



dAISy

March 2003 Edition

AIS Support Group Australia's Newsletter

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

ISSN 1446-8026

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
Web: <http://www.vicnet.net.au/~aissg>
(Payments payable to AIS Support Group Australia please)
Note: The AISSGA is independent of the AISSG(UK).

ISSN 1446-8026 © 2003

Tony's Message



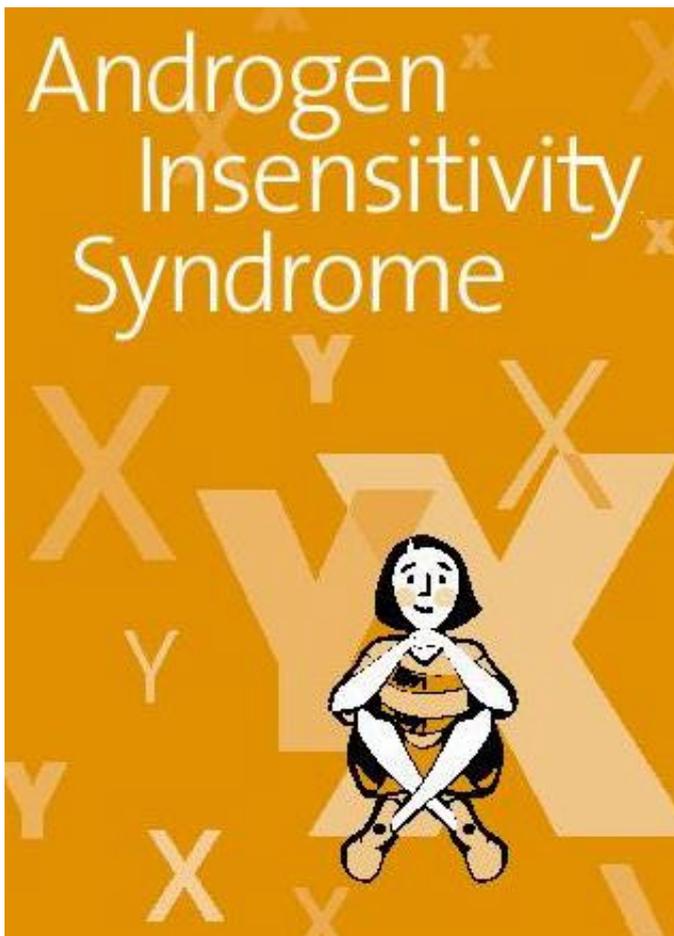
Welcome to the first dAISy for 2003. Producing dAISy is a big task undertaken by a large group of people from those who submit articles to the person who edits the final product. It's reassuring to know our efforts provides information and/or support to so many people affected by AIS and other intersex conditions and many medical professionals from all over the world who read it. dAISy as we know it turns three years old this month and readership has grown to well over 1000 people all over the world. It has now been three years since I first became a committee member and I am extremely proud of the work we have done as a group since then. The number of families contacting us and visiting the website increases constantly and our membership has grown steadily.

As always, the time since our last newsletter has passed very quickly and much has happened, including the launch of our new AIS Brochure at a Milton Diamond seminar in Melbourne, National AISSGA meeting and AGM, and taking an active part in political lobbying in QLD, NSW and the ACT. Andie and I had the pleasure of taking Milton Diamond and his wife, Connie, to some of our favourite spots in Melbourne and Victoria.

At our AGM we awarded life membership of the AISSGA to Garry Warne in recognition of his contributions to the support group as well as improving the way intersex conditions are treated and perceived. We also voted in our new committee with some new faces putting their hand up to help run the group.

Since the meeting we have had a couple of social evenings and some members met with Dr Susan Fung who was visiting from China to learn more about the treatment of intersex conditions. Apart from an AGM in Melbourne later this year, the AISSGA has meetings coming up in Brisbane and Sydney hopefully giving our members the best opportunity to attend a meeting relatively close to home.

The AISSGA has increasingly been called upon to represent people affected by intersex conditions in a number of processes, particularly those relating to law reform and I have written submissions on behalf of the AISSGA for Queensland, NSW and the ACT. In February I was invited



The cover of our new AIS brochure

to give a presentation to the Anti Discrimination Board of NSW.

The AISSGA continues to build upon our past successes and our membership contributes much to ensuring we remain a group that is well placed to offer support, advice and information to individuals, families and groups who approach us for assistance.

I would like to take this opportunity to thank everyone that contributed to dAISy and acknowledge the courage it takes for people like Jack to tell their personal story. I would also like to congratulate Jeanne on adopting Alex from China and for sharing her experiences of the adoption with us all.

I would also like to make special mention of Jack's wonderful artwork which he so kindly contributed for this issue of dAISy. As you can see, we have some very talented people amongst us! Please feel free to contact Jack for more information about his art.

Best wishes to you and your loved ones,

Tony Briffa
President, AISSGA

State Representatives & Functions

The AISSGA is a national group with a President, Secretary, Treasurer and General Representatives at an executive level, and with State Representatives in all States and Territories in Australia who also form part of the committee. Most of our members are Australian, but we also have many members overseas that we are looking to help support locally by the sponsoring of groups in their area. The AISSGA relies on the State Representatives to organize functions within their state such as social evenings or National Meetings, and to be the point of contact for information and support for members in their state. The President and Secretary are also willing to provide assistance at any time.

The committee is elected by all members annually at the AGM with postal voting available for those unable to attend. The following is a list of our current committee:

President	Tony Briffa
Secretary/Medical Liaison Officer	Andie Hider
Treasurer	Tony
ACT/NSW Rep.	Sandra
Victoria/Tas Rep.	Jocelyn
SA Rep.	Carol
WA Rep.	Danni
NT	Andie
QLD	Peter
Men with AIS Rep.	Peter
Parent's Liaison Officer	Sue

Please contact Tony for contact information for your State Representative.

Index

Tony's Message.....	1
State Representatives & Functions	2
New AIS Brochures!.....	3
Milton Diamond Visit.....	3
You Can Always Adopt.....	4
Jack's Story.....	6
Personal Value	10
AIS Couple Unplugged! (Pt 2).....	11
The Neglected Communities Forum – NSW Anti-Discrimination	13
ACT Law Reform.....	13
New Intersex Study Fuels Debate	14
RCH Surgeon's Paper Under The Knife.....	15
Follow-Up Study On The Treatment Of Children With Intersex Conditions.	16
Letters	16
The Obstacle In Our Path	16
Next National AISSGA Meeting	16
National AISSGA Meeting In Sydney!	16
Next dAISy Deadline	16

Disclaimer:

This newsletter aims to provide information on AIS and other 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. © 2003.

ISSN 1446-8026



New AIS Brochures!

The AISSGA launched our new AIS brochures at a function at the Royal Children's Hospital in Melbourne last October. The function, a combined brochure launch and Milton Diamond Seminar, was held for members and medical professionals and was well attended. Here is an extract of Tony Briffa's speech at the launch:

"The AIS Support Group Australia has established itself as a responsible and well-organised peer support, information and advocacy group which represents the needs of people affected by AIS and similar conditions. For the last three years we have raised money to produce a brochure for medical professionals to give their patients. The feedback from draft versions of the brochures from doctors, parents and adults with AIS and similar conditions has been very positive. I am very confident these brochures will help provide people not only with basic information about AIS, but they will also help them find support. This of course, is the basis of our group.

Tonight I am proud to officially launch this brochure by presenting copies to Professors Milton Diamond and Garry Warne.

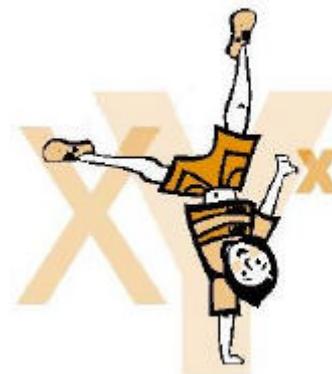
I invite health professionals to distribute this brochure to anyone with AIS or similar conditions, and to circulate the brochures amongst their professional peers. For further copies, please contact the AIS Support Group Australia."

Tony also formally thanked the Genetic Support Network of Victoria and Royal Children's Hospital for their support producing the brochures.

Medical professionals have shown widespread support for the brochure and have been distributing it to many of their patients. State Representatives have also been busy distributing the brochures to hospitals in their state. The response from doctors, patients and parents has been excellent.

The AISSGA has plans to produce a patient-centered publication about intersex conditions that we are currently trying to fund. We will keep you informed with this project as it develops.

Thank you to all members who donated money or assisted with the drafting of the AIS brochure. We should be very proud of our result.



The 'Happy and Healthy' Character in the AIS Brochures.

Milton Diamond Visit

The AISSGA was honoured to present a seminar featuring Professor Milton Diamond for our members and the Australian medical community.

Milton Diamond (or simply 'Mickey' as he is known to many of us) has a long history of researching intersex conditions and helping those affected by them. He has been the major proponent of a patient-centered approach for the treatment of children with intersex conditions for several decades, and his work with exposing the very questionable work of Dr John Money has helped raised awareness of intersex conditions and the issues of surgically assigning sex in infants.

His three main proposals mirror some of the main policies of the AISSGA.

1. Stop unnecessary medical intervention;
2. Perform objective follow-up studies to research the best treatment practices for children with intersex conditions; and
3. Provide patients and families with full disclosure of the diagnosed intersex condition and allow them to make decisions on treatment options based on informed consent.

Many thanks to Mickey and Connie for their time and friendship, and for the members that traveled interstate to attend the seminar.



Tony, Andie and Mickey at Victoria's Great Ocean Road.

You Can Always Adopt

By Jeanne Hastings

When I was 12 years old I heard those horrible words that are very familiar to intersexed people, “you will never be able to have children”. That was some of the most devastating news I have ever heard. Nothing else the Doctor told me that day registered at all except that. I had no idea what else he was talking about nor did I care. I was in physical and emotional pain and just wanted to go home and cry. My mother, trying to make me feel better immediately told me “*you can always adopt*”. Hearing that didn’t help me at all, it was not a comfort. That was such a small Band-Aid to put on such a huge wound. I hurt for years because of what happened that day. **I stumbled through life not really knowing why I couldn’t have children but forever thinking that no one would ever want to marry me and I will be alone for the rest of my life.**

When I turned 40 I discovered the Internet. One of the first things I did was type the words “hermaphrodite” into my browser. My life changed forever from that moment. I discovered that I have PAIS and the truth about what that really meant was right in front of me. I found all kinds of people and web sites full of information. I finally began my quest for truth and started healing from the wounds caused by the secrets kept from me. What a wonderful time in my life it has been. I finally feel like a whole, “normal” person now. If they had given me this information when I was 12, life would have been a little easier.

One of the web sites that really caught my attention was a yahoo group called *aispeople2*. There I found people with intersexed conditions just like mine or very similar. I found friendship and knowledge. The amount of support I have received from my AIS sisters and brothers has been greater than any of the support that I have received throughout my entire life. This group carried me through so many happy and devastating times. I had so many questions and found every answer I was looking for. It is so good to know that I am not alone and not a freak of nature. I consider every member of that group my true friends.

Three years pasted by, much healing and soul searching happened in my life. One day in January of 2002, I was checking the posts in my yahoo group as I do every day. This particular day really caught my eye. In January 2002, Tony Briffa, one of the founders of the group, posted a note about **a two-year-old, intersexed child from China that was available for adoption**. I have no idea why, but I felt this incredible, overwhelming feeling that I should ask more questions about him.

I found out some of the requirements for single people to adopt from China. You have to make at least \$30,000 per year, under the age of 45, have health insurance, and secure income. I met those requirements so I started getting even more interested. I got in contact with the Children’s Home Society of Minnesota about my chances of adopting this child. I found out that three other “couples” were inquiring about him and that they would have preference because they are married and I am not. I understood that they felt a two-parent family would be a better situation for him. I remember thinking, that parents that are clueless to his

intersexed condition will raise this poor child. I felt badly for him. I was excited to hear that one of the members of the group and her husband were one of the couples that were interested in adopting him. One by one each couple for what ever their reasons decided not to adopt him.



Alex in traditional Chinese dress.

Kelly, my social worker called me and told me that I could go ahead and try for the adoption. She assured me that I was the only one interested before I went on. I still had no idea what he looked like nor did care. My social worker would not give me any information until I was pre-approved by China. The couple from our group had a picture that she shared with me. **It was love at first site**. Kelly told me that it would be a good idea to first apply for a pre-approval before I started on the huge process of adoption. I thought it was a great idea and filled out the appropriate pre-approval paper work. The pre-approval form was a document asking how I would care for this child with “special needs” and why I wanted to adopt him. I went into the usual things about owning my own business, having a good education and all about the support, education and understanding that I will be able to give this child because I have an intersexed condition. After finishing my pre-approval and getting used to the idea that I have a “special need” myself, I thought that that there was no way I would be turned down. I got so excited when I emailed my request to CHSM. I really felt that I was going to become a Mom although I kept reminding myself the words that my mother used to say, “if it is meant to be then it will be”. I guess it is how people feel when they first wonder if they are pregnant.

About two weeks later I got the news. I was turned down for the adoption. I was heart broken and kind of angry. I asked ‘why’ thinking it was because I was single or I didn’t make enough money. **I got turned down because I have an intersexed condition and they didn’t feel that I would be “emotionally stable enough to handle having a child with the same condition”**. I could not believe what I was hearing. They felt that my personal experiences with having this condition could hinder my ability to make good health care decisions for this child. After talking with my social worker, mainly through emails for about two more weeks she suggested applying again. I agreed but this time I volunteered to have a psychological evaluation to go with my pre-approval application. She thought it was a good idea. I also turned back to the people that were truly my

supports, my AIS family. I talked Tony Briffa and told him about what had happened. I received emails of support from Tony Briffa and Dr. Milton Diamond supporting the fact that **a person with AIS not only has the ability to parent an intersexed child but also is the best person for the job.** I didn't know any Psychologists in this area so I chose a name from the phone book for my evaluation. I had a very extensive psychological evaluation, which included a written test. It turned out that the Doctor was the single mother of a child from China. She gave me high recommendations for the adoption. I filled out the pre approval paper work again stressing the fact that I would be able to make well-educated decisions about the health care needs of the child and that I was linked with so many professionals in the field. I also included the letters of support and my evaluation.

After going through the evaluation and the approval process I realized that something had changed in me. I am suddenly talking to complete strangers about my intersexed condition and feel perfectly comfortable with doing so. It feels really good to finally not be ashamed or scared with disclosing this information to people. **The amazing thing is, I'm still alive, no one cares and Oprah hasn't called me to be on her show.** All of my fears of disclosure are of my own creation. I also discovered that I was putting the needs of this child before mine. I was actually feeling very maternal.



Alex with a teddy from Australia

A couple of months went by and I didn't hear anything about the adoption. I still hadn't told any of my family what I was trying to do because I really didn't want them to get their hopes up just to be let down. There was also a part of me that did not want to get my hopes up high either. I was feeling very guarded. Then one day when I least expected it the phone rang. It was Kelly. She said, "congratulations, you have been pre approved". I was so excited for an entire 4 seconds. She immediately popped my bubble and said, "you may still be turned down in the end." At this point I thought that this was just torture. I wanted to be excited, tell my friends and family, get the baby room ready, go shopping for baby clothes and enjoy all of the thrills of getting ready for my baby. I still couldn't do that. Instead I

just put my head down and started the adoption process. Yes, start. I thought I was close but I had so much more to do. A list of the things I had to do was sent to me in the mail and I got started. At this point I asked Kelly if I could at least see a picture of him. She said, "I guess it would be OK" and sent me four pictures of him. I glued his pictures all over my office and got started. I truly believe that if not for the efforts of Tony Briffa, this would never have happened. I felt it fitting to declare him the baby's father.

A home study then needed to be done by a social worker which involved her coming to my house on three different occasions and my going to her one time for an interview. It was painless but time consuming. After that approval, I needed INS clearance, local police clearance, passport, bank statements, a letter from my bank, tax returns for the past three years, a physical, a letter from my accountant, an autobiography, a physical and police clearance for everyone living in my house. Letters saying we are not gay, pictures of the house and family and forms upon forms upon forms to fill out. I was forced at this point to tell my family about what I was doing. I needed a letter from my brother stating that he would care for my child if anything happened to me. They were so happy for me. I was glad to finally tell them about it. Everything needed to be notarized, certified and authenticated. **This was my pregnancy.** It took about 9 months to complete and I was always wondering if I would lose him in the end. Not one time did I question if I was doing the right thing. That's what kept me going. The time just flew by because I was so busy getting everything done. Every time I thought I was done, more information was needed.

At this point my expenses were only about \$4,000 which I thought was good since I still may not be adopting him. I am the biggest tight wad in the world. I hate spending money. I always go through buyer's remorse whenever I buy a house or a car or even spend \$200 on groceries. The funny thing is, I don't even see this as spending money. I can write a check for this adoption without even batting an eye. I remember thinking about something my Aunt said to me about how expensive College was, she said; "that's what money is for". I was also reminded what my brother told me when he was getting divorced. He said, "Do you know why divorce is so expensive? Because it's worth it!" That's how I feel about this adoption and the expense of it all. It is SO worth it and this is what money is for. I won't say exactly how much it cost because then it puts a money value on a child. Instead I will say what I tell everyone that asks me that question. I paid more for my used 1999 Nissan and I can't write that off. Remember that includes airfare, hotels, tour guides and interpreters and two weeks touring China as well as everything else. There are loans and grants available for adoption if you are cash poor and really want to adopt. You really don't need to be wealthy. Just ask your adoption agency for resources.

During this time I received numerous emails from the foster family in China. They told me all about him and sent me lots of pictures. He turned three on September 12, 2002. I sent him some presents and they sent pictures of him opening them. They actually told him that he has a Mom in the US and gave him my picture to carry around with him. I was a little worried about that because his heart would have

just been broken if it all fell through and I didn't want him to go through that. **They told me that he was "walking on air" knowing that it was his turn to have a "forever family" and someone wanted him.** They told me he kissed my picture good night and said "good morning Mommy" every day. It was a blessing having so much contact throughout this long process. It kept me focused and made the adoption real.

Once all of the paper work is done it is sent to the lawyer. The lawyer reviews "the dossier" to make sure everything is in order. He has everything translated into Chinese and then sends it to China for final review. He also lets you know if there are any red flags to be aware of. He said mine all looked great. Just when you think you're all done and the hard part is over you're hit with another difficult time. This was it. I did everything I could. I crossed all of my T's and dotted all my I's. I worked hard for almost a year getting to this point. I had nothing else to do. All I could do now is wait. I had to wait to see if China would let me adopt the little boy that I had come to know and truly love. I was asked every day how it was going? All I could say was "good, but I still don't know if he is mine."

On January 6, 2003, I received the phone call. **China said "yes". He is mine. I could not believe it. I started crying.** I barely could talk. I finally could get excited and embrace the fact that I was becoming a Mom. The first thing I did was go to the aisepeople2 club and posted the great news. I then called all of my family and friends. I applied for my Visa and waited for my consulate appointment date in China. I was called a couple of days later and was told that my date was February 20. I called the airlines, drove to the airport and paid cash for my plane tickets. I could not even wait a couple of days for the tickets to come in the mail. I needed them in my hands.

On February 9th 2003 I will leave for China. On February 10th at 3:35 PM I will land in China. It will be almost exactly 13 months to the day that I first started the process. I will be met at the airport by the foster parents Mike and Elisa and **my son, Alex.** On February 22nd WE will return home to start our new life together.

I guess my mother was right, you can always adopt. I just didn't realize that it would be as wonderful and difficult an experience as giving birth. Although at the time it seemed like the process of adoption was endless, painful, and scary, looking back now it was not that bad at all. The process is definitely worth the results.



The new family! Congratulations Jeanne and Alex.

Jack's Story

By Jack Gossar

My name is Jack. I am 47 and live in California. What follows is my story and how I became aware that I have gonadal dysgenesis. Like many - if not most - who are born intersexed I was lied to about my condition and suffered terrible shame and humiliation regarding the 'big ugly secret' of my condition. The telling of my story produces conflicted emotions within me because in doing so I risk appearing bitter, angry and ungrateful. Additionally I risk incriminating my parents who given their circumstances and resources did the best they could do. I admit my resentment for the medical establishment which has evolved little over the last fifty years in its treatment of the intersexed and even yet draws on the falsified publications of John Money regarding the shaping of gender identity. I no longer feel rage that my childhood was essentially reduced to my ambiguous genitals by the medical establishment and that my parents allowed this to occur. Instead I feel regret that the treatment I endured still occurs. **I am saddened as I realize how poorly my parents were served by the medical establishment when they were asked to have faith in a treatment ethic rooted in secrecy and deception.** My parents were uneducated and uncounselled concerning the details of my condition and thus not equipped to cope with their 'freak' child. My mother suffered from guilt and anxiety and was unsupported by my father. My mother's feelings of guilt were compounded when my father in ignorance and without logic blamed her for my condition. My father's psyche was also bruised by my imperfection because my genital ambiguity reflected poorly on his masculinity. I was often aware of his resentment and disgust for me when he would make vulgar comments or jokes about my genitals. Sadly my parents are deceased so no opportunity for dialog exists. I don't hold them culpable however and understanding the reasons why my parents behaved as they did has allowed me to have compassion for the losses and confusion they sustained as a result of my condition. At this point in my life I have resolved most of the painful issues associated with being born neither fully male nor female. In fact I have come to embrace my uniqueness and would not change anything other than my early medical treatment.

A few years ago I had occasion to see a urologist. While the urologist was taking my history I told him that I had been born without testicles. The urologist asked me why this was so. My response was that I did not know, but I was also surprised by his question. I was surprised because it had never occurred to me that in fact my condition could be the result of some syndrome or that there could be a 'why'. Until that day I honestly believed I was the only one on earth born so freakish; why else would my condition have been shrouded in so much secrecy and shame? The secrecy and shame imposed upon me caused me to feel isolated and alienated for much of my life. Eventually however, the urologist's question provided the impetus to learn more about what I had worked so hard to bury and escape from in my day to day life. Escape was not possible though because as soon as I undressed I was reminded again that I was a freak.

Sharing my reaction to the urologist's question of why I was born without testicles with my much trusted physician Dr. David Foster, Dr. Foster encouraged me to begin exploring my condition by ordering my medical records and reading them. When my records arrived I poured over them and quickly became aware that my gender of rearing was indeterminate until the age of thirteen months when a karyotype was performed and I underwent a laparotomy at the Children's Hospital of Los Angeles. The karyotype indicated I had XY chromosomes but that I also had some abnormal cells the Y chromosomes. My laparotomy revealed one dysgenetic gonad, which was biopsied, but my records did not indicate if the dysgenetic gonad had been removed - an important detail because there is a high probability for malignancies in dysgenetic gonads. Other than the one dysgenetic gonad, no other male or female structures were found in my abdomen. Additionally a description of my genitals recorded my phallus as a clitoris/penis with labia and an imperforate vaginal opening but no vagina. **I found this new information about myself more interesting than disconcerting.** I was disturbed that my records did not contain a diagnosis however because I had a tremendous need to know what to call this thing that had chased me my entire life. Eventually I bulldozed my way into the endocrinology department of a teaching hospital and requested a new karyotype and a full diagnosis. The endocrinologist was helpful and willing to do the work to obtain the answers I sought, unlike the previous endocrinologist I had seen who chuckled when he saw my genitals. **Within a few weeks I had my diagnosis; early fetal gonadal dysgenesis. It felt great to finally put a tag on my condition.** I had also during my quest joined an internet support group for people with androgen insensitivity syndrome (AIS) and similar conditions¹. It was tremendously healing and insightful to connect with people who had suffered similarly as I had. **The joy and liberation of learning that I was not a freak and that I was not alone in the universe was inexplicable.**



'Homage to a Fauve' by Jack Gossar (Jax95945@yahoo.com)

¹ AIS People Club – www.geocities.com/aispeople

In my quest to learn about my condition much of the misery I had endured growing up was rekindled. Like most of those who are intersexed, my earliest memories include having my genitals examined, being photographed naked and being paraded before medical and nursing students. Every visit for my 'check up' was an exhausting day. I had to be up very early for the sixty-mile drive to the Children's Hospital of Los Angeles for an 8:00 a.m. appointment that started with the monotonous gathering of vital information - weight, height, etc. Waiting room waits of around two hours in dingy old rooms before being seen by the doctor(s) were typical. The doctor almost always filled the exam room with an audience of onlookers as he measured my phallus, which never changed, poked around my privates and performed a rectal exam etc. The doctor also ensured to manipulate my genitals to provide the best possible vantage to his esteemed audience. If any of the onlookers were interested they were also allowed to examine me as well. I always sat on the exam table completely naked while my genitals were discussed, pointed to, and handled. Over the years I learned to escape the exams by imagining I was elsewhere. I was seldom addressed so it was easy to dissociate from what was being done to me. **It felt as if my genitals were the only part of me that existed.** There was always discussion and doctor speak about pending surgery to 'normalize' me which terrified me, but I was not allowed to ask questions about what 'normalize' meant. I learned to bury my questions and fear since I had no apparent right to know. I did express once that I did not want surgery while I was in the exam room and the result was a suggestion to my mother that a psychiatrist see me so that I would comply with the treatment plan. My mother was so threatened by the possibility of what I might say to a psychiatrist she became very angry with me and once we were out of the exam room told me (in no uncertain terms) that I would have surgery and that I was to keep quiet.

After being seen by the doctor I was often sent to radiology for a bone age x-ray which followed another lengthy waiting room wait. From radiology I was usually off to the lab for the drawing of blood and urine tests. Perhaps the most degrading part of my 'check up' was the regular photographing of my genitals and my naked body. The studio was a small cluttered room with a platform and a chair or two. I was instructed to undress and stand on the platform. The photographer would then take close up pictures of my genitals from every conceivable angle, legs together, legs spread as well as full frontal, rear and profile shots. My mother was always present for these photo shoots but I really didn't mind her required presence. The last photo shoot I endured was not long before my eighteenth birthday and my father happened to be along for this 'check up' so he was instructed to accompany me into the studio. I was so embarrassed and ashamed that he was about to see me naked that I was fighting back tears. I felt helpless and out of control and trapped because I was not allowed to express the turmoil I was experiencing. I could feel my father's eyes on me as I undressed and placed my clothes on the floor. I did my best not to look at him but for a brief moment I made eye contact with him as he stood with one leg propped up on a chair and a cigarette in his mouth while looking at me. I could see the disgust on his face. At that moment it felt as if time stood still. I was mortified to the

point that the photographer had to repeat his instructions because I was unable to concentrate on his words. I have never felt so vulnerable or violated in my entire life. I would have been far less traumatized if a stranger from the street had been there instead of my father. As I recount that event even now I feel terribly small and vulnerable and as if I could cry but for some reason the tears never come.

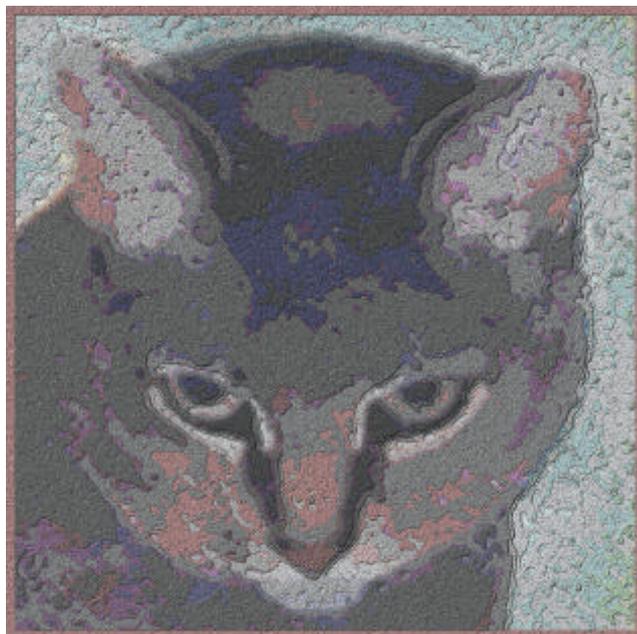
My memory of my quarterly 'check ups' begins from when I was about two years of age when I was the subject of a lecture. I remember being naked and held in a standing position by my mother on an exam table in a lecture hall.

The lecturer wanted me to urinate into a bowl. I didn't have to go and he became impatient with me and told my mother to leave. I was so terrified at being left alone in the lecture hall without my mother that I screamed and cried in my terror. The lecturer, finally in a huff, relented and allowed my mother to stay but by that time I could not be comforted. Forty-five years later I still remember how frightened I was.

As a young child I believed I would grow up to be a girl and other children who saw my genitals expressed the same opinion. Perhaps at around the age of ten I became aware that I was not going to be allowed to be a girl when I grew up. I remember being pressured to act like a boy and do boy things. I recall that if I even so much as touched a toy stuffed animal I was severely reprimanded, but I really liked toy stuffed animals. I felt very confused because I did not have normal male anatomy so how was I going to be a boy? I remember feeling very sad for a long time that I had to be a boy. I didn't know where I fit in. In private I would act out being a girl by putting a towel on my head to pretend I had long hair and place rolled clothing under my shirt and imagine I had breasts. I was confused and conflicted and very afraid my parents would catch me acting out my fantasy and desire to be a girl, yet I was willing to risk exposure. Eventually however I accepted the mandate that I had to be a boy and so I wouldn't allow myself to think about wanting to be a girl. Feeling hopeless I became the boy I was assigned to be.

My adolescence was not easy. I was withdrawn, shy, awkward, and completely lacking in the athletic ability of my male peers. To compensate for the lack of ownership of my body and the resultant misery that buzzed around me I became super competent in my studies and obsessed with my interests. Only in my studies and interests did I find respite from the lack of control I experienced in my life and allow myself to feel emotion. Any challenge to my competence however was cause for a terrible upset. It scared me. It was as though my tenuous grip on my life was slipping. To compound my misery I also suffered from enuresis (bed wetting). I was completely unaware of when my enuresis occurred during the night. I just always woke up wet. My parents were convinced I was too lazy to get up and use the bathroom during the night. Incredibly I was even blamed for a brief roach infestation because of my 'filthy habit'. I'd laugh here at the ridiculous logic if it didn't hurt so much. I digress. I explained to my parents repeatedly, usually through tears that it occurred without my awareness but they never believed me. Up until the point of their deaths they believed I lied about this. Like many children with enuresis I was not welcome to spend the night with family for the reasonable fear that I would ruin their

bedding. As a means of punishment I was shamed and threatened with the public display of my wet sheets and disclosure to neighbor kids of my trespass. Not until I was being medicated for an unrelated cause did my enuresis come unexpectedly under control. My doctor determined that my enuresis was caused by a neurological deficit. I now take anti diuretic hormone and for the last several years my enuresis has been controlled. This freedom from my enuresis has made my life so much easier and enjoyable. Had my adolescence been free of my enuresis I would have fared better during those difficult years.



'Fresco Cat' by Jack Gossar (Jax95945@yahoo.com)

By the time I reached high school I had been taking testosterone for a few years. My response to hormone replacement therapy was minimal. My voice dropped a little but I am often still mistaken for a woman when talking with a stranger on the telephone. I did grow a little pubic hair but what was now referred to as my penis never grew beyond that of an infant even though my testosterone dosage was periodically increased. In an effort to mainstream me into as normal a male role as possible, I was required to shower with the boys after gym. I tried to hide my naked body as much as possible but when other kids saw me it was cause for much ridicule. My embarrassment only increased as I got older and the other kids developed but I stayed the same. Again I just tried to be as invisible as possible to endure the torture and cordon off my misery in my mind by not allowing myself to think about what was occurring. During this period of my life I remember my brother telling some neighborhood boys about my 'little wiener' and kids being kids they all got me off to a semi-private spot and held me down while my brother pulled down my pants so that they could see. There was much laughter, joking and wondering if 'it' could even squirt. I didn't bother to put up a fight. They just had their way with me and I disappeared into my thoughts in order to survive yet another episode of what seemed to be my circus sideshow life. I acquiesced to anyone who said drop your pants. Whenever I was examined, checked, molested, photographed or laughed at I emotionally disconnected from my body to avoid feeling

anything. I didn't even think it odd when my mother wanted to 'check' my genitals every week or two until I was eighteen; I simply complied with her request and checked out emotionally.



'Sunshine' by Jack Gossar (Jax95945@yahoo.com)

Soon after my high school graduation it was decided that I would be 'normalized'. What that meant was, the implanting of prosthetic testicles into a scrotum fashioned from my labia. I was terribly frightened by the prospect of surgery. I was not allowed to talk about the surgery or ask questions. Alone with my fear, at times I felt like I would go insane. I remember crying quietly in the back seat of the car as we drove home from my final 'check up' before the surgery. Once we were home I was unable to eat dinner but sitting at the table I blurted out that I didn't want surgery. My parents argued about the surgery. My father was angry about the expense and my mother believed I was not whole. My mother said that my wife would feel better if I had something down there and I countered that if she loved me it wouldn't matter. I recall my father saying what's the point he doesn't have anything to offer a woman anyway and my brother chimed in just give him a baggie and a couple marbles. **In the midst of this insanity my greatest desire was to be left alone.** I was sick and tired of being laughed at and made to feel guilty because I consumed resources. I was embarrassed by the hushed conversations in my presence regarding 'it' by other family members. I had become reflexive to avoid the blows of shame and I was an expert at reading my mothers signals to avoid saying the wrong thing. My life had become hell. I felt as if I had been reduced to my genitals. **People wanted to know why I was going to have surgery and I wasn't allowed to tell them.** I was alone and terrified except for my high school sweetheart who was a great source of comfort and yet I was too ashamed to tell her many of the details concerning my secret.

Surgery was performed as scheduled and it went well. I was now the owner of uncomfortable plastic testicles, which still

ache occasionally. Soon after my surgery I turned eighteen and I ran as far and as fast as I could from all my childhood misery. I requested that my medical records be sent to an endocrinologist close to my home. I would never again travel to be seen at the Children's Hospital of Los Angeles. I would no longer allow myself to be displayed like some sort of lab rat or to be pawed over by clumsy students. I assumed responsibility for myself and moved away from home into my own apartment. **For the first time in my life I felt some inner peace free of the turmoil of my childhood home and garnered some self-direction.** I worked at a kennel to support myself and to indulge my intense interest in animals. The people who employed me were very kind and loving and became my surrogate parents providing guidance, support, encouragement and spiritual insight. Had it not been for these selfless people and the wonderful example of their lives I don't know what would have become of me. They started me on a path of much happiness and self acceptance. I began to ascribe meaning to my life and what I had endured via biblical scripture, especially from Psalm 139. Having been born with an intersex condition seemed to only make sense to me in light of scripture.

By most accounts I have been successful in life and done well. I live what most would consider a desirable life in spite of all I have endured and I would say even because of it. I went to college, trained as a professional. I have a successful marriage. I am blessed with loving friendships. I have had a career, own a home and have operated my own businesses. My life is truly rich and satisfying. Like anyone, life throws curves at me now and then and there have been obstacles to overcome or accept. I live as a man with as much integrity and dignity as possible even though my brain was not virilized in utero because of my inability to produce testicular androgens. **I have at times felt ill equipped and even fraudulent in my attempt to be and think as a man. Over the last few years however I have stopped trying to be a man. Instead I have focused on being myself and that includes a more feminine perspective that I am not ashamed of, which is a natural component of how I was created.**

I am hopeful that changes in medical treatment and the ethic by which that treatment is delivered to those born intersexed will occur. I am also hopeful that those changes are motivated by what is best for the child and not the best strategy to avoid potential litigation. I believe that my medical treatment was executed by the medical establishment with the best of intentions and without malice. My medical treatment caused me to feel isolated and like a freak however. **My isolation and shame were reinforced by the intense secrecy and shame foisted upon my parents and myself by the medical establishment.** Tragically this ethic is still in operation due in good part to the notion that when a child is born neither fully male nor fully female that it is somehow a medical and social emergency. **The shame and personal responsibility I felt concerning my condition and the requirement that I live in secrecy nearly perfectly duplicate the feelings experienced by a child who has endured childhood sexual abuse** i.e., secrecy, shame, fear and a sense of personal responsibility for what has occurred etc. Similar to childhood sexual abuse, parents are often aware of what is

occurring in the child's life with the seeming unending genital examinations, photographs and so forth. If parents say nothing and allow this treatment of their child to continue the child may grow up feeling helpless and defeated, unaware that their body belongs to them and that they are allowed to decide who has access to it.

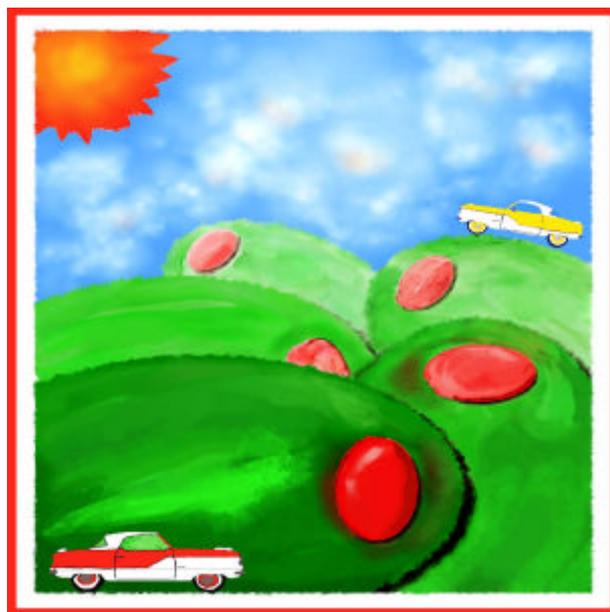
If I was the only intersexed person who had endured the sort of treatment that I did it could be dismissed as unfortunate or as a statistical fluke perhaps but it is sadly the norm. It is tragically the norm! Nearly ninety percent of those born with intersex conditions who have been surveyed suffer from anxiety disorders or other psychopathologies. This is a heinous commentary on the state of care for the intersexed.

Thousands of people with intersex conditions have expressed discontent with their medical care, gender assignment or surgical result but their protests and concerns go largely unacknowledged by the medical establishment. Certainly there are those who are satisfied with the treatment they received but most drop out of site as soon as they are able to in an attempt to put what they have suffered behind them, consequently few follow up studies have been conducted to assess how these people are faring. Intersex conditions are not a public health threat except perhaps for those born with the salt-wasting form of congenital adrenal hyperplasia or if there are problems associated with the urinary tract. **Even in these cases the genitals themselves are not the medical problem.** There is no legitimate need to normalize a child surgically for cosmetic reasons. For practical purposes an intersexed child needs to be raised as a male or female, but that assignment needs to be fluid.

Premature surgery may forever restrict or complicate the ability of the child to express the gender they identify most closely with or feel best suited to express, possibly leading to terrible unhappiness. In that vein, I consider having my prosthetic testicular implants removed because to me they are a symbol of deception and suffering. I am restrained however by the monetary and emotional price paid by parents in their struggle to provide the best care that they were able, as a result I feel I honor them and their sacrifice by not having the implants removed.

Generally families of lower socioeconomic status may require more mental health services in coping with their intersexed child. They may need the reassurance that they are not feeble minded or crazy for needing these services and that mental health professionals need to be a part of the treatment team. In my opinion they are probably more important than the endocrinologist, urologist, surgeon or geneticist. What a difference my treatment experience might have been had I been given the opportunity to talk about what I was experiencing without fear of reprisal or as a ploy to win me over to a treatment plan. **Additionally intersexed children need to know that they are not alone and if at all possible be allowed to meet and play with other intersexed children.** Parents need to be made aware that their child has a well understood biological condition, that support groups are available and that their child is not a transsexual i.e. a person with a normal male or female body, chromosomes, etc but who is dissatisfied with the gender of the body they inhabit. I realize that there is raging debate about transsexualism being an intersex condition, but these two conditions are different. Gender dysphoria (i.e. transsexualism) is regarded as a psychiatric condition and

those with biological intersex conditions are excluded from this group. Parents will benefit from support groups and the opportunity to speak with intersexed adults who are living full and satisfying lives. Removing the secrecy and shame and providing a forum for people to discuss their concerns regarding their intersexed child could go a long way to easing the minds of parents. Intersex conditions occur generally about one in two thousand births. This is about the same frequency as multiple sclerosis or about half as often as Down's syndrome. While not common, intersex conditions are certainly not rare. Let us not scar or alienate another child or family because of an antiquated, ineffectual treatment regimen.



'Olivescape' by Jack Gossar (Jax95945@yahoo.com)

Personal Value

By Sandra

Since June last year I have had the good fortune to be involved in a support group for people with mental illnesses called Grow. It has been a fantastically positive experience for me and has given me great support during some very difficult times. Grow provides support through weekly meetings during which, in a similar way to our own group meetings, people can share their stories and help each other with any current problems they may have. Everyone gains healing from the acknowledgment from others who have been through similar experiences, offering friendship, guidance and support in an atmosphere of trust and honesty. Underpinning Grow's approach to helping people with mental illnesses is the use of the 12 step program modeled from Alcoholics Anonymous. Grow developed its own version of these 12 steps specifically tailored for people with mental illnesses, and out of this came a small booklet giving principles and guidance to assist Grow members in their personal growth and recovery, otherwise known as the Blue Book (it's blue!).

Anyway, the reason I've brought this up is because I wanted to talk about the first principle discussed in the Blue Book

and how I feel it is very relevant for those of us fortunate enough to be born with an intersex condition. (Sorry, I know lots of you are going “What?...Fortunate?” but it is one perspective!). The first principle is called “Personal Value” and basically it says that **no matter what our physical, mental, social or spiritual condition, we are all valued human beings** (in Grow this specifically means valued by God but I don’t think the idea is any less valid if you don’t believe in a higher power). We all have our unique place in the world, the lives of each one of us has a purpose, and we all have something to offer each other and the world at large. This to me is such an empowering idea, although perhaps easily taken for granted sometimes. It reminds me that each one of us, no matter how disabled, or how socially rejected due to our appearance or behaviour or conduct, or how generally undesirable to society we are...we all have personal value and by extension, I think, deserve respect.

I think this is especially relevant for people with an intersex condition because we have been hidden from society for such a long time and our biology is just too unique and (I think) fabulous for people to get their heads around! We are highly stigmatized as a group and there is much confusion and misunderstanding as to the nature of the conditions (as is the case for people with mental illnesses). So there is a great deal of pressure from society on families and the medical establishment to somehow make our perceived devalued bodies more valued. So our bodies have been reshaped to make us look like everyone else (which doesn’t usually work) or we’ve been assured that “you really ARE female” or “you really ARE male” (which also doesn’t usually work) or told lies about our bodies (which definitely doesn’t work!). Such paranoia! What I think we would all like everyone (including ourselves) to realize is that AS WE ARE we have immense value, as does everyone on this earth, as they are. Grow’s first principle is asking us to look beyond preconceptions and judgements about what we think a human being should be like and to realise that what is perceived as imperfection is simply another valid expression of what it means to be human.

I am reminded of a few discussions during support group meetings when I think about this issue. Some people with intersex conditions seem to come through the experiences of things like surgery and peer pressure with their sense of personal value relatively intact, perhaps even strengthened by what they have been through. Others, though, really suffer a blow to their self-esteem almost to the point where life doesn’t seem worth living (and I know for some of us it has reached that point). Why the difference? I guess there’s not really one answer to that...probably a combination of the family environment, acceptance of the condition by the family and medical practitioners, age (I think the younger generation have more opportunities to talk about things related to sex and their reproductive anatomy than earlier generations, and counselling is more widely recognised now as being a necessary part of treatment), the individual’s own personality, the nature of their condition, sensitivity and awareness of treating doctors of the issues involved, support services offered etc. There’s obviously such a diversity in how people cope with difficult circumstances, and when people are isolated and think they are the only one, the effects on personal value would be even further exacerbated.

So how does this help those of us who still panic at the thought of going out on a date, or feel uncomfortable undressing at the local gym or get really angry and upset when the sales assistant at DJ’s calls us sir rather than madam? Well, I’ll leave it to you to think about. I think the path to having a valued place in our society begins with valuing ourselves and that begins with acceptance, which is not always easy. I’ve known about my AIS for 15 years and I’m still working on that one. One thing to remember is that you’re in good company...others feel the same. We can gain strength and solidarity in supporting each other and offer consolation when it all gets too much. It’s a hard world out there for people that are different but through education and the persistent efforts of all of us to stand up for ourselves, it is becoming less so. Best wishes to you all.

AIS Couple Unplugged! (Pt 2)

Hello again everyone. I’m flying solo for this issue of dAISy. Tony has gone to Las Vegas for a few days with a friend of ours from the UK, who is spending his holiday here in California with us. Let’s hope they win a big jackpot!

As promised in the September 2002 issue, I am going to talk about our first meeting and sexual encounter. This won’t be in the same interview format as last time, so bear with me while I ramble on. Some of what I write here could possibly be considered too “explicit” for some individuals. Please understand that is written from the heart, in the hope that by sharing our story, others will benefit and find courage from it.

In May of 2001, after one year of phone calls and emails, we decide the timing was right for the **big** first meeting. Tony made his travel arrangements from the UK to California and I now had about three weeks to prepare myself. In addition to getting my house all tidied up, I had to work on myself! After having every square inch of my body waxed, plucked, manicured, pedicured and buff and polished, I was finally ready. Or so I thought. I still had to work on my mental state and that, as it turned out, was much more difficult. I inherently knew that our meeting in person for the first time was going to be the pivotal moment for the rest of my life. From here on out my life would never be the same. I don’t know how or why I knew. I just **knew**. That is a huge burden to put on what was essentially a “blind date,” but never before in my life has someone traveled 6000 miles to see **me**. I didn’t want to be a disappointment to him and at the same time, I was hoping that he wouldn’t be a disappointment to me. Needless to say, my head was spinning so fast I thought it fly off my shoulders.

When the day finally arrived to pick him up from the airport, I was a nervous wreck. I honestly don’t even remember driving to the airport. I was on complete autopilot. Once I got there I discovered that his flight had been delayed for over an hour, so I paced up and down and probably smoked an entire pack of cigarettes. Poor Tony! I must have tasted like an ashtray for our first kiss. Once the plane landed and I had watched all the passengers disembark from the plane, I still hadn’t seen him. I thought he had missed his

connecting flight. But finally, he was the last one off the plane and there he was! I ran to him and threw my arms around him and then I just sobbed for what must have been a good twenty minutes. So much for all of my meticulously applied makeup, as it was now streaming down my face! I find it difficult to express in words what I was feeling, as not only was I finally with the man I had fallen in love with long distance, I was also meeting another intersex person for the very first time. The dynamics were incredible. I was intersex, I was in love, and for once in my life, I felt safe and *accepted* for whom I was.

When we went to the car to drive home, he did something really adorable. Out of habit, he went around to the driver's side to get in, which for him in the UK would be the passenger side. It broke the ice and provided some much needed comic relief. Once we got to my house, we couldn't stop staring at each other. It is one thing to see pictures and talk on the phone, but it's quite different to see someone in the flesh moving about. Seeing their mannerisms and gestures. Hearing the voice you had become so accustomed to on the phone, now coming out of a living, breathing person who is in the same room with you. Being able to smell them and touch them. It was both wonderful and somewhat disconcerting at the same time.

We had agreed in advance to *not* make love that first night. With Tony having spent nearly 24 hours awake and traveling, not to mention the 8-hour time difference, we just felt that he would be too exhausted to have to *perform*. We had also decided that it would be best not to see each other's "private parts" until we were less nervous and had a good night's sleep. I can't honestly say that we did end up getting all that much sleep, as much of the night was spent kissing and cuddling, along with quite a bit of "groping" in the dark as well. We are only human after all and everyone knows what incredible sexual beings the intersex are! Between my estrogen and his testosterone, it was a very highly charged atmosphere. We did manage to get a few hours sleep, which as things turned out, would be much needed for the following day.

When we awoke the next morning, Tony very softly said, "Would you like to see 'him'?" Well, he didn't actually say "him," as we had already assigned names to each other's genitalia in that disgustingly cute way that couples do. Out of respect for our privacy, I won't disclose them here. But then again, since I'm pro-disclosure, what the heck. His is named "Willie" and mine is named "Sybil." I'm sure that falls into the category of *way* too much information! So, when he asked if I would like to see Willie, I was flooded with several different emotions. I knew that my reaction would be critical to our relationship. I also knew that towards the end of his first marriage his wife had said some not very nice things to him, probably in an attempt to emasculate him. I felt like I was treading on some very thin ice and that even so much as the wrong facial expression on my part would destroy him. I couldn't have been more wrong.

I'll never forget that day. It was a typically beautiful California day with the sunlight pouring in through the windows and a gentle breeze blowing the curtains. He lowered the blankets and there was Willie in all of his glory. All of my worry and concern instantly disappeared and my

"planned" reaction was completely unnecessary. What I saw, to be honest, was unlike anything I had ever seen before, but at the same time it was the most beautiful thing I had ever seen. As much as I already loved Tony, in that instant I loved him even more, if that was possible. I spent the next hour exploring, caressing, kissing and loving my future husband's "ambiguous" genitalia. I was seeing nature at it finest. This was a true work of art. Afterwards, we held each other for a very long time and just rocked each other gently. It was the closest I had ever felt to another human being. It was as if we were two souls from a different lifetime that had rediscovered each other. We then made love, for the first time and for a very long time. It was magical and felt as if we had been together for our entire lives.

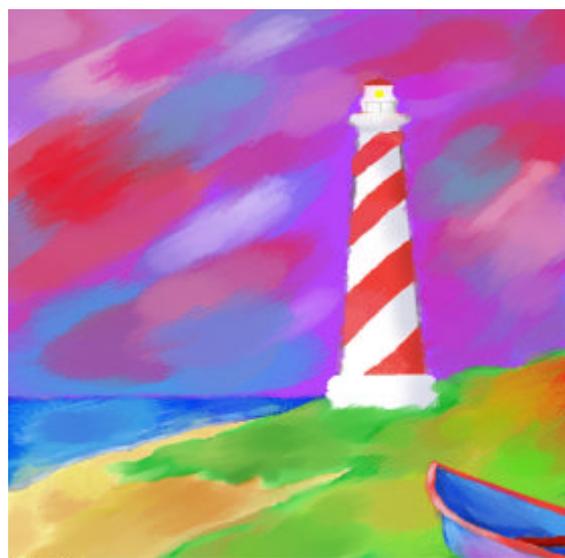
Tony's biggest fear was that I would reject him, that he would repulse me. Sometimes, what you think is the worse possible thing about yourself, turns out to be your best asset. It is what makes you unique and it is what makes you, well, *you*. Yes, if you are truly uncomfortable with it, you can change it. That is the right we all have as intersex adults. Or, you can learn over time to embrace it and leave things as they are. It is a choice that each individual has to make for him or herself; no one can make it for you. But no matter what you decide to do, don't ever let it stop you from living a full life. A life filled with love, romance, and sexuality.

From that morning on, Tony and I have been completely comfortable with our bodies around each other. For the first time in our lives we can walk around nude and not feel that we are being "judged." It is a very liberating feeling. We will never, ever again have to feel shame for whom and what we are and what our bodies look like.

On the last day of Tony's two-week visit, he asked me to marry him.

Can you guess what my answer was?

Next dAISy: Tony's reaction to their first meeting and disclosure (or lack of it) to friends & family. Plus...they get married!



'The Beacon' by Jack Gossar (Jax95945@yahoo.com)

The Neglected Communities Forum - NSW Anti-Discrimination

By Elrae Wilson

On February 25 I was privileged to join an almost packed house to listen to a number of eminent speakers talking on behalf of a number of interest groups, on the general theme of discrimination and legal implications for the various "neglected communities". The papers were designed to inform legislation related to the NSW Anti-Discrimination Board and the NSW Law Reform Commission. The evening was facilitated by Mr. Chris Puplick, Commissioner of the Anti-Discrimination Board of NSW, who despite being unable to keep speakers to time, ably, and sometimes humorously kept some control over events summing up major themes for many of the speakers.

Representatives attended the forum from the Greens, Democrats and Liberal parties with no representative from the Labor Party. The venue was the NSW Parliament House which provided a fitting backdrop to such an important forum. Speakers provided a good balance of personal stories and facts around the topic of "neglected communities" and were asked to submit their information as part of a package made available to each member of the audience.

Following speakers that included Georgina Beyer (Maori Member of Parliament from New Zealand), Elizabeth Riley (Manager of the NSW Gender Centre), Dr Jay Ramanathan (medical doctor who specialises in Health Promotion) and Rachael Wallbank (Solicitor and 'woman of transsexual background), Tony Briffa presented a detailed and well-referenced paper regarding discrimination against people affected by intersex conditions on behalf of the AISSGA. Tony included descriptions of the various diverse conditions which belong under the umbrella of intersex, pointing out the incidence of intersex conditions, that only 25% of people with intersex conditions are born with 'ambiguous' genitalia, and the various issues of people affected by intersex conditions.

Tony also highlighted the clear distinctions between people with intersex conditions and people referred to as transgender or transsexual, and recommends that the definition of transgender in all NSW Acts should "expressly exclude those with intersex conditions". [Now already in law in the ACT – Ed] Tony detailed the reasons for this in his submission and presentation, which includes issues of medical and scientific fact, legal rights, human rights, group identification, reduction of stigma, education and self-image.

Tony's submission on behalf of the AISSGA made a number of recommendations for NSW law reform including:

1. state legislation provide protection from discrimination against those with genetic conditions;
2. parents and people affected by intersex conditions be given full disclosure of their condition;
3. state legislation defines terms in such a way that confusion is removed from surgical procedures for transsexuals and people with intersex conditions;

4. surgery on children with intersex conditions be limited to medically required surgery, with 'cosmetic', 'normalising' and/or non-therapeutic medical intervention only being performed with the consent of the Family Court;
5. expectant parents see a genetic counsellor if prenatal tests reveal a sex chromosome anomaly, particularly given the excellent genetic counselling services available in all states of Australia. They should also be given contact information for the relevant genetic support group so that they have a realistic and factual understanding of the effect of the condition;
6. genetic testing by employer groups is prohibited. Medical information should not be given to employers; rather they should receive a certificate of fitness from an applicant's physician based on an accurate and detailed job description;
7. Medical Defence Organisations review their position on providing medical indemnity insurance for surgeons performing these ethically, legally and medically questionable procedures; and
8. government consult with groups such as AISSGA, when anti-discrimination and other law is formulated, in order to ensure appropriate outcomes for intersexed communities, as regards their care and legal rights.

Tony also presented real-life stories showing that many people with intersex conditions lead happy and successful lives, and are not outwardly different than other non-intersex people in society despite their experiences with their genetic condition.

The discussions with the NSW Government have already reaped some benefits with a formal committee established to review the treatment of children with intersex conditions. Anne Hider is our representative on that group.

A full review of the forum and the AISSGA's submission to the NSW Anti-Discrimination Board and Law Reform Commission is available on the AISSGA website at www.vicnet.net.au/~aissg.

ACT Law Reform

People with intersex conditions had a major victory in the ACT recently when the definition of Transgender was changed to remove people with intersex conditions, and, for what we believe is a world first, include a definition of intersex in legislation. The ACT (ALP) Government, with the support from the Democrats and Greens, passed the following definition of intersex in the Legislation Act 2001 (ACT):

'An intersex person is a person who, because of a genetic condition, was born with reproductive organs or sex chromosomes that are not exclusively male or female.'

This is particularly significant for the intersex community because of the insistence by a small number within the transgender community that falsely claim transsexualism is an intersex condition. Regardless of any possible biological

basis of transsexualism (i.e. Gender Identity Disorder), people with transsexualism are not born with any variation of their reproductive organs and/or sex chromosomes, and have many different issues. One male to female transsexual person even described themselves as having Vaginal Agenesis (i.e. congenital imperfect or non-development of a vagina) when in fact; they were born physically male, fathered children etc. These people have a gross lack of respect and understanding of our experiences and issues.

As the Democrats MLA (Ms Roslyn Dundas) explained in her media release on the 10th of March:

"Intersex and transgender people are different, their needs are different, and the discrimination they face is different. Both of these communities often face discrimination and it is important our laws reflect their different needs."

An intersex person is one who is born with reproductive organs that are neither exclusively male or female, where as transgender identifies as a member for a different sex to the one they were born as."

The AISSGA looks forward to furthering the law reform process in the ACT by working closely with the ACT Government. We would also like to point out that the Liberal Party also supported the recommendations by the AISSGA, although they did not support the Bill for other reasons.

Life is not measured by the number of breaths we take, but by the moments that take our breath away.

New intersex study fuels debate

Tuesday, 17 September 2002

Anna Salleh - ABC Science Online

<http://www.abc.net.au/science/news/stories/s675847.htm>

A long-term study of intersex adults, who were born with genitalia that made it difficult to know if they were a boy or a girl, has found that most are content with the gender they were assigned. However, controversy in the area remains.

The study, by Calude J. Migeon of the Johns Hopkins University School of Medicine www.hopkinsmedicine.org/medicalschool/ and colleagues, is published in the journal Pediatrics www.pediatrics.org/.

The researchers interviewed 39 people who had been seen at Hopkins as infants or children. The participants were all born genetically male (XY) but with genitalia which were either female, not clearly male (a very small penis), or ambiguous. Twenty-one had been raised as men, and 18 as women.

Over three-quarters of study participants were reported to be satisfied with their assigned sex of rearing, their body image and sexual functioning.

According to consultant paediatric and adolescent gynaecologist, Dr Sonia Grover of the Royal Children's Hospital www.rch.unimelb.edu.au/ and the Centre for Adolescent Health in Melbourne, the new study is the first of its kind.

It addresses some of the concerns raised by intersex advocacy groups, who argue that the medical profession should not surgically assign gender at such a young age.

"I think it's a reassuring study because in the last few years those of us involved in this area have had obvious concerns about whether we're doing the right thing," she said.

Previous studies were based predominantly on groups of people who were unhappy with their experience, she explained.

"This outcome suggests the basis the medical profession has been using to make decisions may be appropriate," she said. "But the study still has limitations."

"If three-quarters of people are happy with their assigned gender, why are one quarter unhappy?" she asked.

"I would like to know a bit more about what went wrong for the ones who are unhappy."

About one in 8000 children born in Australia each year have ambiguous genitalia. All of them undergo surgery within a few months of birth to assign them to a male or female gender.

Tony Briffa of the Androgen Insensitivity Syndrome Support Group Australia <http://www.vicnet.net.au/~aissg> welcomed the new US research, but said a "failure rate of 25 per cent" was "not acceptable".

"We support the child's right to physical integrity and are deeply concerned for those children who are not happy with the gender they were assigned - particularly if they have undergone irreversible medical intervention," he said.

He said that children should be informed in stages about their condition, and give their consent to any medical intervention when they are old enough to make these decisions for themselves.

"Doctors need to realise that the genitals of children with intersex conditions are never a medical problem," said Mr. Briffa.

Dr Grover said one reason for the dissatisfaction shown in the Johns Hopkins study could be that medical intervention for intersex conditions is ongoing.

Apart from the initial surgery, such as removal of a penis or construction of a vagina, interventions can involve repeated surgery and hormone treatments.

The Royal Children's Hospital is currently doing a similar study of 130 patients, which will compare the satisfaction of intersex patients with those who have undergone major surgery or have a chronic illness.

RCH Surgeon's Paper under the Knife.

The AISSGA has for some time followed the progress of a long term follow up study being conducted by the Royal Children's Hospital (RCH) Melbourne, the intention of which is to examine a number of treatment practices to see if they are appropriate. Amongst the practices being examined is the appropriateness of surgical reinforcement of gender assigned to a child born with an intersex condition. This is a practice that has drawn much criticism from patient groups and some medical professionals and this is one of the reasons the RCH Melbourne is conducting their study. Some medical professionals still consider surgical reinforcement of gender assignment is necessary for the well being of both the affected infant and their parents for a number of social reasons.

In a paper titled "Androgen Imprinting of the Brain in Animal Models and Humans With Intersex Disorders: Review and Recommendations" written by Zoltan Hrabovszky and John Hutson of the Surgical Department, Royal Children's Hospital, Melbourne, the practice of surgically reinforcing assignment of gender to children with intersex conditions is defended on the basis that previous unsuccessful outcomes were because of miss-timed surgery. Hrabovszky and Hutson put forward a hypothesis that male gender identity forms largely as a result of a peak in testosterone production levels that occurs following birth and that to raise certain chromosomally XY infants successfully as female surgery must occur prior to this peak of testosterone production. Their hypothesis is said to be supported by results of studies using animals and certain observations of groups of patients with intersex conditions or exposure to atypical hormone levels.

Studies conducted on various animal subjects, support the hypothesis that the same hormones responsible for physical sex differentiation are also responsible for certain male or female typical sex behaviours. In some studies researchers have even been able to identify the specific time frame of development of the animal during which behaviours can be influenced in this way. The same cannot be said of studies involving human subjects. Whilst some studies involving human subjects suggest that exposure to androgens can influence the behaviour of chromosomally XX infants so that they exhibit behaviours more usually associated with males, there are no studies that suggest early removal of testes will prevent development of a male gender identity or that retaining them will guarantee formation of a male gender identity. There are members of the AISSGA that prove exceptions to both of these rules and the unpredictable nature of the level of response to androgens in conditions such as PAIS is always going to mean this is the case.

Hrabovszky and Hutson state that there is strong evidence gender identity is linked to genital appearance and that "normalising" surgery is a necessary both for acceptance of an assigned gender by both the infant with the intersex condition and their parents and for proper social adjustment. Nowhere in their paper do they support this assertion with any empirical evidence. Since there have been very few recorded incidences of children with intersex conditions

where such surgical reinforcement has not taken place early in the infants life, it would be very difficult to support such claims especially in the context of "Western" society in which most such surgeries take place.

Hrabovszky and Hutson also comment about the need for surgery in cases where there is a risk of cancer or other physical medical problems, such as the removal of gonads in cases of CAIS. Performing surgery where there is a genuinely established need for the physical well being of an infant is really a different issue, as no patient advocacy groups nor medical professionals that we are aware of dispute the need for this to occur in such circumstances.

In the view of the AISSGA, the research cited in the Hrabovszky/Hutson paper tends, on balance, to equally support the view that gender identity forms prenatally and that anti-natal removal of testes will have little effect on gender identity. The Hrabovszky/Hutson paper concludes that hormonal imprinting very likely occurs both pre and anti nately but they assert that removal testicular tissue after birth will minimise the effects of the androgens produced on gender identity. While this is quite possibly true, we do not believe they provide sufficient evidence that removal post term is enough to negate or override any prenatal hormonal influence. If their hypothesis is wrong then early removal of testes in the manner suggested will once again mean children having to come to terms with the ramifications of removal of health organs if gender assignments are incorrect. The upshot of this is that once again it is parents and support groups left picking up the pieces of experimental medicine and for us this is too high a price to pay.

For the AISSGA, the Hrabovszky/Hutson paper also raises some other questions of significance. The paper has been authored and published prior to completion of a long term follow up study examining the appropriateness of the very medical practice the paper defends. Not only does the study examine the subject of the paper, the authors work at the hospital conducting it and John Hutson is a member of the study team that has proposed and is involved with conducting the study. It may be that publication of the Hrabovszky/Hutson paper can be defended on the grounds it is the stated opinion of the writers only and not meant to represent the views of the RCH team involved with the follow up study. In our view it would have been more prudent to publish the paper after the study results had been published when stated opinions can be more properly assessed against the results of a study that is current and directly relevant.

Above all, do no harm.

Follow-up Study on the Treatment of Children with Intersex Conditions.

The Royal Children's Hospital (RCH) Melbourne, through the Murdoch Children's Research Institute (MCRI), is conducting a very important follow-up study of patients treated at the RCH for various intersex conditions.

The importance of this study cannot be underestimated, as the results will be directly used to formulate treatment practices in the future. The AISSGA has been working with the research team on this project, and while there has been a few teething problems, they have been largely overcome.

Some of you would have received a MCRI 'Quality of Life' Survey from the RCH late last year. Unfortunately, the response rate has been less than ideal. I urge everyone who has received this survey to complete it and send it into the RCH as soon as possible.

If you have not received a survey AND were treated for Androgen Insensitivity Syndrome (previously known as Testicular Feminisation Syndrome), Congenital Adrenal Hyperplasia, or similar intersex condition at the RCH Melbourne, please contact Professor Garry Warne at the RCH Melbourne, or Tony Briffa at the AISSGA at aissg@iprimus.com.au.

Letters

Dear Mother and Daughters and Sons and Fathers,

I read the article 'A Mothers Story' in the last dAISy and it moved me to tears. I am a mother and an Early Childhood teacher in Montessori. I am so convinced that, regardless of gender and all its variations, it is possible to raise children with an awareness and belief in themselves.

I also hear stories from mothers who have been sent 'up the garden path' by medical professionals about their child, making them feel as if they are neurotic parents when all they need is clear and honest information. I can't believe how cruel and incompetent some of those professionals can be, not only in their treatment of patients and their relatives, but they seem to blunder their way through treatments offered!

Wouldn't it make sense to check out the whole physiological situation of a person first, keeping the patient and parents informed, before making (especially mothers) feel as if there is something wrong with them by being concerned about their child's well-being?

I can't do much for you, but I do send you all my thoughts and mental support.

With warm regards,

F. Matthews

The Obstacle in Our Path

In ancient times, a King had a boulder placed on a roadway. Then he hid himself and watched to see if anyone would remove the huge rock. Some of the king's wealthiest merchants and courtiers came by and simply walked around it. Many loudly blamed the king for not keeping the roads clear, but none did anything about getting the stone out of the way.

Then a peasant came along carrying a load of vegetables. Upon approaching the boulder, the peasant laid down his burden and tried to move the stone to the side of the road. After much pushing and straining, he finally succeeded. After the peasant picked up his load of vegetables, he noticed a purse lying in the road where the boulder had been. The purse contained many gold coins and a note from the king indicating that the gold was for the person who removed the boulder from the roadway. The peasant learned what many of us never understand.

Every obstacle presents an opportunity to improve our condition.

I know there are times when having an intersex condition seems like an obstacle, but perhaps it is an opportunity.

Next National AISSGA Meeting

24th May 2003.

Brisbane

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

An invitation will be sent with this copy of dAISy.

National AISSGA Meeting in Sydney!

July 2003.

More information will be sent soon.

Next dAISy Deadline

1st August 2003