

Intersex: It's about Quality of Life (Not just gender!)

ISNA's mission is to build a world free of shame, secrecy, and unwanted genital surgeries for people born with atypical sex anatomies. This mission is fundamentally directed at improving the quality of life for people with intersex conditions. But only recently have we seen real movement among medical professionals towards a focus on quality of life.

In May of 2002, ISNA's Executive Director Cheryl Chase joined two dozen other experts on various aspects of intersex medical management in Tempe, Arizona. The **National Institutes of Child Health and Development** called the invitation-only meeting to develop an agenda for federal funding of research on intersex.

Cheryl reports that the meeting was both inspiring and depressing. She saw there real hope for progress-including the chance of federal funding for organized follow-up studies of various "treatment" protocols for intersex. But at the same time, it was frustrating to witness again the narrow focus of many doctors on anatomical appearance and gender identity with no attention to quality of life.

The NICHD workshop was held in conjunction with the "First World Congress: Hormonal and Genetic Basis of Sexual Differentiation Disorders." At the invitation of pediatric endocrinologist Kaye Fichman, Thea Hillman performed for attendees a new piece about intersex treatment and sexual trauma. At that conference Cheryl and Thea were joined by Garry Warne (shown at right with Cheryl) of the Royal Children's Hospital of Melbourne, Australia, in calling for more focus on the quality of life of people with intersex. (Garry has long been a positive voice for people with intersex conditions. In 1997, he published one of the first plain-language booklets of information for families dealing with a form of intersex, including extensive medical information as well as contacts for peer support.)



Cheryl Chase and Garry Warne

The **Robert Wood Johnson Medical School** hosted an Intersex Panel as the core of their "Sex Week" curriculum in January, 2002. The panel consisted of Betsy Driver, Debbie Hartman, Dandara Kelly Leight, William Reiner M.D., Joan Whelan, and Nina Williams, Psy.D. In her presentation, Joan told the audience of medical students and faculty, "One of the scandals of the treatment of intersexed infants and children is the lack of surgical follow up into adulthood. Until recently, follow up of surgery on girls consisted of examining the physical appearance of the genitals and the assessment often proclaimed normal appearance and adequate function. In my medical records the surgeon who performed the clitorrectomy on me finished his summary of the procedure by saying that after the surgery the patient had 'relatively normal genitalia.' He did not bother to qualify his statement with 'normal looking'; he said 'normal.' Of course my clitoris was less normal than before because it no longer existed." Her future quality of life came second to her genital appearance.

Joan went on, "The belief that early surgery fixes the problems of intersexed people is wrong. It only makes the problem disappear in the eyes of the parents and the doctors and shifts the entire burden onto the child." Read Joan's presentation at www.isna.org/library/whelanjan2002.html

Still today, in spite of the fact that intersex is recognized as a psycho-social issue, it is primarily treated by pediatric urologists (surgeons) and endocrinologists (hormone specialists). Rarely are families and children provided with adequate access to psychiatrists, psychologists, social workers, or peer support groups.

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Change the Textbooks!

One of the most common and problematic ways people learn about intersex is from college and medical school textbooks. We say "problematic" because often the image of intersex in these textbooks is degrading, depressing, and sometimes just plain wrong. Fortunately, more and more textbooks are changing for the better. The latest edition of James Kalat's *Biological Psychology*, for example, features positive images (visual and textual) of people living with intersex. The same is true of *Sexual Interactions* (Allgeier and Allgeier), and *Women and Gender: A Feminist Psychology* (by Crawford and Unger).

Now, for the first time, a major medical textbook has been published which includes an article by a person with an intersex condition! Michael Besser and Michael Thorner's *Comprehensive Clinical Endocrinology* features a patient perspective chapter on Androgen Insensitivity Syndrome (AIS) written by Sherri Groveman, founder of the U.S. AIS Support Group and former board member of ISNA. Sherri tells us that the chapter addresses the physical and emotional needs of women with AIS and includes recommendations for treatment. She notes further that, "While the invitation to write the chapter made clear that it was to be limited to clinical issues in Complete AIS, it addresses the global concerns of *all* women with AIS as well as those of other intersex individuals."

Do you know of a textbook that needs changing? Write to the author. Authors are usually very pleased to receive new information that will help them to improve the next edition.

ISNA News

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Arcus Foundation awards ISNA \$20,000

Did you know that sixty percent of our \$150,000 annual budget comes from individual donors like you? The rest is raised through foundation grants, speaker fees, and merchandising income. We're happy to report that in just the last few weeks ISNA has been awarded \$20,000, our largest grant ever, by the Arcus Foundation! You can read more about Arcus at www.arcusfoundation.org. Please join us in thanking Arcus for its support and leadership.

ISNA is also sponsored by the Astraea Foundation and the Gill Foundation.

Is XXY intersex?

By Alice Dreger

David Strachan, a good friend and long-time member of ISNA, handed me a provocative business card a few years back that asked, *Is XXY intersex?* In his cells, David has two X chromosomes and one Y chromosome, known as Klinefelter's Syndrome (or KS). So does David have an intersex condition?

People who think that sex is just about X and Y chromosomes would probably say "Of course XXY is intersex!" But sex isn't so simple. Most people with conditions we would call intersex have either a simple XX or a simple XY chromosome combination, the kinds we usually associate with non-intersexed females and males. And in practice a lot of medical and popular texts don't list XXY (KS) as a form of intersex. David wrote to me recently, "I appreciate ISNA's referencing XXY on its website but it is rare that anyone mentions it on talk shows or in literature as part of the intersex umbrella definition. I often feel 'left out on a limb' in my perspective!"

So what on earth is intersex? And why can't we define it simply?

To help people understand how intersex is a socially constructed category that reflects real biological variation, we can liken the sex spectrum to the color spectrum. There's no question that out there in nature there are different wavelengths that translate into colors we see as red, blue, orange, yellow.

But the decision to distinguish, say, between orange and red-orange is a social decision. Sometimes social necessity

leads us to make color distinctions that otherwise would seem incorrect or irrational, as when we call certain people "black" or "white" when they're not especially black or white as we would otherwise use the terms.

Like color, sex is variable. Penises, clitorises, gonads—all of these vary in size and shape and morphology—but we simplify sex categories into male, female, and sometimes intersex, in order to simplify social interactions, express what we feel, and maintain order.

That said, the official medical categories for what we might call intersex conditions don't make much sense. Almost universally within medicine, if a boy is born without a penis (if he is aphallic) he is counted as intersexed, but if a girl is born without a vagina (if she has Mayer-Rokitansky-Kuster-Hauser Syndrome, or MRKH) she isn't counted as intersexed.

KS (XXY) and Turner's Syndrome (one X, no second X or Y) usually don't get listed under intersex, probably because most children born with KS and Turner's don't have genital ambiguity, and sometimes people think genital ambiguity is necessary for intersex. But some other intersex conditions (including "true hermaphroditism") sometimes don't involve genital ambiguity either! Genital ambiguity is not the same as intersex.

So forget the official categories. It is best to think about intersex not as a question of your anatomy but as a question of how your anatomy is *treated*. People with intersex conditions are often treated as if their anatomies are shameful. And a lot of people try to "fix" them to make them more male or female, thinking that (rather than acceptance) is the solution.

David notes that "KS support groups put so much energy into denying XXY as intersex. It seems some persons with XXY try to rid themselves of breast tissue through bodybuilding. Then there is the experimental use of testosterone by the medical profession, as supported by some parental KS groups. I assume these parental groups are trying to erase the reality of intersex, or 'cure' it." All of this is reason enough to count XXY as intersex.

When I asked David his own question, "Is XXY intersex?" he wrote back to me, "Knowing that my sexual anatomy is not

like other males is sufficient reason to call myself intersex."

So what does David wish people would understand? Just this: "Many people seem not to realize that sexual anatomy is very different from one's gender identity and sexual orientation. Although I look male, I still feel like neither gender psychologically but a combination that is more female in nature." And furthermore, "I would like to see more medical literature or personal writing to discourage the practice of giving testosterone to boys with Klinefelter's until they are old enough to make their own informed decisions about whether or not they want testosterone supplements used on them."

In the end, we say yes, Klinefelter's Syndrome is intersex, as is MRKH, as is aphallia, because a person recognized to have one of these conditions will typically be treated as if his or her variant sexual anatomy is a pathology that needs fixing.

Does that mean if ISNA succeeds in its mission and these conditions are ultimately treated as variations rather than inherently pathological we may have to reconsider our definition of intersex? That would be fine with us!

ISNA releases medical training video!

ISNA's new medical training video, *"The Child with an Intersex Condition: Total Patient Care"* will premiere at the LGBTI Health Summit 2002 in Boulder at the end of August. The 20 minute long video will be available for purchase at ISNA's online store, www.isna.org.

New evidence and advances in medical ethics have led to the need for a revision in the standard of care for the treatment of intersex. This film outlines the problems with many current practices and provides guidelines for a new standard of care that is more advanced scientifically and ethically.

We gathered a group of experts, including medical professionals, an adult with intersex, and a parent of a child with intersex to talk about these issues.

Report from the board

By Thea Hillman

One of the quieter, but most powerful ways ISNA has grown in the past two years is its Board of Directors. The board supports and builds ISNA's programs and enables ISNA to connect with allies.

As a recent addition to the Board, I'm extremely proud to be part of such a compassionate and committed group of people. At our most recent in-person meeting in March in Chicago, with the help and advice of Angela Moreno we solidified the projects ISNA is working on, including the medical teaching video and the parents' handbook.

As Board members, each of us has educated ourselves about intersex issues and the mission and goals of ISNA. We see ourselves as a resource for ISNA members, donors, allies, and the public at large—and hope that you see us that way as well. To facilitate this, we'd like to tell you a bit about ourselves and our relationship to ISNA and intersex issues.

Alice Dreger, Board member since 1998 and chair of the Board, is Associate Professor at Michigan State University in East Lansing. She's the author of *Hermaphrodites and the Medical Invention of Sex* and editor of *Intersex in the Age of Ethics*. Says Alice, "As an academic, I often see a lot of my colleagues produce good theoretical work that could make a positive difference socially if it made it out of the theoretical realm—but typically it doesn't. ISNA provides me and other scholars, researchers, and theoreticians the chance to take what we've learned and use it to actually improve people's lives."

Julie Dorf, Board member since 2001 and current treasurer, founded the International Gay & Lesbian Human Rights Commission (IGLHRC) and served as its Executive Director 1990-2000. She is on the international advisory council of the Global Fund for Women and the Astraea Foundation's endowment committee. She writes that intersex is "one of many issues that are important to me, but I choose to give my time to it now because the time is right for change of the medical treatment of intersex people and I want to help the organization grow to serve its mission."

Debbie Hartman, new board member this year, is a single mother raising her intersexed child who had gender re-assignment surgery at 11 weeks. She has participated in numerous panels about intersex including presentations to the National Organization of Women and the University of Medicine

and Dentistry in New Jersey. She was interviewed in Canada SexTV's full-length feature, *Redefining Sex*, and has been interviewed by numerous publications including the *San Francisco Chronicle* and the *New Haven Advocate*. She appears in ISNA's upcoming video release on new practices in the treatment of intersexed children.

As for me, **Thea Hillman**, I'm a writer and intersex activist, and author of *Depending on the Light* (Manic D Press, 2001). I have performed my work at festivals, bookstores, reading series across the country, and an international medical conference, and now speak and perform about intersex issues on a regular basis. I have produced many performance events, including the sold-out *Intercourse: A Sex and Gender Spoken Word Recipe for Revolution* for the 2001 National Queer Arts Festival. I am on the Mills College Board of Trustees and one of the co-producers of *ForWord Girls*, the first inclusive all-girl spoken word festival. See www.theahillman.com.

Sydney Levy, Board member since 2001 and current secretary, was born in Venezuela and schooled in Israel. Sydney, currently the Program and Communications Director of IGLHRC, notes, "I was one of those people that had never even heard the word 'intersex' before ISNA approached me. ISNA taught me much more than just the meaning of the word; it reminded me that the fundamental issue is our ability to live with dignity and free from prejudice. ISNA's mission, while particular to people with intersex conditions, is in essence universal." Sydney has helped spread that message this year by hosting



ISNA Board meeting, Chicago 2002 (March!)

our April San Francisco house party in his home with his partner, Mark.

Robin Mathias has ten years of experience in health care data analysis, and has performed finance and development tasks for ISNA on a volunteer basis since 1999. Robin incorporated ISNA, created ISNA's direct mail program, won IRS nonprofit (501(c)3) status from the IRS, and wrote ISNA's first successful grant (to the Gill Foundation). Robin will be leaving the board in December 2002. Reflecting on that, Robin says, "I wish for nothing but the best for ISNA's future. I will tell all my friends about its accomplishments and how proud I am." See Robin's nonprofit technology consulting business at www.mathiasconsulting.com.

Kimberly Saviano is a new Board member and an intersexed activist living in Denver. She served as treasurer of the Androgen Insensitivity Syndrome Support Group from 2000-2001 (www.medhelp.org/www/ais/) and hosted its 2001 national conference. She has spoken at local organizations and been interviewed for articles about growing up intersexed. Kimberly recently found herself ready to move beyond the realm of support groups into advocacy, confessing, "I spent most of my life caught up in the shame and secrecy that ISNA fights against. I know the damage it can do, the wasted years and the opportunities I have missed. Being part of ISNA is important to me because I feel as though I'm getting some of that time back, and most important to me is the idea that I may be helping to spare someone else all that wasted time."

See www.isna.org/about/board/ for more.

Quality of Life

(cont. from page one)

But people in the psycho-social support professions are starting to get more involved. Indeed, the **American Academy of Child & Adolescent Psychiatry** has just given its Norbert & Charlotte Rieger Psycho-dynamic Psychotherapy Award to Vernon Rosario, M.D., for a paper on treating a child with intersex with psychodynamic therapy. The paper will be presented in a panel (with Cheryl Chase and Michael [REDACTED]) during the AACAP meeting in San Francisco, October 22-27, 2002, and will later be published in the *Journal of the AACAP*.

Upcoming Events

Please join us at "**Rated XXXY: An Evening of Erotica and Education Benefiting ISNA**" on October 4, 2002, at the San Francisco GLBT Center, 7 pm. This event will feature spoken-word performances by Thea Hillman and others with intersex conditions, as well as a chance to meet and speak with Thea

and other ISNA board members. For reservations, call (707) 636-0420 or purchase advance tickets at www.isna.org/store/xxxy.

Intersex will be an important topic of discussion at the upcoming **PFLAG** (Parents and Friends of Lesbians and Gays) **annual conference** in Columbus, Ohio, September 27-29, 2002. Kimberly Saviano will be there to represent ISNA at the intersex workshop and caucus meeting on intersex, as will Dandara [REDACTED] from Bodies Like Ours.

In Boulder, Colorado, August 21-25, 2002, intersex will feature as a major topic of discussion at the **National Lesbian, Gay, Bisexual, Transgender, and Intersex Health Summit**. ISNA's new medical training video (*The Child with an Intersex Condition: Total Patient Care*) will premiere. Those speaking about intersex will include Kimberly Saviano, Shane Snowdon, Esther Morris, Emi Koyama, Vernon Rosario, and Cheryl Chase.

Alice Dreger will speak about intersex at the **New York Academy of Medicine** on December 10, 2002. See our website for more information about events!

Bodies Like Ours

We would like to thank Dandara [REDACTED] of Bodies Like Ours for channeling a \$20,000 anonymous gift to ISNA! Bodies Like Ours is a relatively new group founded by Dandara [REDACTED] and Betsy Driver, providing support and information-distribution for people born with atypical genitalia.

The mission of Bodies Like Ours is to provide mentoring of peers including adults and teens with intersex conditions and parents of children (including adult children) with intersex conditions. On their website, www.bodieslikeours.org, the founders write, "We seek to create a place of community for — people who may desire a safe place to understand and discover their uniqueness, while promoting honesty and openness about the way this feels to us." ISNA would like to congratulate Dandara and Betsy for obtaining non-profit status for their organization and would like particularly to thank them for providing peer support, advocacy, and information.

Yes! I want to help ISNA build a world free of shame, secrecy, and unwanted plastic surgery now!

- ☐ Here is my tax deductible gift of:
☐ \$35 ☐ \$50 ☐ \$100 ☐ other \$_____
- ☐ I want to become an Advocacy Partner. Please bill my credit card monthly in the amount of: ☐ \$25 ☐ \$35 ☐ \$50 ☐ other \$_____

- ☐ Enclosed is my check payable to ISNA
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