

dAISy

The Newsletter of the Androgen Insensitivity Syndrome (AIS) Support Group of Australia July 2009 Edition

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"Untitled" by Deadly Daisy & Bellah 2007. Creative Commons license. (Note: it's thought that Queen Elizabeth I had AIS.)

Message from the President

Welcome to the AISSG Australia bi-annual newsletter dAISy. It's been a while since our last publication and I hope that you find our newsletter informative, fun and thought provoking.

Much has been happening in "Phoebe World" over the past 12 months. I recently completed my PhD, looking into intersex identity in creative practice, and in the process making a television documentary film called "Orchids". I hope that this film will find its way to the small screen soon. There was an exegetical component to the thesis, where I analysed films that deal with AIS and intersex conditions. I've included an excerpt of this analysis in this newsletter as I found the way the media portrays intersex to be quite varied and interesting.

In other more personal news, my husband and I were honoured with the responsibility of caring for a young person recently (hence the lateness of this newsletter). After quite some time moving through the adoption process, we finally got the call we were waiting for and our 5-month old daughter came into our lives. Now I have the pleasure of being a mum, and all the daunting challenge of parenthood. The adoption journey, and a deepening understanding of the issues for adoptees and the well-researched benefits of early disclosure of their adoptive status, has caused me to reflect on my own experience as a young person growing up with AIS, "needing to know" the truth about myself earlier on in life. I go into this in greater detail in my article later in this newsletter.

In terms of the support group, there are also some new developments. The new look website includes expanded information on most pages, tag clouds for external pages of interest and a regularly updated News page. Of newsworthy note to AISSG Australia members is the recently tabled Australian Human Rights Commission report on surgery on intersex infants and their human rights, after conducting an a project on human rights and sex and gender diversity in 2008. The AISSG has maintained a conversation with the Australian Human Rights Commission on these issues over the past 18 months, and I invite you to check out the full version of the report (plus to look at the changes to the website generally) on: http://home.vicnet.net.au/~aissg/

Please enjoy our newsletter. I encourage you to consider becoming a member and, for those who are or have been members, to please update your membership and contact details with us as soon as possible. I also hope that you can make it to our conference this year in Sydney in September, which I'm sure will be a valuable and deeply satisfying experience for everyone who attends. More information on the September conference is available in this newsletter. We also welcome any feedback or advice you have about future AISSG events and publications.

With AIS Love,

Phoebe Hart President, AISSG Australia



Message from the Vice President

I would like to sincerely commend and congratulate Phoebe for the incredible work she has done to renew the AIS Support Group. The new website looks great and I'm especially pleased to see our newsletter being produced again.

I remain on the support group committee but am incredibly busy with other things these days. My foster children are now young adults, I've changed government jobs, was elected to my local council last year, and have started a law degree. I was also awarded a research fellowship by the Municipal Association of Victoria earlier this year to research the impact of the Charter of Human Rights and Responsibilities on local government and councilors. Unfortunately this also means I'll be overseas when you have your meeting in September. I encourage as many members as possible to go. It really is an incredible experience meeting other people that can relate with our most personal of issues. I hope you and your families are well and that having AIS (or a similar condition) isn't having too negative an impact on your life (if any). I appreciate there may be times when it makes our lives difficult, but in the main I think people with AIS as incredibly understanding, insightful, passionate, caring and intelligent people. That's another reason you should go to the September meeting!

I'm not just saying all these nice things about people with AIS because I'm one of them! Last year my doctors conducted tests to confirm my genetic condition because they thought my response to testosterone has been very good too good for someone who is supposed to have an insensitivity to androgens. They discovered I have 5-alpha Reductase Deficiency Syndrome and not Partial Androgen Insensitivity Syndrome. It just goes to show that even world leading doctors like Garry Warne and others at the Royal Children's Hospital in Melbourne can get it wrong sometimes, and that it is important to get a second opinion. I must admit it took me a while to get used to the fact I no longer had AIS, but this other genetic condition even though it is similar in many ways.

Good luck with the meeting in September – I look forward to hearing all about it when I return from overseas.

Kind regards and warm wishes,

Tony Briffa www.briffa.org



Message from the AISSGA Victoria

Representative

Ted and I are well and having experienced the summer fires from a distance here in Bright feel that we are not up to defending our home in a future bush fire. Our thoughts are now on a move to a smaller home, probably back to Melbourne but it is not immediate.

We are going to England for six weeks in August so will see our relatives and holiday in Cornwall.

I have been the Victorian rep for AISSGA in the past few years but have not had any enquiries for some considerable time. I am happy to do what I can so please keep in touch.

I have been very fortunate in having a supportive husband who was willing to adopt children in the days when it was possible. We have nine grandchildren whose ages now range from 13yrs to six and it a delight to see them from time to time. They were all here at Easter and this kept

3 time. They were all here at Easter and me busy in the kitchen.

I still have strong feelings at times about the way my sister and I were kept in ignorance about our condition so all we can do to prevent this sort of thing happening to others is so important.

Kindest Regards, Jocelyn [sometimes in AISSGA publications known as Elizabeth which is my second name]



Message from AIS Netherlands (Holland)

Dear people of AISSG Australia,

I would like to use this message to introduce the new AISNederland committee. It has almost been a year since we've officially taken over from Miriam, Inge and Anja who you might probably know from the previous years. It has been a year in which we had to catch up on a lot, learned a lot and fortunately ensured the continuation of our Dutch support group. These are the members:

Mrs Margot Mulder-de Haan - chairperson margot@aisnederland.nl Mr Jos Hoogerhoud - treasurer j.hoogerhoud@tiscali.nl Ms Nienke Barends - editor newsletter nienke@aisnederland.nl Mrs Shahila Admani - 2nd secretary shahila@aisnederland.nl Mr Albert Brinkmann - retired medical academic from Erasmus MC in Rotterdam albert@aisnederland.nl and yours truly, secretary juliette@aisnederland.nl The e-mail address which you can use to reach all of us in one go is bestuur@aisnederland.nl.

As a little introduction of myself; I have been involved in the background with AISNederland since the first meeting in 2001 until I left to travel in 2004. I returned to Holland in November 2006 and sort of settled down. When the then current committee announced their resignation and no volunteers put their name forward I started thinking about doing so myself, since the support group has been very important for me since day one. To make a long story short; luckily with me a few other people volunteered and we were able to continue with AISNederland. A long process because one of the wishes was to have a slightly larger committee than 3, which we now have. It is still a lot of work but it's nice to do it with five other dedicated people!

Should you have questions about what we do in the Netherlands or if you should ever know of anyone with AIS in the Netherlands, please don't hesitate to contact us.

Warm regards, Juliette Kuling





"Cape Daisy" by Tambako the Jaguar 2008. Creative Commons license.

Nehemiah's Story (Myanmar)

To AlSers,

When I was born in 1980 the doctors told my parents to bring me back when I was two years old and they would look towards doing some kind of surgery on my genitals. But my grandma didn't allow my parents to bring me back to hospital because she was afraid they might do many tests and use me as a training aid.

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Like many who were born Intersexed, I suffered terrible shame, humiliation and discrimination regarding my condition. Before I started my school life, my Mum taught me how to use the school toilet, as I couldn't stand to urinate as others did. So, in my childhood, I never went to the toilet with others.

Occasionally, the school medical teams used to come and give us a medical check up. Part of this examination was to check that the boy's testicles had descended. I always took leave for those days.

The secrecy and shame caused me to feel isolated and alienated for much of my life. I was very willing to have an operation so that I would not have any difference with my friends.

When I was seven years old my parents brought me to a doctor who was the one and only person in my country, at that time, to treat people like me. I still remember that day because I thought everything would be changed for me. I was really happy. But when we got there, we met many medical students, so I told my father that I didn't want them to see and touch my genitals. My father agreed with me and didn't allow the medics to examine me. But the senior doctor wanted his students to see my part but I didn't allow.

Later, I learnt that the doctor told my parents that it would cost a large amount of money for my chromosome and other tests. I felt pity for my parents so I didn't ask them again to send me to the doctors - I just tried to protect myself from being shamed throughout my school life. But when I was 12 years old my breast had developed. I had many difficulties. Through the grace of God, I had an operation to cut it.

Subsequently, I try to just simply accept the situation which is still difficult for me to get genital surgery. My experience with Intersex will not be much different from many other sufferers. I read the article on "Person Value" which was written by Sandra in the March 2003 edition, I really appreciated that writing, and so I would like this opportunity to write regarding how I get self acceptance - in the hope that others will benefit.

Being a committed Christian, my grandma helped me to become familiar with the teachings of The Holy Bible. My grandma always said that God was a God of love and that He never made mistakes. So, I read the Bible so that I might know about God's creation and my imperfection.

I found that God didn't accept imperfect animals to be used for sacrifices and that God didn't allow sacrifices offered by handicapped priests (Leviticus 21:20 and 22:24). The Bible verse which made me shocked was Deuteronomy 23:1, because it said that people deformed in external sex organs may not be included in the assembly of God. I asked my Grandma if God also didn't accept me? She said that those verses didn't mean it as an insult, rather, it had to do with the fact that the priest must be as close as possible to the perfect God they served. She always said that I was not alone in this world. So I was longing for friends, community and places which could accept me so that we could share and make light to our burdens. I was always willing to connect with people like me.

From reading Psalm 139:13-15 and Isaiah 56:3, I

learnt that the Bible clearly proclaimed the radical message that God's blessing and love were for all people, even Gentiles and eunuchs (generally the word eunuch is not used today since we have better more accurate words to describe and diagnose intersex condition), who were often excluded from worship and not even considered citizens in Israel. So I wanted to know more about God and the Bible. Reading the Bible started me on a path of much happiness and self acceptance. I came to realize how others judge and see me and how I see and judge myself is not perfectly aligned - only God can see me correctly as He is my Creator. I began to ascribe meaning to my life and what I had endured via Biblical scripture. Having been born with an intersex condition seemed to only make sense to me in the light of scripture. Later I realized that lesus was the only way to bring me to peaceful life and meaningful life.

So after high school I went on to formal study of the Bible. After graduating from Seminary, I worked with a foreign missionary where I could help set up a mission school for poor children. I was really satisfied with my life. Before I worked with that missionary, he had already known that I had an Intersex condition, so I didn't have any secrecy in work with him. Most of the times, I even forgot my Intersex condition as I was focused on my job. I felt freedom.

However, some time later, the sponsoring church which supported our mission field came to know my condition and since that time I did not feel comfortable in working with them. And I learnt that they did not allow women and people with Intersex to be Pastor in their denomination. Although I was not willing to be a Pastor I personally thought it was not fair. Soon after, I had lost connection with them.

I know I am able to worship God who accepts me as the way I am, not according to men who have limitations in understanding my biology. I am relying on Christians who are the children of God and not on man made denominations.

Up to this time, I felt big depression. It's very difficult for me to express my feelings about those days. Here I have some advice to AlSers who are feeling depression as I had. This world is not a perfect world so we will not get complete acceptance. For me, it was tremendous healing to connect with Tony Briffa. The joy and liberation of learning that there are many support groups around the world which stand-up for people with Intersex. I consider every member of those groups as my true friends. I also got spiritual help from Paul Smith (a friend in Australia) so that I could remain standing strong on my faith, otherwise I would have hated very much those who would claim to be Pastors or God's servants.

Trusting in the love of God, being connected with support groups and having connections with Tony Briffa and other Godly people give me self acceptance. I want to thank Dr. Garry Warne who established AISSGA in 1985 and the other founders of AIS support groups which are located around the world. What they did was really great! It has saved many people's lives.

We people with Intersex also have responsibility to give our faithful helping hand to those who are standing-up on behalf of us, so that we can build upon the success of AISSGA and we can reach out to those who are suffering as we are. This work is also the will of God, as it says in the Bible, "Suffer with them as though you were there yourself. Share the sorrow of those being mistreated, as though you feel their pain in your own bodies" (Hebrews 13:3).

May The Lord Jesus Give You Peace!

With Best Wishes,

Nehemiah Contact email: mail4mygroup@gmail.com



Story for Daisy by Sandra

I first found out I had AIS about 20 years ago when I was 27. It took a while for me to find out the truth however. When I look back to when I first went to the doctor because I hadn't menstruated at 16, I was pretty scared. It was hard to understand what was going on. I had blood tests done and a physical examination which was distressing. I was then referred to a gynecologist who informed my parents that I had no uterus and my ovaries weren't working properly and should be removed.

When my Dad told me I was in shock. I withdrew from my family in my distress and tried to understand what had happened. I didn't discuss it with my family or friends. Slowly I realized I wouldn't be able to have children and that I had to face major surgery otherwise my "ovaries" could become cancerous. I decided to go ahead with the surgery and then got on with my life studying for the HSC and doing ballet classes. My emotions had to take a back seat.

10 years later after having a lot of questions unanswered, I finally found out I had CAIS from a caring endocrinologist. It felt really liberating to know the truth even though it was quite a big surprise. I finally understood my body and I started to tell others about having XY chromosomes and that the ovaries I thought I had were actually testes.

Several years later in 1997 I went to my first AIS Support Group meeting in Queensland and later to Melbourne for more meetings. It was great to meet others with AIS. I left those meetings feeling very normal and excited to find others who shared my experiences. I didn't feel so isolated and I was able to talk about how I felt with others who understood. This has been the single most healing thing on my AIS journey.

Now, I am still involved in the support group and have AIS friends around Australia. Although I'm still sad I can't have kids, I have two lovely nieces, I teach dance to children which I really enjoy, and I'm hoping to volunteer for Aunties and Uncles. I also get a lot of satisfaction from helping others on their AIS journey. The future looks good!



Daisies" by Nutmeg66 2008. Creative Commons license.

AISSG Conference in Sydney, September 2009

The AISSG Australia is having a meeting and conference for people with AIS and other intersex conditions and their families in **Sydney** this year, on the **26th of September**. The AISSG invites people interested in attending to contact either Phoebe on aissg@hartflicker.com or Sandra on sandperr@hotmail.com <u>no later</u> <u>than 16th of September 2009</u> to register their interest. Please note that in the interest of protecting the privacy of members and attendees, we will be releasing the exact location and schedule only to those who register.

The conference will be an exciting day of sharing, learning and support. We are organising for specialist experts to also present to the conference attendees and take direct questions on a range of issues relevant to our members.

Accommodation and travel information and a speakers list will be posted on the AISSG Australia internet site closer to the date: http://home.vicnet.net.au/~aissg/



Disclosure: Lessons from the Adoptive

Experience

By Phoebe

It would seem that the issue of growing up with a condition like AIS and any other intersex condition might be somewhat like growing up being adopted. Due societal norms there is a stigma attached to being both 'intersexed' and 'adopted'. In the past, perhaps less so nowadays, it was considered not the done thing to talk about adoption to adoptees. Governments and institutions urged for a clandestine approach, forcing parents to lie, and often times adopted children would grow up thinking for all intents and purposes they were their adoptive parents own biological children. Imagine the shock and feelings of betrayal and shame when these children finally discovered their true identity, often late into adulthood, and sometimes inadvertently from a relative that accidentally drops a 'truth bomb' on an unsuspecting adoptee.

As I recently had the experience of becoming an adoptive parent, the question of what to tell my child about her background at some point in the future has become all the more pressing. Fortunately, my journey to becoming an adoptive parent has involved a great deal of education and reading, and I've found this research to be very interesting. There is quite a well-established body of study around adoption, and the effects of disclosure / non-disclosure on adoptees. Research into adoption has also focused on how the way parents discuss adoption with their adoptive children - whether they spoke of the adoption in a positive, forthright way or an embarrassed, reluctant manner - and the way that makes adoptees feel about themselves. Overall, the research shows that it's clearly better to let adoptive children know about their circumstances early on in an age appropriate manner.

As I delved into the research (which was in many ways an enforced exercise that is part and parcel of the rigorous and invasive adoption assessment in nearly all states and territories of Australia) I was struck by the relevance of the information for parents of children with AIS and of course for individuals with AIS as well. As part of my involvement with the AIS Support Group, I often come into contact with parents of children with AIS who are at a loss as to how to approach disclosure with their understandably inquisitive 5, 7 or 10 year old. The issues compound at the critical stage of puberty if the issue of AIS has not been adequately addressed or acknowledged. Now, I'm not an expert, and I don't know exactly the right words to say to children with AIS, but from my own experience growing up knowing there was a secret around me but not fully understanding what that secret was, I know that a conversation was required as part of an ongoing process of grasping what it means to have AIS. This intimidating task is left largely for the parents of children and teenagers with AIS to broach; these are youngsters who may sense their difference but often don't know how or may be too afraid of upsetting their parents to ask for more information.

But what is the right thing to say, and when? Surely this is the biggest concern for parents of both adoptive children and children with AIS. Surprisingly, I found that many publications in the myriad of books for adoptive parents have some very practical and information in this regard, often times supplying reassuring phrases for parents to practice and use, which could trigger the 'right' words to say to their child. By 'right' I mean words that foster a sense of self-esteem for children about their difference in a way that can be understood at various ages and cognitive development. For example, when a child is young - around 4 or 5 - questions should be answered in a very simple, concrete manner, which become increasingly complex and abstract as the child matures. This might seem obvious but it set my mind at ease that someone had thought long and hard about the right way to frame a difficult subject. Often times, a child won't take in all of what's been said and may need some time to process the information, so really this is a conversation that occurs over a very extended period of time (though don't expect this to be a weekly or monthly conversation!). Of course, children will ask for information and sometimes it's best not to overload a child – go little but little... each parent will gauge their own child's needs best. Jumping in awkwardly would definitely be better than holding off too long in

my opinion. Nobody's perfect but I'm sure your child will (eventually) appreciate child willingness to talk, and if approached positively, could actually result in humans with a greater level of resilience and empathy.

Books are also a great way to introduce complex ideas. There's also some nice books to read might trigger a conversation, such Pink Shirt Blue Shirt as on our website:

http://home.vicnet.net.au/~aissg/reading.htm We also have peer support for parents of children with AIS here at the AISSG Australia, which can be a great sharing information about how to talk about disclosure in a safe space.

Resources:

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"Telling the Truth to Your Adopted or Foster Child" (2000) by Betsy Keefer & Jayne E. Schooler.

"Raising Adopted Children" (1989) by Lois Ruskai Melina (Chapter 4 - Talking with Children About Adoption).

"Adoption: Theory, Policy & Practice" (1997) John Triseliotis, Joan Shirman & Marion Hundleby (pp. 35-45)

Raising Children Network - Raising an adopted child:

http://raisingchildren.net.au/articles/raising_an_ad opted_child.html



"Daisies in a Jar" by Irene... still away, 2009. Creative Commons license.

Representation of Intersex

There is a long history of representation of people with intersex conditions, such as in Salmacis and Hermaphroditus from first century Roman poet Ovid's Metamorphoses. In modern times, people with intersex conditions have debuted in the 'mass media' and have become the subject of several books, films, television shows and documentaries. In part, this increased interest in portraying people with intersex conditions mirrors the rise in intersex activism and awareness of intersex and its issues generally, throughout such western territories as the United States of America, United Kingdom and Australia. Since the early 1990s, political activism has highlighted the inequities of current legal and medical frameworks that impact negatively upon people with intersex conditions, leading directly to widespread media coverage of these emergent debates. News stories appear regularly in Australian newspapers highlighting a range of issues that involve people with intersex conditions. For example, in 2004 ABC Online reported the case of a person with an intersex condition and 'no fixed gender' who challenged legislation to ban same-sex marriage. Other articles since cover issues associated with the choice of gender in the national census, and the on-going debate over surgery on infants born with ambiguous genitals.

Contemporary representations of people with intersex conditions in the media run the gamut of engaging, well-rounded characters such as Cal Stephanides in the Pulitzer Prize winning novel Middlesex (by Jefferey Eugenides in 2002) to characters as objects of ridicule. For instance, in an episode of the long-running 'sitcom' series Friends entitled The One With the Rumor, Jennifer Anniston's character 'Rachel' is rumoured (as a cruel joke) to be a hermaphrodite at high school, insinuating that while her parents 'flipped a coin' to decide to raise her as a girl, she 'still had the hint of a penis' (Halvorson 2001). The episode when aired in the USA generated indignant outcries from the intersex community, due to the program-makers' lack of understanding and sympathy, and their sensationalistic approach.

By contrast, and only seven years later, the Argentinean film XXY (directed by Lucia Puenzo in 2007) was the closing night film at the 2008 Vancouver Queer Film Festival, and winner of a prestigious Jury award at the 2008 Cannes Film Festival. This is a feature-length coming-of-age film about a teenager with an intersex condition ('Alex' played by Inés Efron) being pressured by his/her family to choose a gender. At the same time, Alex begins to explore his/her emergent sexuality.



It is perhaps safe to say that the intersex stereotype is now becoming more identifiable in popular culture. In the British melodrama Footballers' Wives (2003), one versioning of the stereotype is that of the innocent and passive victim. In episode 5 of Season Two (A Change of *Career*), Jackie Pascoe and the child's biological father, lason Taylor, are shocked to discover their 'son' has a womb and ovaries. For the remainder of this high-rating season, the drama plays out around the baby (Paddy), who evokes a violent reaction in Jason, a 'macho' football team captain, who cannot believe that any son of his would be anything less than 100% male. The

father horrifies mother Jackie with his loathing when she catches him with a pillow, poised midair over the helpless infant. The season concludes with Taylor's suspicious death.

More recently, representations of people with intersex conditions have become perhaps even more controversial. In an episode of the American medical comedy-drama series House (which screens on Network Ten in Australia) entitled Skin Deep (2006) the disabled doctor and chief protagonist Dr Gregory House has a patient (Alex). She is a supermodel with mysterious medical symptoms, including angry, unfeminine outbursts. It also becomes apparent that she has had an incestuous relationship with her own father (Austin). When House discovers that Alex has Androgen Insensitivity Syndrome, and in fact is suffering from a cancerous inguinal teste, House's disclosure is (typically for his character) aimed to shock:

HOUSE:

... See we all start out as girls and then we're differentiated because of our genes. The ovaries develop into testes and they drop. But in one in every 150,000 pregnancies a child with an XY chromosome, a boy, develops into something else, like you. Your testes never descended because you're immune to testosterone. You're pure estrogen, which is why you get heightened female characteristics: clear skin, great breasts. The ultimate woman is a man. Nature's cruel. huh?

AUSTIN:

This is obviously a joke. This is impossible.

HOUSE:

No, a joke would be me calling you a homo. See the difference? I'll schedule him for surgery.

Alex gets out of bed.

AI FX: (Shouting) No you're wrong, I'm a girl.

Alex throws off her gown and stands naked before House, and other staff and patients passing by in the hall.

Look at me! How can you say I'm not a girl? See they're all looking at me. I'm beautiful!

HOUSE: The anger is just the cancer talking. Put your clothes back on. We'll cut your balls off and you'll be fine.

HOUSE turns and leaves the room. ALEX falls back on the bed crying....



Perhaps, rather than the 'cancer talking', Alex's anger is the result of an infuriating encounter with the medical fraternity. In any case, like Footballers' Wives, this episode of House details an emotionally fraught dramatic situation dealing with the intersexed character: a point of revelation or disclosure or 'coming out' to the patient herself or to the world at large. Aside from the medical inaccuracies of the script itself (wildly under-estimating the frequency of the condition), the narrative suggests that the intersexed woman has no claim to femininity due solely to her chromosomes and gonads. Another intersex stereotype also emerges, the one of the AlS woman, the 'ultimate woman'. The screening of the episode in the United States incurred a strong response from the Intersex Society of North America, which considered the episode 'so flawed' and 'one of the most offensive and hurtful portrayals of people with intersex conditions'.

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On the other hand, a number of recent television medical drama series have attempted to portray the lives of people with intersex conditions in a sympathetic light, highlighting issues concurrent with the concerns of people with intersex conditions. In an episode of the Australian medical drama series *All Saints* called *Truth Hurts* (2006), the staff attempt to deal with a new patient – a teenage girl (Taylor) who presents with a broken arm (evidence of osteoporosis, which can be a symptom of AIS after the testes have been surgically removed). As it becomes clear that Taylor has the condition, Dr Zoe Gallagher struggles with her own ethics as she persuades the girl's reluctant mother to disclose the family secret, and reveal the news to her daughter. While the episode presents an aspect of actuality, the program fails to acknowledge that it is often doctors who encourage and foster non-disclosure of the intersex condition to their patients. In effect, Truth Hurts puts the onus on the shoulders of parents - a 'softer' more politically-fractured target – making this programme, arguably, a 'politically correct' versioning of the truth. Furthermore, the script plays out the typical stereotypes associated with AIS, (again) labelling AIS women as 'superwomen', the condition as a 'genetic glitch', and emphasising the need to have a 'freak-ectomy' to fix up the problem.

In an episode of American medical melodrama Grey's Anatomy entitled Begin the Begin (2006), a young, tomboyish girl presents for an ultrasoundguided biopsy on an enlargement of the pelvic lymph node. The girl's mother is afraid it might be cancer. After the biopsy, the doctor discovers that troubled Bex (played by Becca Gardner) has testes. A dilemma ensues as Bex's parents decide that she should have sexual reassignment surgery 'to remove whatever boy parts she has' to make her 'normal' and 'put an end to her agony', without telling Bex that this is what will happen. Intern Dr George O'Malley (T. R. Knight) is amazed when he learns of Bex's condition ('Bex is a hermaphrodite?') and believes that Bex has a right to know, as 'biologically and emotionally speaking, she has a choice to make'. O'Malley refuses to lie to Bex about her scheduled surgery, forcing the parents to disclose the situation to Bex. The narrative arc concludes with Dr O'Malley and Bex's parents helping Bex to cut her long, feminine hair off in order to realise or play with her (potential?) male gender identity. Begin the Begin demonstrates the mainstream media's grappling with the emergent visibility of intersex, and debating the appropriate standard of medical care. Begin the Begin offers the possibility of accepting the horror of a hermaphroditic child, as he or she is, without having to 'fix the problem'. However, the

program also misses the mark at several junctures. Bex's intersex condition is never clearly defined. It is reported that she has female-looking genitalia externally but 'internally she has both female and male sex organs'. Initially, she is found to be taking birth control pills because she is 'as flat as a board' and wants 'boobs', and then later, when told that she could be a boy, she whispers 'yes' as if she has always known, and decides to cut off her hair. From the perspective of a person with Complete Androgen Insensitivity Syndrome CAIS, it would initially appear to me that Bex has CAIS too.

However, *Begin the Begin* under-explores the issues of gender identity and intersex, as it does not entirely make sense from Bex's initial position about desiring 'boobs' and a boyfriend that she would want suddenly to be a boy. A distinct lack of clarity and correct information, even from a biological point of view, means little has been done to help audiences understand what intersex is or how it actually works. Nevertheless, there has been an attempt to highlight the most

sensational aspects of the controversy of nondisclosure and surgery surrounding intersex. It could also be said that the conventions of melodrama narrative, and the overriding narrative concern of promoting the relationships between the lead characters, mean that there is simply not enough time to cover all the issues raised by the patients appropriately. Yet perhaps more attention should be given to the informative aspects within such programming. It is worth mentioning that the second series of *Grey*'s *Anatomy* (in which *Begin the Begin* appeared) was the fifth most watched series in the United States, garnering an average audience of 21.3 million per episode.

Turning to factual television programming, which is often broadcast on commercial free-to-air and pay TV networks, the overarching objective is to reach the widest possible audience, and generate high ratings. *Is it a Boy or a Girl?* (2000) is a North American product distributed globally on the Discovery Channel. The documentary carefully details the science around hermaphroditism and enters into general debate on the ethical considerations of the treatment of people with intersex conditions. Its aim appears to be educational, answering the question 'what is intersex?' While this in itself is worthy, Is it a Boy or a Girl? compounds both the cloak of shame and secrecy under which the contemporary hermaphrodite labours, and often exhibits slippage toward anterior representations of hermaphrodites. Interviews with parents of children with intersex conditions are 'blurred out'; conditions are referred to as 'genetic defects'; and doctors reinforce the need for gender assignment, referring to the potential embarrassment families face when they are unable to tell the babysitter the child's gender. Furthermore, case studies are sought in Third World villages rather than from within the USA or Canada. In the end, this is a production that is, though in many ways clearly supportive, still in the business of stereotyping the hermaphrodite as exotic, mysterious and unacceptable.

My Shocking Story: Which Sex Am I? (2007) again adheres to a contemporary medical/biological science discourse, yet attempts to inflect the narrative with an overview of current debates around disorders of sexual development. Notably, the film asks the question whether children should be left to decide their own gender when they are old enough to do so. Which Sex Am I? focuses primarily on the plight of one child, Jacob, born with ambiguous genitalia, in the critical weeks leading up to and following surgery to remove his uterus and effectively assign the young child a boy. The cameras follow lacob and his parents from diagnosis and the parent's decision to go ahead with the surgery, through to the operating theatre. It is a revealing insight into the pathologisation of intersex, and a portrait of the parties that are involved in the process, particularly the medical fraternity. Jacob's surgeon is memorably 'gung ho', scoffing that, as soon as he completed his job, Jacob's uterus would be 'in a jar'. A small section of the documentary addresses an Italian woman with AIS – Tiziana – who is not happy about surgery to remove her testes during her adolescence, which was kept a secret and only revealed when she was 24 years old. Tiziana wishes that she had been left untouched, and raised as a Third Sex.



Through slick production values, medical animations and archival stills of historical hermaphroditic bodies, the film My Shocking Story: Which Sex Am I? attempts to 'scientifically' account for intersex within the population. While the documentary gives airtime to patients in order to explain how they feel about (their own) surgical gender assignment and nondisclosure by doctors and parents, effectively highlighting the painful choices for parents with children with ambiguous genitalia, the subject of intersex is exoticised and fetishised by again electing to follow subjects from the Third World (in this case, the Philippines and Equador) who are charitably assisted to come to the United States in order to receive gender-assigning

surgery on their young children. Even the brave decision of Tiziana to reveal her condition publicly is overshadowed by a sensationalised 'showdown' between Tiziana and her estranged mother, who lied to her daughter by telling her that her uterus was removed due to cancer. The title of the film itself suggests something of the freak sideshow, and undeniably was selected in order to attract curious viewers scanning their program guides for something interesting to watch on TV.

It is quite clear that programs such as My Shocking Story: Which Sex Am I? provoke a discussion around modern medical practices and societal sensibilities, and create awareness of intersex, as they are widely distributed and therefore diverse audiences see them. Both their popularity and continued production is noteworthy. Evidently, mainstream media producers are responding to cultural expectations, and, in turn, perpetuating such a culture, creating at the same time a lucrative cultural industry for the consumption of products that feature people with extraordinary bodies. In recent mainstream factual films such as Which Sex Am I? the producers are obviously responding to the pressure exerted by intersex activists to review medical paradigms of nonconsensual gender assigning surgery. Yet the film continues to conform to conventional expectations. It seems there is a representational gap between the purely expositional, mainstream and conformist films, and what could be said to be an authentic, wholly embodied or dissident portrayal.

In response to this shortfall, subversive factual and fictional treatments of intersex from marginal, less mainstream directors and producers have emerged. While the semiautobiographical situational comedy series, Freaks and Geeks (1999-2000) only enjoyed a limited run on NBC in the United States, it garnered subsequent cult status for its subversive treatment of teenage coming-of-age issues, and celebration of the collective high school identification of 'nerds' and 'stoners'. The series centres on the lives of the unpopular students at McKinley High School in the early 1980s. In the episode entitled The Little Things (2000), the plot deals with the blossoming romantic relationship between band geek Amy Andrews (AKA 'Tuba Girl' played by Jessica Campbell) and loudmouthed 'freak' Ken Miller (played by Seth Rogan). Amy (a subsidiary character) confesses to Ken (a main character) that her parents had to choose whether to make her a girl or boy (though she clearly identifies as a girl), which causes Ken to question his own sexuality. Rumour has it that Judd Apatow - the series creator – initially suggested that they should write Ken's love interest as having a penis as a joke before deciding to portray Amy's condition more sensitively.

Ken wrestles with the fact that he might be gay because he is dating someone who is 'part boy'; and, at this moment, gives an authentic insight into the dilemma such disclosure could invoke in a heterosexual male, even if part of that dilemma is to test one's 'gayness' by listening to David Bowie records (as Ken does). Amy's story is backgrounded; Amy's 'coming out' is used as a narrative device in order to precipitate an existential crisis in Ken. Her disclosure is somewhat ominous, as she says that she had the 'potential to be male or female' at birth without any further explanation, and that she is glad her parents chose for her to be a girl.



Despite this, Campbell's portrayal of Amy is nuanced, recreating a believable hesitancy when telling Ken about her condition, and then at once nervous and upset by Ken's withdrawal postdisclosure. Her script and performance demonstrate an attempt on the part of the writers and director to recreate a 'real' intersex disclosure narrative. Of course, in the context of the series, Amy's freakishness is celebrated. However, her intersex condition has been presented in the format of a love story in order to access a mainstream audience, and it is left to the normatively gendered Ken to decide whether or not their relationship should continue. The episode concludes with Ken coming to terms

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with Amy's difference and his own feelings that Amy's revelation has induced. Ken makes amends with Amy before she goes off to play the tuba. Although it presents a somewhat unbalanced representation of intersex, *The Little Things* offers an alternative, even liberating outcome.

Part 2 of 'Representation of Intersex' in the next edition of dAISy....



Pollution threatens male gender, says

CHEM Trust report

News.com.au, 8 December 2008

POLLUTION is damaging the "basic male tool kit", threatening the future of the male gender, according to new research.

A report released today by the charity CHEM Trust shows that male fish, amphibians, reptiles, birds and mammals have been harmed by manmade chemicals in the environment.

"These findings add to mounting worries about the role of hormone-disrupting or so-called 'gender-bending' chemicals in the environment and the implications for human health," said charity CHEM Trust.

In mammals, genital disruption in males had been widely reported including: intersex features, small penis and testes, undescended testes; abnormal testes; or ambiguous genitals.

The report, which draws on more than 250 scientific studies from around the world, concentrates mainly on wildlife, identifying effects in a range of species.

"Males of species from each of the main classes of vertebrate animals (including bony fish, amphibians, reptiles, birds and mammals) have been affected by chemicals in the environment.

"Feminisation of the males of numerous vertebrate species is now a widespread occurrence. All vertebrates have similar sex hormone receptors, which have been conserved in evolution. Therefore, observations in one species may serve to highlight pollution issues of concern for other vertebrates, including humans," the report concludes.

CHEM Trust director and report author Gwynne Lyons said: "Urgent action is needed to control gender-bending chemicals and more resources are needed for monitoring wildlife.

"Man-made chemicals are clearly damaging the basic male tool kit. If wildlife populations crash, it will be too late. Unless enough males contribute to the next generation, there is a real threat to animal populations in the long term."

Wildlife and people have been exposed to more than 100,000 new chemicals in recent years, many identified as "endocrine disrupters" – or gender-benders – because they interfere with hormones.

They include phthalates, used in food wrapping, cosmetics and baby powders among other applications; flame retardants in furniture and electrical goods; PCBs, a now banned group of substances still widespread in food and the environment; and many pesticides.

CHEM (Chemicals, Health and Environment Monitoring) Trust was set up in 2007, with a mission to protect humans and wildlife from harmful chemicals.



The quest to be one

http://www.thetimes.co.za, 4 July 2009

Am I a he? Am I a she? Oliver Roberts speaks to three South Africans about the torment of achieving identity when you are both male and female.

Sally Gross has been many things in her life, including a revered political activist, a philosophy lecturer and a Catholic priest. She also spent time in the Israeli army.

Gross was born a man and still is; but she's also a woman. At least, she decided to become a woman in the early '90s. She went into hiding in the south of England to adapt to wearing dresses and makeup and turning right instead of left when visiting a public bathroom.

She didn't have any surgery to change her sex, though — it wasn't necessary. Gross doesn't really have a gender. She is both. She is what's commonly known as a "hermaphrodite", though the preferred term is "intersexed". This condition — atypical sexual differentiation — occurs in about one in 50 people. These figures make it feasible that between 45000 and 90000 South Africans are intersexed. According to www.intersex.org.za, we have one of the highest occurrences of intersexed people in the world.

Gross could then add to her extraordinary list of experiences "has been man and woman", but the truth is that Gross — who now works as the research and policy advisor for the Regional Land Claims Commission — has never felt she was either. Her life's struggle has been to achieve humanness or, more correctly, a sense of someoneness. What we take for granted — our sex — is our basic identity and, though Gross most certainly exists, she could also be seen as a flicker of shadow in the murky back streets and alleys of convention; she's an entity unknown, a trick of light that passes us by and makes us look twice.

"I've had a hell of life and, certainly, only a portion of it is about me being intersexed," Gross tells me. "You're looking for a label."

I'm sitting in Gross's home in Observatory, Cape Town. When I walk into it on this chilly Thursday evening, I immediately suspect it is the abode of a somewhat solitary intellect. Chairs are sunken from prolonged use, boxes full of papers chunk up the rooms and there are stacks of books everywhere. In Gross's study is a computer where an online contest of the ancient Chinese board game "Go" is in progress, and two cats are scurrying about the place, tickling the wooden floors with their claws and leaping suddenly from open boxes.

I have just asked Gross, who is dressed in a black skirt and pale blue top, to tell me her story. Three hours later, having moved from her study into the lounge, Gross is reclined on her brown La-Z-Boy, shoes off, toes curled, eyes drooping with sleep, still talking about her life.

"I was born in Cape Town in 1953 to Jewish parents," she tells me, earlier in the evening. "I don't know that much about what actually happened when I was born, but it's blindingly clear in retrospect that it caused somewhat of a fuss; there were questions immediately. It was evidently decided to assign me as male. This involved an attempt at circumcision on my eighth day, which proved to be problematic. I know this because it left a lot of scar tissue. There was clearly a degree of ambiguity."

Gross's circumcision took place before an assembled horde of relatives and parents' friends.

"The difficulty and fumbling would have been seen by lots of people, and a hell of a mess was made of it. A few days later, a second attempt was made and a little bit more was hacked off to tidy up aesthetically. Years later, my father complained to me bitterly in an e-mail, saying that the stupid ritual circumciser should have known I was female."

Gross has a kind of phallus, but almost all of its 'length' is inside her. She has a scrotum too, and two gonads that are not always descended. She is able to grow light facial hair. On her head is a crop of ash blonde hair, and she wears earrings and light lipstick. She also wears gold-rimmed, feminine glasses. Physically, she could easily pass as a woman which, in part, she is.

It is only Gross's voice that might make you notice and follow the shadow down the alleyway. It is deep and deliberate, a bit like the way a voice sounds on television when it's slowed down to protect the speaker's identity. Except in Gross's case, her tone does not conceal her, it exposes him.

Gross was raised as a boy named Selwyn (nicknamed Sally) and, while his childhood was a reasonably happy one, Gross describes it as "a lonely business". He was gentle and isolated and, though unable to comprehend his condition, Gross remembers feeling obviously different.

"From a fairly early age, I had a sense that something was awry, but I didn't really know; it seemed to bear on gender. I didn't feel like a girl trapped in a boy's body, but I certainly had a sense that something was different, but I didn't have the foggiest idea." Gross's parents, and even doctors, decided to almost ignore his ambiguity. Aged 10, Gross was hurt when he slipped down some stairs. A visit to the doctor resulted in a head-to-toe examination, from which the doctor concluded that "everything is okay, there's just one thing, but don't worry about it; just leave it".

"Parents are capable of a great deal of selfdeception," says Gross. "I wasn't brought up to be inhibited about my body; I used to strip down on the beach on holiday. As I grew up my assumption was that there was a range of the way bodies are. I assumed some were more wellendowed than others; I just thought I was an extreme of the range."

Still unaware of his gender duality, Gross entered adolescence. Though he did not experience the hormonal turmoil of most his peers, he did begin to wonder about his sexuality; not because he felt attracted to other boys, but because he felt attracted to nothing. Gross is asexual.

"Asexuality is bloody frightening in adolescence. I wondered whether I was gay, or a transvestite, though I had no particular inclination to crossdress; the thought of it gave me no pleasure." Now Gross laughs at this, holding onto the arms of the chair and throwing her head back. Just then, I see Gross's body briefly enveloped by its lurking masculinity. But it's just a glimmer; seconds later, Gross is a lady again.

Earlier that day, I met with Funeka Soldaat, 48, and Patrick Maseko, 29, two intersexuals from Khayelitsha.

In contrast to Gross — whom you feel has a tentative grasp on her condition — Soldaat and, especially, Maseko, feel betrayed by doctors and even their own families.

In June 1982, on the advice of surgeons, a 21year-old Soldaat — who has a vagina and grew up as a girl, but also has internal gonads — had surgery to remove her "penis", which was probably just a large clitoris.

Before the operation, language barriers made it difficult for Soldaat to comprehend what the operation involved; she was handed a copy of Drum magazine and asked to flip through it and say which she was "interested" in — the men or the women.

"I always looked at the pictures of girls and the doctors said, 'No, no, no — you have to look at this picture,' and then they would point at the male," says Soldaat. "I didn't know what the issue was. When I woke up after the operation they said to me: 'We have made you into a woman."" She has severe scar tissue where her clitoris used to be.

Though tall and broad, Soldaat is inherently feminine. But, like Gross' s voice, it's Soldaat's hands that tilt your perspective. They are strong and masculine, as if transplanted from a man who spent his life working a plough.

"I don't like someone to emphasise the fact that I'm a woman," she says. "I don't want to be boxed. People say 'You are a woman, you must wash clothes,' and I'm like, 'Piss off!' It irritates me. Maybe I still don't know if I'm a woman or a man. But I'm probably comfortable as a woman."

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Soldaat, dressed in jeans and a long-sleeved Tshirt, is an activist for intersexuals and lesbians, conducting workshops for the Engender organisation and speaking publicly about the surgery performed on intersexuals. Though the medical attitude is far less gung-ho than two decades ago, surgery is still seen as the dominant "solution" for an intersexed person.

There are, however, many doctors in the country who are strongly opposed to what Gross describes as an "indescribable form of abuse", especially when you consider creating a vagina requires several surgeries and repeated dilation of the artificial aperture as it tries to heal.

"It is always better not to have the surgery," Soldaat says. "The tricky thing is that people believe that one must either be male or female. I believe I just had a big clitoris, not a penis, so why did they have to cut it?"

Maseko, though small and delicate- looking, appears completely masculine. He is deeply shy and seems folded into himself, both physically and emotionally. On the rare moment when he speaks, his faint tone is just a struggling echo in the stark halls of the community centre where we're sitting.

I ask him whether he's had any surgery. "Ha-ha... lots," he replies. Maseko was born with an unusually large vagina and a tiny penis. His penis was removed a few weeks after birth.

"I never felt like a woman. I did man things, I even stood up when I urinated; so when I was 16 I had a penis and testicles created. But the penis doesn't work, it cannot get stiff."

Unlike Soldaat, who is still able to have a sex life, Maseko yearns for intimate companionship, but is physically unable.

"I asked the doctors why they couldn't have waited until I was older to do the operation, so that I could decide; they said there was no time to wait, they had to do it immediately. That's their excuse."

Both Soldaat and Maseko have been for counselling, but no longer go. Maseko now lives on anti-depressants.

"A person becomes proud of themselves when they realise who they are," says Soldaat. "But if you don't really know who you are, what can you be proud of? I am a lesbian and a woman; but I feel sad for Patrick because he's really stuck and there's no way out. He lives on his own in a little shack and his mother won't have anything to do with him."

I ask Maseko if he believes in God. He says he goes to church every day, and I ask if that helps him. He laughs, plays awkwardly with his hands, looks down and says "... no."

It was while Gross was studying English literature at university in the mid- '70s that he sought God — his creator — for solace and understanding.

"Something overwhelmed me. I realised there was a gap in my life, and it was God-shaped," she says. "My own confusions and personal struggles were all taken up and symbolised by the image of Christ crucified. Life, I saw, was in many ways a crucifixion, but resurrection symbolised suffering being redemptive, and showed there is hope beyond suffering."

Gross went to the Roman Catholic Church for instruction, and was baptised in 1976. He kept his conversion a secret from his parents. And though his conversion was based on this redemptive revelation, Gross observes that the church was also the perfect, if not the only, place for an asexual to be free.

"In contrast to the world of traditional Judaism, there is a healthy respect for celibacy in the Catholic church," she says. "There were roles for celibates, and it was valued; and I sure as hell was one of nature's celibates."

After living for a few years in Israel, primarily to escape apartheid police (he had strong ties with the ANC by this stage), Gross made contact with the English Dominicans in 1980 and went to the order in Blackfriars, Oxford, where he was ordained in 1987 and taught philosophy. After several more unsuccessful attempts to decipher his condition — one even via a kind of counselling hotline for transsexuals — Gross saw a gender

Following a few sessions and an assessment of Gross's testosterone levels (they were unusual for a 'man'), it was suggested that Gross make the transition to become a woman.

Discussions with the church were, in the end, messy and futile (the superior suggested he be institutionalised), and he cut ties with the cloth. It was a few months later, aged 40, that he went into hiding in the south of England, and learnt how to become a woman. She returned to South Africa in 1999.

"It was quite scary initially because I didn't know how to judge people's reactions," says Gross. "Then I realised it's not my job to engage in an Oscar- winning act, I must just be myself... and then it was kind of okay."

For all her acceptance, the one thing that remains socially insurmountable to Gross is her asexuality.

"In my ideal world, there would be forms of intimacy and unions that weren't sexual," she

says. "Unfortunately, in our society, intimacy and being sexually active are inextricably tied up; and, if you're not sexually active, you can find yourself being very lonely. I would like to share my life with someone, with people. The truth is, I think I need a check box that isn't male or female. In a sane society there would be one, but in our society you've got to choose."

I glance to my right at a shelf stacked with hundreds of classical music CDs. I scan the titles, listed alphabetically, and ask if she's heard Henryk Górecki's Symphony No 3: Symphony of Sorrowful Songs — three pieces about motherhood, war, Christ's crucifixion and Mary's agony as she watches her son die on the cross. Before she can answer, I spot it on the shelf, misplaced among Mahler and Mozart.

It's very late and I suggest to Gross, who is almost dozing off, that we call it a night. She sighs and, with a last surge of energy, concludes her story.

"I went through so much pain and difficulty in adapting (to) the female role, that part of me is just being bloody-minded," she says. "It's been hellishly costly in personal terms, so I won't give anyone the satisfaction of presenting me differently; but I see myself as human. I don't perceive myself as gendered, I just want to be considered a person and accepted as this."

For more information on intersexuality, visit www.intersex.org.za and www.engender.org.za



"Daisy in Black" by Bitzcelt, 2008. Creative Commons licence.

counsellor.

Become a Member

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).

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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.

Currently we are:

Phoebe (President & Qld Rep.)

Tony (Vice President) Andie (Vice President) Jocelyn (Victorian Rep.) Sandra (NSW Rep.)

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.

To become a member simply print out the following page and forward it to:

PO Box 1089 Altona Meadows VIC 3028 Australia

Or email your details to aissg@hartflicker.com or aissg@iprimus.com.au

Please find a membership application form on the following page.

The next dAISy

Next issue is January 2010. The deadline for submissions is <u>31 December 2009</u>. To submit articles, art, jokes, information, poems, or whatever you would like to share please email aissg@hartflicker.com

We hope to hear from you again soon!



"Thursdaisy's daisy has far to go" by Harold Lloyd 2009. Creative Commons license.

I wish to apply for membership of the Androgen Insensitivity Support Group Australia Inc. I enclose my annual membership fee of AUD\$20, which ends on the Ist of August 2010.

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