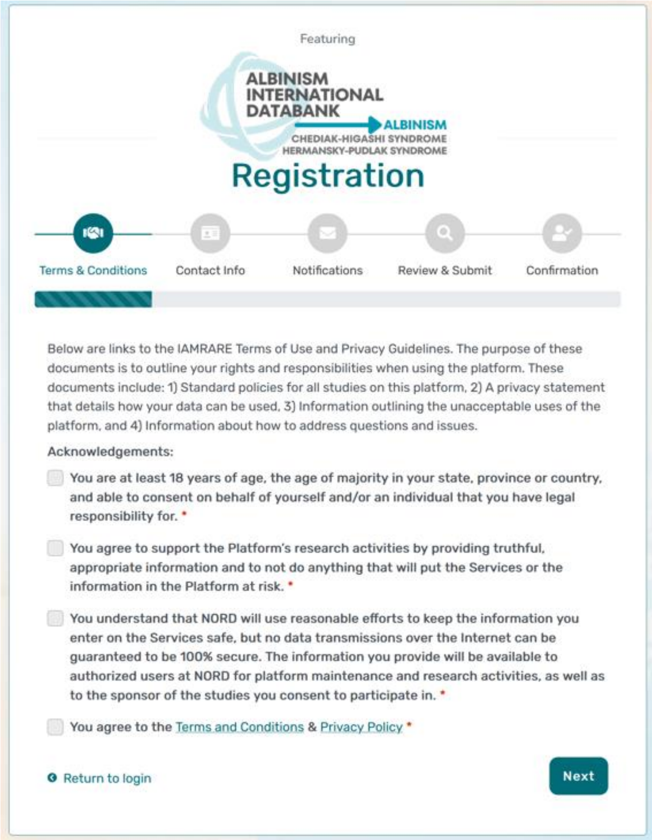
ALBINISM
INTERNATIONAL
DATABANK
ALBINISM
CHEDIAK-HIGASHI SYNDROME
HERMANSKY-PUDLAK SYNDROME

Albinism International Databank 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:

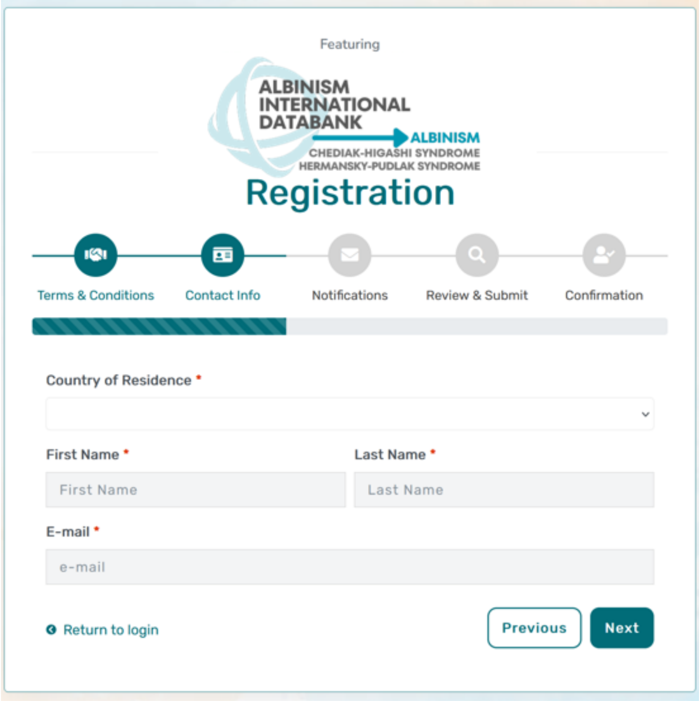
☐ You are at least 18 years of age, the age of majority in your state, province or country, and able to consent on behalf of yourself and/or an individual that you have legal responsibility for. *

☐ 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. *

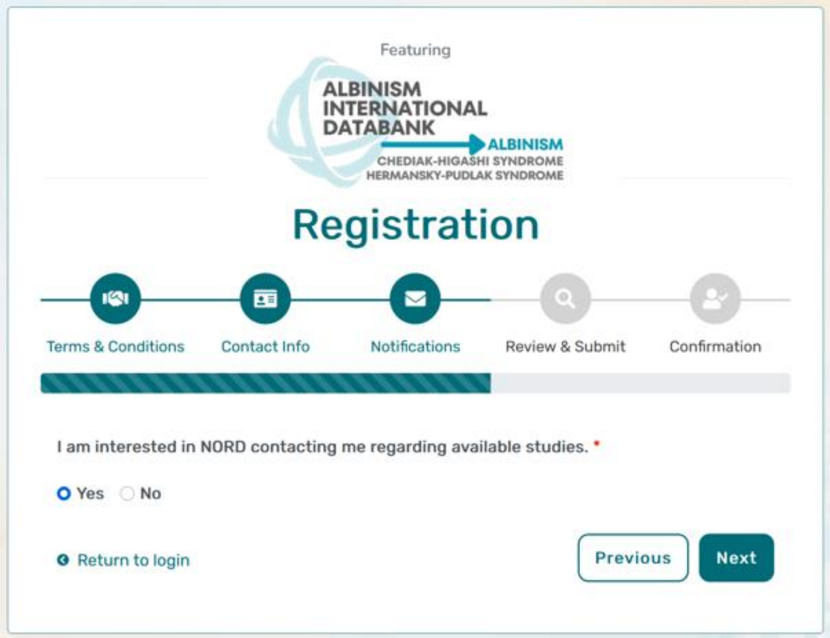
☐ You understand that NORD will use reasonable efforts to keep the information you enter on the Services safe, but no data transmissions over the Internet can be guaranteed to be 100% secure. The information you provide will be available to authorized users at NORD for platform maintenance and research activities, as well as to the sponsor of the studies you consent to participate in. *

☐ You agree to the Terms and Conditions & Privacy Policy *

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



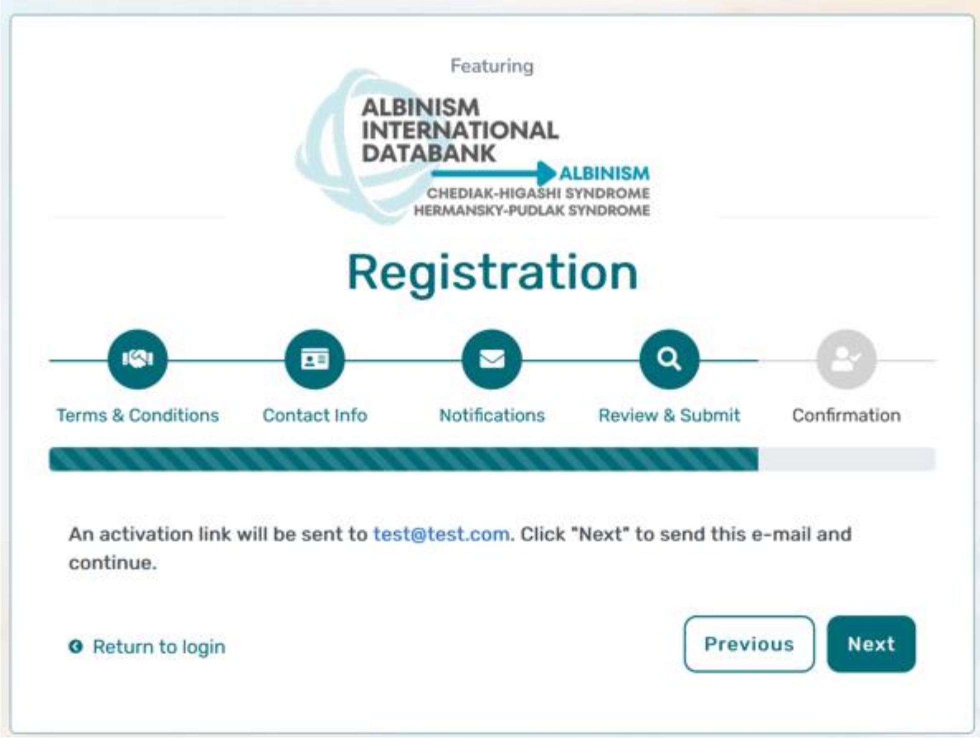
- Step 3: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click "Next".



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

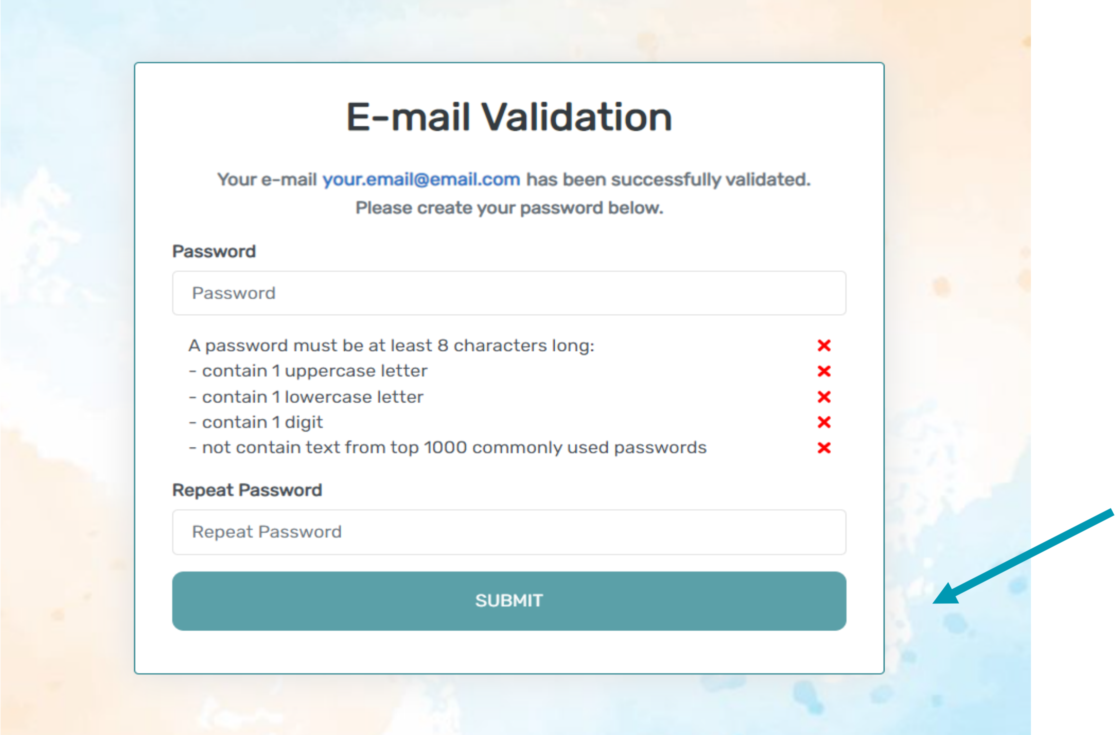
● Yes ○ No

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



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

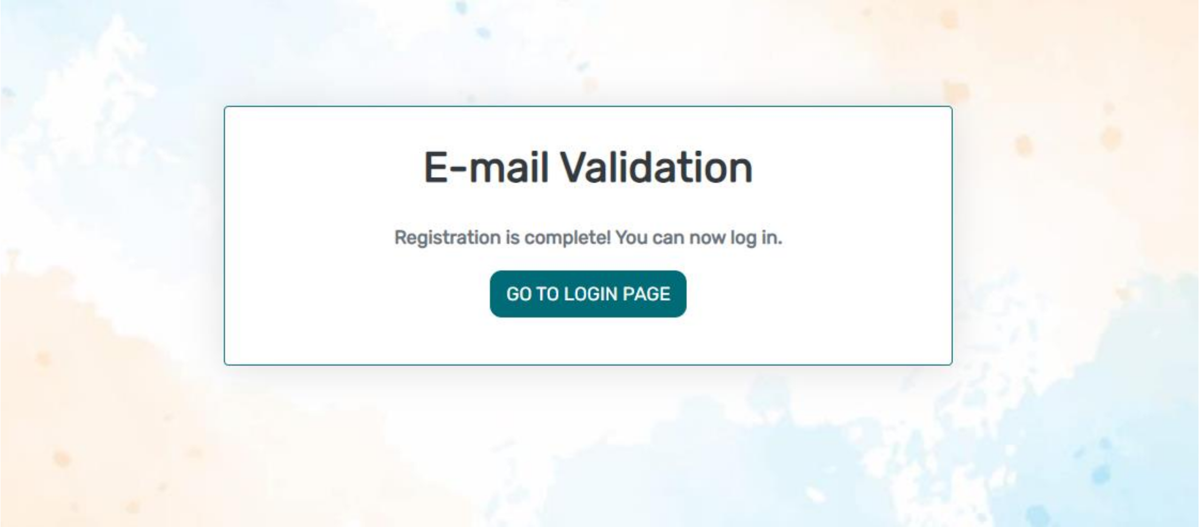
- Step 5: Click the link you are sent via e-mail. Please check your Spam folder if you do not see the e-mail. You will be taken to the following screen in a new tab within your browser. Set your password and click “Submit”.



Your e-mail your.email@email.com 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 ✗

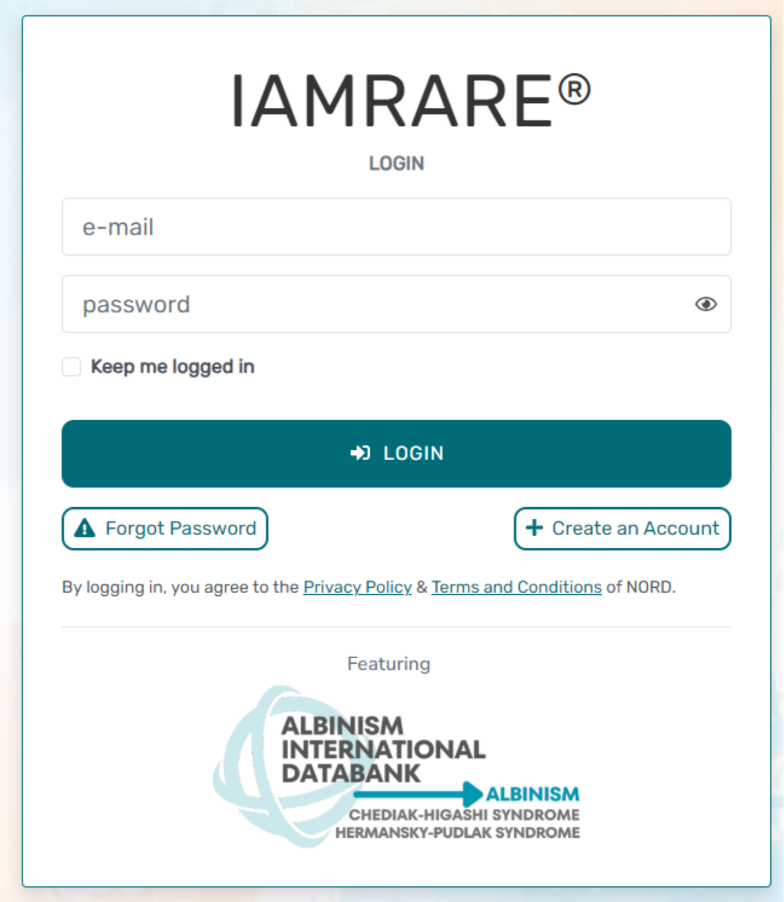
- Step 6: Your validation is now complete. Select “Go to Login Page”.



E-mail Validation

Registration is complete! You can now log in.

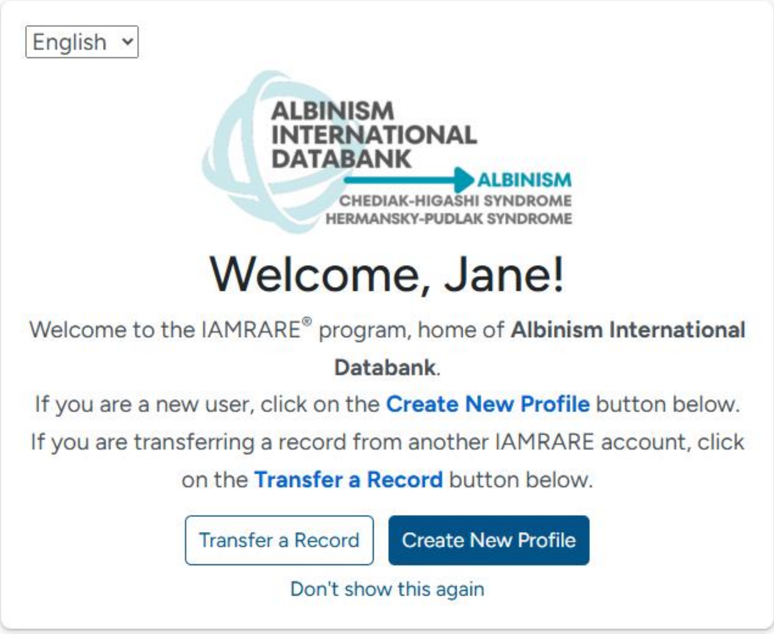
- Step 7: Log in using your new e-mail and password.



By logging in, you agree to the Privacy Policy & Terms and Conditions of NORD.

Add a Participant

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



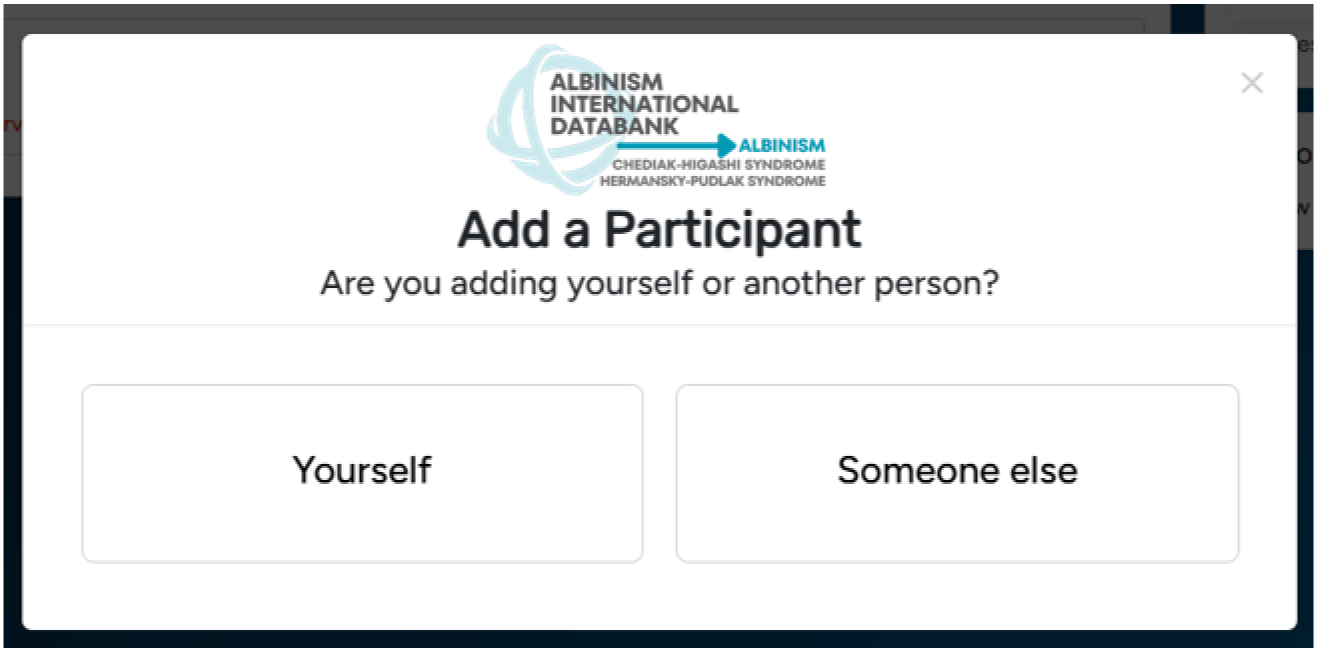
Welcome, Jane!

Welcome to the IAMRARE® program, home of **Albinism International Databank**.

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.

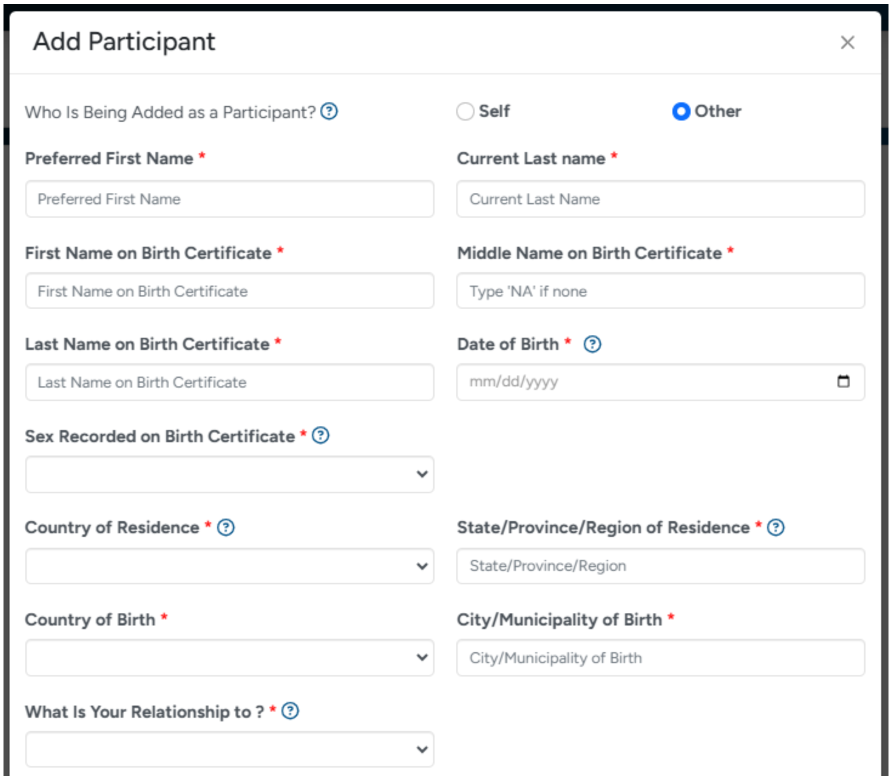
- Step 2: Select who you will be providing information about.



Add a Participant

Are you adding yourself or another person?

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



Add Participant ×

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

Preferred First Name * [Preferred First Name]

Current Last name * [Current Last Name]

First Name on Birth Certificate * [First Name on Birth Certificate]

Middle Name on Birth Certificate * [Type 'NA' if none]

Last Name on Birth Certificate * [Last Name on Birth Certificate]

Date of Birth * ⓘ [mm/dd/yyyy]

Sex Recorded on Birth Certificate * ⓘ

Country of Residence * ⓘ

State/Province/Region of Residence * ⓘ [State/Province/Region]

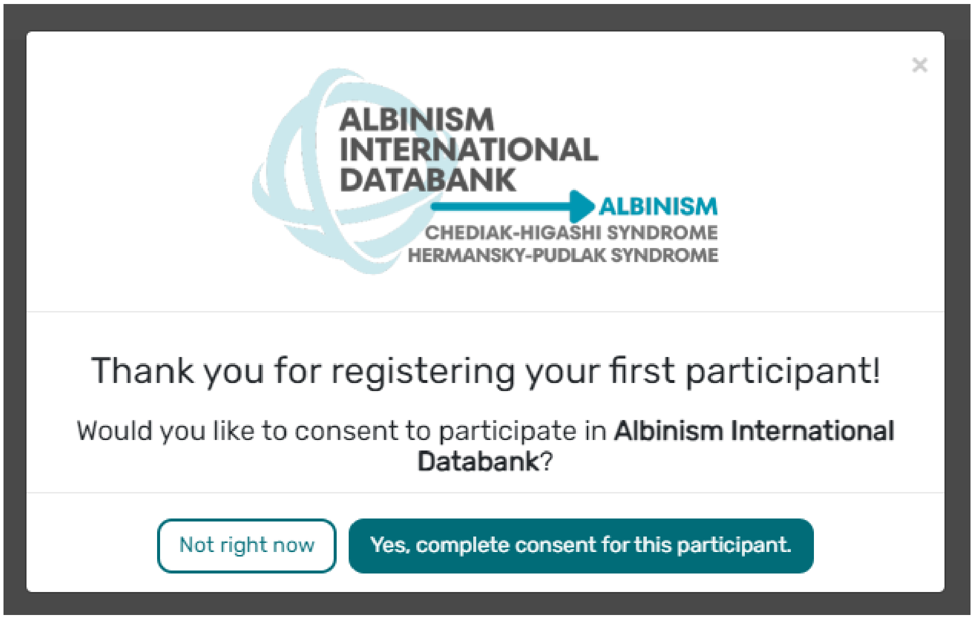
Country of Birth *

City/Municipality 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."



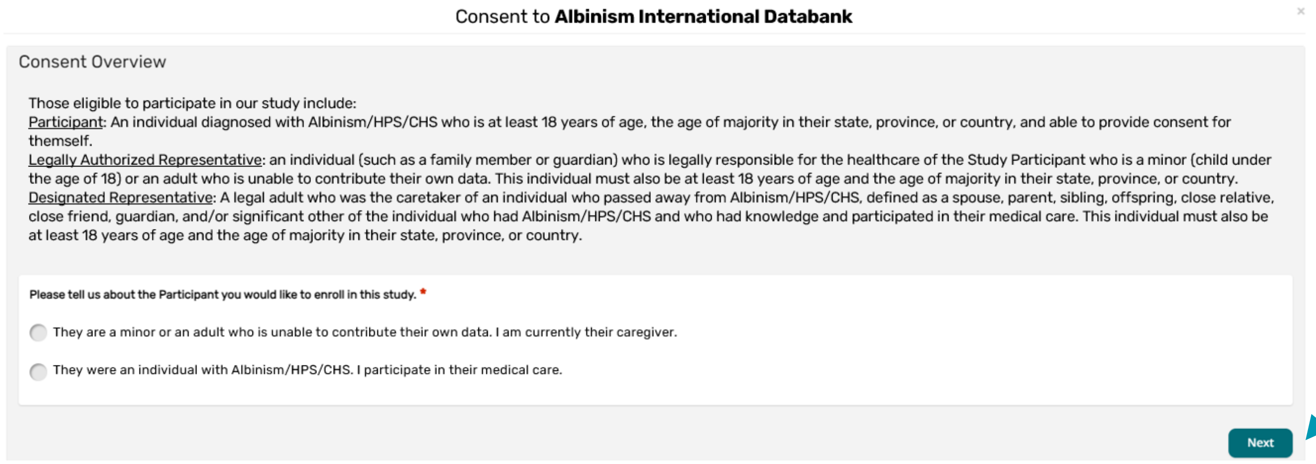
ALBINISM INTERNATIONAL DATABANK
ALBINISM
CHEDIAK-HIGASHI SYNDROME
HERMANSKY-PUDLAK SYNDROME

Thank you for registering your first participant!

Would you like to consent to participate in **Albinism International Databank**?

Not right now | Yes, complete consent for this participant.

- 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 **Albinism International Databank**

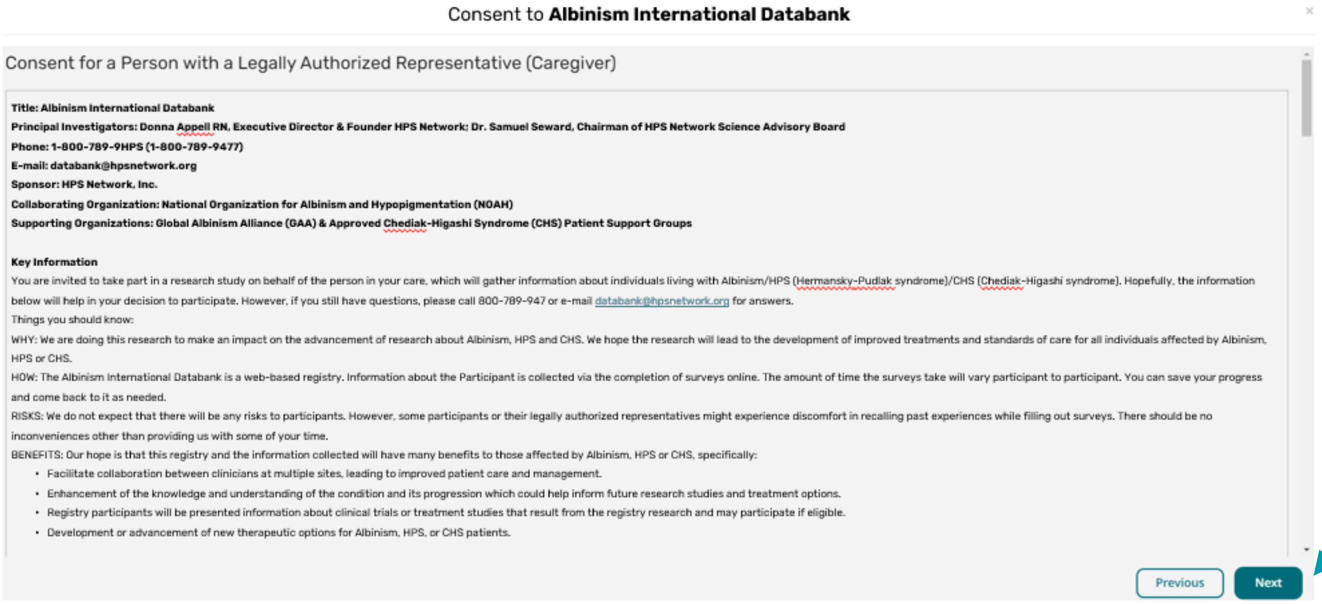
Consent Overview

Those eligible to participate in our study include:
Participant: An individual diagnosed with Albinism/HPS/CHS 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 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 Albinism/HPS/CHS, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian, and/or significant other of the individual who had Albinism/HPS/CHS 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 an individual with Albinism/HPS/CHS. I participate in their medical care.

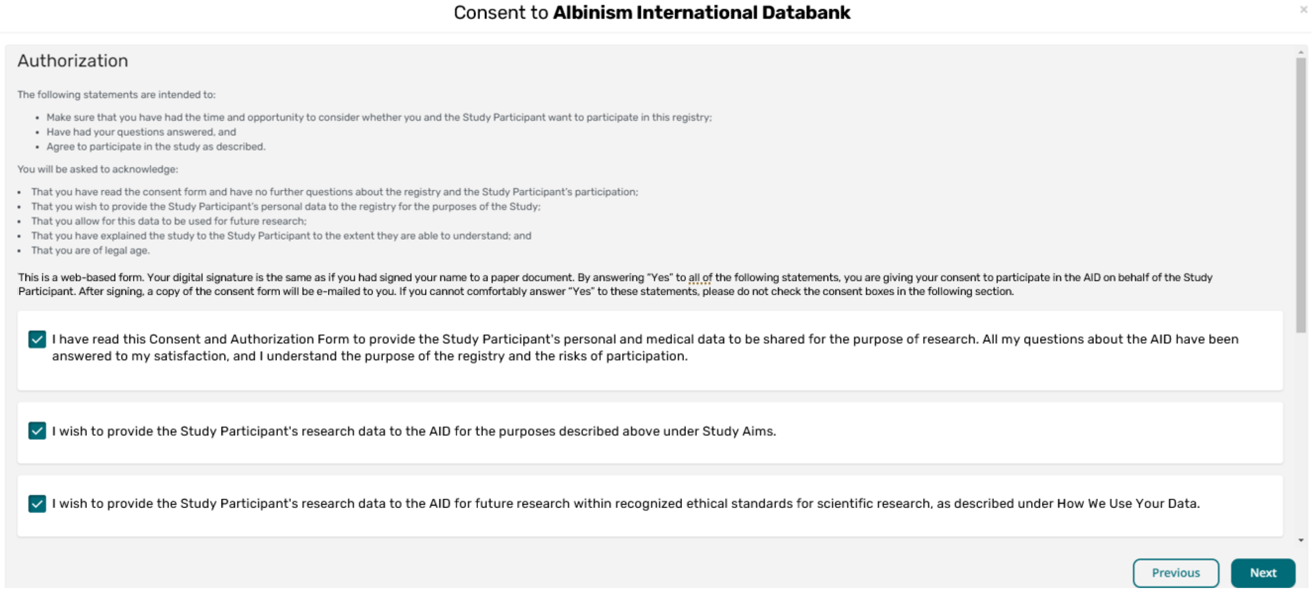

Consent to **Albinism International Databank**

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

Title: Albinism International Databank
Principal Investigators: Donna Appell RN, Executive Director & Founder HPS Network; Dr. Samuel Seward, Chairman of HPS Network Science Advisory Board
Phone: 1-800-789-9HPS (1-800-789-9477)
E-mail: databank@hpsnetwork.org
Sponsor: HPS Network, Inc.
Collaborating Organization: National Organization for Albinism and Hypopigmentation (NOAH)
Supporting Organizations: Global Albinism Alliance (GAA) & Approved Chediak-Higashi Syndrome (CHS) Patient Support Groups

Key Information
You are invited to take part in a research study on behalf of the person in your care, which will gather information about individuals living with Albinism/HPS (Hermansky-Pudlak syndrome)/CHS (Chediak-Higashi syndrome). Hopefully, the information below will help in your decision to participate. However, if you still have questions, please call 800-789-947 or e-mail databank@hpsnetwork.org for answers.
Things you should know:
WHY: We are doing this research to make an impact on the advancement of research about Albinism, HPS and CHS. We hope the research will lead to the development of improved treatments and standards of care for all individuals affected by Albinism, HPS or CHS.
HOW: The Albinism International Databank is a web-based registry. Information about the Participant is collected via the completion of surveys online. The amount of time the surveys take will vary participant to participant. You can save your progress and come back to it as needed.
RISKS: We do not expect that there will be any risks to participants. However, some participants or their legally authorized representatives might experience discomfort in recalling past experiences while filling out surveys. There should be no inconveniences other than providing us with some of your time.
BENEFITS: Our hope is that this registry and the information collected will have many benefits to those affected by Albinism, HPS or CHS, specifically:

- Facilitate collaboration between clinicians at multiple sites, leading to improved patient care and management.
- Enhancement of the knowledge and understanding of the condition and its progression which could help inform future research studies and treatment options.
- Registry participants will be presented information about clinical trials or treatment studies that result from the registry research and may participate if eligible.
- Development or advancement of new therapeutic options for Albinism, HPS, or CHS patients.


Consent to **Albinism International Databank**

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 registry;
- 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 registry and the Study Participant’s participation;
- That you wish to provide the Study Participant’s personal data to the registry 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.

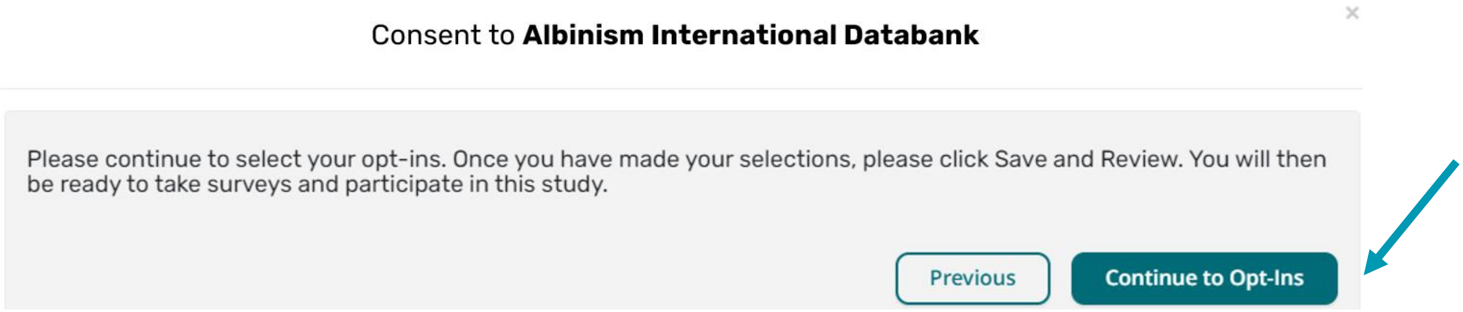
This is a web-based form. Your digital signature is the same as if you had signed your name to a paper document. By answering “Yes” to all of the following statements, you are giving your consent to participate in the AID on behalf of the Study Participant. After signing, a copy of the consent form will 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 the AID have been answered to my satisfaction, and I understand the purpose of the registry and the risks of participation.

☑ I wish to provide the Study Participant's research data to the AID for the purposes described above under Study Aims.

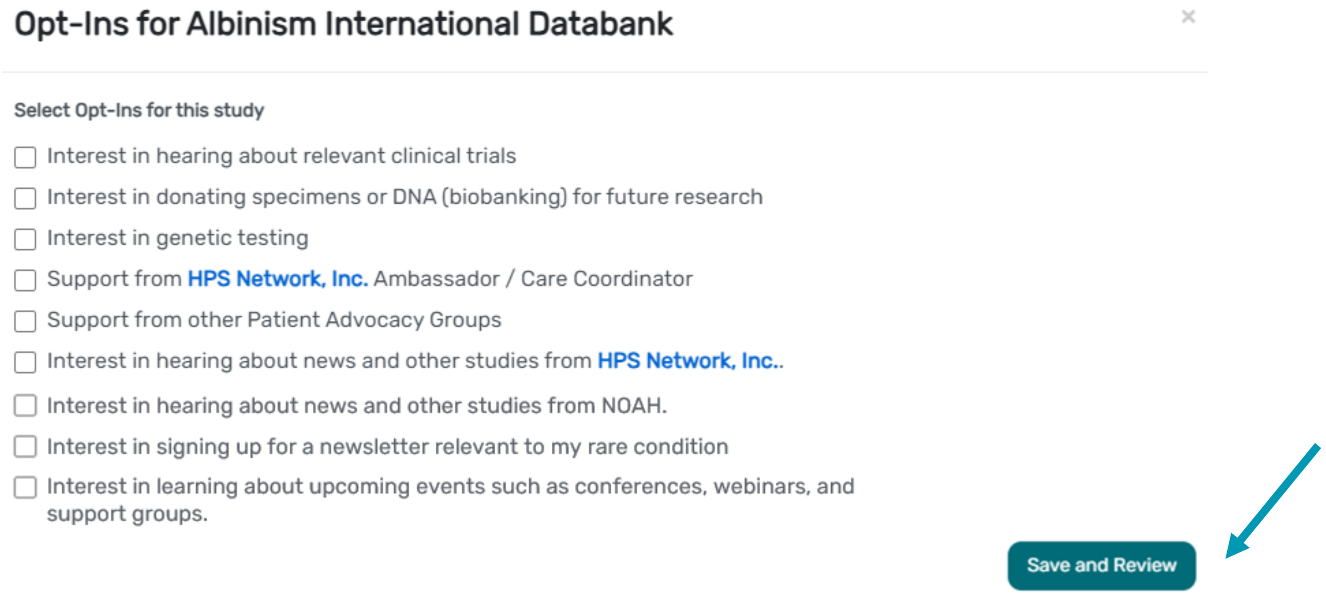
☑ I wish to provide the Study Participant's research data to the AID for future research within recognized ethical standards for scientific research, as described under How We Use Your Data.

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


Consent to **Albinism International Databank**

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 Albinism International Databank

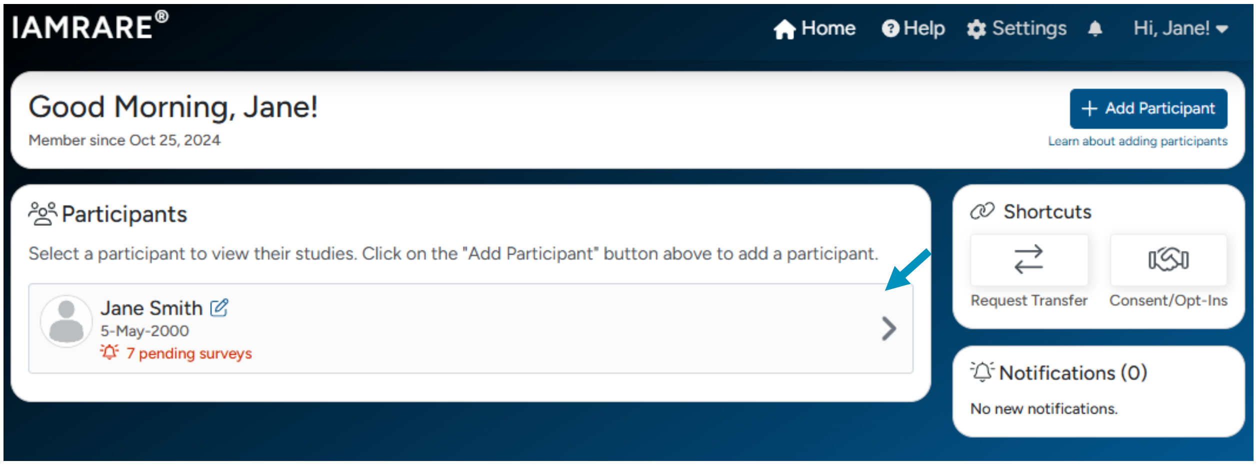
Select Opt-Ins for this study

☐ Interest in hearing about relevant clinical trials
☐ Interest in donating specimens or DNA (biobanking) for future research
☐ Interest in genetic testing
☐ Support from **HPS Network, Inc.** Ambassador / Care Coordinator
☐ Support from other Patient Advocacy Groups
☐ Interest in hearing about news and other studies from **HPS Network, Inc.**.
☐ Interest in hearing about news and other studies from NOAH.
☐ Interest in signing up for a newsletter relevant to my rare condition
☐ Interest in learning about upcoming events such as conferences, webinars, and support groups.

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

Taking Surveys

- Step 1: Click on your Participant.


Good Morning, Jane!

Member since Oct 25, 2024

Participants

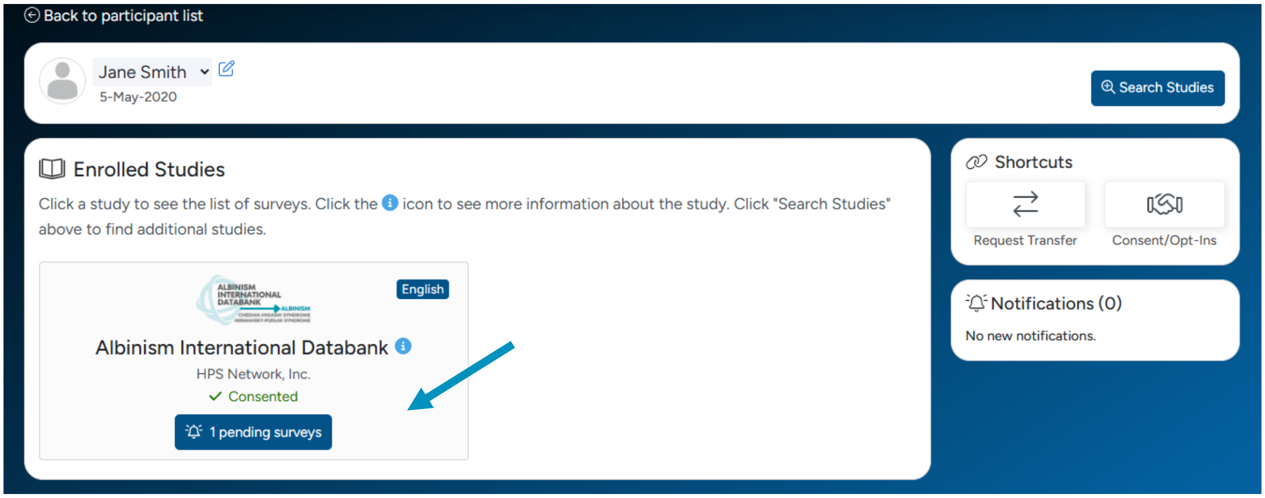
Select a participant to view their studies. Click on the "Add Participant" button above to add a participant.

Jane Smith
5-May-2000
7 pending surveys

Notifications (0)

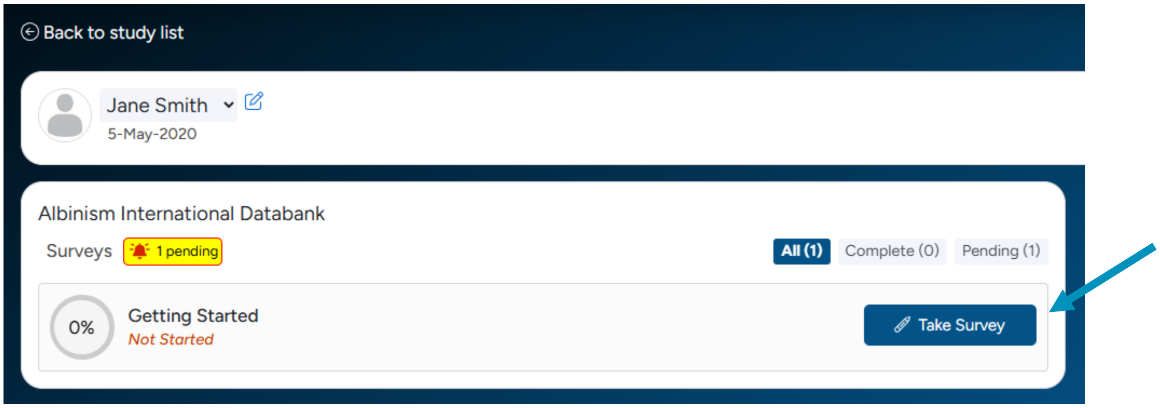
No new notifications.

- Step 2: Click on the appropriate study.



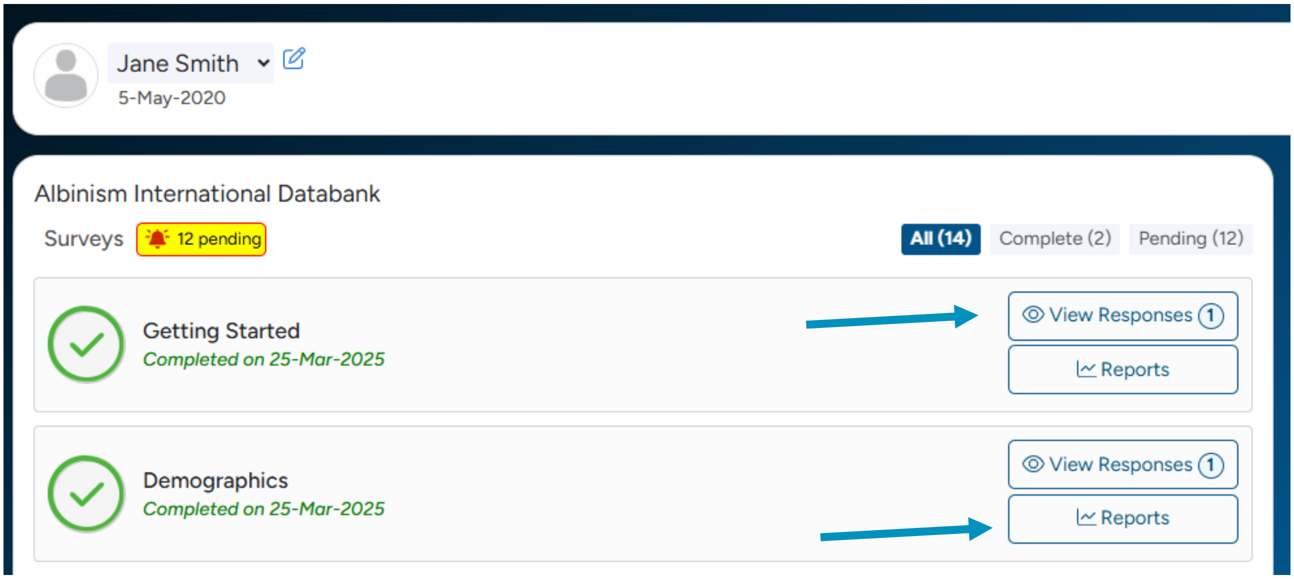
Click a study to see the list of surveys. Click the ℹ icon to see more information about the study. Click "Search Studies" above to find additional studies.

- Step 3: Click “Take Survey” for an available survey.



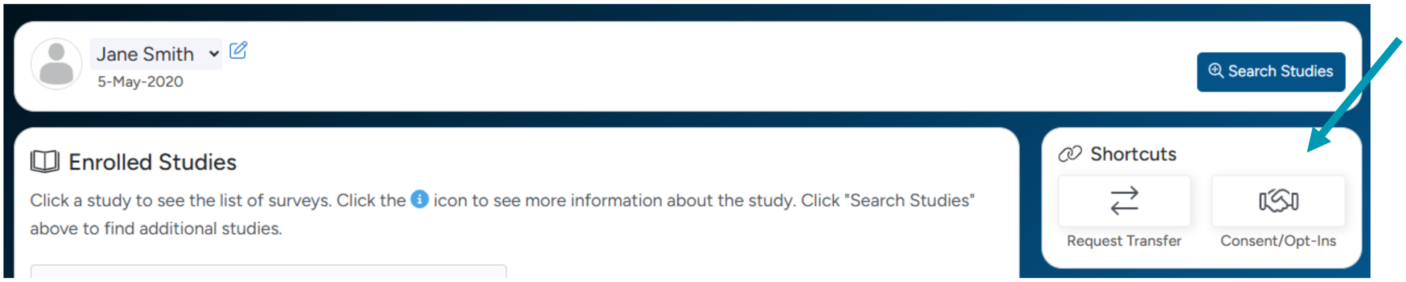
View Responses and Reports

- 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.

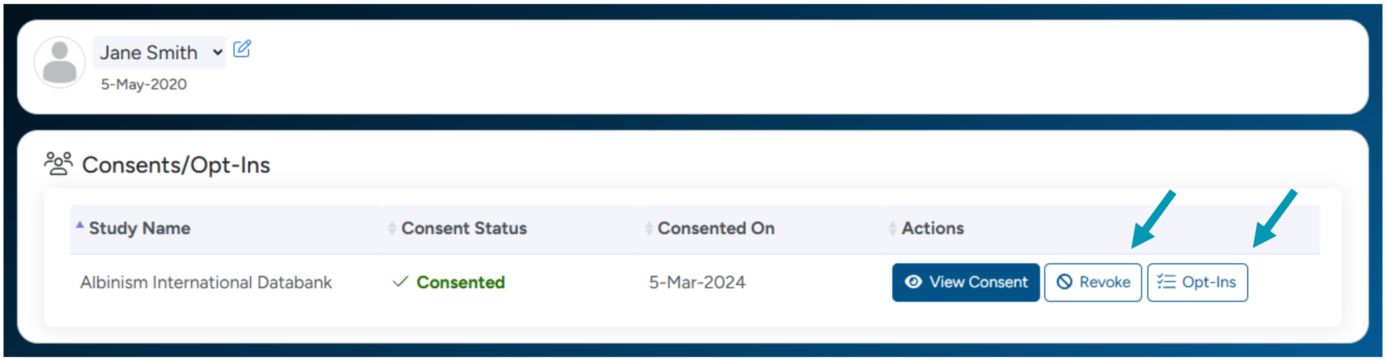


View Consent and Opt-Ins

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



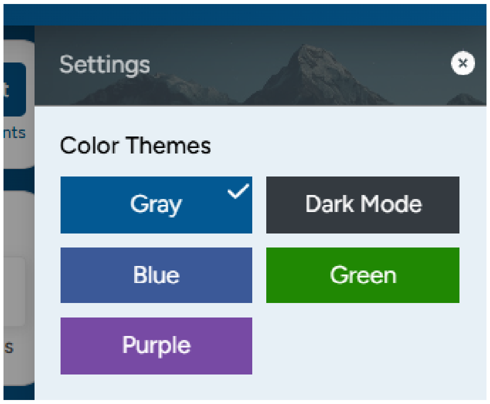
Study Name	Consent Status	Consented On	Actions
Albinism International Databank	✓ Consented	5-Mar-2024	View Consent Revoke Opt-Ins

Dark Mode Settings

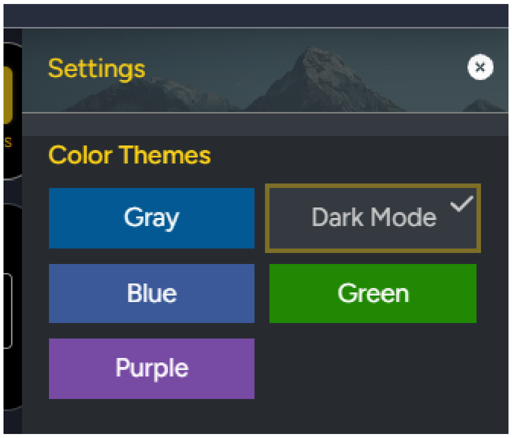
- Step 1: You can view the platform in Dark Mode. First, click Settings.

Good Afternoon, Jane!
Member since Nov 16, 2024

- Step 2: Select Dark Mode.

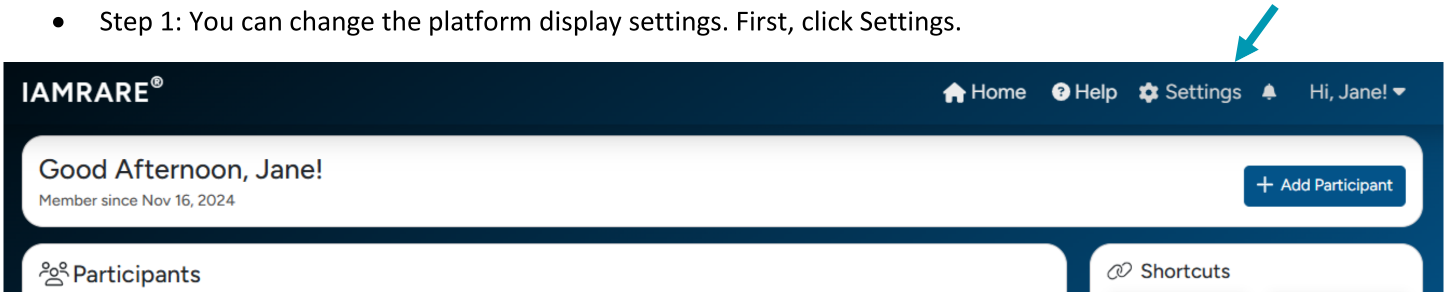


- Step 3: Exit the Settings menu, and your selection will be saved.

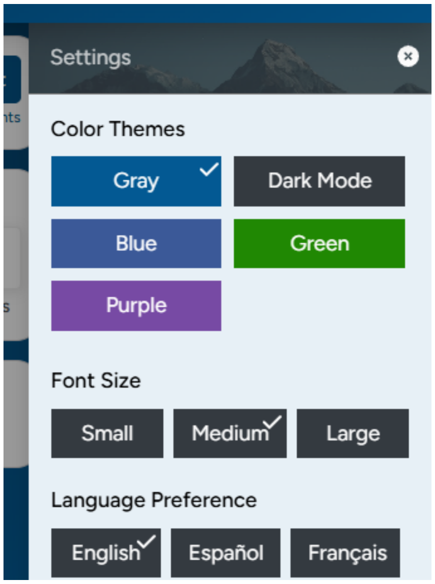


Display Settings

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



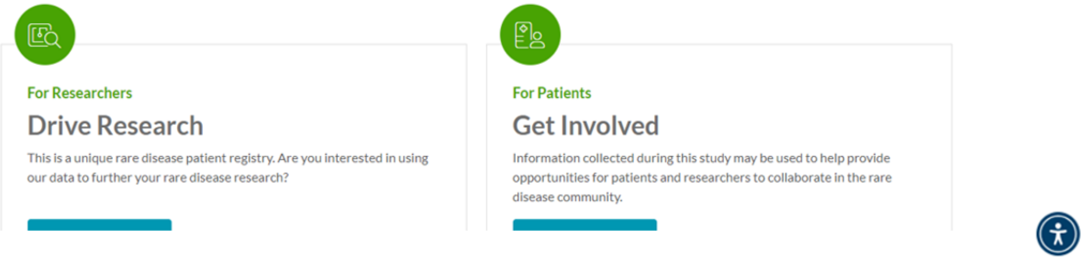
- Step 2: Select a color theme, a font size, or language preference.



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

Microsite Visibility

- Step 1: You can change how you view the microsite (aid.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

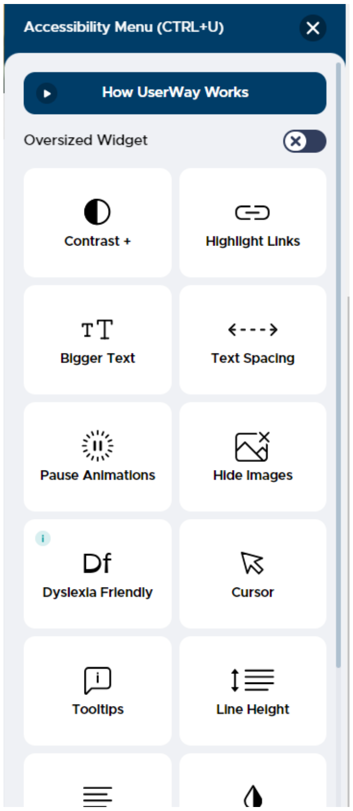
Drive Research

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

For Patients

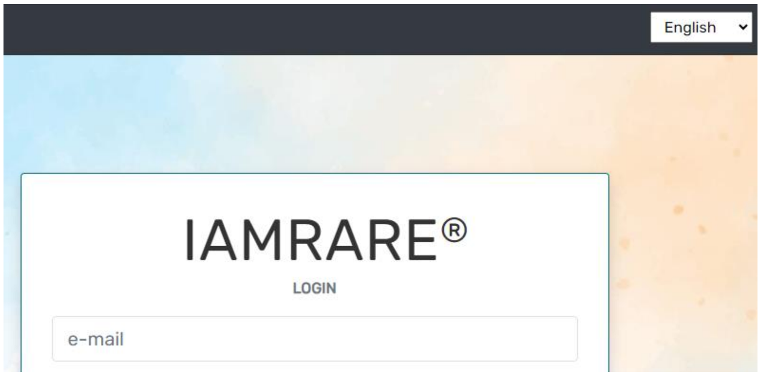
Get Involved

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



Language Selection

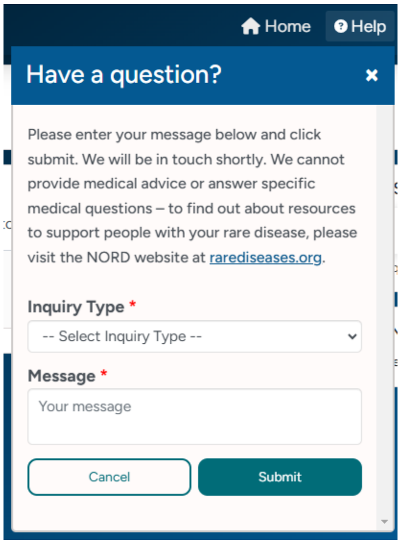
- This study is available in English and Spanish. To change your platform language selection on the login/register page, select the dropdown that says “English”, and choose your preferred language.



- To change your platform language selection after you've logged in, click "Settings", and choose your preferred language.

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.

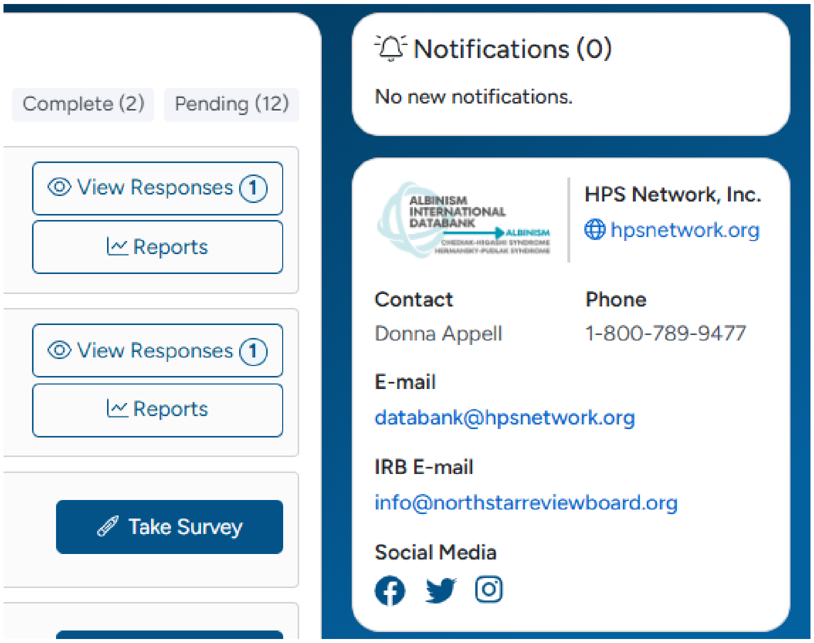
Inquiry Type *

-- 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.



Notifications (0)

No new notifications.

HPS Network, Inc.

hpsnetwork.org

Contact

Donna Appell

Phone

1-800-789-9477

E-mail

databank@hpsnetwork.org

IRB E-mail

info@northstarreviewboard.org

Social Media