



The theme this year is:

Promoting engagement of patients in research

So, for RDD 2018, the



is launching its campaign

« SIGN UP FOR RESEARCH ON RARE! »

Quebec Coalition of Orphan Diseases www.rqmo.org

« SIGN UP FOR RESEARCH ON RARE! »

The RQMO wants to help you take part in research on your rare disease

o *How?*

One way is to sign up to **registries** that researchers can consult and query

o *You don't have the time? You're not a computer whiz?*

The RQMO will help you sign up!

o *Don't wait after researchers, be proactive!*

Sign up to a registry to advance research on your rare disease

Two steps that you can take now -> -> ->



1 - Sign up to RareConnect

- o *RareConnect.org*

"A safe, easy to use platform where rare disease patients, families and patient organizations can develop online communities and conversations across continents and languages."

- o *Something new at RareConnect*

Initiated by Eurordis, now RareConnect is part of [CARE for RARE](#), a panCanadian research project on rare diseases. Soon, researchers will be able to register to RareConnect and connect with communities for their research on a rare disease.

- o *Don't wait after researchers, be proactive!*

Sign up to RareConnect so that researchers can find you and your community!

GO TO WWW.RARECONNECT.ORG

2 - Sign up to a registry for your disease

o What's a disease-specific registry?

It's a database of clinical information on patients. There are two types of registries: 1) those that are set up by researchers; and 2) those that are set up by patient organizations **in which you can enter your clinical data yourself.**

o Why sign up to a registry?

Because there are not many of you with the same rare disease, it helps research when there is data on many patients in one registry. Researchers have more clinical data to help advance their research.

o How can I find a registry for my rare disease?

The Quebec Coalition of Orphan Diseases (RQMO), through its *Rare Disease Information and Resource Centre*, can help you look for a registry for your rare disease and help you sign up.

Write us or call us.

Look for our contact information here

RQMO.org