Steps for children and families interested in participating in the CAUSES Research Clinic

Families who are interested in participating in the CAUSES research clinic are given an information sheet and invited by the child's physician to contact the CAUSES team.

When the CAUSES team is contacted by the family, the team obtains the family's consent to review the child's medical records.

Enrollment:
If enrollment in the study is appropriate for the child, the CAUSES team obtains the family's consent to participate.

The child's physician is updated about their participation.

An appointment is set up between the family, a CAUSES genetic counsellor and a clinical researcher at BC Children's Hospital.

After the appointment, blood samples are drawn from the child and both parents for genome-wide sequencing.

Genome-wide sequencing is conducted and the results are analyzed.

A meeting between the CAUSES research team, the child's treating physician, and other laboratory and pediatric specialists is conducted to review and discuss the results.

Once the most appropriate next step for the child is decided, the family, genetic counsellor and treating physician meet to discuss the results.

Diagnosis

If the child's condition has been diagnosed, a new management plan is started.

No Diagnosis

If the child's condition has not yet been diagnosed, the family is provided with options for additional research.