

By participating in the RUDY Health Study, you will be helping to advance the understanding of rare conditions.

Before anybody can take part in medical research they need to give their *informed consent*. We ask you to visit our website www.rudystudy.org ; carefully read our information sheet, and then register on the website. See overleaf for details

The RUDY Study is open to those with rare disorders, as well as their blood relatives.

If you are under 16, you are welcome to register yourself on the RUDY website, but we will need to talk to your parents and get their consent before you can take part fully (see step 5a overleaf)

Any Questions? Please do get in touch

Partners of RUDY:



For more information, please do get in touch:

Telephone : 07775541615

Email : RUDY@ndorms.ox.ac.uk

RUDY

Uniting Patients and Researchers
to Investigate Rare Diseases

Registering on
the secure
RUDY Website

Instruction Leaflet

NHS
**National Institute for
Health Research**



RUDY Registration Instruction Leaflet

Version 1; 09/08/2017

IRAS NO: 213780

REC No. 17/SC/0501



Step 1:

To register as a participant go to www.rudystudy.org and click the green 'Sign up today' button.

Step 2:

Register your details. If you are registering on behalf of your child, we will ask you to record first their details and then yours also.

Step 4:

On the third registration page we will ask you if you have read the information sheet and if you have any questions at all.

Step 3:

On the second registration page please select your diagnosis from the drop down lists available or enter it in the 'Other Diagnosis' box if it is not listed.

Step 5a:

If you have questions, we will ask you to select some upcoming times for a telephone appointment to discuss the RUDY Study with a member of our team.

Choose date and time periods when you would like to receive your call
Please select at least 3 different dates. If you have a preferred time/date please let us know in the comments box below.

	Tue 15th	Wed 16th	Thu 17th	Fri 18th	Mon 21st	Tue 22nd	Wed 23rd	1 2
9:00								
10:00								
11:00								
12:00								
13:00								
14:00								

Step 5b:

If you don't have any questions, we will ask you to provide your written consent via the website. If there is anything on the consent form you are unsure about, you can always go to Step 5a

Once complete, you will have full access to the RUDY Study website!