



KNOW YOUR RIGHTS

A GUIDE FOR PARENTS

Finding out your child has intersex traits (sometimes called Differences of Sex Development or 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 while advocating for your child.

Rights 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.



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.



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 will only be 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.



KNOW THAT 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 interACT for more information:

info@interactadvocates.org

This pamphlet offers general information only and is not intended to provide guidance or legal advice regarding anyone's specific situation. Please bear in mind that this is an evolving area of law in which there is bound to be uncertainty. Do not rely on this information without consulting an attorney or the appropriate agency.



interACT uses innovative legal and other strategies to advocate for the human rights of children born with intersex traits.

interACT 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 played an important role in protecting the most vulnerable members of society, such as children born with intersex traits or variations of sex development.


Advocates for Intersex Youth

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