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Message from the President

Holiday greetings to everyone and I hope you are having a peaceful and enjoyable start to 2012. Many thanks go to Phoebe, our Secretary and Queensland Rep, for another great edition of dAISy. I hope you all enjoy this edition and have fun catching up on the latest AIS related news. The main event for the AISSGA this year was our Annual Conference, which was held over two days in Brisbane in August. The conference was a great success, in large part due to the brilliant planning efforts of Phoebe and Miriam, our US Intern. More news on this later in the newsletter....

2011 has ended with some significant news with Tony Briffa, our Vice President, being elected as Mayor of Hobson’s Bay Council in the suburbs of Melbourne. This made world news as Tony is the first openly intersex person to be elected to public office. Congratulations Tony and we are sure you will do a fantastic job!

2011 has also been a big year for Phoebe who has been globetrotting to international film festivals with her movie “Orchids”, the story of her journey with AIS. The film has already received numerous awards and has recently been nominated for “Best Documentary” at the AACTA Awards, Australia’s premier film awards, held at the end of January. Congratulations Phoebe and good luck for the Awards night!

These significant achievements will place AIS and intersex more in the forefront of world news and culture, and will contribute greatly to raising awareness and understanding of intersex and hopefully reduce the stigma, ignorance and discrimination faced by intersex people worldwide. It is amazing what can be achieved when we choose to take our personal story into the public domain. It takes a great amount of courage to do what Phoebe



Photo by Diane Cordell (Creative Commons license)

and Tony have done, but in a way we can all make a contribution to raising awareness by talking about AIS and intersex to our families, friends and doctors or even to a local paper if we choose to go to that level.

While going public is definitely not for everyone I have experienced mostly acceptance and goodwill from those I have chosen to tell about my AIS. Whenever I have attended a meeting and shared about my AIS experience, whether it is an AISSGA meeting or other organization, I have always felt affirmed and encouraged by the response of others. I have left the meeting feeling uplifted and feel like I have been accepted for who I am. I think the more we can take a risk and tell people we trust about ourselves, the more the word will spread and the greater acceptance we will feel from society as a whole. For too long intersex conditions have been kept a secret, and only by breaking our silence will society begin to change its attitudes and accept us in all our wonderful diversity!

Ed's note: Phoebe's film Orchids: My Intersex Adventure is scheduled for broadcast on ABC1 on Sunday 29 January 2012 at 10pm. For more info visit www.orchids-themovie.com



AISSGA National Conference, Brisbane,

August 2011

An Overview by Sandra

The AISSGA Annual Conference was held in Brisbane this year on August 6-7. Phoebe and Miriam, our US intern, did a fantastic job of planning the 2-day conference that was attended by ten people. We were fortunate to have received some funding for the event from Self Help Queensland and Queensland Association for Healthy Communities, which allowed us to provide some fabulous catering as well as accommodation for the attendees.

The conference began with an insightful presentation from Dr Wendell Rosevear on "Effective Communication with Physicians". Wendell talked us through a model of relationships that described our interactions with others as healthy or unhealthy. Acceptance, honesty and trust were the key factors that led to healthy relationships, and he challenged us to put some of these techniques into practice in our relationships with loved ones as well as support people such as doctors.

After lunch we heard from Miriam who gave an informative presentation on the biology of AIS and intersex, based on slides from Dr Charmaine Quigley from the US, with the opportunity for questions and discussion. Phoebe followed with a roundtable discussion on infertility and adoption, drawing on her own experience of becoming a mother through adoption. It was fascinating to hear of Phoebe's experiences and how she has managed the challenges of adoption and motherhood. I followed Phoebe with a dance session with the aim of giving people time to process their emotions on a physical level and have fun with some dance and music together. It was good to have a break from the verbal interaction and interact on a different level. I know I had a great time leading the session and from the smiles on everyone's faces I think they did too!

The day ended with a viewing of Phoebe's movie "Orchids" followed by discussion of her trip to the US Support Group Meeting in Seattle earlier this year. The US meeting looks like a mega experience with large numbers of people and an endless choice of events and talks. Amazing! Our very full day ended with a dinner at a local restaurant, which was fun and yummy!

The next day we had an extended time for sharing our personal stories and offering each other support and encouragement. This is always my favourite part of a conference and I really enjoyed hearing from people I hadn't met before and hearing new aspects to stories from people I already know. It was a very safe and caring environment to open up

with others and it was amazing to hear how others have triumphed over very difficult life circumstances and managed to come out all the stronger for it. We ended the day with our election of the AISSGA Committee and discussion of plans for the Conference in 2012. All in all a fantastic conference and I hope that some of you who have never been to a Conference before will consider joining us in 2012. It's well worth the effort!

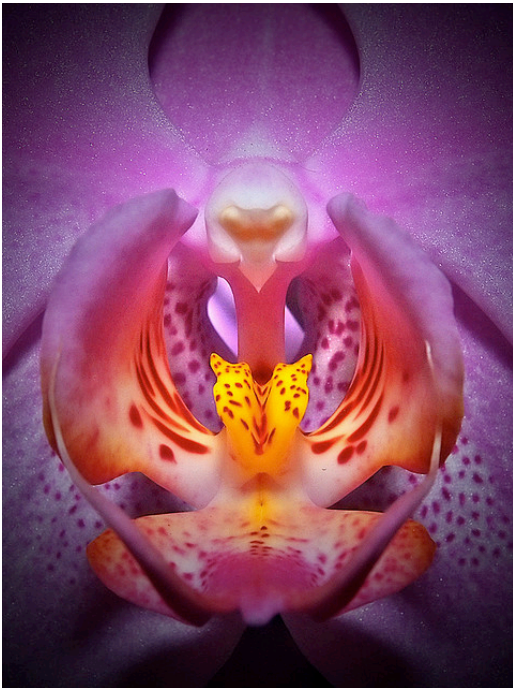


Photo by 'Mdezemery' (Creative Commons license)

Tony Briffa to run for Mayor of Hobsons Bay

13 November 2011

Author: Michael Magnusson, Andrew Shaw

Hobsons Bay councillor Tony Briffa has confirmed he will run for the position of Mayor for the City of Hobsons Bay for 2011-12.

The election will be held at a public council meeting at the Civic Chambers in Altona on December 2.

Briffa is currently serving his second term as Hobsons Bay deputy mayor.

Current mayor, Michael Raffoul, has not indicated he will run and other potential candidates have yet to indicate if they stand for nomination.

Sources close to MCV said no one is expected to stand in opposition to Briffa.

Briffa was behind the formation of Hobsons Bay's first GLBTIQ Community Advisory Group, established in September this year and which advises council on GLBTIQ interests and assists in the review and evaluation of council services.

Briffa told MCV he would continue as chair of the panel if elected mayor.

"I have always been a vocal and passionate supporter of the local community including the GLBTIQ, disability, multicultural and interfaith communities," Briffa said.

Briffa convened the local residents association for five years prior to being elected a councillor and has been a member of various GLBTIQ and Disability sector committees over the years.

Briffa was born with Partial Androgen Insensitivity Syndrome, with doctors originally deciding he should be raised as a girl. From the age of 12 onwards Briffa repeatedly told doctors he was not a girl, that he was a boy.

Briffa appeared before a councillor conduct panel earlier this year after allegedly sending threatening emails to a local resident and was ordered to attend 12 months counselling. Briffa said that may be an issue for some councillors but hoped the council would consider his performance and not focus on that issue.

Briffa said he is developing a mayoral programme and will announce it on the night of the election.

<http://gaynewsnetwork.com.au/feature/feature/2848-consider-my-performance-not-my-gender-diversity-tony-briffa.html>

Interview with Mayor Tony Briffa

Ed: Tony has been long involved with the AISSG Australia – as President and now as Treasurer and Honorary Life Member. We asked Tony a few candid questions about his mayoral campaign for a dAISy ‘exclusive’.

1. Tell us about the seat where you successfully ran for the position of mayor, Hobsons Bay.

I have been involved in local government for the last ten years and was the Convener of the local residents' association until being elected as an independent councillor for the City of Hobsons Bay in 2008. I have since served two terms as Deputy Mayor, and this year decided to stand for the Mayoralty. I am pleased and honoured to have been successful.

The City of Hobsons Bay includes many southwestern suburbs of Melbourne including Altona, Brooklyn, Laverton, Newport, Seabrook, Spotswood and Williamstown. It's a very diverse community and I was born and raised here. Significantly, I lived here for 30 years of my life as Antoinette and went to the local Catholic Girls' School. I am very open about my genetic condition and past, and the community has always been very accepting of me.

2. What prompted you to get into politics, and then run for mayor?

Getting involved in politics is the best way for me to influence the community and make it a better place to live. I have always had an interest in politics and history, and find being

Mayor is something I am good at and enjoy. Being Mayor was a natural progression for me after serving two terms as Deputy Mayor.

3. How did your mayoral campaign run for you? Were there any major hurdles?

The campaign went very smoothly. I announced my interest to stand as Mayor early and enjoyed a lot of support from the community and my fellow Councillors.

4. You've been described as the world's first 'Intersex' mayor and praised by the LGBTI media generally - how does this make you feel? Do you feel it is an important aspect to your success?

I am pleased that my role and success as the Mayor of the City of Hobsons Bay can raise awareness of intersex conditions and issues, as well as promote understanding and acceptance of the wider GLBTI community. I believe having an intersex condition - and being both male and female - has given me an ability to relate to people irrespective of their sex, gender identity, race, religion, physical attributes, ability, etc. It's also made me a passionate advocate for human rights and the rule of law.

5. What are your plans now you have been elected?

I plan to be the best Mayor I can be! I had already planned my Mayoral Program prior to my election as Mayor and am looking forward to implementing it with great enthusiasm. The main areas of my program are community engagement, advocacy and the environment.

Please visit my website for more details:

www.briffa.org

I am also available on Facebook:

www.facebook.com/CrTonyBriffa

Kind regards,

Tony

My Ongoing HRT Journey AKA “Look Mum, I’ve Got BOOBS!!”

By Phoebe

Hello once again kind dAISy readers.

Over the years I have published a number of accounts of my Hormone Replacement Therapy (or HRT) journey. As a woman with AIS, I feel I’ve had all the ups and downs since my gonads were removed at age 17 and I began a life of daily doses of artificial hormones. Yes, I’ve had it all – pills, gels, implants, brushes with osteoporosis – the lot. Now at age 38, my HRT journey has taken another unexpected swerve....

It all began when I took a trip to America this year and attended the US AIS support group’s national conference in Seattle. I Firstly I have to say, it was a blast. I made so many new friends. I shed tears and had many memorable belly laughs. Aussie AISers, I would recommend going if you ever have the time, money or inclination. There were over 100 gals in attendance aged from 3 months to over 90 years of age all with AIS or similar intersex conditions. It was a wonderful experience.

I also learned a lot. The whole weekend was organized just like a regular conference with many speakers from all walks of life and specialist panels of academics, doctors, activists, counselors and even the odd comedian!

While I was there, I really started to get interested in what the latest in HRT for ladies with AIS was and information was in abundance.

The latest craze was a transdermal spray called ‘Evamist’ (unfortunately not available in Australia under the PBS) which is an estrogen plus progestin therapy. You just give yourself 1, 2, or 3 sprays every day to a small area on the inner forearm. While the women who were using the spray reported some weight gain, they also said that their boobs got bigger, their nipples darker and more ‘nippy’

and erect and sex drive better.

There is also a strong movement to keep the testes in or to use a testosterone-based HRT treatment regime, the thinking being our bodies would convert it into the estrogen we need naturally. Inguinal testes could be safely monitored for cancer risk with MRI periodically. A clinical trial is underway in Germany with 30 orchids – it’s a crossover study of testosterone gel versus estradiol gel that measures outcomes such as quality of life, sexual satisfaction and psychological wellbeing.

I even learned about milk production induced with progesterone, which could be handy when I adopt again (I have a 3-year old girl by adoption now). One can get a “lactation consultant” to help achieve this easily enough. A good resource is “Ask Lenore” AKA Dr Lenore Goldfarb of the Jewish Hospital Montreal who has a page on adoptive breastfeeding and induced lactation:

http://www.asklenore.info/breastfeeding/abindex.shtml#adoptive_breastfeeding

Anyway, by the time I got home, I was determined to go back to my endo for the first time in quite some years to see if I really was on the right track, hormonally speaking. The last time I saw him, he upped my daily dose from a measly 0.625mg estradiol tablet per day to four times that dose – a full 2mgs per day. I thought this was rather a lot at the time. I was about to get a shock...

I walked into his office on a sunny morning in August 2011 and without further ado he ordered me onto a new HRT regime! The new product is ‘Microgynon’ – that’s right... THE PILL! This is the contraceptive pill that works by inhibiting the maturation of the ova in menstruating 46XX women or ‘breeders’ as I call them. I just don’t take the red section that is there for when breeders are bleeding – it’s just a lactose pill to keep those girls taking their meds regularly. The ones I take contain 125 micrograms of levonorelrel (synthetic progestogen) and 50 micrograms of ethinyloestradiol (estrogen) per tablet.

Apparently progesterone helps with breast development considerably.

So, what's happened since? I've been taking the dose as prescribed. I feel fine. And I'm happy to report I now have BOOBS that touch when I don't have a bra on. I have cleavage!! Yes, bigger boobs with nice nipples. It seems to give me a better proportion generally, with my broad shoulders and all.

Yay!!

PS. During the American AIS conference, I learned that 2013 is slated for a meeting of all the orchid tribes from all around the world in the US (possibly in Las Vegas). Start saving your pennies!



Politicians should heed grey areas of gender

Michael Cooper 'Opinion'
September 23, 2011

Julia Gillard has repeatedly insisted marriage should be between "man and woman". Her position on same-sex marriage may seem clear, but only if it is possible to define man and woman.

Significant controversy surrounded Caster Semenya, the South African runner who won the 800 metres at the 2009 world championships. Gender testing was performed, although the results have never been released for privacy reasons. The International Olympic Committee decided to cease sex testing in 1999 because of difficulty assigning a "result" in certain cases.

Defining "man" and "woman" is not easy and encompasses a large continuum between the two end points. Unfortunately, society's prejudices to assign a black or white result to what in nature may be a very grey area has

resulted in significant discomfort and distress for many people.

Advertisement: Story continues below

I have seen couples who have experienced great distress at the birth of a child with ambiguous genitalia, when the answer to the question, "is it a boy or a girl?" is not readily forthcoming. Just as no two of us are alike, there is a large grey zone between being male and female.

I have been involved with a small number of individuals over the years who appear as female but have been born without a vagina. At one extreme are individuals with Androgen Insensitivity Syndrome. They are born with a male chromosomal complement 46XY and secrete normal levels of androgen, but a receptor defect means the androgen is not converted to an active form and they appear female.

They have no vagina, uterus, tubes or ovaries, but with medical techniques a new vagina can be created. Like the rest of the population they are able to marry and, with technological assistance, conceive. It is possible to obtain donor eggs, fertilise with the partner's sperm and implant an embryo into a surrogate uterus for a pregnancy to occur. This has been done many times.

Another, more common anomaly, Mayer-von Rokitansky-Kuster-Hauser Syndrome, involves people born with the normal female chromosomal complement, but whose genital tract fails to develop. Again, the outside genitalia appear normal, but the upper vagina and parts of the uterus and tubes are absent. These individuals have ovaries, so their own eggs may be harvested, but they do not have a uterus and require a surrogate for conception.

Individuals with genetic mosaicism may have cells with both male XY and female XX chromosomes. Variations of this theme are not as rare as many may think, as evidenced by testing from prenatal genetic diagnosis. How should we define the gender of such people? Australians appear increasingly

relaxed about sexual orientation, but the idea remains that you must be male or female. The International Olympic Committee has decided it is unable to make that definition. By contrast, Australia attempts to do so.

The Family Court recognises a post-operative transsexual female-to-male person as a man for the purposes of the Marriage Act. He is able to enter into a valid marriage with a woman. But others live in limbo.

Politicians should be aware of these conditions - rare as they are - before passing legislation on issues relating to sex, gender and relationships.

Michael Cooper is a clinical associate professor in the department of obstetrics and gynaecology at Royal Prince Alfred Hospital.

Read more:

<http://www.smh.com.au/opinion/politics/politicians-should-heed-grey-areas-of-gender-20110922-1kn2e.html#ixzz1ZmzQkjps>

Gender 'X' on Australian Passports

September 2011: You've probably heard about the Federal Australian government's announcement regarding passports this month. In media reports, it claims intersex people, who are biologically not entirely male or female, will be able to list their gender on passports as "X."

At the time, various media outlets contacted the AISSG Australia to comment and we responded by telling them that the announcement by the Commonwealth is laudable but largely insignificant for people with genuine intersex conditions.

Australians with intersex conditions have been able to get the sex on our passports corrected for years irrespective of surgery.

Press Release from StopGenitalMutilation.org

September 17, 2011

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<http://stop.genitalmutilation.org>



(Image from Demotix.com)

Today marks the beginning of the 'IV. World Conference of Genital Mutilators in Children's Clinics' a.k.a. 'ISHID 2011' at the Royal College of Surgeons, picketed by survivors remembering the victims and commemorating 15 years of peaceful protests against their tormentors.

For three days, the ruthless docs will propagate and perpetrate their unethical, inhumane and illegal deeds, culminating in a whole day of 'Live Genital Mutilations' on Monday, beleaguered by some of their former victims. During their first peaceful vigil today, they will remember the first public protest by survivors against the mutilators organised by the Intersex Society of North America (ISNA), when 'Hermaphrodites with Attitude' took to the streets picketing the Annual Meeting of the American Academy of Pediatrics in Boston on October 26th 1996. This first public protest by survivors was announced by a press release titled 'Hermaphrodites target Kiddie Docs' – a motto today unfortunately still as up-to-date as 15 years ago...

On Sunday, the London protestors will hand in an Open Letter to the perpetrators of the 'IV World Congress of the International Society

for Hypospadias and Intersex Disorder (ISHID)' and their local accomplices offering them hospitality and support, amongst others the Royal College of Surgeons of England and the Great Ormond Street Children's Hospital. The protests will continue on Monday in front of the University College Hospital Education Centre, where the 'Live Mutilations' will be televised for the 'ISHID 2011' pedo docs.

The human rights advocacy group Zwischengeschlecht.org demands the prohibition of cosmetic genital surgeries on children and minors and "Human Rights for Hermaphrodites too!"

Kind regards

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<http://stop.genitalmutilation.org>
<http://humanrights.4hermaphrodites2.org>

One to two in 1,000 children are born with 'atypical', 'ambiguous', or 'otherwise deemed unworthy' genitals. At least 90% of them are submitted to cosmetic genital surgeries and other invasive medical interventions in western children's clinics—without actual medical need, without evidence of any benefit for the children, but in blatant violation of their human rights. Survivors have been accusing these systematic, massive and irreversible practices as a gross violation of physical integrity and as Western Genital Mutilation for at least 20 years.

On September 17-19, perpetrators of 'cosmetic genital surgeries' on children with 'atypical genitals' will celebrate 'IV. World Conference', culminating in a 'live surgery' marathon — while their victims deplore non-consented removal of healthy genital tissue resulting in loss of sensation, and will be protesting 'gross human rights violations.'

The mutilators wax lyrical about 'clitoris reductions,' 'penile reconstructions' and other 'surgical challenges,' hell bent on 'correcting' what they deem 'too big clitorises' and 'imperfect penises' as quickly as they can, before the parents might start loving their children the way they were born.

The victims call it 'medical crimes' and 'western genital mutilation', publicly protesting life long trauma, pain and/or loss of sexual sensation, drawing parallels to female genital mutilation and child sexual abuse. Accusations, which during the last decade again and again have been backed by human rights experts and honest clinicians alike, perhaps most notably by doctors from Middlesex/UCL.

Yet still the majority of pediatric endocrinologists and surgeons turn a blind eye to the victims' pleas, as well as to the mounting evidence-based data on the negative impact of the unwanted surgeries. Case in point: The 'IV World Congress on Hypospadias and Disorders of sex Development' a.k.a. 'ISHID 2011.'

Peaceful pickets lead by survivors will remind the perpetrators that it's not OK to mutilate defenseless little children.

Ed's note: Recently, in the concluding observations of the Committee Against Torture, set up by the United Nations, several recommendations were made on 'intersex' to the Germany government, including the effective application of legal and medical 'best practice' of granting informed consent to medical and surgical treatment of intersex people, and ensuring the investigation of incidents of surgical or other medical treatment of intersex people without effective consent and adoption of legal provisions in order to provide redress to the victims of such treatment, including adequate compensation.

Research, Research, Research

Ed: A number of requests have come through for help with research projects coming out of universities, etc.

We here at the AISSG Australia have vetted these projects and now present a list of the acceptable ones for your consideration to participate.

Often these surveys are time critical, and if so, we are more likely to email our membership with details.

However, these projects below are ongoing. Read on if you might be interested in participating.

History of AIS and Intersex Groups

My name is Dr Stephen Craig Kerry (sckerry@lycos.com). I am an Australian independent social science researcher and over the past ten years I have investigated the social relationships, gender identities and lived experiences of people with Androgen Insensitivity Syndrome (AIS). At the end of this email I have included a brief bibliography of my work. At the outset I acknowledge that while I do use the term 'intersex' it is not universally accepted and is only used as a temporary short-hand for a range of so-called 'conditions', such as Klinefelters Syndrome, Turners Syndrome, Androgen Insensitivity Syndrome, Congenital Adrenal Hyperplasia, MRKH and hypospadias. I also acknowledge that recently other phrases such as 'disorders of sex development' (DSD) have been suggested.

I would like to invite you to participate in my current research project. I am investigating the history of the intersex movement over the past 25 years. My research to date has included an overview of this history as it has been reported in the literature to date - but it has been made clear to me that there are some inconsistencies and at times conflicting accounts. Thus I want to clarify this history if possible.

My request then is for first person accounts of dates, key individuals and events in regards to the founding of your organisation. For example is your organisation an offshoot of another organisation? I also ask if these accounts can reflect initial aims, activities and member's demographics and whether these have changed over time. That is, some organisations began as peer support but evolved to include a range of activities such as advocacy and campaigns that challenge the medical profession.

Any assistance you, your organisation and/or your members can provide would be greatly appreciated. Please do not hesitate to contact me for further details.

Request for Research Participants

I am currently undertaking doctoral research looking at how different marginalised people experience and story home. I would greatly appreciate any advice or assistance in contacting anyone that might be interested in being interviewed as part of my research. I am aware that many people who are intersex or who have AIS are reluctant to be subsumed under the umbrella of 'queer' or consider themselves part of a GLBTIQ community - however, I am committed to include the voices of those marginalised from mainstream society and would really like to a diversity of voices and experiences.

Many thanks.

Lesla Beel

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New UK guidance on the initial evaluation of a child with a suspected disorder of sex development

New guidance from the Society for Endocrinology highlights the importance of a multidisciplinary team in diagnosing children with a suspected disorder of sex development (DSD).

The guidance is published in the journal *Clinical Endocrinology*. This is the first time guidance on the best practice for initial evaluation and diagnosis of a DSD has been applied to a UK clinical setting.

Disorder of sex development is an umbrella term applied a wide range of conditions, present from birth, where the development of chromosomal, gonadal and/or anatomical sex differs from expected. A DSD is most often diagnosed at birth (if the appearance of the external genitalia is ambiguous) or at puberty (for example, a boy with pubertal delay, a girl who develops male characteristics or a girl who does not start menstruation).

Approximately one in 300 newborns may be born with a concern about the development of the external genitalia. However, the prevalence of complex anomalies where the sex is unclear upon expert examination is more in the region of one in 5000 births.

Managing these clinical situations can be very complex, both for parents and the medical team, especially when the sex of rearing is uncertain. This guidance aims to bring together good clinical practice and standardise the UK approach to diagnosing DSDs in infants and children.

The guidance recommends:

An experienced multidisciplinary team, accessible through a regional centre, should treat infants or adolescents with a suspected DSD. As a minimum, this team should include specialists in endocrinology, surgery and/or urology, clinical psychology, radiology, nursing and, for infants, neonatology.

One main contact person should be assigned to each family; in most cases, this will be the paediatric endocrinologist. The family should be told of the range of support available to them and provided with contact details for these personnel. They should also be made aware of the stepwise process used to diagnose and manage DSDs, with the ultimate goal of achieving long-term well-being.

Access to specialist psychological support during and after the diagnostic process is essential for both the affected person and their parents. In addition, any adolescents with an existing DSD who need medical/surgical attention should be routinely offered clinical psychological support. The pace of how information is shared should be set by the family and issues of confidentiality discussed and respected.

The exact tests used to diagnose a DSD will vary between patients. However, as a minimum, the multidisciplinary team should take into account the patient's external appearance, internal anatomy, genetic make-up and hormone profile. The most important goals of the initial assessment period are to support the affected child and parents, assign a sex of rearing (in infants) and exclude the possibility of any early medical problems.

Patient groups can provide important psychological support and information to affected individuals and their families. Healthcare professionals upon diagnosis should provide contact details of relevant support groups as routine.

All medical personnel involved in the care of a patient with a DSD should have access to a regional DSD team. The team has a responsibility to educate other healthcare staff (including the family's primary physician) and should have a regular forum where they meet to discuss the case and review its own performance.

Prof Faisal Ahmed, Chair of the DSD guidance taskforce, said:

“The aim of this guidance is to support clinical professionals in the initial evaluation and diagnosis of children with suspected disorders of sex development and to provide a framework to standardise clinical practice throughout the UK. It is of paramount importance that an experienced multidisciplinary team assesses a child with a suspected disorder of sex development.

“Having a child diagnosed with a disorder of sex development can be a very traumatic time for families. It is essential that they are offered specialist psychological support, both at initial evaluation and later on once diagnosis has been confirmed.”

This guidance was produced by the Society for Endocrinology in association with the Androgen Insensitivity Syndrome Support Group, the Association for Clinical Biochemistry, the British Society for Paediatric Endocrinology & Diabetes, the British Society for Human Genetics, British Society of Paediatric & Adolescent Gynaecology, the British Society of Paediatric Radiology, Climb CAH Support Group, the Clinical Genetics Society and the Royal College of Nursing.

A UK DSD taskforce was convened to develop guidance on the initial evaluation and diagnosis of patients with a suspected DSD. Taskforce members took responsibility for individual sections and based their findings on observational studies and expert opinion following group discussion. Prior to publication, the guidance was subjected to open external review from the professional societies involved and their members, as well as patient group representatives.

Full bibliographic information:

Ahmed et al. 2011. UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development. *Clinical Endocrinology*, 75, 12-26.

<http://www.healthcanal.com/child-health/20258-New-guidance-the-initial-evaluation-child-with-suspected-disorder-sex-development.html>

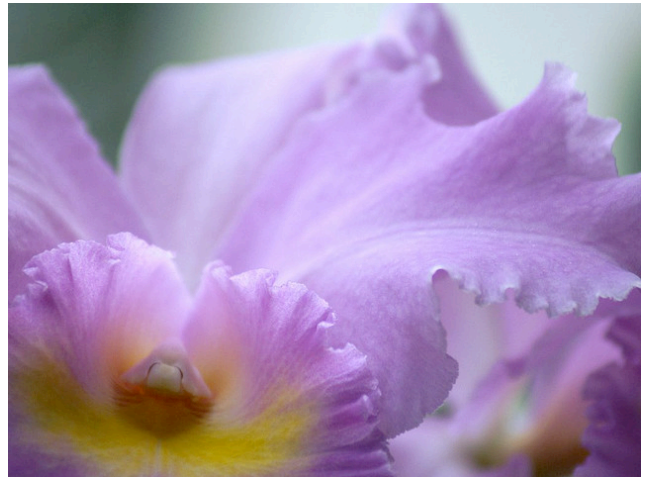


Photo by Tim K Hamilton (Creative Commons license)

Hormonal Management of Complete Androgen Insensitivity Syndrome from Adolescence Onward

Horm Res Paediatr. 2011;76(6):428-33. Epub 2011 Nov 29.

Bertelloni S, Dati E, Baroncelli GI, Hiort O. Source

Adolescent Medicine, Department of Obstetrics, Gynecology and Pediatrics, Santa Chiara University Hospital, Pisa, Italy.

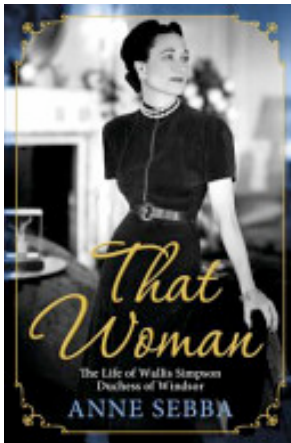
Abstract

Complete androgen insensitivity syndrome (CAIS) represents a main disorder of sex development. Women with CAIS may have their gonads removed before, during or after adolescence, thus requiring hormonal replacement therapy to induce puberty and/or maintain secondary sexual characteristics, to optimize bone mass accrual, and to promote physical and social well-being. Usually estrogens are used for this purpose, but formulations and doses should be better defined in multicentric prospective studies. Some women started testosterone as hormonal replacement therapy, but this practice remains anecdotal. Bone health remains a crucial aspect in the management of persons with CAIS, but few sound data are available to guide clinical practice.

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www.karger.com.



**Books | That Woman: The Life of Wallis
Simpson, Duchess of Windsor**
Anne Sebba



One of Britain's most distinguished biographers turns her focus on one of the most vilified women of the last century. Historian Anne Sebba has written the first full biography of Wallis Simpson, Duchess of Windsor, by a woman, which attempts to understand this fascinating and enigmatic American divorcee who nearly became Queen of England. 'That woman', as the Queen Mother referred her to, became a hate figure for allegedly ensnaring a British king.

Ed's note: Matthew Bell of the IoS Diary in The Independent (UK) reported in August 2011 a bone of contention between another royal biographer and Sebba's research around Simpson's alleged AIS.

'Royal biographer Hugo Vickers has launched a withering attack on Anne Sebba, author of a new biography of Wallis Simpson, for claiming the Duchess of Windsor might not have been all woman. Sebba's book says Edward VIII's

wife was born with androgen insensitivity syndrome, or AIS.

'But Vickers, whose own biography of Mrs Simpson was published in April, dismisses this as "complete rubbish". "I am absolutely sickened by these suggestions," he tells me. "Anyone who has bothered to look into this can tell you it's complete rubbish. I researched this extensively for my book and found not a shred of evidence to support it."

'But Sebba holds her ground when I call. "Hugo Vickers would be well advised to wait until he has read the whole book," she says. "I have got a lot of new material, but I can't talk about it because of a Channel 4 film I've made." Vickers claims the theory first surfaced in 1996, when Michael Bloch published his own biography. "He got a massive advance and was told to come up with something sensational. And that was what he did."

Vickers, who also wrote a biography of the Queen Mother, adds that Mrs Simpson has become one of the most maligned figures of the 20th century. "I seem to have embarked on a one-man crusade to defend her."

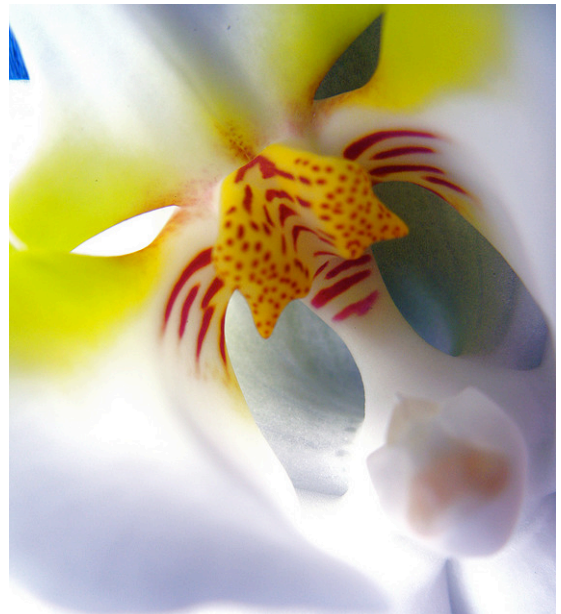


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dAISy

The Newsletter of the Androgen Insensitivity Syndrome (AIS) Support Group of Australia
January 2012 Edition

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.

President:	Sandra
Vice-President (Media)	Bonnie
Vice-President (Medical)	Andie
Secretary:	Phoebe
Treasurer:	Tony
Victoria/Tas Reps:	Sam and Jocelyn
SA/NT Rep:	Carol
NSW/ACT Rep:	Deirdre
Queensland Rep:	Phoebe & Kylie
Parent's Reps	Annette
Men's Rep:	Tony
Public Officer:	Andie

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... and the word is out that partners of people with AIS need support too!

Now is the time to join, renew or rejoin your membership.

The next dAISy

Next issue is July 2012. The deadline for submissions is 30 June 2012. 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!