

# 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.



## 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.





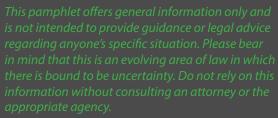


## KNOW THAT YOU HAVE OPTIONS



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



**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.



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