



CReATe Connect An RDCRN Contact Registry

What is CReATe Connect?

CReATe Connect, a part of the Rare Diseases Clinical Research Network (RDCRN) Contact Registry, is a way for patients with rare disorders and their family members to receive information from the RDCRN about their disorders, research studies that they may be eligible to join, and results of studies performed by RDCRN researchers. The RDCRN is a National Institutes of Health (NIH)-funded network that is dedicated to rare disease research including ALS and related diseases.

Why Should I Join CReATe Connect?

By signing up for CReATe Connect, you will join the effort of doctors and researchers who are working to identify ways to develop effective treatments for rare disorders. Joining CReATe Connect does not mean you have to participate in a study – it simply provides a way for you to receive information about rare disorders, research opportunities, results of research studies, and more.

How Do I Join CReATe Connect?

1. You may join online at: www.rdcrn.org/createconnect

OR



2. You may complete this form and send it to us by fax, email, or mail so that we can email you an invitation to join CReATe Connect.

Contact Information	
<i>Please clearly print your contact information below.</i>	
First Name:	
Last Name:	
Email Address:	
Preferred Phone #:	
Other Phone #:	

Disorder Information		
<i>What disorder(s) does the patient have? Please check all that apply.</i>		
<input type="checkbox"/> Amyotrophic Lateral Sclerosis (ALS) <input type="checkbox"/> Amyotrophic Lateral Sclerosis Frontotemporal Dementia (ALS-FTD)	<input type="checkbox"/> Hereditary Spastic Paraplegia (HSP) <input type="checkbox"/> Primary Lateral Sclerosis (PLS)	<input type="checkbox"/> Progressive Muscular Atrophy (PMA)

Fax: (877) 776-2228
 E-mail: RDCRNContactRegistry@epi.usf.edu

Address: RDCRN Attn: CReATe Connect
 3650 Spectrum Blvd., Suite 100
 Tampa, FL 33612

If you have any questions, please email us at RDCRNContactRegistry@epi.usf.edu.