

Paediatric Urology Research Registry (PURR)

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About the Research Registry

As in all areas of medicine, the basis for the best care for paediatric urology patients is still not completely known. Very little quality clinical paediatric urology research, based on planned data collection, is available. Most is based on information collected before a study question is designed. This often leads to lesser quality results. This has long prevented or slowed meaningful advances in many areas of health care.

The patient population of the Division of Urology at The Hospital for Sick Children (SickKids) is one of the largest for paediatric urology in the world. As such, this group of patients presents an important opportunity to generate meaningful clinical studies to move the field of paediatric urology forward. Such forward progress has the potential to improve diagnosis of urologic conditions, responses to care, and the medical and surgical outcomes in urologic function.

We wish to use your child's past and future medical urology data, and other relevant medical data as necessary, for any future urology research study questions we develop. We wish to include all 12,000 patients coming to the Paediatric Urology Clinic annually in this effort.

This collection is called the **Paediatric Urology Research Registry (PURR)**. We will still require Research Ethics Board permission before proceeding with any specific future studies coming from this registry.

Participation in PURR

You will be asked to participate when you come to clinic but you can also print a copy for yourself here, to peruse and bring a signed copy with you on your clinic visit.

- - [Parent / guardian consent form](#)
 - [Independent consent form](#)
 - [Parent letter](#)

Paediatric Urology Research Registry (PURR) FAQs for Parents and Patients

What is a Research Registry?

It is a database or a record of patients' /and or parents' consents.

Why should I consent?

Consent is completely voluntary. You do not have to consent. However, your/your child's

medical information, along with other children's data, can help us answer research questions about why urologic conditions happen.

What can I consent to?

You can consent to being part of the paediatric urology research registry which permits the use of your/your child's urology data for research. If you consent being part the registry, you can determine the level of your involvement by further consenting to three options.

How can I determine the level of involvement?

You can determine the level of your involvement. in several ways. You can further consent to:

- A) Your/child's anonymous medical data be pooled with data from other children's hospitals.
- B) Allow permission to be contacted in the future if there is some information missing in your child's record.
- C) Be emailed about research studies using data from PURR.

Will my/my child's information be kept safe?

Absolutely. Your information will be stored in password protected, encrypted computers secured under lock and key, at the Hospital for Sick Children. It will receive the same level of protection as the information in your medical record. Remember, we are not collecting any additional information, but asking permission to use data already in your secure medical record for research.

Who will have access to my child's medical data?

Only a few individuals - researchers and data managers - authorized by the Research and Ethics Board at SickKids.

What happens if I don't consent?

We will note your response so that we do not approach you in the future. You will receive and can expect to receive exactly the same care as someone who did consent.

What if I want to become part of the registry at a later time?

You can approach any of the nurses on your next visit, or contact the data manager at martha.pokarowski@sickkids.ca.

What if I change my mind and don't want not to be a part of the registry at a later time?

You can send an email to the data manager at martha.pokarowski@sickkids.ca and you will promptly be removed from the registry.

What if my child is too young to provide consent?

Parents/Guardians can provide consent on behalf of the child. If your child is old enough to understand the registry, they can also sign the assent form.

What is an assent form?

It's a consent form for young kids who can understand the registry.

Who can I contact if you have questions about the registry?

You can email martha.pokarowski@sickkids.ca about any questions.