




# 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 & ConditionsContact InfoNotificationsReview & SubmitConfirmation

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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 **Organic Academia Association**

## Registration

Progress bar: Terms & Conditions (active), 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

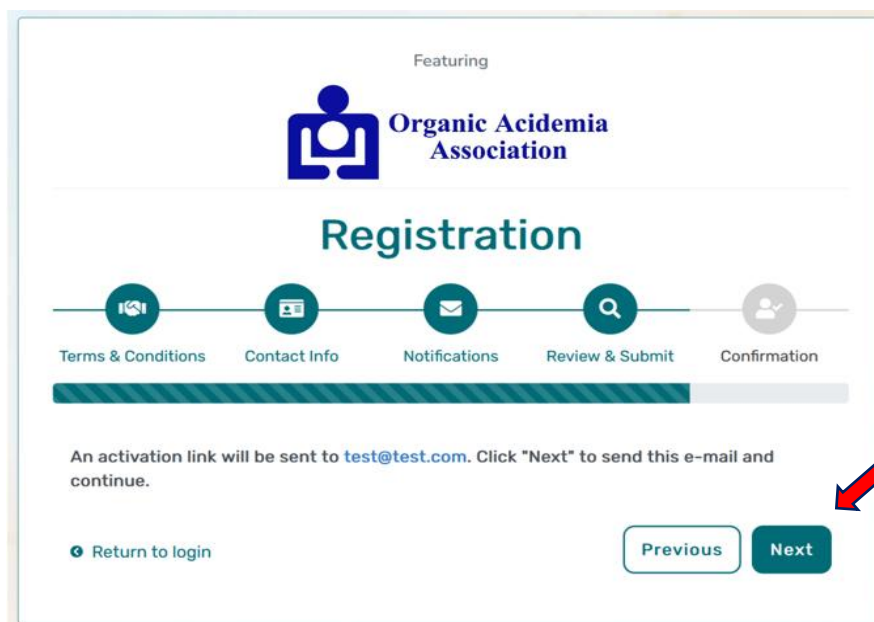
Progress bar: Terms & Conditions, Contact Info, Notifications (active), Review & Submit, Confirmation

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

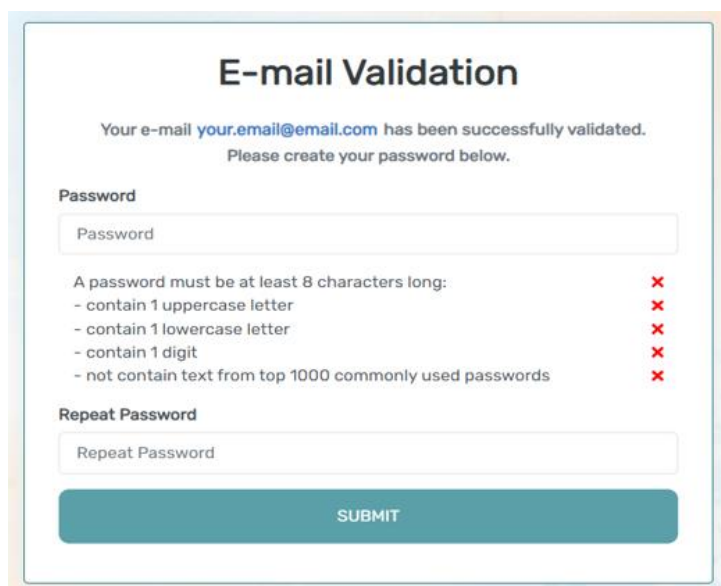
Terms & Conditions   Contact Info   Notifications   Review & Submit   Confirmation

An activation link will be sent to [test@test.com](mailto:test@test.com). Click "Next" to send this e-mail and continue.

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

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”.



## E-mail Validation

Your e-mail [your.email@email.com](mailto:your.email@email.com) has been successfully validated.  
Please create your password below.

**Password**

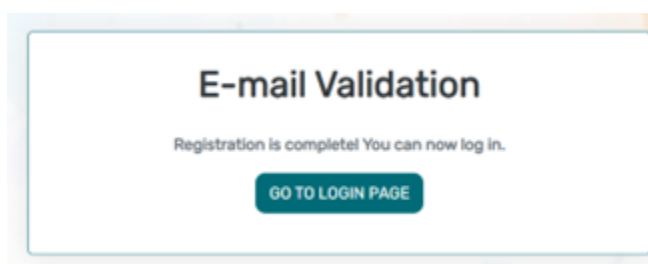
A password must be at least 8 characters long: ×

- 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”.

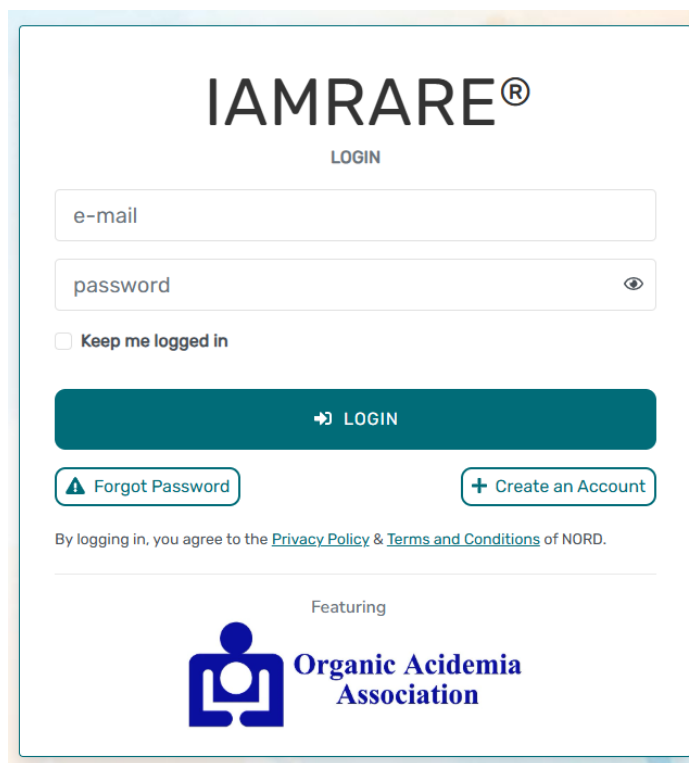


## E-mail Validation

Registration is complete! You can now log in.

[GO TO LOGIN PAGE](#)

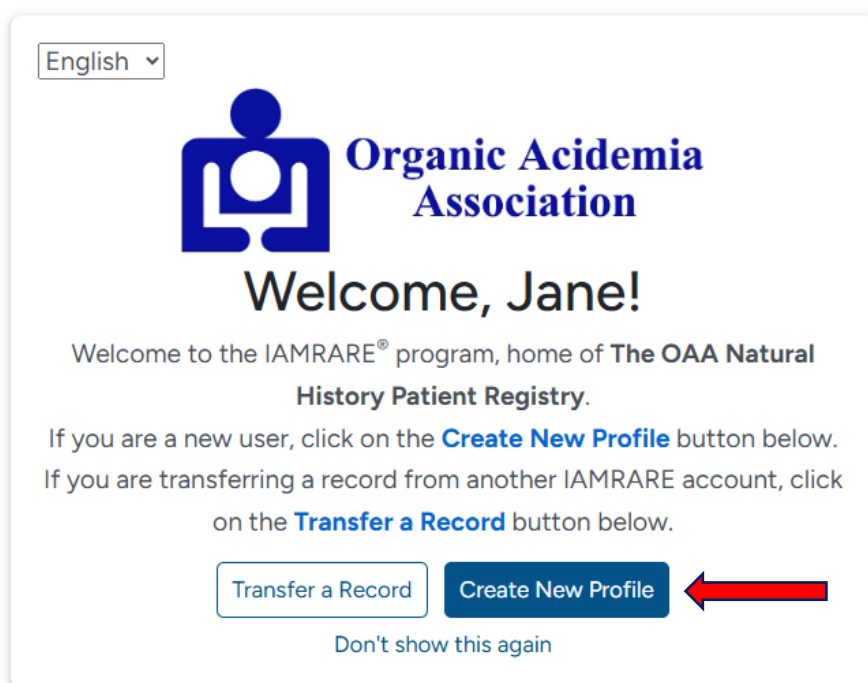
- Step 7: Log in using your new e-mail and password.



The image shows the IAMRARE LOGIN page. At the top is the IAMRARE® logo. Below it is the word "LOGIN". There are two input fields: "e-mail" and "password" (with an eye icon for toggling visibility). Below the password field is a checkbox labeled "Keep me logged in". A large teal button with a right arrow and the word "LOGIN" is centered. Below this are two smaller buttons: "Forgot Password" (with a warning icon) and "Create an Account" (with a plus icon). A line of text states: "By logging in, you agree to the [Privacy Policy](#) & [Terms and Conditions](#) of NORD." At the bottom, it says "Featuring" above the Organic Acidemia Association logo and name.

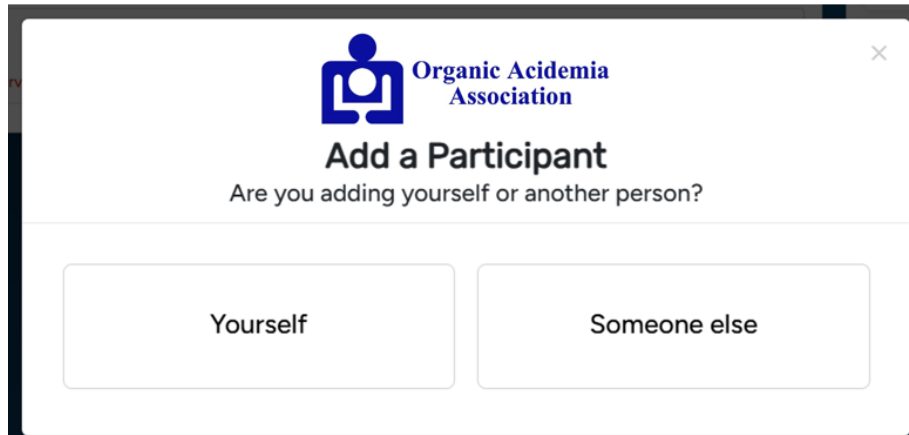
### Add a Participant


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



The image shows the Organic Acidemia Association welcome screen. At the top left is a language dropdown menu set to "English". Below it is the Organic Acidemia Association logo and name. A large heading says "Welcome, Jane!". Below this is a paragraph: "Welcome to the IAMRARE® program, home of **The OAA Natural History Patient Registry.**" Another paragraph follows: "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." At the bottom are two buttons: "Transfer a Record" and "Create New Profile". A red arrow points to the "Create New Profile" button. Below the buttons is a link: "Don't show this again".

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

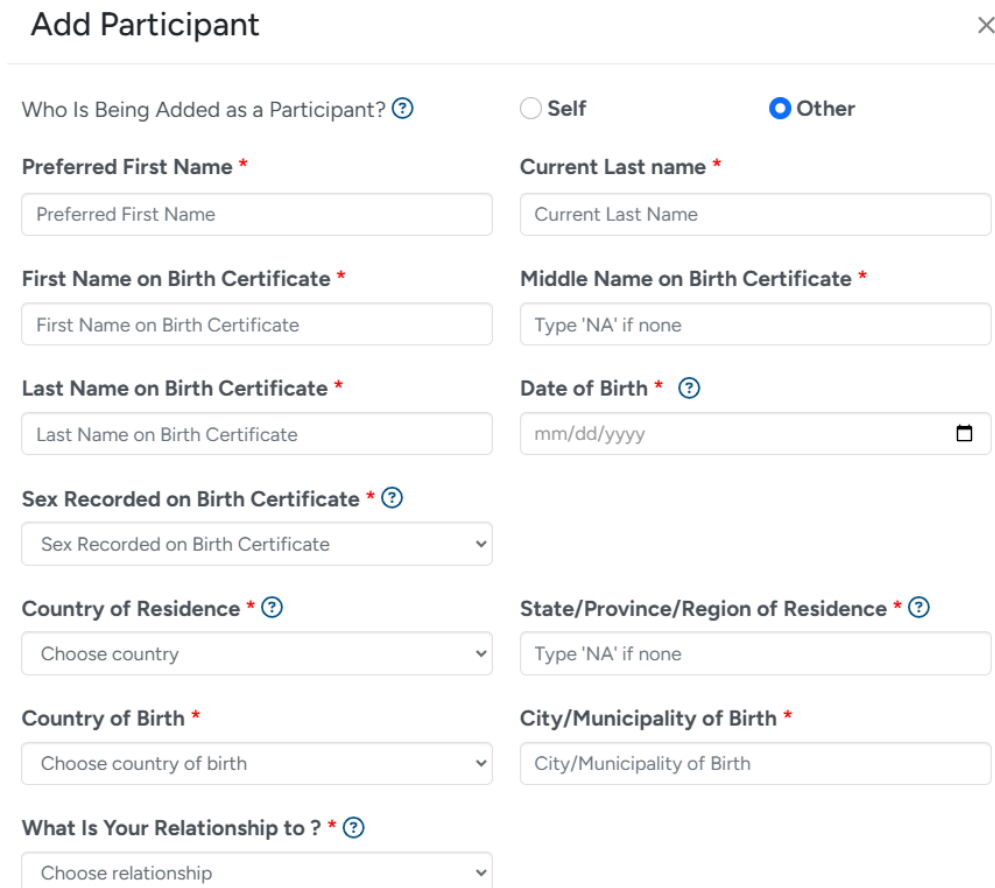


 Organic Academia Association


## 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 \***


**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 ? \*** 

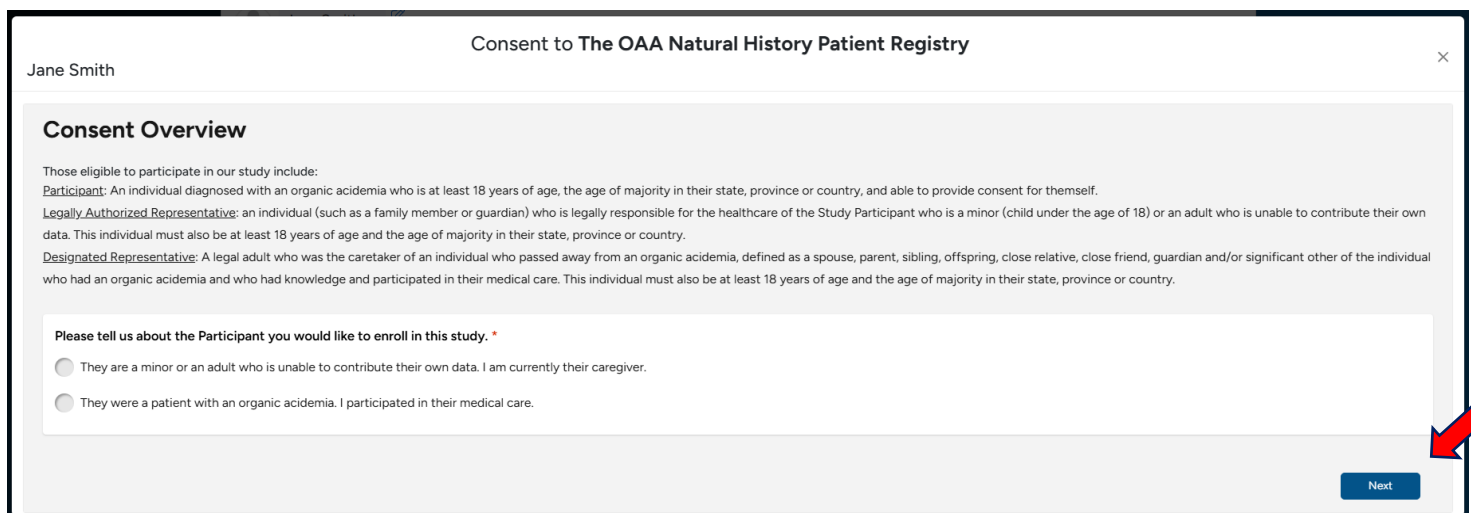
## Consent to the Study

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



The screenshot shows a white rectangular dialog box with a dark gray border. At the top left is a blue icon of a person sitting at a desk. To its right is the text "Organic Acidemia Association" in a dark blue serif font. Below this, the text "Thank you for registering your first participant!" is centered. Underneath that, the question "Would you like to consent to participate in The OAA Natural History Patient Registry?" is centered. At the bottom, there are two buttons: "Not right now" in a light blue rounded rectangle and "Yes, complete consent for this participant." in a dark teal rounded rectangle. A red arrow points to the right button. A small 'x' icon is in the top right corner.

- 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.”



The screenshot shows a web form titled "Consent to The OAA Natural History Patient Registry" with a close button (x) in the top right. The user's name "Jane Smith" is in the top left. The section "Consent Overview" contains three paragraphs of text defining "Participant", "Legally Authorized Representative", and "Designated Representative". Below this is a section titled "Please tell us about the Participant you would like to enroll in this study. \*". It contains two radio button options: "They are a minor or an adult who is unable to contribute their own data. I am currently their caregiver." and "They were a patient with an organic acidemia. I participated in their medical care." A red arrow points to the "Next" button in the bottom right corner.

Jane Smith

Consent to The OAA Natural History Patient Registry

×

### 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](mailto: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).

Previous

Next



Jane Smith

Consent to The OAA Natural History Patient Registry

×

### 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.

Previous

Next



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

Jane Smith

Consent to The OAA Natural History Patient Registry

×

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 The OAA Natural History Patient Registry**

Select Opt-Ins for this study

- ☐ Interest in hearing about other studies from [Organic Acidemia Association](#)
- ☐ 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 [Organic Acidemia Association](#)
- ☐ Support from other Patient Advocacy Groups

[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 study list](#)

Jane Smith [✎](#)  
5-May-2000

**The OAA Natural History Patient Registry**

Surveys 🔔 6 pending

[All \(6\)](#) [Complete \(0\)](#) [Pending \(6\)](#)

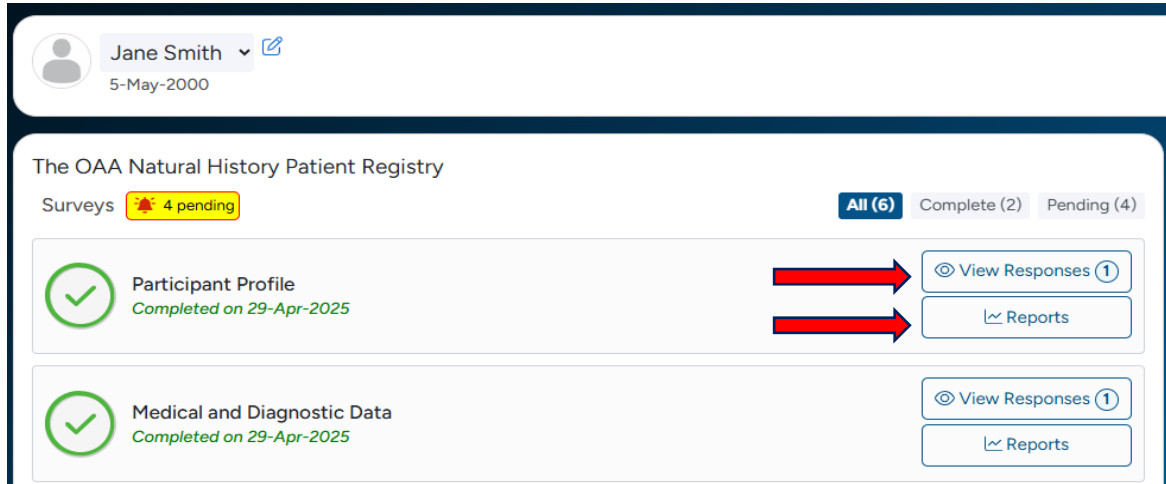
**Participant Profile**  
*Not Started*

[Take Survey](#)



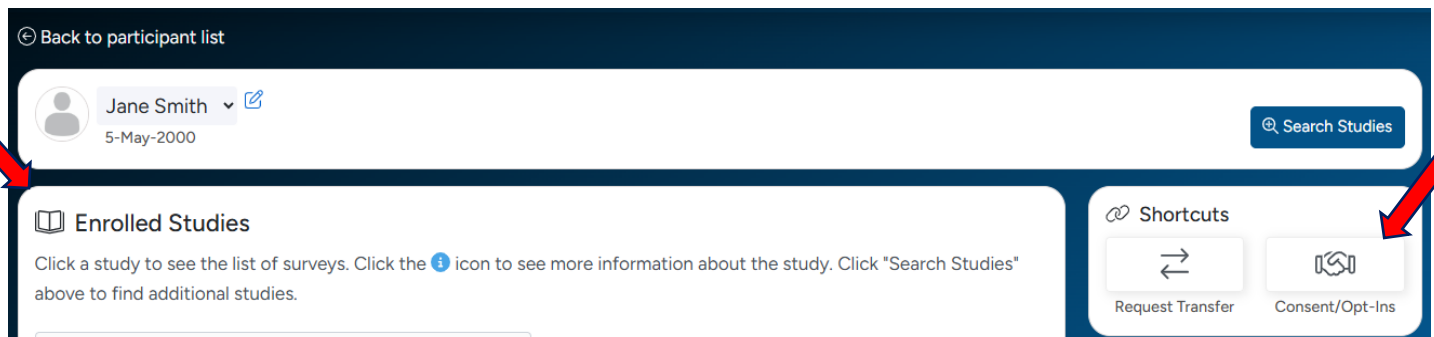
## View Responses and Reports

- 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.

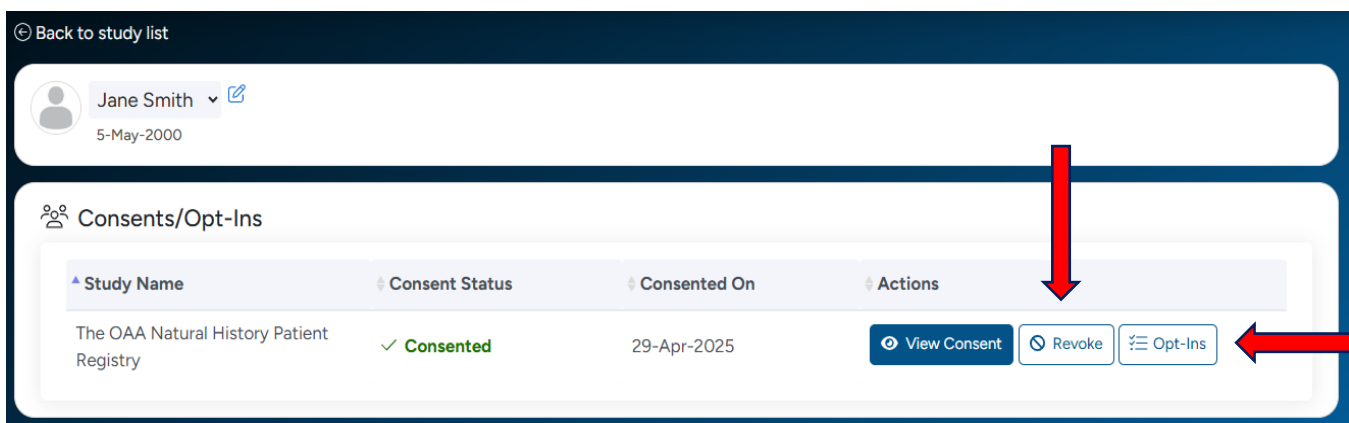


## View Consent and Opt-Ins

- 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.



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

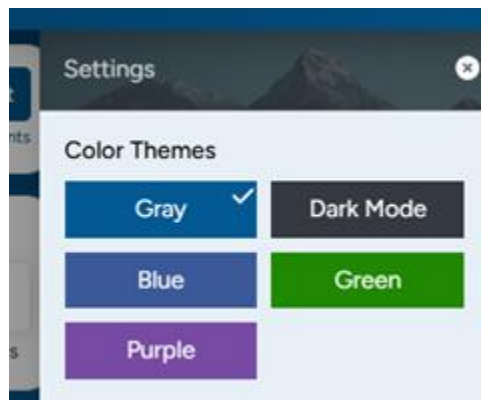


## Dark Mode Settings

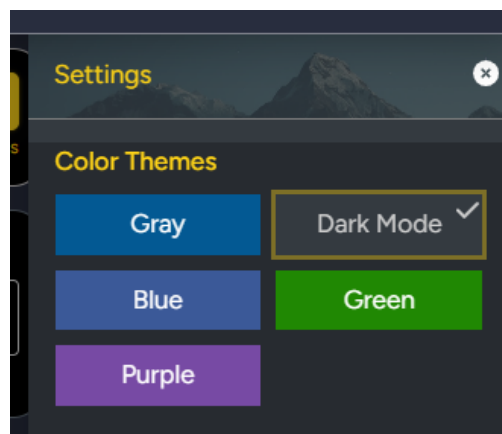
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

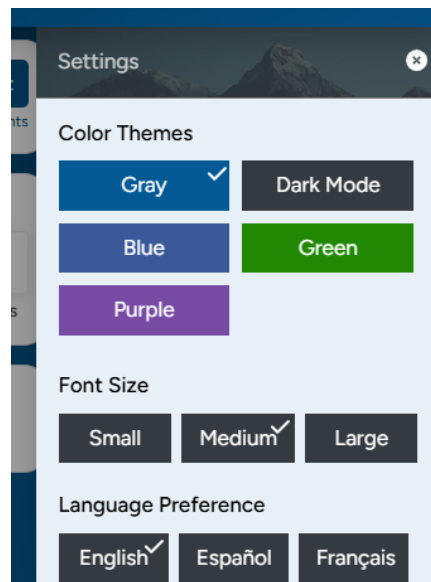


## Display Settings

- 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 (<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?

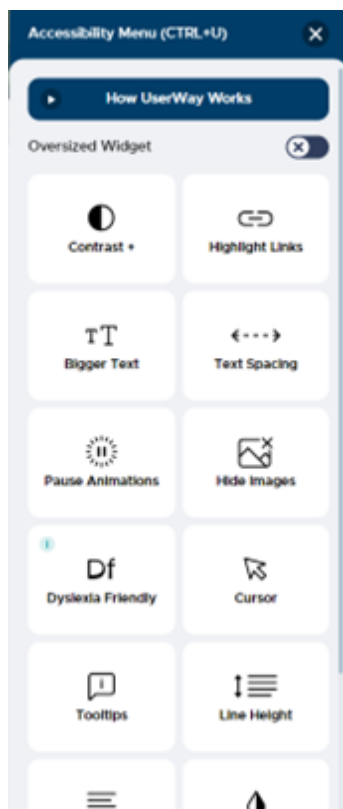


For Patients

### 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.

A screenshot of a mobile application's "Have a question?" form. The form has a blue header with a home icon and "Home" text, and a question mark icon and "Help" text. Below the header is a blue bar with the text "Have a question?" and a close button (X). The main area is white with a light gray border. It contains a paragraph of 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](\"http://rarediseases.org\")." Below this is a dropdown menu labeled "Inquiry Type \*" with the text "-- Select Inquiry Type --". Below the dropdown is a text input field labeled "Message \*" with the placeholder text "Your message". At the bottom 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.

View Responses 1


Reports

View Responses 1

Reports

Take Survey

Take Survey

 Organic Acidemia Association

**Organic Acidemia Association**  
[oaaanews.org](https://www.oaanews.org)

**Contact**  
Organic Acidemia Association

**Phone**  
763-559-1797

**E-mail**  
[info@oaaanews.org](mailto:info@oaaanews.org)

**IRB E-mail**  
[info@northstarreviewboard.org](mailto:info@northstarreviewboard.org)

**Social Media**  
