



What is CReATe Connect?

CReATe Connect, a part of the Rare Diseases Clinical Research Network (RDCRN) Contact Registry, is an online international system to help facilitate communication between doctors/scientists and patients and their families. CReATe Connect is hosted by the RDCRN, a National Institutes of Health (NIH)-funded network that is dedicated to rare disease research including ALS and related diseases. CReATe Connect provides a means for patients with these rare diseases (and their family members) to indicate their willingness to be contacted in the future about clinical research opportunities and to receive updates on the progress of research. It also provides a way for the CReATe team to contact patients about new educational opportunities sponsored by CReATe, such as original content articles and virtual journal clubs.

Why should I join CReATe Connect?

By signing up for CReATe Connect, you will join a community of patients with a range of rare diseases (and people who may be at genetic risk for developing these 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 mean you have to participate in any study – it simply provides a way 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. Those who sign up will also be kept informed about new educational opportunities sponsored by CReATe such as original content articles and virtual journal clubs. Starting in 2016, the CReATe team will be empowering all those in CReATe Connect to have an even greater role in directing the CReATe team's educational efforts. Through regular surveys, those who have signed up for CReATe Connect will vote for the original content articles and virtual journal clubs that they are interested in and these will be the ones the CReATe team sponsors. **To enroll in CReATe Connect, visit RDCRN.org/CReATeConnect.**

How is CReATe Connect different from the National ALS Registry?

While CReATe Connect is part of the RDCRN Contact Registry, it is quite distinct from the National ALS Registry that is maintained by the U.S. Centers for Disease Control and Prevention (CDC). CReATe Connect 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, CReATe Connect will help to advance the goals of the National ALS Registry. It is important to understand that participation in CReATe Connect does not mean that you have also enrolled in the National ALS Registry. The registries are different and information in CReATe Connect 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.