

CONFIDENTIALITY

- Your confidentiality will be respected according to the **Canadian Personal Information Protection and Electronic Documents Act** (PIPEDA S.C.2000c.5).
- Your file will be assigned a unique **ID number** that cannot be traced to your identity.

QUESTIONS ABOUT THE REGISTRY

If you have any questions about the registry, you may visit our website at www.fhcanada.net.

You may also contact the **national coordinator**:

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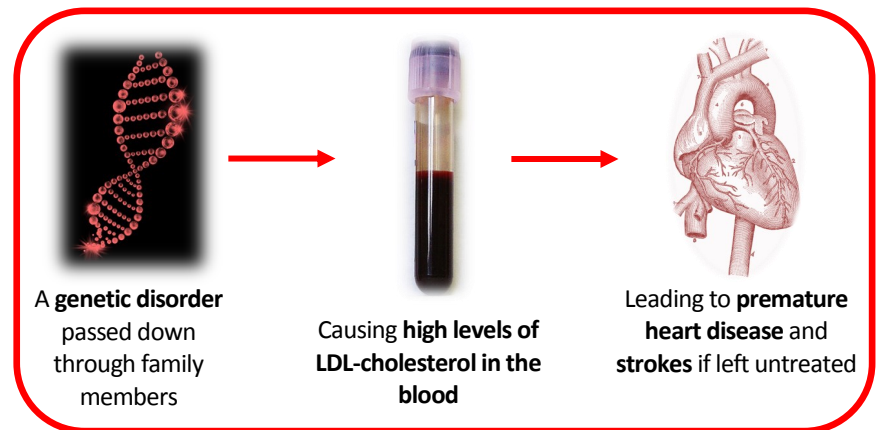


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WHAT IS FAMILIAL HYPERCHOLESTEROLEMIA (FH)?



WHAT IS THE FH CANADA REGISTRY?

- A **registry of subjects** with a diagnosis of FH and other severe lipid disorders in Canada

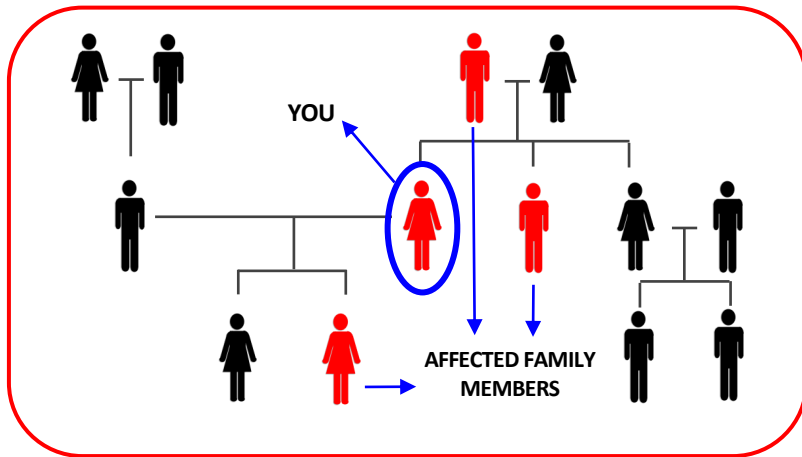
AIMS OF THE REGISTRY

- Improve the **detection** and **management** of individuals and families with FH and other severe lipid disorders in Canada
- **Lower** their high blood cholesterol and **prevent** early cardiovascular diseases

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STRATEGY OF THE REGISTRY

We will use the method of **cascade screening** which involves testing of lipid levels in all primary, secondary and third-degree relatives of the family member diagnosed with FH.



WHAT ARE THE POSSIBLE BENEFITS OF PARTICIPATING?

- **Early diagnosis of FH** particularly of family members who may not yet know they have FH
- **Better management** of high cholesterol levels
- **Prevention** of heart disease in patients with FH
- Access to **new medications** as part of clinical trials



WHAT DOES THE REGISTRY INVOLVE?

MEETING WITH THE SITE PRINCIPAL INVESTIGATOR AND THE SITE STUDY COORDINATOR

CONSENT FORM
Reading and signature

PATIENT QUESTIONNAIRE

You will be asked about your family history of high cholesterol, your personal medical history and use of lipid-lowering medications.
We will ask your permission to review your health records for relevant data on past medical history.

BLOOD TEST

We will be testing your cholesterol and sugar levels in the fasted state. The lab will take about 15 mL (1.5 tbsp.) of blood.
With your approval, a sample of blood plasma and DNA will be kept at the clinic.