



NCBRS WORLDWIDE FOUNDATION
NICOLAIDES-BARAITSER SYNDROME

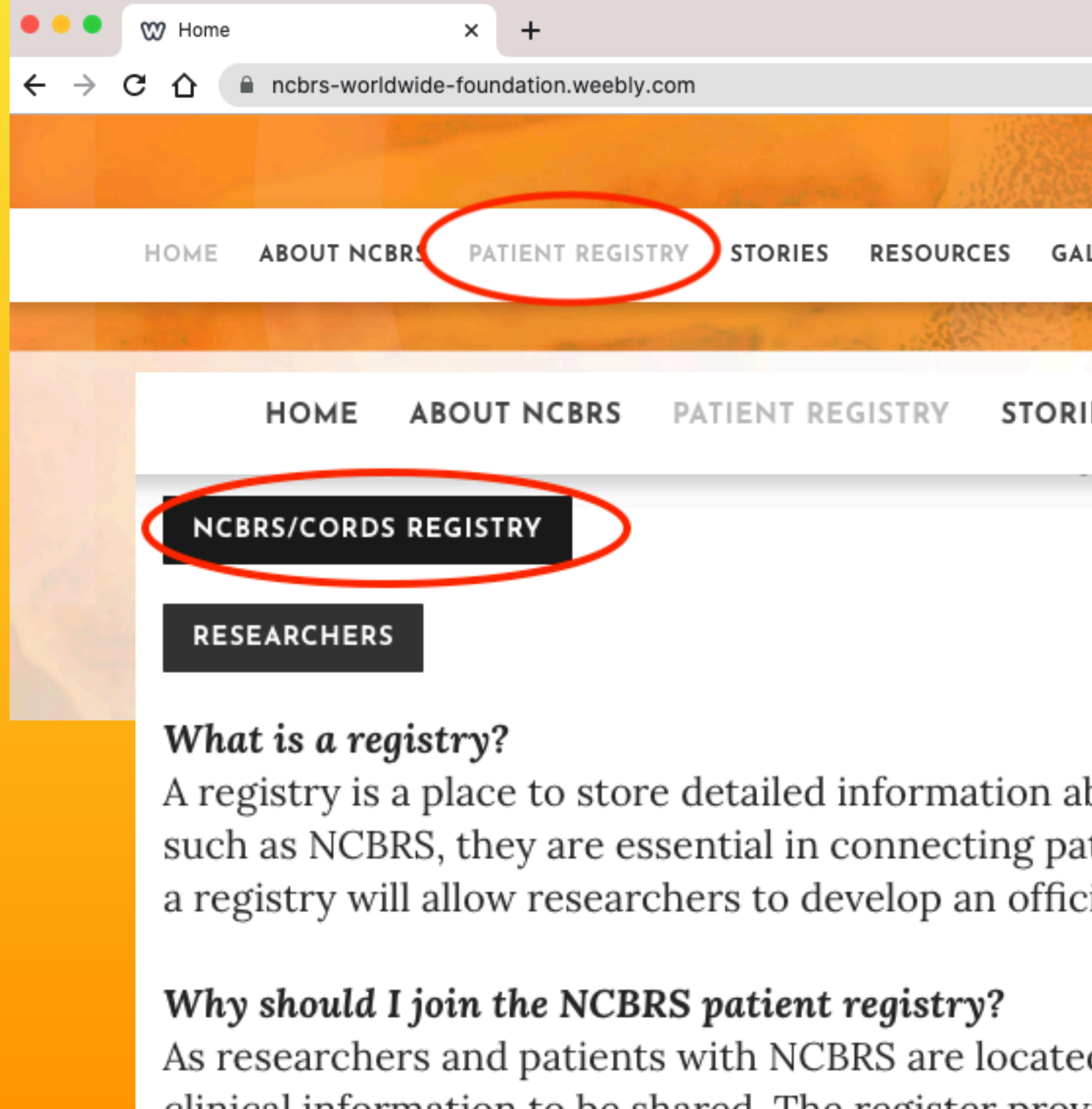
ALONE WE'RE RARE, TOGETHER WE ARE **STRONG**

Guide to Enrolling in the NCBRS/CoRDS Patient Registry

Go to NCBRS.com

At the top of the home page
click on the Patient Registry
tab - (this will take you to
the patient registry page)

Then... underneath the
video click on the
NCBRS/CoRDS REGISTRY
button...



**You will then be taken to the CoRDS
activation form page**

CoRDS
Rare Disease Registry



Activation Form

Introduction

Activation Form

Introduction

Please answer a few questions to help us create your participant account. If you have any questions, please contact cords@

Participant Type

- I am enrolling myself (18 years or older)
- I am enrolling my child (child under the age of 18)
- I am enrolling an adult who is not cognitively able to enroll (Must be the Legally Authorized Representative (LAR))

If you are over 18 and enrolling yourself as the participant affected with NCBRS select the above statement...

Then... you'll be able to select your Date of Birth (see picture)

The screenshot shows a web browser window with the URL cordsconnect.san.org/Bay. The page title is "Activation Form". Below the "Participant Type" section, there is an "Information" section. A date picker is open, showing the month of August and the year 2002 selected. The date picker interface includes a calendar grid with days of the week (Su, Mo, Tu, We, Th, Fr, Sa) and numbers 1 through 10. The year 2002 is highlighted in the year selection dropdown.

Activation Form Type

Introduction

Please answer a few questions to help us create your participant account. If you have any questions, please contact [cordsconnect](#)

Participant Type

- I am enrolling myself (18 years or older)
- I am enrolling my child (child under the age of 18)
- I am enrolling an adult who is not cognitively able to enroll (Must be the Legally Authorized Representative (LAR))

If the participant is over 18 and your enrolling for them please select the above statement...

Then... you'll be able to select their Date of Birth (see picture)

The screenshot shows a web browser window with the URL 'cordsconnect.san...n.org/Bay'. The page title is 'Rare Disease Registry' and the main heading is 'Activation Form Type'. Below this is an 'Introduction' section with a link to 'cordsconnect'. The 'Participant Type' section has three radio button options, with the third one selected and circled in red. The 'Information' section is partially visible, showing a 'Name' field and a date picker. The date picker is open, showing the month of August 2002, with the year 2002 selected. The date picker shows a calendar grid with days of the week (Su, Mo, Tu, We, Th, Fr, Sa) and dates (1-10).

Activation Form

Participant Type

- I am enrolling myself (18 years or older)
- I am enrolling my child (child under the age of 18)
- I am enrolling an adult who is not cognitively able to enroll (Must be the Legally Authorized Representative (LAR))

- 2002
- 2003
- 2004
- 2005
- 2006
- 2007
- 2008
- 2009
- 2010
- 2011
- 2012
- 2013
- 2014
- 2015
- 2016
- 2017
- 2018
- 2019
- ✓ 2020

Introduction

Please answer a few questions to help us create your participant account. If you have any questions, please contact cords@sanfordresearch.com

Participant Type

- I am enrolling myself (18 years or older)
- I am enrolling my child (child under the age of 18)
- I am enrolling an adult who is not cognitively able to enroll (Must be the Legally Authorized Representative (LAR))

Participant Information

Please provide your child's basic information

Participant First Name *

Birth Date *

Do you speak and understand English? *

Aug ✓ 2020

Su Mo Tu We Th Fr

Parent/Guardian/LAR

2	3	4	5	6	7
---	---	---	---	---	---

As the participant's Legally Authorized Representative

9	10	11	12	13	14
---	----	----	----	----	----

If you are enrolling your child who is under 18 years old, select the above statement...

Then... you'll be able to select their Date of Birth (see picture)

Participant Information

Please provide your child's basic information. Red asterisk (*) indicates a required field.

Birth Date *

mm/dd/yyyy

Aug 2020

Su Mo Tu We Th Fr Sa

1

You can enter the Date of Birth by typing it in the American format above (see picture) as well as selecting the date through the drop-downs.

If you are enrolling your child who is under 18 years old, or an adult on their behalf you will need to fill in the Parent/Guardian/LAR information (see picture below)

Then... select your preferred method of enrolment (see picture below)

Parent/Guardian/LAR Information

As the participant's Legally Authorized Representative (LAR), you will be the primary contact. Please provide your own information below in this section.

First Name *

Middle Name

Last Name *

Enrollment Information

Preferred method of enrollment *

Online

Postal Mail

**You will then be asked for your diagnosis/rare disease
Start to type Nicolaides-Baraitser..... and the diagnosis NCBRS will
automatically come up (see picture below) -**

Then... PLEASE CLICK THIS

Diagnosis

Please select the participant's diagnosis from the "Rare Disease Diagnosis" section. You can add or remove multiple diagnosis from the field with a maximum entry of 5 diseases.

- If you have not officially been diagnosed with a Rare Disease, please enter "Undiagnosed or Unaffected Carrier" (along with a rare disease) if applicable to the participant.
- If you can not find your disease search for "Other" and add your diagnosis in the Other Rare Diseases Diagnosis below.

Rare Disease Diagnosis 1

Rare Disease Diagnosis 2

Rare Disease Diagnosis 3

Rare Disease Diagnosis 4

Rare Disease Diagnosis 5

Specify Other Rare Disease Diagnosis

You will now be asked to read the consent forms and if you agree please click the I agree to participate box... (see picture)

Then... CLICK the SUBMIT button (see picture)

Consent

Assent

[www.cordsregistry.org](#)
Phone: (877) 658-9192

Instructions for Parents and Legally Authorized Representatives: If the participant is between the ages of 7-17 or is otherwise unable to give informed consent, the following information before you enroll them in the CoRDS Registry. If your child/the participant does not agree to participate, you should not enroll them in the study.

Introduction

We would like to tell you about a research study we are asking you to be in. A research study is like a big science project. If you are interested in participating, and if you are okay with you, we will ask your parent(s)/legally authorized representative(s) a few questions about you and use this information to help us decide if you are eligible to participate in the study.

The scientists and doctors may ask you to help them again in another research study in the future. If you don't feel like participating, that's okay. If you let us put your name and information in the CoRDS Registry, you don't have to. If you let us put your name and information in the CoRDS Registry, you don't have to.

By checking this box, I agree to participate in the CoRDS Registry

Submit

You have now completed the activation form for CoRDS, you will now be taken to the questionnaire to complete.

Remember you only have to fill in as much information as you feel comfortable to do. All information is fully de-identified.

We thank you for taking the time to complete our Patient Registry and in helping to better understand NCBRS and what it means for our children.

Thank You



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