

# How Do I Enrol in the Canadian Rett Syndrome Registry?



Canadian  
Rett Syndrome  
Registry

## Accessing the Canadian Rett Syndrome Registry

To access the Canadian Rett syndrome registry visit: [www.rett.ca/registry](http://www.rett.ca/registry) and follow the link to the secure site.

## Create an Account

Before accessing detailed information on the registry or entering information into the registry you must create a user account. This involves supplying your First Name, Last Name and an email address. Please note that this information is likely the contact information of a parent or legal guardian of an individual with Rett syndrome, not that of the affected individual themselves.

## Informed Consent

As the Canadian Rett syndrome registry is used for research and to facilitate research, information collected by the registry must be obtained in an ethical manner. Therefore, before you can supply information about your loved one affected by Rett syndrome you will be provided with detailed information about the registry and asked to answer some questions to confirm how you would like to participate. For example, you can choose to tell the registry to contact you about research opportunities your family may be eligible for. Or, you can choose not to be contacted. You can also choose to share the medical information you provide about the person with Rett syndrome with other registries around the world if available. Or you can choose not to share this information. Neither choice will affect your ability to participate in the registry.

It is very important that if you have any questions about the registry that your questions be answered to your satisfaction. Please feel free to contact us at any time with your questions via email at [registry@rett.ca](mailto:registry@rett.ca) or via phone at 519-474-6877.

## Providing Information

The initial registration in the registry will take about 40 minutes to complete. You can save your progress part way through and come back to complete the record at your convenience. The registry will collect detailed information on the individual with Rett syndrome including their genetic test results, information

about their birth and early development, information about their current health, routine examinations, medications, abilities, and some information about the current services the person accesses for healthcare and in the community. You will need to provide a copy of the genetic test report if available, so please make a scan of this to upload during your initial registration. You may also wish to locate birth records such as birth date, weight and head measurements if available.

## Updating Information

Depending on the age of the person with Rett syndrome that you have provided information about you will be asked to update information as frequently but not more often than once per year. Information updates require less time than the initial registration and typically would take about 20 minutes to complete. As mentioned, you can save your progress part way through and come back to complete the record at your convenience. Information updates are critical to ensuring that the registry provides up to date information to researchers who are planning studies, and to ensure families are accurately matched with study opportunities to avoid disappointment. We appreciate your assistance in helping to make the Canadian Rett syndrome registry a success.

## What if I have difficulties?

If you have difficulty entering information into the registry please contact us at [registry@rett.ca](mailto:registry@rett.ca) or telephone us at 519-474-6877. Our registry team would be happy to assist you in getting registered and supplying the information needed.

## How long will the Registry operate?

The Canadian Rett syndrome registry does not currently have a planned end date, and aims to support Rett research for many years to come. Funding for the registry comes entirely from fundraising by families affected by Rett and their community supporters. The Ontario Rett Syndrome Association (O.R.S.A.) was the founding sponsor of the registry. O.R.S.A. is dedicated to ensuring the sustainability of the Canadian Rett syndrome registry. Keep informed and show your support by becoming a member of the O.R.S.A. You can also support the registry financially using the form below.

## Donate to help support the Canadian Rett Syndrome Registry

PLEASE PRINT LEGIBLY

Method of payment:  Cheque in the amount of \$ \_\_\_\_\_

Credit Card:  Visa  Mastercard Card Number: \_\_\_\_\_ Expiry: \_\_\_\_\_

I authorize the Ontario Rett Syndrome Association to charge the amount of: \$ \_\_\_\_\_

Name on Card: \_\_\_\_\_ Signature: \_\_\_\_\_

Please issue me a Tax Receipt for my donation over \$20.00 Name \_\_\_\_\_

Email \_\_\_\_\_ Street Address \_\_\_\_\_

City \_\_\_\_\_ Province \_\_\_\_\_ Postal Code \_\_\_\_\_

Developed and administered by the Ontario Rett Syndrome Association

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