



## Clinical Research Bill of Rights

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Boston Children's Hospital is committed to respecting and protecting the rights of its patients and families. We strive to provide care that is sensitive to cultural, racial, religious and other differences. This bill of rights provides information about our commitment to you, and your responsibilities as a member of your child's health care team.

You and your child have a right to information about:

- why this research is being done and who is responsible for the research;
- what will happen to your child during the study;
- whether any of the procedures, drugs or devices are different from standard practice;
- the important risks, side effects, and discomforts of the things that will happen to your child in this study; also if there are things that are unknown that could happen.
- the benefits from taking part in the study;
- other treatment choices and their risks and benefits; and
- medical treatment in case of complications;
- possible compensation or reimbursement for you/your child's time to participate.

You and your child also have the right to:

- refuse to take part in the study;
- change your mind about taking part after the study is started. This decision will not affect your child's right to the usual care not related to study.
- receive a copy of the consent form;
- be free of pressure when deciding whether to take part;
- ask questions concerning the study, both before and during the course of the study;
- talk with an individual who is not involved in the research about you as a research subject and about any research related concerns or complains. You may call (617) 355-7052.

For more information about patients' and families' rights and responsibilities, please refer to [\*\*Boston Children's Hospital Patient and Parent or Legal Representative Rights and Responsibilities\*\*](#). This information is available in the office of Patient Relations.

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A [\*\*Spanish\*\*](#) version of this education sheet is available from your provider.