



KrabbeCURES Participant User Guide

Register for an Account

- Step 1: Read the Terms and Conditions and Privacy Policy and attest to the statements provided. When you are finished with this page, click “Next”.

Featuring



Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

Below are links to the IAMRARE Terms of Use and Privacy Guidelines. The purpose of these documents is to outline your rights and responsibilities when using the platform. These documents include: 1) Standard policies for all studies on this platform, 2) A privacy statement that details how your data can be used, 3) Information outlining the unacceptable uses of the platform, and 4) Information about how to address questions and issues.

Acknowledgements:

- You are at least 18 years of age, the age of majority in your state, province or country, and able to consent on behalf of yourself and/or an individual that you have legal responsibility for. *
- You agree to support the Platform's research activities by providing truthful, appropriate information and to not do anything that will put the Services or the information in the Platform at risk. *
- You understand that NORD will use reasonable efforts to keep the information you enter on the Services safe, but no data transmissions over the Internet can be guaranteed to be 100% secure. The information you provide will be available to authorized users at NORD for platform maintenance and research activities, as well as to the sponsor of the studies you consent to participate in. *
- You agree to the [Terms and Conditions](#) & [Privacy Policy](#) *

[Return to login](#) Next

- Step 2: Enter your personal information in the spaces provided. When you are finished with this page, click “Next”.

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 **KrabbeConnect**
CONNECTING PATIENTS & RESEARCH

Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

Country of Residence *

First Name * Last Name *

E-mail *

[Return to login](#) [Previous](#) [Next](#)

- Step 3: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.

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Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

I am interested in NORD contacting me regarding available studies. *

Yes No

[Return to login](#) [Previous](#) [Next](#)

- Step 4: Select “Next” so that an activation link is sent to your e-mail to complete registration.

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Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

An activation link will be sent to your.email@email.com. Click "Next" to send this e-mail and continue.

[Return to login](#) [Previous](#) [Next](#)

- Step 5: Click the link you are sent via e-mail. Please check your Spam folder if you do not see the e-mail. You will be taken to the following screen in a new tab within your browser. Set your password and click “Submit”.

E-mail Validation

Your e-mail your.email@email.com has been successfully validated.
Please create your password below.

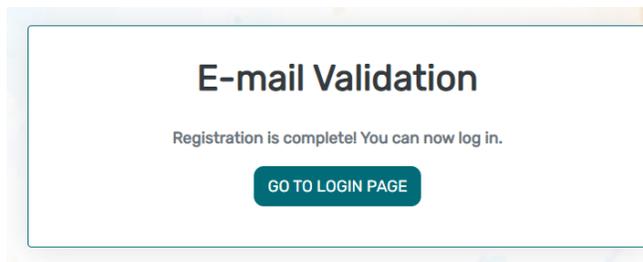
Password

A password must be at least 8 characters long: ✘
- contain 1 uppercase letter ✘
- contain 1 lowercase letter ✘
- contain 1 digit ✘
- not contain text from top 1000 commonly used passwords ✘

Repeat Password

[SUBMIT](#)

- Step 6: Your validation is now complete. Select “Go to Login Page”.



- Step 7: Log in using your new e-mail and password.

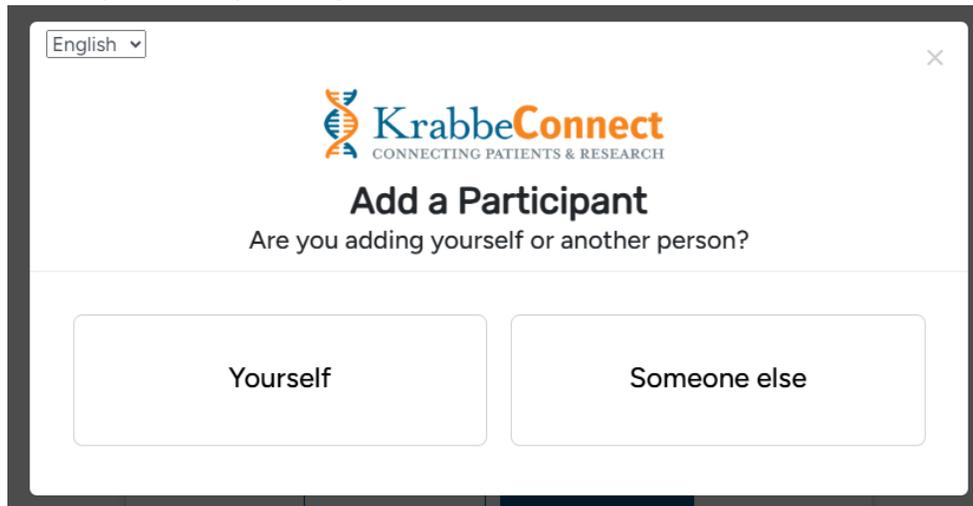


Add a Participant

- Step 1: To start, click Create New Profile.



- Step 2: Select who you will be providing information about.



English

 **KrabbeConnect**
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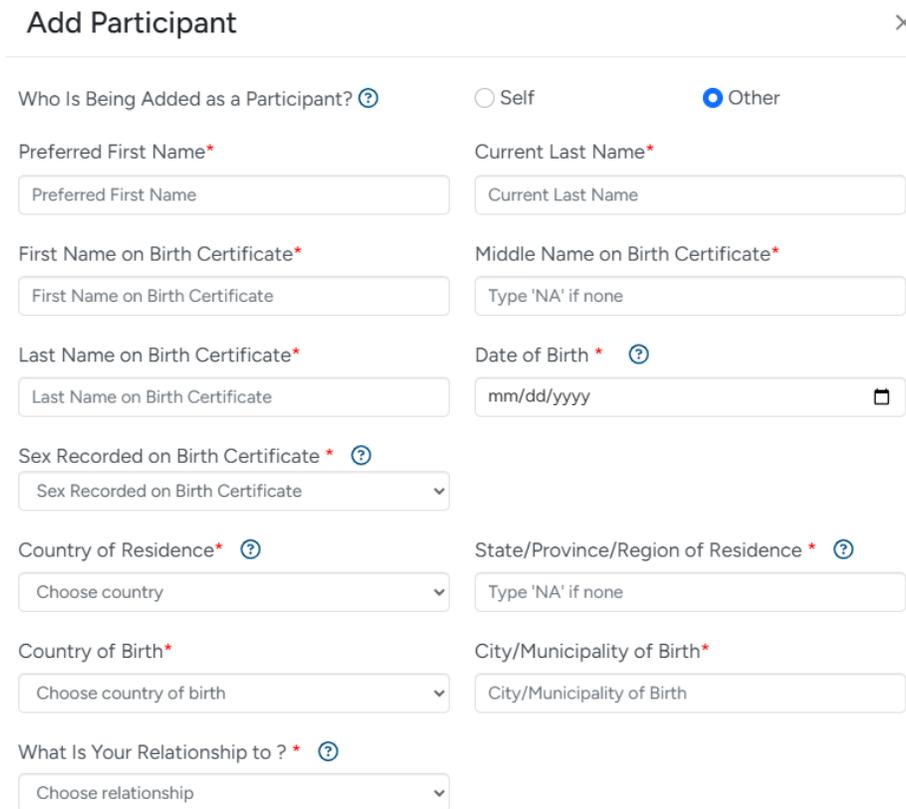
Add a Participant

Are you adding yourself or another person?

Yourself

Someone else

- Step 2: Fill out the Participant's information.



Add Participant

Who Is Being Added as a Participant? [?](#) Self Other

Preferred First Name*

Current Last Name*

First Name on Birth Certificate*

Middle Name on Birth Certificate*

Last Name on Birth Certificate*

Date of Birth* [?](#) 

Sex Recorded on Birth Certificate* [?](#)

Country of Residence* [?](#)

State/Province/Region of Residence* [?](#)

Country of Birth*

City/Municipality of Birth*

What Is Your Relationship to?* [?](#)

Consent to the Study

- Step 1: Click on “Yes, complete consent for this participant.”

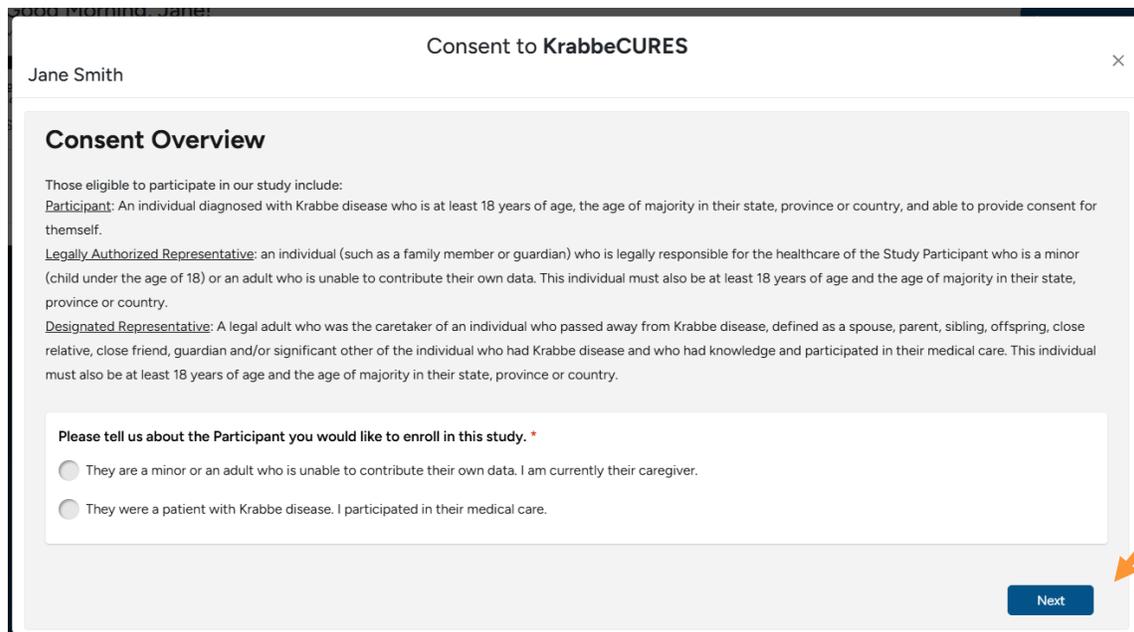


KrabbeConnect
CONNECTING PATIENTS & RESEARCH

Thank you for registering your first participant!

Would you like to consent to participate in
KrabbeCURES?

- Step 2: Scroll down and read through the consent form thoroughly. Once you finish each page, click the “Next” button. Once you reach the Authorization form, read through the statements thoroughly. If you are comfortable consenting to participate in the study, please read each statement and authorize your consent. After checking the boxes, click “Next.”



Jane Smith

Consent to KrabbeCURES

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with Krabbe disease who is at least 18 years of age, the age of majority in their state, province or country, and able to provide consent for themselves.

Legally Authorized Representative: an individual (such as a family member or guardian) who is legally responsible for the healthcare of the Study Participant who is a minor (child under the age of 18) or an adult who is unable to contribute their own data. This individual must also be at least 18 years of age and the age of majority in their state, province or country.

Designated Representative: A legal adult who was the caretaker of an individual who passed away from Krabbe disease, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had Krabbe disease and who had knowledge and participated in their medical care. This individual must also be at least 18 years of age and the age of majority in their state, province or country.

Please tell us about the Participant you would like to enroll in this study. *

They are a minor or an adult who is unable to contribute their own data. I am currently their caregiver.

They were a patient with Krabbe disease. I participated in their medical care.

Consent to KrabbeCURES

Jane Smith

Consent for a Person with a Legally Authorized Representative (Caregiver)

Consent To Participate In KrabbeCURES And To Allow Data To Be Shared For Future Research

Title: Krabbe Community United Research and Engagement Study (KrabbeCURES)

Stacy Pike-Langefeld, Co-Founder and President, KrabbeConnect

Phone: 1-800-800-5509

KrabbeConnect E-mail: info@krabbeconnect.org

Study E-mail: iamrare-help@rarediseases.org

Sponsor: KrabbeConnect

Key Information

You are invited to take part in a research study for individuals with Krabbe disease on behalf of the person in your care who is no longer able to provide their own consent. Your role is called Legally Authorized Representative (LAR). We hope that this form will help you decide whether or not to participate, but you can also call or e-mail the study staff at the contacts above if you have any other questions.

[Previous](#) [Next](#)



Consent to KrabbeCURES

Jane Smith

Authorization

The following statements are intended to:

- Make sure that you have had the time and opportunity to consider whether you and the Study Participant want to participate in this study;
- Have had your questions answered; and
- Agree to participate in the study as described.

You will be asked to acknowledge:

- That you have read the consent form and have no further questions about the study and the Study Participant's participation;
- That you wish to provide the Study Participant's personal data to KrabbeCURES for the purposes of the Study;
- That you allow for this data to be used for future research;
- That you have explained the study to the Study Participant to the extent they are able to understand; and
- That you are of legal age.

This is a web-based form. Your digital signature is the same as if you had signed your name to a paper document. By answering "Yes" to all of the following statements, you are giving your consent to participate in KrabbeCURES on behalf of the Study Participant. After signing, a copy of the consent form will be e-mailed to you. If you cannot comfortably answer "Yes" to these statements, please do not check the consent boxes in the following section.

I have read this Consent and Authorization Form to provide the Study Participant's personal and medical data to be shared for the purpose of research. All my questions about KrabbeCURES have been answered to my satisfaction, and I understand the purpose of the registry and the risks of participation.

[Previous](#) [Next](#)



- Step 3: Once you click "Next" and reach the Thank You page, click "Continue to Opt-Ins".

Consent to KrabbeCURES

Jane Smith

Please continue to select your opt-ins. Once you have made your selections, please click Save and Review. You will then be ready to take surveys and participate in this study.

[Previous](#) [Continue to Opt-Ins](#)



- Step 4: Once you click “Continue to Opt-Ins” read through the opt-ins thoroughly. If you would like to receive information about the topic, check the box, and click “Save and Review”.

Opt-Ins for KrabbeCURES [X]

Select Opt-Ins for this study

- Interest in hearing about other studies from **KrabbeConnect**
- Interest in hearing about relevant clinical trials
- Interest in donating specimens or DNA (biobanking) for future research
- Interest in genetic testing
- Interest in learning more about **KrabbeConnect**
- Interest in signing up for **KrabbeConnect's** newsletter
- Support from **KrabbeConnect** Ambassador / Care Coordinator
- Interest in hearing about family conferences and events run by **KrabbeConnect**
- For US Residents: If eligible, I would like to receive a thank you token that would be sent via electronic or postal mail.
- Interest in learning about upcoming events such as webinars and conferences
- If eligible, I would like to receive Krabbe disease awareness tokens that would be sent via electronic or postal mail.

Save and Review

- Step 5: Once you’ve reviewed your consent, click “Close”. You will then have access to start taking surveys.

Taking Surveys

- Step 1: Click “Take Survey” for an available survey.

← Back to the study list

Jane Smith [edit] 5-May-2020

KrabbeCURES

Surveys **4 pending** **All (4)** Complete (0) Pending (4)

0% Getting Started *Not Started* **Take Survey**

View Responses and Reports

- Step 1: Once you have submitted a survey, you are able to view your responses to that survey as well as the graphs for any questions that are programmed to show graphs. Click “View Responses” to see your completed survey. Click “Reports” to see any available graphs.

Jane Smith 5-May-2020

KrabbeCURES

Surveys 🔥 2 pending **All (4)** Complete (2) Pending (2)

Getting Started *Completed on 4-Jun-2025* View Responses (1) Reports

Demographics Survey *Completed on 4-Jun-2025* View Responses (1) Reports

View Consent and Opt-Ins

- Step 1: Once you have consented to the study, you are able to view your consent at any time. Navigate to the Enrolled Studies page. Then, click “Consents/Opt-Ins” to see your consent and opt-ins.

Back to the participant list

Jane Smith 5-May-2020 Search Studies

Enrolled Studies

Click a study to see the list of surveys. Click the ⓘ icon to see more information about the study. Click 'Search Studies' above to find additional studies.

Shortcuts

Request Transfer Consent/Opt-Ins

- Step 2: You may revoke your consent at any time by clicking “Revoke”. You may also edit your Opt-Ins by clicking “Opt-Ins”.

Back to the study list

Jane Smith 5-May-2020

Consents/Opt-Ins

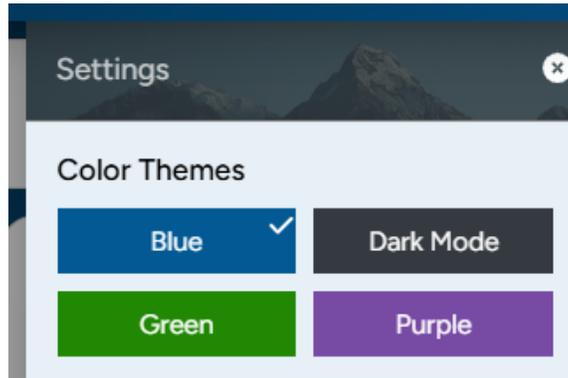
Study Name	Consent Status	Consented On	Actions
KrabbeCURES	✓ Consented	4-Jun-2025	<a>View Consent <a>Revoke <a>Opt-Ins

Dark Mode Settings

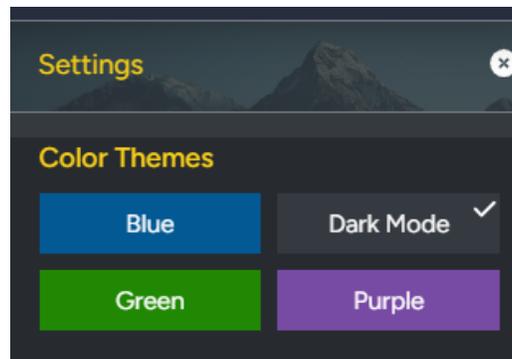
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



- Step 3: Exit the Settings menu, and your selection will be saved.

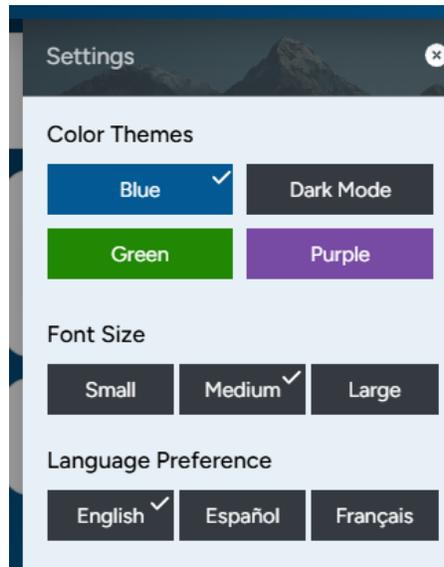


Display Settings

- Step 1: You can change the platform display settings. First, click Settings.



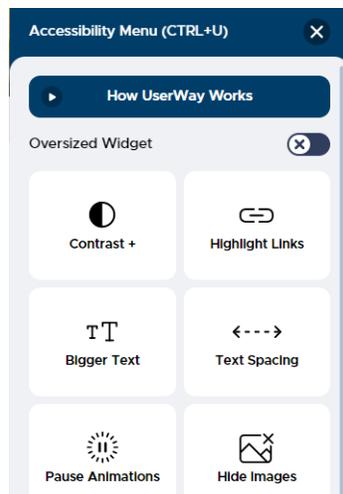
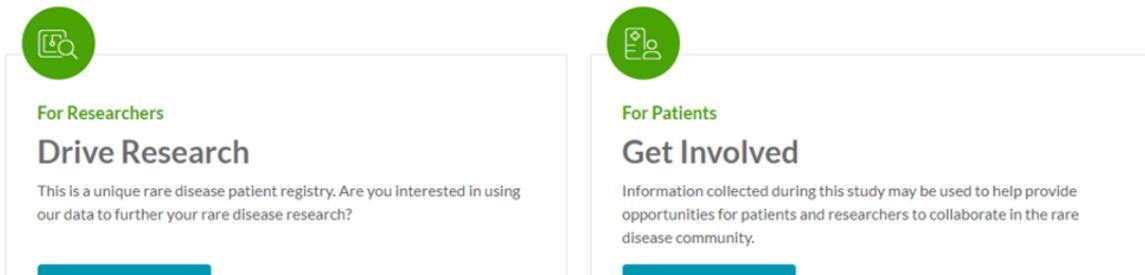
- Step 2: Select a color theme, a font size, or language preference.



- Step 3: Exit the Settings menu, and your selection will be saved.

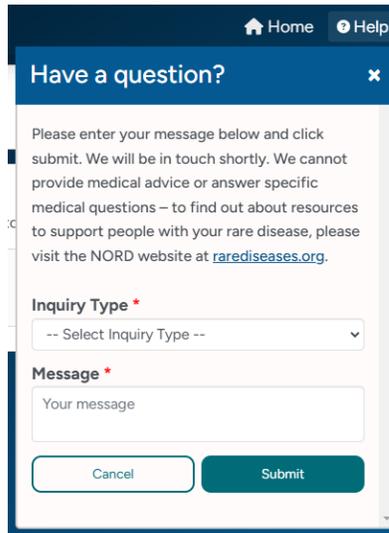
Microsite Visibility

- Step 1: You can change how you view the microsite (krabbecures.iamrare.org) using an Accessibility menu. Click the icon of a person at the bottom of the screen. You are able to change the settings such as the contrast, text sizing, and text spacing.



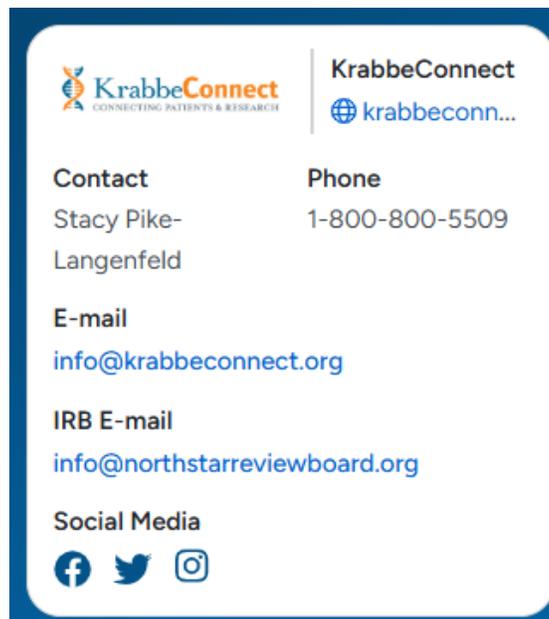
Need Assistance?

- Step 1: If you need help while using the platform, click Help.
- Step 2: Select an Inquiry Type and type a message.



The screenshot shows a mobile application interface with a dark blue header containing 'Home' and 'Help' icons. Below the header is a white modal window titled 'Have a question?' with a close button (X). The modal contains the following text: 'Please enter your message below and click submit. We will be in touch shortly. We cannot provide medical advice or answer specific medical questions – to find out about resources to support people with your rare disease, please visit the NORD website at rarediseases.org.' Below this text is a dropdown menu for 'Inquiry Type' with the placeholder text '-- Select Inquiry Type --'. Underneath is a text input field for 'Message' with the placeholder text 'Your message'. At the bottom of the modal are two buttons: 'Cancel' and 'Submit'.

- Step 3: Click Submit.
- You may also contact the study sponsor directly by using the contact information shown on your dashboard or the study website.



The contact information card features the KrabbeConnect logo (a DNA helix) and the tagline 'CONNECTING PATIENTS & RESEARCH'. To the right, it shows the website 'krabbeconn...'. The card is organized into sections: 'Contact' with 'Stacy Pike-Langenfeld', 'Phone' with '1-800-800-5509', 'E-mail' with 'info@krabbeconnect.org', and 'IRB E-mail' with 'info@northstarreviewboard.org'. At the bottom, under 'Social Media', are icons for Facebook, Twitter, and Instagram.