

The publication of the

Intersex Society

of North America

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www.isna.org

Hermaphrodites with *Attitude*

Focus on local activism

Volunteers are working at the local level to make the world a safer place for intersexed people and their families. You can help! To start a local group, contact isnaMI@hotmail.com.

In San Francisco, **Sam [REDACTED]**, **Kristi Bruce** and **Howard Devore** started a speaker's bureau. They have presented to medical students at Stanford, University of California at San Francisco, and twice at Berkeley, and will soon present to the

local Metropolitan Community Church. Contact isnaCA@aol.com.

Marge Witty, a professional psychologist and instructor at the Illinois School of Professional Psychology, sponsored and organized an ISNA workshop in Chicago. Therapists, activists, a Chicago Tribune reporter and others attended the showing of ISNA's video *Hermaphrodites Speak!* and discussion with **David Vandertie** and **Angela Moreno**. This laid the groundwork for the formation of



Environmental Protection Agency attorney Hale Hawbecker lauded by employer

an Illinois chapter of ISNA. Contact isnaIL@hotmail.com.

When **Hale Hawbecker**, an attorney with the Environmental Protection Agency, was preparing his talk on the applicability of the federal Female Genital Mutilation Act to intersex surgeries for the *5th Annual Sexual Orientation and the Law Conference* at Vermont Law School, he worried about how coming out as intersexed would affect his colleagues' opinions of him. The answer came last May, when the EPA awarded him an Employee Recognition Award for outstanding community service in recognition of his work with ISNA.



photo: Phyllis Christopher

Howard Devore Ph.D., Cheryl Chase, Kristi Bruce, and Sam [REDACTED] speak to UC Berkeley medical students about their lived experiences of intersexuality.

Martha Coventry contributed an intersex perspective to a panel headed by psychologist Walter Bockting with a mandate to improve the medical curriculum at University of Minnesota in Minneapolis. Martha also addressed the entire first year medical student class (of over a hundred) in June. "Afterwards the students came up to me, one after another, to tell me how grateful they were for my talk. They were visibly moved by the injection of such humaneness into the curriculum. Physicians need to know the lived experience of their patients."



Martha Coventry, a Minneapolis journalist, is writing a personal memoir.

Sally Gross co-authored "Lifting the Veil on Intersexuality," an article in South Africa's Weekly Mail & Guardian in August. Sally, whose work in the anti-apartheid movement had kept her in exile for many years, has now teamed up with a national organization which campaigns on gay and lesbian issues in South



The past meets the future: intersex activist Mani Mitchell (right) is introduced to John Money (left) in New Zealand.

Africa, and is in the process of forming an Intersex Society of South Africa.

Mani Bruce Mitchell, the founder and director of the Intersex Trust Aotearoa New Zealand, reports that the organization this year won NZ\$15,000 of federal funding. Like more than one other intersexed person, Mani has chosen to change careers—as a therapist she will be able to provide the kind of help for intersexed families that would have made her own life so much easier. Mani will obtain registered counselor credentials this year, and continues her work toward the status of psychotherapist.

Like Mani, **Michael** is in the process of becoming a therapist. Michael completed his Ph.D. in 1998, and is now accumulating the supervised clinical experience that will earn him status as a therapist in California. His thesis is based upon open-ended, face to face interviews with five adults born with hypospadias, and includes an introductory chapter on his own experience. Until such time as Michael refashions his thesis into a book, photocopies can be obtained from ISNA.

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Speaking to medical students around the Bay Area wasn't enough for **Kristi Bruce**. Kristi, who works at Borders Books, knew that important new publications about intersexuality weren't easy to find. They might be shelved in the medical, psychology, gay/lesbian, feminist, or sociology sections. So Kristi took the initiative to organize a special display of Kessler's and Dreger's books on intersexuality "Sales increased noticeably with the display," says Kristi.

ISNA Michigan, headed by **Robin Mathias**, participated in three Pride events this summer, producing 100 additions to ISNA's mailing list. Parents are organizing, too. The Support Group for Parents of Intersexed Children had its first meeting in Detroit in July. Contact isnaMI@hotmail.com for information about either group.



Volunteers prepare for ISNA's participation in Michigan Pride 1999.

Would a group or church you belong to benefit from learning about intersex? You and your group can help ISNA reach new people. Here's how:

- ✓ Include a brochure about intersex in a mailing to the group's members. Often, this can be done without increasing the cost of postage and handling—the most costly part of a mailing.
- ✓ Write an article about intersex for your group's newsletter. We can provide samples for you.
- ✓ Talk about intersex and show *Hermaphrodites Speak!* at a meeting or event sponsored by the group. ■

Ethics makes inroads; media take note

Heralding the changes taking place in the medical establishment of Chicago, on June 20, 1999, the Chicago Tribune ran intersex at the top of its front page.

The paper devoted over 2,000 words and the front page lead to Louise Kiernan's discussion of intersex and recent challenges to harmful medical treatments of intersexed people. The article featured our own Angela Moreno, as well as two physicians at Children's Memorial Hospital of Chicago, the very hospital where in 1985 Angela's clitoris was cut without her consent.

After participating in a course on medical ethics with Tod Chambers of Northwestern University, pediatric endocrinologist Jorge Daaboul and medical ethicist Joel Frader, began to doubt the "standard of care" protocols which called for misleading patients and performing risky surgeries without the patient's direct consent. The Tribune article begins with Dr. Daaboul's recollection:

"With a Magic Marker and the swipe of a hand, Dr. Jorge Daaboul can demonstrate how he and other doctors used to lie to the families who anxiously awaited some explanation for the terrible, puzzling thing that was wrong with their children.

zing thing that was wrong with their children.

"Daaboul would draw a pair of X's. This, he would say, was what a normal female's sex chromosomes looked like: XX.

"Then, with the heel of his hand, he would erase the leg of one X. That, he would say, was what had happened to one of their daughter's X chromosomes. It was incomplete, unfinished...

"What he did not say is that the 'incomplete' X was not an X chromosome at all. It was a Y chromosome, the genetic marker for a male."

The article goes on to quote Dr. Daaboul: "Many of my colleagues do not believe we have been deceptive, and they would resent my saying we have been deceptive... But we have been deceptive."

When Cheryl Chase and Alice Dreger met Dr. Daaboul and his team at Children's Memorial Hospital in Chicago, he told them how his own experience of being "the only Hispanic kid in Ken-

tucky" gave him some insight into what it is like to grow up different. In spite of being trained to think otherwise, Dr. Daaboul now realizes the solution is not to pretend that difference can be erased. Instead, children who are "different" must be fostered and supported, their experiences taken seriously.

**"We have
been deceptive."**

Dr. Daaboul has just relocated to the Pediatric Endocrinology Department of Children's Hospital of

Oakland, California. He will carry to the west coast the message of reform. We are sure Dr. Daaboul's big heart, sharp mind, and lively spirit will help win more converts among his colleagues. ■

Make a wake-up call

The words of Drs. Hatch (next page) and Daaboul (this page) make clear that one of the best ways to change medical practice is for former patients to contact their physicians and tell them their experiences of their treatment. We realize this can be a frightening and frustrating experience, especially when your doctor may write you off as a "bad outcome," an "unstable personality," or, worse yet, may not bother to answer you at all.

But if you have the courage and the capacity to do so, consider contacting the medical professionals who treated you as a child. The best way to do this is to confirm your doctor's address and send them a letter. You might wish to enclose a copy of this newsletter. Tell your doctor exactly what worked and what didn't work for you, how you would like to see practice improved.

Even if you get no response or a negative response from your former "caregiver," remember that one drop is easy to ignore, but a flood isn't, and together we drops form a flood. ■



The Chicago Tribune carried a major story on the burgeoning controversy over social and medical treatment of intersexed people on its front page in June.

New paradigm Hatched

"This news (that the medical treatment of intersex needs major reform) is spreading like wildfire!" an Australian pediatric endocrinologist emailed to ISNA. In April of this year, Cheryl Chase (of ISNA) and Alice Dreger (of Michigan State University) teamed up for a whirlwind tour of Chicago's medical establishments. Ethicist-allies David Ozar of Loyola University and Tod Chambers of Northwestern University helped arrange meetings with interested professionals at Children's Hospital of Chicago, Northwestern University, Illinois School of Professional Psychology, and Loyola University Medical School.

At each of these venues, Alice and Cheryl presented stories and photos of intersexed people and their families, and engaged the audiences in a reflection on the past, present, and future of the medical treatment of intersex. They appealed to audiences to work toward the day when all intersexed people will be treated with honesty, respect, dignity, and informed consent. After several of the gatherings, clinicians approached them to share words of encouragement: "Your message has already reached a much larger audience than you realize."

Need evidence to back this up? After Cheryl and Alice finished their presentations at Loyola, Dr. David Hatch, a pediatric urologist at Loyola University Medical School, stood up to give his invited response. What a wonderful and welcome response it was! Dr. Hatch told those gathered, "My study of intersexuality has convinced me that some aspects of the intersex management paradigm I learned as a urology resident have undesirable consequences."

Reminding the audience of Loyola's mission, Dr. Hatch noted, "I am here tonight because I feel a responsibility to respond to the changes that are taking place in medicine in respect to intersexuality. I am here also because I am a member of the Loyola community, where we claim that 'We also treat the human spirit.'"

In his response, which forms the beginnings of a paper he plans to publish, Dr. Hatch outlined basic changes that he is calling for. Here are some excerpts:

"Parents need accurate information as soon as they can get it... They need to be told what is known and what has yet to be determined. They should be told that their child is intersexual and that prompt evaluation will be helpful in determining what the ramifications of intersexuality may be."

"Parents need to be given the opportunity to absorb and ponder all of this information and to talk it out with skilled and understanding professionals. Efficient management of intersexuality can prevent emotional trauma and needless confusion."

"I believe that it is entirely appropriate for surgeons to recommend and for par-

ents to consent to certain [medically indicated] surgical procedures in intersexual children."

"However, I see no clear benefit and potential harm in performing the surgical procedures of clitoral recession and vaginoplasty on infants."

"It is clear to me that physicians should not do anything that will impair assumption of any gender role should an individual wish to assume a role different from the one assigned at birth."

"No clear benefit in clitoral recession or vaginoplasty"

Dr. Hatch praised the work of ISNA members, saying "I firmly believe that many of the changes advocated by ISNA and others will provide valuable benefits to intersexuals. He then concluded on an upbeat and hopeful note: "So long as physicians are receptive to the voices of our patients and so long as we acquire and analyze short and long-term data regarding the outcomes of medical therapies we will be true to our Hippocratic charge." ■

Teach the teachers

Another way you can help the cause of intersexuals is to find out who in your area is teaching about sex, gender, and/or intersex, and to make sure they are aware of the importance of broadcasting the voices of intersexuals themselves.

Do you know a person teaching a college course on gender, a medical school class on endocrinology, a birthing workshop? Tell her or him about intersex, and suggest the following resources:

✓ The ISNA website (www.isna.org) includes a thorough bibliography, lists of recommended readings, and links to many other intersex websites.

✓ *Intersex in the Age of Ethics*, a "reader" containing 21 autobiographical and scholarly essays as well as many

non-pathologizing ("real people!") photos of intersexed people (see page 6).

✓ *Hermaphrodites Speak!*, a half-hour video of eight intersexed people sitting in a circle talking honestly about their lives and medical treatment (ordering information available at www.isna.org).

✓ Best of all, why not ask the teacher to invite a panel of intersexed people to come speak about their experiences? ISNA can help you arrange such panels.

The realization that intersexed people are real people changes many people's perceptions of us for the better. So help spread the word that non-pathologizing images of real, live, uncloseted intersexed people are available and should be used in place of medical textbook "horror show" images. ■

Growing acknowledgment of need for change

In the past year, the work of members of ISNA and other intersex advocacy groups around the world, along with allies in health care specialties and a variety of scholarly disciplines, has begun to create visible shifts in medical thinking.

In October 1998, University of Hawaii sex researcher Milton Diamond's keynote presentation to urologists at the American Academy of Pediatrics called for a moratorium on early genital surgery.

In January, Saunders' major new text "Pediatric Surgery and Urology: Long Term Outcomes" carried a similar call by urologist Justine Schober.

In February, the *Journal of Clinical Ethics* published a special issue devoted to the ethics of intersex treatment, with every contribution—including those by pediatric endocrinologist Bruce Wilson, urologist turned pediatric psychiatrist William Reiner, and pediatric urologist Justine Schober—calling for fundamental changes in the standard of care. The special issue has now been expanded and published as a book (see page 6).

In April, the annual gathering of the Lawson Wilkins Pediatric Endocrinology Society heard Claude Migeon of Johns Hopkins present initial findings from a follow-up of a handful of adults with partial AIS. He revealed that most of those assigned male had clearly male

identities and had fared quite well, contradicting the standard prophecies of doom. He acknowledged his regret to conclude that genital surgeries never produce perfect results, in either male or female assignment. Asked what sex assignment he would now recommend for infants born with PAIS, Migeon responded, "Ten years ago, I would have said raise them all as female, without any question," but today, "I have no answer."

Immediately after Migeon, Jean Wilson presented his careful search for a genetic determinant of gender identity in 5-AR and 17-beta. His conclusion? There is no such determinant. Some individuals raised female develop male identities, and some do not, even siblings who share the same genotype and are raised in similar circumstances.

The same day, urologists had gathered for a meeting called "Pediatric Gender Reassignment: A Critical Reappraisal." Though no intersex people were allowed to speak, by all reports the presentations dealt a major blow to surgeons' faith in the beneficence of the long-standing practice of early surgery; we have information that some attendees changed their practice immediately upon their return home.

In May, the *Journal of Pediatrics* carried an article by Bin-Abbas and the influential UCSF pediatric endocrinology duo

Grumbach and Conte, calling for an end to female assignment of those boys with small penises which result from pituitary deficiencies. An accompanying editorial by Van Wyk—also an elder statesman in the field—acknowledged that small penis may not preclude healthy male adjustment, and cautioning that "the complexity of female sexuality should not be underestimated."

Also in May, the *Journal of Urology* carried a report by Alizai's team at Leeds in the UK, titled "Feminizing genitoplasty for congenital adrenal hyperplasia: What happens at puberty?"

"I have no answer."

The authors found "disappointing results, even in the hands of specialists," including scarring

and clitoral atrophy, called for an end to some early surgeries, and acknowledged that psycho-sexual issues in intersex remain inadequately researched and poorly understood.

These are encouraging signs, but there is much more work to do. As doctors realize the need for meaningful mental health care and peer support, there will be a great need for trained counselors (currently almost non-existent) and for community based patient/family organizations.

By joining ISNA now you can help us work to make these resources available. We need your help! ■

Get your card!

Want to be a card-carrying hermaphrodite? Now you can! ISNA is now issuing personalized membership cards. See the enclosed registration card to learn how you can become a card-carrying Member, Hermaphrodite with Major Attitude, or True Hermaphrodite. You don't have to be intersexed, you just have to care! ■

Thank you, ISNA donors!

Thank you to the following people, each of whom has made a major donation (\$100 to \$1000) in the first three quarters of 1999: Al Barr Ph.D., Ann Blasing, Bill Byne M.D., Howard Devore Ph.D., Cindy Doherty, Jack Drescher M.D., Philip Gruppuso M.D. and Martha Manno, Isabelle Gunning Ph.D., Hale Hawbecker, Mark Holzbach and Dana

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Books!

Lessons from the Intersexed

Reviewed by Phil Gruppuso, M.D.

I recently purchased a book by Suzanne Kessler titled *Lessons From the Intersexed* (Rutgers University Press, 1998) that is worthwhile—in my opinion, essential—reading for pediatric endocrinologists. My interest in this area intensified last year when a teenage male pseudo-hermaphrodite who had been

assigned as a female gender when newborn—but who had always felt himself a male—was referred to me. I began focusing on the literature regarding gender self-identification, and on the pediatric endocrine practices that affect the long-term outcome in intersex individuals. The literature was voluminous, controversial and difficult to access.

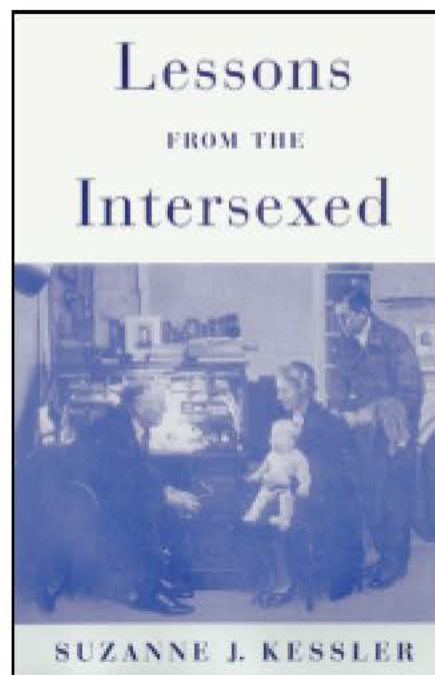
Kessler, a professor of psychology at Purchase College, SUNY, has done a wonderful job of bringing together the points of view of children, parents, physicians and psychologists. It was sober-



ing to see information compiled in one lucid text that so clearly brings into question the empirical basis for “standard” pediatric endocrine practice in this area.

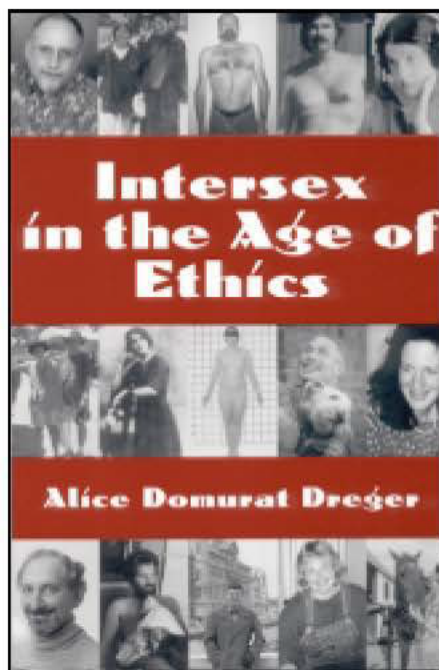
I wish I had read this book prior to my becoming involved in the care of the young person mentioned above. The historical and clinical facts, and the points of view offered in Kessler’s book, provided me with the reassurance to take an approach to intersexed patients that is quite different from what I learned while in training.

[The *Journal of Pediatrics* has accepted an article by Dr. Gruppuso, a professor in the Pediatrics Department of Brown University, documenting his experience with this patient, and calling for changes in medical practice. Ed.] ■



“Fascinating in what it tells us about the astonishingly weak empirical foundations upon which the medical orthodoxies of binary sex and gender are built.”

—Ruth Hubbard, Professor Emerita, Harvard University



Intersex in the Age of Ethics

Intersex in the Age of Ethics (University Press Group, 1999, 301-582-2200, www.upgbooks.com) marks the first time an entire volume has been dedicated to the exploration of the ethics of intersex treatment. It could not be more timely; professional conferences, gender clinics, and the popular media are abuzz with the controversy over how medicine and society should handle intersex and intersexuals. The volume will provide some much-needed perspective. The writings approach the issue of intersexuality and its treatment from numerous perspectives, including the personal, ethical, clinical, legal, anthropological, histori-

cal, sociological, and philosophical.”

—Alice Domurat Dreger, Editor.

“By incorporating the perspective of patients and their stories in its account, *Intersex in the Age of Ethics* does more than introduce the question of healthcare ethics in microcosm. It also leads the reader to examine the effect of ethical reflection on the lives of patients.”

—David T. Ozar, Loyola University of Chicago. ■