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President's Update

Hello everyone! And welcome to a bumper issue of dAISy to make up for a lapsed issue.

Things have been buzzing along here at the AISSGA! Welcome to all the new members, it's really great to have you here.

A senior researcher from the University of New England has published the first Australia-wide survey intended to give direct voice to intersex people. [Intersex: Stories and Statistics from Australia](#), is an important publication that gives us a real insight into the long term experience of having a body with an intersex variation. There are jaw dropping statistics and big-hearted stories, told in our own words.

The survey explores participants' social health, education and life experiences and is open to people with a broad range of congenital sex variations whether hormonal, chromosomal or biological.

UNE academic, [Dr Tiffany Jones](#), engaged peer intersex groups to develop a survey that was both respectful, suitably open to accommodate the diversity of our experiences and to meet the need for larger-scale Australian research data.

Co-Authors on this research project are Morgan Carpenter of Organisation Intersex International (OII) Australia, Bonnie Hart of The Androgen Insensitivity Syndrome (AIS) Support Group Australia, and Dr Gávi Ansara of the National LGBTI Health Alliance.

A very big thank you to Astraea Foundation! At the end of last year we received some funding from [Astraea's International Intersex Human Rights Fund](#). This money has allowed us to engage in more advocacy and activism to help protect our rights and those of future generations.

Heads up! With this funding we are launching an exciting project. In partnership with Oii Australia and the National LGBTI Health Alliance, we are looking at having our Own

Intersex Engagement Retreat. The retreat will be a way for us to gain skills and share experience about engaging in activism, advocacy and providing peer support. The tentative date is set for July 16-17 2016 which is soon so definitely email us if you are interested in engaging more with the "to do" list.

This idea came from last year's conference and hopefully the retreat will be an inaugural event (held in March) that compliments our awesome August annual support conferences.



The 2015 annual conference in Brisbane was one of our best! So many new faces and a great program of speakers and activities! **This year's 2016 Conference is scheduled for 6 – 7 August in Melbourne.** Mark it in your diaries and book your time away for some time together.



We continue to have regular meet ups in Brisbane, Sydney and Melbourne. Email me to find out the date and venue of the next social gathering.

Thanks to Phoebe for another great edition of dAISy and thanks to you for being a part of the AISSGA, it brings me so much joy to know that we are together here to support each other in staying wise, happy and healthy.

I wish you all the very best in life, love and body.

xx Bonnie

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AISSGA at Mardi Gras

Once again, the AISSGA, in league with OII Australia, marched in the Sydney Gay and Lesbian Mardi Gras in March 2016. Another opportunity to don our purple fishtail tutus and boogie up Oxford Street. And each time we march, more we create greater visibility for our community.



This year, the theme we marched to was “rare, not invisible” – borrowing the catchphrase coined for Intersex Awareness Day last year. We also had our professionally printed banner this year, which is a step up from the last minute fix up when we marched last time!



Our participation in the march generated a mini-trend on social media. Have a look at the hashtag #mardigras2016 on Twitter and Instagram for some great pics of the night.

Also, for the second year running, the board of Sydney Mardi Gras allocated OII Australia, and the AISSGA a free stall at their annual Fair Day. This is a great opportunity to face-to-face with the broader community and talk about our issues, and find new allies to support our aims. Thanks to everyone who has manned the booth over this time!

Attack on the Safe Schools Coalition

Last year, the AISSGA had the opportunity to contribute to an anti-bullying program to combat homophobia and transphobia in Australian schools. The result was a groundbreaking teaching resource that supports gender diversity, sexual diversity and intersex

topics.

Conservative elements in the Australian government reacted, calling the program "indoctrination". Then the PM Malcolm Turnbull bowed to pressure from the backbench and ordered a review of the program, leading to an announcement that the federal government will water down and cut the Safe Schools program.

Some, but not all Australian states have vowed to continue the program, so there's hope that children with intersex variations might be better protected and understood by their classmates in some parts of Australia.

We here at the AISSGA were really impressed by the people who created the program, called *All of Us*, which was funded through the Safe Schools Coalition.

If you also feel strongly about this issue, we urge to contact your local MPs and Minister for Education and ask they support the resource.



No Child Should Endure My Ordeal

Last year at the AISSGA National Conference, we had the pleasure of welcoming Small Luk, from Hong Kong. This is her story, as told by the South China Morning Post on Thursday 28 January, 2015.

Born neither male nor female, bullied as a

child and driven to attempt suicide by repeated anatomical operations, Small Luk hid her bodily ambiguity for 20 years until a proper diagnosis allowed her to choose surgery and live as a woman. Now she wants Hong Kong to change laws so 'intersex' babies don't have their sex decided for them, like hers was



Small Luk is a survivor.

Born neither fully male or female, Luk was one of seven people operated on as children at Hong Kong's Kwong Wah Hospital in the 1970s to correct their anatomies – and the only one still alive. The rest have killed themselves – an indicator of the stigma and trauma they faced.

He, too, tried to kill himself before he was in his teens, so harrowing was his childhood. It's an experience Luk hopes to ensure others born in a similar state don't have to endure any longer in Hong Kong.

Luk is what is called intersex – someone with genitalia, reproductive organs and sometimes a set of chromosomes that do not conform to what's expected of either sex.

Born with vestiges of male genitals and so classified as male, it was only in his teens, when he started to develop breasts, suffer stomach cramps and see blood in his urine that Luk was diagnosed as genetically male but suffering from a condition in which the body is resistant to hormones, such as testosterone, that control the development of male traits. And Luk was 36 before a physical

examination revealed an undeveloped uterus and vagina, allowing doctors to classify Luk as hermaphrodite.

Acting on his doctors' advice, he eventually had surgery to remove his male genitalia, began treatment with female hormones and now lives as a woman.

[When I was 12] the doctors told me my surgery failed again and asked me to come back next summer. So I attempted suicide. I made a second attempt one year later.
Small Luk

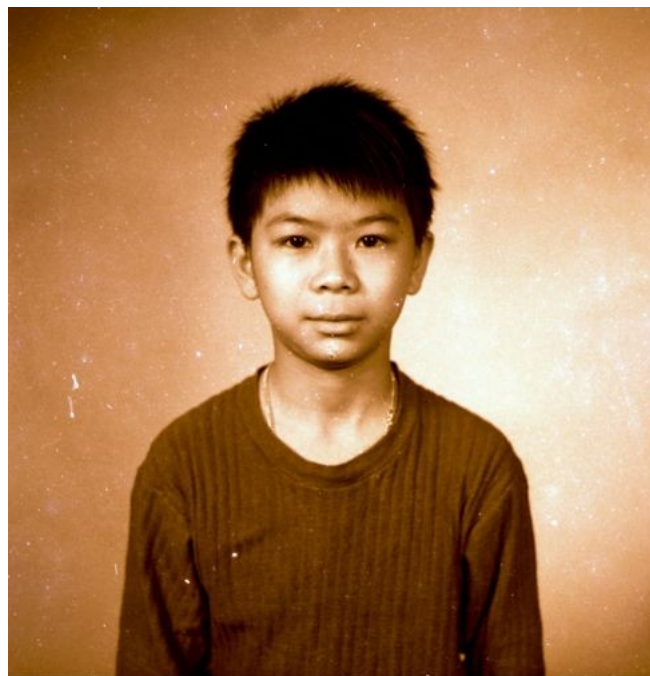
An activist for the welfare and rights of intersex people, Luk, now 50, founded a group, Beyond Boundaries – Knowing and Concerns Intersex, five years ago to work on the issue. In February 2015, she addressed a United Nations meeting in Thailand on the rights of intersex people and used the occasion to come out as an androgynous person.

She wants Hong Kong laws changed to end intrusive and irreversible treatments, included forced genital normalising surgery and “conversion therapies”.

Countries like Germany and Australia allow parents to leave the gender blank on a child's birth certificate. In Hong Kong, however, parents are required to obtain a birth certificate for their child within a year of their birth, on which must be stated their sex.

“My previous gender as a male was decided by my family and doctors,” Luk says. It was a decision that brought untold misery.

Because Luk lacked the correct anatomy, he had to urinate like a girl. He was sent to the urology unit at Kwong Wah Hospital, where he underwent more than 20 operations between the ages of eight and 13 to construct a urethra – the duct that conducts urine from the bladder.



“The surgeries were done during the summer holidays so as not to disrupt my studies,” Luk recalls.

Doctors managed to insert a tube in his penis, but because blood circulation in the area was poor, the wounds never healed properly and were easily infected, and leaks developed when he urinated.

That's a devastating situation for anyone and even more distressing for a child; when he was 12, Luk found it so unbearable he tried to kill himself in hospital and was later tied to his bed.

“The doctors told me my surgery failed again and asked me to come back next summer. So I attempted suicide,” Luk recalls. “I made a second attempt one year later. I tried to walk into oncoming traffic but people pulled me back from the road.”

After the last operation at the age of 13, Luk refused to put himself under the knife again to have his genitalia reconstructed.

As he grew up, he tried to maintain contact with the six other children who underwent similar operations about the same time at Kwong Wah, “but they all eventually killed themselves”, Luk says.

All the guys worked bare-chested in the sweltering boiler room but I had to keep on my thick overall as I had breasts
Small Luk

Luk was an effeminate boy and, not surprisingly, became a frequent target of bullies at school.

“Decades ago, cubicles in school and public toilets were only separated by low walls, so other boys could see me squat down to pee. They made fun of me, pulled down my pants to see and beat me up after school,” he says.

In his teens, when he started to develop breasts, suffer stomach cramps and see blood in his urine, Luk was diagnosed as suffering from androgen insensitivity syndrome - resistance to male hormones.

The syndrome is among more than 70 conditions that come under the umbrella term intersex, which refers to people born with a reproductive anatomy that does not fit typical definitions of male or female. For instance, a person might look female but have mostly male anatomy. Or a person might develop both male and female genitals.

Luk left school after Form Three and got a job so he could be financially independent and would not be forced into more operations. Then aged 16, he did odd jobs before securing an internship at China Light & Power as a technician.

“All the guys worked bare-chested in the sweltering boiler room but I had to keep on my thick overall as I had breasts.”

When he was eventually found to have undeveloped female sex organs and was classified hermaphrodite, doctors explained to Luk that because his body did not respond to androgens, his brain continued to signal for increased production of the hormones – raising his chances of getting testicular cancer to six times the norm. That led to surgery to remove his male genitalia.

“My family always wanted me to be a male, as I am the eldest of four siblings. I didn’t tell my parents before I did the surgery since they would definitely have objected.”

Since then Luk has been taking female hormones, and says she prefers being a woman.

Through studying part-time after work, Luk not only passed the public exams but went on to earn degrees in social work and traditional Chinese medicine as well as a master’s in gender studies. She now runs a holistic treatment clinic in Tsim Sha Tsui, using her knowledge of Chinese medicine and social work as well skills in hypnotherapy.

The cruelty and anguish Luk endured growing up led her to become an activist for the welfare of intersex people.

If a baby is born intersex, doctors will typically persuade parents to make a choice about the child’s sex before they are a year old and then carry out operations on their genitals so they conform with the chosen sex.

Doctors think that if they don’t help the children make a decision early [and perform the necessary operations], they will be subjected to lots of stress.

Joseph Cho

Luk is appealing to the Hong Kong government to educate the public about intersex conditions, extend anti-discrimination laws to cover intersex people and stop foisting surgery on intersex children without consulting them.

Some intersex conditions will lead to illnesses, but doctors can treat the conditions without touching the genitalia, she says, adding that androgynous people do not necessarily face health problems.

“[Intersex] people should have the right to leave their genitalia intact and choose their gender, whether male or female or intersex.

The choice should be made when the person grows up.”

Joseph Cho Man-kit, a lecturer in gender studies at Chinese University, agrees.

“Doctors should delay surgeries on intersex children. Some intersex conditions can be fatal and medical intervention is warranted. But others should be allowed to make the choice themselves after they grow up, Cho says.

“Due to the rigid classification in Hong Kong, people are either male or female. Doctors think that if they don’t help the children make a decision early [and perform the necessary operations], they will be subjected to lots of stress in life from being neither female nor male.

“But this [stress] can be alleviated if there’s enough counselling. Children should be given counselling about how to see themselves and whether they should tell their school and others about the condition. But such services are lacking in Hong Kong.”

I know some androgynous people [abroad] who live normally without having a fixed gender. Sometimes they wear male clothes, sometimes they wear female or neutral clothes.

Dr Ng Man-lun, a former psychiatry professor specialising in sexology, says that from a medical and psychological perspective, it’s best is not to fix the sex of intersex people.

“Even if you operate on them, the surgeries can be meaningless medically. I know some androgynous people [abroad] who live normally without having a fixed gender. Sometimes they wear male clothes, sometimes they wear female or neutral clothes. They have sex lives. They cohabit without a problem,” he says.

Overseas experts have long argued that intersex people can live as a non-male or non-female or as third-gender people, Ng

says. He has tried to raise the issue with legislators, but they were too shocked to consider it.

“Hong Kong’s social mores and culture do not allow people with ambiguous gender to live a normal life. Society forces them to fix the gender early on. Otherwise, which public toilet can [the intersex child] use? People will also discriminate against the child if the gender is not fixed. That’s why parents and doctors want to decide for the child as soon as possible.”

However, problems arise after the child grows up and has regrets, Ng says.

Frustrated by the public’s confusion about intersex people, Luk is keen to establish their unique identity. “We are often wrongly mixed with transgender people,” she says.

Some transgender groups try to include intersex people under their banner, but Luk rejects such efforts. “We do not accept that at all. Transgender people are not born with their condition ...

They should develop a gender identity of either male or female, otherwise they cannot integrate into society
Billy Wong, Committee on Children’s Rights

Transgender people have their own agenda in equating us with them. As androgynous people, we are allowed to choose our gender without undergoing any operation. But transgender people must complete their sex realignment procedures before they can change the gender [designation] on their ID. So they want the government to [classify] them as intersex people, as many of them don’t want to complete all the surgeries,” Luk says.

“Muddled public perceptions of intersex people will only increase our distress.”

Billy Wong Wai-yuk, the executive secretary of the Hong Kong Committee on Children’s Rights, acknowledges that “local awareness

and education about [intersex children] is zero”.

Still, she says: “Our committee does not think that the child’s gender should be left blank on their birth certificate like in some Western countries, as it might not be in the best interests of the child. In Hong Kong, once such a baby is born, it will be seen as an emergency case and the birth will trigger cross-departmental involvement, including endocrinologists, paediatricians and other medical professionals. They will do tests to try to see which sex the child is more slanted towards and suggest a sex to the parents.

“They should develop a gender identity of either male or female, otherwise they cannot integrate into society.”

Luk clearly faces enormous odds in her quest to win acceptance for the intersex community.

To know about about how intersex is regarded in Hong Kong, check out this report released earlier this year entitled ‘Study on Legislation against Discrimination on the Grounds of Sexual Orientation, Gender Identity and Intersex Status’ commissioned by Equal Opportunities Commission to the Gender Research Centre, Hong Kong Institute of Asia at The Chinese University of Hong Kong

<http://www.eoc.org.hk/eoc/upload/ResearchReport/20161251750293418312.pdf>

Born Intersex: People who are neither biologically male nor female

November 30, 2015 10:25am
Ginger Gorman, The Advertiser

A decade ago, when a baby was born with both male and female physical characteristics, doctors and parents faced a difficult choice. Now, things are changing.



“I CONSIDER myself to be agendered, so I’m neither male or female,” 27-year-old Cody says.

Cody was born with a naturally occurring intersex variation. This means she has biological characteristics that are both female and male.

For the purposes of this story, Cody gives me permission to use the pronouns “she” and “her.”



This is not because Cody is a female. It’s from generosity — to make life easier for me when I’m writing the story, and for you when you’re reading it. After all, there are no universally accepted pronouns in the English language for a person who is not a man or a woman.

“I don’t mind how people gender me ... because I don’t feel like I have a gender,” she says, adding: “I’m okay with that.”

Today, Cody speaks with ease and confidence about her intersex status. It wasn’t always this way. Growing up was hard.

Cody went to an all-girls school and from about the age of 12 she was picked on “for being quite a masculine girl.”

“I never felt like I fitted in,” she says.

Her childhood was riddled with regular, uncomfortable visits to doctors in Sydney and Canberra. She recalls seemingly endless blood tests, bone density scans and physical check-ups.

“You go to the doctor, and the doctor says, ‘Okay, we’re just going to have a quick look now.’ What they were talking about was looking up your shirt for breast development or looking down your pants for development there as well, just to make sure everything was normal and okay.

“It was always very invasive,” she says, “it felt very violating.”

Suddenly, Cody looks upset and says: “Yeah, I can’t talk about this.”

With what can only be described as courage, she takes a moment to gather herself and then presses on.

“It just comes back to this idea of trust in the medical community, “ she says.

“I never had the language to ask why it was happening. I never really understood the reasons why the doctors would ask me questions.”

As a child, Cody believes she was treated like a “dumb kid” by medical staff.

“There was no way to give informed consent to anything they ever asked of me, because they never presented the information,” Cody says.

Like many other Australian adults who are intersex, Cody was operated on as a baby. While she deeply loves her parents and believes they made the best possible decision with the information they had at the time, Cody still wonders if she was “turned into a woman, whether or not that was something I’ve wanted to be.”

Dr Shubha Srinivasan, a paediatric endocrinologist at The Children’s Hospital at Westmead in Sydney, has been working in the field for a decade.

Dr Srinivasan says this kind of so-called ‘normalisation’ surgery for children born with “differences in their sex development” is rare

in Australia today.

“No one would do any cosmetic genital surgery purely because of the parents requesting it.

“If we think that the parents are requesting something that we don’t think is necessarily a medical need, and may not be in the best interest of the child, then legal advice would be sought and the family law court would be involved,” she says.

According to Dr Srinivasan, surgery on intersex children mainly occurs because of specific medical problems.

“There is a range of conditions where there are differences of sex development, and each of those conditions is unique and has varying medical issues,” she says.

For example, Dr Srinivasan says an intersex child may need surgery if precancerous cells were found in the gonads or if there were urine flow issues that may cause infection.

In contrast to Cody’s experience, Dr Srinivasan says nowadays doctors working with young intersex patients include them in the conversation.

“Sometimes as paediatricians, one of the difficulties for us is parents find it difficult to tell their child about their condition or diagnosis.

“But we are always trying to give them the tools and resources to keep informing the child from a young age in age-appropriate language,” she says.

Dr Srinivasan says sometimes when a baby is born with genitals that look different, parents need support answering the common question “What did you have? A boy or a girl?”

She advises them to say something along the lines of: “We have a beautiful healthy baby who needs a few tests. We’ll be in touch soon.”

Dr Srinivasan says doctors work to ethical principles that highlight the human rights of the intersex children that they treat. They also working towards improving psychological support.

While there’s no expert consensus on how

many types of intersex variations exist, a recently released United Nations [fact sheet](#) explains that up to 1.7 per cent of the population “is born with intersex traits.”

To put this in context, it means about 407,000 people in Australia may have an intersex variation.

Gina Wilson, 64, is an intersex activist and consultant. She describes being intersex as “an extremely unpleasant experience.”

“A lot of people will say I’m courageous or things like that. I disagree. I had no choice to be intersex. That’s how I was born,” she says.

“I had to carry that burden all my life and people have let me know, in no uncertain terms, about my differences. I’ve been excluded, marginalised,” Gina says.

Just like Cody, Gina gives me permission to use female pronouns although she doesn’t use them herself.

“The whole business of male, female, and gender ... has been an ongoing tragedy in my life, which I wish could bail out of, but I can’t,” she says.

Gina politely tells me that some of my questions about her medical history are inappropriate. After all, why should she be required “to reveal my medical diagnosis and my medical procedures”?

“I strongly oppose the pathologising of intersex,” she explains.

However, Gina does tell me she was also “subjected to infant surgery.” To her, this is proof that intersex is related to gender.

“I was certainly assigned a gender when I was born, because my sex was unknown. “That is true of all children who are born where their sex is unknown.

“Intersex is completely about gender and gender assignment,” Gina says.

Community attitudes towards intersex people have “come light years” from the stigmatisation she grew up with in regional Victoria, according to Gina.

“The justification that surgery should be

performed for psychosocial reasons is falling by the wayside,” she says.

Even so, Gina believes there’s still a long way to go. She’d like to see the focus shift onto “intersex as whole-life experience.”

“Over 90 per cent of people who are intersex are adults. There are no services to help us with having lived an intersex life,” she says.

“We need services to help with ongoing medical issues and also the psychological issues that come out of medical trauma and social marginalisation,” she says.

In Gina’s case she has complex and ongoing metabolic issues related to her intersex variation that make her physically ill. She was also sexually abused as a child.

“My abuse was in fact focused around my physical differences. It was fascinating to some people,” she says.

Gina says that as a child, she had no language to articulate either her abuse or her intersex status.

“George Orwell is right, if you deprive people of language, if you deprive them of words, then they have no way to express the idea,” she says.

Although life hasn’t been easy for Gina she says: “I’ve made the best of it that I can and I found happiness with my partner of 11 years.”

For Cody, it has been a long road that led her to finding a voice. Seven years ago, she was in a human biology class at university. The lecturer was presenting information about intersex variations.

“It was just this really cold, clinical parading of variation after variation with words and images,” Cody says.

“It was very, very confronting,” Cody recalls, “I just locked down. It was just textbook depression. It was hard to get out of bed. It was hard to eat. It was hard to take care of myself. I started having suicidal ideation.”

Eventually Cody sought help and found an online community that seemed to fit.

“They call themselves ‘gender queer’. They

practice sort of confrontational androgyny. They take on unisex names. They're just all about blurring the line between male and female," she explains.

Just recently, Cody was asked to tell her story at an educational workshop held at a Federal Government department. The experience transformed her into an activist.

"Being able to talk about it so freely was so empowering. Just knowing how that was going to change how those people treat others," Cody says.

Ginger Gorman is an award winning print and radio journalist, and a 2006 World Press Institute Fellow. Follow her on twitter: @GingerGorman

My body is more than an object of fascination or repulsion to be 'fixed'

Cosmetic gender-assigning operations on children with ambiguous genitalia can have devastating long-term implications. As genetic screening of embryos increases, we can expect variations like 5-alpha-reductase deficiency to disappear from the gene pool.

Wednesday 7 October 2015, Independent UK



by Phoebe Hart

A few years ago, I produced and directed an autobiographical documentary called "Orchids: My Intersex Adventure" on my story of growing up intersex. Intersex applies to an individual with a combination of male and

female biological sex attributes, and it is also known as a disorder of sex development or hermaphroditism.

Although it is generally considered pejorative, some within the intersex community have reclaimed the word "hermaphrodite", although it is technically incorrect for humans because we can't reproduce as either a male or female.

Being born intersex wasn't so bad in of itself, but I could not help but get the pervasive sense that I was very different, and not in a good way. These negative impressions had a profound impact on my self-esteem and they seemed to come from everywhere – my family, my doctors and even the media.

Later, as an adult, when I became a documentary filmmaker I looked into the representation of people with intersex variations in the media some more, and it formed part of my doctoral thesis. I discovered, if even mentioned at all, we have long been positioned in literature, popular culture and the media as objects of fascination, repulsion and titillation.

Recent stories in the news media on the Guevedoces (which translates as "penis at twelve", according to the BBC), highlight some of my concerns about the impression given to younger generations of people with intersex variations. While I am sure Dr Michael Mosely's account of the children who live in Salinas, Dominican Republic in the BBC2 series "Countdown to Life – the extraordinary making of you" tries to be sensitive, the labelling of the variation 5-alpha-reductase deficiency by some media outlets reporting on the documentary as a "disorder" and the children as "astonishing" and "abnormal" is exoticising and pathologising. I acknowledge that it is hard even for people with an intersex variation to find the words to describe ourselves more generally, but the framing must change so that our diversity might be more readily accepted as natural.

To be clear, intersex is not common, but it's not as rare as one might expect – the frequency is as high as 1 or 2 in every 100

individuals. In fact, it is now thought all humans start as intersex in utero before typically developing towards male or female phenotypes. My own "condition" Androgen Insensitivity Syndrome (AIS) means although I have male sex chromosomes and gonads, I presented as female at birth.

That doesn't mean my variation escaped the notice of others though. I was diagnosed at age 5 but did not find out the truth about my body until much later. At age 17, finally all was made plain about my AIS and had surgery to remove my testicles. Prior to this, I only knew scant details yet I was certain that I was not like any of my peers, particularly during adolescence, and I felt completely isolated. I feel I would have taken in the facts more readily and felt better about myself had I known more from a young age.

In modern times, medicine employs surgery and hormonal cures to drastically alter anything other than complete maleness or femininity. Gender-assigning operations on children and infants with ambiguous genitalia for purely cosmetic reasons can have devastating long-term implications. Intersex advocacy and activism has meant that many medical practitioners and hospitals have reviewed their protocols with regards to interventions and have even led to some countries adopting a moratorium on infant genital surgeries.

In 2013 the United Nations condemned normalising surgeries on children with intersex variations in a Special Report on torture as cruel, inhuman and degrading. However, we are still at risk of erasure. As the availability of genetic screening of embryos increases, we can expect variations like 5-alpha-reductase deficiency to gradually disappear from the gene pool.

As a society, I have to wonder why we are choosing to go down this path, which, to me, is not unlike the future as described in the 1997 science fiction film "Gattaca".

One of the goals I had in telling my own story in a documentary and publically revealing me as intersex to a global audience was to change minds and show how our lives are not

so unlike anyone else. In particular, I wanted to create a positive frame for young people with intersex variations, who I hoped would not have to go through what I experienced. I had to hide who I was from others, and was constantly terrified of being excluded for the monster and freak I had come to believe I was.

In my own life, I've been healthy and physically active; I have been able to get an education, form intimate relationships and a family, and contribute to my community. We all want to find our potential and be acknowledged. For many of us, the pressing issues might not be so much about what doctors and scientists have to discover or say about our bodies, but the shame, stigma and secrecy we endure every day.

I strongly believe it is beholden on the media to attempt to describe people with intersex variations and their bodies as something more than a medical mystery or fabulous anomaly, and promote ethical debates and a re-visioning around what is considered to be aberrant and abject.

Dr Phoebe Hart is an award-winning television writer, director and producer of Orchids: My Intersex Adventure and a screen studies academic at the Queensland University of Technology.

Eliminating intersex babies is not a legitimate use of genetic embryo testing

Celeste Orr for The Guardian

It is done to reinforce the inadequate sex binary and even to police non-heterosexual, queer attractions or acts



A much wider variation of people can live joyful lives than most seem to think.

“Designer babies” seems like a concept from a dystopian future, but they’re here now: would-be parents who utilize in-vitro fertilization to conceive often also have the option of genetically testing embryos and then picking which one to implant.

Scientists can test for hundreds of things, from fatal genetic traits like Tay-Sachs and Huntington disease to non-fatal but culturally devalued embodiments like Down syndrome, deafness, blindness and intersex conditions.

Like pre-natal tests, the purpose of preimplantation genetic diagnosis (PGD) is clear: to allow women to choose which embryo or fetus to try to bring to term, and to terminate those which they do not. Like many scientists, I support women’s choices to terminate pregnancies or select against a potential fetus, even when I might prefer they did not. But it is important to acknowledge that using PGD to select against culturally devalued bodies, like those of people with disabilities or who are intersex, is simply a contemporary example of eugenics.

Eugenics is not a horrific memory of the past; it is an ongoing practice that hides under the guise of benevolent medical technology like PGD. Using these technologies to select against traits that we consider to be imperfections or deformities rather than normal and celebratory human variations reproduces the very prejudices –like intersexism, ableism and queerphobia – that oppress living people. Using technology to eliminate “imperfect” or “unviable” humans reproduces the false ideology that people with bodily variations have unliveable and pitiable existences.

Using PGD to select against intersex people is an especially pernicious use of the technology because it is done to reinforce the inadequate sex binary and even to police non-heterosexual, queer attractions or acts.

Intersex is a general term applied to (but not always claimed by) people with biological sex – genitals, chromosomes, gonads – that

cannot clearly or exclusively be classified as male or female; it may, on a case-by-case basis, be the result of genetic, chromosomal or hormonal variations or environmental influences. It is estimated that around 1.7% of the population has intersex traits.

Intersex is commonly associated exclusively with variant (or “ambiguous”) genitalia, but intersex anatomy can become apparent at any point in life: at a routine medical exam, during puberty, whilst trying to conceive, or even after death during an autopsy.

Despite the fact that intersex “conditions” typically pose no health risk, intersex infants and children are often subjected to lawful but non-consensual sex or genital surgery to “cure” the “disorder” by ensuring that the child will grow up with genitals that can engage in heterosexual sex, even if genital sensitivity is compromised. Intersex and allied activists refer to this practice as mutilation.

Still, while overstating the medical issues intersex traits cause, certain bioethicists believe that using PGD to select against intersex embryos is both intuitive and benevolent because, they claim, the social stigma against intersex and the medical issues outweigh the potential positives of their lives. But, while it is true that intersex people will face social stigma and systemic oppression (as do women, LGBTQ folks, people with disabilities, and people of color) and they may experience medical issues (as do all people throughout their lives), eradicating potential people who face these very human experiences is not self-evidently logical. People’s embodied lives cannot be reduced to such an equation; it does not capture the complexities of being human.

And preventing the birth of intersex people is not a productive or ethical way to deal with or change discriminatory societal beliefs or the oppressively violent ways intersex people are treated. Society needs to change, not intersex bodies. Most of the trauma that intersex people experience comes from the social and medical response to their bodies, not their bodies themselves.

Rather than trying to reduce a potential life to

an equation and investing our time and resources in eradicating these bodies, we ought to start valuing bodily variation and listening to people who live with and through difference. When we value bodily variance, unlearn our prejudices and listen, we can understand that our ideas about people's relative happiness do not reflect the true value of their lives and bodies. Intersex people, along with those who are deaf and/or blind, people with Down syndrome and numerous other people with supposed disabilities and impairments not only lead fruitful and fulfilling lives but their innate value ought to be celebrated.

I do not support getting rid of PGD or limiting women's choices; it is unethical to try to institute laws that limit women's ability to practice bodily autonomy. And history has shown that laws that deny women this ability is dangerous – and does not and ought not prevent them from making the choices they know are right for them anyway. But we do need to think critically about which bodies we deem acceptable and viable, and how those beliefs create a cultural climate that still renders certain types of eugenics benevolent.

Instead of thinking about which lives are supposedly, inherently not worth living, we need to think about what we can do to celebrate bodily variance – how we can change to make every person's life both liveable and filled with joy.

Abandoned Intersex Baby Rescued and Raised by Migrant Worker

Fan Yiying

Sixth Tone, May 25 2016

Riding home on his electric scooter after work one day, Fan Xifa was stopped dead in his tracks by the sound of an infant crying. The cries, cutting through the noise of the heavy rain, led him to a cardboard box that lay beside the road.

It was November 2012, and Fan, a migrant worker in Sanya, in China's southern province of Hainan, had just made a discovery that was to change his life beyond measure.

Inside the box was a newborn baby. Its lips were blue from cold, and its naked body was covered in blood from its uncut umbilical cord. Instinctually, Fan wrapped the baby up in his coat, and took it to the nearest hospital two blocks away, where a doctor told Fan it was unlikely that the baby would survive. It weighed just 1.4 kilograms.

Once the doctor had cut the baby's umbilical cord and wiped away all the blood, Fan noticed something. The baby was intersex, born with both male and female genitals. This, Fan believes, was the reason the baby was abandoned.



Fan Xifa, at his rented home near Beijing Children's Hospital, holds a photo of him and Zheng Zheng in Sanya, Hainan province, March 8, 2016. Huo Junjun/VCG

Three and a half years on, Fan is still the guardian of the child, who goes by the pet name Zheng Zheng. Ever since finding Zheng Zheng, Fan has been preoccupied with the question of what can — and should — be done about the child's gender. Fan's dilemma has also heralded a chorus of conflicting voices from charities, NGOs, and intersex advocates around Asia.

The United Nations defines a person as intersex if they are “born with sex characteristics that do not fit typical binary notions of male or female bodies.” Being intersex is different from one's gender identity — female, male, both, or neither — or sexual orientation. According to U.N. statistics, those with intersex traits account for between 0.05 and 1.7 percent of the world's population.

Like many places around the globe, discrimination against intersex people in

China — particularly rural China — is commonplace, and the consequences sometimes tragic. Fan has firsthand experience with this: Two people in the small village where he grew up in the central province of Henan were intersex.

One of them, who self-identified as a woman, was discarded by her newly-wed husband when he discovered she was intersex. That divorce was the first of several.

School bullying drove the other intersex villager to suicide.

Memories of their plights motivated Fan — a widower without a child of his own — to take the baby under his wing. He left his job as a construction worker, and took on the role of parent full-time, relying on his 30,000 yuan (around \$4,500) of life savings to get by. Determined that his child would not suffer the same fates as the two intersex individuals from his village, he decided to explore surgical options.

In 2013, tests by doctors in Hainan's provincial capital Haikou showed the child had both mature ovarian and testicular tissue, a condition known as "true hermaphroditism." Yet a chromosomal balance leaning a few percent to the male side has led Fan to decide that his child will be raised a boy, beginning as soon as possible with genital surgery. "I don't want Zheng Zheng to hate me for not fixing the problem at an early age," Fan says.

Dreams of rearing sheep and bringing up his child in his home village led Fan to make the 2,200-kilometer journey back to Henan in 2015. Fan's village is not far from Zhengzhou, Henan's provincial capital. It was then that Fan gave his child a name — Juzheng, a homonym for "living in Zhengzhou."

Still determined to pursue surgical options for his child, Fan went to a local hospital for a second opinion on the available options. The hospital advised Fan that Zheng Zheng should undergo surgery that would remove his ovaries, pull down one of his testicles from his groin, and adjust his penis so that he could urinate standing up. Following the

surgery, Zheng Zheng's female reproductive functions would be irreversibly damaged.

Not everybody is convinced that such drastic surgery is the right course of action. Among them is Taiwan-based intersex rights advocate Chiu Ai-Chih, who speaks to Fan twice a month by phone to give advice on intersex issues. Fifty-year-old Chiu is a firm believer that an intersex individual must be able to give consent before any irreversible gender-assignment surgery is performed, a belief she emphasizes without fail to Fan each time they speak.

For Chiu, the subject is very close to home. Chiu's body is genetically female, yet produces a high level of testosterone. Chiu was made by family members to undergo surgery to reduce what they considered an enlarged clitoris, when Chiu was just six years old, causing severe damage to the sexual function of Chiu's genitals.

While advocates like Chiu have been appealing to Fan to reconsider his decision, Zheng Zheng's case has also attracted the interest of some children's charities who share Fan's concerns that Zheng Zheng's condition will lead to a life of prejudice and discrimination.

After raising money for Fan, the China Charities Aid Foundation for Children advised him that he should take Zheng Zheng for a health check-up at Beijing Children's Hospital, considered one of the country's best pediatric hospitals.

A consultation there in February this year revealed that Zheng Zheng was suffering from heart disease, a condition that had no relation to his hermaphroditism. Surgery on his heart was successful, and now Fan is waiting for him to recover before he broaches the issue of Zheng Zheng's hermaphroditism with the hospital, which he plans to do with a formal consultation in June.



Zheng Zheng sleeps soundly in Fan Xifa's arms at their rented home near Beijing Children's Hospital, April 26, 2016.
Fan Yiyong/Sixth Tone

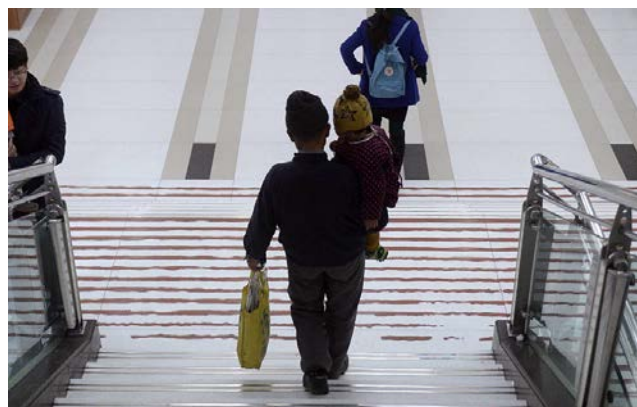
Gong Chunxiu, director of the hospital's department that oversees hormones-related procedures, shares the same view as Chiu. Drastic and irreversible surgery should be delayed until the child is old enough to decide which gender they identify as, she tells Sixth Tone.

Nevertheless, she believes Zheng Zheng should undergo so-called "repair surgery" at the hospital in June that would give his penis full functionality yet would not remove his female sex organs. Gong explains that the treatment would leave Zheng Zheng the option to change his sex in the future, should he identify as female.

Luk Small Ela, an intersex woman from Hong Kong, has also weighed in on Zheng Zheng's plight, having communicated her concerns directly to Fan. The 51-year-old is not against the less drastic surgery for Zheng Zheng in June if it's necessary, as she believes temporarily raising Zheng Zheng as a boy has its benefits. "It's the safest way to protect the child from being discriminated against at school," she says.

"When I was at school, there were no separate cubicles in the men's bathroom," Luk recalls. "The boys could see how I urinated." This is Fan's biggest concern. He worries about how difficult it will be for Zheng Zheng in school as an intersex person. "Which bathroom should Zheng Zheng go to — male or female?" Fan says. "The discrimination could be traumatizing."

As a child Luk underwent a series of unsuccessful surgeries to enable her to urinate standing up. After over a dozen painful surgeries, a 13-year-old Luk refused any further procedures. A large part of Luk's parents' desire for her to undergo surgery came from the wish that — as a male — Luk could continue the family line. Yet in her twenties, she learned that she had no sperm in her body. "All the surgery I went through was in vain," she says.



Fan Xifa holds Zheng Zheng as they leave Beijing Children's Hospital, Feb. 29, 2016. TAORAN/IC

The focus on fertility was also behind the recommendations by doctors in Hainan and Henan that Zheng Zheng undergo the drastic, irreversible genital surgery. According to them, Zheng Zheng's chances of fertility are greater as a male than as a woman.

The question of fertility, along with concerns about how Zheng Zheng will be treated by those around him in later life, weighs heavy on Fan's mind. But following his communication with people like Chiu and Luk, it seems likely that Fan will forego the irreversible surgery in favor of the less drastic procedure, which would preserve Zheng Zheng's female sex organs. If, at a later date, Zheng Zheng wishes to identify as female, Fan says he will support that decision.

Whatever path Zheng Zheng takes, Fan says he will have no regrets. "If I passed by without picking up the baby that day, I wouldn't have been able to forgive myself for the rest of my life."

Arianna

We've been waiting for this film to make the rounds of film festivals for a while. Here it is reviewed by Variety for the Venice Film Festival



Alternative gender identity is a hot topic in contemporary cinema, surrounding interest in which could secure a larger audience than might otherwise be expected for Italian filmmaker Carlo Lavagna's dreamy, heat-hazed character study "Arianna." By framing its eponymous heroine's condition as a puzzle to be unpicked rather than a subject for candid discussion, however, the pic resists presentation as an "issue movie" — perhaps to its credit as well as its disadvantage. In telling the story of a 19-year-old girl's belated coming of age over the course of one idyllic summer, Lavagna dramatizes her plight with a mixture of oblique sensual saturation and, later on, more on-the-nose emoting. An uneven but strikingly presented debut for its helmer, it will find a particularly welcoming niche in gender-themed and LGBTQ fest programs.

"I was born three times," admits the title character (Ondina Quadri, an arrestingly pale-eyed, tousle-haired newcomer) in voiceover at the outset of the film. "As a boy the first time, and a few years later as a little girl." She goes on to explain that she was "born" once more nearly two decades later, and it's this second figurative rebirth — one of heightened self-knowledge, it is suggested — that forms the spine of Lavagna's initially elusive narrative. This may seem a cryptic opening gambit, though in fact, it's a fairly prosaic preemptive explanation of a truth that Arianna spends the bulk of the film figuring out. Some viewers may deduce Arianna's personal history

straight away; it's not clear whether Lavagna intends for the audience to have more knowledge than his protagonist, though her arc of discovery is affecting either way.

Now a woman, though not yet wholly independent of her highly protective parents (Massimo Popolizio and Valentina Carnelutti), Arianna has a healthy social and academic life, though is plagued by one particular medical peculiarity: She has yet to experience her first period. Achingly conscious of the differences between her and other women her age, she spends a considerable amount of time before the mirror, scrutinizing her boyish frame and petite breasts. Her sexual development, too, is very much at the beginner stage, though a summertime encounter with fellow teen Martino (Eduardo Valdarnini) triggers an unprecedented flush of carnal desire in her. Lavagna's script, co-written with Carlo Salsa and Chiara Barzini, is pleasingly frank about the intuitive randiness of unformed sexual beings of any sex; in its sensitive depiction of a teenager getting more deeply acquainted with her own body, "Arianna" would pair up well on a screening bill with the otherwise dissimilar U.S. pic "The Diary of a Teenage Girl."

For her summer vacation, Arianna travels with her parents to the family's long-abandoned holiday villa on the blissfully unspoiled edge of Lake Bolsena. It's a place she hasn't visited since early childhood, and thus rife with stray sense memories — evoked by Lavagna in a woozily fragmented style, with accomplished d.p. Helene Louvart (a standout contributor to Alice Rohrwacher's 2014 Cannes mood piece "The Wonders") amplifying already ripe seasonal shades into dazzling jewel tones.

When her parents pack up for the city, Arianna asks permission to stay behind and study until the summer's end. It's not quite the lie it seems. Though some harmless shenanigans with friends are also on the agenda, she takes advantage of this rare lack of parental influence — even her gynaecologist, we learn, is a family friend — to conduct more thorough research into her medical history. It's a trail that leads her through a bewildering assortment of doctors,

longtime acquaintances and sympathetic support groups, with an outcome that calls the effectiveness of her parents' well-meaning concern trickily into question. As the film progresses, Arianna's articulation of her psychological state can be a little pat, verging on the kind of therapy-speak that is, in fairness, not entirely improbable considering her youth and vulnerable uncertainty of self. But the catharsis of simultaneous relief and fury that accompanies her realization lends the film a worthy emotional climax.

As Arianna, Quadri is a compelling performer, if not quite a comfortable one: There are moments where the character's tenseness may well be inextricable from that of the actress, though her subsequent blossoming seems equally organic to the performance. Lavagna, who has a few nonfiction credits on his resume, has stated that he originally envisioned the project as a documentary, and his facility with his non-pro lead bespeaks a tender interest in first-hand human observation. Still, "Arianna's" occasional surges of stylized technique — enabled by first-rate work from Louvart, editor Lizabeth Gelber and composer Emanuele de Raymondi — confirm that narrative filmmaking was a viable way to go.

'Faking It' breaks new ground with first intersex actor to play an intersex character on TV

"Walking onto a studio set was perhaps one of the more surreal things that I've done in my life," says Amanda Saenz.



MTV's *Faking It* has been inclusive from the start—spotlighting the complicated relationships between straight teen Karma and her lesbian BFF Amy, their out friend Shane and intersex classmate Lauren.

Now the show is making history by featuring television's first intersex character played by an intersex actor: On the April 5 2016 episode, "Jagged Little Heart," Amanda Saenz debuts as Raven, a youth advocate who helps Lauren connect with the intersex community.

In the episode, Amy decides to make a documentary about Lauren to keep her mind off Karma, who has formed a band with Shane.

"Walking onto a studio set was perhaps one of the more surreal things that I've done in my life," says Saenz, a member of the advocacy group [interAct](#).

"I'm so excited that the intersex community is growing more and more visible, and that our movement is building momentum."

Intersex representation is rare in the media landscape, and is usually disingenuous or sensationalized. But *Faking It* creator Carter Covington consulted with interACT from the start of Lauren's storyline to make sure it was accurate and respectful.



"Being portrayed in an honest fashion is something that we have been fighting for for a long time," Saenz explains.

The show is also adding a trans teen character, Noah (Elliot Fletcher), increasing its commitment to diversity even further.

Become a Member

Membership fees for 2014-2015 were due on August 1 2014. 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:	Georgina
Victoria/Tas Reps:	Elly & Christy
SA/NT Rep:	Carol
NSW/ACT Rep:	Melissa & Sandra
Queensland Rep:	Kylie
Parent's Reps	Annette & Sam
Men's Rep:	Leon
Specialist Role:	Trace

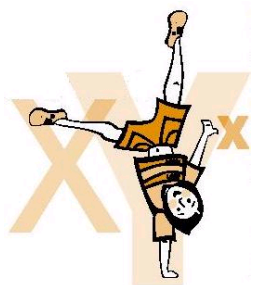
We'd love to have representatives in other states and territories. We also have representatives for parents of children with AIS and men with AIS / intersex... and the word is out that partners of people with AIS need support too!

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

The next dAISy

Next issue is January 2017. The deadline for submissions is 31 December 2016. 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 (2016-2017)

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 2015.

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:

Organisational Membership:

1 year \$20

1 year \$40

3 years \$50

3 years \$100

Please indicate your membership category:

Person with AIS, Gonadal Dysgenesis or other intersex variation (Please specify)

.....

Family / Partner / Friend of an intersex person

.....

Medical Professional (please state interests in AIS / intersex community)

.....

Organisation (please state interests in AIS / intersex community)

.....

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!