

## How will information in the registry be used?

Medical information will be pooled in a computer database together with information from other families affected by Rett syndrome.

Information will be collected as frequently as once per year to enable researchers to understand how the disease impacts affected individuals over time. Researchers may use the information for the following:

- To plan their studies
- To learn new things about Rett syndrome
- To improve clinical care and disease management for individuals affected by Rett syndrome
- To improve the delivery of health care services needed by people with Rett syndrome.

Information from the registry may also be combined with that of other registries around the world to better inform the international research community about the disease and about Canadians with Rett syndrome.



The registry will also collect identifying information. This includes the full name of the affected individual, their birth date, their province of residence, and some contact information. This information is collected for the following reasons:

- To ensure that there are not duplicate records on a person in the registry.
- To contact your family if you qualify for research opportunities and have indicated you are interested in them.
- To contact your family to obtain regular updates to the medical information on the person with Rett syndrome.

Your identifying information will never be shared.

## How do we join the registry?

To join the Canadian Rett syndrome registry, please visit [www.rett.ca/registry](http://www.rett.ca/registry)

## What should we do if we have questions?

If you have any questions about the Canadian Rett syndrome registry please feel free to contact us at [registry@rett.ca](mailto:registry@rett.ca) or by phone at 519-474-6877.



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## Canadian Rett Syndrome Registry

### What is a patient registry?

A registry is a collection of information about people who share something in common. Typically, registries are electronic databases that contain important health, genetic, and identifying information to assist researchers studying a disease and to help plan research studies.

### Why are registries important?

Patient registries can provide the following benefits:

- Help find patients for research studies by organizing their information for researchers – this enables research dollars to go further.
- Help to improve the amount of information known about a condition or a disease.
- Help to increase the understanding of patient needs and health service delivery.
- Provide a way to monitor therapies and treatments where clinical trials are not possible (i.e. if there are not enough patients with a particular disease).

### The Canadian Rett syndrome registry

The Canadian Rett syndrome registry is a national database for individuals diagnosed with Rett syndrome. The registry aims to enroll all living Canadian residents diagnosed with Rett syndrome. Unfortunately at this time the registry will not collect information on people with Rett syndrome who have passed away.

The registry is a critical step that will organize the Canadian Rett syndrome population to attract more research opportunities to Canada with a special focus on clinical trials of potential new treatments.

### Why is this registry important?

Researchers studying Rett syndrome need good information to understand how the disease affects people. Scientists who want to start research studies, including those testing new treatments, can use the registry to find people who are eligible to participate in these studies. This helps to reduce study costs and makes it easier for eligible participants to find these important studies.

The registry will serve to improve the quality of life of people affected by Rett syndrome by enabling research into new and improved treatments and by promoting up-to-date and consistent care across Canada.



### Why should our family get involved?

There is no guarantee that your family will benefit from joining the Canadian Rett syndrome registry. However your participation may be important for the following reasons:

- It will help to increase information available to researchers about people with Rett syndrome
- It will help to increase the information available about how many Canadians are affected by Rett syndrome
- It will help to locate people in Canada affected by Rett syndrome who are interested in participating in research opportunities.