



**ISNA Board and Staff** (from left to right) Sherri Groveman (treasurer), Sydney Levy (secretary), Robin Mathias (development director), Cheryl Chase (executive director), Julie Dorf (boardmember), Hazel, Aron Sousa (boardmember), Kepler, Alice Dreger (chair).

## Face-to-Face

ISNA's board met for two days in San Francisco in February. It was the first time the new board, formed late last year, met face-to-face. We spent two days making important decisions about ISNA's future. Topics included: Medical Advocacy, Diversity Outreach and Fundraising. The board holds monthly conference calls and meets in person twice a year.

## Emi Koyama is our summer intern

Emi Koyama will be working for ISNA this summer. She was selected from 18 impressive applicants. Emi is the Board Chair of the Survivor Project in Portland, Oregon. She speaks about intersex in public forums across the country and is currently co-editing an anthology on intersex and trans feminisms. We are excited to have this opportunity to work with her.

## ISNA has moved to Petaluma, CA

We accomplished a great deal during our time in Ann Arbor and will miss seeing our many wonderful Michigan allies, who will continue this great work.

We especially want to thank the Triangle Foundation, WRAP, and University of Michigan Office of LGBT Affairs for embracing our mission and opening many doors for us in Michigan. The University of Michigan's Departments of Pediatric Endocrinology and Pediatric Urology have had the courage to open their hearts to the voices of intersex patient advocates.

There are many other wonderful people in Michigan doing incredible work, including the chair of our board, Alice Dreger (who writes most of the newsletter), Aron Sousa, Bruce Wilson, Sallie Folley, and Chris Feick.

## New Address

Our new address in California is PO Box 301, Petaluma, CA 94953-0301.

## Thank you, ISNA donors!

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

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(\$50 to \$99 per month): William Byne MD, Howard Devore.

(\$10 to \$49 per month): Cindy Duffy, Randy Sandoval, Suzanne Nemeth & Celest M. Roth, Sherri Groveman, Eric Peterson, Estelle Disch.

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## ISNA News

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## Why Do We Need ISNA?

By Alice Dreger

### Barriers to Change

Most people who hear about intersex and the dominant treatment system for it — a system that favors secrecy, “normalizing” surgeries, and gender-assignment based mostly on phallus length — realize how messed up this system is. They know, from their own experiences, that secrecy about key features of one’s identity typically leads to shame and loneliness, that “normalizing” procedures don’t make difference go away, that “normalizing” procedures tell people that difference is bad, and that gender is based on a lot more than how small one’s clitoris or how big one’s penis is.

So a lot of people assume that the medical treatment of intersex must be changing, very fast, for the better, because the dominant system is so obviously screwy, and there can’t be anyone treating intersex who hasn’t heard of the challenges and taken them seriously.

But the fact is that it takes a long time, and a lot of work, to change an institution. And the dominant system for treating intersex is indeed an institution, with a long history, a significant number of professional reputations riding on it, and a lot of people invested in believing it works, in spite of much evidence to the contrary.

### Breaking Through

About six years ago Cheryl Chase contacted me to tell me about the current treatment of intersex and to ask for my help in improving it. I was skeptical that things were as bad as she said, but since I was working out of medical libraries for my research, it was easy for me to look up the current literature for myself.

Wow, was I surprised! There were medical textbooks advising present and future doctors that, if a boy couldn’t pee standing up, he might turn out very depressed or even (gasp!) gay, and that girls born with big clitorises had to have surgeons cut off parts of those clitorises or their parents might not love them. The more I looked, the more I realized how messed up the system was. It was full of practices that we had long since learned are harmful to patients:

- ◆ withholding medical information and medical records
- ◆ treating conditions as shameful and freakish
- ◆ basing treatments on hunches and anecdotes rather than evidence

It was pretty obvious to me that all Cheryl and others needed to do was to go to the physicians treating intersex and to show them that they had good goals — like producing happy, healthy patients — but that their practices were undermining those goals. When it became clear that Cheryl couldn’t even get in the door, because physicians were afraid she was some sort of anarchist, I used my Ph.D. as often as I could to slip her in the door. All we had to do, I was sure, was talk rationally about this, and the system would be fixed.

Oh, boy, was I naïve! Travelling around, I learned that a lot of the physicians treating intersex were really good-hearted souls. But they were so convinced that “no one could live like this” (with the intersexed genitals they were born with, with the knowledge of being born

intersexed) that they really thought the best thing to do was to shield parents and children from as

As is typical, the surgeon was primarily concerned with how others would see the patient, rather than how the patient might feel about the surgery.

much of the truth — and as much of intersex — as possible. They thought this even when we pointed out they were violating almost-universally accepted principles of medical ethics. They thought this even when we pointed out the lack of scientific evidence for their approach, and the growing mounds of anecdotal evidence challenging it. They thought this even when former patients confronted them to tell them how badly their treatment had turned out.

Now, you’re probably saying to yourself, “But Alice, that was a few years ago, when there had not yet been the swell of criticism and challenge. Today surely all doctors must know that, if they use the concealment-centered system, they’re on shaky ground. The system must be very different now.” Is it?

### Real Trouble

Well, let me tell you about what happened recently to my friend and colleague Tod Chambers, a bioethicist at

Northwestern University in Chicago. A few months ago, at a local hospital, two children were born with ambiguous genitalia in the space of just a couple of weeks. A physician at the hospital thought it might be a good idea to call Tod in for a discussion with the involved physicians, because he knew Tod had taught about the ethics of the treatment of intersex to medical students. So Tod went to the discussion hoping to help out.

An endocrinologist began the meeting by explaining the biological details of the two cases, including how each particular condition was caused. The group then had a general discussion about the concerns of the parents. Tod told the group that it is important for parents in such situations to be in contact with other parents and intersex support groups; he mentioned the ISNA website and suggested it was a good resource to start with. He also told the gathered physicians it was likely the parents would benefit from grief counseling, because parents in these situations often feel some sadness over the loss of the “perfect” child they expected, and so they needed help sorting out their emotions.

At this point in the meeting, the surgeon proceeded to give a half-hour presentation on his own experience of

treating intersex, showing slides of children’s genitals before and after “normalizing” surgeries. The surgeon confirmed that his approach centered on phallus length: was the phallus big enough to assign the boy gender, or small enough to assign the girl gender?

As is typical, the surgeon was primarily concerned with how others would see the patient, rather than how the patient might feel about the surgery. He went on to tell a story of a previous patient he had operated on: a child was born with ambiguous genitalia (and, I’m presuming, testicles), the surgeon and a colleague did a work-up on the child, and decided the child’s phallus was long enough to count as a penis, so they labeled the child a boy and decided not to do turn him into a “girl” — cut-down his phallus, remove his testes, build a “vagina” (a hole).

Well, later that night, the surgeon got a call. The Intensive Care Unit nurses were very upset to see a boy with a

## Real Trouble (Cont.)

small penis—so the surgeon decided the child should be made into a girl, and indeed he was.

At this point Tod's mouth was hanging open. The tone of the surgeon's story at the meeting indicated that the nurses' distress was rather amusing. The general lesson was that you have to assign gender and do surgeries based on what adults around intersex children think.

By the time the surgeon ended, Tod "just sort of exploded. I said, 'I don't understand why you're doing the surgery. It's just for the parents, isn't it?'"

The surgeon told another story, about a intersex child born to parents who both worked. The parents didn't believe the daycare providers could handle "a girl with a penis," so the surgeon did a "clitoral reduction" surgery.

Tod pressed the surgeon: "This is

really for the benefit of the parents, isn't it?" Finally the surgeon confessed that that was essentially true. So Tod asked about whether the

surgeon knew of any good follow-up studies showing that this approach benefited *the patient*. The surgeon admitted knowing that some adult intersex people are upset with the way they are treated, but the surgeon said he didn't think it was fair to look at cases handled 20 years earlier, because "surgery is better now."

"So we can't ever stop these surgeries," Tod noted to the surgeon, "because you'd always be looking at data from 20 years ago, so you don't bother to look at the data?" (Indeed, Tod had hit upon the most frustrating Catch-22 I've encountered: physicians claim — without careful follow-up studies — that they are sure most of their adult patients are happy with the way they were treated as children, but if any are unhappy, it doesn't matter, because "surgery is better today!") If they're happy, the treatment is credited and likened to the treatment today. If they're unhappy, the claim is the treatment today is different.)

When he was recounting this story to me, Tod told me he was shocked the surgeon wouldn't be interested in outcome studies, the surgeon was so convinced they wouldn't tell us anything

about treatments today. Tod asked the surgeon if there was any way to know if his treatments were working.

"Well," answered the surgeon, "I have enough information, because my own patients are happy."

People in the room were by this point pretty uncomfortable. Ethicists usually help physicians think about their actions; they don't usually actively challenge their actions. Tod had, in his outrage, violated a cultural norm. When the meeting broke up, the physicians went over to talk to the surgeon, and avoided Tod. Tod felt frustrated and angered, and felt like the discussion hadn't helped much at all.

## Paradigm Shift

When Tod told me this story, I gave him my sympathies, but I wasn't really surprised. By this point it was clear to me that trying to reason with surgeons one at a time wasn't making too much of a difference. Instead, the institutional

culture has to be changed, a new paradigm put in place that is patient-centered. The only way to do this is with an

organized effort, like the one being led by ISNA. I told Tod this, and asked him to support ISNA financially. Tod promised to make a \$500 gift to ISNA.

Tod recognizes that doctors like the surgeon he confronted are not going to do outcome studies on their own, and the only way to get studies done are if organizations like ISNA press for them. In our conversation, Tod said to me, "It's obvious we need to do long-term studies of these treatments, and we need a moratorium on them until that happens. I'm a strong believer in finding out what the studies can tell us. But until then, we have to stop this! Surgeons working on anecdotal evidence is ridiculous."

## Wanted! Happy Adult Patient

Many physicians who have been treating intersex for years believe, like the surgeon Tod encountered (see above) does, that their adult patients are happy with the treatment they received. Some of them might be — though for four years now I've been asking doctors to give me evidence of one such happy adult patient,

and I have yet to be provided any evidence.

Probably one of the reasons doctors assume their patients are happy is because it is pretty hard for a patient to tell her doctor that she is unhappy with the treatment she has received. This is especially true for intersex patients who have gotten the message that their intersex is a secret to be kept between themselves and their doctors, and so their doctors may be the only people they feel they can talk to about their concerns. Patients come to doctors because they are in need, and it is pretty scary to criticize someone who has helped you when you're in need, especially someone who has shown kindness to you. So it can be very hard for an intersex person to let a doctor know that the treatment didn't work the way the doctor intended.

## Speaking Out

ISNA's media campaign and website (which receives about a half-million visitors per year) have helped intersex adults realize they are not alone, and that they are certainly not alone in their feelings of confusion and frustration over the way they were treated. The consequence has been that more and more intersex people have been willing to let their doctors know the truth of what happened. We know this changes practice.

Consider this letter (page 4) from Joan, an intersex woman, to her doctor. Joan shared this letter with ISNA, and gave us her permission to reprint it, with identifying information removed because she is not seeking to harm the physician's reputation, but rather to convince the physician to reconsider the system's implications. Joan was born with Congenital Adrenal Hyperplasia (CAH), an intersex condition that caused her to have a large clitoris.

This must have been a tough letter for Dr. M to receive. And in fact, I have found that one of the reasons physicians resist calls for reform is the pain of having to face the possibility that they have inadvertently harmed their patients. I know if someone told me that, after years of dedicating my life to helping people, I had accidentally been harming people, I would be pretty resistant to that criticism.

The Intensive Care Unit nurses were very upset to see a boy with a small penis so the surgeon decided the child should be made into a girl, and indeed he was.

January , 2001

### Peer support for doctors?

One of the ways ISNA addresses this problem is to help doctors considering long-term studies and reform find, talk, and work with each other. Peer support for doctors? Sure! *Everyone* benefits from talking with people like them, whether they be parents, intersex children and adults, or doctors. And doctors who find colleagues like-minded in terms of reform are better able to face the challenges of reform.

### Doctor Training

The real key to effecting institutional change that will benefit intersex people and their families is changing the way medical professionals are educated about intersex. We need to change the way medical students and residents are trained about intersex, so that they know:

- ◆ intersex is a variation, not a disease,
- ◆ one's gender is not determined by one's gonadal tissue or phallus length.

They need to know intersex people as people, not freaks. ISNA is working to effect this institutional change.

### What s in a Name?

Right now, if they're even trained about intersex, most medical students are still told intersex comes in three types, true hermaphroditism, and male and female pseudohermaphroditism. This is a taxonomic system developed over a century ago that is incredibly harmful. It uses the misleading and outdated term, "hermaphroditism," it tends to equate the patient with the condition, and it is so far behind the findings of medical science that it doesn't even include some basic intersex types!

### Training Materials

We work with textbook and case-study writers to update their information and their representations of intersex people. And we are currently producing high-quality educational videos with the latest information that will be marketed to (continued on page 5)

Dear Dr. M,

Because I know that you are involved in new debates about how doctors should treat children born with genital ambiguity, I would like to tell you how my treatment under your care has affected my life.

Though I enjoy success in my professional career, I have never enjoyed sexual or romantic intimacy in my life, with men or with women. I believe that this is a direct result of my treatment. The clitoral surgery that was performed on me damaged my ability to experience sexual pleasure and it failed in its putative purpose of creating "normal" appearing genitalia. The inspection of my genitals at each checkup was hard enough to endure, but having groups of doctors, interns and medical students present at those examinations made it quite clear to me that I was not and would never be like other girls. In my teens, when I first realized exactly what had been done to me, my reaction was that I must have been truly repulsive to my parents and doctors if the result of the surgery performed on me could be considered an improvement. The assurances of my therapist that my doctors considered my surgery to be a success only strengthened that conviction.

The insistence that surgical techniques are better today is debatable and to my mind irrelevant. There have been no large scale, long term follow-up studies on the results of clitoral surgery. The few studies that have been done have emphasized the cosmetic result; the physical and emotional impact on the patient is given little consideration. It takes many years before it is possible to assess the impact of the surgery on erotic sensation, a fact that effectively makes all of the current techniques for clitoral surgery experimental. To make matters worse, current techniques are based on outdated and inaccurate information. The recent work by Larry Baskin, a urology surgeon at UCSF, has shown that the model of clitoral innervation underlying so-called "modern" clitoral reduction surgeries is simply wrong [1].

I have taken the time to discuss these issues with other women born with genital ambiguity, and with parents. I have found many women who, like me, never formed the heterosexual relationships that their parents desired and that doctors implied would be one of the benefits of trimming an unacceptably large clitoris. I have noticed an undercurrent of homophobia in some of the comments of parents who defend their decision to allow surgery on their infant daughters. I have spoken with many women who resent the surgery that was performed on them. Ironically, it seems to be intact women who most often form heterosexual relationships.

Whenever I get the chance, I tell parents that permitting genital surgery on their infant daughters is a terrible choice; their daughters should be allowed to make that decision when they are old enough to understand the risks involved. I am pleased that I seem to have dissuaded a number of parents from going ahead with surgery.

You once asked me whether I would agree to be interviewed for a study on the psychological effects of CAH on females. I refused because my feelings about my surgery and subsequent treatment were too painful for me to talk about, especially when it meant that I would be assuming the role of a research subject. I knew I would be unable to reveal my most personal thoughts and feelings and rather than lie and thus validate the assumption that I was happy and well-adjusted I chose not to participate. Ask yourself how many others who refused to participate were like me. When I read published studies on the psychological effects of CAH, I suspect that the majority of non-responders were, like me, so traumatized and humiliated by their treatment experience that they refused to participate. I also wonder how many of the respondents actually gave sincere answers. It seems impossible that the results from these studies have not been affected by these kinds of sample bias.

Doctor M, this has been a difficult letter for me to write but I can no longer stay silent. I wish I had spoken out long ago, but the feelings of shame and humiliation that I struggled to conceal created a powerful gag. Years of trying to hide my feelings have taken their toll on me. Today I suffer from depression and find myself plagued with thoughts of suicide. I now realize that I unless I can come to terms with what was done to me, my life is going to continue to feel pointless and empty.

I hope that what I have said encourages you to help put an end to these surgeries. Therapy for the family and doctors is a far better response to the birth of a child with ambiguous genitalia than allowing personal fears and prejudices to drive a decision to perform surgery that is not only medically unnecessary but also carries a risk of causing lasting physical and emotional damage to the patient.

Sincerely,

Joan W.

1. Baskin, LS, A Erol, YW Li, WH Liu, E Kurzrock, and GR Cunha. 1999. Anatomical studies of the human clitoris. *Journal of Urology* 162 (3 Part 2)1015-20.

## Training Materials (Continued)

medical schools. These videos include real parents and intersex people talking, without shame, about their own experiences.

It's important to remember that we need to educate all medical professionals who might find themselves dealing with intersex, not just future doctors. Right now, very little if any education about intersex is provided to nursing and counseling students. Yet, because of ISNA's public outreach, we have been getting more and more calls from people who want help in these areas.

## Vaginoplasty Leads to ICU

Andrew Hamilton, B.S., R.N., learned how important education is for pediatric nurses during one particularly challenging experience he had a couple of years ago while working in the Pediatric Intensive Care Unit (PICU) of his institution's hospital.

Andrew was assigned to care for a toddler who had just had genital "normalizing" surgery, including surgery to build her a vagina. This surgery, designed to make the parents more comfortable about their daughter's gender, is not normally done on newborns because the anesthetic risks are considered too great. So, even though parents like these live for over a year with a daughter with intersex genitals, many doctors still consider this "normalizing" surgery necessary for parent-child bonding and gender development.

The little girl Andrew was caring for landed in the PICU because, after the surgery, she developed a bladder infection that then turned into sepsis, a huge, body-wide infection. The child became so sick that she essentially wound up on life-support, with mechanical ventilation and drugs to paralyze her temporarily, in order to stop her from trying to pull the uncomfortable ventilator tube out. She was put on massive doses of antibiotics and drugs to maintain her blood pressure.

There was no medical indication for this surgery. This girl could have lived at least until puberty without a vagina, and could have chosen later in life, for herself, whether she wanted to risk this

surgery. In fact, vaginoplasties done in infants and toddlers have a much lower success rate than vaginoplasties done later.

## Surgeons Fill Training Gap

When we talked about the current treatment of intersex, Andrew (see *Vaginoplasty Leads to ICU* above) expressed to me his sense of "the incredible knowledge deficit among medical and nursing staff, about these interventions. Our understanding of the conditions in terms of what they mean for patients and families seems to me quite minimal."

For most conditions there are nurse practitioners and social workers trained to provide families with support and education. But in the cases of intersex, the surgeons were doing all the patient education and support, and they had neither the time nor the training to succeed in this.

Meanwhile, the doctors are trained to have a fix-it model, where the "it" being fixed is the unusual genitalia and not the

The child became so sick that she essentially wound up on life-support, with mechanical ventilation and drugs to paralyze her temporarily

parents' fears and concerns. This medicalized approach doesn't solve

the problems the parents and the children will face, and indeed, as we have seen, may only increase them. Besides working to help directly remedy the problems intersex families face, Andrew has pledged financial support to ISNA in order to help achieve sweeping change.

## So why do we need ISNA?

We are so grateful that there are good people out there like Tod Chambers and Andrew Hamilton who, when they encounter ignorance about intersex, challenge the authorities and seek institutional change.

But the voices of people like Tod and Andrew are like voices in the wilderness if there isn't a context of challenge and reform. **ISNA provides that context** to support them.

There was a time when we thought that reform could be achieved part-time — when we thought activists, academics, and reform-minded physicians could write letters to medical journals in their spare time, and that that would change things. But it is clear, as we have seen,

that the scattershot approach doesn't make for major institutional change, and without major institutional change, there will still be many, many intersex children, adults, and families who are left to suffer treatments based not on scientific evidence and careful moral reasoning but on traditions, hunches, and wishful thinking.

## How to Help

There are two major ways you can help effect institutional change.

### 1. Educate people about ISNA.

Like Tod and Andrew, you can work within your own spheres of influence to educate people about intersex and about ISNA. If you get together with your family and friends and neighbors, tell them about intersex and about ISNA. If you are an intersex person, write to your doctors and tell them about your experiences (and, if you like, send us copies of your letters so we can keep track of the movement). If you're at an educational or medical institution, work on curricular and clinical reform. No matter who you are, there are people around you who will benefit from your efforts to make intersex known, understood, and accepted.

### 2. Make a tax-exempt donation

Like Tod and Andrew, you can support ISNA through your donations. Your donations will go towards the kinds of full-time, resource- and labor-intensive work noted above: maintenance of the ISNA website, public education, media outreach, development of educational materials including training videos and books, curricular and clinical reform across the country, and more! We know it is a cliché, but we can't do it without your financial help.

## Community Allies

By Robin Mathias

### PFLAG Devotes Newsletter to Intersex

Parents and Friends of Lesbians and Gays (PFLAG) is focusing attention on intersex in the next issue of its newsletter. It will include a shorter version of *Top10 Intersex Myths* from ISNA's February newsletter and other articles, including what PFLAG chapters can do to help.

By working with PFLAG and other activist and support organizations we can spread our message to more people and encourage groups to include intersex in their local support and outreach efforts.

LGBTI: California Leads

Thanks to our amazing volunteers, a growing number of groups are including intersex in their missions and names. As far as we know, East Bay Pride is the first pride group in the world to officially add "I" to LGBT in all of its work. "Getting involved in intersex was natural for us as Queer people," said Executive Director Pete King, "Nobody should be allowed to force a gender identity on you."

In February, the University of California Lesbian Gay Bisexual Transgender Association voted to include Intersex in its name, constitution and mission. Several ISNA activists in California have spoken at UC campuses, helping to make this change possible.

Youth Gender Project includes intersex in its mission and offers a workshop for providers about working with intersex children, youth and young adults. Presenters include YPG Intersex Issues Coordinator, Kristi Bruce and YPG Advisory Board Member, Suegee Tamar-Mattis. Kristi and Suegee are ISNA members and activists.

Of course change is happening all over the country. Mary Kelterborn (our intern from last summer) gives presentations about how local groups can become more intersex inclusive and aware.

If you know about other organizations that now include Intersex in their mission or if you want to learn how to include intersex in the work you do, please let us know by e-mailing Mary Kelterborn (mary@isna.org).

National Leaders Host ISNA Fundraiser

In April, Jerry Clark, the National Gay and Lesbian Task Force's Board Co-chair, held a fundraising party for ISNA at his house in Washington, DC. In addition to Jerry Clark, the host committee included:

- Adrienne Smith  
Gay & Lesbian Medical Association
- Kirsten Kingdon  
Parents and Friends of Lesbians and Gays
- Elizabeth Toledo  
National Gay and Lesbian Task Force
- Pat Wright  
Disability Rights Education & Defense Fund
- Bob Summersgill  
Gay and Lesbian Activists Alliance
- Chanika Phornphutkul MD  
Genetics Fellow, National Institutes of Health
- Michael Feldstein  
International Gay and Lesbian Human Rights Commission
- Riki Wilchins  
GenderPac

- Judy Guerin  
National Coalition for Sexual Freedom
- Cornelius Baker  
Whitman-Walker Clinic
- Chai Feldblum  
Georgetown University Law Center
- Nancy Buermeyer  
Human Rights Campaign

Many thanks to Jerry, the rest of the host committee, attendees and donors for making this event successful!

If you would like to host an ISNA house party, please e-mail Robin Mathias (robin@isna.org).

WWW.ISNA.ORG

Our Web site includes back issues of newsletters and all the latest news, plus our bibliography and in-depth coverage of intersex topics. You can also order any of our merchandise online.

Share this Newsletter

We want you to make copies of our newsletter. Please help people learn about intersex. Give copies of the newsletter to your friends, family and colleagues, and ask them to use the form below to help support our work.

One of our donors distributed copies of the last issue to people he knew. He was able to raise 10 times as much as he could give personally. Make your donation go further by asking others to join!

**YES!** I want to help ISNA to end shame, secrecy, and unwanted genital surgery now!

Here is my tax-deductible gift of:

- \$50       \$35
- \$75       other \$\_\_\_\_\_
- \$100      I'd like to make this gift monthly

- Enclosed is my check payable to ISNA
- Please charge my
  - Visa     Mastercard

Credit Card Number: \_\_\_\_\_

Expires: \_\_\_\_\_

Signature: \_\_\_\_\_

Name: \_\_\_\_\_

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