



**advocates for
informed choice**

**NEWSLETTER
FALL 2007**

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a new name

The Institute for Intersex Children and the Law is nearing its first birthday, and we have a lot to celebrate! In just one year we've built a national network of advocacy groups, legal and medical experts, parents and allies, all interested in supporting children born with differences of sex development, or DSDs (also known as intersex conditions).

We've mapped out a plan for promoting the rights of these special children, and we are beginning to attract the attention of medical professionals and hospital risk management departments. We've also had great success in our fundraising endeavors. For our first year of operations, we have raised over \$60,000, including grants from Equal Justice Works, the Small Change Foundation and the Gill Foundation.



directors note

As our plans take shape and our networks grow, we are listening carefully to the many different groups who care about the future of children with DSDs or intersex conditions. After extensive conversations with stakeholders, we have decided to change our name to better reflect the spirit and mission of our organization. Our new name will be Advocates for Informed Choice (AIC). Our goal remains the same: promoting the rights of children with DSDs or intersex conditions and their families.

This change acknowledges the fact that there is a wide diversity of opinion about what is best for children born with DSDs or intersex conditions, and that these differences extend even to such basic matters as what language we will use to describe affected children. The new emphasis on informed choice in our name grows from AIC's conviction that more information, and more sharing of information, is critical if we are to understand how best to support children with DSDs or intersex conditions. In order to have a complete picture, we need to listen to all the many stakeholders with unique perspectives on what life is like for these precious children: their families, adults with similar conditions, medical caregivers, mental health specialists, and the children themselves. Our new name and our usage of both "DSD" and "intersex" reflect our commitment to listening with compassion and respect to all of these different groups as we work to promote the rights of affected children.

Another sign of AIC's growth is this newsletter. This first edition of what will be a bi-annual publication offers a way for AIC to stay in touch with the many stakeholders who have invested in our work. Read on to hear about all the exciting things we are doing!

our national roundtable

A historic event took place in February 2007. Recognizing that a community-based legal approach must involve both legal experts and community members, AIC convened the first-ever National Roundtable for legal strategists, medical experts, parents, and leaders in various intersex communities to engage in dialogue. This diverse group spent three days in discussion about the needs of children born with DSDs or intersex conditions and possible legal strategies to address the problems we identified. The result of this historic meeting is a legally sound plan for action that addresses shared priorities.

This plan includes improving the process of informed consent, designing a medical education campaign, addressing the rights of children with DSDs or intersex conditions in foster care, and educating parents about their children's privacy rights. The AIC National Roundtable also created a national network of professionals and community members all committed to promoting the rights of affected children. This meeting was a milestone in the journey to improve conditions for children with DSDs or intersex conditions.

*I thank you – as the mother of two girls with
AIS – for your hard work to advocate for them.*

– Dr. Arlene Baratz



getting the word out!

AIC is already beginning to draw attention! In April, the Journal of Pediatric Endocrinology and Metabolism printed letters from Executive Director Anne Tamar-Mattis and Advisory Board members Milton Diamond, Ph.D, and Dr. Arlene Baratz. The letters, written in response to an editorial, outlined parents' rights to complete and accurate information and cautioned clinicians against reacting to parents' distress with excessive optimism when discussing infant genitoplasty. In September, Anne will be conducting a workshop at the annual conference of the Gay and Lesbian Medical Association on the legal aspects of providing care to children with DSDs or intersex conditions.

We are continuing to build new connections. AIC is reaching out to organizations serving parents of children with DSDs or intersex conditions. We have also joined a national network of foster care providers, where we are available to give information and referrals to providers who care for affected children.

aic can help

AIC was contacted recently by a social worker who was looking for support for Lucía,* the mother of a child born with congenital adrenal hyperplasia (CAH). Lucía spoke only Spanish, lived in a rural area, and relied on Medicaid to pay her child's medical bills. Her baby was only a few weeks old, and she felt pressured to schedule genitoplasty right away. Lucía was uncertain that surgery was right for her child, and felt she was not getting complete answers to her questions from her medical providers. AIC was able to clarify Lucía's rights to full information and to make medical decisions without pressure. We also explained that she had the right to refuse elective procedures without risk of losing access to life-saving care her child needed. The social worker located a sympathetic gynecologist who could explain the options, and AIC was able to find a Spanish-speaking adult who had a condition similar to the infant's. This person was willing to share her story with Lucía, and also to provide translation in her conversations with medical providers. Through AIC's work, this mother gained access to crucial support and legal and medical information as she worked her way through a challenging situation.

** Not her real name*

are you accepting donations to make this happen? how do I make out the check, and where do I send it?

– anonymous intersex person

upcoming projects

As we move into our second year, AIC will be unrolling some exciting projects. Efforts will center on strengthening the informed consent process for parents making decisions about genital surgery and hormonal treatment on behalf of young children. We will be surveying parents and affected adults and talking with doctors, working to identify what parents need to know to make fully informed decisions. This information will help us educate clinicians about ways to improve communication and reduce legal liability by making sure that parents fully understand the risks and unknowns of these procedures. We are still in the process of designing our survey, but be sure and look for it on our website in coming months!

We will also be designing informational guides and decision-making aids to give parents access to a range of medical opinions as well as insight from adults who have lived with conditions similar to their children's. Other goals include advocating for children with DSDs or intersex conditions in the foster care system, addressing issues of school accommodation or teasing, and promoting the privacy rights of affected children and families in medical settings.

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 like Lucía. Through our fiscal sponsor, Lambda Legal, we are a tax-exempt 501(c)(3) organization. You can send donations to Advocates for Informed Choice, PO Box 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!