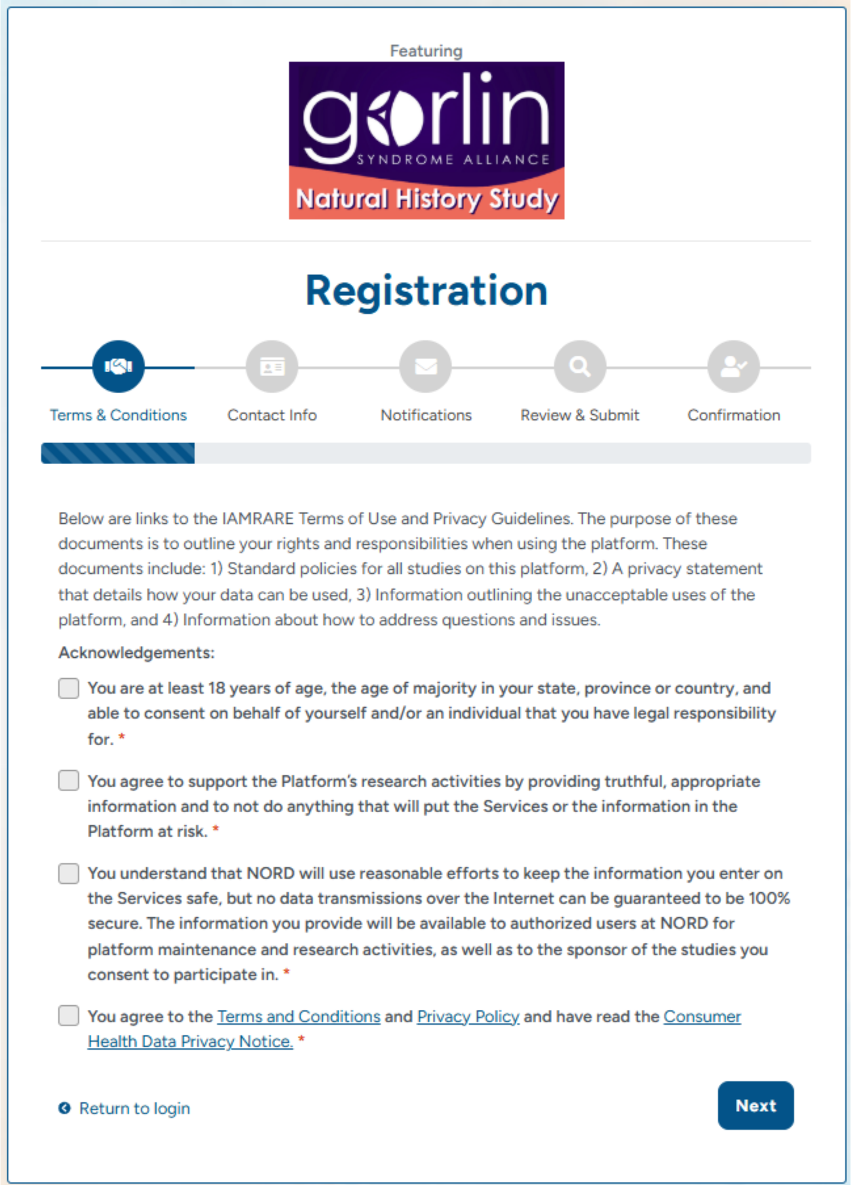
gorlin
SYNDROME ALLIANCE
Natural History Study

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”.



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:

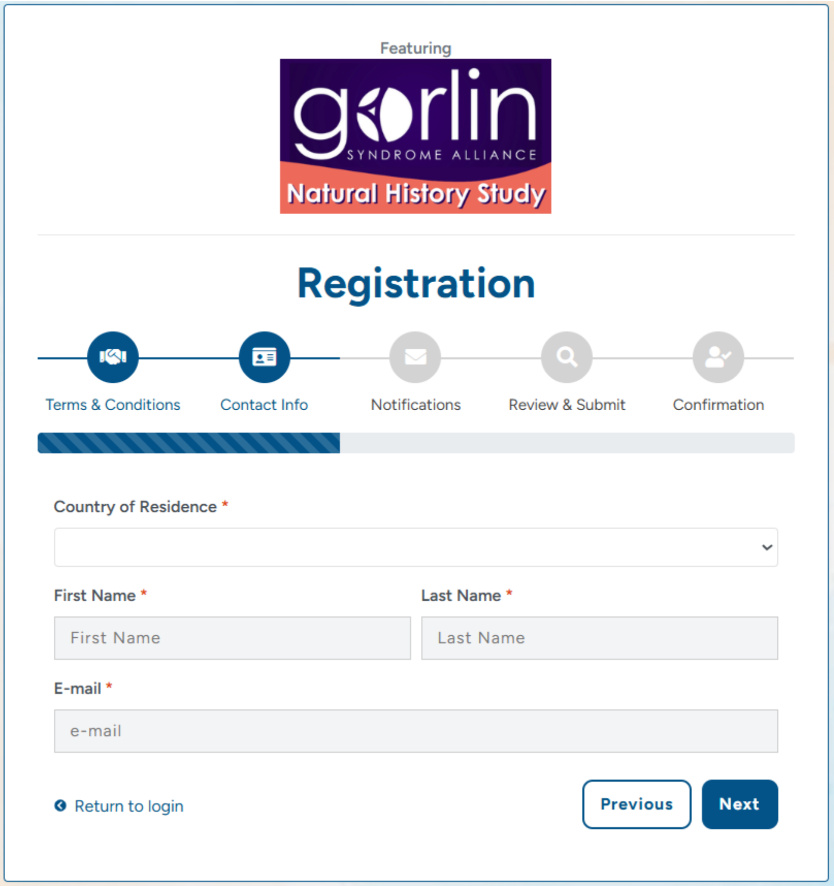
☐ You are at least 18 years of age, the age of majority in your state, province or country, and able to consent on behalf of yourself and/or an individual that you have legal responsibility for. *

☐ 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 and Privacy Policy and have read the Consumer Health Data Privacy Notice. *

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



Registration

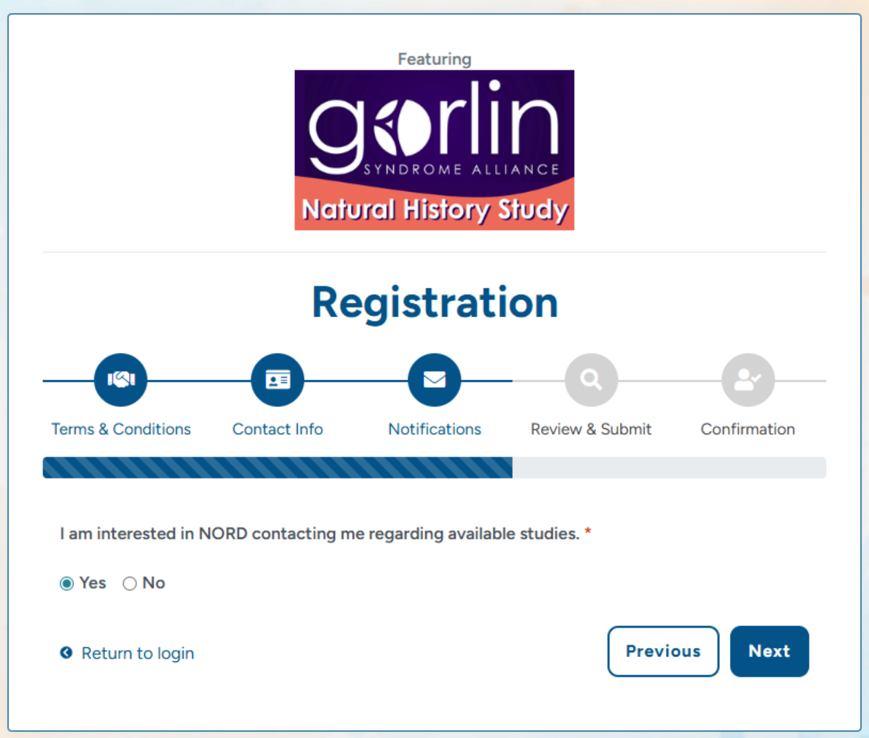
Country of Residence *

First Name *

Last Name *

E-mail *

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

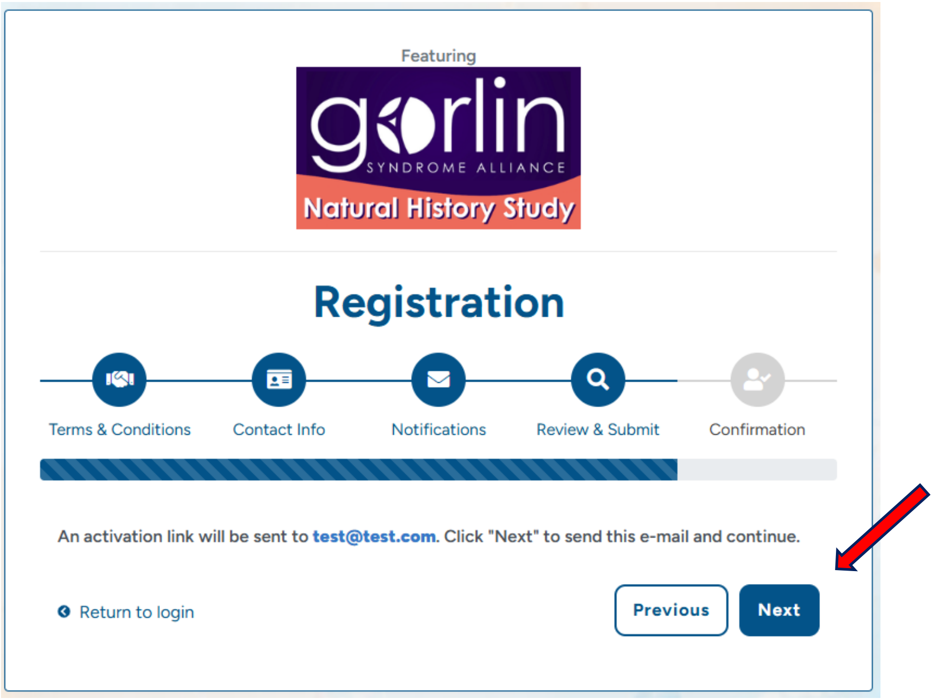


Registration

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

● Yes ○ No

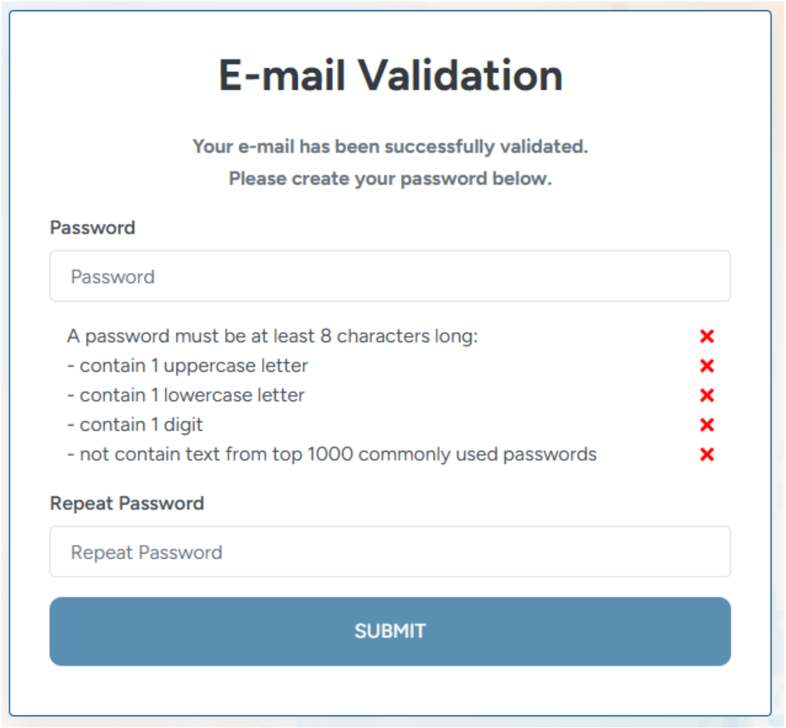
- Step 4: Select “Next” so that an activation link is sent to your e-mail to complete registration.



Registration

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

- 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”.

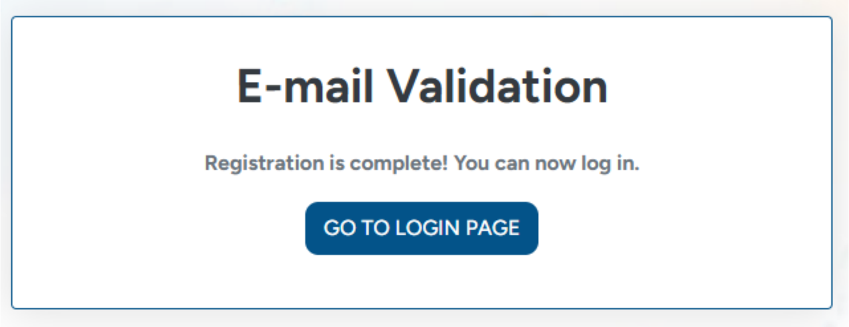


E-mail Validation

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

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 ✗

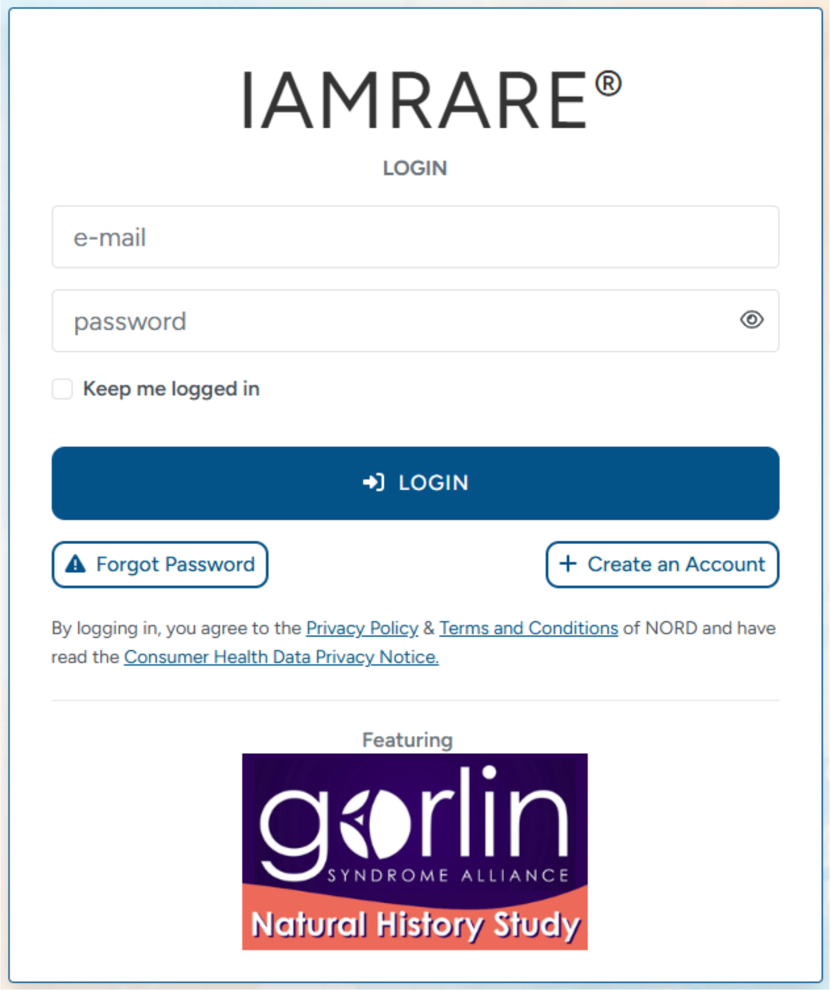
- Step 6: Your validation is now complete. Select “Go to Login Page”.



E-mail Validation

Registration is complete! You can now log in.

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



IAMRARE®

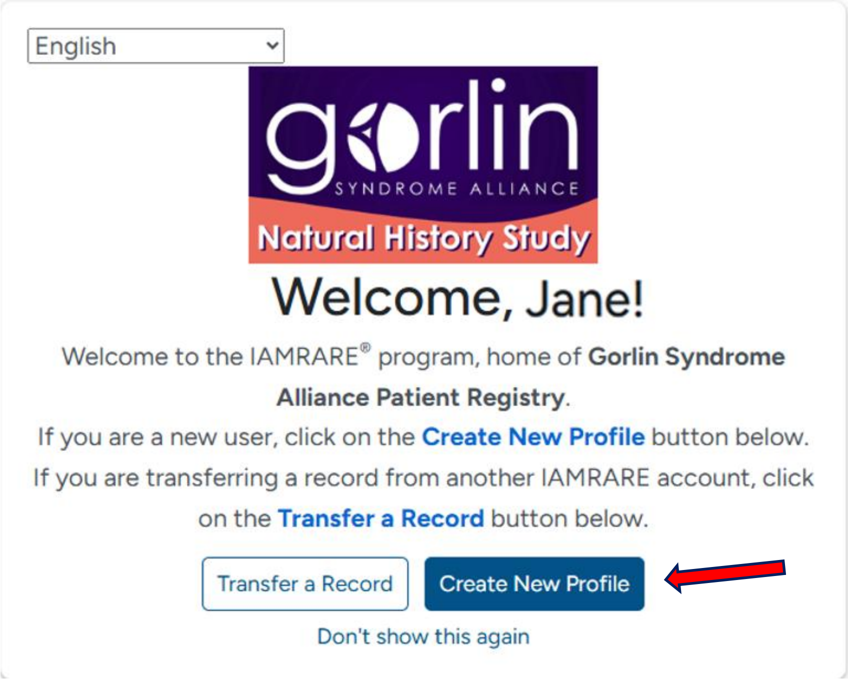
LOGIN

By logging in, you agree to the Privacy Policy & Terms and Conditions of NORD and have read the Consumer Health Data Privacy Notice.

Featuring

Add a Participant

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



English

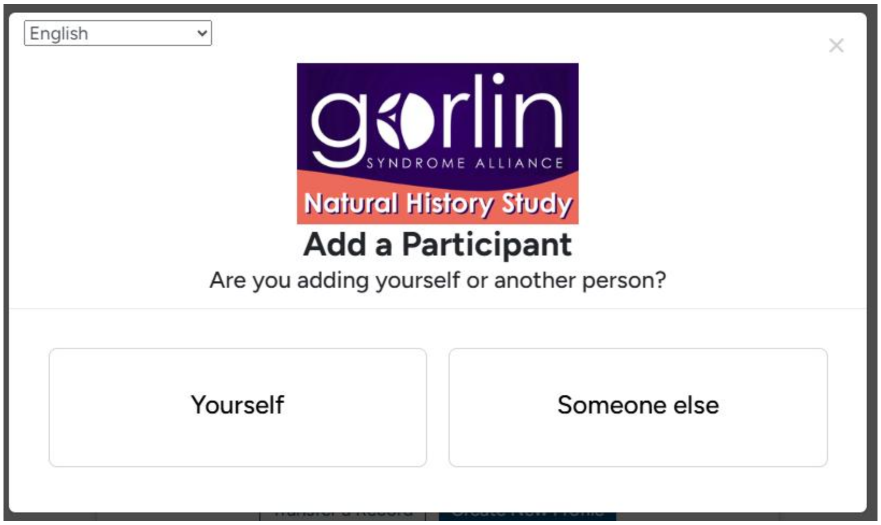
Welcome, Jane!

Welcome to the IAMRARE® program, home of **Gorlin Syndrome Alliance Patient Registry**.

If you are a new user, click on the **Create New Profile** button below.

If you are transferring a record from another IAMRARE account, click on the **Transfer a Record** button below.

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

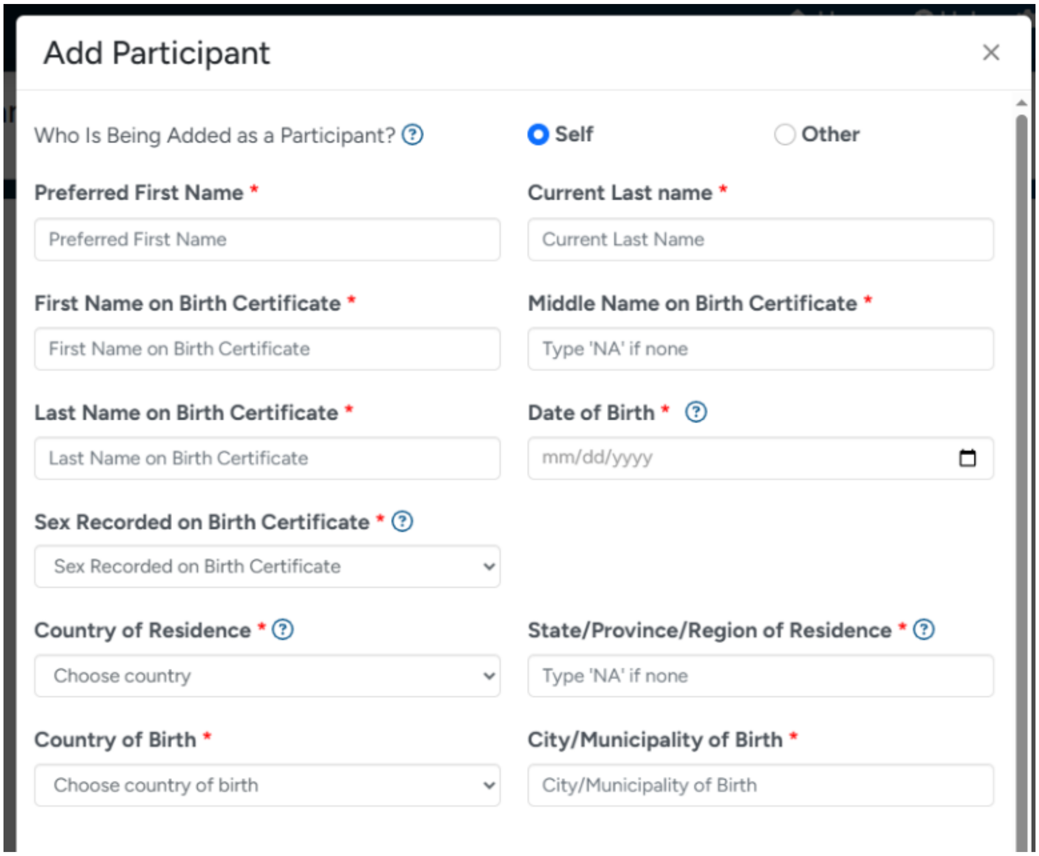


English

Add a Participant

Are you adding yourself or another person?

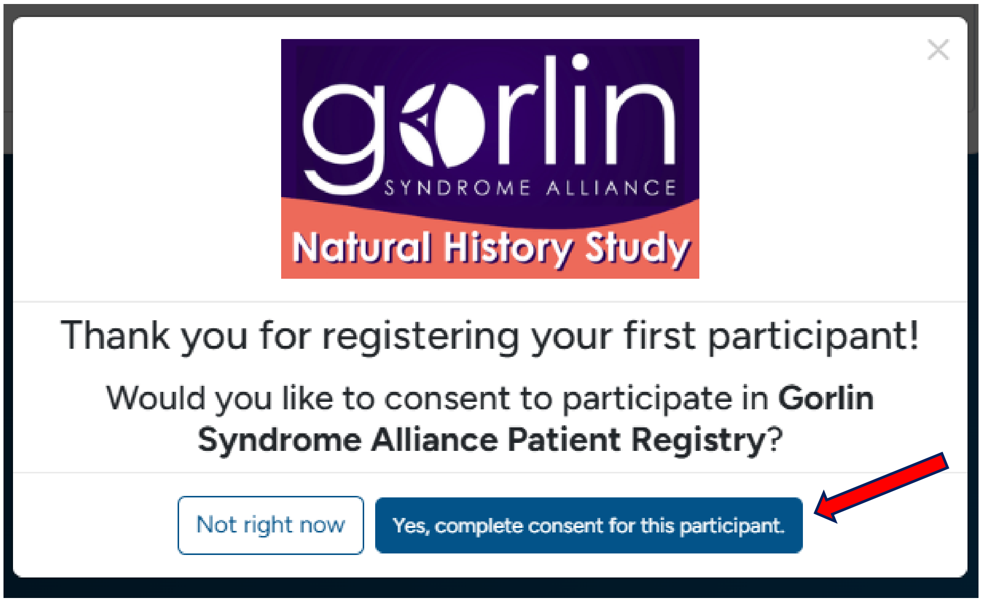
- Step 3: Fill out the Participant's information.



Who Is Being Added as a Participant? ● Self ○ Other

Consent to the Study

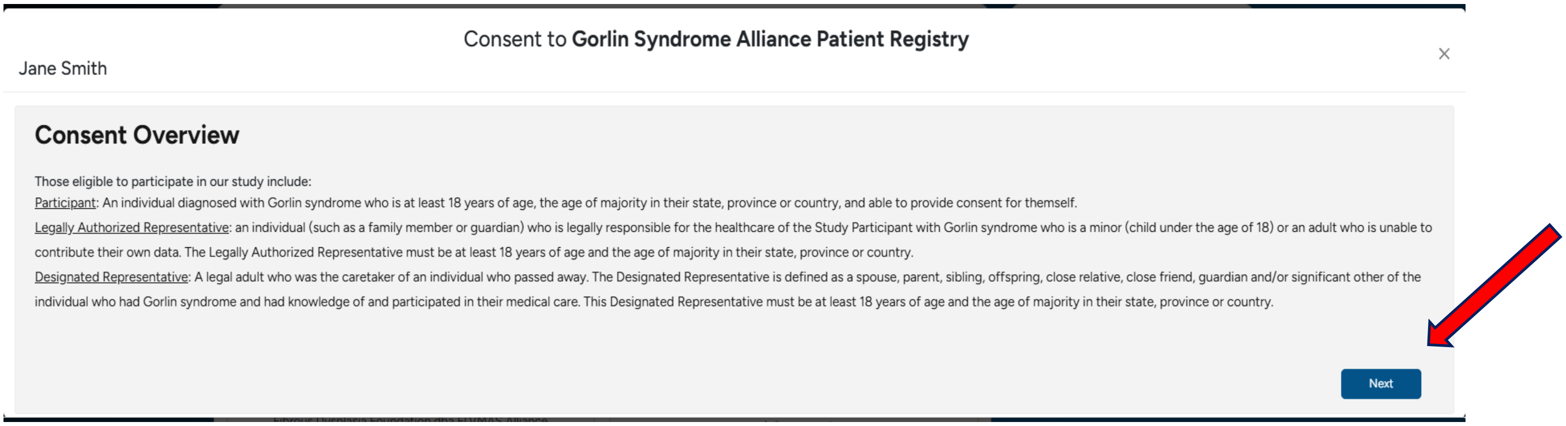
- Step 1: Click on "Yes, complete consent for this participant."



Thank you for registering your first participant!

Would you like to consent to participate in **Gorlin Syndrome Alliance Patient Registry**?

- 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.”


Consent to **Gorlin Syndrome Alliance Patient Registry**

Jane Smith

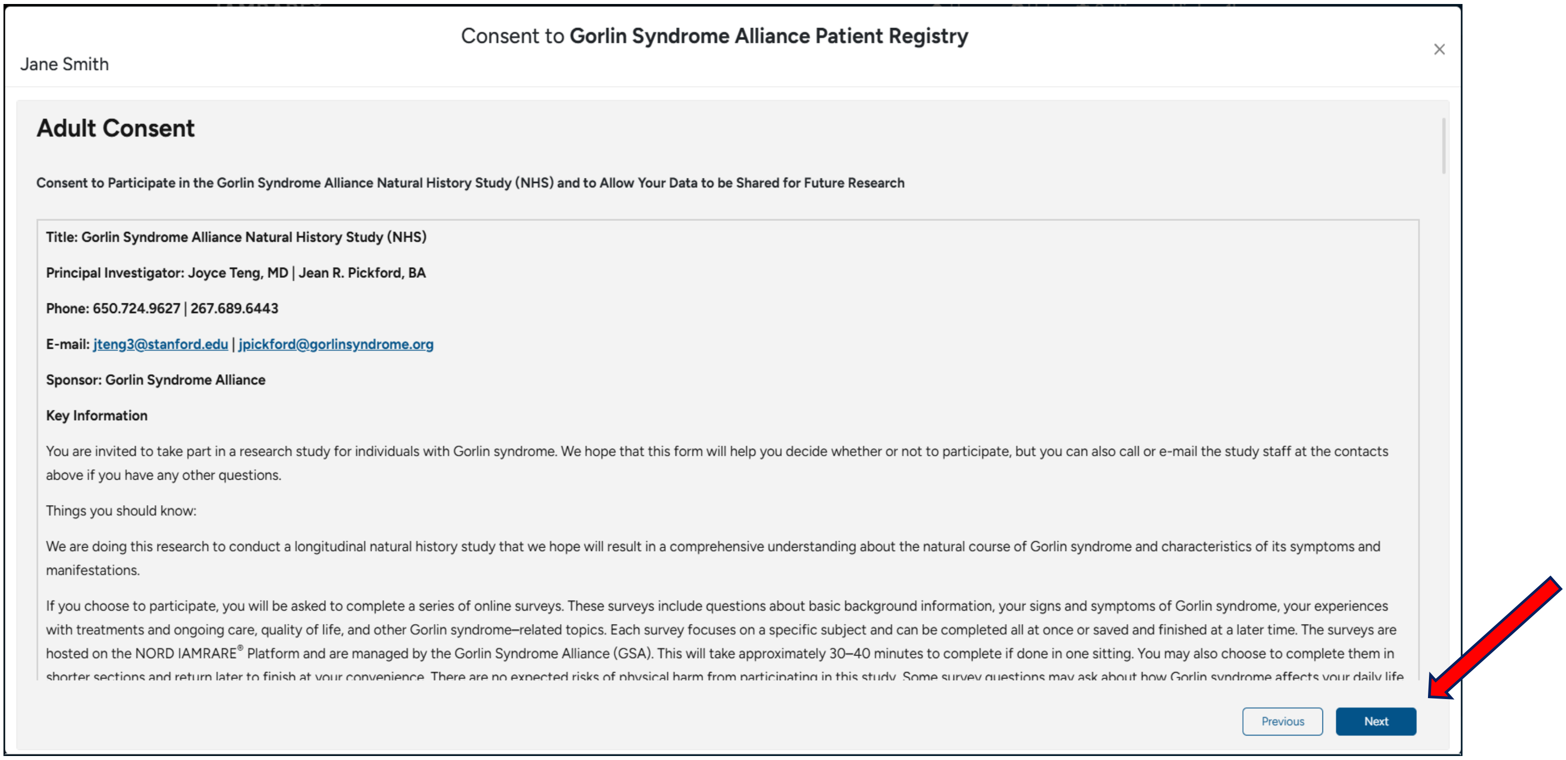
Consent Overview

Those eligible to participate in our study include:

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

Legally Authorized Representative: an individual (such as a family member or guardian) who is legally responsible for the healthcare of the Study Participant with Gorlin syndrome who is a minor (child under the age of 18) or an adult who is unable to contribute their own data. The Legally Authorized Representative must 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. The Designated Representative is defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had Gorlin syndrome and had knowledge of and participated in their medical care. This Designated Representative must be at least 18 years of age and the age of majority in their state, province or country.


Consent to **Gorlin Syndrome Alliance Patient Registry**

Jane Smith

Adult Consent

Consent to Participate in the Gorlin Syndrome Alliance Natural History Study (NHS) and to Allow Your Data to be Shared for Future Research

Title: Gorlin Syndrome Alliance Natural History Study (NHS)

Principal Investigator: Joyce Teng, MD | Jean R. Pickford, BA

Phone: 650.724.9627 | 267.689.6443

E-mail: jteng3@stanford.edu | jpickford@gorlinsyndrome.org

Sponsor: Gorlin Syndrome Alliance

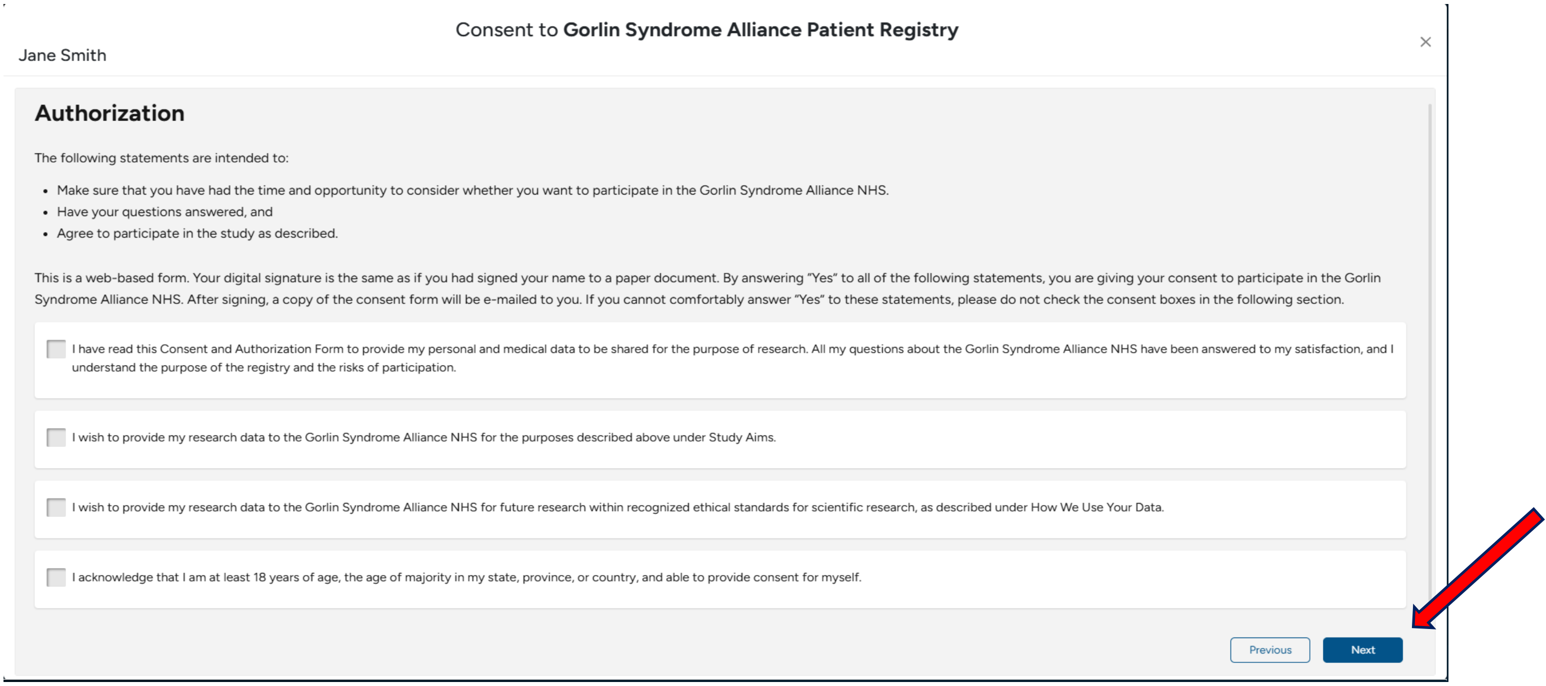
Key Information

You are invited to take part in a research study for individuals with Gorlin syndrome. 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.

Things you should know:

We are doing this research to conduct a longitudinal natural history study that we hope will result in a comprehensive understanding about the natural course of Gorlin syndrome and characteristics of its symptoms and manifestations.

If you choose to participate, you will be asked to complete a series of online surveys. These surveys include questions about basic background information, your signs and symptoms of Gorlin syndrome, your experiences with treatments and ongoing care, quality of life, and other Gorlin syndrome–related topics. Each survey focuses on a specific subject and can be completed all at once or saved and finished at a later time. The surveys are hosted on the NORD IAMRARE® Platform and are managed by the Gorlin Syndrome Alliance (GSA). This will take approximately 30–40 minutes to complete if done in one sitting. You may also choose to complete them in shorter sections and return later to finish at your convenience. There are no expected risks of physical harm from participating in this study. Some survey questions may ask about how Gorlin syndrome affects your daily life


Consent to **Gorlin Syndrome Alliance Patient Registry**

Jane Smith

Authorization

The following statements are intended to:

- Make sure that you have had the time and opportunity to consider whether you want to participate in the Gorlin Syndrome Alliance NHS.
- Have your questions answered, and
- Agree to participate in the study as described.

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 the Gorlin Syndrome Alliance NHS. 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.

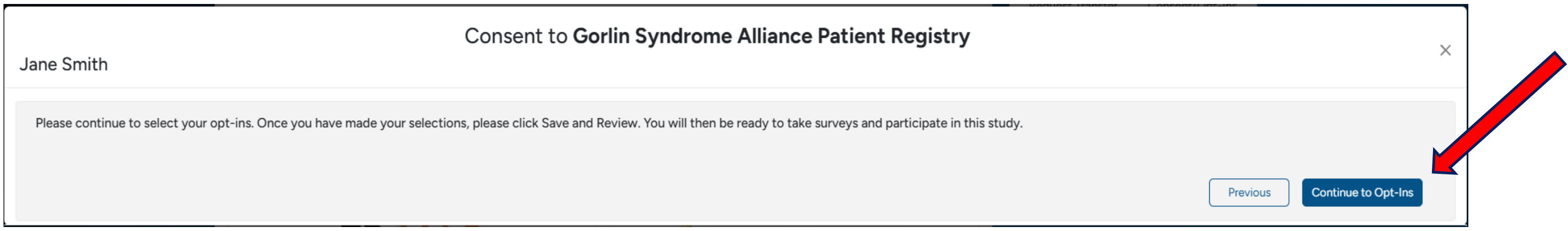
☐ I have read this Consent and Authorization Form to provide my personal and medical data to be shared for the purpose of research. All my questions about the Gorlin Syndrome Alliance NHS have been answered to my satisfaction, and I understand the purpose of the registry and the risks of participation.

☐ I wish to provide my research data to the Gorlin Syndrome Alliance NHS for the purposes described above under Study Aims.

☐ I wish to provide my research data to the Gorlin Syndrome Alliance NHS for future research within recognized ethical standards for scientific research, as described under How We Use Your Data.

☐ I acknowledge that I am at least 18 years of age, the age of majority in my state, province, or country, and able to provide consent for myself.

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


Consent to **Gorlin Syndrome Alliance Patient Registry**

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.

- 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 Gorlin Syndrome Alliance Patient Registry

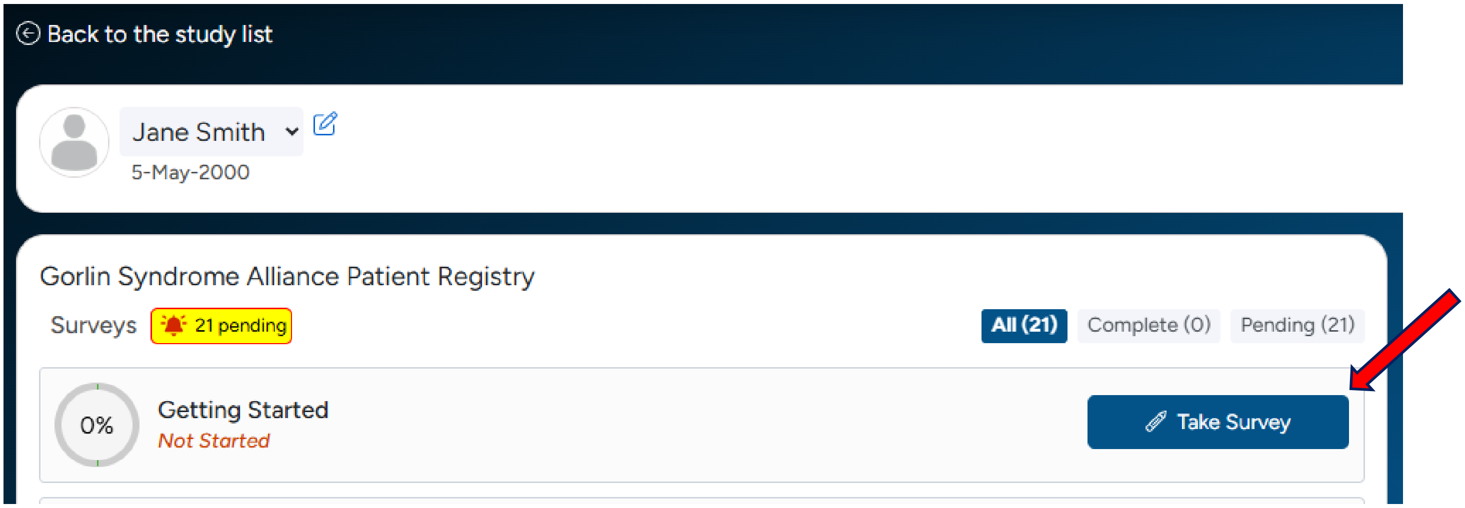
Select Opt-Ins for this study

☐ Interest in hearing about other studies from **Gorlin Syndrome Alliance**
☐ 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 **Gorlin Syndrome Alliance**
☐ Interest in signing up for a **Gorlin Syndrome Alliance** newsletter
☐ If eligible, I have interest in receiving **Gorlin Syndrome Alliance** merchandise that would be sent via electronic or postal mail
☐ Support from other Patient Advocacy Groups
☐ Interest in learning about upcoming events such as webinars and conferences

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

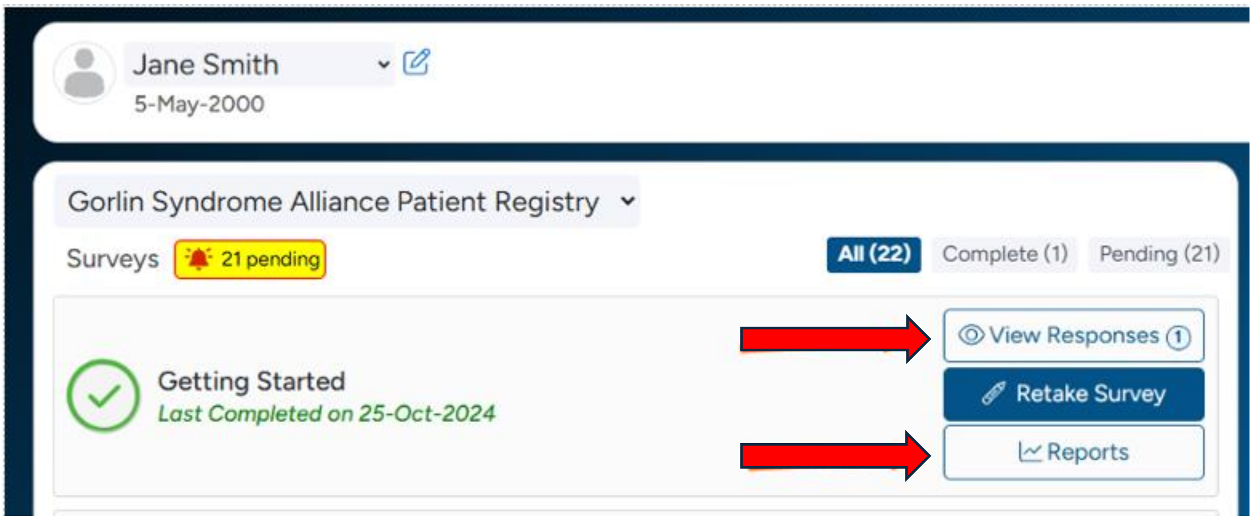
Taking Surveys

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



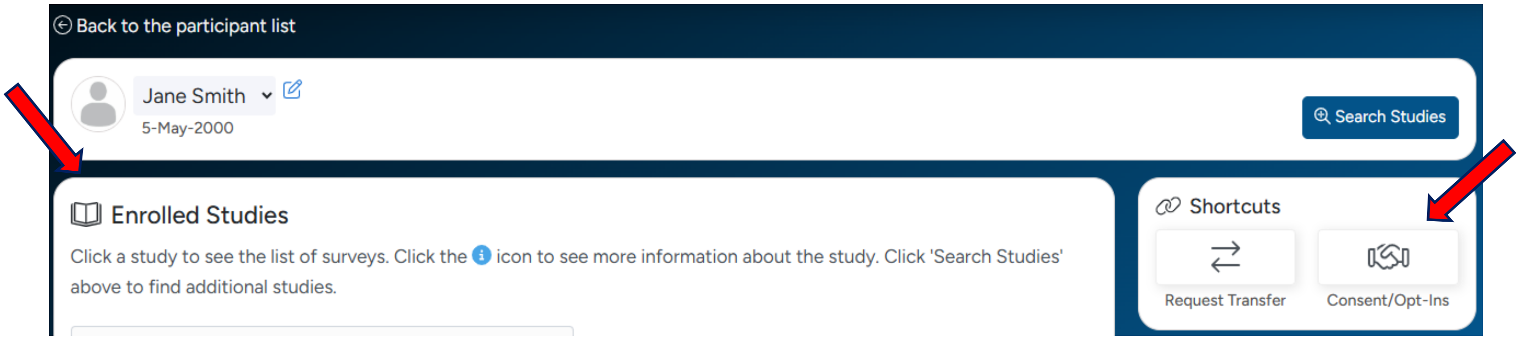
View Responses and Reports

- 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.



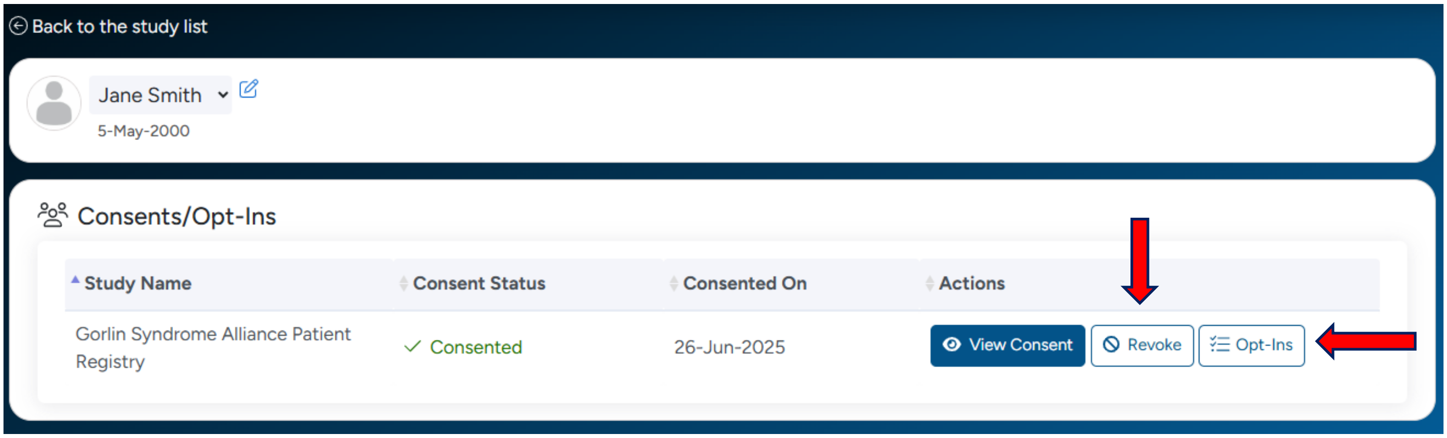
View Consent and Opt-Ins

- 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.



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

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

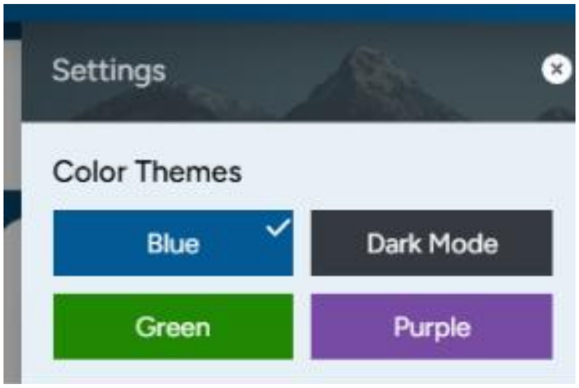


Study Name	Consent Status	Consented On	Actions
Gorlin Syndrome Alliance Patient Registry	✓ Consented	26-Jun-2025	View Consent Revoke Opt-Ins

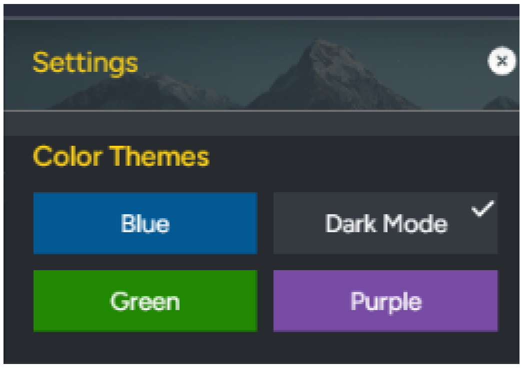
Dark Mode Settings

- 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.

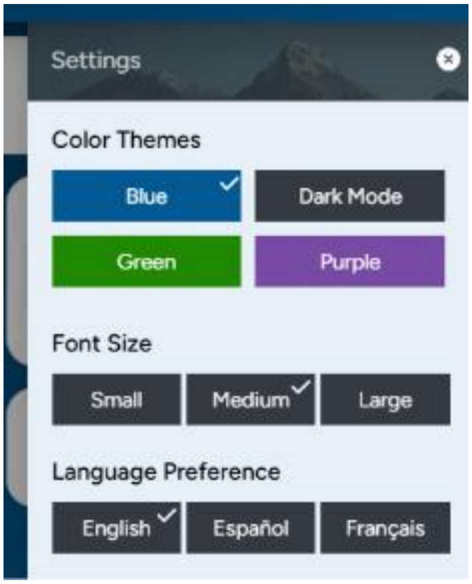


Display Settings

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

Good Afternoon, Jane!
Member since Jun 26, 2025

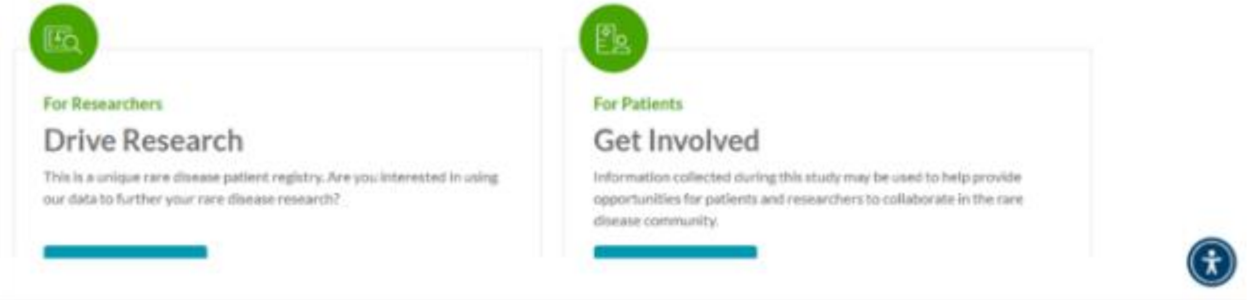
- Step 2: Select a color theme, a font size, or language preference.



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

Microsite Visibility

- Step 1: You can change how you view the microsite (https://gorlinsyndrome.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.


For Researchers

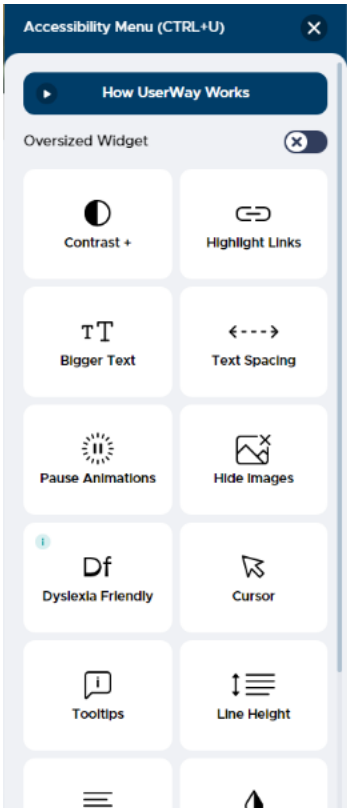
Drive Research

This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?

For Patients

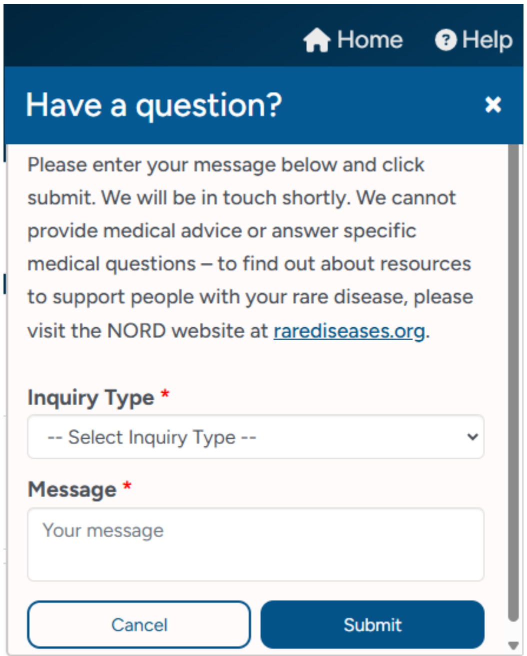
Get Involved

Information collected during this study may be used to help provide opportunities for patients and researchers to collaborate in the rare disease community.



Need Assistance?

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



Have a question?

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.

Inquiry Type *

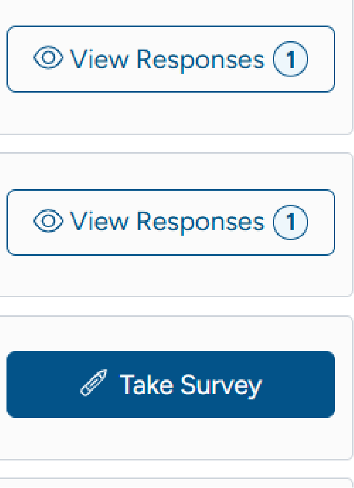
-- Select Inquiry Type --

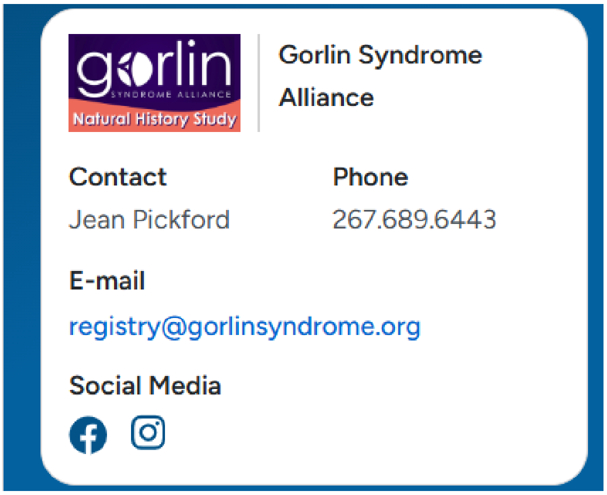
Message *

Your message

- 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.





Gorlin Syndrome Alliance

Contact
Jean Pickford

Phone
267.689.6443

E-mail
registry@gorlinsyndrome.org

Social Media