

# dAISy

September 2002 Edition

AIS Support Group Australia's Newsletter

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## AIS Support Group Australia Inc.

PO Box 1089

Altona Meadows

Victoria 3028, Australia

Tel: +61 3 9 315 8809 or 0418 398 906

Email: [aissg@iprimus.com.au](mailto:aissg@iprimus.com.au)

Web: <http://www.vicnet.net.au/~aissg>

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Angelo - Saint Peter's the Vatican, Rome Italy

## President's Message

Welcome to another issue of dAISy. It's remarkable how quickly time seems to go these days, particularly with so many things happening in the support group and with the world at large. Not a week goes by without more people affected by AIS or similar conditions contacting us, we have continued to provide support and information, held another national meeting in Brisbane, continued with community education and consultations with the medical community, and progressed and finalised some long-term projects.

Our information sharing role over the past six months has included some media work (ABC 'Catalyst' program, Good Medicine Magazine and various newspapers), authoring some fact sheets, maintaining our website, organising a seminar with Milton Diamond and responding to misinformation by various individuals and organisations (the Australian Democrats labeling those with intersex conditions as 'transgender' for example).

We are very fortunate to have Professor Milton Diamond presenting a Seminar in Melbourne at the end of October, where he will detail some outcomes of his research on AIS and other intersex conditions. We will summarise his presentation for the meeting in November and publish the summary in the next dAISy for those who are unable to attend. Invitations to the seminar will be sent out separately.

I am pleased to announce our 'Androgen Insensitivity Syndrome and similar conditions' brochure has been completely revised and will be printed by the meeting in November. It is hoped medical professionals will use the brochure to inform newly diagnosed patients and/or families about their condition and the AISSGA. The committee will be distributing these brochures to major hospitals by the end of the year. On behalf of the AISSGA, I would like to thank the Genetic Support Network of Victoria for their special grant which helped funding printing of the brochures.

Undoubtedly the core role of the AISSGA is support for people affected by conditions like AIS. Over the last six months this support has included organising a National AISSGA meeting in Brisbane, telephone and email support, personal meetings and several dinners. I encourage all our State Representatives to organize functions for the members in their State such as get-togethers for dinner at a café, a family BBQ at a park on a weekend, or even just catching up for a coffee. If I can do

anything to help the States organize a function (like emailing all the members in your state etc) please contact me. Some of our Victorian members have met several times this year and it is always a fun night.

I would also like to reassure males with AIS that I am still trying to find a source for DHT. It seems that Dr Bruce Wilson in the USA might be our best chance because he has recently written about the benefits of DHT treatment for men with AIS.

Our next National AISSGA meeting will be held in Melbourne on the weekend of 16 and 17 November. Everyone with AIS or similar conditions and their families are welcome to attend. As usual, we will be having a health care professional afternoon on the Saturday afternoon and possibly the Sunday morning. If anyone has an endocrinologist, gynaecologist, urologist, general practitioner, counsellor, sex therapist or other health professional they would like invited to this session, please contact me with their details.

The meeting in November will also include our Annual General Meeting (AGM) on the Sunday afternoon. Part of the proceedings of the AGM includes our annual elections for office bearers. I urge ALL members to consider nominating for any of the positions on the committee, including the position of President. I also urge as many people as possible to become financial members of the support group, which will help us with future projects.

On a rather more personal front, we have had another wedding in the support group! Graham Hague, our UK Representative who has PAIS, recently married Mindy. We wish them all the best for the future. I would also like to convey my best wishes to Jeanne who is trying to adopt a child from China. I hope she hears something about her special little bundle of joy soon.

Lastly, I want to make special mention of the mother who wrote "A Mothers Story" which is featured in this issue of dAISy. It took a lot for her to write her painful story and I appreciate her sharing it with us for the benefit of others. I have been told by many that they cried when they first read her story and I must admit I did too. It serves as another reminder of why it is so important to have the AIS Support Group.

Best wishes to you and your loved ones,

Tony Briffa

**Disclaimer:**

This newsletter aims to provide information on AIS and similar intersex conditions. Care has been taken to select well-regarded sources of information, but materials included or referenced do not imply approval or recommendation by the AISSG Australia. © 2002.

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## AGM & Elections

The AISSGA's Annual General Meeting (AGM) will be held on Sunday 17<sup>th</sup> November 2002 at the National AISSGA meeting. The AGM will include the formal election of office bearers for the following positions:

- President
- Secretary
- Treasurer
- Editor dAISy
- State Representative NSW/ACT
- State Representative Queensland
- State Representative SA/NT
- State Representative Vic/Tas
- State Representative WA
- Parents Liaison Officer
- Men with AIS Representative
- Medical Liaison Officer

The nomination period is now open and closes at 5pm on the 10th of October 2002. If an election is needed for a particular position, voting will take place at the AGM. Postal ballots and proxy forms will be made available upon request to members who cannot attend the AGM. All postal ballots must be returned by 5 pm, Monday 11th of November 2002.

The AISSGA needs to consider its succession plan (keeping the Democratic process in mind), so please consider nominating for any position on the committee and becoming an active representative. This may be the last year I will serve on the committee so I welcome those willing to work closely with me if I am re-elected.

## Membership Fees

Annual AISSGA memberships expired in August this year and a renewal form is included with this issue of dAISy. Annual membership fees are AUD\$20 and include the subscription to dAISy and access to our support, information, and advocacy services including our national support group meetings.

The AISSGA has been financially supported by a small group of people to a large degree over the past few years. If we are to continue our vital work and future projects we need more people to become financial members.



## A Mother's Story

This is the story of our beautiful daughter who, after a healthy childhood, was diagnosed with 46XY complete gonadal dysgenesis when she was fifteen-and-a-half years old. Writing this down has been cathartic for me and hopefully will prove interesting to the reader, especially those involved in the medical profession.

In 1995, during a school holiday break my daughter underwent orthodontic treatment but appeared very quiet a couple of days later and eventually rang me up at work and said that she was in such a lot of pain would I book her in to see our GP. On talking to her further, and to my surprise, it was her stomach that was hurting and not her mouth!

That night my daughter was seen by a doctor at our local family practice and told she was constipated and prescribed laxatives. The next day she was still in a lot of pain so I stayed off work and kept an eye on her. In the middle of the night it became obvious that she was suffering from a lot more than constipation so we took her up to the local hospital where she was admitted. The young resident on duty said to my daughter that her arms felt rough like a man's. The following afternoon, after an ultrasound, the medical superintendent looked at the report and told me he hadn't seen a case like this before and didn't have a clue what was wrong with my daughter. He also said that she was too tall. Too tall? She came from a tall, slim family and I had had no need before to question her height. I am 175cms and my daughter was approximately 172cms.

Later that afternoon she was transferred to a teaching hospital in Brisbane, looking very yellow, but slightly more relaxed because the nurse had finally been able to give her something for the pain. This was our introduction to the hospital system, the insensitivity of the medical profession, and our daughter's two-and-a-half year ordeal.

Our daughter was seen early in the evening at the teaching hospital by a gynaecology registrar who, after examining her internally, spent some time looking at her Xrays, reports, etc and eventually told us that she most likely had an ovarian cyst and booked her in to theatre for the following morning.

A consultant gynaecologist visited us just before my daughter's operation and said everything would be fine and wondered what my husband and I were worrying about saying, "It's like shelling peas!" The nurses were jolly and supportive but I thought it strange when they disappeared from sight after my daughter had been in theatre for more than two hours. Where was she and where had all the nurses disappeared to? Half an hour later my husband and I were ushered into a tiny office and the consultant gynaecologist introduced us to her colleague, a gynaecologist oncologist. And so our nightmare began.

We learnt that during the operation our daughter was found to be bleeding internally. Her intestines had adhered to other organs and more surgeons were

summoned into theatre, including a general surgeon, gynaecologist, oncologist and pathologist. One 'ovary' had been removed and they said they thought she had a type of cancer that could be cured quickly with a short cycle of chemotherapy. I mentioned to the specialists that ten months prior to this our daughter had complained of severe stomach pains whilst at school. My husband had taken her to a GP near to his work and the doctor said she had been doing too much swimming! His consultation took all of three minutes. When her pains continued my husband took her to our local hospital where she was seen by a senior resident who said it was very odd for a fourteen year old not to be menstruating, but said nothing about signs of her being hirsute. She was x-rayed but that apparently revealed nothing. The doctor diagnosed constipation and told my daughter to come back if it didn't get better. She did get better in twenty-four hours! When the specialists heard my story I saw them glance at one another but they both dismissed this previous trip to the hospital as insignificant.

The next day numerous blood tests were done. Results started coming back in and we were informed that our daughter had an ovarian germ cell tumour and they wanted her to have a CT scan as soon as possible. After the CT scan we were told the tumour had spread to her lungs and chemotherapy had to be commenced immediately. By that night she had had a portacath inserted, ready for what they said would be four or five months of very heavy chemotherapy, remaining in hospital for much of the time.

An oncology registrar said to me in passing that they were also carrying out a chromosome test and a clinical nurse mentioned that sex change operations were carried out on the ward. My imagination went into overdrive as I tried to remember things my daughter had said to me, things that had seemed strange at the time, but I had dismissed because doctors we had seen previously had not mentioned anything unusual.

My father, a doctor living in the UK, sent me an article from the Lancet which stated that the prognosis for patients with germ cell tumours was extremely good these days. However, at the end of the article it mentioned that a percentage of intersex patients suffer from this type of tumour. From that moment on I was desperate. I needed to know exactly what was wrong with my daughter, but I didn't really want to hear it. What was I to do? The first thing I did do was ask a nurse to mark on my daughter's file that she wasn't to be seen by medical students and my wishes were always respected. I then spoke to the oncology registrar and asked if we were likely to hear any more bad news. Was there anything else they wanted to tell us? She said we wouldn't hear any more bad news; there was nothing more to tell. I felt relieved but I wasn't convinced.

I started looking up medical books and dictionaries for intersex conditions, but unfortunately at that time I wasn't able to access the internet. In the meantime my daughter was responding well to chemotherapy and her HCG level (tumour marker) started to drop. Funnily enough the more chemotherapy she received the better she began to look, but I noticed that her shoulders were getting wider and her

hands bigger (could this have been my imagination?) and it dawned on me that the doctors hadn't meant that she was too tall, but that her limbs were too long.

My anxiety grew by the minute and I was at a loss as to what to do or who to turn to. I couldn't talk to my husband about my suspicions because he was having difficulty coming to terms with the fact that our daughter had cancer and I didn't want to burden him with any more problems. I just knew that I had to keep my daughter's spirits high and keep my fears to myself. But by this time I could hardly eat or sleep and lost nearly two stone in twelve weeks which I could ill afford.

I tried to talk to the oncology registrar and consultant on a number of occasions and repeatedly asked the social worker to get someone to talk to me, but I was fobbed off every time.

Eventually I met up with a nursing friend of mine and started to tell her a few of my concerns. She told me that her sister had performed my daughter's chromosome test and it was discovered that she had XY chromosomes! She went on to say that this information had leaked outside the hospital and was the talk of Brisbane gynaecologists. I was stunned. My worst fears had just been confirmed by someone who could not explain any more to me and said I should talk to my daughter's doctors as soon as possible. (I was later told by the oncologist that nothing remains confidential in a hospital!)

After about three more weeks of trying to talk to someone the oncologist rang me up at home and told me that my daughter had gonadal dysgenesis (without any explanation as to what this was) and seemed surprised that the gynaecologist hadn't told me that they had found my daughter to be deformed when they operated on her! I was so distressed by this news that I couldn't continue our conversation and put the phone down. A couple of days later I threatened to stop my daughter's chemotherapy treatments and the oncologist had no alternative but to agree to my request to speak to an endocrinologist. Looking back I can't believe what I did, but I was absolutely desperate by this time and feeling very suicidal.

I was able to have a very brief telephone conversation with the hospital endocrinologist a day or so later (the oncologist sat in on the conversation), because he was on holiday at the time. The oncologist thought this conversation was sufficient for my needs but, if I wished, I could talk to the endocrinologist when he returned from leave!

I eventually spoke face to face with him three weeks later and during our half hour conversation I began to feel better about the situation and felt a load lifting from me as he explained as best he could about 46XY complete gonadal dysgenesis. At the end of our conversation he said that I should go and see a psychiatrist because I was suffering from clinical depression. However, I was more than grateful for the half hour he spent with me after more than three months of being kept in the dark.



I know now that if I had never requested to speak to an endocrinologist I would never have seen one at all during the course of my daughter's treatment.

Medical literature on 46XY complete gonadal dysgenesis was supplied to me via a friend of the endocrinologist, a paediatrician from another Brisbane teaching hospital, which made me realise that the specialist I was dealing with was not an expert in intersex conditions. However, after our brief talk and looking at the literature, I began to slowly recover from a darkness which I had hidden expertly from my daughter, family and friends and was more able to concentrate on helping my daughter through chemotherapy and radiation treatments, which ultimately we hoped were going to save her life.

(In 2001 I found out that there is a paediatric endocrinologist specialising in intersex conditions at the children's section of the hospital we were with! It has been suggested to me that possibly because of professional jealousy he was not consulted about my daughter's case.)

Meanwhile, I tried to read everything I could about GD and ovarian germ cell cancer - I was hungry for information of any kind and eventually felt that I should seek out a specialist in genetics because half an hour's talk and a couple of sheets of notes were now not enough for me.

I eventually met with a geneticist who was more concerned as to who had given me the original information sheets and where the endocrinologist had accessed them from. He told me that he saw worse cases than my daughter's every day. When I told the social worker that I had sought out more information from a geneticist she couldn't understand why - wasn't half an hour with the hospital endocrinologist enough?

After six months of heavy chemotherapy my daughter's HCG began to rise again, which was not a good sign. Eight months after commencement of treatment the gynaecologists and oncologist decided to take her other 'ovary' out in case this was the problem and decided now was a good time to tell my daughter she had GD. (Surely this second 'ovary' should have been removed shortly after the first?) So, the oncologist, endocrinologist, social worker, my daughter and I met during a twenty-minute outpatient's appointment. I asked for the social worker to be present so that she could support my daughter and intervene if the specialists handled it badly, but as it turned out my daughter would rather not have had the social worker present and couldn't talk to her for quite a while afterwards because of embarrassment.

The oncologist explained the need to take my daughter's other 'ovary' out and the endocrinologist explained GD to her. His final words to her were that Olympic athletes undergo chromosome tests and as she wasn't interested in becoming an Olympian she didn't have to worry about anyone finding out. My poor daughter hardly uttered a word during all this and my heart went out to her. But, at the time, I was grateful to anyone who took the trouble to talk to us. I now know that this was totally inadequate.

After the appointment I drove my daughter home but she did not utter a word on the trip back, however shortly after arriving home she sat on the bench in the kitchen and I knew this was a signal that my beautiful teenager wanted to talk. So, we talked and talked non-stop for the next couple of hours and I did my utmost to convince her that she was absolutely female, indeed she would even be able to carry a baby later on (from a donor egg). And I told her that I loved her to bits. We ended up laughing and hugging one another and I am sure she was relieved because I believe she had known there was something else wrong with her besides germ cell cancer, but she couldn't talk about it. She swore me to secrecy and asked me never to tell anyone about her intersex condition, even her father.

After her second streak ovary was removed (and oestrogen therapy finally commenced), the HCG level remained high and the cancer was found to have spread to her brain. Chemo was inserted into her spine and radiation commenced, which worked for a while. The HCG level continued to rise and the decision was made to give her a stem cell transplant, which meant remaining in hospital for a month in isolation whilst she underwent treatment.

Before the stem cell transplant could commence she had to have a Hickman's line inserted, which was attempted by a haematology registrar. This was not successful so she went down to theatre in the evening to have it inserted by a general surgeon. That night I slept with her in the ward because she had been very distressed on returning from theatre. During the night a nurse tested the Hickman's line and my daughter nearly hit the ceiling in pain and wouldn't let anyone near her again. A few hours later she was visited by the surgical registrar who announced, in a voice loud enough for other patients to hear, that my daughter's procedure had not been a success because she was physiologically different from other people and that is why they had encountered difficulties. I later learnt that someone (quite possibly this registrar?) had not tested the Hickman's line before my daughter left theatre and instead of the tube going around in a loop it had gone through the artery. No wonder my daughter had felt so ill and suffered a tremendous amount of pain. A third attempt by a vascular surgeon was successful.

After one month's gruelling treatment my daughter expected her HCG level to fall to zero and desperately hoped to go into remission, and naturally she was nervous about meeting the hospital's haematology consultant at an outpatient's appointment. This specialist and some of his team had been very kind to our daughter and I knew if the marker level wasn't what we expected he would be the best one to give us the bad news.

Unfortunately the specialist was held up with a BBC TV film crew so his assistant stepped in and took over his appointments. Our daughter's HCG level was around the eight mark which she said was a good result! We must have looked aghast. This was not the news we had wanted to hear and it was a terrible outcome! She quickly said that she was not used to dealing with patients with germ cell tumours and said we should go back and talk to our GP. My daughter, husband and I were speechless by this time and showing signs of distress, so she decided to

phone the oncologist and made an appointment for us to see him in another week's time. How we all managed to get through the rest of that day I'll never know, but we did, and we found the strength from somewhere to carry on. We willed our daughter to keep going, continue with her studies, socialise with her friends and above all not give up.

The news wasn't to get any better and a little later on the tumour returned to her brain. I travelled down to Sydney with my daughter so that she could undergo stereotactic treatment, which was fairly gruelling and resulted in four permanent "dent" marks on her head. However, she was seen by one of the nicest specialists we were to encounter during her illness and I was extremely thankful for the kindness this man bestowed upon my daughter. The treatment was a success and the tumour did not return to her brain.

Sadly, the tumour could never be eradicated from her lungs and after a two-and-a-half year battle with cancer our beautiful and brave daughter passed away. It was and still is a tragic loss.

A few hours after her death we had a phone call from a doctor at the hospital asking if we would donate our daughter's eyes. We didn't think cancer patients could donate organs but he said it was possible with the type of cancer our daughter had been suffering from and hadn't the hospital talked to us about donating her eyes before she died. No, they hadn't! We felt that our daughter had suffered quite enough and we wanted her left in peace. We refused permission and to this day we don't regret that decision.

It was only after watching a television program some time during 2000, and two years after losing our daughter, that I found out about the AIS Support Group in Australia and contacted Tony Briffa. If only I had known about this group at the end of 1995 I am sure it would have made a big difference to my daughter and me.

I feel the medical profession has a very long way to go before attitudes become more enlightened but with Tony and the AISSG, including Dr Garry Warne, surely progress will be made. I hope my story will assist in some way and show the medical profession how not to treat intersex patients and their families!

***Many thanks to this mother who was so generous in sharing her personal experiences with us. This is truly a touching story that reminds us of the importance of obtaining an accurate diagnosis, having clinicians that are open and supportive, and the need for support groups and the medical community to work together. – Tony Briffa***

## **AIS Couple Unplugged! (Pt 1)**

As reported in the AISSG-A News in October 2001 and in the March 2002 edition of dAISy, Renee P. and Tony M., two of the most loved AIS People, were married. Renee is one of the founders of the AIS People Club, an Internet based support group for people with AIS and similar intersex conditions. She met Tony, who has PAIS, at the club and after going out for over a year and an engagement lasting several months, they decided to tie the knot.

Renee and Tony have been kind enough to share their experiences with us in a series of interviews over the next few issues of dAISy. I know many people are going to find these interviews very interesting.

### ***So, how did the two of you meet?***

**TM:** Well, I was researching intersex issues on the internet, having only recently learned the name and nature of my condition, when I came across Tony Briffa's website. I took up the invitation to email Tony and tell him a little about myself. I was very pleased to get a reply very quickly as up to that point I still thought I was the only person in the world to have anything like this and to find Tony was a great relief to me. He suggested that I join the newly formed AIS People Club, which I did straight away.

**RP:** Tony Briffa, Anna and myself had formed the AIS People Club on May 5, 2000. About a week later, Tony M. joined the club and he was the first person that identified as a male to join the group. Having only found out that I was CAIS two months prior, it was my first indication that AIS males existed. Up until that point, I foolishly thought that everyone with AIS lived as women. It was a real eye opener for me!

### ***How did your relationship develop?***

**RP:** It was really during the weekly club chats that we struck up a rapport. He was so nice, so polite and so very British; I really thought he was quite charming. I teased him about the differences in our cultures and was he always very quick with a comeback and played right along with me. I was still in shock over recently learning about having AIS and the fact that my chromosomes were 46XY and it was refreshing to be able to laugh and joke with Tony M. and the others about it and life in general. Starting a new relationship was the last thing on my mind, however, I found myself really looking forward to the weekly chats. It was until about two months later that we started to send private emails to each other that a serious friendship got started.

**TM:** I started coming to the weekly chats and joining in with the other members in discussing AIS subjects. It was refreshing to be able to talk freely with others that would not condemn or misunderstand me for my genital deformities. But it was not all-serious stuff! I started having a lot of fun and merry banter with two members in particular. Clare, Renee and I were having a ball, just joking and messing around with each other and I have to

admit that it was the best time I'd had for years. However, I was beginning to have very special feelings for Renee. There was something that was "natural" in the way we could communicate with each other, despite being 6000 miles apart. Renee could say a word and I would match it. She could say a word from a song and I could finish it and vice versa.

### ***When did you have your first telephone conversation?***

**RP:** We were already being "naughty" and using the club's chat room for private meetings and I thought it was time to speak one on one and I phoned him the first time, which was about three months after we initially met. I was incredibly nervous and could barely understand a word he said. He didn't type online as a Cockney! We spoke for an hour and a half and it wasn't until after I hung up that I called my long distance company and asked them what the charges would be. Needless to say, I signed up for the International Calling Plan that same day!

It was the next day when I began to tell family, friends and co-workers, "I've met someone and I think it's serious!"

**TM:** We had an arrangement to meet in the chat room an hour after the chat ended. I had a snack and was sitting waiting for our personal chat time to arrive when the phone rang. I answered it not even thinking it would be Renee, after all she didn't even have my phone number. I answered with my number, as we usually do in England, and Renee said "HI". I said who is this and she said whom do you think. This is when it dawned on me that I was listening to an American accent. I said "Renee" she said yes! We talked for an hour and a half, my mind was spinning, she was fantastic to talk with and we just gelled from the start. After we hung up I thought she must be wealthy to pay for the international call.

### ***At this point, what were your feelings about the possibility of having a relationship with someone who was intersex?***

**RP:** I was very fortunate with having CAIS that my vagina was pretty much average size and I never needed to have a vaginoplasty or use dilators. Other than my gonadectomy scars, I didn't have anything physical in relation to AIS that I was ashamed of or embarrassed about. With me, it was completely a mental thing, I saw myself differently after I found out that I was 46XY and it was all about coming to terms with that. I began to learn about Tony's ambiguous genitalia during club chats and through his postings at the club. I wasn't sure how I felt about it at the beginning. Prior to this, I didn't have a clue what a hypospadias or chordee was. I began to do a lot of research on my own to find out more about it, because not only was I curious, I also wanted to be able to understand it all so that I could be a better friend and partner to him.

**TM:** I always knew that I was different! When I was a child I didn't have the same! as the other boys but I never knew what the name of my problem was until I was 48 years old. I had been married for 24 years and although I

knew my genitals were "different" we had a good relationship, until she wanted to go her own way and suddenly used my genitals and inability to produce a child as an excuse to end the marriage. When I met Renee I was excited about the possibility of a relationship but I was very worried about how she would view my genitals, my divorce experiences had left me feeling like I was useless in that field. I knew that for all intents and purposes Renee had normal genitals, apart from the lack of pubic hair. I knew that she had had relationships with other "normal" men in the past and so I was very worried that when we met I could not fulfill her with my small, hypospadiac penis. I went out of my way to let her know what to expect and make sure that I didn't exaggerate it in any way. We talked about it at great length and she assured me that the size didn't matter to her; it was the person that counted.

**RP:** He is absolutely right. I told him that I didn't care what he had between his legs; it's what's between the ears that count. Although, at this point, I was concerned that if and when we met, I wouldn't hurt his feelings in any way based on my reaction.

**Next dAISy:** Their first meeting and sexual encounter, disclosure to friends & family and life as a married intersex couple.

Here are the links to Renee and Tony's personal stories:

Renee P.: <http://home.vicnet.net.au/~aissg/renee.htm>

Tony M.: <http://home.vicnet.net.au/~aissg/Tony.htm>

## **Scare for Women on HRT**

By Andie Hider, Medical Liaison Officer

In July this year, selected findings from a US study examining the long-term use of Hormone Replacement Therapy (HRT) by women to manage such things as bone mineral density were widely reported in the Australian Media. Television and newspaper reports singled out adverse findings from the study and these reports, allied to warnings issued by a government appointed committee evaluating the appropriateness of HRT for treating Osteoporosis, caused a flood of enquiries to medical practitioners from women concerned about continued use of HRT. Nearly all adult women with AIS will be on some form of oestrogen based HRT, so naturally women with AIS are asking questions about use of HRT to maintain their bone mineral density (BMD). Whilst the findings of such studies should not be ignored, it is important that they are considered in context with a number of matters not appropriately addressed for post-menopausal women, let alone for women with AIS.

The US study focussed on combined oestrogen/progesterone HRT. Discussions with various medical practitioners have strongly suggested there is no benefit for women with AIS taking combined oestrogen/progesterone HRT. This means that oestrogen only based HRT is probably more appropriate for women

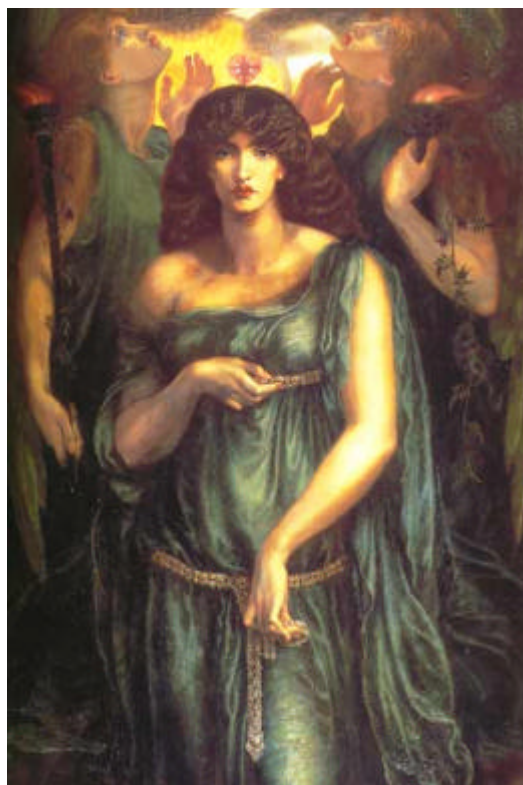


with AIS than the combined therapies that formed the basis for the US study. To my knowledge, the only definitive studies to date about the effects of long-term oestrogen only therapy show a possible increased incidence of ovarian cancer. As this is not an issue for women with AIS the oestrogen only therapy once again should be safe for long-term use.

The US study also did not report any overall increase in the death rate in a given sample population made up of women on long term HRT and those not taking hormone therapy, what changed was the reason for deaths in the sample population. Those who used HRT in the long term, as would be expected, had a higher incidence of HRT related illnesses and deaths whilst those not taking HRT had a higher incidence of illnesses many of which could be prevented or reduced by HRT. The sample population used in the US study also included participants with other factors present that significantly increased the risk of illnesses reported to be a result of long term HRT use.

One of the most important medical considerations affected by the findings of this study is timing of orchidectomies for those with CAIS. Medical practitioners will now have to consider the potential risks of early prescription of HRT against the risks associated with orchidectomies later in life.

As with all such decisions, you should consult your general practitioner or medical specialist for further information before changing treatments for any reason.



## The Age Article on HRT

*The following is an article titled "Urgent meeting on hormone safety" by David Wroe and published in The Age on July 11 2002.*

The weight of medical opinion on hormone replacement therapy appears set to change after research found that long-term therapy raises the risks of heart disease and breast cancer.

A team of experts assembled urgently by the Federal Government yesterday is expected to report on the implications of the US findings by tomorrow.

Trish Worth, parliamentary secretary to the Health Minister, told the estimated 600,000 Australian women who use HRT not to panic but said the findings should be taken seriously.

"It is important that Australian women feel confident about the medications that they use," she said.

As news of the findings broke on Tuesday, doctors and menopause clinics were flooded with calls from anxious women.

The Women's Health Initiative study, which followed 16,608 women aged 50 to 79 for five years, found that long-term use of oral combination oestrogen-progestin HRT raised the risk of heart disease by 29 per cent breast cancer by 26 per cent, strokes by 41 per cent and doubled the risk of blood clots.

The benefits included a 37 per cent drop in colorectal cancer rates and 24 per cent fewer fractures.

An accompanying editorial to the research, published in the Journal of the American Medical Association, stated that it was "unarguable that the risks outweigh the health benefits" for women on combination HRT for more than five years.

The Australian Medical Association and menopause experts yesterday called for calm and urged Australian women on long-term HRT to see their doctors. Doctors have prescribed HRT in the belief that it lowered the risk of heart disease.

The National Health and Medical Research Council, which advises doctors on treatments, would review its guidelines on HRT, said Adele Green, chairwoman of the council's health advisory committee.

NHMRC guidelines state that HRT lowers the risk of heart disease – the opposite of the new finding – and that scientific opinion is divided on the breast cancer risk.

"When we have new, high-level evidence like this it is certainly time that we would begin now to reassess," Professor Green said.

The National Heart Foundation is also likely to strengthen its position

against HRT, said Andrew Tonkin, director health, medical and scientific affairs.



The New South Wales Cancer Council has called on health authorities to restrict the availability of combination HRT.

Helena Teede, a senior lecturer in endocrinology at Monash University, said most Australian women used HRT only for short periods to reduce menopausal symptoms such as hot flushes and mood swings.

Dr Teede said the US research did not apply to the majority of Australian women. She said the findings were much more relevant to women in the US, where long-term use of the Premarin and Provera pills used in the study was more common.

It was unclear how many Australian women could be affected by the study's implications, although menopause clinics and doctors were beset by "pandemonium" yesterday, Dr Teede said.

"It's just mass panic. Women don't know what to do and doctors haven't had a chance to view the research and let it sink in," she said. "I've got GPs ringing me left, right and centre."

David Healy, chairman of obstetrics and gynaecology at Monash University, urged the government to pay for Australian research on HRT.

He said research on women's health was a "secondary priority" in Australia.

Wyeth Australia, which supplies combination HRT treatment, said women needed to see their doctors to weigh up the risks and benefits they could expect from HRT.

Helen Keleher, a Deakin University sociologist who also heads the Australian Women's Health Network, said: "We don't know enough about (HRT) for it to be so widely prescribed. There is such conflicting advice out there."

## Access to Medical Records on Request

From AAP

01 July 2002

Victorians will have unprecedented access to their medical records under new regulations effective today.

Health service providers will be legally required to give patients access to information held about under the new Health Records Act.

Insurers, government agencies, schools and fitness clubs will also be bound by the new law.

Health Services Commissioner Beth Wilson, who will oversee the Act, and handle complaints, said patients would only be denied access to information about them if it constituted a serious threat to their life or health.

However, such decisions would be subject to appeal, she said.

Ms Wilson said the Act would give patients a greater say in their treatment and improve confidence in the health system.

"It will give all Victorians the right to access health information held about them, whether that is held by health service providers or others," she said.

"I think it's got the potential to improve the therapeutic relationship, because openness is really conducive to trust."

## Community Input wanted for Discussion Paper on Human Genetic Information Privacy

The Australian Law Reform Commission (ALRC) conducted a public inquiry into the protection of human genetic information earlier this year. The AISSGA submitted a paper on this important issue which is also available on our website. The ALRC have now released an 800 page discussion paper which is available for comment by any interested parties.

To obtain a copy of this discussion paper, please contact the ALRC at:

The Law Reform Commission of Australia  
GPO Box 3708  
Sydney NSW 2001  
Phone: 02 9284 6333  
email: [publications@alrc.gov.au](mailto:publications@alrc.gov.au)  
website: [www.alrc.gov.au](http://www.alrc.gov.au)

## Royal Children's Hospital Melbourne Bio-ethics Study Update

In the September 2001 issue of dAISy, we printed an article summarising the current (at that time) status of the Royal Children's Hospital Melbourne follow up study into the past treatment of children with intersex conditions treated at that hospital. At that time we reported a number of concerns we had about the direction the study was taking, these were subsequently discussed and certain issues clarified. Initial approaches have been made to former patients and copies of a questionnaire forwarded to them for completion.

Upon receiving a copy of the questionnaire Tony and I went through the questions with a view to gauging how these might be interpreted and answered depending on the level of knowledge a person had about their condition. Some of the questions we considered to be leading, especially if a person did not fully understand their

condition and the risks involved with various treatment practices. As an example, one question was: "Should ovarian or testicular tissue be removed early when there is a significant risk of developing cancer in the next 20 to 30 years?" This question does not define what early is (infancy, childhood, pre-puberty, post-puberty?) nor quantifies the risk of cancer in any way. Without the question being qualified in any way, most people would answer yes. As there is no information provided about the positive effects of retaining gonads until after puberty on things like bone mineral density, it is difficult to understand how the answer to such a question could be made on any sort of properly informed basis.

We raised these concerns with the Bio-ethics team and had some discussion with them about the issue. As the questionnaires have already been distributed to a number of people it is too late to change these. We did, however, suggest sending a follow up to those who received the questionnaire in this form giving plain language information statements and then asking the questions again once the person answering is fully aware of all the options and the medical reasons for choosing them. This would provide an almost unique opportunity to gauge "before and after" answers to a number of questions about treatment that should prove extremely valuable.

Our relationship with the research team is particularly good at this point in time, something we are hoping to reinforce through a number of other co-operative efforts. It is this sort of continued consultation with the medical profession that has the potential to provide world best practice treatment for those with intersex conditions and we look forward to further discussion and input.

## **Am I A Defect? (The Importance of Language)**

By Tony Briffa (written for the Genetic Support Network of Victoria <http://www.gsnv.org.au>).

For centuries humanity has been shaped by words and language to convey ideas, perceptions, attitudes and feelings and this is our primary form of communication. In particular, sense of self worth, self image and self esteem are all affected by the use of positive or negative descriptive language. Aside from individual communication, language reflects the general attitudes of society, which language on the one hand if negative, acts as a barrier for those with any level of disability and conveys negative stereotypes and misconceptions. Positive attitudes on the other hand can help society and those with various conditions by simply being considerate about the tone of what is said about people affected by these conditions and the conditions themselves. Most importantly, the use of appropriate words and language can actually change attitudes toward people with disabilities by referring to them and their conditions accurately. The use of appropriate language by medical

and associated health service professionals is especially important.

People with various conditions and their carers deserve to be treated with respect and dignity, and the following simple points are intended to illustrate a few examples where appropriate and respectful language will help a person feel more positive about themselves or their child.

- Words such as 'defect', 'victim', 'disease', 'sufferer' and 'abnormal' are highly offensive and should never be used to describe a person with a disability or condition. Instead words such as "birth variation", "medical condition", "person affected by (condition)" and "person with (condition)".
- When speaking about someone with a disability or condition, only refer to the condition if it is necessary. Remember the person is the most important thing, not the disability or medical condition. Whilst a person may make an interesting case or research subject, they are much more than the sum of their disability or medical condition.
- Language should emphasize the person first and the disability second. For example, rather than referring to someone as being 'a Down's Syndrome boy', say 'the child has Down's Syndrome'. Likewise, rather than referring to someone as "intersexed", refer to them as "someone with an intersex condition".
- Language that is negative and inaccurate should also be avoided, particularly when a condition is first diagnosed. First impressions will form a basis upon which parents will continue to consider their child and those perceptions will be passed onto the child as parent/child interaction takes place. In the case of a child with a disability or medical condition, the parents will have a more specialised carer role and so their perceptions of their child will have considerable impact on the child through disability or condition specific care.
- Parents are also more likely to absorb important information from the outset if they are not "shocked" by the language used. Telling a couple for example, that their child was born with a 'congenital defect' or 'congenital abnormality' is considerably different to telling them their child was born with a particular condition but is otherwise healthy. Many parents may not hear important information associated with initial diagnosis because of inappropriate language and often it is this information which forms the basis for the understanding of their child's disability or condition.
- Language that suggests a course of treatment without first providing complete and accurate information about the advantages and risks of that and other treatment options is unethical. Parents and, where appropriate, children should be given full and frank explanations about all possible treatment options. If you don't know, say so and find out rather than guessing or hypothesising.

- Ask check questions to ensure the information has been understood up until that point, before providing more information. This will ensure you are building information and understanding on a sound foundation, rather than continuing to provide information long after a person has given up trying to understand.
- Whenever possible, never refer to a person present in the “third person”, this objectifies them and more often than not is easily avoided.

Like many things, use of language is habit forming. This is particularly true of frequent use of technical language, such as is often used by the scientific and medical communities. Given the impact language may have and the lasting impressions it may form, the onus is on any medical professional or associated care provider to choose their words carefully. To do this may take a deliberate effort to avoid habitual language we recognise as potentially damaging, but improved relationships and quality of information communicated makes the effort well worth it. As Mother Teresa said, *“kind words can be short and easy to speak, but their echoes are truly endless”*.



## Dr Bruce Wilson's Article on Androgen Insensitivity Syndrome

By Andie Hider

<http://emedicine.com/PED/topic2222.htm>

A recent search of the internet revealed an article about AIS written by Bruce E Wilson MD, Clinical Associate Professor, Department of Paediatrics and Human Development, Michigan State University. This article would have to be one of the most thorough, well balanced articles about AIS currently available.

Dr Wilson's article describes AIS in language that is easy to understand and then goes on to discuss in detail various current thoughts about treatment of the condition. The article itself is not about general treatment practices for intersex conditions, but rather quite specific to AIS and even includes “sample questions” at the end for medical

students (no prizes for getting the answers right for anyone in the support group!).

Dr Wilson does not wade into arguments about the timing nor necessity of surgery for infants with AIS presenting information about all options currently available for parents and adults with AIS alike. He discusses potential legal issues from current practices and suggests that more “enlightened” treatment practices may avoid patients feeling they need to resort to recourse via the legal system.

Psychological issues including those arising from inappropriate medical intervention such as insensitive or inappropriate medical examinations are covered by Dr Wilson, as are issues about identity and difficulties encountered by some patients finding specialists with sufficient knowledge of AIS. The need for psychological support is well documented and he describes the requirement to sufficiently separate and explain the concepts of sex and gender and the need for full disclosure about AIS. Genetic counselling and the need for parents to receive guidance about age appropriate language to explain the condition to their child is also discussed in the article. Contact with peer support groups for information and to reduce the feeling of isolation is another aspect of psychological care recommended by Dr Wilson.

Hormone replacement therapy, including some discussion about the use of DHT for males with AIS and the use of progesterone treatment for women, is also considered in the article. Dr Wilson also mentions the issue of osteoporosis and the requirement that HRT compliance and effectiveness be carefully monitored.

The breadth of information included in this article is very impressive, covering issues for CAIS and PAIS ranging from hormonal treatment through psychology and counselling to surgery and parental issues. Generally speaking, medical articles are not the best information source for parents who are placed in the position of making decisions about their child's treatment, but in this case an exception should be made. Although it includes facts of a specifically medical nature, there is much useful discussion regarding treatment options such that it will also provide parents with enough information to make some truly informed decisions about treatment for their child. Adults with AIS will find much for themselves in the article as it may help to further explain their condition.

As a final note, language in the article has been well chosen in what appears to be a deliberate (and to my mind successful) effort to avoid referring to those with AIS in a way that will stigmatise them or hurt and upset parents of infants with AIS. Dr Wilson's article is thoroughly recommended to anyone who has an interest in AIS, professional or personal.

## AISSGA Preferred Treatment for Children with Intersex Conditions

The AIS Support Group Australia supports calls for a moratorium on non-urgent medical intervention in children with intersex conditions. This includes gonadectomies and clitoral recession on infants with AIS, but does not mean all surgeries should be stopped completely. The preferred treatment paradigm of the AIS Support Group Australia is simple:

1. Obtain an accurate diagnosis from an expert in intersex conditions – preferably an experienced Endocrinologist.
2. Raise the child as a boy or a girl - depending on medical advice and with the complete support of the parents.
3. Give parents complete information about their child's condition. A booklet describing the condition is best so they can refer to it if they have any questions between doctor visits.
4. Offer the parents and any other family members peer support and professional counselling.
5. If surgery is medically required, discuss all treatment options with the parents including the consequences of not having the surgery. Ensure parents are given the opportunity to ask questions and seek support and counselling. A period of several weeks to consider alternatives is also advised if medically possible.
6. Ideally a child should be educated about their condition in stages as they become old enough to understand certain concepts.
7. When a child with an intersex condition is around 12 years old (or just prior to puberty), they should be given professional counselling and told about options to treat their condition. Counselling should also include an opportunity for the child to openly discuss their gender. This will give those raised in the incorrect gender an opportunity to voice this to the counsellor.
8. From this point on, the child's consent should be given for any further medical intervention, including hormone therapy.
9. If the diagnosis of an intersex condition is made later in life, doctors should still provide their patient with complete disclosure and offer the contact details of the AIS Support Group Australia.

The AIS Support Group Australia is committed to ongoing working dialogue with the medical profession to establish improved treatment practices for those affected by intersex conditions. We welcome any of them to contact us, join the support group, and/or attend our meetings.

## Most Vaginal Surgery in Childhood Should be Deferred

British Medical Journal 2001;323:1264-1265 1 December 2001  
<http://bmj.com/cgi/content/full/323/7324/1264>

For over 40 years doctors have been in the impossible situation of making momentous decisions for intersex children, without well founded scientific principles and with little more to guide them than a personal hunch that they were doing the "right thing for the child." Despite rapid advances in understanding sexual differentiation and increased accuracy of diagnosis, the clinical management of intersex has changed little. Recently the medical profession has been confronted by the powerfully critical voices of intersex consumer groups ([www.cah.org.uk/](http://www.cah.org.uk/); [www.isna.org/](http://www.isna.org/); [www.medhelp.org/www/ais/](http://www.medhelp.org/www/ais/)). With a serious deficiency of any evidence base, emotive debates on ethics, and clinical concerns over the long term consequences of interventions, it is time to stand back and rethink every aspect of this management.<sup>1-4</sup>

Intersex conditions consist of a blending or mix of the internal and external physical features usually classified as male or female—for example, an infant with ambiguous genitalia or a woman with XY chromosomes. Actual prevalence figures are unknown, with population estimates of 0.1% to 2%, though figures can be distorted by varying definitions of intersex.<sup>5</sup> When intersex is recognised in infancy, doctors decide if the child with an intersex condition is to be raised as a boy or a girl and they recommend surgical and hormonal treatment to reinforce the sex of rearing. Core to this process is a belief in a societal binary two gender system. In the 1950s-70s, John Money gained widespread acclaim for work analysing differentiation of gender identity with intersex subjects.<sup>6</sup> He stated that to achieve a stable gender identity a child must have unambiguous genitalia and unequivocal parental assurance of the chosen gender. Extrapolated into clinical management, the accepted keys to successful outcome were believed to be an active policy of withholding any details of their condition from the child and early genital surgery, before 18 months of age.<sup>7</sup> Hence the current intervention of genital surgery has focused on early cosmetic appearance of the genitals rather than later sexual function.

A paternalistic policy of withholding the diagnosis is still practised by some clinicians. No objective work has analysed the widespread effects of such non-disclosure, but the impact on individual patients has been eloquently described.<sup>1, 8</sup> There are more than just medicolegal reasons for abandoning non-disclosure. Most patients eventually become aware of their diagnosis through a variety of ways—from mortgage applications to television and magazine articles on intersex. Some articulate feelings of anger, distrust, and betrayal directed towards their doctors and families.<sup>9</sup> Surely if a patient is going to learn the truth whatever happens, it would be more appropriate if they learnt it from their doctor and were given accurate information and appropriate psychological input. Policies



of non-disclosure also prohibit access to genetic screening and the important option of peer support groups for shared learning and experiences. Once we accept that there is no place now for non-disclosure we can devote more research to appropriate ways of educating both the family and the patient, and how to tailor psychological support accordingly.

Genital surgery is one of the most controversial interventions in current intersex management. A large proportion of infants with ambiguous genitalia are raised as girls, and surgically feminising the genitalia usually involves a clitoral reduction and a vaginoplasty. In the absence of clinical trials and with minimal objective cohort studies providing data on outcomes on cosmetic, gender, social, or sexual function after this surgery, along with anecdotal evidence of dissatisfaction of adult patients with childhood surgery, both clinicians and parents face huge dilemmas. Current theories of gender development say that both prenatal factors (for example, testosterone) and postnatal factors, including the social environment, are important, and that genital appearance is less relevant.<sup>10</sup> Clinicians, however, remain uneasy about gender development if the genitals remain uncorrected and are concerned over the possible psychological distress from bullying over different genital appearance. Recent work has shown that most children undergoing vaginoplasty will require another operation to permit use of tampons and sexual intercourse.<sup>3 4</sup> The vagina is non-essential and not even visible in childhood, and most vaginal surgery should be deferred.

Conversely the clitoris is visible in childhood. An erotically important sensory organ, both the clitoris and the clitoral hood are densely innervated.<sup>11</sup> Most cosmetic clitoral surgery removes the paired clitoral corpora. The physiology of female orgasm, however, is poorly understood. It is only logical to consider that any surgery to the clitoris, which risks vascular, anatomical, or neurological compromise, could potentially alter sexual response. To date, published studies on outcomes of intersex clitoral surgery contain observer bias and non-objective assessment. None provides evidence for the assertion that adult clitoral sensation and sexual function remain undamaged by clitoral surgery.<sup>12</sup> Indeed it would be expected that people with intersex conditions might suffer an increased incidence of sexual dysfunction owing to the nature of their condition and the many psychological factors that impact on sexual function. Unravelling the complex interplay between surgery and psychology to understand their impact on adult sexual function remains the unconquered challenge. In the meantime, any decision regarding clitoral surgery must be taken with the knowledge of potential damage.

We need to rethink our approach to the management of intersex conditions. We must abandon policies of non-disclosure and manage patients within a multidisciplinary team. Long term follow up studies of adults with intersex conditions are crucial. However, such studies can be done only with the equal involvement of people with these conditions and of peer support groups and the cooperation of all clinicians managing intersex. It is time to create a

major intersex research partnership to begin tackling these questions and move forwards towards enlightened and patient empowered care.

**Sarah Creighton**, consultant gynaecologist.

Elizabeth Garrett Anderson and Obstetric Hospital, University College London Hospitals, London WC1E 6DH

**Catherine Minto**, gynaecology research fellow.

Academic Unit of Obstetrics and Gynaecology, University College London, London WC1E 6AU

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*“Legal challenges to the management of patients with CAIS have not been a problem to date, and such management appears to have little likelihood of becoming a legal problem. In PAIS cases, however, intersex activists are pursuing the possibility of suing physicians who perform early genitoplasty. Legal challenges appear likely in cases involving demonstrable loss of sexual function or in which the adult gender identity conflicts with the surgically created sex. Physicians providing care for children with PAIS and genital ambiguity should be aware of this possibility, although enlightened management should lead to outcomes that make lawsuits unlikely.”*

- Dr Bruce Wilson, Endocrinologist

## Catalyst Program on Intersex – “Is it a boy or a girl?”

Thursday 25 April 2002  
<http://www.abc.net.au/catalyst/stories/s539666.htm>

On 25 April 2002, the ABC television “science” programme Catalyst featured a short segment on intersex conditions, primarily focussed on surgical intervention. The programme focussed on a young couple who had moved to Melbourne from New Zealand so that their child could have surgery. A number of members of the Royal Children’s Hospital Melbourne (RCH) team that specialises in treating intersex conditions were interviewed for the programme, including Dr Garry Warne and Dr John Hutson. The Catalyst programme raised the profile of intersex conditions and included the contact details for the AIS Support Group Australia.

The AIS Support Group Australia has been actively co-operating in a follow up study being conducted by the RCH Melbourne that is examining the issue of the appropriateness of a number of treatment practices. The follow up study is being facilitated by interviewing patients with a number of different intersex conditions that were formerly treated at the RCH Melbourne and is examining such things as disclosure and genital surgery. AIS Support Group Australia cooperation has extended to such things as discussing and formulating ways of initially approaching former patients and making ourselves available to help anyone wishing to contact the support group as a result of the study.

Members of the AIS Support Group Australia have spoken with members of the RCH Melbourne team interviewed for the Catalyst programme. We are concerned that no mention was made in the programme of the RCH Melbourne follow up study or the doubt existing about the appropriateness of certain medical practices, despite the fact that members of the RCH team say they commented at length about the study and the reasons for it. An American physician featured on the programme made mention of doubts about infant surgeries, but no mention of such doubts made by members of the RCH Melbourne team was aired. This would give the impression for anyone watching the programme that the RCH team had no doubts about their current treatment practices, a fact not borne out by the existence of the follow up study.

Dr Hutson also mentioned a “new theory” about a testosterone wash shortly after birth that required infant surgeries to be carried out in the first couple of months following birth if a child is to be successfully raised as a girl. The AIS Support Group Australia has anecdotal evidence that directly contradicts this theory. We are concerned that such “theories” have been used in the past without empirical proof to justify such things as withholding information from patients and the entire treatment paradigm upon with the “surgical model” is based. Whilst many people have theories about a great many issues, we consider it irresponsible to air them

publicly in a forum such as Catalyst when they cannot be scientifically proven beyond doubt, especially when using them as a basis to support existing treatment practices that are subject to review.

## Transcript of Catalyst Segment on Intersex

Narration: When this baby was born, the parents asked whether it was a boy or a girl. They were in for a shock

Jacinda: Some nurses would call him a she, some nurses would call him a he, some nurses called him an it.

It was horrible.

Narration: Not even the doctors knew the sex of their child.

Jacinda: I had to get changed to Wellington Hospital in an ambulance within hours of his birth and I had to share it with another mother and that mother said oh you know congratulations what did you have? And I had, I just said to her I don’t know.

Narration: Bryden was born with uncertain gender, also known as intersex. It’s a condition that affects one in 4,000 children. And it poses some of the most difficult questions a parent or a doctor would ever have to face.

And given the social stigma of this condition, parents often face them alone. That’s why Jacinda, her family and doctors decided to share their story.

Jacinda: You feel like you’re on a different plane to everyone else because everyone else is worrying about you know their children with teething and they were doing this and that and we were talking about you know what sex is our child going to be? You know what are you telling me he’s got a uterus but he’s a male you know?

Narration: Parents face a nightmare decision. Radical genital surgery. But how do they know whether their baby should be a boy or a girl? And how early do you make this life determining choice?

So emotionally and socially charged are these questions, even the scientists are sharply divided.

Professor Eric Villain: I usually recommend to hold off the surgery on the genitalia until at least the baby becomes old enough, and that’s usually about six or seven years of age, and old enough to tell us if he or she feels like a boy or a girl.

Ass. Professor Garry Warne: We don’t think it’s acceptable to ask the child to grow up through childhood and into adolescence with genitalia that are neither male nor female, because they, it forms their, their self image.

Narration: So faced with these conflicting opinions, what’s a parent to do?

When Bryden was born, Jacinda was initially told by the New Zealand doctors to do nothing for 18 months.

Jacinda: We got sent home and mother's instinct kicked in and I felt that there was more wrong with Bryden, more internal things wrong and it was actually quite funny because I did focus on internal things more and I started asking questions.

Narration: She went to see another doctor. And was horrified by what she learned. Not only were Bryden's male genitalia incomplete, but internally, the anatomy was part female.

Nigel: Our primary concern was to get Bryden the best surgery we could get him. We decided to move to Australia because that was the best for him.

Narration: They came here, to the Royal Childrens Hospital in Melbourne. It's home to a versatile team who manage the wide range of intersex cases. Their lead surgeon is John Hutson.

Professor John Hutson: Gender assignment is the hardest thing to do. And it's because it's extremely complicated and it's rare and so you have to practice doing this all the time to get it right but even then it's still difficult.

Narration: To help make the difficult decision, Jacinda and baby Bryden met with the team's endocrinologist, Garry Warne.

Ass. Professor Garry Warne: It certainly wasn't clear cut. If you looked at him when he was born you would not know if he was a boy or a girl. And it is possible to make the decision either way.

Narration: The big question is one of gender identity. If they create the genitals of one sex, but the mind doesn't match, the consequences will be disastrous.

That's why some scientists say wait, until the child is old enough to choose for themselves.

Professor Eric Villain: Sometimes there can be some confrontation with the surgeon. Absolutely. Because the traditional view of the surgeon has been to perform early surgery. Now I have to say, that it sometimes puts me at odds also with the parents.

Narration: But the Melbourne team maintains surgery is more successful medically, if it's done much earlier.

More importantly, they think they can now largely predict gender identity, based on a new theory.

They suspect that in boys, it's a surge of testosterone, two months after they're born, that primes the brain to be male.

Professor John Hutson: Well, if the if our theory is right and the and the postnatal hormone production between 2 and 4 months really does programme the brain to be male, then there'll be no way if we delay treatment that we can ever raise a child as a girl in adolescence or adult life. It will fail because those people will become masculinised by hormone exposure.

Narration: By the time the team saw Bryden, he was already 8 months old. According to their theory, his brain had been masculinised. It was too late for any other decision. Bryden would be a boy.

Jacinda: as we always say to people, if it was finger or a toe he's he's got nine others, but he had one shot at making a penis.

Narration: At 18 months of age, Bryden went under the surgeons knife.

Professor John Hutson: In this particular child we've brought the testes to the scrotum so we've done what we call orchidopexy which is to bring the testes operatively from where it is in the groin into the scrotum on each side. We've joined the scrotum together to form a single bag instead of these two half bags that we have at the moment. And we've taken the vagina cavity out so that that doesn't fill with urine and get recurrent infection in it and we've made the tube that would form the urethra so that it's now inside the penis.

Narration: It took four surgeries, but by 3 years of age, Bryden had fully male anatomy.

So what accounts for this extraordinary condition in the first place?

Surprisingly, all embryos are primed to become females. But a cascade of genes and hormone directs the baby to male. It begins at 7 weeks, when the master male SRY gene switches on the development of testes.

The testes then produce testosterone. Testosterone switches on the development of other male features like the penis.

If all the switches work, it's a baby boy.

Ass. Prof Andrew Sinclair: I think one way to think about it is that the female is the basic body plan, so that an ovary will automatically develop. And you need some active switch, the SRY gene on the Y chromosome, to activate testes development.

Narration: If anything goes wrong with this complex sequence of events, it can result in intersex.

Dr Andrew Sinclair is the man who discovered the original male master gene, SRY. He's now looking for the remaining sex determining genes. And children like Bryden will help.

Ass. Prof Andrew Sinclair: Bryden is very important to us. Patients like that provide us with information about the normal functioning of the gene in the testis, and by the same token we can provide information back to the family about the variation we see in that gene in Bryden's case, and that gives the family better information about understanding the condition, but also about how that particular gene may be inherited within the family.

Narration: As for Bryden, his prospects now look good. New research shows he has more than a 75% chance of a successful sex life. What's more, it shows good self esteem is related to the supportiveness of the family.

Jacinda: I just want him to be happy. I don't want for him to be doctor or lawyer. Of course I don't want him to be a gigolo either – although I'm sure the doctors would be really happy. But no, I just want him to be happy and use what he's got and be proud of it.

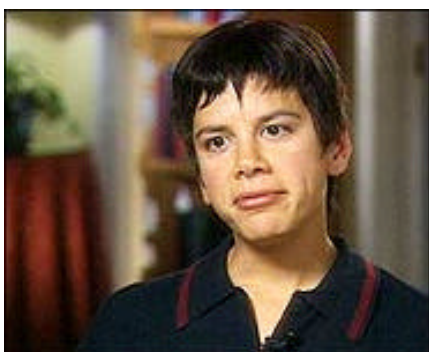
## Controversy Over Operating to Change Ambiguous Genitalia

From ABCNews.com. 19 April 2001.

[http://abcnews.go.com/sections/2020/DailyNews/2020\\_intersex\\_020419.html](http://abcnews.go.com/sections/2020/DailyNews/2020_intersex_020419.html)

Hida Viloría, 33, is not the least bit confused about her gender. "I'm female," she says, "I just feel like I'm a different variety of female."

She's different because she was born with ambiguous genitalia. "My clitoris is much larger than, I think, the average size clitoris," she explains. "And so because mine is larger, it's grown a little more to where it starts to resemble a small penis."



Viloría had no idea she looked different from other little girls until she was 11, when she saw one of her friends as they changed into their bathing suits.

Thousands of girls like Viloría who are born with ambiguous genitalia - known as hermaphrodites or intersexual - have routinely undergone surgery as babies to remove or reduce an enlarged clitoris.

Many doctors believe that operating on an intersex baby's genitals within the child's first year is best for both the child and the parents.

"We believe operating on the genitals in infants is psychologically better to do when the child is younger," says Dr. Kenneth Glassberg, a pediatric urologist. "I think the individual who is not operated on will have problems in society as we know it today."

The American Academy of Pediatrics also says early genital surgery may be best for intersex babies. But over the last few years, a storm of controversy has erupted over the ethics of surgery for intersex babies. Some intersex adults, like Viloría, who has not undergone any surgery, charge that the surgery, for cosmetic purposes, is nothing short of mutilation.

### For Viloría, Information - Not an Operation

Growing up, Viloría says she was a popular, sociable tomboy who excelled at sports, but never doubted she was a girl. She got her period and knew she could have a baby some day. She did, however, hit a rough patch when she became sexually active. First she dated men, but then, like many intersex women, she says she realized she was a

lesbian. That's when she understood just how different her genitals were from other women's.

"Everybody knows how penises function," says Viloría. "But clitorises actually function the same way. And so for an enlarged clitoris, there's a pretty visible difference when you're being sexually active."

Essentially, she explains, she had an erection: "I enjoyed that immensely, and so did my partners."

But she was mystified, and wanted some answers. "I did kind of wonder if maybe I was male," she says. "But I knew, technically, I wasn't."

At 27, she figured it out - far less traumatically, she says, than if she'd had surgery. She happened to see a newspaper article about intersexuals, a term she had never heard before.

"I just remember being like . Oh my God, I think this is me," she says. "I was overjoyed to know what I was."

Because her answer came from information - not the operating room - she thinks intersexuals should not undergo operations as babies. Instead, she says, they should be allowed to decide as adults if they want their genitals altered.

### The Scars of Surgery

A growing number of doctors, who argue that the surgery is about as medically necessary as a facelift, agree with Viloría.

"We've heard more and more and more people coming forward saying, 'This hurt me, either physically, psychologically or both,'" says Dr. Bruce Wilson, a pediatric endocrinologist at Michigan State University. "To hear a group of people saying, 'I don't have normal sexual response,' 'I have painful sex because of the scar tissue,' 'I feel completely asexual because of what was done to me,'" says Wilson, was all he needed to lead the revolt.

Cheryl Chase is one of the angry intersexuals who had an operation at 18 months old. Doctors removed her clitoris because it was enlarged, a surgery known as a clitorectomy.

"I can't have an orgasm," says Chase, who believes her inability is due to the surgery.

Glassberg believes the clitorectomy would not have been performed if Chase were now an infant, because doctors now reduce the size of the clitoris instead of removing it. But some physicians say that even a reduction may damage nerves and interfere with sexual pleasure.

"Any time I think about it, and think about the fact that it could have happened, I just thank the universe above," says Viloría. "Accept that we're here," says Viloría. "Don't try to cut us up or change us or shame us or hide us."



## 'Bodies Like Ours' Appear on ABC News Health Special

betsydriver@bodieslikeours.org  
www.bodieslikeours.org

On July 31, 2002, ABC News broadcast a special on women's health and focusing on the brain in the US. One of the segments in this special health show will include the role of Congenital Adrenal Hyperplasia on female brain development and behavior.

Dandara Hill and Betsy Driver of Bodies Like Ours were interviewed for the segment on Congenital Adrenal Hyperplasia (CAH). In the interview, Dandara talked about growing up with CAH and Betsy Driver spoke about how CAH has affected her adult life.

Behavior and gender theorists have recently started to study women with Congenital Adrenal Hyperplasia in an effort to better understand the effect of hormones on the brain. Congenital Adrenal Hyperplasia is unique because of the role the excess androgens play in the growth and personality of females with CAH. Congenital Adrenal Hyperplasia is the most common cause of all intersex conditions.

Founded in 2002, Bodies Like Ours provides support and information for people born with atypical genitalia and the elimination of the shame and secrecy of intersex births through education, awareness, and community. Bodies Like Ours is a non-profit 501(c)(3) organization, incorporated and based in Tewksbury, NJ, USA.

To learn more about Bodies Like Ours, please visit our website at [www.bodieslikeours.org](http://www.bodieslikeours.org)

## Not so "odd" spot.

In a first, a US railway company has paid US\$2.2m to settle a complaint that it had genetically tested 36 of its employees without their knowledge or consent. The Equal Employment Opportunity Commission mediated the settlement, which came after Burlington Northern and Santa Fe Railway Company employees complained the company had breached the Americans with Disabilities Act by requiring them to submit to a medical examination, which included a blood test for a specific genetic marker. Some employees claimed they were disciplined for refusing to submit to the exam.

## Good Medicine on Intersex

The April 2002 edition of Good Medicine Magazine included a very good article about intersex conditions, including AIS. Written by Dr Gillian Eastgate with considerable input from Dr Andrew Cotterill, amongst other things the article is encouraging of joint efforts

between the medical profession and the AISSGA. Good Medicine Magazine appeals to a wide readership and this article is a significant step towards increased understanding of intersex conditions. There is a glossary at the end of the article that has good, easy to understand explanations of various intersex conditions. Tony Briffa's story appears as a side bar to the main article and full contact details for the AISSGA are also included.

The following is the complete article.

## Congratulations it's a....?

Raising an intersex child calls for love and courage. Dr Gillian Eastgate looks at the problems parents face when coping with the gender dilemma

The new baby arrives, pink and squealing. Mum gives the first feed and cuddle, while dad gets on the phone and calls all the friends and relatives. "It's a..."

But what if it's not clear whether the baby is a boy or a girl? Believe it or not, this is the case for about one in every 4500 babies born in Australia each year. At least 18,000 Australians are living with one of a number of "intersex" conditions.

So what do you tell your family and friends? Do you write "M" or "F" on the birth certificate? Which toilet should the child use at school? What about puberty and adult life?

Dr Andrew Cotterill has treated intersex children since 1986. The Brisbane-based paediatric endocrinologist has helped to develop a new test for androgen insensitivity syndrome (AIS), and is currently working with the AIS Support Group to develop an information booklet for families with an intersex child.

### Accepting your baby

Dr Cotterill says that parents need encouragement to accept their baby first as a person, and to see their child's gender as secondary.

"We'd say, 'You have a beautiful healthy baby. As you can see, we can't tell yet what sex the baby is,'" he explains. "During the first few weeks we do genetic and hormonal tests, then we decide with the parents whether to raise the child as a boy or a girl." In some cases babies undergo surgery to make their genitals look more typical for the chosen gender.

"Some adults who are unsure about their sexuality confess, I wish I had not had an operation as a baby'," reveals Dr Cotterill. "But when I talk to parents, most want a clear-cut decision, male or female, blue or pink. It's asking a great deal of a family to live with gender uncertainty until the child grows up."

### The need to know

Families need information about their child's condition and encouragement to be open about it. "We advise the family at the beginning that secrecy is no good for the

family or the child,” says Dr Cotterill. “We advise them to discuss it bit by bit as it comes up in conversation. Kids only need snippets of information.”

“It’s important to reveal the diagnosis gradually without damaging the child’s developing personality.”

Full disclosure should be given at adolescence, preferably as the child asks for information. Teenagers need to know that they will be infertile and will have to take hormones. They also need information about sexual function and any possible difficulties before becoming sexually active.

Young adults may be confused about their gender and sexual orientation. “Parents may ask themselves, ‘Did I make the right decision?’ about their gender, and try to push their child in a particular direction,” says Dr Cotterill.

“It’s very important for the family to accept them, and for them to accept themselves, as people.”

Frequent medical attention can be upsetting for intersex children. “Many people have been so traumatised by full-on medical examinations that their sense of self is not strong,” explains Dr Cotterill.

Fortunately, community awareness and medical knowledge are growing, and there is less secrecy today than there was in the past.

“We’ve gained experience, and have learned from problems that have arisen,” says Dr Cotterill.

“Hearing the perspective of support groups helps us improve the way we deal with patients.”

Hopefully, today’s intersex babies will find growing up a little easier.

### **Intersex conditions**

**AIS** In this genetic condition the sex chromosomes are those of a typical male (XY), and androgens are produced normally. However, androgen receptors in the body cells are unable to respond to these androgens.

**Complete AIS (CAIS)** In this condition there is no androgen (male hormone) response. The baby appears female, with a vagina, but no uterus or ovaries. Testes are present in the abdomen or the groin. People with CAIS are raised as girls and usually have no conflict over their gender. The androgens in the body are partly converted to oestrogens, and feminine development occurs at puberty, but they have no periods and are infertile. The vagina can be shorter than usual, causing difficulty with sexual intercourse.

**Partial AIS (PAIS)** In this condition there is a partial response to androgens. The baby may appear to be male, female or somewhere in between. The testes may be in the abdomen, the groin or the scrotum. People with PAIS may be raised as girls or boys.

At puberty there may be a mixture of male and female development. But all are infertile, because the testes do not produce sperm.

After puberty there is a 10 per cent risk of testicular cancer, so the testes are usually removed.

This is often done in childhood because, says Dr Cotterill, “It’s difficult to explain to a 14 year old girl that an operation is, in fact, to remove her testicles at a time when she is coming to terms with her condition.”

Some doctors recommend waiting until after puberty to operate, because the hormones produced help with body development and bone strength.

Regular testing may be an alternative to surgery, but is not yet common practice in Australia. After the removal of the testes, hormone treatment is required to maintain health and prevent osteoporosis. Women are given oestrogens, while PAIS men may try androgens – however, the response to this treatment varies.

### **Other conditions**

The testes may fail to develop in a baby born with XY chromosomes. There are a number of conditions, all thought to be genetic.

Several enzymes are needed for androgen production. Genetic anomalies in these can cause either a lack of androgens in boys or an excess in girls.

Some people have variations in sex chromosomes, including XXY, known as Klinefelter’s syndrome, and XO/XY, known as mosaicism.

Very rarely, a baby is born with both male and female organs. Usually the chromosomes are male (XY) but the usual mechanism to “switch off” female development does not occur.

Most, but not all, people with these conditions are infertile.

### **How do we become male or female? (sidebar)**

At conception we receive half of our genetic material, or DNA, from each parent. This DNA is arranged in 46 strips called chromosomes, and each strip contains thousands of genes. The sex chromosomes – called X and Y – determine our “chromosomal” or “gonadal” sex. Usually females have two Xs (XX), while males have one X and one Y (XY).

Early in pregnancy the genitals of boys and girls are the same, a cleft with a small button of tissue at the front end. In a typical baby boy, the button enlarges to form the penis and the cleft closes over to form the scrotum. In a typical girl, the button becomes the clitoris, the cleft remains open as the vagina and the uterus develop internally. The gonads (testes in boys, ovaries in girls) form in the abdomen, and the testes move down into the scrotum. Typical male development will only happen if there is both a Y chromosome and male hormones (androgens – the main one is testosterone). If either of these is absent, development is partly or completely female.

At puberty a surge of hormones (androgens in boys, oestrogens in girls) causes rapid growth, development of adult male or female body shape and the maturing of the genital organs.

## Tony's story (sidebar)

"The doctors were unsure of my sex when I was born," says Tony Briffa 31, who has partial androgen insensitivity syndrome (PAIS). He was christened Antoinette and raised as a girl – though he knew he was different from this twin sister.

His testes were removed at age seven, though "even my parents didn't know that my gonads were, in fact, testes," he says. "I was told when I was 11 that I couldn't have children, would not have periods and would have to take hormones for the rest of my life. I was treated like a medical curiosity at the hospital. The secrecy, shame and confusion over my gender made adolescence very difficult indeed."

Tony was given oestrogen as a teenager, but didn't take it regularly because he wasn't comfortable with a female identity. As a result, he now has severe osteoporosis. He didn't even know the whole truth until he was 30, and recently he has started testosterone treatment. "The results have been incredible," he says. "I have masculinised somewhat and have changed my name to Anthony. I feel that I am finally becoming the real me."

Gender issues haven't stopped Tony from leading a full life. He works as an engineer, and is a foster parent to a nine year old boy. He is also president of the AIS Support Group in Australia, and an advocate for people with AIS and other intersex conditions.



## Yale Law and Policy Review Examines Surgical Liability

[http://ai.eecs.umich.edu/people/conway/TS/Ford\\_Yale\\_Law.htm](http://ai.eecs.umich.edu/people/conway/TS/Ford_Yale_Law.htm)

The following are excerpts from "First, Do No Harm" - The Fiction of Legal Parental Consent to Genital-Normalizing Surgery on Intersexed Infants. By Kishka-Kamari Ford and published in Yale Law and Policy Review 19 (469) 2001.

From the introduction:

"Medical professionals recognize the Latin mantra *Primum, non nocere*, "First, do no harm," as the first principle of medicine. Yet, between one hundred and

two hundred times a year in America, pediatric surgeons do harm when they surgically "correct" the ambiguous genitalia of intersexed infants. These surgeries, which I call "genital-normalizing surgeries", are unjustifiably performed on an emergency basis and supported only by questionable science.

For at least two intersex conditions - clitoromegaly (large clitoris) and micropenis (small penis) - both the diagnosis of the condition and the ultimate result of the surgery are based on subjective notions of what doctors, parents, and society believe to be "normal-looking" genitals. The benefits of genital-normalizing surgery have yet to be documented. The physically and psychologically harmful effects have been all but ignored despite the outraged cries of the procedures' victims.

This Note exposes these surgeries as lacking legally necessary informed consent."

Once the author describes the history of the treatment of people with intersex conditions, he then details the current medical diagnosis and treatment of intersexed infants in America. The basis of the current treatment paradigm are then reviewed, which is followed by a comprehensive overview of the doctrine of informed consent to medical treatment, and discussion on whether the emergency exception to this doctrine can reasonably be applied to the birth of an intersexed infant.

The legalities of parental consent to medical treatment for minor children is then reviewed followed by an analysis of the current model of treatment of intersexed infants to determine whether or not it can fairly be characterised as "experimental" treatment and thus outside of the bounds of that to which the parents of an intersexed infant can legally consent.

The following is from the article's conclusion:

"Surgeons who perform genetic normalizing surgery, whether on an emergency basis or at the behest of the intersexed infant's parents, should be aware that, because genital-normalizing surgery is not necessary nor proven beneficial for the infant with clitoromegaly or micropenis, the required elements of legal informed consent are likely to have not been met. In light of the questionable scientific basis behind its use, the lack of follow-up data on its benefits, and the overwhelming evidence of its negative physical and psychological results for many intersexuals, a moratorium should be declared on the use of defenseless infants as the experimental subjects of genital-normalizing surgery."

It is certainly interesting reading the legal perspective of the treatment of intersex conditions. Ultimately however, the medical and human rights point of view is what the AISSGA is concerned about, and we welcome an open review of the current treatments practices with all concerned.

**“It is my contention that it is the parents and doctors of intersexed infants who are experiencing a medical emergency, not the intersexed infant.”**

- Kishka-Kamari Ford, Yale Law and Policy Review

## Reflection Time...

Mohandas Karamachand Gandhi, one of the most influential figures in modern social and political activism, considered these traits to be the most spiritually perilous to humanity.

- Wealth without Work
- Pleasure without Conscience
- Science without Humanity
- Knowledge without Character
- Politics without Principle
- Commerce without Morality
- Worship without Sacrifice

## The Appropriation of the Intersexed.

By Chris Somers

There are a number of people within the transgendered (TG) and transsexual (TS) communities who have appropriated the word ‘intersex’ and use it to gain political advantage. This is doing a major disservice to those who have been born both physically and or genetically different to the mainstream, thereby undermining their differences and their value as people. It assumes that a gender dysphoric person is the same as an intersexed person. The incorrect usage of intersex has been used primarily to gain a powerful validation of TG and TS peoples who have found difficulty in being accepted; both within the community and within themselves.

When a group of peoples uses other people’s realities in order to reinforce and validate their own at the expense of those whom they misappropriate, they become the oppressor and suppresser of those they exploit unwittingly or by design. In so doing, they deny the reality of those whom they have disadvantaged, in this case the intersexed communities whose realities are then in danger of being subsumed by focusing undue attention on themselves.

This denial of the intersexed communities’ intrinsic differences by a number of people within the TG and TS communities is debilitating to say the least; for it denies

the personhood of a peoples who have been severely disadvantaged for centuries and in particular in recent modern history. This I believe is because those who are TG and TS have a real need to find acceptance within the general communities. A number of them have as a result searched for an interpretation that they feel they could use to validate their acceptance, which is understandable. In so doing they recognised the reality of the intersexed persons physical and or genetic actuality as an extremely powerful tool for political change. As a result those that do appropriate the word intersex for their own, use it for their own political agendas. And in so doing deny those who are intersexed by devaluing their existence by commandeering their reality for their own use or cause.

The intersexed person is not normally gender dysphoric and recognise they are both physically and or genetically different to the majority of sexes.

The problem arises then, that the intersexed community who have been successfully hushed up for centuries, become further subsumed by those wishing to acquire aspects of their reality, and consequently the intersexed are in danger of being either severely compromised or totally negated as people. Those members within the TG / TS and other communities who are appropriating intersex as their reality are negating those of us who have for years been hidden from view. This misinterpretation and acquisition of the intersexed terminology by an increasing number within the TG / TS and other gendered communities is quite disturbing and is without doubt being used as a political strategy. The tragedy here is that the genuinely intersexed person is again negated by the whole of society, which becomes further confused by this misappropriation and with it the ignorance within the community is further reinforced.

Whereas there are some parallels between the intersexed and the TG and TS communities, it is important for us all to recognise each other’s differences without undermining any one group of peoples to reinforce the existence of another.

I am certain that we can all help each other, but in doing so must recognise that we all have certain actualities that are intrinsic to ourselves and should not be exploited in a detrimental way where we are in danger of being undermined by another. We must find the common ground and where we can help without balking at the difficulties we should, if we are to make substantial, equitable and progressive changes in genetics, medical, social and clinical practice and in education, ethical considerations, human rights, legislation and politics inclusive of the whole gambit of society in the way in which we are understood and accepted. So in conclusion let us work together where we can, while recognising our differences without inadvertently undermining or exploiting each other without mutual consent...



## ALSORTS

By Andie Hider

On Monday evening 29 July 2002, I attended the launch of a booklet called ALSORTS a resource for youth workers, counsellors and other associated health care workers that may have to deal with relationship, sexual development or sexuality issues. Tony Briffa had worked extensively with the ALSO foundation up to this point to ensure accurate and up to date information about intersex conditions was included in the booklet and his contribution was publicly acknowledged at the launch.

6000 copies of the ALSORTS booklet have been widely distributed throughout Victoria and interstate. The booklet includes full contact details for the AIS Support Group Australia as well as the contact details for relevant health care professionals. Initial feedback about the booklet has been excellent and the AIS Support Group Australia has a number of copies of ALSORTS if members would like one.

## Gynaecological Awareness Forum

### VIVA LA VULVA

An awareness-raising afternoon for women about female genital health and sexuality.

#### When:

Thursday 28 November 2002, 2.00pm to 5.00pm.

#### Where:

Yvonne Bowden Auditorium, Royal Women's Hospital, 132 Grattan Street Carlton.

#### How much?

\$17/12 concession (Refreshments included)

#### Topics and speakers:

Maggie Kirkman (chair) Introduction  
Tanya Bohl - Female genital anatomy and ailments  
Diane Perry - Loss, pain and sexuality  
Alexa Rosengarten - Wholeness and intimacy  
Panel: includes speakers, Kath Mazzella and Stella Heley,

#### Organised by:

GAIN Gynaecological Awareness Information Network,  
[www.gynsupport.com](http://www.gynsupport.com), Key Centre for Women's Health in Society, University of Melbourne, Absolutely Women's Health, Royal Women's Hospital.

#### Enquiries & Booking: 8344 4333

For catering purposes it would be helpful if bookings were made, but paying on the day is quite acceptable.

## Lenore

by Edgar Allan Poe

Dedicated to a special friend with an intersex condition.

*Ah, broken is the golden bowl! the spirit flown forever!*

*Let the bell toll! -a saintly soul floats on the Stygian river -*

*And, Guy De Vere, hast thou no tear? -weep now or never more!*

*See! on yon drear and rigid bier low lies thy love, Lenore!*

*Come! let the burial rite be read -the funeral song be sung!*

*An anthem for the queenliest dead that ever died so young*

*A dirge for her, the doubly dead in that she died so young.*

*"Wretches! ye loved her for her wealth and hated her for her pride,*

*And when she fell in feeble health, ye blessed her -that she died!*

*How shall the ritual, then, be read? - the requiem how be sung*

*By you - by yours, the evil eye, - by yours, the slanderous tongue*

*That did to death the innocence that died, and died so young?"*

*Peccavimus; but rave not thus! and let a Sabbath song*

*Go up to God so solemnly the dead may feel no wrong!*

*The sweet Lenore hath "gone before," with Hope, that flew beside,*

*Leaving thee wild for the dear child that should have been thy bride -*

*For her, the fair and debonnaire, that now so lowly lies,*

*The life upon her yellow hair but not within her eyes -*

*The life still there, upon her hair -the death upon her eyes.*

*Avaunt! Tonight my heart is light. No dirge will I upraise,*

*But waft the angel on her flight with a paean of old days!*

*Let no bell toll! -lest her sweet soul, amid its hallowed mirth,*

*Should catch the note, as it doth float up from the damned Earth.*

*To friends above, from fiends below, the indignant ghost is riven*

*From Hell unto a high estate far up within the Heaven -*

*From grief and groan to a golden throne beside the King of Heaven."*

## Letter from Bev in Canada

This is a copy of an email I received from one of the AISSGA's past Presidents about a meeting of the AISSG Canada. For those that have joined the AISSGA after Bev returned to Canada, she was always very supportive and passionate about her role with the group, and took new members particularly under her wing. Since returning to Canada she has become involved with the local AIS support group.

Hi Tony. Thanks for keeping me in touch with my Aussie AIS friends. We had a great meeting of AISSG(Canada), Western Canada Branch on July 1. This was one group I didn't help organise. It was well attended with lots of new people, especially young people from across Canada, California, Seattle and Mexico. The morning was a talk and multi-media discussion on the genetics of AIS births, and similar conditions. It generated a good deal of discussion and we came away with a print out of the lecture. This was followed by AIS folk meeting in one room, parents, and health care workers in another. I went between both groups to make sure a support person was there and to keep discussion going and feelings acknowledged. We had a wonderful lunch catered by one of our regular members and the afternoon was attended by both groups.

In summary we had an hour to plan our next meeting and discuss attending the US meeting being held in Toronto August 2003. As the facilitator of this meeting I learned a lot from the dynamics, and felt good about my role in making newcomers welcome and also creating the space for people to talk, feel, and express their emotions. My Aussie friends would be proud that I was practicing all that I learned in Australia. I hope many of you will consider coming to Toronto for our meeting so that I can see you and give you a big hug. Keep on with your good work. Love to all.

Bev.

We wish Bev and the AISSG Canada well for the future.

## **Prof. Milton Diamond Intersex Conditions Seminar 20 October 2002, 7 pm. Melbourne**

The seminar will include details of Prof. Milton Diamond's AIS research, and will provide the audience with an opportunity to engage in discussion on the treatment of people with intersex conditions.

This forum is open to people affected by intersex conditions and interested health professionals only.

People must RSVP by 15th October 2002 to attend this seminar.

Contact Tony for further information on 03 9315 8809, 0418 398 906 (mob) or [aissg@iprimus.com.au](mailto:aissg@iprimus.com.au).

For information about Prof. Milton Diamond and the Pacific Centre for Sex and Society, please visit their website at <http://www.hawaii.edu/PCSS/>.

## **Next National AISSGA Meeting 16 & 17 November 2002. Melbourne**

Contact Tony for further information on 03 9315 8809, 0418 398 906 (mob) or [aissg@iprimus.com.au](mailto:aissg@iprimus.com.au).

## **Next dAISy Deadline 1<sup>st</sup> February 2003**