Rare Diseases Clinical Research Network (RDCRN) Contact Registry

What is the RDCRN Contact Registry?

The RDCRN Contact Registry is a way for patients with rare disorders 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 Contact Registry is hosted by the RDCRN, a National Institutes of Health (NIH)-funded network that is dedicated to rare disease research.

Why Should I Join the RDCRN Contact Registry?

By signing up for the RDCRN Contact Registry, you will join the effort of doctors and researchers who are working to identify ways to improve your quality of life and develop effective treatments for your disorder. Joining the registry does not mean you have to participate in a study – it simply provides a way for you to receive information about your disorder, research opportunities, results of research studies, and more.

How Do I Join the RDCRN Contact Registry?

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

   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 the RDCRN Contact Registry.

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

Disorder Information

What disorder(s) does the patient have? Please check all that apply.

☐ CK Syndrome & CHILD Syndrome (Congenital Hemidysplasia w/ Ichthyosiform Erythroderma & Limb Defects)	☐ Mevalonic Aciduria
☐ Cerebrotendinous Xanthomatosis	☐ Niemann-Pick Disease Type C Sitosterolemia
☐ Hyperimmunoglobulinemia D with Periodic Fever Syndrome	☐ Peroxisome Biogenesis Disorder (Zellweger Spectrum Disorder)
☐ Dolichol Metabolism Disorder	☐ Sitosterolemia
☐ Hyperimmunoglobulinemia D with Periodic Fever Syndrome	☐ Sjögren-Larsson Syndrome
	☐ Smith-Lemli-Opitz Syndrome
	☐ Sterol-C4-methyl oxidase deficiency (SC4MOL gene defect)

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