Intersex International Australia Ltd
Vice-President, AIS Support Group Australia Inc

For more information about my wedding in New Zealand - www.briffa.org/wedding-news

<http://oii.org.au/23942/tony-marriage-equality/>

Surfing the Internet

If you have a little time on your hands, why not check out the following clips on the Net:



Quimera Music has composed a lovely song, just for women with AIS:

<http://www.youtube.com/watch?v=RcS7Ghdz62c>

My Story with AIS from NZ:

<http://www.youtube.com/watch?v=AKWK7vhspS4>

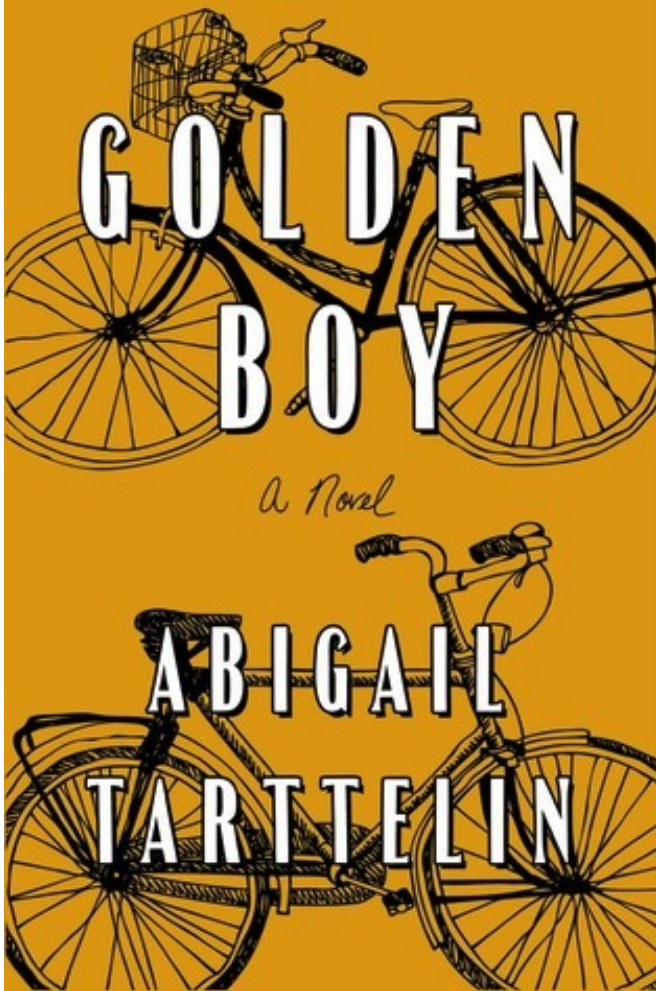


Director of *The Matrix* trilogy, Lana Wachowski's Moving Speech on Being Transgender:

<http://www.wired.com/geekmom/2012/10/lana-wachowski-transgender/>

An animation about Tony Briffa by Daniel Witthaus, Kenton Penley Miller and Jonathan Duffy for the NICHE IDAHO campaign against homophobia:

<http://www.youtube.com/watch?v=fFtXJOIxtPQ>

Book: Golden Boy

by Abigail Tarttelin

The Walker family is good at keeping secrets from the world. They are even better at keeping them from each other.

Max Walker is a golden boy. Attractive, intelligent, and athletic, he's the perfect son, the perfect friend, and the perfect crush for the girls in his school. He's even really nice to his little brother. Karen, Max's mother, is a highly successful criminal lawyer, determined to maintain the façade of effortless excellence she has constructed through the years. Now that the boys are getting older, now that she won't have as much control, she worries that the façade might soon begin to crumble. Adding to the tension, her husband, Steve, has chosen this moment to stand

for election to Parliament. The spotlight of the media is about to encircle their lives.

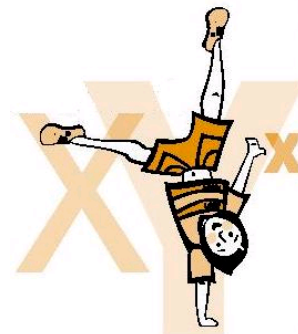
The Walkers are hiding something, you see. Max is special. Max is different. Max is intersex. When an enigmatic childhood friend named Hunter steps out of his past and abuses his trust in the worst possible way, Max is forced to consider the nature of his well-kept secret. Why won't his parents talk about it? What else are they hiding from Max about his condition and from each other? The deeper Max goes, the more questions emerge about where it all leaves him and what his future holds, especially now that he's starting to fall head over heels for someone for the first time in his life. Will his friends accept him if he is no longer the Golden Boy? Will anyone ever want him — desire him — once they know? And the biggest one of all, the question he has to look inside himself to answer: Who is Max Walker, really?

Written by twenty-five-year-old rising star Abigail Tarttelin, *Golden Boy* is a novel you'll read in one sitting but will never forget; at once a riveting tale of a family in crisis, a fascinating exploration of identity and a coming-of-age story like no other.

Hardcover, 352 pages

Published May 21st 2013 by Atria Books (first published 2013)

<http://www.goodreads.com/book/show/15803173-golden-boy>



Become a Member

Membership fees for 2013-2014 were due on August 1 2013. Please complete the attached form and return by email or post with your payment. **Please note!** Payment by direct fund transfer into our account is now available. Account information is at the bottom of the form. Don't forget to include a reference with your name and "membership".

The Androgen Insensitivity Syndrome (AIS) Support Group Australia Inc. (A0041398U) is a peer support, information and advocacy group for people affected by AIS and/or related intersex conditions, and their families.

We support members (both in Australia and overseas) that have any grade of Androgen Insensitivity Syndrome, and support any issues relevant to living with AIS. These issues include infertility, disclosure, hormone therapy, gender identity, surgical intervention of children with intersex conditions, sexual intimacy, etc.

We also provide support to those with related intersex conditions like Partial and Complete Gonadal Dysgenesis, MRKH (also known as Vaginal Agenesis), 5a-Reductase Deficiency, 3b-Hydroxysteroid Dehydrogenase Deficiency, 17-Ketosteroid Reductase Deficiency and 17b-Hydroxysteroid Deficiency. (The previous name for AIS was Testicular Feminisation Syndrome).

We acknowledge that people with intersex conditions (including AIS) range from female to male and anywhere in between.

The AISSG Australia believes in a holistic model of health as per the World Health Organisation definition of 'health':

"Health is a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity".

There are many benefits to becoming a member of the AISSG Australia, including the dAISy

newsletter, regular conferences and meet-ups, and up-to-date information and news relevant to our members. Of course, there is also the wonderful benefit of supporting and meeting others who have so much in common and much to share! We are also always looking for people who want to become more involved as representatives and/or committee members.

President:	Bonnie
Vice-President:	Tony
Secretary:	Phoebe
Treasurer:	Tony
Victoria/Tas Reps:	Elly & Christy
SANT Rep:	Carol
NSW/ACT Rep:	Melissa & Sandra
Queensland Rep:	Kylie
Parent's Reps	Annette & Sam
Men's Rep:	Leon
Specialist Role:	Trace

Now is the time to join, renew or rejoin your membership.

The next dAISy

Next issue is July 2014. The deadline for submissions is 30 June 2014. To submit articles, art, jokes, information, poems, or whatever you would like to share please email aissgaustralia@gmail.com

We hope to hear from you again soon!

Membership Application (2013-2014)

I wish to apply for membership of the Androgen Insensitivity Support Group Australia Inc. I enclose my annual membership fee, which ends on the 1st of August 2014.

Name/Organisation:

Address:

State: Postcode: Country:

Telephone Number(s):

Email address:

Age: (optional) If organisation name of contact person:

Signature: Date:

Membership type: (Please tick one)

Individual Membership:

1 year \$20

3 years \$50

Organisational Membership:

1 year \$40

3 years \$100

Please indicate your membership category:

Person with AIS, Gonadal Dysgenesis or similar condition (Please specify)

Family/Partner/Friend of someone with AIS or similar condition

Medical or Other Professional (please state interests in AIS and similar conditions)

Organisation (please state interests in AIS or similar conditions)

Would you like to make a donation to the AIS Support Group Australia?
(Donations of \$2 or more are tax deductible)

\$10 \$20 \$50 \$100 other \$.....

Please make all cheques payable to the AIS Support Group Australia. Direct fund transfer to our bank account is now available. BSB: 032285 Account no: 483996. Please include a reference with your name and "membership". Thank you!