

Intersex Society of North America

Building a world free of shame, secrecy, and unwanted genital surgeries for people born with atypical sex anatomies

What Really Matters

We've come a long way, baby! And we've got a long way to go. Read about what's changed and what makes us say, "The more things change, the more they stay the same."



What's still wrong with this picture? Page 2

Consensus around Patient-Centered Care

Two new handbooks feature path-breaking consensus around patient-centered care for intersex. Discover how these materials provide practical advice to clinicians and parents and offer a clear alternative to the

concealment-centered "standard of care."

Page 3



How ISNA Works

Secrets of our success revealed! Find out which of ISNA's staff members has 0's and 1's running through her bloodstream.

Page 3

Plans for 2006

What will your donation support? Learn about plans for the coming year.

Page 4



Help ISNA keep changing the world!

The map you see here shows something extraordinary. This is called a "cluster map," and it shows where visitors to our website, www.isna.org, are coming from. The bigger the red dot, the more visitors come from that region.

What makes this map extraordinary is that it represents a *single week's worth* of visitors to our website (16,422 distinct visitors in the week starting 8/29/2005). Every day, we provide truth, guidance, and support to over 2,500 people. This year, just through our site, we will reach close to a million people worldwide.

How many people have we reached all together? We recently did the math and, factoring in the work we've done with television shows, filmmakers, scholars, novelists, educators, and our own website, we estimate conservatively that, in the last 12 years, *we've reached tens of millions of people* with ISNA's message of ending shame, secrecy, and unwanted genital surgeries for people born with atypical sex anatomies.

So, after hearing this, what would you guess our annual budget to be? Would you guess a half-million dollars, or maybe two million? Nope. Right now our annual budget is about \$160,000.

Do we not dream big?

Oh, we do! You will read in this Annual

Appeal about just some of what we've been doing and hope to do in the near future. At ISNA, there is no lack of hopes, dreams, plans. Indeed, *there is no lack of allies wanting to help.*

The only thing holding us back from doing more is money. We have been successful with grants; for example, in the last year we have had large grants from the Arcus Foundation and The California Endowment, and additional grants from the Gill Foundation, Kicking Assets, and the Small Change Foundation. But grants alone cannot carry us to where we want to be, in part because grant agencies look to see whether we can show a solid base of support in the form of individual donors like you.

We need you. We need your heart, your mind, and—honestly—we need your money.

Why you? Because you understand us! You understand that families with intersex deserve the truth from their doctors. You understand that children with intersex deserve the right to decide whether their bodies will be changed to look more like the average female or male. *You understand, first and foremost, that an individual's civil rights should not depend on the frequency of his or her condition.*

Won't you help today by answering this appeal? We promise that we will make you proud you did.

With appreciation and affection,

Cheryl Chase

Cheryl Chase, Executive Director



16,422 visits to www.isna.org (week ending 8/29/2005)

What Really Matters?

by Alice D. Dreger, Ph.D.
Director of Medical Education

I had an eerie experience the other day. I was scanning my old slide collection, turning into PDFs the images I had collected of intersex people from the 19th and early-20th centuries, when I started thinking about the stories behind those images. I found myself realizing that, although we've come *so far* since ISNA's birth in 1993, some things are still as they were 100 years ago.

Take the story of the woman shown here, identified in the early-20th century



medical record only as "Russell Andrew's patient." Judging by the pictures and text relating her story, this intersex woman had complete AIS. In many

ways, her story was like most others that showed up in medical journals: she seems to have been concerned with her physical health, her sexual function—her *basic well-being*. But, like his colleagues, her doctor was busy obsessing over something else entirely: her gender identity. He and his colleagues were so busy arguing and theorizing about what to make socially of a woman with testes that they failed to realize that was *their* problem, not hers.

I wish I could tell you things were different today. Yet again and again, we still find clinicians worried primarily about gender assignments, while their patients want more. For example, in a recent intersex-themed issue of the *Archives of Sexual Behavior*, nearly every article is about gender identities. Indeed—frighteningly—we are seeing more and more outcome studies that claim "success!" just because a simple majority of patients have kept the gender assignments given to them by doctors.

I guess I should be happy clinicians are doing outcome studies at all. That's real progress over 10 years ago! But if these particular clinicians stopped and listened to what their *patients* cared about, they would realize that—like Russell Andrew's patient almost 100 years ago—people with intersex today don't think that getting the gender assignment

"right" is the same as providing quality care. ISNA's board Chair Angela Moreno Lippert (shown here) will tell you that what went wrong in her care was *not about her gender*; it was about the way the clinicians treating her inadvertently created rifts in her soul and her family



through their hasty and ill-advised attempts to conceal her intersex from her and others.

The medical obsession with gender identity (and especially gender norms) leads to neglect of many other critical issues.

For example, it detracts from the importance of patient education, peer support for parents and patients, and truth-telling. (A recent BMJ article shows that, as doctors still worry whether a woman with a Y chromosome can "handle" the truth, the patient is not even told the name of her condition, and thus she is unable to find support and information.) This obsession with gender identity even has left doctors from Johns Hopkins asking former patients the most absurd question: Do you think intersex children should be raised without a gender assignment or do you think they should have genital surgery?

Hello?! Either you get plunked in a third-gender or you get genital surgery? What ever happened to the option of best-guess gender assignment of boy or girl (which we advocate) and holding off on elective surgeries until patients can decide for themselves (which we also advocate)? But so many doctors are just unable to see that gender assignment—a labeling process requiring no surgery—can and must be separated out from other issues, like optional surgeries and hormone treatments, truth-telling, the harm from repeated unnecessary genital exams, etc.

Meanwhile, we've got the Traditional Values Coalition coming after ISNA, complaining that we are really the Gender Confusion Movement. While fending off their hateful attacks, we've pointed out that we didn't invent intersex, and that babies born intersex aren't confused about their genders, any more than they feel ambiguous about their sexes.

Yes, after all these years, too many people still seem to treat people with intersex primarily as fodder for their pet theories about gender.

The good news, as you know, is that people with intersex have challenged this pattern and demanded that medical care be centered on *their* needs, not the needs of others. They have made clear that what has hurt them most—a system of shame and secrecy—must end. *On this systemic change we remain fully focused.* What Max Beck's sign insisted at a 1995 intersex protest we still insist today:



Silence=Death. No more silence and lies. No more shame.

And more people are hearing our call each day!

This year, following persistent activism from ISNA board member David Iris Cameron and former board Chair Thea Hillman, the San Francisco Human Rights Commission declared the medical "normalization" of people with intersex a human rights issue. The report, chiefly authored by Marcus Arana, condemned the standard medical treatment, and included an objection to the failure to adequately address parental distress, informed consent, and mental healthcare needs of patients.

Meanwhile perceptive clinicians around the world *have* started thinking beyond gender identity! ISNA Medical Advisory Board (MAB) member Justine Schober has been studying adult sexual health to understand what intersex children need in the long run, and several MAB members have starting working to organize medical care for adults with intersex. Three members of our MAB (Aron Sousa, Phil Gruppuso, and Joel Frader) recently joined me and Cheryl Chase in writing an article arguing for an end to all medical terminology based on the outdated and stigmatizing Victorian term "hermaphrodite."

But there's still so much for us to change to make the world a safe place for people born with intersex and for their families! As we work, *we truly appreciate the support you show us in your own outreach, your work, and your donations.* Your meaningful alliance with us keeps us centered and moving. *Thank you!*

Clinical Guidelines for the Management of Disorders of Sex Differentiation in Childhood



CONSORTIUM ON THE MANAGEMENT OF
DISORDERS OF SEX DIFFERENTIATION

Copyright © 2005

Funded by the California Endowment
and Arcus Foundation

New Handbooks Feature Collaboration and Patient-Centered Care

Hot off the presses! Practical advice to clinicians and parents about how to implement the progressive care we've been advocating!

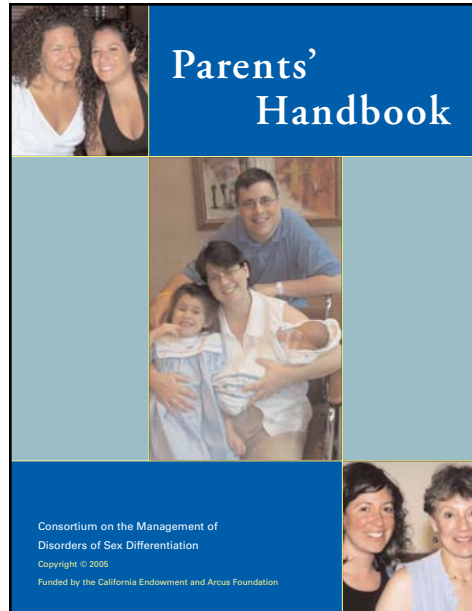
Now available through www.dsdguidelines.org: *Clinical Guidelines for the Management of Disorders of Sex Differentiation in Childhood* and the companion *Handbook for Parents*.

These two new handbooks represent a truly extraordinary collaboration of three key groups: parents of children with intersex, adults with intersex, and clinicians who care for people with intersex. *Nothing like these consensus documents has ever been seen in the history of intersex.*

ISNA provided critical leadership in this endeavor. Under grants from The California Endowment and the Arcus Foundation, we brought together over 40 collaborators for each handbook and worked carefully to make the most of their combined experience and wisdom. Collaborators included the founders of ISNA, the Hypospadias & Epispadias Association, MRKH.org, and the CARES Foundation. The *Parents' Handbook* features words of comfort and advice from other parents, as well as thoughts on the theme "What I Wish My Parents Had Known" from adults with intersex. Best of all, next to answers to common

questions and advice about explaining intersex issues to children, it includes positive photographs of individuals and families with intersex.

While the term "disorders of sex differentiation" would not be our first choice—as it risks having children themselves labeled "disordered"—we learned in this process that the term



"intersex" causes some adults and parents to feel added stigma, and causes many doctors to think we're not talking about the people they treat. In the end we felt this compromise and collaboration was well worth it, as some of the biggest players in intersex advocacy came together over our common desire to greatly improve the clinical and personal experiences of intersex. We are really proud to have played a central part in these astonishing marks of progress, and we are so grateful to all who helped.

How ISNA Works

by Jane Goto
Director of Community Relations

Want to know a secret of our success? Cheryl Chase is a computer gear-head. Those of us on ISNA's staff privately speculate that, when Cheryl gets her cholesterol checked, the lab readout comes up all 0's and 1's. But this has been enormously good for the Intersex Rights Movement! Because of Cheryl's technological brilliance, ISNA is truly a twenty-first century machine.

You might think it would be impossible to operate with your staff members living in 5 different states across 3 time zones.

Add to that a Board of Directors of 7 and a Medical Board of 23 that stretch across 4 time zones. Plus calls for help and offers of aid from all over the world!

But we make this all work by using the latest technologies to work in a highly efficient and extremely productive manner. Board and staff intranets (private web-based systems) allow us to communicate internally according to our varied schedules. High-tech collaborative software lets staff members work jointly on educational materials, press reports, e-news, blogs, etc. Meanwhile, I use what's known in the geek world as a "trouble-ticket system" to triage the numerous email requests for information and aid that come into our Help Desk.

We also use the human touch as often as we can. As you'll see if you check out the "events" column at our website, we present at universities, medical centers, churches, and film festivals. We are now formalizing that outreach through our Speakers Bureau which includes fantastic speakers like intersex activist Lynnell



Stephani Long (shown at right), and clinician-researcher Eric Vilain of UCLA (shown at left). We attend national and local intersex support group meetings to check in with the most important constituency we have. And we pick

up the phone (well, Cheryl picks up her VoIP!) to talk one-on-one with the people who want our help and the people whose practices and attitudes we're trying to change.

But, as Cheryl mentions in her welcome letter on page 1, we can only do as much as our funding allows. So as Director of Community Relations, I ask you to think about donating to make those relations stretch ever further. Please consider joining us by being a donor to ISNA.

A word from our programming director:

We have big plans for 2006, and we want you to be a part of them! Here is just some of what we're hoping to do. Whether we achieve these dreams will depend largely on funding. So won't you help by donating?

Project Roz

After Roz Weiss, a mother of a young child with intersex, saw the *Parents' Handbook*, she asked what it would take to get this and the new *Clinical Guidelines* into the hands of every pediatric endocrinologist and urologist in the U.S. Our goal is to make Roz's dream happen by the end of 2006, and with your help, it can! It is especially important for this kind of work to have Advocacy Partners (donors who automatically donate monthly via their credit cards). So please consider becoming an Advocacy Partner.

Teaching Packets

Hundreds of undergraduate educators are now teaching about intersex, and they look

to us to help them teach accurately and respectfully. We're revamping our teaching kits to include the most accessible written materials and videos, including the award-winning documentary *Mani's Story* (which we have just acquired rights to distribute).

Website Overhaul

Our website has gotten to the point where it contains so much information and addresses so many diverse audiences that it has become rather unwieldy. So we are looking in 2006 to redesign and reorganize the site. The new design will have portals specifically designed for our various constituencies: adults with intersex, parents of children with intersex, clinicians, educators,

students, journalists, and so on.

Medical Curriculum Reform

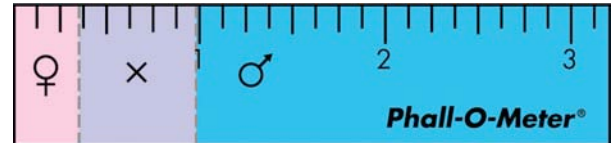
A funny thing happened on our way to success; a lot of medical schools heard about the intersex treatment controversy and stopped teaching about intersex. We believe that if we provide medical schools with good Problem-Based-Learning (PBL) units on intersex, they'll start again educating future doctors about intersex...only this time medical students will be taught why it is *good and necessary* to tell patients the truth! The medical curriculum we're hoping to develop in 2006 will feature our film, *The Child with an Intersex Condition: Total Patient Care*

as well as the new Clinical Guidelines.

The Archives Project

As the founder and world leader of the Intersex Rights Movement, ISNA has amassed an historically

archives. Cornell University, which houses a special collection on the history of sexuality, has expressed strong interest, and we look forward to working with them in 2006. (No confidential correspondence will be



important, deeply moving collection of correspondence, drafts, videos, and more. (Remember our famous "Phall-O-Meter", shown here?) It is so important that these records not be lost to history. So we've been looking for a home for our

released from Cheryl's own files without permission of the writers.)

Please help us reach these goals by providing financial support to ISNA! Thank you!

April Herndon, Ph.D.
Director of Programming

Intersex Society of North America

979 Golf Course Drive #282
Rohnert Park, CA 94928
www.isna.org

Board of Directors

Angela Moreno Lippert — Chair
Adam Mathias — President
Jane Goto — Treasurer
Laina Marie Git Jung Poon — Secretary
David Iris Cameron
Debbie Rode Hartman
Eric Vilain, MD, PhD

Staff

Cheryl Chase — Executive Director
Alice Dreger, PhD — Director of Medical Education
Jane Goto — Director of Community Relations
April Herndon, PhD — Director of Programming
Colleen Kiernan — Programming/Research Asst.

Medical Advisory Board

Joel Frader, MD — Chair
Arlene Baratz, MD
Charlotte Boney, MD
David R. Brown, MD
William Byne, MD
Anita Gatlin, DNSc, FNP, FAAN
Tod Chambers, PhD
Howard Devore, PhD
Ellen Feder, PhD
Kaye Fichman, MD
Sallie M. Foley, ACSW
Philip A. Gruppuso, MD
Barbara Neilson, MSW, CSW
John Park, MD
Sharon Preves, PhD
Charmian A. Quigley, MBBS
William G. Reiner, MD
Justine Schober, MD
Aron Sousa, MD
Norman P. Spack, MD
Eric Vilain, MD, PhD
Nina Williams, PsyD
Bruce E. Wilson, MD