Who can participate?

You and your child may participate if:

Your child has CKD and receives care at BCCH.

Your child is between the ages of 6-18 years old.

Your child has at least one sibling within the same age range also willing to participate.

OR

Your child received a solid organ transplant and receives care at BCCH.

Your child is between the ages of 6-18 years old.

Your child has at least one sibling within the same age range also willing to participate.

Questions?

Contact our research team!

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Research Staff sotresearch@bcchr.ca

Research informs care.
Clinical care informs research.

Approved by the UBC Research Ethics Board: H23-00561

Find more info on:



Principal Investigator: **Dr. Tom Blydt-Hansen**

The Family Study

Chronic Kidney Disease (CKD) Clinic

Multi-Organ Transplant (MOT) Clinic



Background

Young people living with CKD and their families deal with very challenging situations on a daily basis. Past research has shown children with chronic illnesses are at risk for a wide variety of difficulties in multiple areas of functioning, but the specific context in the CKD population is still unknown. The wellbeing of the parents and siblings of young people with CKD remains under-studied.

We also know that solid organ transplant (SOT) recipients and their family members endure many stressors on a regular basis.



What is the purpose of the study?

We are hoping to learn more about the experiences of CKD patients, as well as SOT recipients, and those of their siblings and parents.

Throughout this study, we are hoping to better understand the psychosocial difficulties, resilience and post-traumatic growth of young people with CKD and young people with SOT, and their family members.

Where is the study happening?

The study takes place at BC Children's Hospital (BCCH) in the CKD and MOT clinics.
There is also an online option.



What do I need to do?

- Each family member (caregivers, young people, and their siblings) will complete questionnaires.
- Each family member will also participate in an open-ended interview and complete an ecomap activity.
- Each will be encouraged to tell small stories about themselves and/or their family members, relating to their CKD or SOT experience.

