



advocates for informed choice

NEWSLETTER SPRING 2010

our mission

An estimated one in 2,000 babies is born with reproductive or sexual anatomy and/or a chromosome pattern that does not seem to fit typical definitions of male or female. The conditions that cause these variations are sometimes called "intersex" or "DSD" (differences of sex development).

Advocates for Informed Choice (AIC) is the first non-profit organization in America formed for the express purpose of developing and using legal strategies to protect the civil rights of intersex children or children born with DSDs.

AIC works to engage parents, doctors, attorneys, and intersex activists in strategy discussions; stimulate legal dialogue about the fundamental rights of children with intersex conditions or DSDs; and employ traditional and non-traditional legal tools to ensure justice for children with intersex conditions or DSDs. AIC's efforts are grounded in a sense of respect and compassion for the children, parents, doctors, and intersex adults involved.

contact us!

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voices of experience

We want to use this space to share the voices of some of the many people who make up AIC. This time, we'll hear from Mani Bruce Mitchell, a long-time intersex activist, member of AIC's Board of Directors, and Director of Intersex Trust Aotearoa New Zealand.

I was a post-war baby. Though my parents were determined to put their shattering experiences of the second World War behind them, a far more intimate test began with my birth in 1953. My parents were kind and gentle people who found themselves without the tools to manage my birth, which was seen by my doctors as a crisis. I was an intersex



baby and it was not clear what gender I should be assigned. The doctors, who my parents trusted and respected, decided I was a baby boy. I was sent home to rural New Zealand as their son. A year later my gender was changed to female. At the age of eight I had genital surgery and various other procedures to feminize me. My parents were told to keep me secret, keep me safe. But however safe I was the secrecy succeeded in filling me with an indefinable shame I carried with me for years. In my early 40's, after a period of reflection, learning, repair, and decision-making, I retrained as a therapist. I made a clear decision that I could not change my past but I could manage

my old wounds, move forward with grace, and work for change. I now know everything was done with loving intention, without malice, and yet I live every day with the brutal consequences of those well-aimed but poorly conceived intentions. But I do not live in silence. I choose to be visible, to be out as an intersex person, with the understanding that the language available to us all fails to describe who I joyfully am. If my own, and others', visibility is key to education, then a strong advocate is critical to improving standards of care for children born intersex. Very few organizations are working to create positive change for intersex people, their families, and their caregivers. I am not aware of another organization looking at the intersex issue through legal eyes. AIC is a well-credentialed, rigorous, ethical, and qualified group of impressive humans, and I am honored to work with them to support a population which continues to require a defender.

changing lives

More than two years ago, AIC was approached by a woman from a small African country who had just given birth to a child with an intersex condition. In her culture, such a birth can be taken as a sign of witchcraft and she was deeply afraid that her family would find out and harm her or her child. She managed to hide the child's atypical genitals for some time, but eventually her family members did find out and her fears were realized. With her life in danger, she fled to the United States. She arrived in New York City, with no family or friends she could turn to for help. Again, she contacted AIC, and we were able to connect her with a network of support. We helped her find housing, expert medical care for her child (who had health issues in addition to his DSD), and funds to support transportation. We facilitated her connection to other parents of children with similar conditions who could help her come to terms with her feelings and sympathize with her fears. Through an organization called Immigration Equality, we met David Ernst at White & Case, LLP, who offered free legal representation. AIC helped locate experts who could testify on conditions facing children with DSD/intersex conditions in her part of the world, and helped her immigration attorneys understand the medical issues her child faced. Just last month, we learned that the asylum claim has been granted. She and her child will be able to stay in the United States.

*"Thank you for all you are doing for us...
Now I have hope."*

– Mother of an intersex child recently granted asylum



since last we spoke...

- In addition to AIC's frequent columns in *Endocrine Today*, executive director Anne Tamar-Mattis recently co-authored an article on shared decision-making and genital surgery. The article has been accepted for publication by *The Journal of Pediatric Endocrinology & Metabolism*. We look forward to seeing it in print by year's end!
- AIC will be co-presenting the feature film, "The Last Summer of La Boyita" (El Último Verano De La Boyita) at the San Francisco International LGBT Film Festival. Screenings are scheduled for June 21 & 24. For more info visit www.frameline.org/festival.
- After four fantastic years under the fiscal sponsorship of Lambda Legal we are proud to announce we have almost completed the process of becoming an independent 501(c)(3) nonprofit corporation! Thanks to Alyson Tufts of Reed Smith LLP, for her pro bono representation.
- AIC offered legal information and referrals to 12 individuals and families, and led a workshop at a parents' conference for Hypospadias/bladder exstrophy.
- Anne Tamar-Mattis led Grand Rounds and other presentations for 16 medical and legal audiences.
- We developed and published a Spanish translation of our 'Know Your Rights' pamphlet. (online at www.aiclegal.org)
- We recruited many wonderful volunteers and interns: bookkeeper Karmen Kohl; medical student intern David Posner; legal interns Christina Shea, Skylar Curtis, Jacqueline Latteri, Kate Greenberg, and Tatiana Filippova; and Yale LGBT Law Clinic interns William Moon, Jake Lucchi, and David Lebowitz. A warm thank you to all!

"I am honored to be associated even in a small way with such a thoughtful and effective organization."

– Shannon Minter
Legal Director, National Center for Lesbian Rights (NCLR)

support aic

Your support is crucial to AIC's success. Your contribution will help us travel to give educational presentations to medical providers, produce informational materials for parents, improve our website as a resource for the community, and offer support to parents.

Through our fiscal sponsor, Lambda Legal, we are a tax-exempt 501(c)(3) organization. You can send donations to Advocates for Informed Choice, 502 East Cotati Ave #676, Cotati, CA 94931. Donation checks should be made out to "Lambda Legal" with "Restricted to AIC" in the memo line. Together, we are making a better world for children with DSDs or intersex conditions!

aic advocates on behalf of mothers of children with CAH

AIC has joined with bioethicists, researchers, doctors, and intersex/DSD activist organizations in a campaign calling for a halt to the experimental and risky practice of treating pregnant women who may be carrying a child with CAH (a DSD/intersex condition) with the steroid dexamethasone in order to prevent genital masculinization and "tomboyish" behavior without appropriate informed consent or human rights protections. AIC has taken this position because we believe that children born with atypical genitals and their mothers deserve the same protections that other families enjoy. Our concern is well-founded: we have already been informed that two federal agencies have opened investigations into the practices of a leading researcher who may have violated rules for human subject research. For more information, see www.fetaldex.org.

healing words: aic negotiates written apology from major hospital

Last year, AIC was approached by a woman with CAH who wanted our support. She was seeking apologies from her former doctors for harm she had suffered as a result of old treatment methods now recognized to be less than ideal. After almost one year of negotiations with AIC, the major teaching hospital which had treated her throughout her childhood issued an extensive written apology to our client. Her doctors had always done their best. However, the hospital recognized that she was harmed by years of secrecy, stigma, and excessive display of her body, and they offered a sincere expression of regret. To our knowledge, this is the first such apology. Recently, we also received an apology from the doctor who supervised our client's treatment throughout her childhood. He is widely acknowledged as a leading figure in this field. These path-breaking providers have taken a vital step. When doctors express regret for harm caused by medical treatment – in spite of their best efforts – healing becomes possible for both doctors and patients.