

ISNA Welcomes New Executive Director and Three New Board Members!

We are pleased and proud to announce that Monica J. Casper, Ph.D., an internationally recognized medical sociologist and biomedical ethicist, has been selected to head the Intersex Society of North America as its new Executive Director. Monica is the author of the award-winning and groundbreaking book, *The Making of the Unborn Patient: A Social Anatomy of Fetal Surgery*, which examines the controversial practice of operating on unborn fetuses. Monica's energy, commitment, and her expertise in dealing with health care advocates, doctors, and scientists are great assets for ISNA!

ISNA is also strengthening the leadership of people with intersex conditions in the board of directors with the promotion of Thea Hillman — author, performer, and intersex activist — to the position of Board Chair, and with the addition of intersex activists David Cameron Strachan and Esther Morris Leidolf to the board.

David attended his first ISNA meeting in 1996 and has been a leader and volunteer ever since. As a person with XXY sex chromosomes, David has written about his experience in *Hermaphrodites with Attitudes*, *Chrysalis*, and *Intersex In the Age of Ethics*. A retired master craftsman and former international school teacher, David brings to the ISNA board of directors a contagious enthusiasm for educating others about intersex.

Esther, currently a data manager for the Boston Public Health Commission, is the founder of the MRKH Organization, a support and networking group for women with the intersex condition MRKH. You may know her as the author of "The Missing Vagina Monologue" (use the search box to find it on www.isna.org). Esther brings to us her passion for intersex activism as well as the benefits of her years of experience in public health, grass roots organizing, and local service projects.

Our board is also honored to welcome Vernon Rosario, MD, Ph.D. Vernon is a Los Angeles-based practicing psychiatrist and medical historian noted for his outstanding scholarship in the history of sexuality and his award-winning leadership in the care of transgender youth and children with intersex conditions. Vernon's many publications include the books *Science and Homosexualities* and *The Erotic Imagination*.

ISNA is now happily ensconced in its new headquarters located in Seattle's University District just off of I-5. Our neighbors in the building include Planned Parenthood, a graduate student union, a chiropractor, a consultant on business relations in the Middle East, a therapist, a medical journal, and a host of other interesting organizations. Coffee shops and restaurants abound nearby, and we are just down the street from the Apple computer store, a graphic designer, and Kinko's. Our new address is 4500 9th Ave. NE, Suite 300, Seattle, WA, 98105. Please come by and see us if you're in the area!



Old and new: Cheryl Chase and Monica Casper work on transition plan.

Greetings from Executive Director Monica Casper

I want to tell you all how delighted I am to be leading ISNA into the next phase of its growth. Following in the footsteps of founding Executive Director Cheryl Chase is both daunting and inspiring. Cheryl is largely responsible for putting intersex issues on the map and she is an impassioned advocate — a tough act to follow! But because of her careful and successful leadership of ISNA and the current robust position of the organization, my job will be easier. Cheryl deserves huge applause for her efforts and for paving the way for those who follow.

There is a great deal on our agenda this coming year: our continuing work with the medical profession to change how intersex conditions are treated; the distribution of our excellent new video *First, Do No Harm: Total Patient Care for Intersex*; and ongoing public education campaigns. We also hope to expand our current base of support while forging new connections to women's health, children's rights, disability rights, and civil rights communities. As always, you can keep up and collaborate with us through our website, www.isna.org.

We have a terrific new office in Seattle (see article at left), a committed and talented Board of Directors, a growing and vocal presence among the medical profession and the public, and the organizational vigor to carry out ISNA's mission. We are quickly building relations in the Pacific Northwest with many potential allies, supporters, and funding sources, and we continue our work nationally and internationally. I am thrilled to be part of such a dynamic team working on important issues. Our network of friends and supporters — people like you! — is vital to our continued success, and I look forward to hearing from all of you.

Appreciating Founder Cheryl Chase

By David Vandertie

Editor's note: David produced this inspiring testimonial as part of the Cheryl Chase Appreciation Campaign, a year-long campaign aimed at honoring our recently retired founder, Cheryl Chase, and providing for the continued well-being of ISNA. We hope you will consider sending your own written appreciation of Cheryl and donations in her honor by writing to our new address (shown on bottom p. 1) or by going to www.isna.org/appreciation/.

I read the old letters I exchanged with Cheryl Chase, ISNA's founder, back in the summer of 1993 and I try to remember what it was like before ISNA, before there was any public discussion at all by and for intersexed people. We were alone then, caught in an isolation imposed by society and a misguided medical model. Not only was there no contact between people with intersex conditions, there was no hope of it. I believed the myth that most of us were handed: that hermaphroditism was so incredibly rare that we had no chance of ever meeting another like ourselves. I think the loneliness we experienced living in a world of binary gender exclusivity is hard for anyone to imagine.

Cheryl changed all that with an act of incredible courage. She broke the silence in a letter to *The Sciences* magazine in July of 1993. She announced herself and the Intersex Society to the world, and things have not been the same since. Reading her letter, a masterpiece that still thrills me, my world slowly, slowly, turned itself up on its head. I wrote to her. She called. We talked and talked and talked.

A world, once completely empty, started to fill with real people and real stories and very real feelings. Ideas and beliefs and feelings about who I was as a herm, things that I believed were unique to myself, my own intimate constructions, were discovered to be common ground between intersexed people. There was a pattern that linked us together, a pattern in the way we were born into the world, how we were treated and mistreated, the lies we were told by parents and doctors, and the lies we told

ourselves in order to survive. There were patterns too, that showed the strength and courage and creativity we cultivated as survivors. I was not alone, not anymore.

It is impossible for me to express how much this has meant to me. Even though my decision to live as myself, as an intersexed adult, with an intersex identity, has been very difficult at times, I feel better, happier, more integrated, more alive than was ever possible living by someone else's definition of who I was. I can only be who I am, and the further I stray from my reality, the more painful my life becomes. Cheryl's incredible labor, her beautiful obsession with intersex human rights helped create space for intersexed people to live in, as ourselves.

In 1992, as I started to talk about my intersex issues with my therapist for the first time, she looked for any information that may be "out there" for me to read. There was nothing. Nothing. Every time I struggled to tell my story to someone new, I had to start from scratch and provide all the information myself in one-on-one conversation. I couldn't give anyone even a single article to read that supported me or discussed the real issues of intersexed people. Now, thanks to Cheryl, I can point people to isna.org, or hand them a book or two, or let them watch one of many videos. Thanks to her, no intersexed person ever has to stand alone again.

How can I express the difficulty of bearing the wholly unnecessary and unreasonable burden intersex people carry in a culture that insists that everyone (and practically every thing!) be forced into a male or female pattern and identity? An insistence that means almost all of us will be subjected to very inhumane treatments meant to guarantee our conformity to a cultural ideal? How many people will ever appreciate our countless nights spent crying alone with no one to talk to, no one to give help or support or comfort? With no one to offer us hope that this cruelty will ever be stopped, much less acknowledged and healed?

When Cheryl sent her letter off to the editors of *The Sciences*, she started a process of openly talking about the cruelty that the current (at that time) medical model subjected us to and we have seen changes, we have been given hope. Though this cruelty is still

happening to many children every day in this country, this must eventually stop. When it does, it will be because the work that Cheryl started and nurtured, shared with and taught to many activists will finally open the hearts and minds of the "experts" and leaders to what people with intersex conditions truly need to live healthy and authentic lives.

Rated XXXY a Spectacular Success

Our October, 2002, San Francisco blow-out success, "Rated XXXY: An Evening of Erotica and Education Benefiting ISNA," drew hundreds of people and netted over \$4,000 to benefit ISNA! Performers included *solidad decosta*, Thea Hillman, Emi Koyama, Les Milstein, Shorona se Mbessakwini, Hida Viloría, and Fairy Butch (a.k.a. Karlyn Lotney).

Middlesex and the Limitations of Myth

By Thea Hillman



Editor's note: Lots of people have been asking ISNA board members what we think of Jeffrey Eugenides' new hit novel, Middlesex. The book, informed by ISNA's work and publications, mentions the Intersex Society of North America by name (the protagonist is even a member of ISNA), and Mr. Eugenides has said publicly that he hopes the book advances the intersex rights movement. It has certainly made many more people aware

of intersex, the complexities of life with intersex, and ISNA, and we are grateful for that! We asked our Board Chair Thea Hillman to share with you her own personal thoughts on the book and its buzz, and here they are.

People keep asking me about Jeffrey Eugenides' new novel *Middlesex* because the main character is considered a hermaphrodite and so am I. But really, neither of us is. Outside of myth, there are no hermaphrodites. It is physiologically impossible to be both fully male and fully female.

But you can be born with a mix or blending of male and female parts, known as "intersex," and indeed this is what Eugenides' protagonist Cal and I have in common. People with intersex conditions are those who were born with sexual anatomy that someone else decided isn't "standard" for males or females.

Unlike Hermaphroditus, the mythical creature who was both a man and a woman, people with intersex conditions are not magical. We're not even that rare. Every year in the U.S., approximately 1 in every 2,000 babies are born with an intersex condition, which makes intersex more common than Cystic Fibrosis. Intersex conditions include Congenital Adrenal Hyperplasia, Klinefelter's Syndrome, Androgen Insensitivity Syndrome, MRKH, and Gonadal Dysgenesis, among others. Why all the mystery and secrecy then? Because we're talking about genitals, here, and sex. And our intersex bodies have become collision sites for Western society's obsession with sex and fear of difference.

Intersex bodies are considered freakish because society has fallen prey to the myth that humans are sexually dimorphic, that is: all women look like X and are designed to have sex with men, while all men look like Y and are designed to have sex with women. Problem is, that's just not what happens in real life.

In real life, variations in genes, hormones, and maternal environments mean that some boys are born with very small penises or undescended testes, and some girls are born with enlarged clitorises or without a vagina. More and more people — including parents and doctors — are learning that our intersex bodies are just one of the many ways that human bodies vary. Unfortunately, many

people in hospitals with decision-making power consider our genitals defective, even though in most cases they are perfectly healthy.

Each day in the U.S., five babies born with intersex conditions are subjected to unnecessary plastic surgery on their genitals. It's standard operating procedure to treat an intersex birth as a psychosocial emergency and to perform cosmetic sexual surgery as early as possible. There's another myth that intersex will go away with "corrective" surgery. It doesn't. But sensation often does.

Yet many people, including many physicians who treat intersex, remain under the illusion that technology can and should fix everything, and that anything that's different should be corrected, regardless of risk. This belief keeps them from listening to real people with intersex conditions, many of whom challenge unnecessary surgeries. (None of us object to surgery that preserves health or life, but these surgeries are performed for social reasons, not medical ones.)

Sometimes I think they just don't want to hear the real stories. I get cynical and think, who wants the everyday details of someone's life when you can use people with intersex to fulfil erotic fantasies, narrative requirements, and research programs? People with intersex continue to be used to satisfy the interests of others: as scientific specimens, as naked teaching models for medical students, as literary metaphors, as gags for popular sitcoms, and lastly — where we at least might get a cut of the profits! — as circus freaks and peep show attractions.

Intersex has increasingly been in the public eye, due to the work of the intersex rights movement, led by the Intersex Society of North America. The result has been that Eugenides and others are now realizing how compelling the idea of intersex is. Problem is, few of them are actually talking to people with intersex. But we've been here all along and we have plenty to tell. What we have to say may shock and surprise you.

We're not actually all that different. We are women, men, and occasional alternative genders such as transgender — just like non-intersex people. We are straight, gay, married, single — just like non-intersex people. We like to decide what happens to our bodies and like to be asked about our lives, rather than told.

We've told our own stories in books, websites, newsletters, and videos. I can promise you they are far more moving and powerful than any fictionalized account. While the myth of Hermaphroditus has captured the imagination for ages, it traps real human beings in the painfully small confines of someone else's story.

What do you think of Middlesex? Let us know by writing to us at newsletter@isna.org or to the postal address shown on the bottom of page 1.

ISNA on the East

By Esther Morris Leidolf

I'm very excited about joining the Board of ISNA this year. ISNA has done a lot to open doors on the Northeast, and I am looking forward to walking through many of them, as often as possible.

Since follow-up data on intersex treatments is so limited, it is essential for adult patients to converse with medical professionals to keep our realities in their minds so they see us as people rather than cases. To that end, in March I will be participating in an educational program at Harvard Medical School. This is a great opportunity to make current information available to future doctors, and provide them with resources that the medical community doesn't usually consider.

I am also currently working on a pilot study that compares medical standards to quality of life in adults with intersex conditions. Anyone interested in participating in the study can contact me at info@mrkh.org. Although ISNA is not sponsoring this study, ISNA always encourages people with intersex conditions to speak out about their experiences and voice their opinions about how the treatment systems could be improved. (All contacts in this study will be kept confidential.)

I am also looking forward to presenting our views at the 13th Annual Gay, Lesbian, Straight Education Network (GLSEN) conference. Educating the educators about intersex is very important! I believe that most of the fear and panicked responses to intersex conditions are due to ignorance and incomplete education. Including intersex variations in sex-ed and biology classes could relieve some of that. People need to

know just how common and livable intersex conditions are.

Also upcoming...

- Look for growing signs of the truth about intersex at V-Day (“Vagina Monologues”) events all over the country this February, thanks largely to ISNA members Emi Koyama and Esther Leidolf. If intersex is still misrepresented or un-represented at your local performance, go to our

website to find out what you can do to remedy this before next year.

- Long-term members and supporters of ISNA Michael Walker and Howard Devore and ISNA board member Vernon Rosario will be participating in a comprehensive conference on hypospadias in Boulder, Colorado, in March, 2003.
- ISNA’s Executive Director Monica Casper has secured a place for information about intersex and ISNA in the next edition of the women’s

health bible, *Our Bodies, Ourselves*. This will give many more women and healthcare providers easy access to critical, accurate information.

- In May, 2003, at the invitation of Dr. Donna Caniano of Children’s Hospital in Columbus, Ohio, ISNA allies Drs. William Reiner and Jorge Daaboul will speak on an ethics panel with Alice Dreger at the American Pediatric and Surgical Association meeting in Florida.

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