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Hover Fly on Oxeye Daisy by Reini68, 2006. CC.

Message from the President

Happy New Year and welcome once again to another edition of dAISy. I hope that you find this one a ripper of a read.

The past six months have been quite busy. Firstly, there was all the controversy over Caster Semenya, the South African athlete who is alleged to be a ‘hermaphrodite’ with AIS. We were upset

by how quickly the world was out to shock and shame. However, the sensationalism did give way to understanding and a number of media outlets began to seek a better understanding of intersex and AIS.

At the AISSG Australia, we received numerous requests for interviews to put the debate into perspective. Tony Briffa and myself gave interviews to the ABC and other independent media sources, and another member who wished to stay anonymous gave a great interview for Marie Claire. Some of the news stories that came out of the hullabaloo, some of which we have posted on the website. The media storm has abated for the moment but we hope for Ms Semenya’s sake that her talent will be recognised and that she will be able to compete at an international level as a woman.

Secondly, we were pleased to host our first conference in Sydney in quite some years. Thank you for all who turned out for a very special day in September for a session of unabated conversation and sharing. Gratitude goes out to Sandra for her coordinating efforts, and for her report on the meeting, which follows in this newsletter.

In the next six months, I’ll be working closely on the re-edit of my film about AIS for the ABC and I’ll be looking forward to working towards the

continued support our friends within Australia and abroad with continued vigour and passion.

All the best,

Phoebe Hart, President



AISSGA Meeting 2009 – Sydney: A Report by Sandra

The AISSGA annual meeting was held in Sydney on September 26 2009. 10 people attended the meeting having traveled from around NSW, Victoria and Queensland. There was a mixture of people with AIS, parents of children with AIS, and partners offering support.

We began the day with a getting to know you session when we each had the opportunity to share our stories. It was very moving to hear people's stories of struggle and pain, but also of courage and determination to rise above the difficulties they faced. There was a sense of hope and encouragement of each other as we spoke of dark and difficult places within ourselves, as well as a sense of sharing experiences we had in common. This sharing created a bond that strengthened as the day progressed. It is often amazing at how aspects of our stories are so similar and how telling them can be a very cathartic experience. We can somehow feel more "normal" and come to accept ourselves more easily.

After lunch we had an enlightening session led by psychiatrist Dr Elizabeth O'Brien. We discussed the topic of the social stigma around intersex conditions, which was raised in the morning session in the light of the recent media attention on Caster Semenya. We also touched on how to inform children of their AIS and generally issues around disclosure and self-esteem.

Later in the afternoon we watched a movie directed by Phoebe called "Orchids" which included interesting interviews with people with intersex conditions including some members of our group. The day finished with a brief AGM and a discussion on the future of the support group. New ways of using the internet to assist with the running of the group were explored, as well as the suggestion that a number of people take on some of the responsibilities of keeping the group going.

Some of us went on to a nearby Lebanese restaurant for dinner which was a fun and delicious way to finish the day. On a personal note I had a strong feeling of peace within myself that evening, a feeling which seems to happen for me at the end of every meeting I've attended. I think I experience a sense of acknowledgement and acceptance of a part of myself that is hidden from others most of the time. In bringing this part of me to the light once again it became clear to me that sharing one's most personal self with others who have been there too is a truly healing experience.



My Marie Claire Interview by Sandra

I had been thinking over in my mind for quite some time now what it would be like to go public with my AIS story. The thought did scare me a bit but I realized that if I did it could bring hope and inspiration to others with AIS. I wanted to give back what I had received from reading the stories of others in newsletters and on the internet. I had previously written my story for Daisy, but when the opportunity came to be interviewed for Marie Claire magazine I decided now was the time.

I had an initial meeting with the journalist Julietta just to get a sense of what angle she would take on the article and whether it would be sympathetic to my perspective. I liked Julietta immediately and discovered we both shared interests in writing and travel. She explained she wanted to give an alternative to the sensationalized approach the media had taken with the Caster Semenya story and that she wanted to educate people on what life was really like for people with intersex conditions. I agreed to do the interview on the condition that I could use a pseudonym, which turned out to be Martha.

A week later Julietta came to my flat to do the interview. I felt quite at ease sharing my story with her, and although it was hard to talk about such personal things with someone I didn't know that well, I was pleased with how it went and felt I

had given her a good picture of my journey with AIS.

Seeing the story in print was very exciting. I read the story on the train and couldn't believe a part of my life was there in print. I felt proud of myself for this achievement and I realised it was one more step forward on my healing journey. I also hope that it will lead to further opportunities to share my story with others in the future.

Male, Female or In-Between – The Marie Claire Article



Runner Caster Semenya made headlines after a gender test discovered she was "intersex". Julietta Jameson talks to people who've received the same disturbing news.

The sun was shining on a glorious spring afternoon when Mani Mitchell sat down in the kitchen of the family's home, in New Zealand's rural south, to ask her mother about the day she was born. Far from a cosy reminiscence, she knew the conversation would be difficult – for years,

she had felt an elusive secret hung in the air between them, but discussing anything intimate was just not what her family did. As she joined her mum at the kitchen table, Mani – then in her early 20s – finally managed to pluck up the nerve.

At first, her mother fidgeted and avoided her daughter's eye, before slowly opening up in a low-key, almost dismissive, tone, as if she were discussing the weather. "She said: 'Oh, well, you know, the waters broke early in the morning and Dad got up and drove me to the hospital,'" recalls Mani. "Mum was sent down to the birthing room with a young nurse and apparently I was born about 20 minutes later. The nurse bent down to pick me up and her first words were: 'Oh, my God. It's a hermaphrodite!'"

Dropping this bombshell on her child had a powerful effect on Mani's usually unflappable mother. "She started screaming and ran out of the room," says Mani, now a Wellington psychotherapist. "So I'm left with these two pieces of information; my mother screaming – because I had never seen her show such strong emotion in my life – and this word 'hermaphrodite'. I didn't know what

it meant and I certainly didn't locate it as meaning anything for me."

She didn't know it then, but Mani had been born "intersex" – the now widely accepted term, replacing the clumsy "hermaphrodite", for people with ambiguous sex physiology, be it internal, external or both. So-called "hermaphrodite"

genitals – a fully functioning penis and vagina – are mythical. Mani had ambiguous external genitalia and had undergone "corrective" surgery when she was a baby. Commonly, intersex people like Mani, who are raised as females, have a small, penis-like protrusion where the clitoris is usually found.

Although the condition remains, in Mani's words, shrouded in "silence and secrecy", it's astonishingly prevalent, with some doctors claiming that one per cent of the population can fall into the category, along a spectrum of conditions ranging from misplaced urethras to enlarged clitorises and ambiguous exterior genital physiology. Internal conditions include male or female chromosomes in the opposite sex, hormonal imbalances and male gonads in women. Yet despite its frequency, this "third sex" is poorly understood, and carries "freak show" connotations that make those with it reluctant to speak out.

It wasn't until years after the kitchen encounter with her mother, who has since died, that Mani found records of the genital correction surgery she'd undergone as a baby. "I got that piece of information when I was in my early 30s, and it would take another 10 years before I could find the people to work with to make sense of that," she says. Prior to that "there was a lot of running away". Today, though, Mani is comfortable in her own skin. "I don't see myself as exclusively female or male," she says. "But I also know generally how uncomfortable the world is with difference."

To read more... try and grab the December 2009 issue of Marie Claire magazine.



A Parent's Story

My daughter (our first child) who is now almost five years old was diagnosed with CAIS when she was fifteen months old. During an operation to repair inguinal hernias the surgeon found that she had testicles instead of ovaries. The surgeon came out to speak to us while she was still under anaesthetic to explain to us what he'd found and that he thought she had CAIS. I will never forget the shock of hearing the words '*she has no uterus*'. I had never heard or read anything prior to this about sexual disorders so it was very hard to comprehend and of course we were devastated. The operation was on a Friday and the surgeon organised for us to see the paediatric endocrinologist at our local hospital on the Monday, and told us not to spend the weekend looking at information on the internet (which we didn't). The endocrinologist spent several hours with my husband & I on the Monday explaining CAIS to us and answering our questions. I presume she had to shift several appointments in her very busy clinic to speak with us that day. We continue to see her once every 12 months at this stage and we have been happy with her knowledge and advice.

As our daughter was so young when we found out she had CAIS there were no immediate issues

around disclosure for us to deal with, and so we got on with life (we had plenty to keep us busy as I was 3 months pregnant with our second beautiful daughter when we found out). But I did feel the need at that time to make contact with someone who could tell me first-hand more about what we might expect in the future. I don't remember now whether our endocrinologist told us about AISSG or I found it on Google, but I contacted Tony Briffa by email and later spoke to him on the phone. Tony gave me Phoebe's contact details and I also spoke with Phoebe. It was extremely helpful to speak with Tony and Phoebe at that time as it gave me some reassurance that while CAIS was going to be very challenging for my daughter and us to deal with, it was not necessarily going to be as 'world shattering' as I might have initially imagined. Most parents have the same wish for their children – that their children have happy, healthy and fulfilling lives. We don't know what the future holds, but I believe that with the right support our daughter will be able to deal with the challenges she'll face. Being such a rare condition, and one that is difficult to discuss with other people, it is easy to feel very isolated. Support groups are not for everyone, but I have certainly appreciated knowing that there is a supportive community of other people with the same/similar condition who are willing to share their knowledge, experiences & advice.

I was able to attend my first support group meeting in Sydney in September last year. I took so much away from that meeting and Phoebe has asked me to share some of my thoughts. Meeting

and speaking with other women with CAIS, and listening to their stories was a very valuable experience for me. Everyone's journey has been unique and for me the most useful knowledge to take away was hearing both the good and bad experiences, and to draw on that in the years to come to help me provide the best possible support and advice to my daughter. I guess I am trying to learn from others what has helped them and what has not. I feel fortunate that we are bringing her up in what seems to be a more enlightened era of medical advice (perhaps not always as enlightened as we'd like). It is reassuring to have the support group to draw on instead of having to 'wing it' completely on my own. In the end I can only approach things in the way that seems best at the time, but part of that process for me is to prepare myself as best I can. As my daughter grows older it is good to know that the support group can provide her with the opportunity to make contact with other members if she wishes to. In the immediate future though we are looking forward to our little girl starting big school – she can't wait to start school and it's great to see her so enthusiastic!

So finally I'd like to just say a big thank you to all who help out with AISSG - it is much appreciated.



Calling all teens and young adults with AIS!

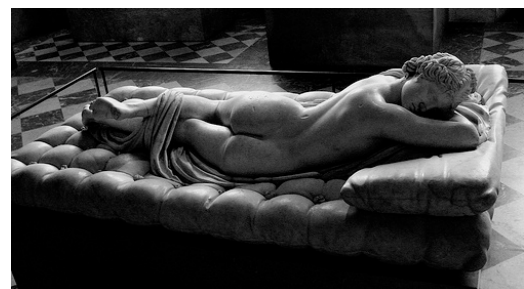
Hi! My name is Miriam and I am a teen liaison to the United States AIS-Support Group, and I am interested in getting in contact with teens and young adults with AIS (anyone from their teens into their 20s would be wonderful!) We would love to be in contact with you about your perspectives with AIS and connect you with an online group for our perspectives and experiences to combine. Many young women from all across the world are a part of our community, and we'd love to have you!

Please email me at: aissgusa@hotmail.com with the subject line "Teen referral- to Miriam". Please include some information about yourself (first name, interests, location, if you are in secondary school or university, etc) and we'll be in touch!

I will get back to you soon after and connect you with our Teen Support group.

We hope to hear from you soon!

Warmly,
Miriam, the US AIS-SG, and the US Teen Support Group



Oestrogen HRT – The Right Dose

In December 2009, Phoebe wrote to Dr Paul Bartley, Consultant Endocrinologist about his opinion on what is the 'right dose' exactly when it comes to hormone replacement therapy for women with AIS, particularly in regards to the problem of low bone density which often times is a great concern to CAIS women in the years following a gonadectomy (ie. surgery to remove testes). This is his reply....

In CAIS because of the absence of oestrogen and in spite of high levels of testosterone which, as you know, are ineffective biologically there is a high incidence of low bone density or osteopenia and even osteoporosis. Osteoporosis due to the absence of oestrogen with premature and normal menopause was first elucidated by Fuller Albright in the 1920s. Following that pioneering research oestrogen replacement for premature and normal menopause was shown on to prevent the development of osteoporosis in women with premature menopause.

As I'm sure your membership is aware of osteoporosis and osteopenia are very common in CAIS and patients with it are usually given oestrogen. However the oestrogen replacement that they are given is usually that designed for postmenopausal women 55 years and older and is only about 20% of the amount of oestrogen that is produced normally by the ovaries in premenopausal women. As a result this does not prevent the development of osteoporosis in the women with CAIS. There have been many

studies done of bone density and osteoporosis in women with CAIS and all them show the same findings.

They show that there are two groups of women those on the low-dose postmenopausal oestrogen and whose bone density declines and develop osteoporosis and those on normal levels of oestrogen replacement as would occur in the normal premenopausal woman whose bone density does not decline.

The solution to this problem is very simple and not expensive and involves taking oral contraceptive tablets such as Levlin ED or Microgynon ED 30 however there is no requirement to take the sugar pills as no menstrual period can occur. The 21 day packs of the contraceptive tables can be taken end to end. Obviously women taking the oestrogen medication need to have their breast surveillance with respect to the development of breast cancer and also need to be aware that deep venous thrombosis or DVT as it is called, is more common. The taking of full oestrogen replacement through until about 55 years of age will maintain normal bone density providing it starts at a young age. After that age postmenopausal oestrogen medication can continue to be taken.



Ladybird on Daisy by nutmeg66, 2008. CC

Dilators Needed for Art!

This email arrived from Bonnie recently....

Does anyone out there have some vaginal dilators that they would like to donate to ART! I have a mental image of boiling them in h2o until they become⁸ bendy and then making a sculpture out of them. Funny how I can be attached to that old bag full of clunky torture devices. Stockholmesque.

Please contact Bonnie to help out:

loln@ventinggallery.com

Viva la revolution!



Representation of Intersex (Part 2)

In the last instalment, this article discussed the frequently sensationalised portrayal of people with intersex in the media. Here, this discussion continues with a look at some representations of intersex that attempt to rebalance the status quo.

More authentic representations of intersex can be found in films such as *XXXY* (Soomekh and Porter 2000), marking a shift in portraying the actual lives of intersexed people with a greater degree of sensitivity. The film's purpose seems loftier than a mere explanation of the finer points of human biology to a general audience, and seeks perhaps to more deeply delve into a depiction of the experience of having an intersex condition. The directors of *XXXY* interview two people born with intersex conditions, including prominent intersex advocate and psychologist Howard Devore. Both speak candidly and emotively about their conditions. *XXXY* is well shot and edited, and is a fine, straightforward example of expositional short documentary filmmaking. While the film clearly communicates the human face of current medical and social paradigms and practices, and illustrates a sympathetic approach to the subject directorially-speaking, arguably, it does not follow the minutiae of daily life and relationships as an observational documentary would, nor does it capture the depth of human experience one might find in an autobiographical documentary.

Other short documentaries in the same vein include *Intersexion* (Hammer 2001) and *Gender Trouble* (Mortimer 2002), both of which espouse

the same political ideology as *XXXY*, incorporating also a pronounced visual and aural aesthetic. *Intersexion* and *Gender Trouble* blur the lines between documentary and other more experimental cinematic modes, opting for a photomontage of medical photos of genital surgery in the former. In the latter film, interviewees are placed in front of an ever-evolving tapestry of background images of orchids and family photographs, which suggests a poetic mode of documentary address. Like *XXXY*, the director of *Gender Trouble* has recruited four [British] hermaphrodites, who relate their stories frankly to an unseen/unheard off-camera interviewer. Both films have received praise and toured extensively on the festival circuit. The filmmakers (in both cases women, though not intersexed) have attempted to portray the emotive aspects of the stories of people with intersex conditions quite successfully.

In further investigating the contextual, inspirational field for my project *Orchids*, I found that some individuals from the intersex community have emerged as ‘intersex celebrities’. *Yellow for Hermaphrodites: Mani’s Story* (Keir 2002) is a one-hour television documentary that chronicles the life story of Mani Bruce Mitchell, an out-and-proud hermaphrodite residing in New Zealand. This biographical film gives voice to Mani’s critical view of the surgical intervention in his/her life, the experience of childhood abuse, and evokes the shame, secrecy and subsequent trauma that Mani underwent. However powerfully Mani’s personal testimony resonates,

the documentary itself rarely deviates from the expositional mode with a Griersonian twist, replete with male voice-of-God narrative and written and directed by a white, middle class male. Like *Is it a Boy or a Girl?*, *Mani’s Story* is made for the mainstream – for ‘Mums and Dads’ with only an inkling of the marginal world of the hermaphrodite. Mani may be more satisfied personally with a short documentary *Black and White* (MacDonald 2006) produced in New Zealand, which features Mani’s life story and the artistic collaboration between Mani and photographer Rebecca Swan (Figure 1). Mani’s ‘unflinching’ narrative is potently augmented by the artful performative representation of his/her own intersex identity in still photography, and the documentary has enjoyed a successful tour of the international queer film festival circuit.

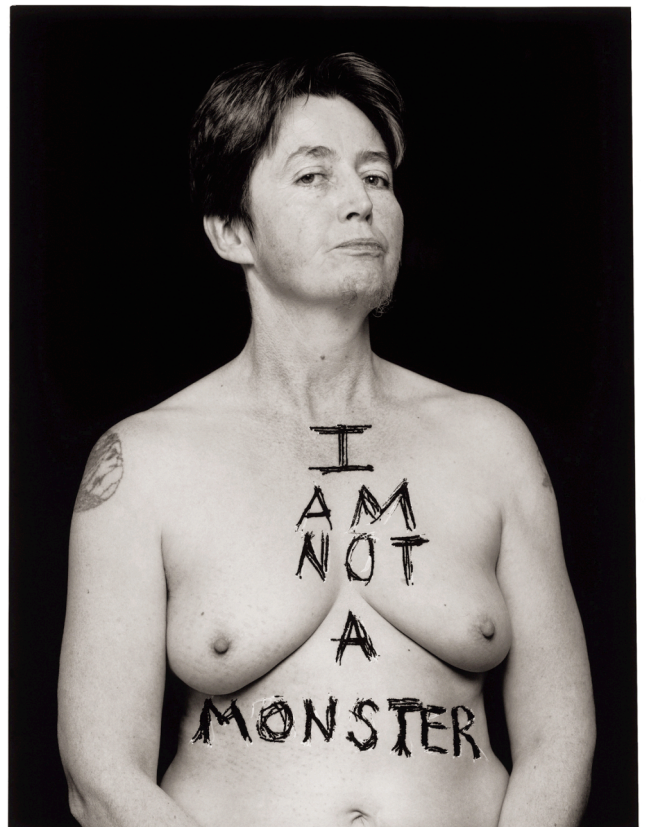


Figure 1. Mani Mitchell. Photographed by Rebecca Swan, 2006. Courtesy of Women Make Movies, www.wmm.com.

Significantly, *Hermaphrodites Speak!* (Chase 1997) claims to be the first film ‘by and about intersex people’. The documentary records the first retreat of the then newly formed Intersex Society of North America (ISNA). Participants at the retreat speak candidly about their lives while sitting in a circle, passing a microphone from one to another. While lacking production value (the session is presented as a single unedited, over-exposed, hand-held long take) the key messages of the emergent intersex movement are conveyed with sincerity. Its audience is clear: this is a message-film for others ‘out there’, to let them know that they are not alone. It is also a message to ¹⁰the medical community that people with intersex conditions are not happy. As a result, the content is groundbreaking, and subsequently the film has been widely used to raise awareness for the movement at a number of conferences and film festivals, as well as having been acquired by medical and university libraries around the world.

While *Hermaphrodites Speak!* is a collective statement, recently a number of individuals – intersexed artists and activists – have begun to tell their stories each in his/her own distinct voices, using documentary as a means of expression. Del La Grace Volcano and Eli seMbessakwini are both deeply embedded within queer politics and their works express potent struggles for identity. Del La Grace Volcano is a gender variant visual artist and filmmaker who has been living in London since 1982. *Journey Intersex* (Volcano

and Lavan 2000) follows an investigation motivated by Volcano to aid his cousin, Heidi (born ‘Travis’), an intersexed woman. The documentary explores the mystery surrounding Heidi’s unexplained medical treatment in infancy, and follows the pair as they travel to confront family members on the secrets surrounding Heidi’s birth and subsequent rearing as a girl. Volcano’s artistic work extends across most visual mediums, including photography. His/Her objective is to challenge ‘sexist and hetero-normative constructions’:

I want to be seen for what I am: a chimera, a hybrid, a herm. After seven years of living as a herm I have to question if it is even possible for others to see beyond the binary and validate those of us who choose to live outside its confines, as well as those who have never been given the chance to (Volcano and Windh 2005, 134).

Intersexed Australian filmmaker seMbessakwini (now living in San Francisco, USA) began her foray into documentary filmmaking with *Intersex Exposition: Full Monty* (seMbessakwini 2002) and followed up with *Born Queer: dear doctors* (seMbessakwini 2003a). These poetic expressions include an experimental fusion of live performance and ‘spoken word’ text to express feelings of pain and anger. In the case of *Intersex Exposition*, seMbessakwini simultaneously undresses at a lesbian strip club while ‘exposing’ herself as a hermaphrodite via a monologue to the audience (**Error! Reference source not found.**).

The language is autobiographical; seMbessakwini describes the outcomes as a ‘big step in empowerment and shifting the pattern of shame, guilt and self-doubt’ (seMbessakwini 2003b).

Judith/Jack Halberstam notes that representations of gendered identities on the screen have shifted from simply being a ‘tricky narrative device designed to catch an unsuspecting audience off guard’ (read: *House*) to productions that attempt to revise concepts such as ‘heroism, vulnerability, visibility, and embodiment’ (Halberstam 2005, 96). Both Volcano and seMbessakwini have set the stage for autobiographical filmmaking by artists with intersex conditions.

Similarly, *Orchids* is a personal documentary, and an auto/biographical film that also deals with the issue of intersex. On the set of *Orchids*, we made use of a small production crew: I was the Producer/Director and sometimes Camera Operator, and Bonnie – my sister – was also filming, contributing to the visual aesthetic and narrative structure. Volcano identifies in *Journey Intersex* a familial link and investigates the family secret with his cousin, Heidi. However, in *Orchids* Bonnie is more than a character in the film; she is an active, creative participant in the documentary filmmaking. We are sisters who share the same intersex condition. Despite our differing perspectives and aesthetics, our goal was to work together to make a long-form film of approximately sixty minutes in length (or longer) about the experience of having an intersex condition.

It is expected that Orchids will be broadcast on the Australian Broadcasting Corporation in late 2010.



Tensió by marestra, 2009. CC.

Author's request – Intersex

I'm writing a book on the science of sex and gender for UNSW Press and was hoping people might be prepared to talk to me about the intersex experience. The essential idea underlying the book is that both sex and gender are more complicated than the binary of opposites we generally talk about. I am also talking to scientists and clinicians who work in this area, but I understand some people with intersex conditions would have criticisms of some of the approaches they take and I would be keen to hear your views.

Thanks for your help.

Jane McCredie

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Hi-tech microscopes make androgen therapy 'personal'

Dipali Pathak, Baylor College of Medicine

RSS icon HOUSTON -- (December 9, 2009) --

On rare occasions, an infant is born with outward
12
appearance of a female but the XY chromosomes
of a male. If the child has a normal Y
chromosome -- the chromosome responsible for
testicular development -- the condition is known
as androgen insensitivity syndrome.

Experts estimate such births occur in about one in
20,000 infants. Other children are born with a
partial form of the condition that can affect their
genitalia and/or fertility, but how many is not
known.

The cause is a wide range of androgen receptor
(AR) mutations that fail to perceive the presence
of the male hormones testosterone and
dihydrotestosterone to differing degrees. How to
overcome the problem remained a mystery until
Baylor College of Medicine and Michael E.

DeBakey Veterans Affairs Medical Center experts
used a high throughput, automated microscopy
technique called high content analysis to solve the
puzzle. A report of their findings appears in the
current issue of PLoS One, an open access
journal.

Reverse effect of mutation

They not only identified the functional
abnormality of the AR, but also used high content
analysis to "personalize" a treatment that reverses
the effects of that mutation.

"With this microscopy technique, we have been
able to quantify how the receptor moves and
functions inside cells taken from children with
normal receptors and in those with the mutation,"
said Dr. Marco Marcelli, professor of medicine-
endocrinology at BCM and a physician at the
Michael E. DeBakey Veterans Affairs Medical
Center. He and Dr. Michael Mancini, associate
professor of molecular and cellular biology at
BCM, and director of its Integrated Microscopy
Core, are senior authors of the report.

Androgen insensitivity syndrome

They used banked cells taken from patients – both
those with the mutation and those without – to
study the action of the receptor in cell cultures
grown in the laboratory. Dr. Michael J. McPhaul,
a collaborator on the study and a professor of
internal medicine—endocrinology at The
University of Texas Southwestern School of

Medicine Dallas, provided the samples from patients with androgen insensitivity syndrome.

"We did this on a cell-by-cell basis, using high content analysis," said Mancini. "It is a proof-of-principle study carried out as though we had a patient and a library of hormones. We tried to find the perfect hormone for the mutation through high-speed collection of dozens of measurements from thousands of cells."

"In two of the three specimens we tested, we found we were able to reverse the activity of the mutated receptor to almost normal," said Marcelli.

In one patient, large doses of the male hormone dihydrotestosterone were sufficient. In another, they used a synthetic androgen that also activated the receptor.

These approaches overcame the central problem – the mutation changes the shape of the receptor and prevents it from maintaining normal contact with the hormone. It is as though a key is bent and can no longer turn the tumblers in a lock. In these cases, the hormone is designed to go into a pocket created by the receptor. When the pocket is changed by the mutation, the hormone is unable to establish good contact.

"Large amounts of testosterone may create more stable contact," said Marcelli. "The synthetic androgen may have a conformation that establishes better contact."

Superandrogen

In the future, scientists may be able to screen large banks of such compounds to find a "superandrogen" that may be even more efficient.

"We might be able to use this technique to create a personalized medicine test," said Mancini.

Similar techniques might be used to screen drugs for treatment of different cancers, particularly those in which the androgen receptor is responsible for cancer progression. This study proves that the concept is valid providing quantitative information collected quickly on numerous measurements normally requiring separate biochemical tests and huge numbers of cells.

Marcelli said they have yet to use this kind of technique in patients, and such studies will require careful preparation, and go through a variety of approvals before it can be used in clinics. He also said it would be used only in individuals with the partial form of the syndrome. Finding well-matched hormones to defective androgen receptors through screening of thousands of compounds from available libraries could be one of the future developments of this technique.

The paper's first author, Dr. Adam T. Szafran, an M.D./Ph.D. student who worked in Mancini's laboratory, championed these studies, said Mancini. Szafran is now finishing the clinical part of his studies at BCM.

Others who took part in this study include Drs. Sean Hartig and Ivan P. Uray, Maria Szwarc, Jennifer Bell, Huiying Sun, Yuqing Shen and Sanjay N. Mediwala, all of BCM. Sun, Shen and Mediwala are also of the MEDVAMC.

Funding for this work came from the National Institute of Diabetes and Digestive and Kidney Diseases, the John S. Dunn Foundation and the Veterans Administration.

Become a Member

The Androgen Insensitivity Syndrome (AIS) Support Group Australia Inc. (A0041398U) is a peer support, information and advocacy group for people affected by AIS and/or related intersex conditions, and their families.

We support members (both in Australia and overseas) that have any grade of Androgen Insensitivity Syndrome, and support any issues relevant to living with AIS. These issues include infertility, disclosure, hormone therapy, gender identity, surgical intervention of children with intersex conditions, sexual intimacy, etc.

We also provide support to those with related intersex conditions like Partial and Complete Gonadal Dysgenesis, MRKH (also known as Vaginal Agenesis), 5a-Reductase Deficiency, 3b-Hydroxysteroid Dehydrogenase Deficiency, 17-Ketosteroid Reductase Deficiency and 17b-Hydroxysteroid Deficiency. (The previous name for AIS was Testicular Feminisation Syndrome).

We acknowledge that people with intersex conditions (including AIS) range from female to male and anywhere in between.

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

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

There are many benefits to becoming a member of the AISSG Australia, including the dAISy newsletter, regular conferences and meet-ups, and up-to-date information and news relevant to our members. Of course, there is also the wonderful benefit of supporting and meeting others who have so much in common and much to share! We are also always looking for people who want to become more involved as representatives and/or committee members.

Currently we are:

Phoebe (President & Qld Rep.)

Tony (Vice President)

Andie (Vice President)

Jocelyn (Victorian Rep.)

Sandra (NSW Rep. & Secretary)

We'd love to have representatives in other states and territories. We also have representatives for parents of children with AIS and men with AIS.

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

PO Box 3239
South Brisbane Q 4101

Or email your details to aissgaustralia@gmail.com

Please find a membership application form on the following page. Please remember that for a short time to give you added incentive to become a paid member we are offering membership until August 1, 2011 for the price of a one-year membership. In addition, if you join by 30 June 2010 you will go in to the draw to win a beautiful Phoebe lamp by Australian designer Peter Harding.

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The next dAISy

Next issue is July 2010. The deadline for submissions is 30 June 2010. To submit articles, art, jokes, information, poems, or whatever you would like to share please email aissgaustralia@gmail.com

We hope to hear from you again soon!



Membership Application (2010-2011)

I wish to apply for membership of the Androgen Insensitivity Support Group Australia Inc. I enclose my annual membership fee which ends on the 1st of August 2011.

Name/Organisation:.....

Address:

State: Postcode: Country:

Telephone Number(s):

Email address:

Age:(optional) If organisation name of contact person:.....

Signature: Date:

Membership type: (Please tick one)

Individual Membership:

Organisational Membership:

1 year \$20

1 year \$40

3 years \$50

3 years \$100

Please indicate your membership category:

Person with AIS, Gonadal Dysgenesis or similar condition (Please specify)
.....

Family / Partner / Friend of someone with AIS or similar condition
.....

Medical Professional (please state interests in AIS and similar conditions)
.....

Organisation (please state interests in AIS or similar conditions)
.....

Would you like to make a donation to the AIS Support Group Australia?

(Donations of \$2 or more are tax deductible)

\$10 \$20 \$50 \$100 other \$.....

Please make all cheques payable to the **AIS Support Group Australia**. Direct deposit available on request. **Thank you!**