



Organic Acidemia Association

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

Organic Acidemia Association

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”.

Featuring



Organic Acidemia Association

Registration

Progress: Terms & Conditions | Contact Info | Notifications | Review & Submit | Confirmation

Country of Residence *

First Name * Last Name *

E-mail *

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

Featuring



Organic Acidemia Association

Registration

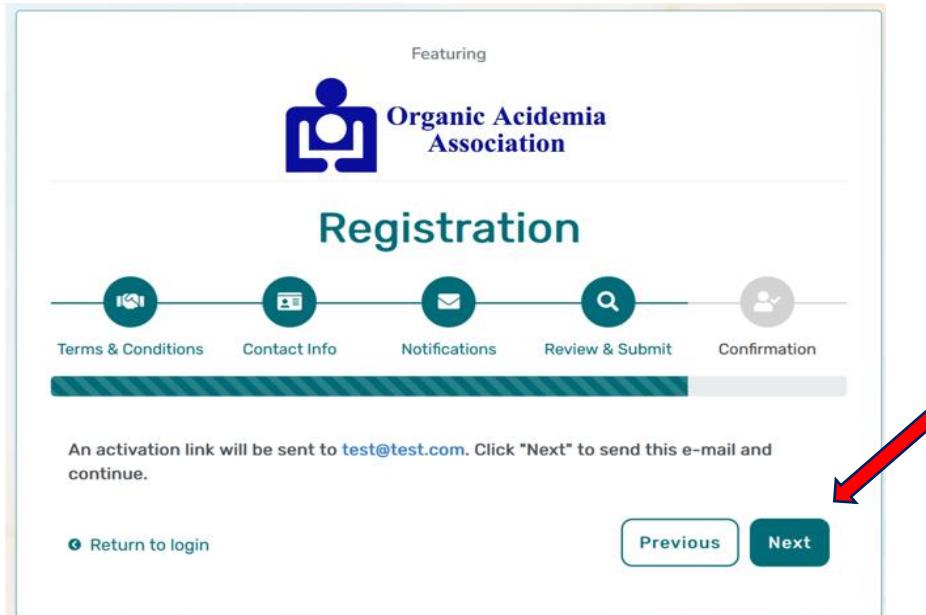
Progress: Terms & Conditions | Contact Info | Notifications | Review & Submit | Confirmation

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

Yes No

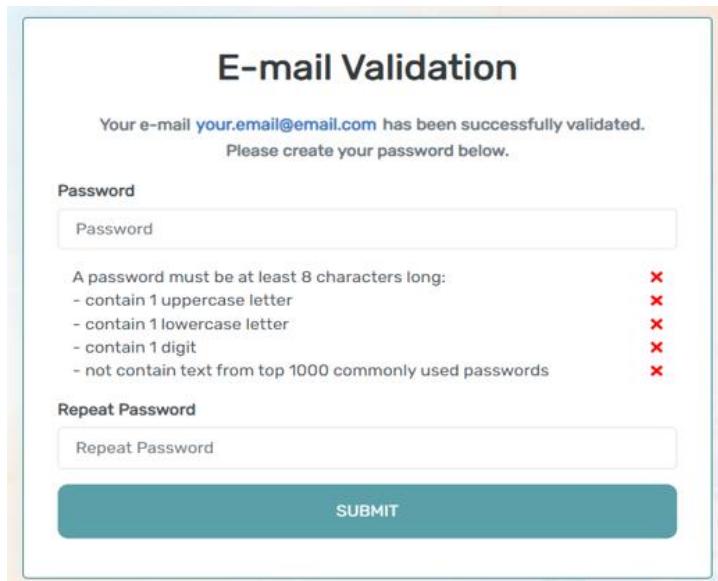
[Return to login](#) [Previous](#) [Next](#)

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



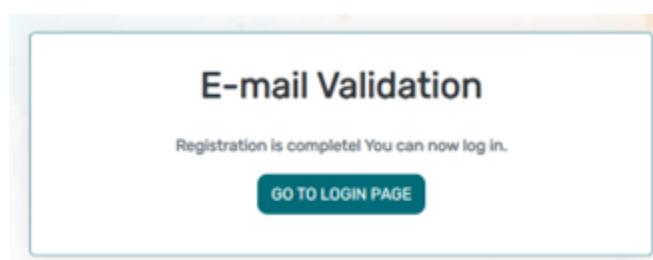
The screenshot shows the 'Registration' step of the process. At the top, it says 'Featuring Organic Acidemia Association' with a logo. Below that is a progress bar with five steps: 'Terms & Conditions', 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. The 'Review & Submit' step is highlighted with a dark blue background. A message in the center says: 'An activation link will be sent to test@test.com. Click "Next" to send this e-mail and continue.' Below the message are three buttons: 'Return to login', 'Previous', and a large 'Next' button. A red arrow points to the 'Next' button.

- 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”.



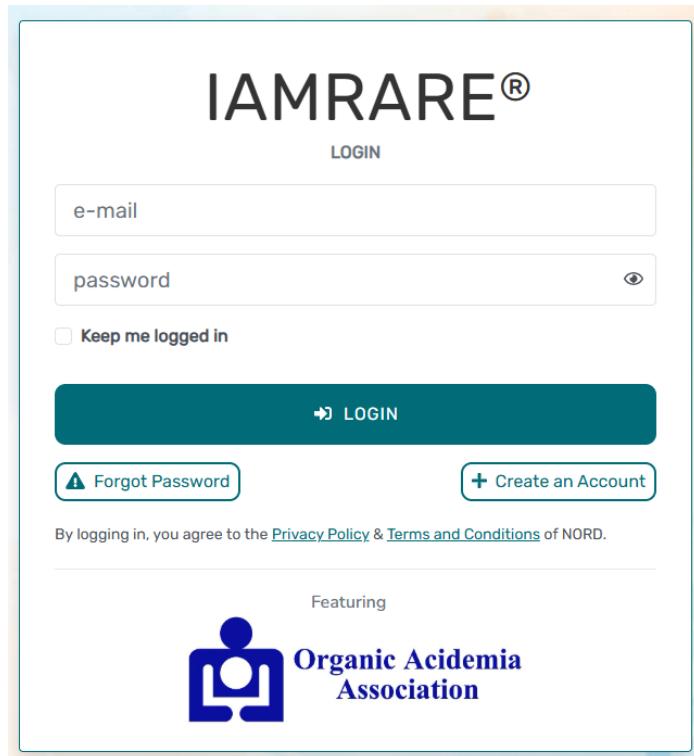
The screenshot shows the 'E-mail Validation' step. It displays a message: 'Your e-mail your.email@email.com has been successfully validated. Please create your password below.' Below this is a 'Password' input field. To its right, a list of validation rules is shown with red 'X' marks: 'A password must be at least 8 characters long', 'contain 1 uppercase letter', 'contain 1 lowercase letter', 'contain 1 digit', and 'not contain text from top 1000 commonly used passwords'. Below the password field is a 'Repeat Password' input field. At the bottom is a large 'SUBMIT' button.

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



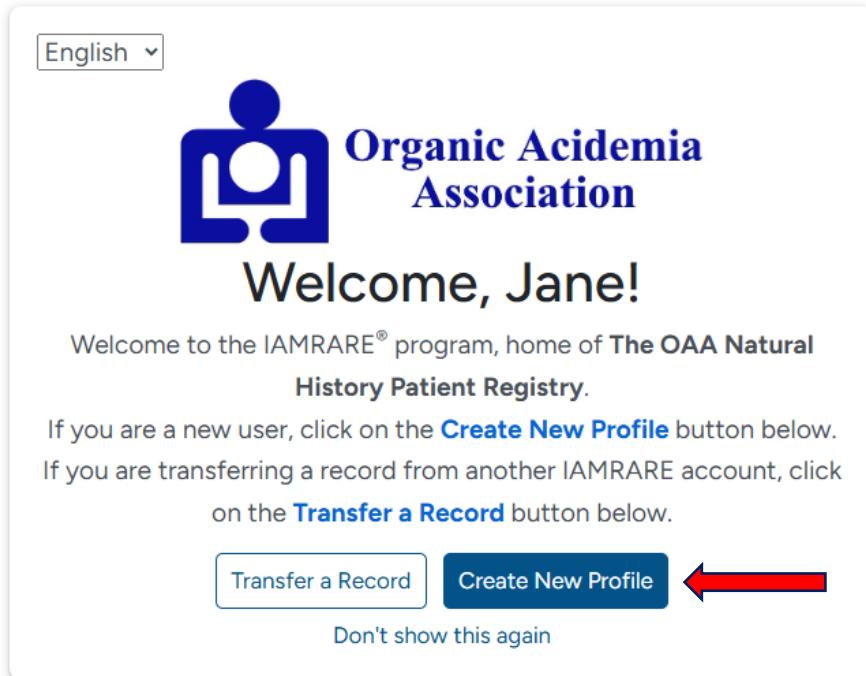
The screenshot shows the 'E-mail Validation' step again, but this time it says 'Registration is complete! You can now log in.' Below this is a large 'GO TO LOGIN PAGE' button.

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

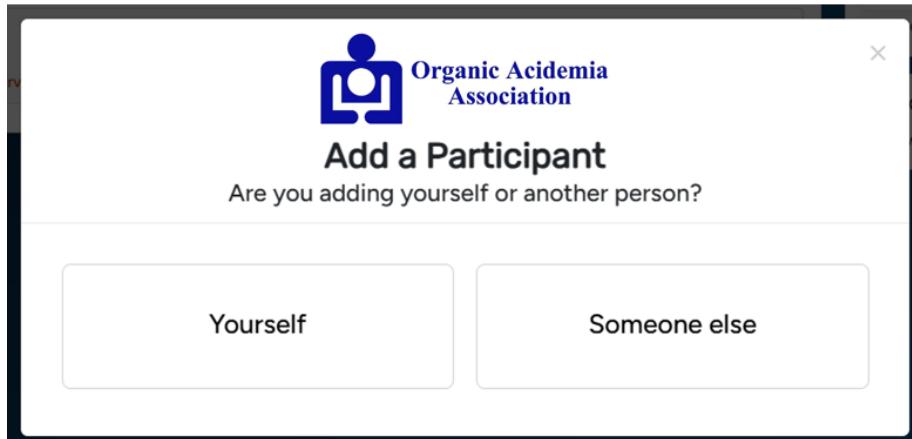


Add a Participant

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



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



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

Add Participant

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

Self Other

Preferred First Name *	Current Last name *
<input type="text" value="Preferred First Name"/>	<input type="text" value="Current Last Name"/>
First Name on Birth Certificate *	Middle Name on Birth Certificate *
<input type="text" value="First Name on Birth Certificate"/>	<input type="text" value="Type 'NA' if none"/>
Last Name on Birth Certificate *	Date of Birth * ?
<input type="text" value="Last Name on Birth Certificate"/>	<input type="text" value="mm/dd/yyyy"/>
Sex Recorded on Birth Certificate * ?	
<input type="text" value="Sex Recorded on Birth Certificate"/>	
Country of Residence * ?	State/Province/Region of Residence * ?
<input type="text" value="Choose country"/>	<input type="text" value="Type 'NA' if none"/>
Country of Birth *	City/Municipality of Birth *
<input type="text" value="Choose country of birth"/>	<input type="text" value="City/Municipality of Birth"/>
What Is Your Relationship to ? * ?	
<input type="text" value="Choose relationship"/>	

Consent to the Study

- Step 1: Click on “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 The OAA Natural History Patient Registry

Jane Smith

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with an organic acidemia 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 an organic acidemia, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had an organic acidemia 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 an organic acidemia. I participated in their medical care.

Next

A red arrow points to the 'Next' button at the bottom right of the form.

Consent to The OAA Natural History Patient Registry

Jane Smith

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

Consent to Participate in the Organic Acidemia Natural History Registry and to Allow Data to be Shared for Future Research

Title: Organic Acidemia Natural History Registry

Principal Investigator: Kimberly Chapman, MD PhD

Phone: 323-361-2178

E-mail: kchapman@chla.usc.edu

Sponsor: Organic Acidemia Association

Key Information

You are invited to take part in a research study for individuals with an organic acidemia on behalf of the person in your care who is not 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.

Things you should know:

We are doing this research

1. To characterize and describe the organic acidemia population as a whole and to gain a better understanding of the spectrum of clinical variants in individuals with organic acidemias of all stages. This includes but is not limited to collecting information on: diagnosis, treatment, medical history, socio-economic environment and outcomes.
2. To understand the changes in organic acidemias over a lifetime as well as to gain information on clinical practice patterns and variations over the course of treatment.
3. To facilitate the development of best practice and management guidelines and recommendations to optimize care, improve quality of life and outcomes and standards of care.
4. To provide information regarding ongoing research studies and clinical trials. You, on behalf of the Study Participant, may consent to be contacted by researchers for recruitment into Institutional Review Board (IRB) studies.

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Consent to The OAA Natural History 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 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 Organic Acidemia Natural History Registry 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 Organic Acidemia Natural History Registry 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 Organic Acidemia Natural History Registry for the purposes described above under Study Aims.

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

Consent to The OAA Natural History Patient Registry

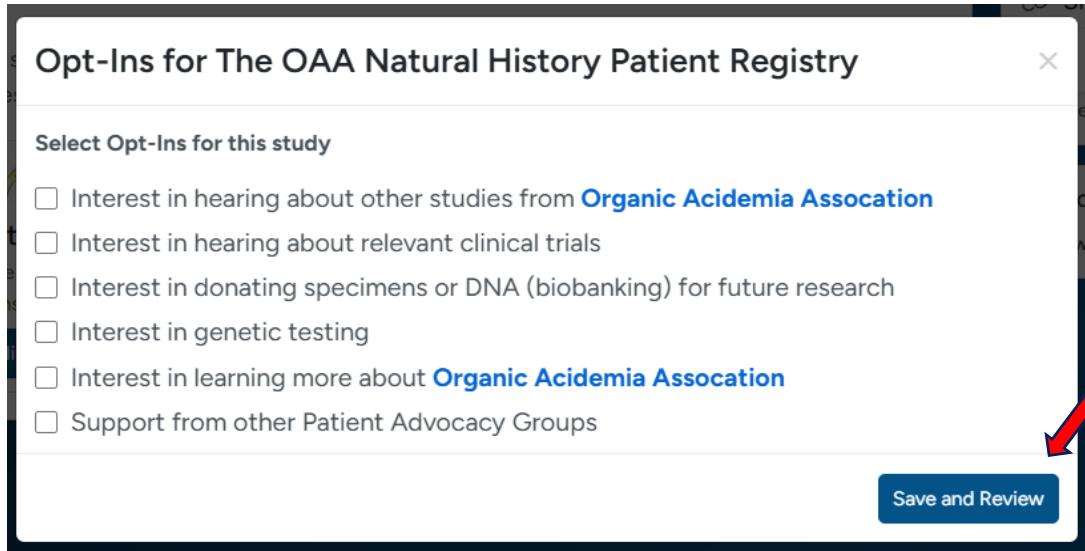
Jane Smith

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.

[Previous](#)

[Continue to Opt-Ins](#)

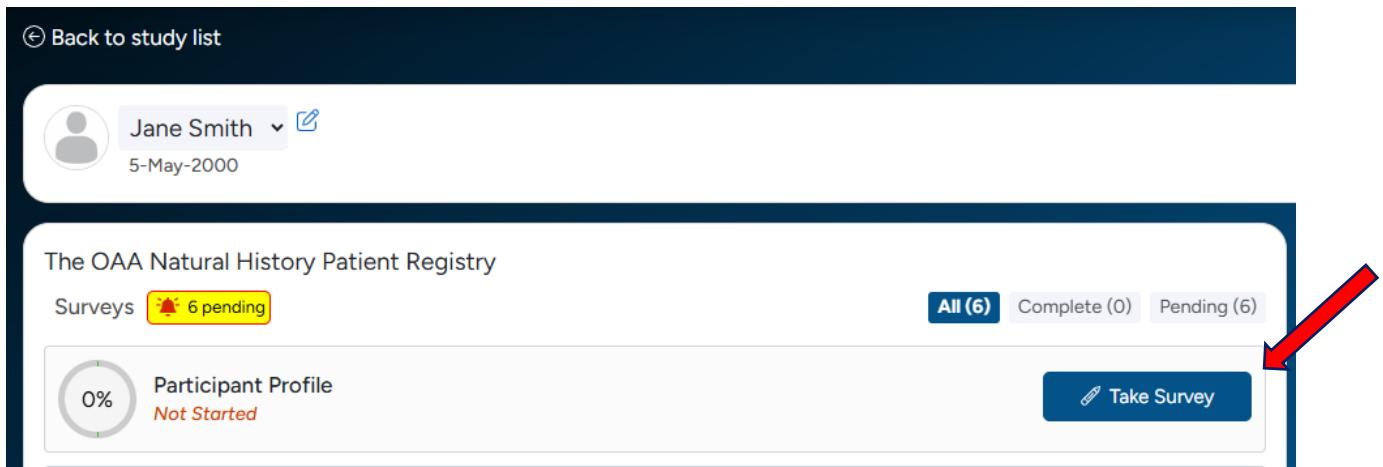
- Step 4: Once you click “Continue to Opt-Ins” read through the opt-ins thoroughly. If you would like to receive information about the topic, check the box, and click “Save and Review”.



- 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.

The screenshot shows the participant profile for Jane Smith. At the top, there is a participant profile card with a placeholder image, the name "Jane Smith", a dropdown arrow, and the date "5-May-2000". Below this is the main dashboard for "The OAA Natural History Patient Registry". The dashboard includes a "Surveys" section with a yellow warning icon showing "4 pending" surveys. A summary table lists two completed surveys: "Participant Profile" (Completed on 29-Apr-2025) and "Medical and Diagnostic Data" (Completed on 29-Apr-2025). Each survey row has two buttons on the right: "View Responses" (with a count of 1) and "Reports". Red arrows point from the text description to the "View Responses" and "Reports" buttons for both survey rows.

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.

The screenshot shows the "Enrolled Studies" page for Jane Smith. At the top, there is a participant profile card with a placeholder image, the name "Jane Smith", a dropdown arrow, and the date "5-May-2000". To the right is a "Search Studies" button. Below this is the "Enrolled Studies" section, which contains a list of studies and a note: "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." To the right of this section is a "Shortcuts" box with "Request Transfer" and "Consent/Opt-Ins" buttons. Red arrows point from the text description to the "Consent/Opt-Ins" button in the shortcuts box and to the "Revoke" and "Opt-Ins" buttons in the "Consents/Opt-Ins" table below.

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

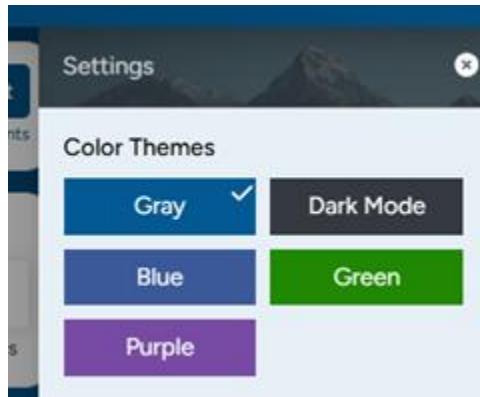
The screenshot shows the "Consents/Opt-Ins" page for Jane Smith. At the top, there is a participant profile card with a placeholder image, the name "Jane Smith", a dropdown arrow, and the date "5-May-2000". Below this is the "Consents/Opt-Ins" section, which displays a table of study information. The table has columns: "Study Name", "Consent Status", "Consented On", and "Actions". A single study entry is shown: "The OAA Natural History Patient Registry" with a "Consented" status and a date of "29-Apr-2025". The "Actions" column for this row contains three buttons: "View Consent", "Revoke", and "Opt-Ins". Red arrows point from the text description to the "Revoke" and "Opt-Ins" buttons in the "Actions" column.

Dark Mode Settings

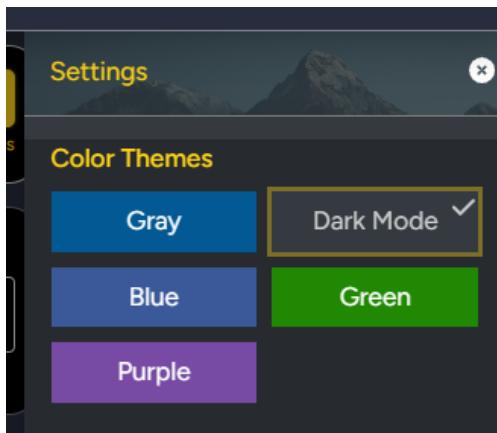
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

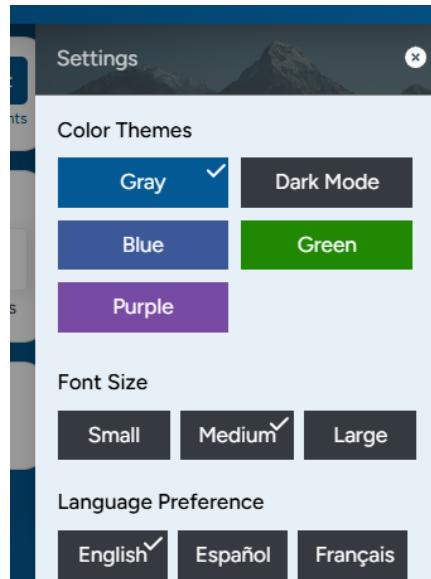


Display Settings

- 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 (<https://oaaregistry.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?

[Learn More](#)



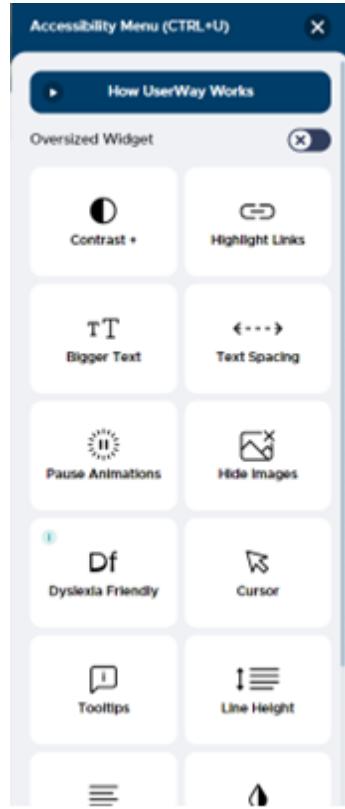
For Patients

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.

[Learn More](#)





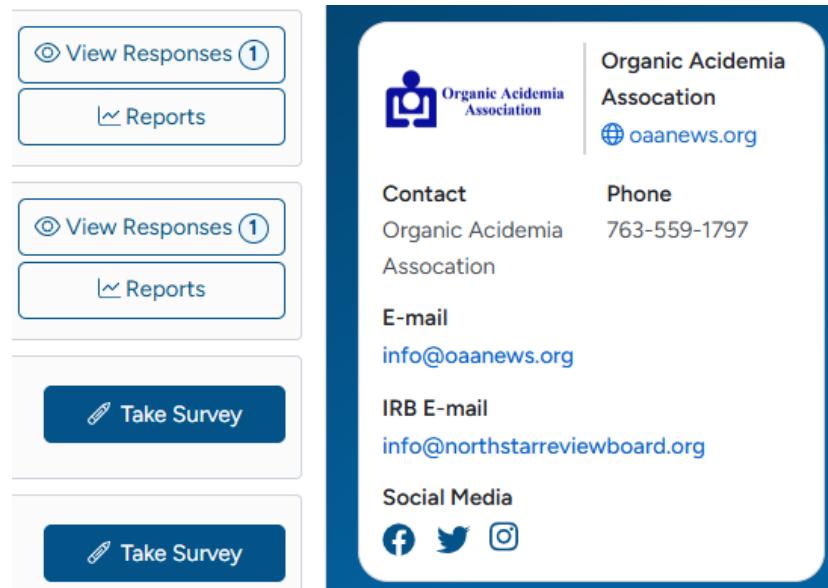
Need Assistance?

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

A screenshot of a modal window titled 'Have a question?'. The window has a dark header bar with a home icon, 'Home', a help icon, and 'Help'. The main area contains a text instruction: '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 is a form section with a label 'Inquiry Type *' and a dropdown menu with the placeholder 'Select Inquiry Type'. There is also a label 'Message *' and a text area with the placeholder 'Your message'. At the bottom are two buttons: a white 'Cancel' button and a blue 'Submit' button.

- 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 image shows a study dashboard with four main sections. The first three sections are identical survey completion status cards, each featuring a 'View Responses' button with a count of 1 and a 'Reports' button. The fourth section is a study contact information card for the 'Organic Acidemia Association'.

Organic Acidemia Association
oaanews.org

Contact	Phone
Organic Acidemia Association	763-559-1797
E-mail	info@oaanews.org
IRB E-mail	info@northstarreviewboard.org
Social Media	  