

Dear Friend,

We are proud to bring you the first issue of the new newsletter of the Intersex Society of North America. In an effort to make sure we can update you on our work several times a year, we decided to use a much simpler format than the old newsletter. That will let us continue to focus our energy on changing the treatment of intersex people and their families but still provide you with timely information.

In every issue of our newsletter, you'll find out about important work we are doing to change the lives of intersex people. We could not have accomplished any of this without the help of our supporters. Please support our work with a financial contribution, so we can be there for the families making difficult decisions about how to help their intersex kids. Please make a donation to ISNA today.

We have found that the only way to effect positive change is to deal with the core issue—the invisibility and supposed shame of intersex—simultaneously in both the medical and the social realms.

Through our media advocacy, we are reaching millions of people in the US and abroad. Last year, the *Discovery Channel* broadcast "Is it a Boy or a Girl?," an hour long documentary on the controversy over medical management, and the program has also aired around the world. The film, which features Cheryl Chase and other ISNA activists, has been nominated for a GLAAD award for outstanding TV journalism. We have had very positive coverage in features in *Discover Magazine*, *The Advocate*, the *New York Times*, *BBC Horizon*, *Ms. Magazine*, *The Sciences*, and many others. Visit our web site for more information about our media advocacy successes, and to read some of these articles online.

In the medical realm, ISNA's work has been nothing short of stunning. Many specialist clinicians now seek our help as they work on reforming their teaching and practices. In January, we wrote to over 700 pediatric endocrinologists, encouraging them to read about the history of the medicalization of intersex and offering them a copy of Alice Dreger's *Hermaphrodites and the Medical Invention of Sex*. Donations to ISNA from these doctors, who are directly responsible for treating intersex children and their families, are beginning to roll in. Next month we begin shooting on a teaching video which will give medical professionals specific helpful guidance on how to care for intersex children and their families.

This newsletter is part of a broader effort to improve communication with our supporters and constituents. Our web site, www.isna.org, is another place to find the latest news, and we will soon add materials that are more helpful for first-time visitors.

We want to get your feedback on how we are doing. If we have not contacted you lately, please send us e-mail or mail. We would love to hear from you!

Yours Truly,



Robin Mathias
Development Director

Thank you, ISNA donors!

Benefactors: (\$5,000 to \$20,000 lifetime total): Freema & James L. Hillman.

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And 427 more of you! (\$35 to \$499): We wish that we could recognize all of you in this column, but there's just not enough room! Julie Dorf and Jenni Olson, Jud Van Wyk MD, Kristi Bruce, Lynnell Long, Dossie Easton, Sydney Levy and Mark D. Hodgson, Mariano Castro-Magana MD, Phyllis Lyon and Del Martin, and Angela Moreno are among you. Please see our website for the complete list.

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Medical change picks up speed

What a year it has been! In May, the Lawson Wilkins Pediatric Endocrine Society devoted a third of its annual meeting to the controversy over medical management of intersex. Cheryl Chase was invited to give the final address, "Sexual Ambiguity: A Patient Centered Approach." But Cheryl wasn't the only one calling for change. Many of the physicians, psychologists, and ethicists who spoke before her expressed skepticism about the traditional, surgery-focused treatment. William Reiner's presentation was the subject of an Associated Press article that brought widespread attention to the issue.

The North American Task Force on Intersex was formed, with the blessing of eight professional medical societies, and it brought together people with widely diverging views, including intersex people and other professionals who are strong advocates of reform.

When intersex advocates spoke last year at medical schools such as Albert Einstein College of Medicine, Denver Children's Hospital, Michigan State University, University of Michigan, we frequently found a very receptive and respectful audience, who wanted practical advice on how to reform their practices.

And of course, 2000 was the year of *As Nature Made Him*. In this book, author John Colapinto tells the life story of David Reimer. After David's penis was accidentally destroyed in a circumcision accident, Hopkins physicians attempted to remedy the situation by reassigning him female. This case was always used to prove that reassignment works—until David finally came forward to tell us about his life. He never developed a female identity, and today lives once again as a man, married and with adopted children. Of all the medical attention intended to make him into a girl, David says, "They kept making me feel as if I was a freak."

Dramatic financial growth for ISNA in 2000 and 2001

Last year ISNA tripled its income, bringing in \$100,000 (including \$23,000 which was restricted for use in 2001). The vast majority of this money came through gifts from individual donors.

We also began to win foundation grants. We congratulate Gill on having

the courage and vision to make ISNA's first grant, a \$10,000 challenge grant. See our other foundation sponsors on page 1.

Though we expect quite a bit more income from grants in 2001, our success depends upon you! We will continue to rely mainly on gifts, large and small, from a broad base of individual donors. Nurturing a broad base of donors furthers our outreach and educational goals; it provides long term stability; and it allows us to be mission-driven.

We ended the year with a healthy cash balance in the bank. That is crucial, as we plan another year of aggressive growth, to \$253,000.

Who's who at ISNA

In the second half of 2000, we began to pay salaries for the first time in ISNA's history. Thanks to all of you who helped with your gifts, time, and advice to get us to this stage!

Cheryl Chase is our Executive Director, and is ISNA's primary spokesperson, advocate, media contact and manager of the organization. In addition, she maintains the web site, writes numerous articles, processes the mail, does the bookkeeping, represents ISNA at conferences and on the North American Task Force on Intersex, raises money, and responds to requests for information.

In January we brought Robin Mathias on full time as Development Director and Chief Financial Officer. Robin has planned and managed our financial growth as a volunteer over the past 18 months. She brings to ISNA her experience in health care data analysis and a Masters of Public Affairs degree in Policy Analysis and Public Finance.

As Development Director, Robin is responsible for expanding ISNA's development program, which currently includes income raised through direct mail and foundation grants. She plans this year to expand ISNA's fundraising program in major gifts, direct mail, board of directors' role in fundraising, house parties, sales of videos, speakers' fees, and monthly donor program.

Chris Feick, our dedicated social work intern, is a student in the University of Michigan's MSW program. Chris is working under the supervision of social worker/sex therapist Sallie Foley to create educational materials for counseling professionals and less harmful

medical protocols. Chris brings to ISNA clinical experience in outreach and support groups with the University's Lesbian, Gay, Bisexual, and Transgender Affairs office, and as a student residence advisor.

ISNA builds its board of directors

As you may know, ISNA is now a 501c3 (tax exempt) corporation. As part of our effort to grow ISNA into a strong, sustainable national advocacy organization, we have begun to build our board of directors.

Alice Dreger, the leading expert on the history and ethics of the medical management of intersex, is Chair of our board. Alice has published two books about intersexuality and many articles, including one that appeared in the *New York Times*.

Sherri Groveman is the Treasurer of our board. Sherri is a tax attorney and an intersex activist—she founded the U.S. branch of the Androgen Insensitivity Support Group. Sherri has spoken widely and her writings about intersex have appeared in many professional publications.

Julie Dorf is best known as the founder of International Gay and Lesbian Human Rights Commission (IGLHRC). After Julie retired last spring as IGLHRC's Executive Director, we recruited her for ISNA nascent board, and she is also our board development consultant. Julie is also on the international advisory council of the Global Fund for Women and the Astraea Foundation's endowment committee, and she is a Vice President of the Vanguard Foundation.

Sydney Levy is a key program staffer at IGLHRC, and has worked with ISNA over the years on a number of projects, most notably our *amicus* brief to the Constitutional Court of Colombia, which contributed to the Court's decision creating new human rights protections for intersex children. Sydney brings "passion, passion, passion" to his new role as ISNA's Board Secretary.

Aron Sousa is an internal medicine physician and a faculty member of the Department of Medicine at Michigan State University. His scholarly interests are in Evidence-Based Medicine and the ethics of using unproven medical treatments. He spends much of his time training medical students and Internal

Medicine residents, and Aron's students are enthusiastic advocates of reform in medical treatment of intersexuality.

Cheryl Chase founded the Intersex Society in 1993. Her work has been hailed in the *New York Times*, *Dateline*, and *Newsweek*, and she is a frequent speaker around the country on intersex and social justice.

Become an Advocacy Partner!

ISNA is changing lives. Lynnell Long writes, "Years ago I would not have had the courage to tell my story. I was too ashamed to tell anyone else my 'secret' or the family secret." Says Max Beck, "Cheryl and ISNA have played a (literally) life-saving role in my life."

We have changed the lives of parents and grandparents. "You are doing great things," writes Doreen. "Had I had been more informed at the time of (her) diagnosis, perhaps I would not have opted for early surgery." "You can never know how deeply we appreciate the many hours and seemingly unlimited patience with our multitude of questions," says Anita Jones.

We have changed the lives of intersex children; quite a few doctors have now stopped early surgery and parents are learning to raise their intersex children in love and openness instead of shame and secrecy. Dr. Phil Gruppuso had a young patient whose parents went with his advice to avoid genital surgery after seeing ISNA spokespeople on the *Discovery Channel*. Pamela and John have a son who was "reassigned" female as an infant. By age 10, it was clear she would never be a girl. We introduced Pamela and John to Max Beck, who also made the transition back to manhood after infant female sex reassignment.

Help us change more lives—become an Advocacy Partner with an automatic monthly contribution to ISNA charged to your credit card. We want to make it easier for you to support our work. By contributing to ISNA each month, you will help create the financial base that ISNA needs to improve the social and medical treatment of intersex people. As an Advocacy Partner you will help us direct more resources to our medical advocacy and public awareness campaigns.

If you give \$50 a month or more, you will also be eligible to be part of our True Hermaphrodite donor group (an honorary status, having nothing to do with the

microscopic appearance of your gonads!) And your gift would pay for a mailing to over 700 doctors who treat intersex children.

1st National Conference on Gender and 6th Annual Lobby Day

ISNA is proud to be a sponsor of the 1st National Conference on Gender and 6th Annual Lobby Day, May 18-21 in Washington, DC. This exciting weekend will feature three days of workshops, policy, politics and strategy on everything from gender law, gender and racism, and gender discrimination on the job to gender in the new cinema ("Boys Don't Cry," etc.), gender-based violence, gender and feminism, and issues of queer and trans youth and elderly.

The 1st National Conference on Gender and 6th Annual Lobby Day is hosted by GenderPAC, the national advocacy organization working to ensure every American's right to their gender, free from stereotypes, discrimination, and violence, regardless of how they look, act or dress or how others perceive their sex or sexual orientation.

You can get more information by visiting their website at www.gpac.org/ngc, calling them at 202.462.6610, or emailing them at NCG@gpac.org Join ISNA there. ISNA donors get 10% off!

Top ten myths about intersex by Alice Dreger

MYTH #10: Intersex is extremely rare.

First we need to acknowledge that it's hard to say exactly how frequent intersex is, because the sex spectrum is like the color spectrum; nature provides us with a range where one "type" blends imperceptibly into the next. For our linguistic and social convenience, we break that spectrum into categories. It makes it easier to talk about "that blue car" or "that man over there." But nature doesn't tell us that there are 7, or 10, or 100, or ten million colors, and nature doesn't even know that there are two sexes. We humans, with our words and our cultures, decide how many categories to delineate. While the "male" and "female" types are relatively common, nature presents a full range of sex types, and people decide where the line should

be drawn between "female" and "intersex" or "intersex" and "male."

That said, we do know that about 1 in 2,000 children is born with genitals that are pretty confusing to all the adults in the room. We know this from the statistics of how many newborn babies are referred to "gender identity teams" in major hospitals.

But wait, you say, 1 in 2,000 sounds rare! Well, if only 1 in 2,000 persons is intersexed, then intersex is more common than cystic fibrosis, a condition most people have heard of. In fact, as Sherri Groveman (now the Treasurer of ISNA) pointed out in her article in *Intersex in the Age of Ethics*, if you do the math, you realize that there are more intersexed people in the world than there are Jewish people!

And if all of the intersexed people of voting age had voted for a single presidential candidate, the outcome of the election would have never been in doubt. (Not that we're telling you who you should have voted for—though you might want to know for future reference that Al Gore made a public, educated statement about intersex at a meeting of LGBT leaders. We were unable to find out from the Bush team the Republican platform on intersex.)

In fact, maybe it's time to print t-shirts that say, "I'm intersexed, and I vote!"

But wait, are you intersexed? That leads us to . . .

MYTH #9: Only true hermaphrodites are really intersexed.

The term "true hermaphrodite" is a nasty Victorian term invented in an effort to make intersexuality go away. (My first book, *Hermaphrodites and the Medical Invention of Sex*, is all about this.) The term "true hermaphroditism," a term that sounds fancy and special, refers simply to the condition in which one person has both ovarian and testicular tissue, whether or not that tissue is functional physiologically. But it is silly to count only these folks as intersexed! Their internal and external anatomy varies all over the place, and many of them look less "ambiguous" than other folks. Some of them have XX chromosomes, some of them XY, and some of them have mixes or variations on those themes. Keep in mind that nobody has two full sets of sex organs, as some people mistakenly imagine. People with ovarian and

testicular tissue, like other intersexed people, have one set of genitals, though they may be kind of in-between in appearance.

In practice, the term “intersex” is used to refer to anybody who was born with anatomy other than what the Powers That Be define as “standard male” or “standard female.” What counts as “standard”? Check your phall-o-meter (purchase online at ISNA’s website), and stay tuned for a later newsletter, which will explore the deep and oh-so-hot question, “Who *really* is intersexed?”

For now, on the topic of who is intersexed, let’s move on to dispel . . .

Myth #8: If you re transsexed, then you re intersexed.

This myth comes from our nutty cultural notion that your identity has to find its basis in your anatomy. It’s just like the old-fashioned (sexist) idea that if you’re a strong woman, you must really be a man inside. In fact, it’s the same kind of stereotype that assumes that all black people are lazy. Aren’t we past the point of believing that one type of anatomy necessarily maps to only one type of identity? Get over it!

Transsexed people are sometimes people who were born intersexed, but far more often they are people who were born with “standard” male or female anatomy. By a common definition, transsexed people are people who were assigned a gender that doesn’t work for them. ISNA supports the right of all people, regardless of what their body looked like when they were born, to assume the gender identities that makes sense to them. This leads us to . . .

Myth #7: ISNA advocates doing nothing and raising intersexed babies in a third gender.

Sorry, gender warriors, that’s not us! We certainly would like to see people become less gender-phobic, but we don’t think dumping intersexed kids into a gender-phobic world with no gender or with a “third gender” is the way to go. We believe there are two problems with trying to raise kids in a “third gender.”

First, how would we decide who would count in the “third gender”? How would we decide where to cut off the category of male and begin the category of intersex, or, on the other side of the spectrum, where to cut off the category of

intersex to begin the category of female? (See Myth #1.)

Second, and much more importantly, we are trying to make the world a *safe place* for intersexed kids, and we don’t think labeling them with a gender category that in essence doesn’t exist would help them. (Duh, huh?)

ISNA recognizes that it can be damned hard to be intersexed, or to have an intersexed child. That’s why we exist. That’s why we *don’t* advocate “doing nothing.” What we do advocate is providing parents of intersexed newborns—and within a couple of years, intersexed children themselves—with honest and accurate information about intersex, psychological counseling by professionals who are not gender-phobic, medical help for any real medical problems, and especially referrals to other people dealing with the same issues. Time and again researchers have found that, no matter what the condition—being gay, dealing with a serious disease—peer support, even if informal, saves families and lives.

ISNA believes that intersexed children and adults should not be subject to surgeries designed to “make the genitals look normal” without their explicit consent. (And consent of your parents isn’t the same as your consent. Think about it—would you want your parents making medically unnecessary decisions about your sexuality?) Some people think surgery is the only possible medical response to intersex. Not so! Everyone agrees that intersex is a psycho-social issue, so why not deal with it as a psycho-social issue first and foremost? This leads us to . . .

MYTH #6: You can t raise an intersexed child as a boy or girl without surgery.

Of course you can! When people ask me whether my baby is a boy or girl, do I have to show them his genitals to answer their question? No, I tell them, “He’s a boy.” To gender a child, we give that child the label of “boy” or “girl” and thereby float them into the (admittedly often problematic) gender stream of our culture.

How would we decide what gender to give an intersexed baby? Doctors and parents should consider an intersexed baby’s genitals and physiology and, using the best knowledge they have of various

intersex conditions and our culture, decide which gender the child is most likely to grow up to have. Sure, this requires recognizing that the child might express a different gender later. But the fact is that even with “corrective” surgery designed to “lock in” one gender, many intersexed children transition gender later.

We also have to recognize that everyone’s gender assignment is preliminary. Mine was, yours was, so is my son’s. Intersexed people are more likely than others to transition genders, but everyone, intersexed and not, has that potential. And it is worth remembering that the idea of “locking in” a gender using “corrective” surgery feeds into . . .

MYTH #5: Surgery makes normal-looking genitals.

This simply isn’t true in the vast majority of cases. As Cheryl Chase, the Executive Director of ISNA, noted in *Intersex in the Age of Ethics*, “Surgery is good at removing structures . . . it is much less useful for creating structures.” ISNA believes that medically necessary surgeries should be employed when a child or adult’s physical health is threatened. We believe that, for example, if a child’s urine is not draining in a healthy way, the child should receive medical treatment for that problem. But “cosmetic” surgeries designed to make genitals look “normal” are not medically necessary.

Intersexed genitals are not diseased! They just look different. And don’t go giving into . . .

MYTH #4: Once surgery is better, we won t have to worry about intersex.

When is it ever going to be OK to risk a baby’s future sexual function, fertility, and even life, just because her genitals force you to realize gender and sex aren’t simply dichotomies? Who are you to decide she wouldn’t be happy with the genitals she was born with?

If it is true that intersex cosmetic surgeries are getting better (and we lack the data to know), then why not let the intersexed person himself decide when, in his own opinion, the likely benefits to him of the surgery outweigh the burdens and risks to him of that surgery?

Keep in mind, too, that surgeries designed to “correct” intersexed genitals will always, by definition, carry with

them the message that intersex is shameful and bad. And we don't think intersex is shameful or bad. Nevertheless, we keep running into . . .

MYTH #3: Corrective cosmetic surgeries make parents forget their kid was born different and undoes all their confusion, shame, guilt, and fear.

Hello? This might work if the surgery being done was a lobotomy on the parents. "Normalizing" surgery just gives parents this message: Your kid is a freak, we had to correct it, don't talk to anyone about it because this is a really scary, shameful condition.

There is no question that the parents I talk with whose children had "normalizing" surgery still have all the confusion, shame, guilt, and fear after the surgery. Some parents say they are even worse off. Some have ended up with disabled kids. Others have wound up with more guilt after realizing they risked their children's sexual function and fertility. Many worry openly that their kids will later accuse them of not accepting them as they were.

I don't have a smooth transition to the next myth, so let's move on to . . .

MYTH #2: John Money is responsible for all of the troubles that have befallen intersexed people.

Psychologist John Money became widely known through John Colapinto's book, *As Nature Made Him*. Money often argued that you could make any kid a girl or a boy, as long as you made the genitals look "right." It turns out gender identity is much more complicated than that, but unfortunately legions of doctors thought Money was right and did "normalizing" surgeries in an attempt to make intersex go away.

While it is true that a lot of doctors justified their work via Money's own work, it is also true that burning Money in effigy won't make any difference in the lives of the five girls who *today* had their clitorises cut down by a surgeon who thinks no one can live with intersexed genitals. Every time you sit around and blame Money, ask yourself what you've done today to try to see that tomorrow there will be only four children subjected to medically unnecessary surgeries on their genitals.

What can you do? For starters, don't give into . . .

MYTH #1: My little contribution to ISNA can't possibly make a difference.

What? You doubt our powers to change the world on a shoestring budget! Consider the fact that in the last year, with just a few thousands of dollars, we have provided educational material to tens of thousand of people, supported doctors and activists working for positive reform, put intersex on the national agenda, and helped a few wonderful intersexed people realize that they are not alone.

Remember what Margaret Mead, that gender maven, said: "Never doubt that a small group of thoughtful committed citizens can change the world: Indeed it's the only thing that ever has."

We're sure that right after that, she added, "*Send money!*" Help us now end shame, secrecy, and unwanted genital surgeries for people born with atypical sex anatomies. With your help, we can make the world a safer place for people born intersexed.

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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