What is the Rare Diseases Clinical Research Network (RDCRN) Contact Registry?

The Contact Registry is an online international system to help facilitate communication between doctors/scientists and patients and their families. The Contact Registry is hosted by the Rare Diseases Clinical Research Network (RDCRN). RDCRN is a National Institutes of Health (NIH)-funded network that is dedicated to rare disease research including ALS and related diseases. The Contact Registry provides a means for patients with these rare diseases to indicate their willingness to be contacted in the future about clinical research opportunities and to receive updates on the progress of research.

Why should I join the RDCRN Contact Registry?

By signing up for the Contact Registry you will join a community of patients with a range of rare diseases who are partnering with scientists to help develop effective treatments. Periodically you will receive information about new opportunities to participate in research studies, including clinical trials. Joining the registry does not obligate you to participate in any study – it simply provides a mechanism for doctors and researchers to share information with you about research. With this information, you can decide which research studies you want to learn more about. To enroll in the Contact Registry, visit rdcrn.org/CReATe.

How is the RDCRN Contact Registry different from the National ALS Registry?

The RDCRN Contact Registry is distinct from the National ALS Registry that is maintained by the U.S. Centers for Disease Control and Prevention (CDC). The Contact Registry is not meant to compete with the National ALS Registry, but rather to work alongside it. By facilitating direct communication between physicians/scientists and patients with ALS and related diseases, the Contact Registry will advance the goals of the National ALS Registry.

It is important to understand that participation in the Contact Registry does not mean that you also have enrolled in the National ALS Registry. The registries are different and information in the Contact Registry is not shared with the National ALS Registry. If you are a person with ALS, we encourage you to sign up for both registries. To enroll in the National ALS Registry, visit the CDC’s ALS Registry website at www.cdc.gov/als.