

Beyond X & Y

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For a long time, intersexed people have been an invisible group without an organization of their own, but now the group is given attention by other than doctors. The world's most vocal organization for intersexed, ISNA, is coming to Sweden.

We are the reason that the question of treatment of intersexed is debated at all, says Jane Goto, member of the board of ISNA (Intersex Society of North America), on her way to her first visit to Sweden.



Since the start in 1993, ISNA has, by their visibility in media and through a lot of networking, built up an organization with allies over the whole world. A small fumbling circle of friends has grown to become the most vocal intersex organization in the world.

ISNA is working both as a spreader of knowledge, support organization for intersexed and their families and has developed a growing number of doctors who are critical of the current treatment practice.

Jane Goto was told that she had no uterus, but testicles and XY chromosomes, when as an 18 year old she was examined by a doctor because of an inquiry for contraceptives. She had not yet started menstruating, but many women in her family came into puberty late which Jane thought was the explanation for not starting to menstruate.

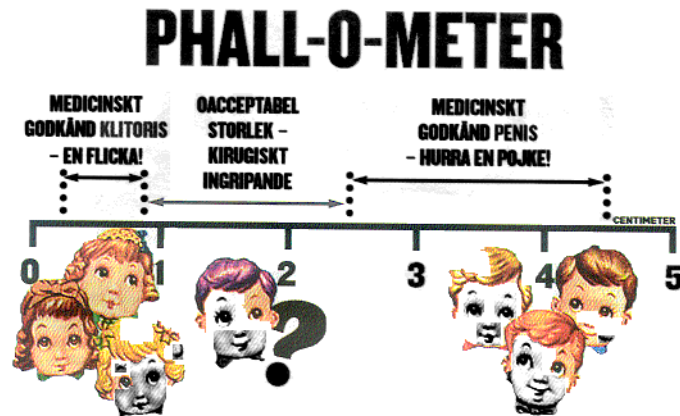
Jane was never informed that she had something that in medical language is called Complete Androgen Insensitivity Syndrome (CAIS). She was talked into having her testicles removed surgically with the motivation that they could start developing cancer. She was not informed about the possible side effects of the operation. In Jane Goto's case, it resulted in changes in her personality, lowered libido and life long hormone treatment.

The secrecy and the shame that was associated with Jane's intersex condition resulted in a 25 year long period of denial and sometimes very severe depression. Finally, she found a support organization for other intersexed with AIS and met people with similar life stories. For the first time in my life I felt almost *normal* when I met other women with AIS, Jane says.

Today, Jane Goto regularly gives lectures on intersex issues at medical and other universities in

Washington where she and her husband of 30 years current live. Together with ISNA, she works for ending all unnecessary medical interventions on children born with ambiguous genitalia that don't fit in the standard template of male/female.

According to ISNA, the current treatment practice is built on false facts and stale medical ethics that don't put the children and their families in the centre. Relevant information on the child's condition is often withheld by many doctors to make sure that the family will agree to genital surgery on their children. The reason is to make the children look as normal and heterosexual as possible.



Many surgical interventions are made only because of social norms. This has started to be questioned at some medical conferences and clinics, says Jane. At some medical centers, they have stopped or at least toned down the importance of surgical solutions. At some places the children can decide for themselves.

All newborns should be assigned a sex without any medical interventions at an early age, ISNA says. When the child is old enough, it will show which gender it belongs to and is old enough to consent. Interventions can be made to affirm or enhance the gender identity if desired, ISNA says.

Regarding the sexist and heterosexist causes of the current treatment, our work has made it more untenable to express this in medical publications. The values often shine through when the patients are treated, even though many younger doctors don't accept sexist assumptions anymore.

ISNA means that a patient-centered approach to treatment practice should be based on [the fact] that intersexuality in the first place is a collection of states connected with stigma and trauma, rather than gender identity. Therefore the crisis situation of the families should not be solved by permanent interventions on the bodies of the children. Instead of surgery and hormone treatment, they first want to see psychological support as the method for dealing with crisis.

No doctor in USA will openly say anymore that withholding information is a good strategy, even though some still lie to patients and relatives, Jane continues. It has also become more common that doctors get mad at their colleagues who still use lies as a tool.

Follow-up studies have also been missing for a long time, but they are starting to show up. ISNA is often quoted as one of the sources of why you should think critically around these questions. Many of the studies are scientifically mediocre and sloppily made.

Some results are withheld in documentation, which indicates that for example women with congenital adrenal hyperplasia (CAH) and boys with Klinefelters syndrome are homosexual in a higher degree than the rest of the general population. Some things discussed internally at scientific conferences are not talked about in the public debate.

What is your view on the future development how medical science views intersexuality?

We feel that the development goes towards a more psychosocial direction since psychiatry and support groups are brought in to a higher degree. On the other hand, we see that the development goes towards more dubious forms of treatments at the early stage of the child's development, for example testosterone injections for boys with Klinefelters to cure possible learning disabilities and medication of girl fetuses with CAH. We suspect that these treatments are also done to stop the children from becoming homosexual, Jane says.

Has your work had any breakthrough in the more broad debate on gender?

ISNA has not had any intentions to participate in this debate. Our focus has mainly been on medical reforms and education. But we have undoubtedly had certain impact on LGBT politics. To start with, our media work has resulted in that some 30 million viewers being reached by our message – mainly from TV – and that means that maybe some 30 million viewers who thought that sex (and therefore possibly also gender) was divided into two watertight categories, have had these ideas questioned.

Intersexuality also seems to be a key issue in the debate on same sex marriage. People start to realize that the scientific definitions of man and woman are questionable and that these definitions cause a lot of people a lot of damage.

Do you have any advice for those who want to work with intersex rights?

In Sweden there are almost no openly intersexed people and no organization that works with these questions. Within the LGBT community there has been a debate on whether intersexed people can be considered a part of the LGBT concept and if the existing organizations should address the issue.

Our experience has shown that it is a very hard to work with both activism and support within the same organization. My advice is to run the activities separately or to run them separately within the same organization as we do within ISNA.

Another important strategy to reach people is to start with real life stories. Faces, names and stories of families are what people can relate best to. Don't claim that intersexuality is an identity without medical aspects, or that doctors are horrible homophobics who mistreat their patients with malicious intent. Be realistic. Only do what can be done not necessarily what *has* to be done. And avoid martyrship. Everything revolves around creating relations and building bridges to accomplish change.

Swedish medical specialists have dismissed the criticism from organizations like ISNA, and say that it mainly comes from a small group of unhappy women with male sex chromosomes that has gone through treatments that are no longer in use.

What is your comment on this kind of criticism?

Sure, progress has been made in certain areas. But the tragic truth is that the change in the view of the doctors regarding intersexed is very slow. ISNA daily hears examples of how intersexed are withheld from information and have to search for facts themselves on Internet and in medical literature.

We hear daily how young intersexed women are recommended vaginal surgery without being informed on alternative treatments and how parents are advised to give doctors their consent to use surgery on the genitals of the children to make the children look normal and "be spared from a future trauma from surgical interventions later in life."

Any medical text on the subject affirms that the beliefs are still alive that intersexed bodies are not okay as they are, and that intersexuality should be "cured" as early as possible.

During Pride, Jane Goto will hold a lecture on the theme "Intersex and Identity Politics", Wednesday 3rd of August, in Pride House.