



Advocates for Informed Choice uses innovative legal strategies to advocate for the civil rights of children born with variations of reproductive or sexual anatomy.

The project:

- Engages parents, doctors, attorneys and intersex activists in strategy discussions;
- Stimulates legal dialogue about the fundamental rights of children born with intersex conditions or DSDs; and
- Employs traditional and non-traditional legal tools to ensure justice for children born with intersex conditions or DSDs.

These activities are grounded in a sense of respect and compassion for the children, parents, doctors and intersex adults involved.



advocates for
informed choice

For more information on INFORMED CONSENT
and PRIVACY RIGHTS, please contact us at:

Advocates for Informed Choice
P.O. Box 676 Cotati, CA 94931

(707)793-1190
director@aiclegal.org
www.aiclegal.org



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informed choice

know your rights

a guide for parents

www.aiclegal.org • (707)793-1190

know your rights

Finding out your child has a DSD can be a confusing and overwhelming experience. We understand that as a parent, you want to do your best to ensure that your child has the care and support that will enable them to grow up happy and healthy. We also understand that you want to make sure your child is receiving the best care possible. While the weight of this responsibility may be heavy, knowing your rights can lighten your load. This pamphlet is designed to give you a clear perspective on what rights you have when advocating for your child.

in general

You have the right...

- To receive considerate, respectful, and compassionate care regardless of your or your child's age, gender, race, national origin, religion, medical condition or disabilities;
- To be treated as a partner in making decisions about your child's care;
- To consideration for your personal beliefs and values;
- To responses to your requests, needs, and concerns;
- To request a language interpreter if necessary;
- To ask for protective and advocacy services in cases of abuse or neglect.

you have options

If you feel that your rights or your child's rights have not been respected, you can:

- Speak to your child's doctor or nurse;
- Request a consultation with a patient advocate or ethics committee;
- Request a different doctor;
- File a grievance with the hospital or with state or federal regulatory agencies'
- Contact AIC for more information.

right to informed consent

You have the right...

- To information that is complete and understandable;
- To be told about the specific nature of your child's condition;
- To be told why your doctor is recommending a specific treatment;
- To be told of evidence supporting the recommended treatment;
- To be told of evidence not supporting the recommended treatment;
- To receive information about the possible risks and benefits resulting from the recommended treatment;
- To be told about possible alternative treatments including non-treatment;
- To receive information about the risks and benefits resulting from possible alternative forms of treatment and non-treatment;
- To make decisions free from coercion and pressure;
- To have adequate time to make your decisions;
- To be informed if your child's doctor is considering your child as part of a medical research program;
- To decline to participate in or withdraw from a research project without fear that your child's care will be compromised;
- To refuse treatment that is not in the best interest of your child.



the right to privacy

You have the right...

- To full consideration of privacy and confidentiality in care discussions, examinations, and treatments;
- To expect that your child's condition should not be the subject of gossip and only discussed when necessary for treatment;
- To accompany your child during examinations;
- To know of the psychological consequences unnecessary exams may have on your child;
- To only allow exams of your child that are necessary for treatment;
- To limit persons present during examinations to only those individuals necessary for treatment;
- To see or get a copy of your child's medical records and have the information explained to you.

The privacy of your child's medical records is protected by a federal law, the Health Insurance Portability and Accountability Act of 1996 (HIPAA). You may have additional rights protected by state law, professional guidelines, or regulatory agencies.