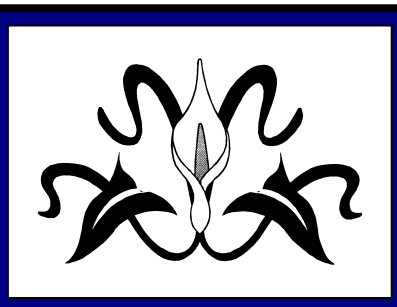

dAISy

March 2002 Edition

AIS Support Group Australia Inc.

http://www.vicnet.net.au/~aissg

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Please note we are fully independent of the AISSG (UK).

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Tony s Message

Welcome to the first dAISy of 2002. The last edition was released the week before the terrorist attacks on the US, the collapse of Ansett Australia and Andie's stay in hospital (all in the one week!). A lot has happened since then which means this edition of dAISy contains a lot of articles and information.

As most of you would be aware, the AISSGA held a National meeting and Annual General Meeting in Melbourne last November. The number of members who attended was down on the previous year, but this was mainly due to the effects of September 11 and the Ansett collapse. Nevertheless the meeting went ahead and we all appreciated the invaluable contribution of Counsellors Mandi McShane and Anne Baxendale, and Gynaecologists Andrea Walker and Sonia Grover. There are more details of the meeting later in this newsletter.

I am very honoured to have been re-elected as the President of the AISSGA for another year, and am very confident of the abilities and commitment of the new committee. I would also like to welcome Marija, Peter and Sue to the committee, and look forward to consolidating and furthering the work we have done in various States over the next year. I also urge the State Representatives to be as proactive as possible and draw from the experiences of the rest of the committee to support people living with AIS and other intersex conditions in their State, along with educating the general community about our issues and needs.

I would also like to congratulate Jocelyn on becoming the first person to be recognised with an honorary life membership of the AISSGA. Anyone who knows Jocelyn understands how much of an inspiration she is to many of us and the hard work and dedication she has shown to the AISSGA over the years.

The website and dAISy continue to grow both in size and recognition. We average 1000 hits per week on the website, and dAISy has recently been issued its own International Standards Serial Number (ISSN) by the National Library of Australia. The number of people contacting the group also continues to grow.

Andie and I have been busy working on a few different projects including a submission to the Australian Law Reform Commission (ALRC) as part of their community consultation process on the protection of human genetic information. The official AISSGA response has been uploaded on our website.

The Victorian Health Minister's community advisory group has consulted with the AISSGA on the health needs of people (including families) living with intersex conditions. Topics discussed included counselling, accurate diagnosis, truth disclosure, importance of support groups, bone mineral density, hormone replacement therapy, childhood surgeries, self-esteem and body image, research and the important role of education in reducing the shame and stigma experienced by many people with AIS and other intersex conditions.

Those involved with the Royal Children's Hospital (RCH) Melbourne follow-up study will know that the letter of introduction and the first questionnaire have now been posted. I was particularly encouraged with the letter of introduction inviting people to participate in the study, although there are some issues I will raise with the RCH regarding the questionnaire. I'm sure the researchers at the RCH have the best intentions in mind, but as this study is of global importance we need to ensure the questions and hence the data is as accurate as possible, preferably without any ambiguity. The team at the RCH should be commended for taking on this study and for working so closely with appropriate support groups.

The Federal election last October was a good opportunity to educate the community about the needs and issues of people living with intersex conditions. The Greens launched their national intersex policy which was formulated in consultation with the AISSGA and based on our aims and objectives. The ALP and Democrats, while not having a specific policy dealing with intersex issues, did strongly indicate a great deal of support. It was also a very satisfying election for me personally, as I ran for the House of Representatives seat of Lalor as the Greens Candidate. I was very heartened by the support of my local community, particularly as I was very open about my personal experience with my intersex condition and have 30 years of history in the electorate as Antoinette. Both Andie and I appeared on television in the lead up to the election to discuss matters relevant to those with intersex conditions.

A handful of transsexuals have recently been busy espousing their view that they should also be considered intersex, following their misinterpretation of Justice Chisholm's judgment which validated the marriage of a man of transsexual background. The Family Court of Australia at Sydney found that "Kevin" is indeed a man for the purposes of marriage because he is seen and accepted as a man by his family, peers, and various government departments. I am very pleased with the Court's decision, and fully support the family involved, but the judgment was clear that the matter dealt with transsexuals and not intersex people. I have since had confirmation from the Family Court of Australia and various Attorneys General that people with intersex conditions are legally considered differently to those with transsexualism and are recognised for the purposes of marriage etc despite any ruling to do with those with transexualism. Unfortunately, the people involved are continuing to misinterpret the judgment despite advice to the contrary, although it is only a few of them and the rest of the transgender community, as always, are very supportive and understanding of the AISSGA and our position.

On a more personal note, there has been a lot of exciting news for some members of the AISSGA with a few marriages taking place! Two of our members (Renee and Tony) married each other last year, and Phoebe (our Queensland State Representative) was married earlier this year. I would like to wish them the very best from all of us. I would also like to wish one of our AIS sisters well in her attempt to adopt a child with an intersex condition. I hope to have some good news about that in the next dAISy!

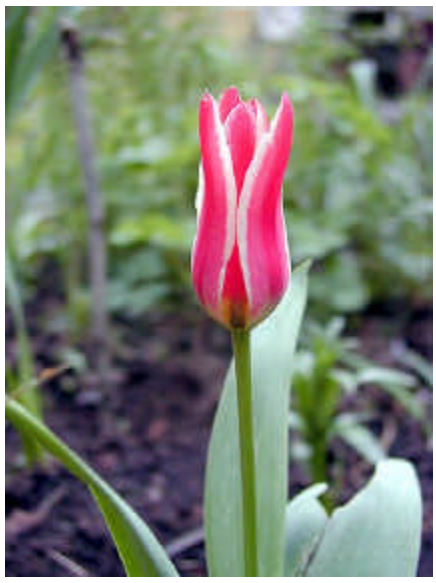
For those of you that don't know, my foster son is returning to his family this month. While I probably won't foster children again, it was a worthwhile experience that I hope will help him grow to be a caring, intelligent, and happy person who is better able to accept and embrace the diversity of our community. We are hoping to remain in touch, but we'll see how it works out over time.

Well that's it for me for this update. As you can see, it has been a very busy six months!

Best wishes to you and your loved ones,

Tony Briffa
President, AISSGA

P.S. Don't forget to have a look at April's Good Medicine Magazine. One of the most understanding and experienced doctors dealing with people with intersex conditions (Dr Andrew Cotterill) has contributed to a very good article on intersex issues.



National AISSGA Conference/Meeting Overview November 2001.

The AIS Support Group Australia held a national conference/workshop and AGM in November 2001 at the Royal Children's Hospital Melbourne. This was the second national meeting for 2001, the first being held in Brisbane in May 2001.

The participants included parents and siblings of people with AIS, people with PAIS and CAIS, people who self-identify and live as male or female or intersex and various medical professionals including genetic counsellors gynaecologists.

Personal Experiences/Stories

Personal experiences, stories and issues were discussed following the introductory session on the first day, and continued the following morning. It was made clear from the outset that those present were welcome to share as much or as little of their stories as they felt comfortable with.

As with the Brisbane meeting in May, stories included details of:

- the need for parents to learn of the support group as soon as a child is diagnosed as having AIS or a related intersex condition;
- general misconceptions/urban myths about AIS believed to be fact by some in the medical profession;
- difficulties with relationships (including sexual and intimacy issues);
- questions about what to tell partners and when;
- experiences with going to school and dealing with peers in childhood, adolescence and early childhood when you have AIS;
- feelings associated with not menstruating for girls with AIS;
- infertility;
- adoption;
- success of reconstructive surgeries;
- some doctors refusing to put people in contact with others with AIS, even when asked by older adolescents and parents;
- difficulties in making choices for children with AIS - especially when the "big picture" isn't explained and doctors place urgency on making a decision regarding gonadectomies;
- late discovery of the truth about AIS because of inaccurate or misleading information regarding the condition;
- the possible strain on the family and on the parent's relationship when dealing with a child with AIS or a similar condition;
- lack of knowledge or research on the timing of gonadectomies and the relationship it has with bone mineral density and body image;
- lack of knowledge or research on hormone therapies for people with AIS and similar conditions (both oestrogen and testosterone therapy);
- the poor manner in which some parents are treated when a newborn is diagnosed with AIS or similar condition;
- lack of knowledge by the medical profession in general on AIS and other intersex conditions;
- the feeling that members learn more about their condition from support group meetings rather than from their doctor;
- the expense of lifelong medical treatments like oestrogen, testosterone & Fosomax;
- the inability to obtain DHT for males with AIS; and
- a need for a booklet on PAIS.

One member spoke of the support group in terms of the one place she did not feel that she had a secret she had to keep from others. A parent spoke of the way her child's diagnosis was given to her in hospital and the fact that she was given absolutely no follow up support after being given the information. She spoke of her disagreement with the medical recommendations she was given, deciding to rely on her own parental instincts and an approach of openness with her child from an early age. This same parent, after repeated requests of specialists, only found the details of the support group after taking a length of time off work to specifically look for such a group on the internet.

Question & Answer Session with Clinicians.

On Saturday afternoon, a general discussion was held with invited medical professional. As a starting point, positive aspects of treatment were discussed with the emerging common aspect of positive treatment being provision of accurate information at every step of the decision making process. It was generally felt that the best clinicians were those who took the time to thoroughly research the subject matter in order to give their patients all information necessary to make informed choices. One gynaecologist present asked for the general opinion of the group about disclosure to one of her patients. She had been instructed by senior medical staff not to disclose to the woman concerned, her diagnosis of AIS. The senior staff justified their position by stating that they believed the patient too old to tell the truth. Members of the support group all agreed that this was an old fashioned, paternalistic attitude and that all it really meant was that the woman concerned would spend the rest of her life wondering why she was "different" to other women. The genetic counsellors present spoke of the need for lines of communication to be opened up so that they were brought into dealing with the situation of a newly diagnosed infant much earlier. This is a particularly important message to get through to paediatric specialists.

Sunday Morning Session With Dr Sonia Grover (Gynaecologist)

A further question and answer session was held Sunday morning with Dr Sonia Grover. Discussion topics varied widely and included such things as:

- hormone therapy, including oestrogen, progesterone, testosterone, and DHT;
- various types of hormone therapy administration;
- bone mineral density issues;
- questions about any need to maintain non-surgical dilation when not in a relationship;

- the advantages of non surgical dilation against surgery (including the ability for women to successfully "construct" or deepen their own vaginas);
- the need for effective hormone therapy to assist intercourse issues including the possible use of oestrogen cream where hormone administration is not effective by itself;
- whether a prostate gland would be present in those with "low grade" AIS; and
- discounting a few "urban myths" about hormone treatment as it relates to AIS.

As always, Dr Grover discussed all issues and answered all questions in an open, straightforward, and direct manner and her contribution to the meeting was appreciated by all present.

Comments & Conclusions

All appreciated the contributions of the invited medical professionals. This was particularly the case as two genetic counsellors who attended, travelled from interstate for the meeting, and participated in both days of the meeting. One of the counsellors commented about how much the support group had grown in the last 12 months or so. Members of the support group enjoyed another excellent opportunity to discuss various ways of improving both the perception and treatment of intersex conditions. The variety of members present, either with AIS, their parents or clinicians, contributed to thorough discussion of a wide variety of issues. Feedback from all present was very positive and once again the inclusiveness of the support group was cause for favourable comment. Unfortunately, many who had planned to attend did not do so because of recent world political events. The next meeting is to be held in Brisbane in May 2002.

New 2001-2002 Committee.

President	Tony Briffa
Secretary	Andie Hider
Treasurer	Tony Briffa
State Representative – Vic./Tas.	Elizabeth
State Representative – QLD/N.T.	Phoebe (Peter currently Acting Rep.)
State Representative – N.S.W./Canberra	Sandra
State Representative – W.A.	Danni
State Representative – S.A.	Marija
Men with AIS Representative	Peter Reilly
Parents Liaison Representative	Sue Reilly
UK Representative	Graham Hague

Personal Stories Fran.

I cannot remember a time when I didn't know I was different.

I believe I am intuitive most of the time. One of my earliest recollections regarding my syndrome is sitting in the bathtub, weeping. I was weeping there, waist-high in water, at the age of 6 or 7, because I felt betrayed. I was positive that I was "supposed" to be a boy and my mother wouldn't tell me. The only reason I felt this way was because a testis had descended into my labia majora. There it was… this half walnut… making me feel like a freak. I didn't know what it was; all I knew was that my sister didn't have it and it looked more like a boy's testicle than a girl's vagina. I didn't like it. I cried about it a lot when I was alone.

I was born with double hernias, one being repaired at 2 months of age and the other at 10 months. My mother was told by doctors to be as honest with me as she could while I grew up. My older sister was told she would have babies "here" (as her tummy was being rubbed) and I was told I would adopt. At a very young age, I had no trouble accepting this fact. My mother claims she knew that I was sterile but that she did not know I was CAIS. I did not and do not believe her. She knew. My mother is a registered nurse. She knew. **This entire topic was never discussed in my home, shrouding it with shame and secrecy, in my mind.** My parents did nothing to prepare me for any of what I might encounter in AIS life. Part of that is due to, I believe, the fact that I am their daughter, plain and simple. I believe they saw me as "whole". What difficulty could there be?

At the age of nine, my mother told me that we would have to visit Johns Hopkins University (JHU) so that the doctors could check on me. I felt the grip of panic start to grab hold of the back of my neck. I was so embarrassed of my difference that the idea of anyone looking at me was enough to start an overwhelming emotional response. I wept and wept but had no choice – I had to go.

My mother, father and I went to Baltimore and my genitals were examined by Dr. Blizzard, other endocrinologists, other surgeons/doctors, more residents and medical students than I can count, etc. Then I had to be examined by Dr. Howard Jones. I was lying on the table, spread-legged, with my feet in stirrups. The nurse came over to me and insisted upon holding my hand. I thought this was a nice gesture but I didn't know her and thought it unnecessary - unnecessary until the moment arrived when Dr. Jones broke my hymen, that is. The pain shot through my body like a bullet searing my flesh. I was utterly shocked. No one had warned me of what was about to happen. As tissue was ripped from my body, my hand went into a reflexive contraction and I am sure that the nurse is trying to get blood into that hand still, 30 years later. This procedure was performed to assess the length of my vaginal canal and the likelihood of future vaginoplasty, as I later found out.

I didn't stop crying for hours. It was not a loud cry – it was a soft, mournful, visceral cry. My father is not the most patient of men and I remember him looking at his crying daughter on the

sidewalk outside Johns Hopkins and saying to her, “What are you crying about? Don’t you know they are trying to help you?” I’ll never forget those words or the tone with which he used them. My father never came along on any future trips to Baltimore, even when I had my surgery.

I bled the entire trip home. I was losing so much blood that I thought I was going to bleed to death. My mother tried to reassure me but in the light of what seemed like pints of blood, words are not very powerful. I would never be the same after this first trip to Baltimore.

Part of me died.

Trips to Johns Hopkins occurred roughly 18 months apart. Each trip evoked the same response in me. It was hell. I hated everyone there although I knew that no one was trying to hurt me. The most humiliating part, I think, were the photographs. I am sure many people reading this have seen the medical photographs of people in which their eyes are blocked out, in an attempt to hide their identity. Well, one of those pictures might be me. I was nine years old when I had to have medical photos taken at JHU. My mother tried to joke with me that I was posing for Playboy. I failed to see the humor. I had to stand naked in front of a white wall with height markings etched on it. “Please turn to the left”. “Face forward”. “Please turn to the right”. “Face the wall”.

Then I had to lie down on a table while the photographer zoomed in on my spread legs and exposed genitalia. My mother had to assist in spreading apart the lips of my vagina so they could get an even more graphic view. I was so embarrassed. I was so ashamed.

My meetings with John Money, MD were, apparently, not very memorable ones. I remember him but I don’t recall anything he said when I was a child. I do remember him giving me a very long questionnaire to fill out at home and send back to him. I never did it; I thought all my answers were foolish. I had my IQ tested on my first trip to JHU, which highly entertained me. I genuinely liked the woman (Mrs. Clark) who administered the test. Most of the questions were math problems or puzzles. I had fun with it.

Dr. Money, I remember, treated my family well on these visits. He never once charged us for the visits prior to my surgery and never billed the insurance. I understand that some people have had difficulty with him but I am not one of those people.

My JHU visits continued until finally, at age 15, my surgery was scheduled. The testis was removed and the vaginoplasty was not needed. I was actually happy to have the surgery as I felt much more “normal” without the testis.

I remember being sad all my life.

You would never have known that if you knew me. I seemed like a fun, outgoing, well-adjusted little girl who was popular, athletic and smart. But I was sad. When I was 14, I developed an eating disorder. It started out as anorexia nervosa but developed into a full-blown case of bulimia. This coincided with the fact that I had my first boyfriend and started a sexual life. Perhaps the eating disorder was a subconscious attempt at putting off my sexual development. Perhaps it was the result of unconscious struggle with my suspicions concerning my syndrome. I still don’t know. The eating disorder grabbed hold of me and has never really let go. It will be something I struggle with for the rest of my life, I am sure.

When I was 15, I began my preoccupation with suicide. I would think about how lovely it would be not to have to struggle with any of this anymore – my feeling like a freak, my eating disorder which was uncontrollable at that time, extensive family problems, etc. Then I went to a movie, which dealt with death and life after death. I have never been a particularly religious person but this movie made me dispel all thoughts of suicide. It depicted the experiences of those who had near-death experiences and when I saw what the suicide victim experienced, I knew I would never attempt it. It wasn’t worth the risk or I wasn’t depressed enough. At any rate, I wasn’t going to take the chance. If I hadn't seen that movie, I think there is a good chance that I would not be here today.

As I said, I was 14 when my romantic life began. I couldn't believe it when Bob, a good-looking 17 year old, fell in love with me. Me! I was not in love with him but was in love with the idea that someone could care for me so much. I have never thought of myself as physically attractive and was shocked that someone else did. I knew that I couldn't get pregnant and was very sexually curious, so I relented and stopped thwarting Bob's advances. The idea of anyone seeing me naked prior to that was abhorrent to me. Bob didn't care that there was a lump in my vaginal fold (Bob is the only one to behold that sight) or that I had sparse pubic hair. Bob thought I was beautiful, God bless him. Since that time, I have always had an initial hesitation to be naked in front of lovers but it is quickly overcome after that "first time". No lover has ever shrieked in horror at the sight of me, much to my surprise.

My sex life has had its share of feasts and famine. Most of my relationships were long term, lasting 1 - 2.5 years, so I can still count all my lovers on two hands.

I will say this: although I was sexually curious at a young age (who isn't?) and I gave in to that curiosity, I don't think I was truly ready for an adult sexual relationship until I was in my twenties. Suddenly, at that age, my sex life took on a whole new and wonderful meaning. Perhaps it was that inhibition was lost, I don't know. Perhaps it simply came with a degree of maturation. Maybe not. I still can't undress comfortably in front of people who are not lovers, family included (so much for maturation?). I have never married. I don't think the right man exists for me.

When I was in college, I still had many of the problems that existed as an early teen. I was confused and angry. My roommates were not treating me fairly in the room and would not listen to reason. I became angry and lashed out at them by stealing money. The crime was discovered; I confessed, suffered the consequences, left the room for another, and went back to Johns Hopkins University. It had been 6 years since I had been there and I went to see Dr. Money. It was at this time that Dr. Money told me I was CAIS. I was 21. I only remember him telling me of my syndrome, nothing else. I was with him for one and a half hours and I remember absolutely nothing else of what he said. I heard “Androgen Insensitivity Syndrome” and that I was genotypically a male. From that point on, my mind was reeling, hearing nothing else. I thought about that 6 year old crying in the tub because she knew she was supposed to be male and I was amazed. Wasn’t this science fiction? Dr. Money told me this now because it was his belief that I might subconsciously be struggling with this, which is what caused me to steal the money and behave inappropriately. Maybe he was right; I have never done anything like that again.

I find it very interesting that I am a scientist and that I did very little research to discover more about my syndrome. For years I just avoided the words and thoughts. Denial was my middle name. When I was 25 and in medical school, Johns Hopkins sent me my medical file. It was considered a dead file as it had been over a decade since I was there for medical treatment. I went to my gynecologist (a new one) soon thereafter, having discovered a lump in my breast. I brought her the file. I had not read it, gave it to her so she could become familiar with my case and asked her to hold it for me. I was not ready to look at it. The lump, it turns out, was fibrocystic disease, probably as a result of estrogen therapy. Two years later, I was interested in reading my JHU medical file. I called my gynecologist to tell her I was coming to the office for the file. It was at this time that I was told they lost the file. They had no idea what happened to it. I was mortified. Now, I would never know exactly what the medical professionals noted during all of those visits. To this day, I am still very disappointed.

Sometimes, I feel like an unfinished person.

I've done a fine job of ignoring my syndrome. I think this has been a very big mistake. I am now over 40 years old and think that I have never really been happy. I have had happy moments in my life, to be sure, but I think that I have never generally been a happy person. Maybe it is because I have not confronted this part of me. I hope to start my journey and either put it to rest or happily incorporate it into my life. I think it's time I learn to embrace myself.

I am new to this despite my years. I have no strength or real wisdom to offer others, unfortunately. I do say this, though, to those who are young and, perhaps, new to discovering this part of themselves: Do not ignore it. Do not play 'ostrich' as I have. Learn vicariously from my mistake. Learn about your syndrome and deal with it the best way possible. Ask for help, if you need it. Don't let shame and embarrassment guide your decisions, as I believe they have guided me.

It's later than you think.

Personal Stories Bobby Jo.

I was born in 1954. My mom always tells me that I was the only "girl" born the whole day in that hospital and the nurses made a fuss over her and me. When I was delivered the doctor told my mom that I was crying a lot and it was due to a hernia down in my groin area but "not to worry" that it would "correct itself"! So my mom took me home.

I grew up on farm with my three brothers and couldn't have been happier. I wanted so much to have a baby sister and remember when my last brother was born I was just devastated when I heard it was a boy. My second oldest brother and I were and still are very close, and then my youngest brother and I have a good brother/sister relationship. However, my oldest brother has never been close to any of us.

I was a real tomboy and loved climbing trees and buildings. In school I could outrun boys older than me but I also loved dolls and all the "girl" things. I loved getting dressed up in frilly dresses and black patent shoes. My mom loved to dress me in red. We didn't have a lot of money but my dad worked hard and my mom went beyond the call of duty as a mother. She was and still is the best mom in the world. Her and I have always been close and I know she'd do anything she could for us kids (and has).

I went to school in the old one room schoolhouse where grades 1 through 8 were taught. I loved school and being with all my friends. I was an average student (never good at math) and excelled in certain subjects. My hernia that I had as a baby did settle down because it never bothered me again or not so that I knew. I remember in about grades 7 and 8 my girlfriends were developing breasts and I wasn't yet. I think it was the summer before entering grade 9 in the fall that I finally did get breasts and I hated them (and still do this day!)

I remember that summer my mom got a small package in the mail from Kotex and promptly hid it somewhere. A few days later when my dad and brothers were all out, she came out and gave me this package of 2 little books for me to read. I literally freaked out when I read them. One was titled "On Becoming a Woman" and of course about ovaries, periods, and all that. I remember running into the house and throwing them both at her and swearing my head off that no way that this was ever going to happen to me and that I didn't want to grow up! I knew I never wanted to have babies and I even said I never wanted to get married. I know I really upset her and it still bothers me. If only I knew how prophetic my words would be!

Although my mom and I have always been the best pals in the world, she couldn't talk to me about sex, periods, and all that. I learned some of the basics because I grew up on a farm and one gets an early sex education from the bulls and cows and all the other farm animals! Not another word would be spoken about periods and such for at least another 12 years when I was 24 or so! I guess my mom just thought I was taking care of myself with periods throughout the rest of my school and teen years!

I should regress a bit here and say that I was a healthy girl and right through until I graduated at the age of 17 I never went to doctor! I was never examined once. I remember once I got into my teens (I'd love to know if this happened to other AIS women) I started getting severe pains in the groin area. Terrible terrible pains that I would just double over with and cry. My second oldest and youngest brother had both had appendicitis in the last few years before this and my parents thought I had it too. The pain was in the same general area.

I had a severe attack one night and my parents were going to take me to the city the next day to the hospital but by the next morning the pain had gone away and I was fine. This went on until I was in my early 20's and then never bothered me again. (I now know it had to be the testes that I never even knew I had!) If I still had pains that next morning I would have gone in for an operation and then the truth would have come out. My parents had no idea. How could they?

I then graduated, moved into the city, got a full time job and a nice room in a rooming house and went on my own to make a living! I hop on the bus every weekend, go home to the farm, come back into the city every Sunday night, and cry myself to

sleep because I'm so homesick and friends are now scattered all over.

Back to high school and of course girls were all talking about their periods. I would just stay quiet or change the subject or just plain lie. Although I was actually glad I didn't have to go through all the mess and winging that my girlfriends did every month, I began to worry about not having periods when I was 17.

When I was 18 it started to bug me so much that I closed my eyes, picked a doctor (any doctor) out of the yellow pages, and made an appointment to see her. I leave work early and finally find this place.

This old lady doctor finally comes out to see me and I'm thinking to myself "OK - how are you going to bring up the subject of never having periods"? I had gone to see her on the pretence of having bad canker sores in my mouth. She starts doing a medical history on me and then she asks "How long are your periods"? I tell her I have NEVER had any!! I remember the look of horror on her face.

"You've never had a single period, what no spotting or nothing"? I said "Absolutely nothing!"

She didn't know what to say. Eventually she composed herself and said, "I've got to get you on hormones right away, this can't be delayed any longer". With the tone in her voice and the look on her face she scared the hell out of me and I just got out of there fast!! I never went back. That was that and I wouldn't see another doctor about it for another 6 years when I was 24!

I never had a boyfriend until I was about 21 and then it was just casual dating and kissing. I was having a great time and my life was very happy. I enjoyed going to pubs, dances, vacations, having my own car, a nice apartment, and a good job. Life was good.

Of course it bothered me that the periods had never started. I just told myself that it would never happen now and hey, I didn't care... I was saving a ton of money on pads and tampons and being "sick" once a month like so many girls. Besides, I was just going to stay single and I still didn't want kids anyhow. I truly felt 'blessed' by not having this monthly curse and thought of myself as a very unique special girl. I had just accepted the fact that I just never developed "downstairs" and my insides there were still like a little girls. OK, I can live with that! **I never spoke about it to a single person.** None of my closest friends - absolutely NO ONE! It was my neat secret.

After Christmas 1978 I thought the time had come to get the answers to why I didn't have periods or hair under my arms etc. This time I did careful research through co-workers (not giving away my secret though) and found a good doctor (so I thought) at a respected clinic in the city. It had to be a female doctor and when I went in I cut right to the chase and told her I'd never had a period in my life and wanted to find out why. At least she didn't freak out on me. She said there would have to be testing done.

She gave me a complete physical and ran blood tests but said nothing to me except that she'd get back to me in a few days. I left thinking finally I'll get my answers! Wrong!

She did call me back at work the next week and said she was setting up an appointment with an endocrinologist. But then just as quickly (within a few days) I got a call from the doctor (not the endo) that they were cancelling the appointment. I remember the words exactly "There's nothing he can do for you anyway, so it would be a waste of time"! I was shocked but the regular doctor wanted to see me back the next week. So I went back to her office BUT she never told me one dam thing about my test results or anything. **I was only told I'd never be able to have children and asked if I wanted to see a psychiatrist to help deal with that issue.** I said no because I didn't want kids anyway. "Well if you change your mind and get married you can always adopt".

THAT WAS IT CASE CLOSED!! She must have known but told me nothing. So again I left a doctor's office being no wiser. After that experience it would be another 16 years (and I was 40) until I'd even go near a doctor again to discuss anything! I really really hated doctors and their mightier than thou attitude. They could all go to hell as far I was concerned. They couldn't diagnose their way out of a wet paper bag!!

OK fast forward to about 28 years old. I had boyfriends over the years but kept them at bay. I just didn't want to be intimate with anyone, but I met this great guy (Grant) that year. We started out being friends but it just grew deeper and deeper. I couldn't be falling for this guy could I? He just let me be me. I've always been very independent and I wasn't going to sacrifice that if I married him. I told him up front that I couldn't have kids and if he wanted kids to go looking somewhere else. He didn't care. He just wanted me and since we both loved animals we'd get a dog or two. **So after 3 years of dating we got married.** We've had our ups and downs and I've been ready to pull the pin on numerous occasions with his in and out of jobs, family "crap" on his side, money troubles and other stuff, but we've stuck by each other and its been 16 years now.

He's the only guy I've been with sexually and as far as I knew we were having normal great sex, so how could there be anything wrong with me!!

So at this point I still didn't have a true family doctor and once again the old hauntings come back that I need to find out. Over the years I had tried to find out things from medical books and magazines and being a librarian I'd get inter-library loans articles but nothing conclusive ever came up. My husband actually told me I should go and see his doctor (woman doctor) who other members in his family were seeing. She apparently was very nice.

So I thought what the heck its been 16 years maybe I'll try and find out AGAIN! So I made the appointment and this time for my first full physical in my life at 38 years old!! When I met this doctor, I couldn't believe how nice she was and how easy she was to talk to. I could tell her anything. It was like talking to your best friend. So I opened up and told her about never having periods and I HAD to find out now at this stage in my life. She assured me she'd do everything in her power to help me. So I went through the full physical, blood tests etc. I told her about my going to the clinic at 24 and just being turned away cold. She thought they could still have my records of that time and she put in a request for them.

She phoned me back a few days later and my records from that clinic were gone which she found very odd but it had been 16 years after all. Well things started moving rapidly. I was back in her office within a week and told I had to go for an ultrasound at one of the hospitals. So I went there and got that done. Then another appointment was made with a specialist (endocrinologist and gynaecologist) for more blood work and tests.

Then finally I was back to my doctor's office and I waited anxiously for the results. THIS IS IT. This will be the answer

after 25 years of wondering why why why? Well, she had a talk with me and told me in effect that when I was being "made", I had never developed ovaries, a cervix, fallopian tubes or a uterus, but I had gonads which had never developed.

"Gonads, what the hell were they?" I asked. "They are what you have when you're pre-puberty". They highly recommended surgery ASAP to remove them for fear of becoming cancerous. I was already pushing the big 4-0, so I should have the operation within the next month or so or when a bed became available. I left there thinking I had finally found out the answers I needed but being very upset.

I cried all the way home because she had really scared me about the cancer thing.

But I had to get rid of those damned gonads. The surgery was scheduled for the next month but a terrible blow came to my husband and me. I lost my "secure" wonderful job after being there for 12 years. I went into a tailspin of depression and worry. I didn't even care about an operation now. I just needed to get another job and a good one at that. So I cancelled the operation until I got back on my feet. Then 6 months later my husband lost his job where he had been for 10 years. Talk about a black cloud starting to form. Things just went from bad to worse.

Well I found two decent part-time jobs and it was about a year later and I thought I better get in and get the surgery done. So I had the operation at the end of November in 1993 (just shy of my 40th birthday).

I remember my husband driving me to the hospital that day and being a complete basket case waiting upstairs before they come and get you. I was totally convinced that they'd open me up and I would be chock full of cancer or that I'd die on the operating table! I even scratched out a will and informed him I wanted a tape of Elvis Presley singing "Amazing Grace" and "How Great Thou Art" at my funeral! (Total Elvis fan). They gave me a sedative to calm me down and that was it. I went in had my "gonads" removed! The surgeon came to me after and said it was a complete success and that he had "gotten them". **There was no cancer or pre-cancer or anything.** I went home from the hospital in 2 days and was back at work in a week (still very very sore though).

I went back to see the surgeon in 6 weeks at his office and he examined my scar and me and said I was healing beautifully. I asked him why this had happened to me and he told me that in all his years of being a doctor he had only come across maybe 2 other women with my same "condition". I asked him what it was and he gave me this long name that I promptly forgot as soon as I left his office. But I could look forward to a long and healthy life now. OK I thought. That's great.

I went back to my doctor and she really never told me anything more but that I should go on HRT pills or patches. I had the operation in November so I went on a low dosage of HRT but after a month or so I'd forget to take them and quit taking them all together. I guess after my body got over the shock and trauma of the operation (about January), 6 weeks later or so well I went into complete menopause cycle! I remember just tearing the covers and sheets off myself and throwing wide open my bedroom window. And this was with a temperature of 30 degrees below!! I would just boil inside and sweat. I thought I was going insane. My poor husband just couldn't cope with it. **How the hell could I have menopause if I had never even had a period in my whole life???**

I went back to my doctor and she said my body had estrogen before the operation, but the operation threw all my hormones off. Well I was cursing the day I even had the operation. I suffered with this menopause crap for another 4 months until everything settle down. It was pure hell at its worst. The other thing was always being a very slim person I packed on 10 pounds within 3 months of the operation. I was 130 lbs when I went in and 3 months later I was already 140 lbs!! (I'm 5 foot 7). And I just kept putting on more weight where today it has become a real problem for me. I now weigh close to 170 lbs.!! All because of that operation and my whole system getting whacked out. **I still curse that operation to this day. But I guess better to be heavier than dead with cancer. But now I read that its only 9% chance of cancer. So if I'd know that back then I would have taken my chances.**

Otherwise I'm very healthy but the extra weight has caused my cholesterol to climb 2 to 3 points and it's the bad cholesterol. So I'm really trying to lose 20 to 30 pounds now and its so hard. Has this happened to anyone else? I realize most of you "got done" pre-puberty or soon after. And I still hate my breasts. I kept thinking that why did I have to even get them especially if I wasn't going to have periods!! Or I would have gladly have taken it in the reverse (i.e. gladly have had the periods and no breasts!!) That's one of the attributes of this AIS (we are given generous breast development aren't we?). Or are some women not??

Anyways I quit my HRT treatments from age 40 to 44 and after one of my yearly checkups my doctor sent me in for a bone density test. **The results came back showing that I could be headed for osteoporosis if I didn't get back on HRT right away.** So I've been going in for a monthly shot. It's a combination of estrogen and some testosterone. I'll be tested again next year to see how I'm faring. Hopefully good!

So I had the operation 8 years ago and just in the past few months I started thinking about things again and something just wasn't totally right as far as my diagnosis went. I'd go in for my yearly checkups and my doctor and I would talk about things and I'd refer to the operation now and then but really nothing more was said.

This past summer I stared digging and searching on the net. But I couldn't come up with anything. I'd type in key words like "missed periods" or "women not menstruating" etc. Nothing concrete would come up. Then it was only in the last month I was searching at work one weekend, I typed in the word "gonads", and a whole slew of hits came up. Then I found words like Androgen Insensitivity Syndrome and WOW it just hit me between the eyes. Did I have this, is this what it was? NO way? **XY chromosomes in a female?** My head was spinning. I just couldn't get enough. I read more and more and more and website upon website. **Then I came across the Australian AIS website and read all the biographies. Their stories fit me a T.** The puzzle was coming together after 33 years of wondering. I downloaded a whole pile of documents and had them ready when I went to see my doctor for my next HRT shot. I just couldn't believe it.

"What? I was actually supposed to be born a boy but my body wouldn't respond to androgens and I stayed a girl?"

When my doctor came into the office she seen I had this pile of papers. My heart was racing. She said "oh I see you've been doing some research?" I said yes and I showed her one with a deep bold print on top with Androgen Insensitivity Syndrome on

it. **I said "is this what I have"? And she took a breath and said yes! And all I said was WOW and she said "yes WOW". She had known 8 years ago before my operation after all the preliminary testing was done. She even had to research it.**

She said right away to me "but Bobby-Jo you ARE 100% female". Then she showed me my records from 8 years ago and from all the specialists and the surgeon. "Thank you for sending me Bobby Jo' one of them said. "She is quite the unique remarkable young woman and so healthy!" Like I should be in wheelchair because of this?? I indeed did have XY chromosome and am compete AIS. Shorter than normal (blind ending) vagina but longer than most with same condition, juvenile nipples, sparse pubic hair and no underarm hair, smooth skin, even juvenile looking at almost 40 years old!!! Hey maybe us AIS people have unlocked the key to youth eternal and will live to be 200!!!

So my doctor and I talked for a long time. (Keep in mind this was only 2 weeks ago!) She then asked if I was mad at her for not telling me 8 years ago. I'm not mad at her at all. At least she took the time to finally diagnose me and be with me through everything else the past 8 years. I told her when I first met her I knew she was someone I could easily talk to after being shutdown by other physicians, and I thank her for that. Yes maybe she could have told me 8 years ago but I really think with slowly finding out on my own and with the help of the net (which wasn't there 10 years ago) maybe it was even better this way. I found out slowly and surely and not a major shock all at once.

She said she herself debated whether or not to tell me everything but "if the patient isn't asking questions then its not time yet". So on my prior HRT visit the month before I had started asking questions and she knew it was only going to be a matter of time especially when I told her I searching the internet now. That's why she wasn't too surprised when I walked in with my bundle of papers. **So I'm not mad at her at all and think how lucky I am to have such a great doctor.**

WHEW! So that's my story. Boy it feels good to write it down as other people with AIS will understand. I just spoke to my mom yesterday and told her (not everything). She is 77 and I don't want her to think I blame her in any way. The same with my father. I'm so lucky to have both my parents and they're both in great health. Hey it happened, so live with it! **I have never ever thought of myself of anything but female.** So I have a few "male" chromosomes in my body - so what! We're all nothing but a 100% cells and tissue and water anyways. **AIS had made me the special unique individual I am today and I'm quite happy with her.** I don't need a psych to talk to.

Sure it bothers mesometimes. Sure I cry now and then. But I probably came through it less scarred than most by being totally ignorant and never going to doctors or checkups most of my life. I think if I'd found out when I was 13 or 15, I might have wanted to "checkout", but now NO WAY! I don't know if other AIS women feel like this but I know I do.

Inside I still feel like a little girl that hasn't grown up. Is this part of it? I'm not religious in the least but I think this is the body the Good Lord gave to me, a special body. What? 1 in 30,000 or something like that? What are the odds eh? I have a great husband who stands by me, I'm healthy, have a nice home and my wonderful dogs and a parrot. **I've been through a lot but I want to live to be 105 years old and just enjoy life. I'm so thankful I have found Renee and Tony and the whole lot of you. I know you'll be there for me and I'll be there for you. God, I'd love to go to one of the meetings in person to meet just one other real live person with AIS!**

Maybe it'll happen one day soon. I truly believe we were made this way for a reason.

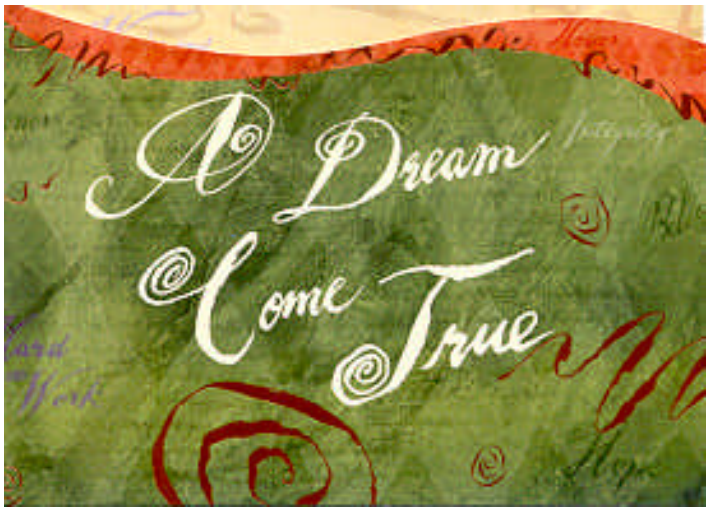
"Never be afraid to try something new.

Amateurs built the ark.

Professionals built the Titanic."

I think most of us have had to build our own arks, despite the professionals we've encountered!

-Sent by Clare



Personal Stories Sue.

My name is Sue and I have CAIS. I am now 51 years old.

I always knew from an early age that I was different but did not know the half of what was to come until I was 11 years old. I was born the middle child of five. I had an older sister and brother and two younger sisters. Both my younger sisters have CAIS. My older sister has three daughters, the youngest of which, has CAIS also.

When my youngest sister was 5 years old, a lump was found in her groin (sound familiar?). She was admitted to hospital and the lump removed. A few months later, myself and my two younger sisters were also admitted to hospital for tests. We spent a week being poked and prodded around, and various blood tests were taken.

The biggest humiliation was when we were shown into a hall that was full of doctors, and bombarded with personal questions. Both my sisters found this unnerving and the talking was left to me. At that time my sisters were 5 and 6 years old, and I was 11. That experience scared me emotionally for life, we were made to feel like freaks although at that time none of us had been told the reason. I can never go into crowded places, without those memories flooding back.

We were sent home and my parents told me that although I was a girl, I would never be able to have children. As I was the biggest Tom-boy, that statement never really sank in. The subject was never brought up again. As far as I was concerned, I was a boy at heart and always did boyish things, cricket, football, climbing trees, war games, you name it, I loved it. I know I should have been male, I have never felt female, although I look more female than male. My childhood carried on in this manner, until I reached my early teens. Then came the inevitable, all my classmates were starting their periods, and I was left out. From this day, I consider my life to be a lie. All my mother ever said was that I would never have periods, and obviously no children, and not to tell anyone.

My growing years were a nightmare, I felt so ashamed, I always used to carry sanitary pads around so that I would feel "normal". I left school and home at sixteen, and started a job working with horses. This was my escape from reality, no-one new or had any idea that I was not normal. I never let anyone get close to me, never had serious boyfriends, well, there was one, but I found out to my horror and shame that I was too short(vagina) to have sex. I wish I had known that I could have had surgery, perhaps that would have made me feel more normal, but no-one ever told me it was an option.

Looking back, I must have been really lonely, but I threw myself into my vocation with horses, that in a way was fulfilling. This went on until I was 41 years old. One of my younger sisters had found a lump in her breast and had to have surgery and blood tests. It was found that she was XY, so questions were asked and the outcome was that I saw a gaenacologist for tests. His opinion was that I should have a scan so that he could see what was going on. I was told that I had testes and no womb and that I should have a gonadectomy, there was a danger of cancer otherwise. I agreed, not knowing it would change my life forever.

At that time I was working with National Hunt Racehorses, I had a beautiful stallion to look after, also brood mares and youngstock, the latter which I used to prepare for the bloodstock sales, as well as breaking and training. To me it was the perfect job. After the operation, and after having three months off, to recover, I went back to work. It was a disaster, I had no strength, could not cope emotionally or physically. I had to give up my career with horses for good.

By this time, I was on HRT. I gained two stone in weight, had mood swings like I had never experienced, in short an emotional wreck. I also suffered severe migraine headaches, these would last for days on end. I tried various HRT drugs but they all had the same effect. In the end, I took myself off the treatment.

At the time of me giving up my horses, I met a young man with 2 Weimaraner dogs. He has become my best friend, in fact he gave me both his dogs, they became the foundation of my show kennel. He helped me through a very traumatic part of my life, for which I will be forever in his debt.

Early this year, I saw an endocrinologist, Dr Gerry Conway. If only I had seen him, or someone like him years ago. I asked him if he thought I would have been better if I had taken Testosterone replacement therapy, as I always felt I should have been male, and I know that having the gonadectomy upset my bodies balance in more ways than I care to mention. I tried this treatment, but unfortunately it has not had the effect I would have desired. It seems so unfair, having the gonadectomy has feminised me. I wish I had not gone through with it. I wish that it would have been possible to have had a sex change, but the CAIS condition means that would not have worked either. I settle now for being intersexed. Nothing can change that, I get very depressed at times, but the good thing is I have some wonderful dogs, my own business, and my health.

Also this last year, I found this group via the internet. All of us are the same, yet all different. We have all had similar experiences, some of which have been awful. I am so proud and privileged to be part of this group, I know that I have a long way to go, but I also know I have come on a long way. I hope my story can be a help to anyone who feels the way do.

If I had my time again, I would most certainly have refused the gonadectomy, and taken my chances on the cancer possibility. There is no doubt that I have come through this a different person, but now that I have found the friendship of the AIS group, I am on the way to becoming a stronger person.

Sorry for what we did. Can we do anything to help?

By Tony Briffa

Every Good Friday for as long as I remember, the Royal Children's Hospital (RCH) Melbourne has conducted a community appeal for donations. This appeal is widely supported, with volunteers collecting money at street corners, businesses conducting their own RCH fundraisers, and radio and television shows devoted entirely to showing how much work the RCH do in improving and saving the lives of many children.

This is one of the most depressing days of the year for me.

I look at the many lives the RCH have helped, and I wonder what happened. Why is it that they have helped so many children and yet they treated my family and I so badly? I wonder why I have never received an apology from the RCH or the doctors that "treated" me, or an offer to help undo what they did to me without my consent.

I also wonder why they refused to help me become my real self when I began asking for help at the age of 12. That's when I finally told doctors I wasn't a girl.

Why did they shift my healthy testes into my groin when I was a baby? Why did they perform genital surgeries on me? Why did they remove my testes when my phallus grew bigger than they liked? Why did they give me oestrogen? Why did they make me look like a girl? Why did they give me breasts? Why did they deliberately stunt my growth? Why did they ignore me when I told them I wasn't a girl? Why did they refuse to give me testosterone for 18 years?

I try to put my feelings for the RCH aside, but on Good Friday my emotions are a little too raw. I know the RCH is a wonderful hospital and they save many lives. I know they improve the lives of many children with a large variety of conditions. I also suspect they probably did what they thought was best at the time, but why not acknowledge a mistake and offer to help undo it? Why continue to lie about possible outcomes of testosterone treatment and refuse to give me the treatment that will enable me to be what I would have been without their unnecessary medical intervention?

All I want to hear from the RCH is "Sorry for what we did. Can I do anything to help?"

"I'll lean on you and you lean on me and we'll be okay."

Sexuality and Relationships

By Sandra Perrin

Each person's experience of AIS is different but there are probably very few of us who don't feel their sexuality isn't affected by it in some way. It's very difficult not to feel some degree of insecurity about your sexuality when your reproductive organs and/or genitals are different from the norm.

For me with CAIS, having a short vagina and no female reproductive organs has been difficult, more psychologically than physically. For those with PAIS it may have been the appearance of their genitals or for others scars left by surgery that create feelings of inadequacy or insecurity. Whatever the degree of AIS there is sure to be at least one thing that sticks in our minds as being a point of fear and trepidation, particularly when sexual contact with another person is anticipated. To live with this fear can severely hamper our ability to enter into intimacy with someone and to feel confident of our worthiness to be loved, especially during the difficult adolescent years.

I feel at times afraid that I am not good enough for a relationship, that I will just do whatever I think will please the person I am with, and feel panicky at the first sign of them being ambivalent or not so interested. It's as though I feel I have to be twice as beautiful or twice as attentive and caring to make up for the feeling of inadequacy in my own femaleness.

Learning to express our sexuality confidently is probably one of the most difficult challenges AIS people face. No matter how many times a lover or partner may tell us that our physical attributes don't matter and that we attractive and sexy as we are, there is often a nagging doubt deep inside that tells us that it does matter…we're not quite right somehow, no matter how physically attractive we may be.

As a teenager I badly wanted to have a normal female body. I didn't understand why my vagina was the way it was, and was fearful that I wouldn't be able to have intercourse, or even more scary that if I could it wouldn't be satisfying for the man I was with. I worried that I might feel rejected or humiliated if things didn't go well. Time has shown me that I needn't have worried so much…my vagina did stretch and men I've had sex with seem to have had no problems. The insecurity is still there, however, and colours any potential relationships that come my way.

I guess it is up to each of us to recognise these feelings in ourselves and find our own way towards healing them in whatever way we feel is right for us. I've had much success with this by doing something as simple as buying some sexy lingerie! It helped me to express my feminine side and to feel more comfortable with looking attractive. It was a big self-esteem boost! I've begun to trust my own attractiveness as a woman and am learning to let myself be vulnerable without compromising my own feelings and boundaries. I'm also letting myself acknowledge my sexual desire more often and be more confident in expressing that.

For AIS people, our awareness of our own difference may at times lead us to try too hard to impress a prospective partner or to not really just be ourselves. If you're not comfortable with who you are it's unlikely you're going to want to reveal yourself to someone else. But with a gradual build-up of trust and shared experiences it's possible to feel comfortable and secure enough with someone to be able to discover intimacy and love….at least I hope so!

So to those of you who, like me, are still single and really don't want to be, don't give up hope! There are plenty of others feeling similar to yourselves…lonely and fed up with dealing with everything on their own. An intimate relationship with someone might be scary when you have to tell them things about yourself that may be confronting for them to hear, but from my own experience people are usually much more open-minded and supportive than I expect them to be. Telling your partner about your AIS can be an opportunity for both of you to come closer together and be a source of strength in your relationship. If you make a commitment to support and protect yourself in the best way you can, you can't fail to win!

ABC Radio Discusses Intersex.

ABC radio recently braodcast a discussion on intersex conditions titled "Boy or girl?" on Monday 25th February, 2002. The interviewer was Rae Fry, and the panel included Gynaecologist Sonia Grover, Endocrinologist Assoc. Prof. Garry Warne and Researcher Prof. Milton Diamond. In fairness to those medical professionals who took part, it is my understanding that the interviews for the programme were conducted some time ago and so some of their points of view may now be different.

The programme looked at a variety of intersex conditions and the issue of the gender of rearing in children with intersex conditions and the many ethical questions this raises.

Garry Warne describes the typical situation where he is called shortly after a child has been born with atypical genitalia. I might be called to a maternity hospital where a baby has been born, and no-one in the room is able to tell what the sex is, so that the penis might be too small to be really called a penis, there might be a cleft but not one that would be typical for a girl, the urinary opening might be in the wrong place for either a boy or a girl, and perhaps we can feel either no testes at all, or perhaps one testis."

Assoc. Prof. Warne also details one woman's experience of when her child was born with an intersex condition. "I remember hearing a story from one young woman, she was a single mother, the baby was born in a country hospital, and first of all they took the baby out of the room and didn't say anything to the mother about why they were whisking the baby away. So she was left there, thinking the worst, and then later on, some hours later, a doctor came back and tried to explain to her what was wrong and the doctor burst into tears because he didn't have the words for it. The mother actually felt compassion for the doctor, because at least, you know, the doctor was able to appreciate the difficulty of the situation so that she wasn't angry about that. But subsequently, a nurse brought the baby to the mother and she was relieved to find that it was only a genital problem, because she'd begun to think that either the baby had died or it had something dreadful like a cerebral haemorrhage and would be handicapped forever. So she was relieved to learn that it was only a problem of ambiguous genitalia."

"These are cosmetic surgeries, they're not medically needed."

- Professor Milton Diamond

The program then went on to discuss the surgical reinforcement of the gender assigned to a child with atypical genitalia, and the urgency with which the surgery is done. Milton Diamond, a Professor of Anatomy and Reproductive Biology at the University of Hawaii, said "These are cosmetic surgeries, they're not medically needed. Now those who do it say, 'Well yes, it is medically needed because the parents are quite disturbed or the child will feel bad growing up with ambiguous genitalia.' Well, my comments to that are first, it's the individual that has to live with those genitals then he or she may not like what's been constructed for them, and that's what happens. These people, when they become adults, complain that they've had their genitals restructured in ways that they don't approve of."

The discussion then turns to Gynaecologist Sonia Grover, who details the anatomical success of infant genital surgeries, and explains the good surgical outcomes of surgeries performed at the Royal Children's Hospital on women she treats.

The issue of whether or not the surgery had been consented to by the child, or whether the child is being raised in the correct sex is briefly mentioned later in a comment those with intersex conditions who were raised in the wrong gender would find highly offensive. "Well of the few that we've made the wrong gender assignment to, could we have retrieved that situation earlier, but how different is the rate of that occurring to transgender, transsexual issues occurring in the rest of the population?" The comparison between those of us who, as children, were surgically and hormonally assigned a gender of rearing without consent, and those who are transgender/transsexual is grossly unfair, inaccurate and offensive. It may also lead to medical professionals feeling they have an "out" if the gender of rearing of an intersex child and the usual surgical and hormonal reinforcement is wrong. Some, like our Medical Liaison Officer, would also argue that there is a much higher prevalence statistically speaking of those with intersex conditions who have some question about their gender identity than those in the general community such as transsexuals.

Also, it is hard to argue the case for transsexuality as against incorrect assignment in childhood for a child born with male chromosomes, that has descended testes, has good response to androgens, repeatedly questions their gender assignment as female as a child, and who subsequently later asserts their male gender by living full time as male.

Dr Sonia Grover then went on to discuss the issue of repeated unnecessary genital examinations and body image.

"I have to think very hard about what we're doing. And one of the difficulties in this is that this surgery is so variable, and I'm looking at outcomes of John's [Dr John Hutson, Paediatric Surgeon at the Royal Childrens Hospital Melbourne] surgery and saying, 'Well I think I'm seeing good outcomes'. And then I also know that there are other substantial factors that influence outcome. If you have had during your medical visits to hospital through your childhood, and it doesn't happen now, but it did happen 25, 30 years ago [I personally experienced these repeated unnecessary examinations at the RCH 16 years ago], as standard practice, the repeated looking occurred and sometimes repeated examinations of genital areas. Now that can't have a good impact on a young girl who's developing and in fact I've had some of my young women who are now in their early 20s who've said to me, 'Look, having sex is a bit like having a medical examination. You lie there with your legs open.' Now if they've got such clear recollections of uncomfortable experiences, and that may not be uncomfortable physically but emotionally uncomfortable, that is going to have a lousy impact on how they're going to function down the track. So when we say the outcomes of surgery elsewhere haven't been good, it's not just surgery we're talking about, we're talking about surgery and what happened to all those consultations over the years. So it's not just an anatomical outcome we're talking about. If you feel lousy about your body, if you're convinced your body is abnormal, then you' re not going to be relaxed when you're having intercourse, and if you're not relaxed and comfortable with yourself, you don't get aroused, you don't lubricate, it'll be dry and therefore it will be painful. So was it the surgery that made it painful, or was it the fact that the whole

thing was too scary and terrifying, that you didn't have a good experience sexually."

"I've had some of my young women who are now in their early 20s who've said to me, 'Look, having sex is a bit like having a medical examination. You lie there with your legs open.'"

- Dr Sonia Grover, Gynaecologist

Dr Sonia Grover also raised the issue of gonadectomies in women with AIS. "**There's room for debate about the women who have got androgen insensitivity syndrome. The risk of those gonads, those testes, becoming malignant, is far, far lower, so the need to remove the gonads in that group is not as urgent."** She also suggested that gonadectomies should be performed after adolesence because of the difficulties in getting teenagers to take hormone therapy. "They don't take their medications, because it's part of growing up, being dependent, rebelling. So for people with Androgen Insensitivity Syndrome who've had their gonads removed at an early age, we need to make sure that they're taking their hormones during their adolescent years, and it's a very critical time, because during your adolescent years, is when you're making your bones strong, and if you don't have oestrogens around at that time, then you end up with osteoporotic bones."

This ABC interview was another case of intersex conditions being openly discussed in the media, and another opportunity to educate the general community on our issues. Associate Prof. Garry Warne, Dr Sonia Grover and Prof. Milton Diamond should be congratulated on participating in this discussion so openly.

The transcript of the interview can be found on the ABC website at:

http://www.abc.net.au/rn/talks/8.30/helthrpt/stories/s490535.htm

The Weekend Australian Hidden Genders .

The Weekend Australian magazine supplement to The Weekend Australian newspaper, 8-9 December, 2001.
GPO Box 4245 Sydney NSW 2001 Australia
By Christine Toomey

Imagine if you'd grown up thinking you were female and discovered at 20 that, genetically, you were a man. Imagine you are a happily married man of 29, whose only problem is that your wife is failing to conceive, and that tests reveal the problem lies with you – your genes are 100 per cent female. Or you discover your parents had been advised by doctors never to tell you there had been doubts about your gender, or that surgeons operated on you and did not tell you the real reason for the surgery. These people were born with a medical condition called intersex, and their stories are not as unusual as you might suppose. The large brown envelope that made sense of Melissa's troubled past arrived in the post shortly after her 18th birthday.

Melissa took the package to the privacy of her bedroom before breaking the seat on information she hoped would explain the feelings of shame and secrecy that had dominated her childhood, and the reasons for the repeated gynaecological surgery she had endured. She was shocked and angered by what she read.

As Melissa was growing up, she had been told that she suffered from a rare metabolic disorder that caused her body to lose excessive amounts of salt and led to her being placed on medication she would need for the rest of her life.

She knew she had been a small, sickly baby who had not been expected to survive. She knew the condition she was born with was called congenital adrenal hyperplasia (CAH). What she was not told, but discovered from the information sent to her, was that CAH is an "intersex" condition. She had been born of mixed gender, with ambiguous-looking genitalia, neither wholly female nor male.

"I was told as I was growing up that something was 'not quite right down there'. But I was also told not to ask too many questions. I thought it must be something horrible," recalls Melissa, now 33 and living in Britain. "My mother just told me that I should always use a cubicle to change at school and that nobody but a doctor was ever allowed to touch me."

When Melissa confronted her mother and asked her why she had never been told the truth, 'She said she thought the truth would upset me,' says Melissa. "She told me for the first time that doctors had thought I was a boy when I was born, and that she and my father had named me Nicholas."

But when doctors pumped dye through her genital tract when she was three weeks old, they discovered Melissa had a womb and ovaries. "My parents were told I was a girl after all, but that I would need surgery to 'normalise' things. **I was devastated. Not that I was intersex, but that I had been lied to."**

After requesting her medical records, Melissa discovered that the operations she had undergone as a baby, and later at the ages of four, 12 and 14, involved a complete removal of the clitoris – hers was considered too large. She also underwent extensive reconstruction of her vagina. "The outcome," she says, "was a mess."

Those born with intersex conditions are often referred to, incorrectly, as hermaphrodites. True hermaphrodites (people born with both sets of genitalia) are comparatively rare. Intersex covers a much wider spectrum of medical conditions, including chromosomal abnormalities in which a person's genitals do not match the chromosomes, or do not conform to male or female norms.

According to some estimates, as many as one in 2000 babies is born with one of these conditions. If accurate, this means that more babies are born intersex than are born with cystic fibrosis, the incidence of which is one in 2500.

Some doctors prefer a stricter definition of the term, so argue that this figure is exaggerated. Others believe it is a conservative estimate, arguing that the condition may go undetected or unreported because of its delicate nature. Beyond doubt, however, is the culture of shame. In the past, and sometimes still today, doctors have preferred to draw a veil of secrecy around the treatment given to people with intersex

conditions, on the grounds that the truth would be too traumatic for the patient.

In Britain, it is “still regular practice in some units not to tell patients their diagnosis”, according to Sarah Creighton, a consultant gynaecologist at University College London Hospitals (UCLH), who specialises in the treatment of intersex patients.

“I see many letters sent from consultants to GPs – particularly concerning the treatment of women – saying, 'She is fine. She does not know her diagnosis and I do not feel it is appropriate for her to learn it, as it would be devastating' ."

Treatment of intersex conditions in Australia is, by comparison, enlightened, according to the medical community, and regarded as progressive by world standards. Professor Garry Warne, paediatric endocrinologist at Melbourne's Royal Children's Hospital, says full disclosure to patients is the norm. “If you asked all paediatric endocrinologists in Australia, I don't think you'd find one that would defend non-disclosure of intersex conditions,” he says. “Since at least 1985, this has been the case.” Growing pressure from patients who believe their lives have been ruined by surgery performed without their consent may change medical practices around the world. Angry patients have called for a moratorium on early intervention surgery.

The only circumstances in which early genital surgery should be performed, they argue, is if a condition leads to medical complications – undescended testes can, for instance, cause hernias, and testicular tissue can, in some intersex patients, become cancerous. Intersex individuals – and a growing number of doctors who treat them – argue that those born with such conditions should be allowed to decide which gender they most identify with when they mature. This has made intersex management the focus of heated debate. The British Association of Paediatric Surgeons recently set up a working party to look at new guidelines for the treatment of babies born with intersex conditions, and is expected to advise against early genital surgery.

An Australian study, soon to be launched by Warne, will collate the experiences of every intersex patient to have sought treatment at Melbourne's Royal Children's Hospital and learn from the outcome. “We don't believe there are very many patients who have experienced a poor outcome as a result of early surgery,” he says. “But we could be mistaken, and we're prepared to wear that if it's the case and completely revise our policies.”

Some of the controversy surrounding treatment is about what constitutes aesthetically acceptable genitalia. “Part of this debate is about how we can balance the rights of the individual against the pressures that will be brought to bear on that individual because of their appearance,” says British endocrinologist Peter Hindmarsh. “Medicine does not usually accept the views of society if they are in conflict with the needs of the individual. But we seem to need a categorical statement about a person's sexuality. Anything to do with sexuality and the propagation of the species touches on a very deep nerve.”

Sexuality and gender are so fundamental to our lives that some believe that if the distinction between male and female is called into question, society will be thrown into confusion.

Such attitudes start at birth when parents ask: 'Boy or girl?' If there is no clear answer, the medical establishment sets out to create one. When an intersex baby is born in Australia, surgeons, geneticists, endocrinologists and clinical psychologists form a team to decide, usually within days, what sex the child is to be designated.

The parents, says Warne, are provided with information and all the options that they could consider, including that of the body of advocacy for leaving the condition untreated for the time being. **“If a family did choose that option, we would fully support them, and we would have to bring in a lot of extra supports to make sure that it was in the best interests of the child, particularly psychologically, in the longer term. But, personally, based on the experience I've had with children who have been allowed to grow up with ambiguous genitalia, I'm not convinced that that is always the right option.”** The traditional medical response has been based on the assumption that normality is essential for parental and social acceptance, and happiness. Such thinking is rooted in a history that has often been cruel to people born of ambiguous sex. The Romans put them to death to pacify the gods. The Victorians treated some as circus freaks, others as mentally ill.

In some Eastern and Caribbean cultures, however, they are revered as expressions of divine will. The arts have traditionally cloaked ambiguous sexuality with the Greek myth of Hermaphroditus, son of Hermes and Aphrodite. The nymph of the fountain of Salmacis considered him so beautiful that she begged the gods to merge her body with his, thus a being, half-man, half-woman, was born.

But in the West since the 1950s, the standard medical procedure for treating a child born with ambiguous genitalia has been to assign a gender quickly and perform whatever surgery is necessary to ensure as close as possible conformity to a norm. The criterion used is that if an infant's sexual anatomy protrudes away from the body by more than 2.5cm, the baby is considered male; if the protrusion is under 1cm, the baby is female. In cases that fall between these criteria, surgery is recommended, and babies are usually rendered female using the crude logic that, as described in one medical journal, 'it is easier to dig a hole than build a pole'.

The practice of assigning female sex to boys with small penises was pioneered in the United States in the 1960s by a psychology professor, John Money, who argued that nurture was more important than nature and that gender was so malleable in infancy that a male consistently raised as a girl would adapt well to life as a female.

He based his theory on the study of a highly publicised case of a boy whose penis was destroyed in a botched circumcision. The child was given rudimentary female genitals, renamed Brenda and subsequently raised, successfully, Money argued, as a girl. His thesis fell into disrepute when Brenda reached the age of 15 and threatened suicide if doctors refused to reverse the sex change surgery and prescribe him male hormones. He had always felt he was a boy, he told doctors. He is now married and a stepfather to three children. Since then, a growing number of doctors world-wide have begun delaying surgery until people are old enough to have a say in which gender they are assigned. In some instances, they argue surgery is not necessary. Support groups for those with intersex conditions believe there should be a network of specialist clinics offering advice on surgery and counselling.

Parents should be offered contact with a support group as soon as their intersex child is born, says Tony Briffa, president of the AIS (androgen insensitivity syndrome) Australia support group [website details were published at the end of the article - Ed] .

"We had an example where a child was born with an intersex condition and a cleft palate," he says. "The cleft palate support group was contacted straight away, and a representative came to the hospital to talk through the problem and discuss the parents' options with them. The intersex condition was left to the parents to deal with alone." Sue Elford, who chairs a support group for those with CAH in Britain, believes parents too often come under pressure from doctors to allow surgery to be carried out on their child. "If parents know they have the option to leave things alone and see how the child matures, a lot more would feel comfortable with this.

The culture of secrecy that surrounds intersex means that those not directly affected usually know very little about it. "People often confuse those with intersex conditions with transsexuals, which they are not at all," says Sarah Creighton. "Transsexuals are people who feel they should have been a male or a female but have no genetic or anatomical problem at all, whereas intersex people have medical problems caused by a mismatch in their genetic make-up."

Such confusion and prejudice means that those who do reveal they are intersex risk humiliation and discrimination; some report being beaten up, others have lost their jobs. "A common misconception people have when they hear about intersex is to think it means someone has something freakish or deviant about their sexuality," says Catherine Minto, a clinical research fellow at UCLH. "The more people know about what it means, the less they will react badly." Melissa is optimistic that society is slowly becoming more tolerant. She is hopeful of finding a partner and one day starting a family: "I grew up thinking I'd never be able to have children. Now I know that, with help, I might be fertile." The irony is that she sounds masculine. Melissa admits that her gruff voice has sometimes led others to make fun of her, and that her experiences as a child led to many problems as she was growing up. "I was very shy. I'd rarely go out. I always felt out of place. Because of all the operations I had as a child, I could not bear to be touched for a long time. But I have always liked men.

I have had a partner and a sex life." (Although she describes that experience as "atrocious".) "I just want a life," she says. "I do not feel as if I have had a life yet." Anna, 44, is sceptical of society becoming more tolerant. On the one occasion she explained her medical condition to an employer in Britain, she was met with extreme suspicion. "I was told that if I had been honest about my condition when I applied for the job, I would never have been taken on. After that, I leant to shut up." Anna was never told the truth about her condition or the real reason she underwent surgery at the age of 20. Years later she leant she was born with XY chromosomes, meaning she is genetically male. Anna discovered in medical journals that she had a rare genetic disorder called androgen insensitivity syndrome, also classed as an intersex condition. The lumps doctors removed when she was 20 were undescended testes. She has a feminine voice. She keeps her greying, curly hair short and swept back in a hair band. She never wears a skirt or dress. On the day we meet, she is dressed in jeans and a sweatshirt. She does not look masculine. She says she does not regard herself as either male or female but, rather, 'mixed gender', and has ended to avoid close relationships. "Society likes to categorise you, and I do not fit neatly with people's expectations. I just deal with it myself. I rarely talk about it." She then adds quietly, as if talking to herself. "It is like being continually punished for a crime I never committed."

Inquiry into the Protection of Human Genetic Information.

The Australian Law Reform Commission (ALRC) is conducting an inquiry on behalf of the Commonwealth regarding the protection and use of human genetic information. As a group with genetic variations, this has many important implications for people living with intersex conditions for current and future generations. We urge all members to participate in the community consultations, and to submit private comments to the ALRC.

The ALRC's website is located at http://www.alrc.gov.au .

The full submission by the AISSGA is available on our website.

Statement of the British Association of Paediatric Surgeons

The British Association of Paediatric Surgeons (BAPS) "Working Party on the Surgical Management of Children Born with Ambiguous Genitalia" released a statement last July following consultations with a number of intersex advocacy groups and understanding medical professionals like Miss Sarah Creighton. Their statement acknowledged the difficulties and controversial aspects of treating children with intersex conditions, but didn't hide from the fact that they are learning and willing to work with support groups to establish better treatment guidelines.

The BAPS "unreservedly recommend" a holistic approach in treating children with intersex conditions, including psychological support for the child/adolescent and their family which is integrated with medical input, easily accessible at the time of need and provided by, or in consultation with, a specialised service. They also stated "while there is likely to be continuing pressure from parents for early corrective surgery, fully informed consent for such procedures would require them to be aware of the possibility of non-operative management with psychological support for the child and family".

The issue of the timing of gonadectomies for people with CAIS is discussed in this paper:

"In relation to malignant change a comprehensive review in 1987 quantified the risk at 2-5% in CAIS patients over 25 years of age, and the risk was deemed 'small' prior to that age. [1] In a study of 17 post-pubertal CAIS patients from Venezuela no malignant change was found. [2] "

This evidence adds support to the AISSGA's position in recommending that gonadectomies be delayed because of better bone mineral density development, better self-esteem and body image, a more natural puberty, problems with compliance with regular hormone therapy and additionally gives the individual the

[1] Verp, MS, Simpson, JL. Abnormal sexual differentiation and neoplasia. *Canc Genet Cytogenet*, vol 25, 1987, p 191-218.
[2] Alvarez-Nava, F, Gonzalez, S, Soto, M, Martinez, C. Prieto, M. Complete androgen insensitivity syndrome: clinical and anatomopathological findings in 23 patients. *Genet Counselling*, vol 8, 1997, p 7-12.

right to decide treatment options for themselves. We also recommend that gonadal health be monitored yearly post puberty.

Cryopreservation of gonadal tissue with the view of utilising possible future fertility treatments was mentioned in the statement, which is very encouraging for those of us wanting to have our own biological children. The possibility of new technology enabling intersex individuals to have biological children is another important factor to consider prior to gonadectomy.

This article is another good example of the medical profession moving away from their traditional model of treatment of children with intersex conditions and working collaboratively with support groups to establish more holistic, humane and sensible approach. Congratulations to the AIS Support Group (UK) for their wonderful work.

The full statement is available on the internet at: http://www.baps.org.uk/documents/Intersex%20statement.htm

Should the Family Court approve surgeries on children with intersex conditions?

By Tony Briffa

An article written by Dr Sonia Grover and published in the February 2002 Medical Journal of Australia (Vol 176, Number 3) discussed the issue of menstrual and contraceptive management in women with intellectual disabilities. Although this is not directly relevant to children with intersex conditions, I was interested in the level of legal protection some with intellectual disabilities rightly have to their physical integrity.

When a young woman with an intellectual disability has problems with heavy or irregular bleeding which affects her quality of life, doctors must first obtain the authority of the Family Court of Australia if their recommended treatment involves irreversible procedures such as hysterectomy. Further, "surgical options were considered only after all other approaches, including education, support and medical treatments, had failed." As a consequence, of the 107 patients seen by the author over the years 1990 to 1999, only two had surgical intervention.

The requirement for the Family Court of Australia to approve these surgeries is a direct result of the judgment of the High Court of Australia in "Marion's Case", which found that a disabled person had a presumption of the right to physical integrity. Given that some people with intellectual disabilities are considered unable to give legal consent to these irreversible procedures, doctors must seek authority from the Family Court who will make that decision on their behalf.

I believe there are similar quality of life and human rights issues that warrant children with intersex conditions being afforded the same legal protection. Children with intersex conditions have no less a right to their physical integrity. Where a child with an intersex condition is too young to give consent to irreversible surgeries, some of which may render them infertile (particularly given the rate of improvement in assisted reproductive technologies), a decision made by the Family Court would best consider representation and outcomes for all parties and ensure that full disclosure of options is made. Involvement by the Family Court may also ensure that doctors are more willing to consider alternatives to surgical intervention, such as support and counselling, rather than opting for a scalpel as a first option and may further provide a degree of legal protection for all parties that currently does not exist.

Osteoporosis

By Tony Briffa

Osteoporosis is a significant concern for everyone with AIS, particularly for those who have had an orchidectomy (surgical removal of the testes) and have not been compliant with hormone replacement therapy (whether that be oestrogen or testosterone, or both).

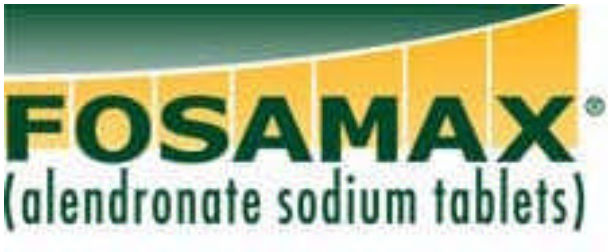
Osteoporosis is caused by a change in the body's bone-building cycle. Bone is usually constantly renewed through a process that removes old bone and replaces it with new bone. Osteoporosis occurs when the body removes bone faster than it replaces it, making the bones porous like a sponge. This makes the bone much easier to break. Osteoporosis is also sometimes referred to as low bone mineral density.

There are a number of things people can do to improve their bone mineral density:

- Calcium – Slows bone loss, although doesn't build it up. Recommended daily intake is between 1000 - 1200mg. Dairy foods are a good source, but supplements are an alternative. (Seek medical advice though, because calcium supplements should not be given to people with various medical conditions like kidney disease).
- Physical Activity – Builds and maintains strong bones, particularly weight-bearing exercise.
- Quit Smoking – Smoking is known to negatively impact bone mineral density.
- Hormone Replacement Therapy – prevents bone loss, may increase bone mineral density and reduces the risk of fracture.
- Vitamin D – helps the calcium being used to slow bone loss. (Some forms may also help the body absorb more calcium from food. e.g. calcitriol)
- Bisphosphonates – (like alendronate sodium & etidronate disodium). Decreases the amount of bone loss and increases the amount of bone growth.

Fosomax (alendronate sodium, MSD) is available on the Pharmaceutical Benefits Scheme (PBS), but only for those who have already had a bone fracture due to osteoporosis. It is the AISSGA's hope that people with AIS have access to this medicine under the PBS regardless of fracture history because of the prevalence of osteoporosis in people with AIS. We suggest that medicine like Fosomax be PBS approved for people with absent/removed gonads and a medically indicated low bone mineral density. Any help and support from medical professionals in making Fosomax and hormone replacement therapy available to people with intersex conditions through the PBS would be appreciated.

There is an osteoporosis & Fosomax infoline in Australia that operates during weekdays between 9 am to 5 pm eastern standard time. Their contact number is 1800 062 844. Please call them if you require further information about osteoporosis and/or Fosomax.



Understanding your Bone Mineral Density results.

By Andie Hider

I was thinking of calling this article "Statistics For Dummies", but two things occurred to me; one was that the publishers of a certain series of computer books of similar title might object, the second was that I have yet to meet someone with AIS or any similar condition that is a dummy.

The idea of this quick article is not to be a comprehensive lesson about statistical information and it's use (or misuse), but rather something brief that will allow people in the support group some better understanding of their Bone Mineral Density (BMD) results.

We will start with the assumption that you have organised to have your BMD checked through your GP or an appropriate specialist. You will (of course!) have arranged to have this done on the same machine in the same clinic you did last time, to ensure that the results have a consistent base line, that is, you are comparing apples with apples. There can be quite a degree of variation of results for the same person if the tests are conducted on different machines. It is not always possible to ensure you have all tests done on the same machine, but where you can it is worth trying to do so. Generally speaking, where testing for BMD is medically indicated (such as in the case of AIS) I would advise having it checked once a year. Some specialists would agree with this, some would say every two years but I personally think two years is too long between tests. A lot can happen in two years if things are not as they should be. For those that have yet to have their BMD tested, the process is painless and just like an X-Ray that takes a bit longer to finish. In the case of AIS, where BMD issues are medically indicated, you are entitled to a Medicare/Private insurance rebate for most of the cost of the procedure.

You (or your GP/specialist) will now have a document that gives you the results of the BMD test and the fun starts. The results are commonly expressed in one of two ways, either as a percentage of the mean or as standard deviations above or below the mean.

The mean is simply the average for a particular group, in the case of BMD it will be somewhere on a scale between the worst BMD result for a particular group tested and the best BMD result for that particular group. It is not necessarily the case that it will be half way between, if there are more results of tests near the top of the scale then the mean (average) will be closer to the top of the scale. Most commonly in the case of BMD, gender and age groups are the groups used to categorise results, as generally speaking there is a consistent age/gender related pattern to the development of peak BMD and BMD decline later in life. Your results will be compared with women of the same age if you are a woman and with men of the same age if you are a man. So far so good.

If your results are expressed as a percentage, then you will get something like 90%, 100%, 110%. Right now you are thinking "she is full of it, you can't have 110% of anything". Mostly that is true, but we are talking a percentage of an average here. You can have above average BMD for someone of your age and gender, so in the case of 110% this simply means your BMD is about 10% above average for your age and gender group.

Standard deviations are a little more complex, in fact I don't know why certain testing laboratories persist in using standard deviations to record BMD results. When we gather information about a particular population the results form a scale or range either side of the mean (average). Some results will be above the mean, some will be the same as the mean and some will be below the mean. If we divide the "above" range and the "below" range into thirds, each third is what is called a standard deviation and of course we have six of them, three in the range above the mean and three in the range below the mean.

Just to confuse the issue there is not a sixth of the results in each standard deviation. Because most people will be near the mean (whether that be average height, weight or BMD), the further you get away from the mean the less people there are that have those results. Generally speaking, 66% of the population will be within one standard deviation below the mean and one standard deviation above the mean (33% below, 33% above). About 98% of the population will be within two standard deviations below the mean and two standard deviations above the mean (49% below, 49% above). All this means is that most people will either be within the first standard deviation above the mean and the first standard deviation below the mean, most of the rest in the second standard deviation above the mean or the second standard deviation below the mean and a very few people will be in the third standard deviations, the last one above and the last one below.

When your doctor tells you that your results are half a standard deviation above the mean, this simply means somewhere above average in the range most others in the population score. Likewise, if you are told you are one and a half standard deviations below the mean, then you are outside the most common range of results, but still within the results of 98 percent of the population as a whole. If your results are anywhere outside the range of two standard deviations above or below the mean, then you are in a very small two percent of people with those results, but still within results recorded for the whole population.

One quick comment about low BMD results (there is more detail later for those that are interested or inclined). Statistical information is gathered in such a way that results expressed as standard deviations can be a bit misleading. If you fall into the category of being two or even three standard deviations below the norm, it is not as low as you think. There is still reason to take steps to try and maintain your BMD though because as the BMD

results of the general population get lower, yours will be getting closer to the average for your age/gender group.

All of this should get you by as a rough guide to interpreting your results, for those wanting to further refine their understanding, read on.

When statistical information about any topic is gathered using a reliable technique, there will always be results that don't seem to make sense because they are so different to most of the other results. This may be because of the way the information has been gathered, it may be because in some cases there is no way to consistently get certain types of information or it may be because the information came as a mistake from a group outside that being studied. Were these very different results to be included, they would make the other results obtained a less than accurate representation of the true picture. It is common practice to take out a percentage of the results that are very different to the rest. This leaves us with a range of results above the mean and a range of results below the mean that should be fairly accurate.

What this does mean though is that the population I mentioned earlier is not a complete record of all samples or answers given, but rather a sample population based on results or answers that fall within what are believed to be the most accurate range of answers. This has the effect of "normalising" the sample population, in practice of course there is no such thing as a "normal" population.

As a case in point, there is much anecdotal evidence about BMD problems in those with AIS, sometimes with BMD results that are within or even below that third standard deviation below the mean. Because statistical information is most often gathered in the way I have described above, scores such as those that might be present in AIS might be discounted because they are considered unreliable. In fact, were it understood that these scores have a reasonable basis, they might be included in the overall population. This would have the effect of moving everybody up the scale, perhaps from one and a half standard deviations below the mean, to one standard deviation below the mean (and hence into that most of the population range) or from the third to the second standard deviation below the mean and into scores that still represent most of the population. Ideally there would be a set of BMD results using a group of people with AIS as a test population so that accurate comparisons could be made, since no such results exist to my knowledge be careful to take this into account when you interpret your results.

As explained earlier, this doesn't mean you should be complacent about a low BMD result though, exercise and HRT have been shown to benefit BMD and Fosomax is another alternative suitable in some cases. As you get older, if you maintain your BMD at the same level, your BMD will get closer to the average BMD range of the general population. Ideally your BMD should fall within that average range of one standard deviation above or below the norm, but again make sure you remember how these standard deviations are arrived at.

Statistical information is a universally accepted way of recording results, but it does have the potential to be misunderstood. For those that are interested in learning more about statistics, I can arrange to send out "plain language" statistics explanations that are very good.

DHT for Men with AIS.

By Andie Hider

Most people with AIS understand that cellular response to androgens is affected by the condition. Many with AIS will also understand to a greater or lesser degree, the feedback loops within the human body that control production of testosterone and why it is regulated this way. There has been some discussion amongst support group members both male and female, and by some parents of affected children about the possible benefits of dihydrotestosterone (DHT) treatment for males with AIS. I hope this article will explain sufficiently some of the basic concepts of the way hormones work in the human body and why it is that DHT may be of benefit. I say may be of benefit for two reasons, firstly because limited trials on some individuals have shown promising results, and secondly because most endocrinologists that the support group President and I have spoken with about DHT agree that in theory, DHT is likely to have the best chance of working on someone with androgen receptor variations.

I apologise in advance to those people who already understand the principles outlined in the biology lesson below, but I wanted to ensure everyone had a good understanding of some basic principles before discussing the possible benefits of DHT treatment.

The human body is made up of millions of cells. Each of these cells has an outer membrane through which some substances may pass to eventually access the nucleus (centre) of the cell. The outer membrane is partly made up of lipids (a group of fats) so hormones that are lipid soluble are able to pass through the outer membrane and gain direct access to the nucleus. Hormones need to bind to a receptor to work. Some receptors are located on the cell membrane (and bind with water soluble hormones that send what are called second messengers to get inside the cell), but the one we are most concerned with here is the androgen receptor, which is located in the nucleus of the cell. Most of you will understand that it is the androgen receptor that is either missing or has some variation in those with AIS and is the receptor that allows a cell to respond to testosterone.

Testosterone is synthesised (converted) from cholesterol by the testes. As testosterone is lipid based it is able to pass through the cell membrane because, as was explained earlier, the cell membrane is also partly made up of lipids. Once the testosterone gets through the membrane it is able to bind with the androgen receptor in the nucleus (what is called an intracellular receptor for those remotely interested), where it then turns on or off particular genes (this is called altering gene expression). Once this takes place, a type of chemical messenger (called RNA - ribonucleic acid) leaves the nucleus of the cell and enters the cell "tissue" (called the cytosol), and causes physical changes to the cell (usually because enzymes direct production of new proteins – "building material"). Response by the cell to certain hormones is controlled by the concentration of the hormone and the number of receptors in the cell (called down-regulation and up-regulation, again for those even remotely interested).

Testosterone produced by the testes can be used by some cells as is, but other cells need testosterone in a further converted form, dihydrotestosterone (DHT). Some testosterone is also converted into oestrogen and this is especially important in the case of AIS. Pre-natally, testosterone stimulates development of the male reproductive system and descent of testes and DHT stimulates development of external male genitalia. Oestrogen has an

important part in development of certain brain structures and development of bone mineral density. Oestrogen is also the principle hormone for female pre-natal development including development of female external genitalia. For males at puberty, testosterone and DHT play an important role in the development of secondary male sexual characteristics, and for women oestrogen again plays the most important role.

Production of testosterone by the testes is regulated by the pituitary gland and the hypothalamus as part of a system that detects the level of testosterone in the body and regulates production accordingly. This testosterone regulatory system is called the brain-testicular axis, and without getting into too much detail suffice to say that a part of the pituitary gland releases a hormone called luteinising hormone that acts on cells in the testes (called endocrinocytes, or interstitial Leydig cells!) that secrete testosterone. In the case of AIS, cells in the body that have a missing or varied androgen receptor include those in the brain-testicular axis so they are unable to accurately detect the amount of testosterone in the body. As a result, testosterone production in people with AIS is generally much higher than is usual.

The level of response to the testosterone produced is what determines development as male or female in those with AIS. As mentioned earlier, some of the testosterone produced is converted to oestrogen. Because production levels of testosterone in people with AIS is usually very high, the amount of testosterone converted to oestrogen is also very high and in the case of very limited response or no response to testosterone (such as CAIS) means the body naturally develops as female because there is still full response to oestrogen whilst response to testosterone is minimal or zero.

In the case of males with PAIS the situation is a little more difficult. Because there is some response to testosterone, some male characteristics develop, but the presence of oestrogen to which there is still full response, means unwanted characteristics such as breast development may occur at puberty.

Giving extra doses of testosterone to a boy or man with PAIS, will inevitably mean that some is converted to oestrogen causing some of the unwanted characteristics described above. This is where treatment with DHT is likely to be of benefit. The DHT has a natural advantage to start with, because it is converted from testosterone and acts on target cells without being able to be converted into oestrogen as is the case with testosterone. Elevated levels of DHT would also effect the operation of the brain-testicular axis so that testosterone produced naturally by the body is reduced, important for boys and men with AIS as it is this naturally produced testosterone that is converted to oestrogen causing negative effects like breast development, which leads to surgical correction including bilateral mastectomies and chest reconstruction.

For those with AIS who have had exposure to DHT treatment, there has not been any significant development of male secondary sexual characteristics, rather the suppression of development of female secondary sexual characteristics which of itself is important as it would mean reduced need for some surgeries. There have been some side effects noted when using DHT. Principally this seems to be nausea which one endocrinologist has attributed to effects on fluid retention by the body. There is also the possibility that use of DHT over time may limit or prevent the body from "kick-starting" natural testosterone production again.

Given the potential theoretical advantages of DHT, resistance seems to be found mainly because of restricted access to the hormone by Government, because of fears of miss-use by some in the body building industry. Because of the very limited application in treating males with AIS, I personally cannot see why strictly controlled approval on a trial basis would not be granted should an endocrinologist consider it an issue worthy of pursuing. **If DHT works in the way many believe it will, then it has to be worth trying for those males with AIS that need something to help them along the way.** This is especially important for those boys with AIS just approaching puberty now or those young males still likely to get any developmental benefit from using DHT.

The Meaning of life

By Andie Hider

For those of you that have laboured through my previous philosophical ramblings, yep you guessed it, here comes another one! After reviewing the contents of dAISy thus far, we were not sure that there was enough in the way of positive material. I had this idea running around in my head (yes, there is plenty of space in there to do it, thanks to all who thought of that!) and I decided to put pen to paper, figuratively speaking of course.

We are not our conditions, whatever condition that may be. As the secretary oblique medical liaison officer, I have written a couple of articles for this issue of dAISy that I hope members (and others) will find of use to them as far as better understanding or management of their condition. Neither article will exactly light fires of passion and leave people waiting with baited breath for the next instalment though. Where is all this going? glad you asked!

A cousin of whom I am very fond, came to stay with me in Melbourne for a weekend last month. Our family has many academics in our midst (gee, you would never guess would you!), but my cousin is just one of those down to earth good people that enjoys some of the simple things in life. While my cousin was here, we had the privilege of being part of something really great. Tony B, who we all love and admire as our esteemed President and friend, brought himself a new car, well kind of new anyway. Next year, Tony's new car will turn 50, a fully restored 1953 MG TF that is one of the most gorgeous things you will ever see (next to Tony himself of course!). Being there when he was handed the keys and watching him drive that car to my place and then home, was a wonderful experience. It was one of those wonderful sunny Melbourne days (yes, we do get them!) that is just perfect for a country drive in a car like that. Even my next door neighbours admired Tony's car. Seeing the grin he has ear to ear every time he drives it, is something no words can ever really describe.

I have also now had the privilege of sitting in the passenger seat of the MG while Tony took me for a beach front drive. It is just so easy to forget everything else and imagine what it must have been like when everybody drove cars that were a little simpler, when life was a little simpler and when we all went out for sunny Sunday walks and chatted with our neighbours. There are many things that progress has brought us that we should be thankful for. Medical treatment is generally better, I can sit down and write this article in half an hour or so in front of my computer, I can chat with someone half way around the world and let them know I

know how they feel and in doing so both of us feel that little bit less alone. We have a support group full of wonderful people who can truly say it is nice to meet other people that share similar experiences. All of these things are things we should be thankful for, but not at the expense of those things in life we can often forget to enjoy.

Living with AIS or a similar condition means we have to take responsibility for our own well being, but we shouldn't forget part of that well being is enjoying the little things in life that we put aside for more "important" things. Those simple pleasures that all too often get buried under responsibilities and the things we have to do, rather than the things we like to do. So go and get that book you have been meaning to read for ages find a nice spot in the sun and start reading, go for a drive somewhere nice, get those plants from the nursery you thought would look great in that little spot in the garden and plant them there. Tony took his dad for a drive in the MG on his birthday and his dad said he felt just like Lindsay Fox. We all deserve to spoil ourselves once in a while, even if it is just taking the time to do one of those little things we like so much.

Letters.

Hi all,

I have just received a copy of dAISy, kindly sent to me by Tony Briffa, who, I would like to thank very much and the team that works with Tony for the work that has been done here.

I found the subjects to be covered in the newsletter in a comprehensive, informative and honest way that was empowering for people like myself whose journey into the intersex world is still unfolding. Through showing a dialogue in which medical professionals were being engaged and so effecting real change it illustrated to me how we can all participate in this process at this level, and signified a way forwards that is assertive and yet not confrontational. A range of personal intersex experience was portrayed in way that was inclusive and positive.

I recommend that everyone has a look and supports this.

Best,

David

Recommended Clinicians

The AISSGA is always willing to work with clinicians from all over the world, and is pleased to forward dAISy to them as soon as it is released. Please contact us if you wish to be put on our distribution list. If anyone has a doctor they think might be interested in receiving dAISy, please ask them to contact us.

Please note that medical professionals are also eligible to join the AISSGA.

Next AISSGA Meeting.

The AISSGA is having a national meeting in Brisbane on May 18 & 19th, 2002. Given the wonderful attendance last year, this will be a meeting not to miss.

Please contact Tony at aissga@iprimus.com.au or (03) 9315 8809 or 0418 398 906 for further details.

You know what I think is great about having AIS?

By Jeanne (posted to AIS People Club)

- We don't have cramps every month, or go through a period (yucko)!
- I don't know about all of you but I never had acne.
- As far as I know, because of our AIS we have soft pretty skin.
- I think we look younger, longer than average people. I have always looked (and acted) younger than my age.
- We have had the opportunity to experience life through the eyes of men and women. We know what its like to be both.
- We can relate to the feelings of anyone.
- We can hang with the boys or enjoy our womanhood.
- We can be great parents rolled into one.
- We can choose to change our gender and no one can question our decision.
- I am strong in body and mind.
- I think we are more creative than others.
- I know we are smarter.
- We are much better at being independent.
- We are much more in tune with our feelings and the feelings of others.
- We don't get flakey.
- We don't get hormonal.
- We won't go through menapause.
- We don't have to worry about ovarian or prostate cancer.
- We can travel anywhere in the world and find a friend.
- I have all of you.

Deadline for next dAISy.

1st August, 2002.