



**advocates for
informed choice**

**NEWSLETTER
SPRING 2008**

ADVISORY BOARD

Hazel Glenn Beh

Professor of Law, University of Hawaii

David Cameron

*USA Spokesperson for Human Rights,
Organisation Intersex International;
living with Klinefelter's Syndrome and
XXY chromosomes*

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School of Medicine*

Nancy Ehrenreich

Professor of Law, University of Denver

Jamison Green

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School of Law*

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Lesbian Rights*

Shannon Minter, Esq.

*Legal Director, National Center for
Lesbian Rights*

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New Zealand*

Cole Thaler

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Project, Lambda Legal*

Peter Trinkl

Board President, Bodies Like Ours

Wenona Whitfield

*Professor of Law,
Southern Illinois University*

Anonymous

Parent of children with AIS

Anonymous

*Living with Congenital Adrenal
Hyperplasia*

Anonymous

*Living with Androgen Insensitivity
Syndrome*

Organizational affiliations given for
identification purposes only.
Advisory Board members serve in
their individual capacities.

CONTACT US!

Advocates for Informed Choice

P.O. Box 676
Cotati, CA 94931
Phone: (707) 793-1190
director@aiclegal.org

visit us online at
www.aiclegal.org

compassion and advocacy

I wanted to take this opportunity to say a little about AIC's mission, and how it relates to the day-to-day work we do. The final sentence of AIC's mission statement is "These activities are grounded in a sense of respect and compassion for the children, affected adults, parents, and doctors involved." It's unusual for a legal organization to have the



directors note

term "compassion" in its mission statement. But AIC believes that the law, properly used, is a tool for achieving justice; and that justice, properly understood, has compassion at its heart.

Legal advocates have always had an important role to play in protecting the most vulnerable members of society, such as children with intersex conditions or DSDs. Parents, doctors, mental health professionals, affected adults and family members all care deeply about protecting these children. However, the historical treatment of children with intersex conditions or DSDs and the reality of society's intolerance of difference has created so much pain and anger that these different groups of stakeholders have had difficulty in communicating with each other. Recognizing that all of these groups have the best interests of children at heart, AIC believes that building bridges between them is a crucial part of improving care for children with intersex conditions or DSDs. So, while we are clear that our constituents are the children, we maintain a constant focus on respectful compassion for all those who care for the children we serve.

check out our improved website!

We've updated and improved the AIC website -- adding new resources for parents, a bibliography, and more community links. Soon we'll be announcing the debut of the AIC Bulletin Board, a forum for parents, youth, affected adults, medical professionals, scholars and attorneys to share information and ideas about how best to protect the rights of children born with DSDs or intersex conditions. We'll also be posting more information for health professionals about meeting legal requirements for informed consent and protecting privacy. Go to www.aiclegal.org to see what it's all about.

current projects

There's a lot going on at AIC right now. We're working with schools on improving policies for inclusion of children with DSDs or intersex conditions. We're coordinating with medical providers on creating legal protocols for informed consent for pediatric genitoplasty. This summer, AIC will be reaching out to parents' organizations and support groups, asking for input into these guidelines and offering legal information. All of these projects will improve the lives of children with intersex conditions or DSDs, and they are just the beginning.

*Although the work that we do today ...
cannot undo the past ill treatment of intersex
people, I believe that future generations will
have a better life. I appreciate the work that ...
Advocates for Informed Choice is doing in the
area of the legal rights of intersex children.*

– Anonymous Intersex Person



aic can help

This winter, AIC was contacted by the parent of a child with a DSD who had concerns about protecting the privacy of her child's medical records. They lived in a small town, and she was concerned that a confidentiality violation could lead to gossip. AIC explained her child's medical privacy rights, including the strong new protections offered by the federal Health Insurance Portability and Accountability Act (HIPAA). We also gave her some strategies to ensure those rights were protected. We've summarized that information into a pamphlet to help other parents advocate for their children's medical privacy, available at www.aiclegal.org/publications.html.

summer law interns

AIC has recruited three full-time legal interns to help with our operations this summer. A big welcome and thank you to Mary Alice Hiatt, Mikyla Miller, and Mark Carlson!

reaching out

Word is spreading about AIC's informative presentations! We have led workshops or discussions for the family practice residency program at Sutter Medical Center of Santa Rosa, bioethics students at University of the Pacific McGeorge School of Law, and three University of California Law Schools -- Davis, Hastings and Berkeley! Topics have included bioethical perspectives on treatment of children with intersex conditions or DSDs, legal requirements of informed consent, surrogate decision-making, legal protections for medical privacy and ensuring access to healthcare. AIC can provide speakers on these or other relevant topics to medical providers, law or medical schools, professional conferences, parents' groups and others. Please contact us for more information.

aic founder honored

Echoing Green provides seed funding in the form of fellowships for social entrepreneurs who are dedicated to addressing the root causes of societal challenges. Recognizing the importance of establishing a framework of rights for children with intersex conditions or DSDs, Echoing Green has named AIC's founder and Executive Director, Anne Tamar-Mattis, as a finalist for their 2008 fellowship. Selected from a pool of nearly 1,500 applicants, Anne is now one of 30 finalists competing for 20 two-year fellowships. Winners will be announced around the end of May, so check our website for updates!

We received extremely positive feedback regarding your presentation. You really went in-depth on very important issues in an ... accessible manner, and for that, we are so grateful. We hope to see you at UC Davis in the near future.

– Judy Sanchez

Community Intern, LGBT Resource Center, UC Davis

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, 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!