

dAISy

The Newsletter of the
Androgen Insensitivity Syndrome (AIS) Support Group of Australia

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President's Update

Hello everyone! Happy 2015!!

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

Orchids: My Intersex Adventure screened twice on ABC over the last month and we had a number of people contact us after seeing it, which is so fabulous! The film has done such a good job at raising awareness of intersex and reaching out to people. It continues to be screened regularly around the world.

On the 4 December 2014 the NSW State Parliament passed a motion to implement the key recommendations from the 2013

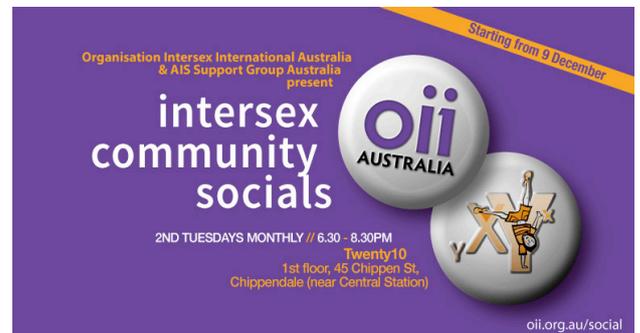
Commonwealth Senate committee report on the involuntary or coerced sterilisation of intersex people. The text also acknowledges Intersex Awareness Day. The motion was put forward to the upper house of the State Parliament by Dr Mehreen Faruqi (Greens) and it needed cross party support to be passed. This is such great news as the Recommendations call for proper guidelines and research into the medical treatment of intersex people. We have been doing some advocacy work to try and get a similar result in other states. You can [download](#) a copy of the report, it is quite heavy going but very informative on the current state of affairs.

The annual conference in August was a great couple of days in Sydney with many informative, through provoking and inspiring sessions. It was wonderful to see everyone and share that unique togetherness that comes from sharing with others who are like-bodied. This years conference has been scheduled for 8-9 August in Brisbane. If you would like anything particular in this years sessions, or know of a wonderful presenter, please contact me.

There's a new secret Facebook group just for parents of children with AIS and intersex variations. It's secret so it won't show up on your friends feed and cannot be searched for by people not in the group. To join, contact

me on bonnie@aissga.org.au

Oii and the AISSGA have collaborated to start a series of intersex community socials in Sydney, which occur every second Tuesday of the month, 6:30-8:30pm, Twenty10, 1st Floor, 45 Chippen Street, Chippendale. Check it out!



We continue to have regular meet ups in Brisbane 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

President
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AISSGA in LGBTI Mardi Gras Parade, Sydney

The Sydney Mardi Gras is coming up in Feb-March with the Parade on Saturday 7 March. AISSGA members have the opportunity to represent the 'I' in 'pride'! Unfortunately we do not have the resources to have our own float in the parade this year however the Camen Rupe Memorial Trust has kindly offered us some of their participant tickets so that we can march in celebration of bodily diversity. We will have our own banner (attached) and will be marching alongside our friends from OII Australia.

It is a wonderfully vitalising and liberating experience to march in Mardi Gras! Some of our members marched last year and it was an unforgettable, positive experience!

Additionally, we will also have an information booth at the Fair Day in Victoria Park on Sunday 22 February. It would be great if you could come down and show your support for our wonderful support group.

If you would like to participate in the Mardi Gras Parade and/or Fair Day booth, please let us know ASAP. There is no cost associated with participating (other than travel, personal costuming, champagne etc ;)

Testosterone – the hormone everyone's talking about!

Hi everyone. It seems like for post-operative CAIS XY women, this hormone is all the buzz. We've been receiving emails and messages asking why, how much, who dispenses, what are the benefits and side effects and how much to take. While that's a lot to answer in one article, I thought I'd try giving it a shot.

Traditional medicine argues that testosterone-producing inguinal testes ought to be removed and, as androgens have limited response in our bodies, a course of estrogen

is the answer. Estrogen preserves bone health, so it kind of makes sense. However, if left in tact, our testes make testosterone which aromatises into estrogen anyway. This works the same for androgen treatments. It's a relatively new treatment for us but has a range of benefits.

I began testosterone treatment coming up to a year ago now after hearing amazing reports from our orchid sisters in the USA. Before that, I had been on estrogen replacement therapy since my gonadectomy at age 17, about 23 years earlier. In consultation with my treating endocrinologist, we started on a monthly dose. The type and amount I take is testosterone enanthate 250mg-1ml (primoteston depot) by syringe into the muscle tissue of the buttocks. It's about 30 bucks for three doses. This treatment is needs a special authorisation but it wasn't a problem for my doctor to get that for me. I simply take the script to the pharmacy to fill out and then go to my GP to have my injection but if you're confident, you can do it yourself or get a trusted friend / partner / orchid sister to do it.

It took several weeks or about three injections until I noticed any effect at all. And in many ways it's subtle yet profound. Psychologically, I felt a lot more grounded and confident. And yes, I started wanting to have sexual gratification much more often! Terrific if you consider I often had low-to-no drive previously. Physically, I think I may have slimmed down a bit and I think am able to put on muscle tone more easily. However, I didn't "masculinize" – so I'm not any hairier, for example. My vagina lubricates more upon arousal and I feel like the clitoris and labia get more stimulated and blood seems to circulate more readily.

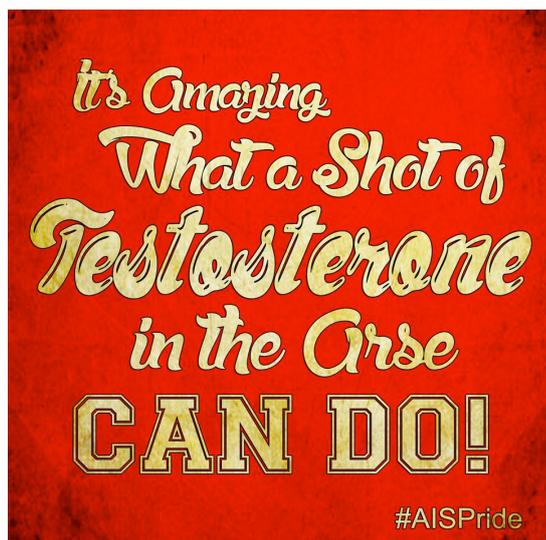
Side effects seem to be quite limited. I have heard some orchid sisters say it can be too full on, and taking a dose of estrogen alongside the testosterone treatment can help "ease off the accelerator". Personally, I used to get a small amount of occasional acne and pimples in my groin or on my bum prior to my

surgery in my late teens, and this seems to have returned since starting the treatment. Annoying, but it seems a small price.

To me, there is almost a spiritual side to being on "T". Having had testosterone naturally during my puberty and adolescence, I felt like I'd returned to the natural me. I am happier! Of course, if you can keep your testes, this side steps all this hoo-ha! For our parents, it's worth taking this into account – the gonads can effectively be left in situ and monitored regularly for cancer risk nowadays, and that risk is (apparently) very small!

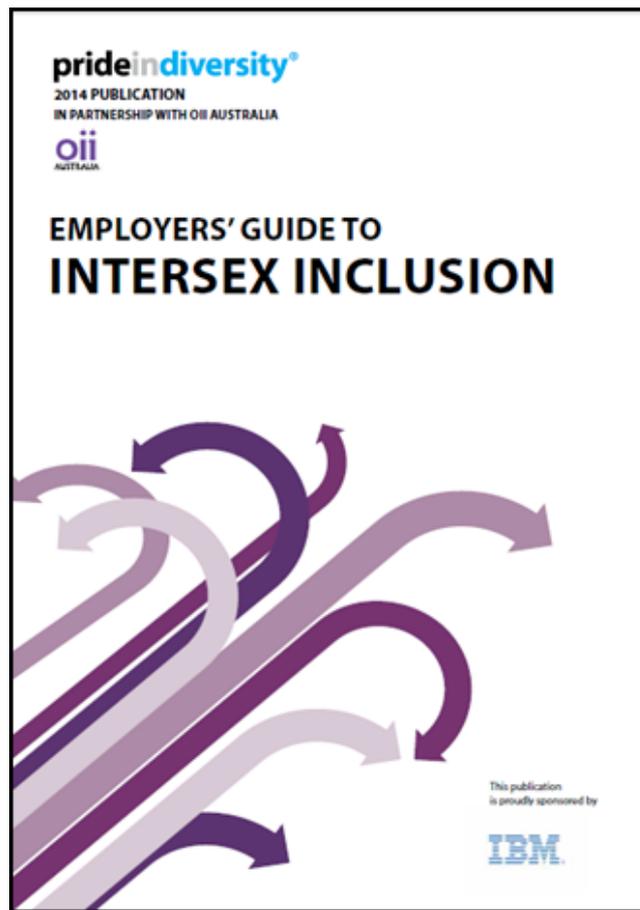
Evidently, there is a formal study of the effects of testosterone on AIS women underway in Germany. We are all looking forward to learning the outcomes of that study. If you have more questions, why not post to our Facebook page and keep the dialogue going?

By Phoebe



World First Publication – Employer's Guide to Intersex Inclusion

Wednesday, October 8, 2014 at 2:19PM
Pride in Diversity Australia is proud and delighted to partner with [OII Australia](#) to publish the Employers' guide to intersex inclusion. Written by Morgan Carpenter (OII) and Dawn Hough (Pride in Diversity), kindly sponsored by IBM.



A world-first, the guide presents information about intersex for employers, including:

- * An introduction to intersex.
- * Intersex bodies, identities, and inclusive language.
- * Disclosure, medical issues in the workplace, and travel.
- * Protections related to "intersex status" in Commonwealth law.
- * Information for diversity and inclusion professionals.
- * Top 10 ways to be an intersex ally.
- * Information for parents of intersex children.
- * Additional information and a glossary of terms.

To download a copy of Employers' Guide to intersex inclusion please [click here](#).

To purchase a hard copy of the publication please [click here](#).

Morgan Carpenter, president of OII Australia, stated:

"Intersex status appeared as a new attribute in Australian Commonwealth anti-discrimination law in 2013, yet employer and community understanding of intersex remains limited. Social and cultural attitudes towards intersex have a huge impact on our lives at work and outside it. This guide is here to help. It hopes to enable more people with intersex variations to just be ourselves, as we are.

We hope that it will make a difference to intersex people who are employed by your organisation, and those who are clients or customers of your business. In the words of an international intersex community consensus statement, we hope that it will help create supportive, safe and celebratory workplaces."

Dawn Hough, director of Pride in Diversity, commented:

"This publication has been specifically written for those working in Human Resources, Diversity and Network Leadership roles but will have a much broader reach in terms of educating people more generally on some of the shared (LGBTI) and unique workplaces experiences of our intersex employees.

There is an opportunity to lead the way in this aspect of LGBTI workplace inclusion globally. We need to be advocates and allies for our intersex employees and colleagues. I challenge and encourage you to be a leader in this area, both personally and organisationally. This publication has been written to instigate change. Change requires action. Here is an opportunity to be at the forefront of LGBTI inclusion and make a real difference to the lived experience of intersex employees within our organisations and beyond."

More information

Pride in Diversity is Australia's first and only national not-for-profit employer support program for all aspects of LGBTI workplace inclusion. Specialists in HR, organisational change and workplace diversity, Pride in Diversity has established itself as an internationally recognised program and a partner to many LGBTI employer support

organisations across the globe. Pride in Diversity are also the publishers of the Australian Workplace Equality Index (AWEI), Australia's national benchmarking instrument for all aspects of LGBTI workplace inclusion from which the Top 20 Employers for LGBTI employers is determined. For more information on Pride in Diversity visit www.prideindiversity.com.au

The Missing Vagina Monologue for VDAY

By Esther Morris www.mrkh.org

Ed – this article was written in 2003 but is a classic.

Curious to learn what women were talking about I read the "Vagina Monologues". I wasn't curious about the play. I was curious about vaginas. I am a woman who was born without one.

My life completely changed when I was 13 and sent home from camp with abdominal pain. When I was examined they found that I had no vagina, and they could detect no uterus. *With sarcasm:* I was labelled with "sexual dysfunction" because I couldn't have intercourse. *Curiously:* ...But I had discovered my own sexuality so I was very confused..... *Resigned:* But my doctors recommended vaginal reconstruction so I could have a normal sex life with my husband when I got married. I never had a chance to want a vagina I simply had to have one. {PAUSE...} I went from selling Girl Scout Cookies to correcting my sexual dysfunction in one afternoon.

I spent the next few years going to specialists, having tests to confirm my gender, being probed by curious doctors and interns with multiple instruments in multiple holes at multiple times. They saw their definition of normal, and I wasn't it. Like an android on an assembly line, I had no concept of feeling that this body was mine. But I was not yet capable of wondering who was having the biggest problem with my body. Was it me or the

people treating me? There was so much focus on the woman I "should be" that I lost all knowledge of the girl who I was.

Wishing I could have had choices... The chance to desire change on my own - embracing opportunity rather than fearing who I was supposed to be. And I was told that I would never meet another woman such as myself. Like the Hunchback in the Bell Tower, I found a place to hide when normalcy failed me. {PAUSE...} Why was my gender challenged in the first place, and then confirmed like something I didn't already know? Why was my body taken away and rearranged like a sexual Action Figure by men with knives? What was the need to feminize my body, which actually neutered my soul?

When I was fifteen I had my 2nd and 3rd surgeries.

"...a slight dimple was present where the vagina was expected to be. By means of sharp and blunt dissection a very adequate vagina was developed... a skin graft was obtained from the buttocks, attached to the mold, and inserted into the cavity... The vagina was closed... All sponges were accounted for."

Two weeks later I had the surgery to have the mold and stitches removed. Then I was told about postoperative therapy to keep my vagina "functional". A "functional vagina" is a vagina that will be able to accept a normal size penis. I wasn't interested in sex, and this plastic vaginal dilator for postoperative therapy wasn't very appealing. One doctor actually compared a vaginal dilator to a shoe stretcher! I had two follow-up visits with my surgeon and never saw him again. I was another surgical success.

As I grew older I realized I was faced with many questions. How will I experience menopause? How do I monitor my ovaries? How many ovaries do I have and where are they hiding? What about pap smears? I was tired of all this and really pissed that I had to ask all the questions.

My sister is the one who told me there was an actual name for my condition. That is when I discovered the other symptoms associated with my Syndrome. The connection to years of disability and hearing loss made me numb. The most important discovery I made was to learn that there are many variations of gender. This wasn't just about bodies - it was about genocide of variation. A whole new perspective was growing from very old emotions....

I also learned that various body parts are transplanted to create vaginas for "normal sexual function". I read one case where an actual vagina was transplanted from the patient's mother. My mother's used vagina?! But regardless of how your vagina is created, you still have to keep it "functional" with regular intercourse. Now who benefits most from that?

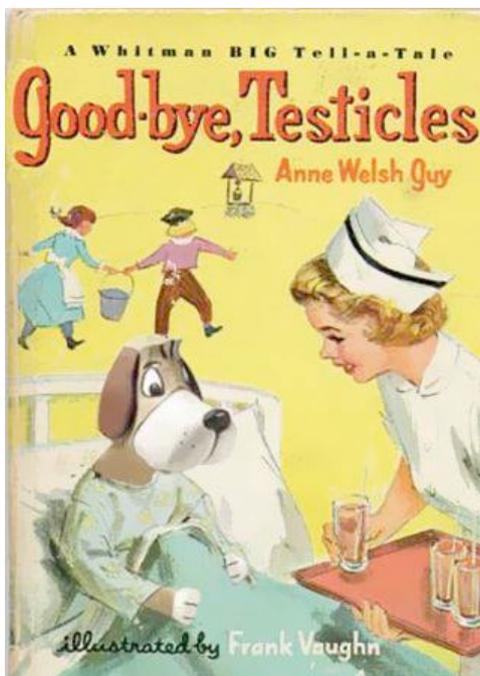
I have read a lot about the "medical challenge" of treating women with vaginal agenesis but I think the challenge is broader than that. We challenge the role presented to women and that makes people very nervous. We challenge the concept of normal for gender and sexual activity, and that makes people fanatic. We are literally molded to fit societal values. We are faced with questions of our most vulnerable selves during our most formative years. But how can you follow your heart to the answer when the process has ripped out your heart?

Questions have haunted me for too many years because I couldn't find the words. Meeting others with my experience has finally allowed me a voice. Some of their stories seemed so traumatic that it challenged me to recognize that their trauma was also mine. We exist in a conundrum because our knowledge is powerful but hidden in embarrassment and shame. The approach to our bodies is very extreme but affects all women in subtler ways. Advances in medicine offer men Viagra, but women still get the knife! Scar tissue does NOT enhance sexual pleasure.

I come out about my surgery in carefully selected ways. I have seen the response of too many twisted faces telling me that they have never heard of such a thing. They show me pity. They tell their friends this great gossip and strangers ask intrusive questions on the street corner. One medical provider told me I was "just too weird". I have been asked if this is what made me a lesbian, by lesbians who were born with vaginas?!?

I want people to understand that doing the right thing often does more harm than good. The standard of normal that we aim for is imaginary. People don't fail to meet the definition of normal gender, but the confines of the definitions fail to meet the people. I feel abnormal because I had to be fixed, not for the truth about my body. I feel different because of my surgeries, not because of my vaginal dimple. Being born without a vagina was not my problem. Having to get one was the real problem! My "sexual dysfunction" posed less of a threat to my health than the parts of the Syndrome that disabled me. So why is a vagina all I was given to cope with a much greater loss?

The complete survey, article, and links to resources can be found at www.mrkh.org
For more information, email:
info@mrkh.org



Lessons From A Christmas Carol: Acceptance and Kindness for Children with Differences of Sex Development

Courtney Finlayson for the Huffington Post
Pediatric Endocrinologist, Ann & Robert H. Lurie Children's Hospital of Chicago Assistant Professor of Pediatrics, Northwestern University.

In Charles Dickens' masterpiece, *A Christmas Carol*, Bob Cratchett says, "But I am sure I have always thought of Christmas time... as a good time; a kind, forgiving, charitable, pleasant time; the only time I know of, in the long calendar of the year, when men and women seem by one consent to open their shut-up hearts freely, and to think of people below them as if they really were fellow-passengers to the grave, and not another race of creatures bound on other journeys."

In this spirit of the holidays, I hope to open your hearts to understand a group of patients that have suffered, often silently, from stigmatization related to "disorders of sex development" (DSD) or "intersex," which [affect](#) up to 1 in 4,500 individuals. I am a pediatric endocrinologist (a physician who treats childhood hormone conditions) and specialize in caring for children with DSDs. I hear my patients, my friends and my family as well as the popular media struggle to conceptualize these conditions. Sadly, this lack of understanding often leads to unwarranted shame among patients or their families and cruel prejudice among the public. As I write this article, I worry that I will err in my wording and cause offense. In the past, terms like hermaphrodite and pseudohermaphrodite were used. These were considered perjorative, and an effort was made to adjust terminology, which led to the term DSD. Even this term, however, may brand these conditions as a disorder rather than a variation of human development. I chose to use the word DSD here as it is the currently accepted medical term and thus as a physician, it is the term I use. I am sensitive that even this word, chosen to refer to an

embryologic process, can be upsetting.

Sex development is a highly complex process of fetal development that relies on an intricate series of interactions. This is not an x-rated discussion, but simply the process by which the fetus develops internal organs (ex. uterus, ovaries, epididymis, testicle) and external organs (labia, scrotum, clitoris, penis). It is imperative to understand that every baby starts out exactly the same! Baby girls and boys develop internal and external genital organs from the same initial fetal structures. For example, the clitoris and penis come from the same tissue which further develops under the influence of specific hormones. Any slight alteration of the sex development signals (chromosomes, genes, hormones) will lead to a DSD. These conditions do not happen as a result of any action or fault of the parents and they can happen to anyone. There are more than 30 types of DSDs of which I have described two in more detail.

A baby was born to parents who had been told, by prenatal ultrasound, to expect a baby girl, had told their family and friends and had equipped themselves with an arsenal of pink baby gear. At birth, the baby's external genitals had a structure which could be either a generous clitoris or a small penis with the opening for urination at the base rather than the tip. There was vaginal opening along with structures which partially resembled labia and partially a scrotum. The baby had a uterus, but also over the first week of life a gonad (the term for the structure that develops into an ovary or testicle after which the testicle usually descends into the scrotum) descended into one of the folds. Hormone evaluation was done and showed the baby made a typical amount of testosterone for a baby boy. Genetic analysis found that the baby's cells had variable chromosomal makeup with some of them containing an abnormal Y chromosome. Ultimately, the complicated medical evaluation led to a diagnosis of mixed gonadal dysgenesis, a condition in which the gonads form abnormally. This can lead to an infant with very little to no genital ambiguity for a girl or a boy or a situation like the one I just described,

dependent on the exact genetic cause and the ensuing hormone production. The parents were faced the quandary of whether to choose to raise this baby as a girl or a boy.

A 17 year old girl presented with the complaint of not having started her period. She said she had started to develop some breast tissue around 12 years old, but had only developed a few pubic hairs. Her external genitals appeared as a typical female. She, however, was found to have a condition called Androgen Insensitivity Syndrome, a condition in which an individual has XY chromosomes and develops testicles and other "typically male" internal organs, but the receptors in their cells cannot respond to the testosterone. Consequently their external appearance may look completely "female" as in this girl who has Complete Androgen Insensitivity Syndrome or have some genital ambiguity in those with Partial Androgen Insensitivity Syndrome, depending on the degree to which their receptors are affected.

So, who are individuals with DSDs? Most importantly, they are defined by the same qualities that define all of us. They have hopes and dreams, strengths and weaknesses, and want to be cherished in their communities. Medically, those with DSDs may have atypical anatomy or hormone production. They might require hormone replacement to go through puberty or surgery to allow them to have sexual intercourse. Many people will ask "well, is that person with a DSD a girl or a boy?" I have learned from individuals with DSDs that binary categorization of gender is over-emphasize, but it remains a defining quality in our society. Often the person's gender identity (whether they identify or know themselves as male or female) does not match all of the internal or external organs. So, the individual with a DSD may have some typically male organs on the inside or have some more male-like organs on the outside, but identify as a female or vice versa. When an infant is born with a DSD, my job as specialist in this condition is to work together with our team in the Gender & Sex Development Program at the Ann and Robert H. Lurie Children's Hospital of Chicago. This

team includes pediatric endocrinologists, urologists, surgeons, psychologists, geneticists and ethicists who evaluate the child's anatomy, genetics, and hormones to determine the specific diagnosis. We then need to educate and explain the findings to the family and work with them to chart the best course for their child, both medically and psychosocially.

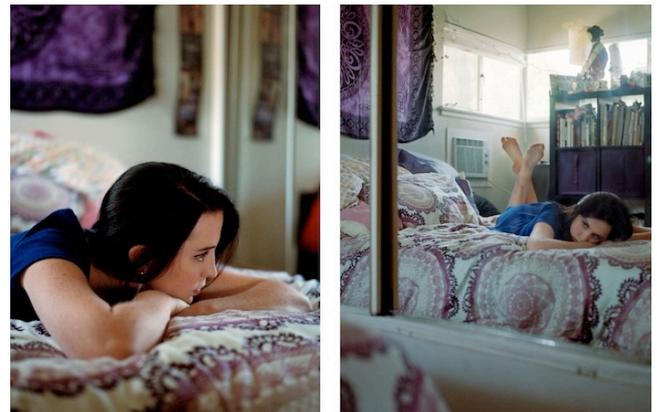
Given our societal norms, most parents feel the need to choose a sex of rearing for the infant. Regardless of appearance, chromosomes and hormone levels, no one can tell you with certainty whether an infant will identify as a boy or girl or somewhere along that continuum. Development of gender identity is part of childhood and human development. Often there are good clues of a child's gender identity by age 4 to 5 years, but there is no test or accurate prediction method. So, we often have to help families to choose a sex of rearing in infancy, but with very open discussion that the child may identify differently later. The parents of the first child I described, with mixed gonadal dysgenesis, ultimately chose to raise their child as a boy, but know that their child will be the one to identify his or her gender later in life. The 17 year old girl with Complete Androgen Insensitivity Syndrome identifies as a girl and is a girl, just with a little different internal anatomy than most girls.

Individuals with DSDs and their families are faced with struggles of a having medical condition as well as the associated psychosocial challenges. The parents of an infant may have to wait to determine the sex of rearing and name of the child for weeks while the medical details are sorted out. The simplest things, like calling their friends or family to announce the birth, are all of a sudden, emotionally charged. A young adult with a DSD wrestles with when to disclose this information to a romantic partner and fears the response. Fortunately, in our society today there is more awareness and understanding of these conditions, but there remains much work to be done to reduce the stigmatization. How would you feel if your child had a condition like this and was bullied

or ostracized? What if you were the parents of the first baby who had expected a girl, but decided to raise as a boy and had to explain it to your friends? How would you feel if you saw friends or co-workers whispering amongst themselves about your precious infant? What if your young adult child with a DSD found it hard to develop romantic relationships for fear of rejection? Please, take time in this holiday season to remember to be considerate of all people, including those with differences of sex development. Do not judge those whose bodies developed a little differently. There are differences in each of us and they make our world a wonderful and inspiring place.

I'm Intersex and My Body Works Just Fine, Thank You

November 10, 2014
By Hanna Hanra, Vice



Emily Quinn. Photo by Chloe Aftel

Emily Quinn is a 25-year-old animator who works at Cartoon Network. She is also intersex. For her this means that, while she has a perfectly normal-looking vagina, it's not a uterus and ovaries she has inside—it's a pair of testes.

Like the rainbow flag, there are many shades to being intersex. The term refers to people born with differences in their sex characteristics, which can occur in genes, chromosomes, genitalia, body hair, or reproductive organs. Quinn—who doesn't

respond to the testosterone that is produced in her testes (her body turns it into estrogen for her)—reckons she represents about one in 20,000 births, with intersex people generally representing about one in every 2,000 in North America.

For many intersex people, the condition is still shrouded in shame and secrecy. Children often have their genitalia removed or "tidied up" at birth, obviously without being able to give consent. Because of this, there is little research into the long-term effects of being intersex, but those who have either had their testes removed or their enlarged clitorises mutilated often have long-term hormone problems.

Striving to stop the perpetuation of false information and general prudishness, Quinn recently came out as being intersex in an open letter after MTV's show *Faking It* brought on an intersex character that Emily consulted with them on.

VICE: Hey, Emily. Why have you come out as intersex now?

Emily Quinn: It all came about with *Faking It*. This is the first time that intersex people have had representation, ever. It's a main character on an TV show—not just one for shock-and-awe value. This is the first time that there's been a series regular who tells a story that is "normal," that being intersex is something people live with every day. I've been consulting with them since June. I have wanted to speak publicly about it, but it never felt like the right time. I wanted to come out in a way that made an impact rather than posting on Facebook one day.

What has been the public reaction to both you coming out and the show itself?

Generally the public reaction has been good. On Reddit you get a lot of... well, let's say people on the internet aren't always the best. But people on there are also really supportive. Whenever it would get rude or out of hand, there would be people who would get on those commenters, which was great. Public support has been really good for Lauren, the character in *Faking It*. Everyone's responded really well to her.

Being intersex is something that most people don't know about—it may not even be a word they've ever heard—and they've been excited to learn about it and support of her character. It's really normalised it, which is exciting.

How did MTV initially approach you?

I work with [Advocates for Informed Choice](#), a legal group that deals with stopping surgeries on intersex children. When MTV decided to do an intersexed storyline they contacted [GLAAD](#), which contacted the legal group, and since I lived five minutes from the studio and already worked in Hollywood, they connected us. They had no idea what they were going to do. I'm still going in and consulting as they don't know much about our lived experiences.

Going back, what were the initial indicators that you might be different?

In my case, there weren't too many when I was first born. They would have had to have done a chromosome test to find out. As I was growing up there were small indicators, like, I was always tall with big feet. I have an aunt who has AIS (Androgen Insensitivity Syndrome) as well, and she told my mom that she thought I might have it, so mom took me to the gynecologist when I was ten and that's when we found out.

But there was nothing visible about me in particular—which is usually the case with complete AIS. If I had responded to the testosterone in my body at all then my genitalia would have "masculinized" a little. But for me that wasn't the case.

Right. So, there's CAIS and PAIS. What's the difference?

AIS is on a spectrum. You could be completely insensitive, which is pretty much what I am, all the way down to just partially insensitive. So there are—albeit not a lot of—AIS men. I fall under CAIS (Complete Androgen Insensitivity Syndrome) so I present as female, but I have male (XY) chromosomes and testes.

What's the AIS community like? Is there a pecking order?

For the most part it's very supportive. We all

go through a lot (of valid, varied experiences). And so to bring pettiness like that to the community, well, it's just not helpful. Although when I was doing my Reddit AMA there were people who were like, "Why do you need to do this?" Because, in my case, I present as fully female and I feel female. A partner wouldn't know. So why would I need to bring it up?

In times like that I'm not "intersexed enough," but that's also part of the reason why I feel like I have to be an advocate for it. Because, like me, there are so many people who either do have AIS or are intersex and are dealt with differently. It's also different because I am one of three or four women I know who have their testes. I could give you a list of 300 women who don't. Sometimes it feels like I don't fit in because I haven't been operated on, but I understand how close I've come to that happening.

That's interesting. Would you ever have them taken out?

At this point, only if they became cancerous. But I don't see that happening. I have them checked once a year. But I don't really want them taken out, and it's also hard to find a doctor who is OK with it.

If it ain't broke...

Right. There's no point in having them removed. Unless they herniate or something, or, like I said, become cancerous. But if I get them removed I'll immediately have to go on hormone replacement therapy until I'm 60. The testes are what are making my hormones, so I would need to replace that or I'd develop osteoporosis or go through menopause. I'm very stable right now, health-wise.

So why might some doctors say you should have them removed?

People want to "fix it." Doctors want to fix the problem that they imagine is there. That's the biggest hurdle, that doctors are uncomfortable with the idea that a girl could have testes. A lot of them believe that they have a high risk of becoming cancerous, because there is not a lot of research on women with AIS with their testes.

Why?

Well, some women might not know they're AIS because they have been lied to, or because they didn't find out until they were a lot older. That's when doctors might persuade them to have the testes removed. The statistics that do exist on internal testes are for men who have theirs inside the bodies, and they are at a higher risk of being cancerous. But they have no statistics on it for women.

You're not only pushing medical boundaries, then. You're also questioning the profession altogether.

A lot of doctors have outdated medical practices. That was the problem with my recent doctor—she's older, and her medical training was a long time ago. When you're a doctor going through medical school you're trained to fix things. It can come from a place that's good, but I know people who have had them removed and have had so many consequent problems arise from it. And because my body is naturally at a place where it's OK—I don't need to take pills to fix a problem that was never there—I do sometimes feel that some people can become a little jealous of that.

Our bodies' ability to adapt is mind-boggling. So, just to rewind a little, the testosterone that's produced by your testes is turned into estrogen?

Yes. All bodies do it, actually. It's called aromatising.

I had no idea.

Well, my body is running fine—why mess with it! Especially when it's dealing with something like hormones, which are so crucial to your everyday needs as well as your development. There's a woman in Australia who I'm about to email my medical records to because she's trying to re-create what the doctors tried to take away from her.

It must be difficult for some people because, if surgery happens when you're a kid, you have no way of knowing or any choice in the matter.

Right. I grew up in Utah, which is a very conservative state. My doctors literally had no

idea about me or what AIS was—like, to the point where they couldn't find my testes. I only found them this year. My doctors didn't know what to look for or where to look. They knew from my blood work that there was something there making testosterone, but they could never find out what.

And where were they?

They were right where they were supposed to be! Right where my ovaries would be in my pelvic cavity. But because my doctors could never find them, they could never remove them. So I was lucky. They scheduled a laparoscopic surgery to have a look, but I never went through with it because it seemed scary. It turned out to be a good thing.

How helpful is it for you to have an internet community?

It's so helpful. If you had asked me ten years ago I might have answered differently because, when you're a pre-teen searching for sexual disorders on the internet, it's terrifying. I turned to the internet for information and clarity, because the doctors didn't know what was going on and my parents weren't very proactive. Being connected to people is so empowering, though—it's the reason we can finally all talk about this stuff.

We are realizing we are not alone. Doctors tell you all the time, "You're the only one like this," or, "You'll never meet anyone else with this," which makes you want to talk about it. Having the ability and resources to connect with others is so vital to make you feel like you're not a freak and you're not alone. You're different, but it's OK.



Protesters in China. Image via Flickr user Shih-Shiuan Kao

Why is it important to have the I and T in LGBTI? They're not sexual minorities.

I mean, L, G and B are about sex. T is about gender, and I is about biological sex. But one of the new acronyms that I keep seeing is GSM, which is Gender and Sex Minority. I think having the I in LGBTI is important, though, because we go through a lot of the same things. We feel ashamed. A lot of people are bullied and do feel like they're different, and being in a minority that's related to gender, sex, and sexual orientation, they're connected in lots of different ways. That's not to say that all intersex or LGBT people feel like that.

It's hard because, with LGB people, there's nothing medical that you can fix (as much as some people like to think their is). And with us, because of a medical diagnosis, a lot of people who are LBG don't think we belong in the LGB community. But I think that the important things that a lot of LBG people go through—feeling stigmatized, being closeted—are important binders that we can take away from the LGBT movement. They are things we feel on a daily basis, too.

Why is it important to you to be such a visible presence for AIS people?

I was told I was the only person like this when I was growing up, and it was very lonely and scary. I wanted to look into the media for somebody to say that they were the same as me. I remember reading about certain celebrities and wanting them so badly to say that they have AIS, just so that I didn't feel like I was such a freak or a horrible person. So that's the main reason. I don't want any kids going through this to feel like that.

I'm in a place where I'm very comfortable with my body, but not a lot of people are, and that's not a good place to be. But more than that, it's about all of these surgeries that happen without consent, on babies, on children that are two or three, even on adults. If people become more accepting about it then we will get more doctors who think twice about operating to try and "fix" us, to try and

take away the thing that is making someone else uncomfortable. We're not broken.

Follow [Hanna Hanra](#) on [Twitter](#).

Surfing the Internet

This is a Wikipedia list of fictional intersex characters, along with their related stories and authors, and tropes... makes for a long reading / viewing list!

A

- Amy, girlfriend of Ken Miller in [Freaks and Geeks](#) teen comedy/drama TV series.
- [Annabel/Wayne](#), character in novel by [Kathleen Winter](#).

B

- [Cornelius Brunner](#), product of merger of Jerry Cornelius and [Miss Brunner](#) in [Michael Moorcock's](#) fantasy novel [The Final Programme](#)

C

- [Vincent Clarkson](#), character in [NBC/DirecTV soap opera Passions](#). Blackmailer, serial killer.
- [Comet \(DC Comics\)](#). Shapeshifter.
- Lauren Cooper, character in [MTV](#) scripted comedy [Faking It](#)
- [Quentin Costa](#), character in [Nip/Tuck](#). Doctor, product of incest, serial rapist.

D

- [Desire](#), one of the [Endless](#), from [Neil Gaiman](#) [The Sandman](#), ([DC Comics](#)).

E

- Therem Harth rem ir Estraven, character in the science fiction novel [The Left Hand of Darkness](#), by [Ursula K. Le Guin](#).

F

- Fawn Singleton Farrell, half-sister of main character Vidamía Farrell, in [Edgardo Vega Yunque's](#) novel [No Matter How Much You Promise to Cook or Pay the Rent You Blew It Cauze Bill Bailey Ain't Never Coming Home Again](#).

H

- Swan Er Hong, lead character in science fiction novel [2312](#) by [Kim](#)

[Stanley Robinson](#).

I

- [Ilario](#), lead character in [alternate history](#) novels by [Mary Gentle](#).

K

- Keral, a member of an alien species in [The World Wreckers](#) science fiction novel by [Marion Zimmer Bradley](#).

L

- Laurence/Laurent in the novel [The Hermaphrodite](#) by [Julia Ward Howe](#).

M

- [Rebis](#), character in the comic series [Doom Patrol](#).
- [Ruby Moon](#), Manga character. Magical guardian.

R

- Rachel ([Friends](#) TV sitcom) was rumoured to be intersex in episode [The One with the Rumor](#).

S

- [Sailor Starlights](#), Manga characters.
- Jackson Smith, basketball player in [The Softer Side](#) episode of [House \(TV series\)](#).
- [Spork](#) lead character in the eponymous movie.
- Cal (or Callie) Stephanides in the novel [Middlesex](#) by [Jeffrey Eugenides](#). Product of incest.

T

- Thorn the Mannamavi, lead character in the historical novel [Raptor](#) by [Gary Jennings](#). Amoral, lovers die.
- [Bel Thorne](#), character in [Vorkosigan Saga](#) science fiction novels by [Lois McMaster Bujold](#). Ship captain.
- Tintomara, character in classic Swedish novel [Drottningens juvelsmycke](#) (The Queen's Tiara) by [Carl Jonas Love Almquist](#). Androgyne. Brings death.

W

- Fitz Wahram, character in science fiction novel [2312](#) by [Kim Stanley Robinson](#).
- Max Walker, lead character in novel [Golden Boy](#) by [Abigail Tartelin](#).
- [Wraeththu](#), post-apocalyptic species in novels by [Storm Constantine](#).

Y

- [Sadako Yamamura](#), antagonist in novel by [Koji Suzuki](#). Demigod, chaste.
- [Yue](#), [Manga](#) character and guardian.

'Faking It' Season 2 Spoilers Reveal That Lauren Is Intersex & That's a Huge Step Forward

Ariel Kay 09.17.2014 Bustle

Like a lot of gay ladies, I was not impressed when I heard the premise of MTV's *Faking It*: two straight girls pretend to be lesbians to gain popularity at school. I thought the show was making light of the struggles LGBT youth go through and capitalizing on straight men's fetishization of lesbians, yadda yadda yadda. But then I watched the show, and it quickly grew on me — it helped that one of the two main girls turns out to actually be gay (or at least questioning her sexuality). Annnnd that she is super fine. Now *Faking It* is back for its second season, and it's doubling down on its representation of queer youth. In an interview with *Entertainment Weekly*, showrunner Carter Covington revealed that in the very first episode of Season 2, we'll find out that Lauren is intersex. At the end of the first season, it was revealed that Lauren was "popping pills," though we didn't know why. Turns out, they're hormone pills.

In the interview, Covington explained that he and the writers decided early in the first season to make Lauren (played by Bailey Buntain) intersex, saying, "I knew I didn't want Lauren to just be the girl who comes in and says bitchy things. Since our show is called *Faking It*, we were talking about what Lauren could be faking or hiding, what could be inside her that makes her this tough-as-nails, hyper-feminine character, and Intersex came up."

For those of you who aren't quite sure what the term "intersex" means, here's a brief rundown: In the simplest terms, "Intersex is

when your biological sex doesn't neatly fit into the male/female binary," according to Inter/Act Youth, an organization that spreads awareness of the intersex community. "Intersex" is a blanket term that covers over 30 different conditions. It can refer to someone who's born with ambiguous genitalia, someone who has XXY chromosomes, or multiple other conditions.

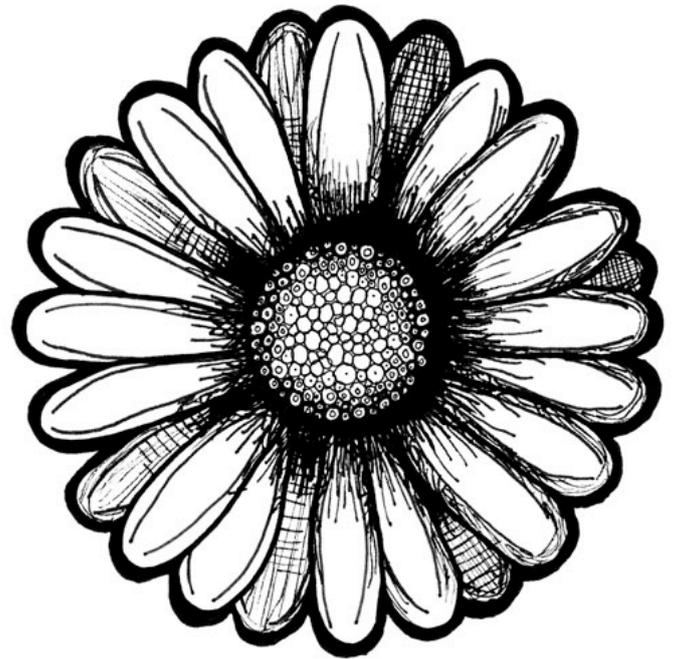
Lauren has Complete Androgen Insensitive Syndrome (CAIS). All people with CAIS have XY (or male) chromosomes, but before birth and during puberty their chromosomes are "unable to respond to male hormones," and thus their bodies develop as female. According to the Intersex Society of North America, "The newborn AIS infant has genital of normal female appearance, undescended or partially descended testes, and usually a short vagina with no cervix. Occasionally the vagina is nearly absent." As biological sex and gender are so closely linked, intersex individuals may also identify as queer, transgender, or another of the infinite gender identities in existence. Transgender actress Laverne Cox will also appear on *Faking It* this season, adding even more to the show's diverse representation of gender and sexuality.

The biology behind being intersex is complex, and then there's the social stigma that goes along with not fitting neatly into the gender binary. Though there have been a few intersex characters on TV in the past (mostly on episodes of medical dramas like *House*), there's never before been an intersex main character, or one that will be given such a positive storyline, before Lauren on *Faking It*. This is a big moment for intersex and LGBTQ representation! According to Inter/Act Youth, one in about every 2,000 people is intersex (that's about the same rate as people born with red hair). It's very exciting that intersex people will finally be represented in pop culture — and not as anything other than normal folks with a medical condition. Yay, progress!

On *Faking It*, Lauren has hidden her condition her whole life because she's afraid of people's reactions. When she confided in her Season 1 boyfriend Tommy, he broke up with her, pulling probably the douchiest move in recent MTV memory. But by the end of the first episode of Season 2, the whole gang, including Karma, Amy, Liam, and Shane, will all learn of Lauren's intersex condition, and from everything I can see, it looks like they react as though they were actual humans capable of sympathy, and don't freak out. Good job guys, you're all not terrible.

We'll have to keep watching to see how the rest of Lauren's storyline progresses throughout the season. I'm personally hoping for a conversation between Lauren, Amy, and Shane about dealing with LGBTQ issues in high school, and maybe sharing those struggles will bring them closer together. Orrrr, maybe Lauren will be exactly the same power-hungry narcissist she's always been, but now we'll have some more insight into her character. She may be intersex, but she's still the same meanie she's always been. And that's progress.

Ed – this program isn't showing in Australia but if you like download TV from the USA then it's worth a watch.



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

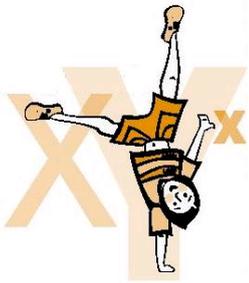
We'd love to have representatives in other states and territories. We also have representatives for parents of children with AIS and men with AIS / intersex... and the word is out that partners of people with AIS need support too!

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

The next dAISy

Next issue is July 2015. The deadline for submissions is 30 June 2015. 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 (2014-2015)

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!