

Race and the Intersexed

By Lynnell Stephani Long

"This demythologizing of black sexuality is crucial for black America because much of black self-hatred and self-contempt has to do with the refusal of many black Americans to love their own black bodies...How does one come to accept and affirm a body despised by one's fellow citizens?" —Cornell West, *Race Matters*

According to ISNA's website (www.isna.org), one in every 2,000 children is born intersexed. That is the total number of people whose bodies differ from standard male or female. The 2000 census bureau reported that 29.3% of the population are people of color (i.e. Blacks, Native Americans, Hispanics and Asians). That would mean 1/3 of intersex children born are children of color. We do not have specific race/ethnicity comparisons for people with intersex conditions. So why are there so few people of color who are also intersex out? Why aren't there more activists of color working with ISNA to help end genital mutilation?



When I first started researching data for this article, my original intentions were to write about what intersex organizations can do to gather the help of people of color. But after careful consideration I think it's important that I write about the stigma that people of color face, and what more we can all do to erase those stigmas.

Someone recently asked me what emotional difficulties I faced when I came out as intersex. At first I thought this person wanted to know about gaining my medical records, changing the name and info on my birth certificate, and so on. Then they carefully explained to me how rough they thought it must have been for me as an African-American intersex woman that was raised male for most of my life. I first told this person that I cannot speak for other people of color born intersex, but I can tell them how I felt, and what I endured.

Like Cornell West elegantly said in his book *Race Matters*, there are different stigmas and stereotypes in the black community. While most of those stereotypes stem from myths, nevertheless they still exist.

It's said that all black men have huge penises. In fact, a lot of black men are so proud of their endowment they walk around grabbing themselves at any opportunity. Well, imagine if a black child is born intersex and raised male with a small penis. In my case, I was raised male because my karyotype is XY. The doctors saw that I have something that resembled a penis with hypospadias, did corrective surgery and handed my parents their baby boy.

Growing up in an all-black community and going to an all-black high school was rough as hell. While a lot of the other boys walked around nude, proud of the size of their penis, I tried my best to hide. Hiding didn't stop the questions though. Questions like, "Why is your penis so small? Why do you have breasts? What are you, a boy or a girl?"

My mother didn't know how to handle the situation, so she did what a lot of other black mothers would do. She told me to keep it a secret, and not to change in the locker room.

Maybe it was because of the lack of information regarding intersex conditions, but my mother refused to acknowledge that I was different. In

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ISNA Launches Medical Advisory Board

ISNA is extremely pleased to announce the creation of a Medical Advisory Board which will offer support and guidance in the pursuit of our mission. The inaugural members, who will serve a two-year term, include some of the nation's leading experts in pediatric endocrinology, urology, general pediatrics, nursing, psychiatry, psychology, social work, and bioethics.

Dr. Vernon Rosario, Chair of the Medical Advisory Board and a member of ISNA's Board of Directors, stated that "the MAB will help guide ISNA's increasingly successful efforts to improve intersex treatment by promoting patient-centered care and by supporting research on functional outcomes of various approaches to treatment."

Over the past ten years, ISNA has moved from "outsider" to "insider" in the medical community. The Medical Advisory Board is an indication of just how much progress ISNA has made over the years in reshaping medical practices. Increasingly, we are working in partnership with health care professionals to improve treatment practices for intersex.

Members of the Medical Advisory Board for 2003-2005 include:

Charlotte Boney, M.D.
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Anita Catlin, DNSc, FNP
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Bruce Wilson, M.D.

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fact, she practically handed me over to the doctors to "fix" me.

Even today, in 2003, I am amazed at the number of people of color who do not know what intersex is. It incenses me that people think being intersex is a "white" thing. I am curious to know how many of these same people thought, or continue to think, that HIV is a gay disease and that people of color are immune to it?

Even though it can be very arduous at times being out as intersex, I believe if I can save one child from the horror I had to undergo then I would have paid my debt to society.

There isn't any one thing an organization like ISNA can do to help the black community, except to make sure that information is available. I strongly believe that people of color need to educate themselves and their families. We need to step outside myths and stereotypes. If a child is born with a small penis, then that child may be intersex. If a girl is born with an enlarged clitoris, chances are she is intersex. There is nothing to be ashamed about. There is no reason to hide the child or try to get that child "fixed" unless the child needs medical treatment.

Whether people of color accept the variations of intersex or not, I think it's important for those of us who are intersex to embrace and love our intersex bodies. I am an African-American intersex woman who has stood in front of countless audiences across North America outing myself as intersex in the hopes of educating that one person who will take information back to their family, and save a child's life.

No one knows why a child is born intersex, and it's not necessary to blame the parents. All we need to know is that in God's world nothing happens by mistake.

"First Do No Harm" a Hit at SF Film Fest

Over 600 people attended the "Intersex Explorations" program at the 27th SF International Lesbian and Gay Film Festival on June 25th which featured ISNA's new film *First Do No Harm: Total Patient Care for Intersex*. Board members Thea Hillman and David Cameron Strachan introduced the program and led a post-film discussion.

All four intersex films screened in that session received enthusiastic applause, and the Q&A period lasted over half an hour!

Research on Intersex: What role for ISNA?

By Monica J. Casper and Esther Morris Leidolf

An important strategy used by intersex advocates addresses the lack of systematic research underlying "normalizing" surgeries. Operating on babies with intersex conditions in order to "fix" gender, today still considered standard practice by many physicians, was based largely on the now-discredited ideas of Johns Hopkins psychologist John Money. Prior to the emergence of surgical "treatment" for intersex, there were no animal studies, no clinical trials on humans, and no experiments designed to offer scientific evidence that surgery was indeed the correct path.

The operations themselves performed over the past half-century have been a kind of large-scale experiment on a vulnerable population, and those individuals who received surgery have often been unwilling or unknowing research subjects. Not only is there little to no scientific evidence suggesting that surgery is the best approach, there has been remarkably little research on long-term effects of surgery, on quality of life issues, and on what approach people with intersex conditions might themselves prefer. Most of what we know about the impact of the surgeries we know because some adult intersexuals were brave enough to share their harrowing stories with us—stories that are often disregarded as "anecdotal" or "biased" by ostensibly objective scientists and health care professionals.

Only very recently—more than four decades after Dr. Money began promoting gender assignment and a full decade after the birth of the intersex patient rights movement—have scientists and physicians begun to offer concrete data on psychological well-being and sexual function following surgery. But all too often, research conducted on intersex focuses on narrow questions. Many physicians want to know if people who

undergo surgery transition later in life to the other gender; if the answer is no, then the surgery is considered successful. The measure of surgery's correctness, then, is defined according to whether the assigned gender "sticks" or not. Left out are questions about how an individual experiences surgery, what his or her quality of life is, degree of sexual function, family dynamics, and so on.

Scholars in the humanities and social sciences (e.g., Suzanne Kessler, Anne Fausto-Sterling, Alice Dreger, and Sharon Preves) have studied intersex as a social/cultural construction, drawing attention to the ways in which sex and gender categories reflect social, historical, and political meanings. These contributions have given us insight into the lived experiences of people dealing with intersex conditions, while also helping to explain why some things, such as dividing society into two genders and medical practices, are slow to change. But there is still much that we do not know.

ISNA advocates community-based research on intersex, especially focused on quality of life issues and on the long-term psychological, physiological, and sexual impacts of surgery. We believe that people with intersex conditions should have a place at the research table, and we have recently begun to pull up a chair and take part. ISNA will collaborate with disability policy scholars at the University of Washington on a long-term quality of life study. The UW team has extensive experience investigating the impact of craniofacial conditions and treatments, focusing specifically on youth populations. What sets the team apart is its emphasis on patient-centered research design; questions and methods are based on the needs of the communities studied.

But engaging in research raises some important and perhaps troubling questions. First, what is or should be the role of research? We already know that surgery often seems to cause great harm; that informed consent should be a paramount consideration; that parents need as much information as possible in order to make the best decisions for their children; and that there is nothing "wrong" with anatomy that does not easily fit into standard categories of male

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(*"Research" cont. from page 2*) and female. We do not need more research to tell us these things are true. But, do we know enough about *how* people with intersex conditions live their lives, and what is needed in terms of psychosocial resources and support?

Also, what should be the appropriate medical response to intersex while this research is unfolding? Some have argued that the status quo should not be changed until we have more data. Others have argued that surgery should continue regardless of what more data will tell us. ISNA contends that cosmetic surgeries should *not* continue; that to operate on children in the absence of solid evidence and with limited to no informed consent violates ethical standards and may do more harm than good.

In the meantime, ISNA has gained a seat at the research table and we are forging ahead, cautiously. We are, perhaps more than anything, sensitive to the very real anxiety shared by people with intersex conditions at the thought of being research "subjects." But we also hope that people with intersex conditions might be willing to participate in studies designed with their needs in mind. To that end, it would help us to know what our supporters think should be studied. What are the important questions? What counts as "quality of life" related to intersex? What issues matter to you? And what should be ISNA's role in research?

Please let us know your thoughts; write to us at newsletter@isna.org. And stay tuned for more information about the projects we are participating in and/or endorsing.

Intersex Down Under

By David Cameron Strachan

On my recent 25th anniversary vacation (with partner Peter) to New Zealand and Australia, I met with several intersex persons and their supporters, and screened *First Do No Harm: Total Patient Care for Intersex* at two venues. Prior to our departure, I corresponded with Mani Bruce Mitchell in Wellington, NZ and with two folks with XXY sex chromosomes.

In Wellington, Mani arranged for a video showing for the Board of the Intersex Trust Aotearoa New Zealand.

We had a discussion and dinner at the home of Dr. Margaret Sparrow, who is also an official "Dame." At Mani's home, Peter and I previewed "Mani's Story," a moving and beautifully filmed documentary of Mani's life, prior to its airing on public TV. [The film is available at the ISNA online store.]

I enjoyed meeting with my XXY correspondents (in Tasmania and Melbourne) and discussing our common life issues. When we arrived in Adelaide, Michael Noble gave me a copy of his manuscript, "Chromosomal Aberration, Endocrinal Disease, or Intersex Variation? Representations of Klinefelter Syndrome (XXY) in Professional and Non-professional Medical Discourses." Michael and Vicki Crowley created a venue at Relationships Australia for 25+ professionals in counseling and medical practice. I gave a history of my involvement with ISNA, talked about my experience of living with XXY sex chromosomes, showed our video, and led a discussion.

Meeting international persons interested in learning about intersex and what can be done to help those born with ambiguous sexual anatomies was a significant highlight of our nine-plus weeks "down under."



Michael Noble (l.) and David Strachan (r.)

Children's Book Sale to Support ISNA

From August 1st through August 27th, just in time for the dog days of summer, ISNA will benefit from an online children's book sale. But we need your help—and your credit card—to make it happen!

Patricia Struck, a Chicago-based Usborne Books sales representative and ISNA supporter, has offered to host an e-fair just for us. We will receive 20% of the profits on all books sold through our e-fair—a higher yield than the company

usually offers for such events. Pat, a grandmother of three, believes in ISNA's mission and goals, and she has convinced Usborne's management to support us, too!

This is a wonderful opportunity to help ISNA simply by purchasing books for the children in your life—something you probably already do. What could be better than encouraging kids to read, and at the same time helping an organization that you care about? To participate in this special e-fair for ISNA, simply go to www.ubah.com/k1916, enter the bookstore, select "e-fairs," and click on "ISNA." It's that easy!

Award-winning Usborne is a major distributor of "the books that kids love to read." The company offers over 1,200 colorful, educational, and fun titles covering activities, puzzles, and a wide range of subjects for children of all ages.

Updating the Vagina Monologues

By Emi Koyama

Two years ago, I saw the play "The Vagina Monologues" for the first time. It was held at a local university and was for a good cause: the production was part of the V-DAY national initiative to end violence against women and girls. As a long-time activist against domestic and sexual violence, I was happy that V-DAY was raising awareness about these issues as well as funds for organizations that confront them.

But there was a problem with the script: while the play portrayed the ritualistic cutting of young women's genitals in Africa in a serious tone, it depicted the ritualistic cutting of intersex genitals in our society as a light-hearted "fairy-tale": "One girl in Oklahoma told me how she had been born without a vagina, and only realized it when she was fourteen. [...] On the way from the doctor, in a noble attempt to comfort her, [her father] said, 'Darlin', we've got an interesting situation. You were born without a vagina. But the good news is we're gonna get you the best homemade pussy in America. And when you meet your husband, he's gonna know we had it made especially for him." The story was "meant to be sweet," according to the V-DAY document.

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I felt invalidated by how the play's depiction trivializes the negative consequences of "normalizing" surgeries, and offended by the sexist and heterosexist presumptions made about women's bodies. So on that evening two years ago, I went home crying and feeling alone. But in reality, I was not alone: many intersex activists and allies have written Eve Ensler to express their concerns.

I coordinated a nationwide campaign last year in which I emailed more than 500 individual campuses participating in V-DAY to support the intersex movement's goal to end genital mutilation in our society. The reaction this time was enormous. Not only did dozens of schools write back to thank us for the information and pledge to do something to raise awareness about intersex, I also received a call from the Executive Director of V-DAY suggesting that we work together. This resulted in V-DAY's endorsement of ISNA's mission to end shame, secrecy and unwanted genital mutilation.

This year, we were able to take advantage of the change in the script that allowed additional monologues to be plugged in by campus producers: we provided them with two of our own monologues (written by Thea Hillman and Esther Morris Leidolf), which were performed at several campuses. In addition, many schools distributed our fliers, showed ISNA's films, and/or

donated their proceeds to ISNA. In fact, I went to see the play at Portland State University which decided at the last minute to include Esther's monologue.

And as I was hearing her piece being performed, I was thinking, wow, what a difference two years had made. And I also realized that this little success is a mirror of other successes we've achieved in medicine, academia, and pop culture. We are also telling our stories now. As the crowd applauded at the end of Esther's monologue, I thought about how much progress we have made, and was filled with appreciation for those who came before me and those who are still working with me. Needless to say, I cried more happily on my way home this time. [The complete article can be found at www.ipdx.org.]

ISNA Board News

By Thea Hillman

ISNA is delighted to announce that Angela Moreno Lippert has joined our Board of Directors. Angela has been involved with ISNA since 1996 when she appeared in the video *Hermaphrodites Speak*. Since then, her intersex activism has been featured in the *Chicago Tribune*, *FOX News Chicago*, *On the Issues*, *Ms.*, and *Mademoiselle*. Known for her powerful presentations, she has spoken widely on the subject of improving treatment for people with intersex conditions and their families. Angela lives in Peoria, Illinois.

Tidbits...

ISNA will host house parties this year in San Francisco, Los Angeles, New York, and East Lansing, MI. If you live in any of these cities and want to attend, please let us know!

Jeffrey Eugenides won the 2003 Pulitzer Prize for his novel *Middlesex*, featuring a protagonist with 5-alpha reductase deficiency.

SASG, a Seattle-based counseling organization, wants to start a support group for parents of children with intersex conditions. Let us know if this is something you would like to be involved in.

In May, Executive Director Monica Casper attended the annual meeting of the Lawson Wilkins Pediatric Endocrine Society.

Board Chair Thea Hillman's event "Intercourse: A Sex and Gender Recipe for Revolution," held in San Francisco in June, was a smashing success. The sold-out performance featured Cheryl Chase, Hida Vioria, Kate Bornstein, Leslie Feinberg, Shorona se Mbessakwini, and many others.

ISNA is blessed with three fabulous summer interns, who will be helping with our strategic planning process. Welcome to Katherine Betzer, Jen Coig, and Sunny Nordmaker!

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

Here is my tax deductible gift of:
 \$35 \$50 \$100 Other \$ _____

Enclosed is my check payable to ISNA
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I want to become an Advocacy Partner! Please bill my credit card monthly in the amount of: \$25 \$35 \$50 Other \$ _____

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