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The Newsletter of the Androgen Insensitivity Syndrome (AIS) Support Group of Australia July 2014 Edition

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It's been a hectic six months for the AISSGA, topped off by our annual general meeting in Sydney in August.

Please enjoy some light reading here about all things AIS!

Ed.

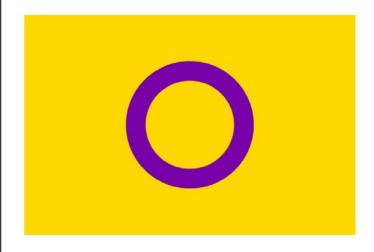
AISSGA in LGBTI Mardi Gras Parade, Sydney

Big ups to our peeps who marched with PRIDE at the Sydney Mardi Gras Parade this year in March.... We would tell you more but the pictures are worth more than a thousand words! Go you good things!





Historic intersex rights inquiry in Senate March 26, 2014



A REPORT into intersex health, sterilisation and rights and its recommendations that was discussed in the Senate last night has become the first of its kind to be discussed in Federal Parliament.

In the course of 30 minutes, senators from all three major political parties spoke about intersex health issues to mark World Health Day in light of what is the first-ever parliamentary inquiry into intersex health and rights.

Western Australian Greens Senator Rachel Siewert spoke as Chair of the Community Affairs References Committee, which published the *Involuntary or Coerced Sterilisation of Intersex People in Australia* report last October.

Meanwhile, Queensland Coalition Senator Sue Boyce spoke as chair of the Community Affairs Legislation Committee, while Queensland Labor Senator Claire Moore spoke as a former member of the committee enquiry.

Organisation Intersex International (OII)
Australia representatives were present in the gallery during the historic discussion and welcomed the occasion.

OII president Morgan Carpenter said: "In three extraordinary and powerful speeches we heard clear recognition that the medical treatment of intersex people is a human rights issue, that intersex is not a disorder, and that intersex people must be heard.

"Our issues are simply when regarded as issues of bodily autonomy, human rights, and individual choice of expression. Alone these statements are momentous, but the Senators also told some of our personal stories, and paid tribute to members of intersex-led organisations, OII Australia and the AIS Support Group Australia.

"We are enormously excited by today's crossparty speeches. We hope that they will promote a better understanding of our health and human rights concerns, and policy changes that will lead to better health outcomes."

OII vice president Tony Briffa echoed Carpenter's sentiments.

"This is a turning point in the way that intersex people in Australia are seen and treated," Briffa said.

"We have long fought for our voices to be heard, so to have the Australian Parliament acknowledge our existence and our issues – as discussed in detail in the Senate report – is vital.

"Today heralds a moment in our movement where our politicians were united in expressing great concern about the current paradigm. It's not okay to pathologise us. We thank the Senators for today's speeches, and we look forward to the implementation of the Senate Report Recommendations."

In her speech, Senator Siewert spoke about the disordering of intersex, and the nature of intersex differences.

"I think most people in the community do not understand 'intersex' and do not understand the issues. People in the past have seen it as a disorder — in fact, I think it is fair to say that many still do," she said.

"So one of our recommendations is that terms such as 'disorder' should not be used. We strongly recommend that government and other organisations use the term 'intersex', and do not use the term 'disorders of sexual development', because intersex people should not be seen to have a disorder.

"We also point out that there is no single condition that is intersex. There are in fact 30 or 40 testable genetic, anatomical and hormonal types of sex difference. We need to make sure that that is clear.

"Most importantly, we need to understand that this is a human rights issue."

Senator Sue Boyce commented on the origins of the inquiry, and how it grew out of an inquiry into the involuntary or coerced sterilisation of people with disabilities – with many similar issues encountered.

"The issues that were similar were issues where some in the medical profession thought they knew better than anyone else; they would make decisions not only on behalf of individuals but on behalf of families as to what gender might be assigned to a baby or to a young child when this was not immediately obvious," she said.

"What differed was the fact that the people with disabilities that we were talking about in many cases were seen as unable to give informed consent because of cognitive impairment. In the case of intersex people, the main issue was that this was being done when they were too young to give consent."

Meanwhile, Senator Moore commented on the issues of stigma, respect, and ignorance: "We heard consistently about the issues of medicalisation. When looking at the history of intersex, we consistently see that it has been defined in a medical way. "As Senator Boyce put it, the political focus has meant that people are ignored to a large extent and are looked upon as 'case load', as things that have treatment rather than people with feelings and human rights. In our recommendations we have consistently said that the issues around intersex in our country should be seen as human rights issues so that people have support, recognition and respect.

"The clear message from our report is that people should be valued and respected. They know who they are and they should be able to share that openly with all of us."

THE RECOMMENDATIONS:

- 1) The committee recommends that governments and other organisations use the term 'intersex' and not use the term 'disorders of sexual development'.
- 2) The committee recommends that health professionals and health organisations review their use of the term 'disorders of sexual development', seeking to confine it to appropriate clinical contexts, and should use the terms 'intersex' or 'differences of sexual development' where it is intended to encompass genetic or phenotypic variations that do not necessarily require medical intervention in order to prevent harm to physical health.
- 3) The committee recommends that all medical treatment of intersex people take place under guidelines that ensure treatment is managed by multidisciplinary teams within a human rights framework. The guidelines should favour deferral of normalising treatment until the person can give fully informed consent, and seek to minimise surgical intervention on infants undertaken for primarily psychosocial reasons.
- 4) The committee recommends that the Commonwealth government provide funding to ensure that multidisciplinary teams are established for intersex medical care that have dedicated coordination, record-keeping and research support capacity, and comprehensive membership from the various medical and non-medical specialisms. All

- intersex people should have access to a multidisciplinary team.
- 5) In light of the complex and contentious nature of the medical treatment of intersex people who are unable to make decisions for their own treatment, the committee recommends that oversight of these decisions is required.
- 6) The committee recommends that all proposed intersex medical interventions for children and adults without the capacity to consent require authorisation from a civil and administrative tribunal or the Family Court.
- 7) The committee recommends that the Standing Committee on Law and Justice consider the most expedient way to give all civil and administrative tribunals in all States and Territories concurrent jurisdiction with the Family Court to determine authorisation for intersex medical interventions proposed for a child.
- 8) The committee recommends that civil and administrative tribunals be adequately funded and resourced to consider every intersex medical intervention proposed for a child.
- 9) The committee recommends that the special medical procedures advisory committee draft guidelines for the treatment of common intersex conditions based on medical management, ethical, human rights and legal principles. These guidelines should be reviewed on an annual basis.
- 10) The committee recommends that complex intersex medical interventions be referred to the special medical procedures advisory committee for consideration and report to whichever body is considering the case.
- 11) The committee recommends that the provision of information about intersex support groups to both parents/families and the patient be a mandatory part of the health care management of intersex cases.
- 12) The committee recommends that intersex support groups be core funded to provide support and information to patients, parents, families and health professionals in all intersex cases.

- 13) The committee recommends that the Commonwealth Government support the establishment of an intersex patient registry and directly fund research that includes a long-term prospective study of clinical outcomes for intersex patients.
- 14) The committee recommends that the Commonwealth government investigate the appropriate regulation of the use of dexamethasone for prenatal treatment of CAH.
- 15) The committee recommends that, effective immediately, the administration of dexamethasone for prenatal treatment of CAH only take place as part of research projects that have ethics approval and patient follow-up protocols.

Ed – although not interviewed for this article, credit must be given to AISSGA President Bonnie Hart, Gavi, etc. for their work toward this landmark outcome. Thanks Bonnie!

World's first intersex mayor Tony Briffa on a new quest for human rights



CREATED ON // Wednesday, 09 April 2014 Author // <u>Rachel Cook</u> www.gaynewsnetwork.com.au

From the world's first intersex Mayor to international activism, Tony Briffa is changing the world one step at a time.

In 2011, Tony Briffa became the world's first openly intersex Mayor. The story made headlines internationally and Hobson's Bay Council in Melbourne's west was suddenly

appearing in media outlets such as the Huffington Post and The Advocate.

Briffa had been part of local government since 2002. Firstly as part of a group to save a local park and eventually as co-convener of the Residents Association. By 2008 Briffa had been elected "very convincingly" to Council, and then one year later to Deputy Mayor. That Briffa made Mayor just three years later is testament to Briffa's reputation.

Briffa's popularity was never in question in the west. The residents had accepted Briffa's condition largely due to her openness about being intersex and largely due to her passion for the area

However, it had been a long road for Briffa who had been raised as Antoinette, then became Anthony, and who now happily resides as Tony.

Briffa was born with Partial Androgen Insensitivity Syndrome, a condition where the foetus only partially has the ability to respond to androgens. This means that the masculinisation of male genitalia may be impaired in its development. However, it does not significantly impair female genital or sexual development. While Briffa was born with the typical male pattern of 46 XY chromosomes and functioning testes, the testes were internal and the genitalia presented as female.



[Image] Tony at Pride March in 2012. Photo: Supplied

"I am a twin and pretty much as soon as I was born the doctors realised I was intersex," Briffa says.

"The doctors decided to raise me as a girl because I looked more female than male."

This meant that doctors began performing surgery to "normalise" Briffa from the age of two months old. The surgeries would continue until she was 15 years old.

Briffa was raised as a girl named Antoinette and she was a child when her testes were removed without her consent. At 11 Briffa started taking estrogen as part of hormone replacement therapy. The plan was to make Antoinette completely female and completely heterosexual.

"I was a pretty confused kid," Briffa says, "not only because of my anatomy and my biology and all the medical tests and surgeries I went through, but my sexual orientation confused me because I was attracted to women.

For some women that would make them think they were a lesbian, but for me I didn't know if I was a lesbian or was I really a straight boy?"

Briffa is not trans and never felt like a boy, but there was the nagging feeling that because her body had been denied the testosterone it was naturally producing, perhaps she had been deprived knowing who she would have actually been had the doctors allowed her body to develop naturally.



[Image] As a child, Briffa was raised as a female - Antoinette

At the age of 29, (after she had been in a straight marriage with a man for two years from 19 to 21 and after coming out as a lesbian at 26), Briffa was told the truth about her condition.

"I had some idea about what had happened, but I didn't know everything," Briffa says. "I didn't know that I would have actually partially responded to testosterone for example, because the doctors lied to me all along saying that my body wouldn't have responded to the testosterone my body was producing."

It was this discovery that led Briffa to "an experiment".

In 2000, at the age of 30, Briffa went on 60 Minutes in a bid to convince doctors to give her testosterone – they had previously refused to. Within months of the program going to air doctors relented and Briffa began hormone therapy again, this time taking testosterone. However, as part of this therapy the doctors also tried get Briffa to undergo psychiatric assessment in much the same way a transgender person has to seek psychiatric approval before undergoing hormone therapy.

"They tried to get me to go through the trans process which I completely refused," Briffa says. "For a start, I'm not trans and they didn't have my approval for what they did to me previously and so I wasn't going to jump through hoops for them to give me what my body naturally had."

The testosterone did have an effect on Briffa's body. It deepened her voice and changed her looks considerably.

"Then I thought as part of this experiement I'm going to live as a male, so I became Anthony," Briffa says.

However, that was not going to be the end of the journey. Living a man made one thing clear though: Briffa realised that she is not male and could not have a relationship with a woman as a man.

"It was an interesting experiment but I realised I'm not male - I'm part male and I certainly can't have a relationship as a man. I wasn't socialiesd as a male, I didn't grow up male and I don't relate to a partner that way, so as Anthony I didn't have any relationships."

In fact, Briffa's issues with her childhood and the decisions the doctors made are not based on being raised female - if pronouns are needed these days Briffa uses 'she' and 'her' - the issues for Briffa are that the medical profession takes such drastic steps as operating on babies for conditions that are not life threatening and that intersex children

should be able to physically develop naturally until they are old enough to either choose to be male or female, or both, or neither.

"I never had an issue with being raised as a girl, it was all the secrecy, the lies and all the surgeries that were done without my consent that I have an issue with," Briffa says.

"Atypical genitalia isn't going to kill a kid, but doing surgery on kids just to make them look male or female and furthermore to make them heterosexual males or females is just unethical and it's a breach of their human rights."

In the 1970s there was no counselling for intersex children or their parents. The medical profession is changing these days but there is still a propensity to try and 'normalise' intersex children and enforce the gender paradigm of male and female. It is Briffa's hope that rulings such as the recent High Court decision on the NSW Registrar of Births, Deaths and Marriages v Norrie (Sydney resident Norrie May Welby) case, where the court decided that Norrie won the right to non-specified sex on registry documents, is a sign that the legal and medical systems are advancing in the area of recognition of intersex people's rights.

Last month Briffa resigned as Mayor of Hobsons Bay to concentrate more on advocacy for intersex people and human rights issues. Briffa is the Vice President of OII (Organization Intersex International Australia) and is working with politicians and the medical profession to change the way intersex people are treated in this country and internationally too. The right to have documentation that recognises the variations of gender for intersex people is also an important issue.

"Most of my legal documentation says female, some still says male which can be difficult. I've been searched at Sydney airport because they were not sure about my sex. They searched me because they asked me 'are you a man or a woman?' and I hesitated because that's a bit of a trick question for someone like me," Briffa laughs.

The legacy Briffa has left behind in Melbourne's west though is substantial. Briffa was an integral force behind Go West, which is a major part of the Midsumma Festival these days and represents the west's LGBTIQ community. At this year's festival Go West featured 22 events.

"We took a leadership base from the outset at Hobsons Bay, but all the western suburbs councils are involved now. So the changes I made did not just affect Hobsons Bay but the whole of the western suburbs. So everything they do now as a council, like 'Volunteer Week' and 'Seniors Month', all include queer events."

Briffa was always completely out as a queer Mayor. In the 2012 Pride March in Victoria Briffa marched in Mayoral robes. That year was an election year and while Briffa had easily won the role of Mayor the previous year she wondered whether marching in full Mayoral attire might have been too much for some voters.

"I packed up my office because I thought maybe I wouldn't get re-elected, I just didn't know how that was going to pan out, and you know what?, I got the highest primary vote out of any councillor in the western suburbs in Melbourne."

During Briffa's time at Hobsons Bay she met Manja Sommeling who Briffa married in New Zealand in September last year. The relationship has had a profound effect on Briffa in many ways. Firstly, Briffa realised after years of devoting herself solely to local government that the time was right to leave Council and spend more time with her wife. Secondly, it was the realisation that some same-sex marriage advocates were getting it wrong.



[Image] Tony Briffa with wife Manja

Although Briffa's birth certificate doesn't specify a sex, the Victorian register of birth, deaths and marriages recognizes her as a male (this was changed from female during the period when Briffa identified as male). This means Briffa could have married Manja in Australia under the guise of a heterosexual marriage, but as Briffa says, they are not in a heterosexual relationship and it was important for Briffa to be able to have the freedom to list her sex as indeterminate, which she could do in New Zealand.

"I was very annoyed with the AME (Australians for Marriage Equality) last year when they made the ACT Bill all about same-sex marriage and excluded intersex people like me. While I could have married Manja as a heterosexual couple that's not how we relate, we are not in a straight relationship, she is a lesbian. Manja and I got married in New Zealand last year so I didn't have to be male or female."

In 2014, Briffa has left local government and gone back to being an aviation engineer, which was her career before politics. She is focused on her new role with OII and confident of the changes she can make for intersex people. And Briffa is more content personally than ever before.

"Sometimes people say to me they are confused about whether I am male or female and I say to them, 'imagine being in my shoes!'

"I'm not going to pretend I have all the answers, it is bloody confusing being born both male and female and having had done what the doctors did to me.

"But I'm lucky. I've got a great family, a great community and a great wife and I never thought I'd be lucky enough to have such a wonderful relationship. I really do feel very fortunate."

Intersex dating: Finding love across the intersection

By Kat Kinsman, CNN April 15, 2014 -- Updated 1702 GMT (0102 HKT)



Romance is hard, no matter who you are. For people with intersex traits, connection poses unique challenges.

STORY HIGHLIGHTS

- Intersex bodies are surrounded by a lot of misinformation and mythology
- Differences of anatomy may be evident at birth, later in life or not at all
- Intimate connections can be difficult due to shame, stigma or physical difficulty
- Experts advocate for early, honest communication with children born with intersex traits

(CNN) -- There's a vocabulary of protection used around the intersex community -- of "escape" from sex assignment surgery to normalize their genitals, of PTSD and survivorship, of guilt from some whose bodies remain intact.

There's also a shared experience of shame, secrecy and disconnection borne of being treated like a physical mistake. They arrived in the world with genetic mutations that affect

them at intimate levels, and were taught to believe, often since birth, that their very existence is a condition that needs to be corrected.

The path to romantic connection with another human can feel isolated and impassible. The risk, impossible.

But it doesn't have to be.

Activists like Bo Laurent, Jim Ambrose and Pidgeon Pagonis have made it their mission to guide people with intersex traits and differences of sex development, known as DSD, toward understanding their own worth in the world. They're demanding visibility and justice in a culture that has long mythologized, marginalized and misunderstood their bodies. And some of them are hoping to find love with someone who truly sees them.

"It's hard for people to wrap their head around what exactly is going on. It gets everywhere -- it's nothing but sprawl. It's not limited to the bedroom," says Ambrose, a writer and the cofounder of The Interface Project, a site that collects and shares personal stories of people living with an intersex condition or DSD.

So let's start in the classroom with a quick lesson on what intersex is not: <u>transgender</u>, though the two are often erroneously lumped together or the "hermaphrodite" of lore and porn, possessed of fully functioning (and physically impossible) male and female genitalia.

It's also not especially uncommon. A visible difference of sexual anatomy occurs in 1 out of every 1,500 to 2,000 births, according to statistics from the World Health Organization.

Medically speaking, intersex is defined as a congenital anomaly of the reproductive and sexual system. <u>Katrina Karkazis</u>, a senior research scholar at the Center for Biomedical Ethics at Stanford University, says that in most cases, people have a genetic mutation that affects development of sex organs. This

might be evident at birth, later in life or not at all.



"Imagine ... you want to connect with someone sexually, and you feel nothing sexual," Katrina Karkazis says.

For example, in the case of people with complete androgen insensitivity syndrome, these women have XY chromosomes and testes. Their bodies produce testosterone, but because their bodies don't respond to it, the genitalia don't masculinize, and they don't develop masculine secondary sex characteristics such as increased muscle mass, a deeper voice and facial hair.

"They have XY chromosomes and testes and you wouldn't know that at birth because they are born with female genitalia," Karkazis says.

From the 1950s until recently, parents of babies born with atypical or ambiguous genitalia were generally presented one option: genital surgery. This is most often done to present the child as female because of doctors' beliefs that it's an easier outcome to achieve with available medical techniques. This often entails surgeries to remove testes, reduce organs that might present as a small phallus or an outsized clitoris, or add a vaginal cavity.

To parents -- shocked and confused by anatomy they don't understand, and envisioning a life of otherness and romantic rejection for their newborn -- surgery to "normalize" can seem like the most loving course of action.

In 1957, intersex rights pioneer Bo Laurent was born into a world of confusion. Medical professionals were "in a state of shock" for three days, unable to determine what sex she was, and her mother was kept sedated. Laurent was eventually labeled a boy, and her parents were dismissed from the hospital, unable to seek additional child care, lest their secret get out. When she was 1½ years old, another doctor decided to change her sex assignment so she could be raised as a girl.

"They performed a clitorectomy and they told my parents to move to another town and not tell anyone where they went and never tell me what happened," Laurent says. "All those things were so traumatizing, frightening and pain-producing for my parents that it made it hard for them to relate normally to me."



"They told my parents to move to another town ... and never tell me what happened," Bo Laurent says.

Alienated from her parents, withdrawn from her peers and deeply disconnected from her medically numbed and scarred body, Laurent avoided romantic and intimate connection with partners well into her 20s. Then, she started to seek answers.

The discovery of her intersex status finally offered a path into the world. Over the course of the past two decades, with her work as an activist, speaker and founder of the now-defunct Intersex Society of North America, Laurent has led others on a journey to connect body and soul -- their own and others'.

"One of the things I'm proud of is that I think that I've helped to provide frameworks to talk about it, narratives that are now available to other people," Laurent says.

'Unequivocal visibility'

Jim Ambrose is one of the people Laurent helped. Though he'd been surgically assigned as female as a baby, furthered by hormones and by additional surgeries his late teens, Ambrose, now 37, vividly recalls how different he felt from the other girls, even at an early age.

"I remember the first girl in my class wearing a bra and I reacted exactly as every other boy in the class did," he says. "I was enamored and fascinated."

Unconsciously, he knew that the interest didn't spring from girl-to-girl solidarity or a glimpse at his future. Watching a school-mandated sex-ed film about menstruation, he thought, "I don't think this is ever going to happen to me."

It didn't, of course. Ambrose's mother disclosed the reason when he was 12 and estrogen treatments soon followed.

Neither did he experience the sexual connections his peers were making.



"I need unequivocal visibility from my sexual partner," Jim Ambrose says.

At 16, Ambrose -- still perceived as female by his peers -- had a girlfriend ("by default," he jokes, rather than a drive to romantically bond). He studiously kept her away from his

intimate parts. In retrospect, it was out of selfprotection. While the girlfriend never argued, she did confess to mutual friends that the distance "weirded her out."

Word got back to Ambrose, and he was suddenly painfully aware that while he felt a deep detachment from his female-assigned body, it was no longer just of interest to his parents and doctors. It was now of interest to his peers -- and his future sexual partners. After all, that's what it had been surgically constructed for.

"The guiding principle was pair-bonding with a man and to be even more specific, to make sure that I possessed a proper vessel for an erect penis," Ambrose says. "The end goal wasn't that I would be a sexually satisfied woman, or a person who was curious about other forms of sexuality. ... My personal sexual pleasure wasn't taken into account."

Stanford's Karkazis sees this all too frequently in her work and friendships with members of the intersex community.

"Imagine for a moment that you want to connect with someone sexually, and you feel nothing sexual in your genitalia. Or you feel pain. I know people who have tried everything under the sun and have even contemplated more surgery. Imagine this kind of searching," Karkazis says.

"The door is closed before it's even opened. You can think you're so damaged that no one will be satisfied with you."

But after Ambrose struck up a friendship with Laurent, he used her framework of disclosure to amplify attempts at connection. A sympathetic and proactive doctor agreed with him that the removal of breasts and vaginoplasty were medically necessary -- and the way to correct a wrong that had been done to him by the medical community. She started him on a regimen of compounded testosterone cream to correct bone density deficits that occurred when he stopped taking estrogen.

While he hadn't consciously considered transitioning to a more male-presenting body before then, his physical response to the hormones was undeniable.

"Almost immediately, I felt a difference,"
Ambrose recalls. "It's like when a hunter is
walking slowly through the woods and he
steps on a branch and it cracks and the deer
pops its head up to see what's going on.
What? What was that? My body was telling
me, 'Hey, this shit is good. Let's do this. We're
into this.' "

A year later, when he was in his late 20s, he began taking testosterone injections and presenting as male in public. His psyche and body were more aligned than they had ever been before, and he had been dating women all along, but the transition ushered in a whole new set of insecurities.

Ambrose says, "I was a man who didn't have the penis that everyone was going to expect. And by 'everybody' I mean that I was really focused on dating straight women. I wanted to date women who were going to desire me as a man. ... I wanted a woman to see me from across the room and say 'Yeah, I want to f*** that guy,' before they knew anything about me."

He adopted Laurent's technique of presenting his story honestly and early, telling prospective partners, "I work at this bookstore, but mostly I do advocacy work and it sends me around the country and I organize and do workshops and I sit on committees and I do fundraising for this little organization and ... why do I do that? Well, because it happened to me."

And it worked. A lot. Date after date after date was "a rousing success," according to Ambrose.

"It puts me in a position of somebody who is being proactive about their life. One who is acting in defense of myself and others," he says. "To couch it that way informs the listener -often a potential sexual partner -- that I care
what you think, but I know enough about
myself to know that if you want to perceive me
as a victim, cry for me, be disgusted by me or
get up and leave, you can do all of those
things.

"My happiness, self-awareness and ability to get up in the morning doesn't hinge on whether you want me to go home with you tonight."

While Ambrose's most recent long-term relationship ended a few months ago, he grows increasingly comfortable in the body he now has, and steadfast in his attempts at romantic connection with the right woman.

"I think there is a resilience gene. There are so many times when I could have packed it in, or subsisted on scraps. Or I could have chosen girlfriends who were bad for me or cruel or abusive, but I didn't," Ambrose says.

"I need for them to see me as plainly and clearly as they possibly can. I need unequivocal visibility from my sexual partner."

'Tickling is my hurrah'

Pidgeon Pagonis sought intimacy and found pain in its place. (Pagonis identifies as neither male nor female and uses the gender-neutral pronouns "they," "them" and "their" to describe themselves.)

"I'm really persuaded by things, like the idea of what high school should be. I really wanted a high school experience and part of that was dating a boy and having sex with that boy," says Pagonis, now 28.

At age 11, Pagonis was told that the genital surgery they had received as a child was to treat cancer, and the one they were about to receive was to fix a urine drip issue. In fact, the latter was to insert a vaginoplasty. At 16, Pagonis was dismayed by difficulty and pain during attempts at intercourse with a boyfriend.

"I'd never had any dilation (which would have kept the passage open), so it was just a shock to my body. I left that moment being like 'That really hurt!' " Pagonis says. "But Cosmo (magazine) said it would get better. It didn't get better in terms of pleasure, but it got better in terms of not hurting as much every single time."

Still, Pagonis soon came to associate almost any intimacy, including kissing, with the impending pain of penetration, and found any desire evaporate the moment they were touched. Alcohol and marijuana offered some distance from the ache, but ushered in a host of other issues, including a cycle of abusive partners and vulnerability to sexual assaults while blackout drunk.

"I wanted to be so drunk that sex felt OK. I thought I'd feel less reserved and that sex would feel good. You strive to be normal when you know you're not normal. Instead of talking it through, I would just drink," Pagonis says.

After a college professor lectured on the topic of intersex traits and DSD to a "psychology of women" class, something clicked. Pagonis walked across the street from their classroom at DePaul University, down into the hospital basement where, coincidentally, their own medical records were kept.

There, Pagonis ripped open the shroud of shame and secrecy that had swaddled their body since the first surgery. The terms were unfamiliar -- "male pseudohermaphrodite" and "46 XY" -- but suddenly, so much made sense.

Their mother confirmed and, after throwing their phone at the wall, Pagonis vowed to tell no one.

But souls are loud and determined things. They seek and reach for connection despite all our best attempts at muffling them. Six months after the revelation, Pagonis started dating a woman to whom they disclosed the diagnosis. While the alignment of anatomy

threw their physical differences into sharp relief -- "I still don't think my high school boyfriend knows I didn't have a clitoris," Pagonis likes to joke -- alternatives to penetrative sex opened up a whole new realm of connection.

"These elements of intimacy are what I needed at the time," Pagonis says. "Tickling is my hurrah!"

For now, the muting of sexual pleasure from the result of surgery and sexual trauma has proved a barrier to romantic pairing. Pagonis is flying solo, and attempting to find peace and pleasure in their own body with the help of a therapist.

" 'Sex is 90% fiction and 10% friction!' "
Pagonis quotes the therapist. "That stuck with
me because when I was with people, I was
always having fiction in my head and I thought
this is because I'm messed up and I can't just
get off from the person."

Pagonis relies on wise words from Laurent, too. "She told me, 'Who cares? Think about whatever you need to. It's in your head and you're not hurting anybody. If you can get off, then good for you.' "

"I let the shame of having a different body and not looking 'normal,' debilitate me," Pagonis says. "I needed that permission and Bo gave it to me."

'Love is like jumping off a cliff'

Pagonis now works as Advocates for Informed Choice's youth leadership coordinator and a teen dating violence prevention coordinator, and firmly believes that doctors' and parents' lack of disclosure to intersexed children is as harmful as cosmetic surgery to conceal the physical differences.

"If people would just be honest and talk to you about your body, you might still make the same decisions, but I might not have -- and I would have had someone to talk to and make healthier, safer choices," Pagonis says.

Ambrose agrees: "I have yet to meet a parent who was intentionally trying to hurt their child. I have as much sympathy for my parents and my friends' parents as I do us. You perform these surgeries aimed to 'normalize' a child and then you expect the child to be quiet and not talk to anyone about it. You're going to color every aspect of the child's life, and your life."

And at 57, Laurent herself is still learning the boundaries of her own worth and wonder. After the end of her marriage and a period of being single, she decided to try again, and was shocked to find herself loved and loving once more.

Laurent found herself opening her heart to a younger woman who she met online and who had never heard of intersex conditions.

"She wasn't familiar with those words or the story, but I did tell her about the clitorectomy. I was surprised and comforted at how well she took that," Laurent says.

For all the people who Laurent has rowed to safety in her years of advocacy, it was a personal risk for her, and this woman could see that. She reached across the distance between them.

As they were becoming more serious, she sent Laurent a quote she still remembers.

"It read: 'Love is like jumping off a cliff,' " Laurent says. "'Your head says you're going to die, but your heart says, that's OK, you can flv.'"

More resources:

The Interface Project

Advocates for Informed Choice

Inter/Act

Global Action for Trans* Equality

Project I Am Enough

dAISy

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Intersex Society of North America

Brief Guidelines for Intersex Allies (PDF)

Further reading and viewing:

"XXXY" - documentary by Porter Gale and Laleh Soomekh

"Silence = Death" - essay by Tamara Beck

"Caught Between: An Essay on Intersexuality"

Full-Frontal Activism: Intersex and Awesome

"Fixing Sex: Intersex, Medical Authority, and Lived Experience"

"Intersexion" - documentary

Surfing the Internet

- http://www.nowness.com/day/2014/3/2 0?utm_source=EM&utm_medium=EM A&utm_campaign=EMA200314EU Arianna Screenwriter Chiara Barzini on the Intersexual Subject of Director Carlo Lavagna's Next Film
- http://www.autostraddle.com/lessonslearned-from-menstruation-popquizzes-while-being-intersex-201027/2/#comments Lessons Learned From Menstruation Pop Quizzes While Being Intersex
- https://m.youtube.com/watch?v=SnYc
 UOT-jz4 Imy's highly anticipated AIS update.
- http://live.huffingtonpost.com/r/segment /raising-an-intersexchild/53456b7378c90a2ff90001bb Raising an intersex child
- http://blogs.wsj.com/speakeasy/2014/0
 7/27/masters-of-sex-tv-recap-season 2-episode-3-fight/ Latest episode of
 Masters of Sex intersperses Bill's
 medical case of the week. A baby he's
 just delivered has ambiguous genitalia,
 although tests conclude the baby is a
 boy. The father of the child could not
 possibly be more extreme in his
 reaction to the news. If his son does
 not have the perfect penis, he wants to
 "cut it off."

Film Review: 52 Tuesdays

52 Tuesdays is a new award winning feature film produced out of South Australia. The film's distributors gave the AISSGA a ticket to go along and see this flick in Brisbane at a preview screening, which I did.

The film follows teenager Billie as her mum transitions from Jane into James. The transition strains the loving mother-daughter relationship, as Billie can only visit her mum

on Tuesday afternoons every week for the period while James is becoming a man. The loss of her mum incites Billie to rebel and explore her own emergent sexuality. SELEMA WITH CITAT WITH 100 A TEAL.

52
TUESDAYS

Overall, this is quite a bittersweet yet

enjoyable little film. There are quite a few laughs, some cool story-telling ideas / filmic techniques and some a-ha moments. Although this is a film about transgender, there are moments that I relate to being intersex, such as a scene when James reflects on his inner turmoil and wishes he'd been born into a body that fits perfectly with his gender identity. It's a "why me?" moment I get.

The film gets a bit messy towards the end and the resolution could have been less corny and shorter. Everything and everyone in this film seems 'too cool for school' – this is what happens when hipsters make movies, I guess. But overall, I would recommend 52 *Tuesdays*. There are some really nice performances and it's got a warm heart at its core.

Phoebe



Become a Member

Membership fees for 2014-2015 are due on August 1 2014. Please complete the attached form and return by email or post with your payment.

The Androgen Insensitivity Syndrome (AIS) Support Group Australia Inc. (A0041398U) is a peer support, information and advocacy group for people affected by AIS and who are intersex, 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, sexual intimacy, etc.

We also provide support to those with related intersex differences such as 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 (including AIS) range from female to male and anywhere in between.

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

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

There are many benefits to becoming a member of the AISSG Australia, including the dAISy newsletter, regular conferences and meet-ups, and up-to-date information and news relevant to our members. Of course,

there is also the wonderful benefit of supporting and meeting others who have so much in common and much to share! We are also always looking for people who want to become more involved as representatives and/or committee members.

President: Bonnie

Vice-President: Tony

Secretary: Phoebe

Treasurer: Tony

Victoria/Tas Reps: Elly & Christy

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 2015. The deadline for submissions is 31 December 2014. To submit articles, art, jokes, information, poems, or whatever you would like to share please email aissgaustralia@gmail.com

We hope to hear from you again soon!



dAISy

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July 2013 Edition

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 2014.

Name/Organis	ation:					
Address:						
State:		Postcod	le:		Country:	
Telephone Nui	mber(s):					
Email address:	:					
Age:	(optional)	If organisatio	n name of cont	tact person	Ľ	
Signature:				Da	ate:	
Membership ty Individual Mem	rpe: (Please tick onbership:	one)	Organisation	nal Membe	ership:	
	1 year \$20		1 ye	ear \$40		
	3 years \$50		3 ує	ears \$100		
Please indicate	e your membersh	ip category:				
	Person with AIS, Gonadal Dysgenesis or similar condition (Please specify)					
	Family/Partner/Friend of someone with AIS or similar condition					
	Medical or Other Professional (please state interests in AIS and similar conditions)					
	Organisation (please state interests in AIS or similar conditions)					
	to make a dona \$2 or more are ta		Support Group	Australia?		
□ \$10	□ \$20	□ \$50	□ \$100	□ othe	r \$	

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!