



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”.

The screenshot shows a registration form titled "Registration" with the "ALL THINGS KABUKI" logo. A progress bar at the top indicates the current step is "Contact Info". The form includes a dropdown menu for "Country of Residence", input fields for "First Name" and "Last Name", and an input field for "E-mail". At the bottom, there is a "Return to login" link and "Previous" and "Next" buttons.

Featuring
ALL THINGS KABUKI

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”.

The screenshot shows the same registration form, but the progress bar now indicates the current step is "Notifications". The form includes a question: "I am interested in NORD contacting me regarding available studies." with radio buttons for "Yes" and "No". At the bottom, there is a "Return to login" link and "Previous" and "Next" buttons.

Featuring
ALL THINGS KABUKI

Registration

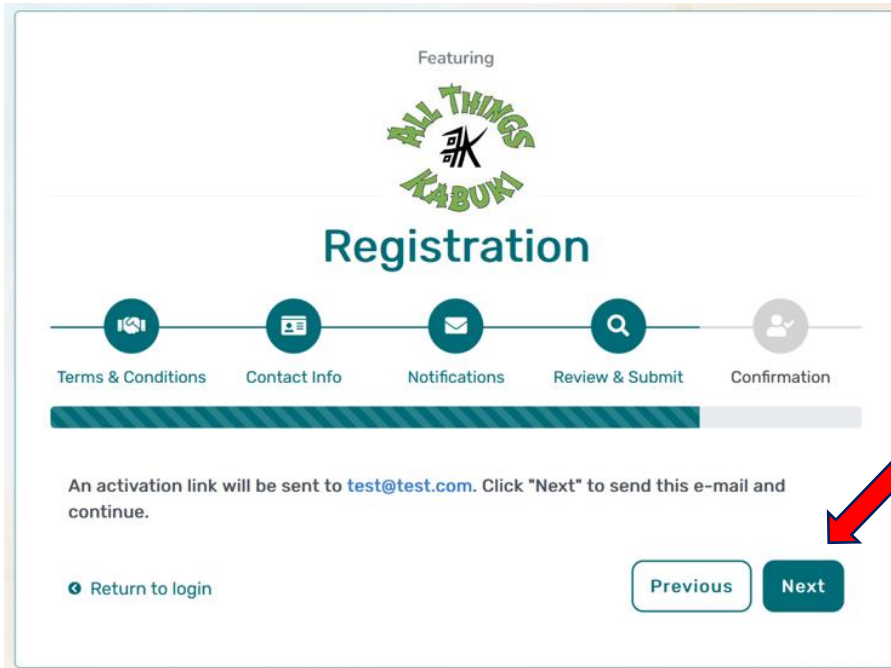
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

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.



Featuring

ALL THINGS KABUKI

Registration

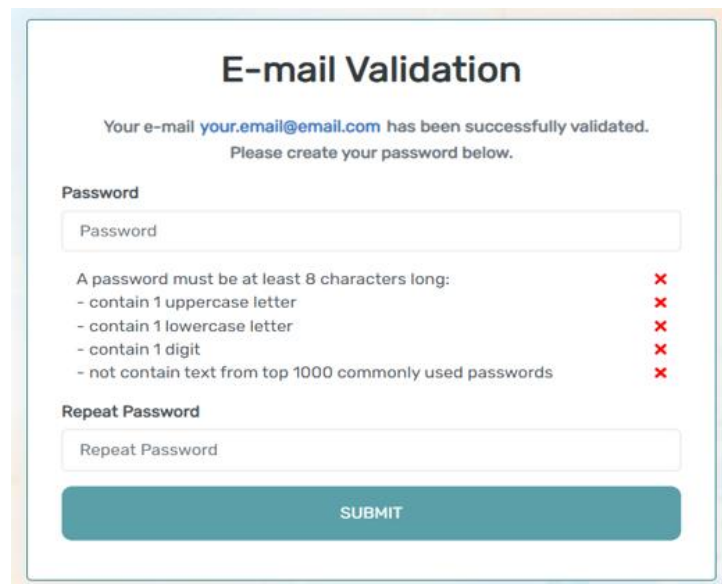
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

An activation link will be sent to 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 has been successfully validated.
Please create your password below.

Password

A password must be at least 8 characters long:

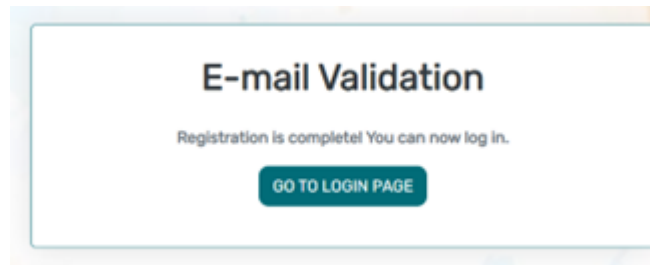
- contain 1 uppercase letter
- contain 1 lowercase letter
- contain 1 digit
- not contain text from top 1000 commonly used passwords

Repeat Password

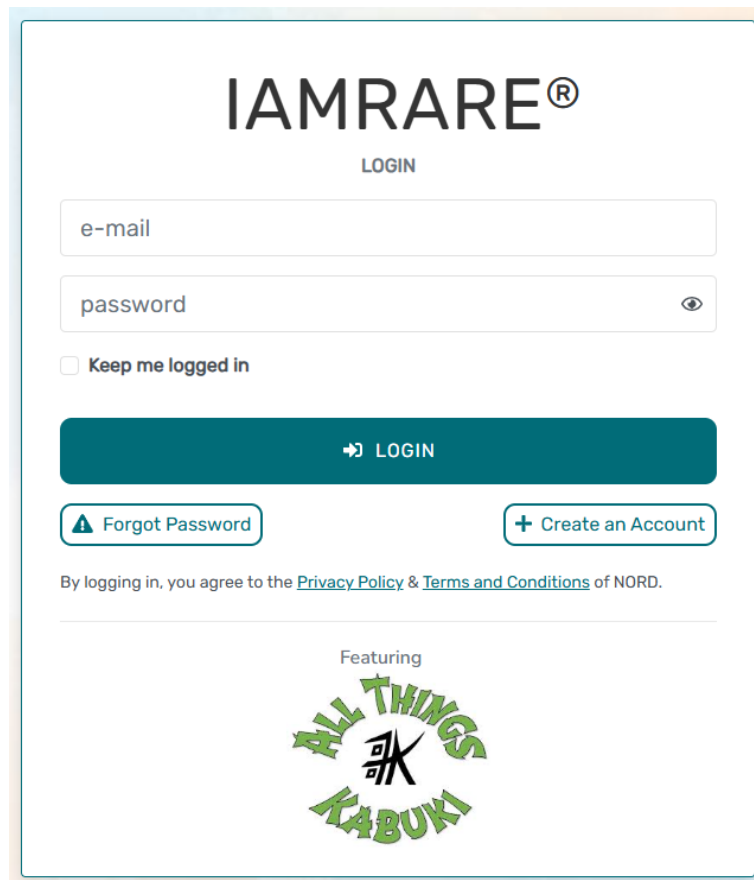
[SUBMIT](#)

Red 'x' marks are next to each password requirement.

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

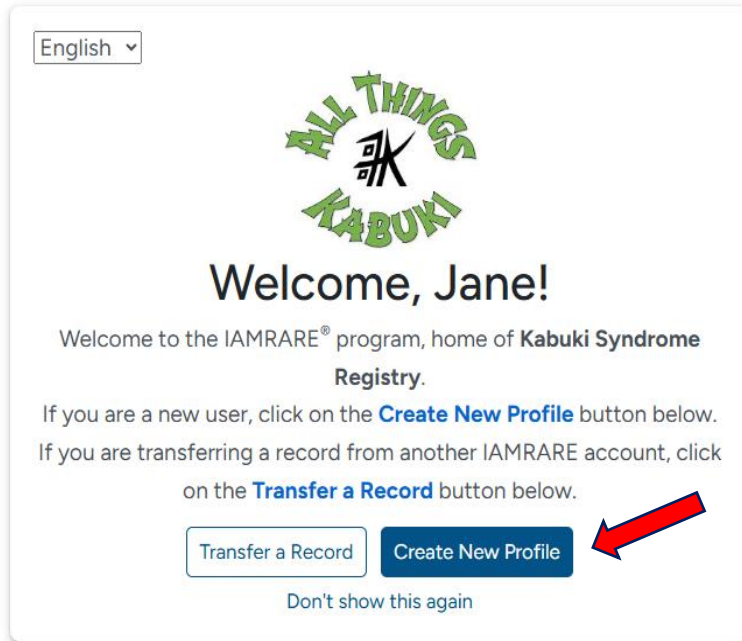


- Step 7: Log in using your new e-mail and password.

The login page for IAMRARE®. It features the brand name "IAMRARE®" at the top, followed by the word "LOGIN". There are two input fields: "e-mail" and "password" (with a toggle icon). Below these is a checkbox labeled "Keep me logged in". A large teal button with a right arrow and the word "LOGIN" is centered. At the bottom of the login section are two links: "Forgot Password" (with a warning icon) and "Create an Account" (with a plus icon). A disclaimer states: "By logging in, you agree to the [Privacy Policy](#) & [Terms and Conditions](#) of NORD." Below this is a section titled "Featuring" which displays the "ALL THINGS KABUKI" logo, a circular emblem with a stylized "AK" in the center.

Add a Participant

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



English ▾

**ALL THINGS
KABUKI**

Welcome, Jane!

Welcome to the IAMRARE® program, home of **Kabuki Syndrome Registry**.

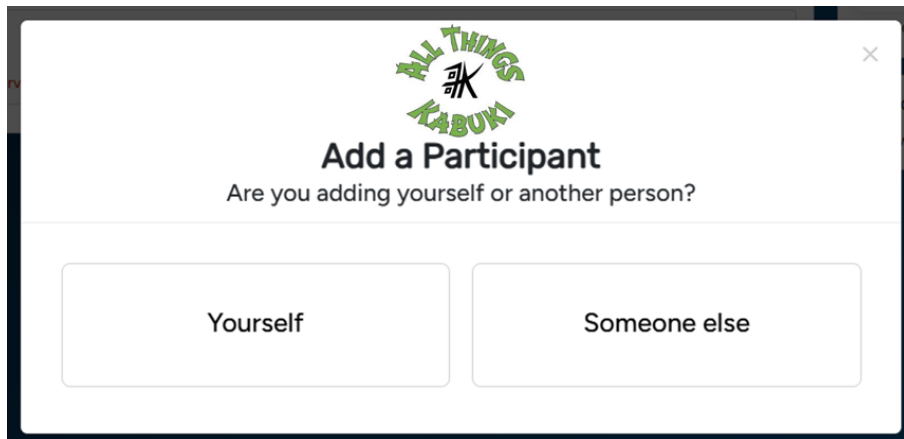
If you are a new user, click on the [Create New Profile](#) button below.

If you are transferring a record from another IAMRARE account, click on the [Transfer a Record](#) button below.

[Transfer a Record](#) [Create New Profile](#)

[Don't show this again](#)

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



**ALL THINGS
KABUKI**

Add a Participant

Are you adding yourself or another person?

[Yourself](#) [Someone else](#)

- 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.”



Thank you for registering your first participant!
Would you like to consent to participate in **Kabuki Syndrome 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.”

Jane Smith

Consent to Kabuki Syndrome Registry

Consent Overview

Those eligible to participate in our study include:
Participant: An individual diagnosed with Kabuki 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 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.

Next



Jane Smith

Consent to Kabuki Syndrome Registry

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

Consent to Participate in the Kabuki Syndrome Registry and to Allow Data to be Shared for Future Research

Title: Kabuki Syndrome Registry
Principal Investigator: Margaret L.P. Adam, MD, MS; Seattle Children's Hospital
Phone: 907-360-8590
E-mail: registry@allthingskabuki.org
Sponsor: All Things Kabuki, Rene King, President & Founder

Key Information
You are invited to take part in a research study for people with Kabuki syndrome on behalf of the person in your care who is not able or no longer able to provide their own consent. Your role is called Legally Authorized Representative (LAR). This form will help you decide if you want to participate. You can contact the study staff above if you have any other questions. Their phone numbers and emails are listed above.
Things you should know:
We are doing this research to describe the people who have Kabuki syndrome and to better understand the different stages of Kabuki syndrome.
If you choose to participate on behalf of the Participant, you will be asked to provide personal and medical information by answering online surveys and uploading medical information on a secure internet site. The amount of time the surveys take will vary from Participant to Participant. You can save your progress and come back as needed.
If you participate, you might experience the following risks, discomforts, or inconveniences: Some surveys may ask questions about the impact of Kabuki syndrome on your daily life, your economic status, mood, and other topics that you may find unpleasant or disquieting.

Previous

Next



Jane Smith

Consent to Kabuki Syndrome Registry

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 this registry;
- Have had 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 Kabuki Syndrome Registry on behalf of the Study Participant. After signing, a copy of the consent form will be emailed to you. If you cannot comfortably answer "Yes" to these four statements and you have no further questions, 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 Kabuki Syndrome 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 Kabuki Syndrome Registry for the purposes described above under Study Aims.

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

☐ I have explained the study to the Study Participant to the extent they are able to understand, and the Study Participant has given their assent to participate in this study

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



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

Jane Smith

Consent to Kabuki Syndrome 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 Kabuki Syndrome Registry

Select Opt-Ins for this study

☐ Interest in hearing about other studies from **All Things Kabuki**

☐ Interest in hearing about relevant clinical trials

☐ Interest in donating specimens or DNA (biobanking) for future research

[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 on your Participant.

The screenshot shows the IAMRARE® dashboard. At the top, there's a navigation bar with 'Home', 'Help', 'Settings', and a user profile 'Hi, Jane!'. Below the navigation bar, a greeting 'Good Afternoon, Jane!' is displayed along with 'Member since Apr 24, 2025'. On the right, there's a '+ Add Participant' button. The main section is titled 'Participants' and includes a description: 'Select a participant to view their studies. Click on the "Add Participant" button above to add a participant.' Below this, there's a list of participants. The first participant is 'Jane Smith', with a date '5-May-2000' and a status '9 pending surveys'. A red arrow points to the '+ Add Participant' button.

- Step 2: Click on the appropriate study.

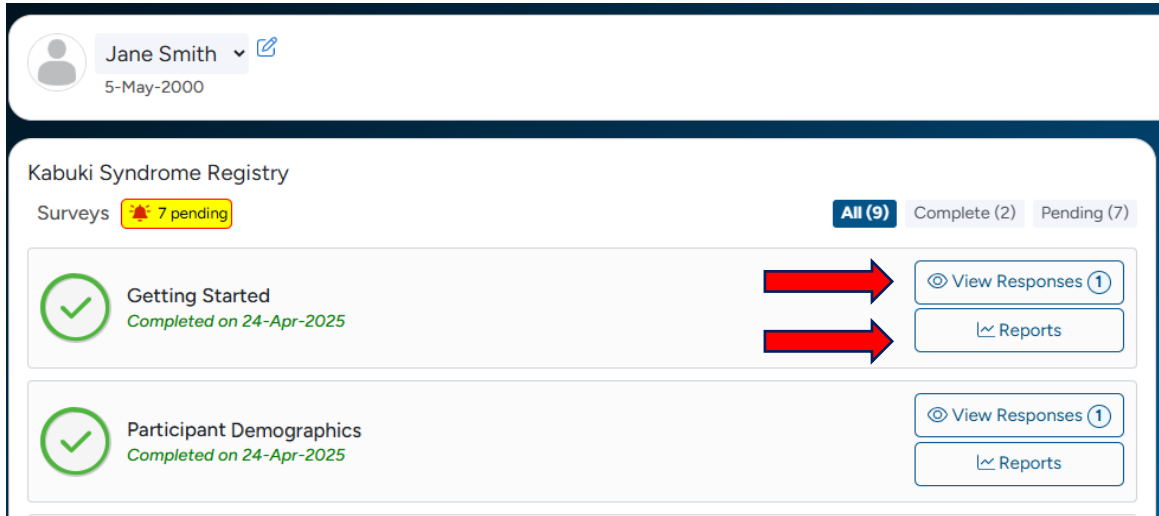
The screenshot shows the 'Enrolled Studies' section for Jane Smith. At the top, there's a 'Back to participant list' link. Below it, there's a dropdown menu for 'Jane Smith' and a 'Search Studies' button. The main section is titled 'Enrolled Studies' and includes a description: 'Click a study to see the list of surveys. Click the ⓘ icon to see more information about the study. Click "Search Studies" above to find additional studies.' Below this, there's a list of studies. The first study is 'Kabuki Syndrome Registry', with a date '5-May-2000' and a status '9 pending surveys'. A red arrow points to the 'Kabuki Syndrome Registry' study.

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

The screenshot shows the 'Kabuki Syndrome Registry' study page. At the top, there's a 'Back to study list' link. Below it, there's a dropdown menu for 'Jane Smith' and a 'Search Studies' button. The main section is titled 'Kabuki Syndrome Registry' and includes a description: '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.' Below this, there's a list of surveys. The first survey is 'Getting Started', with a date '5-May-2000' and a status '9 pending surveys'. A red arrow points to the 'Take Survey' button.

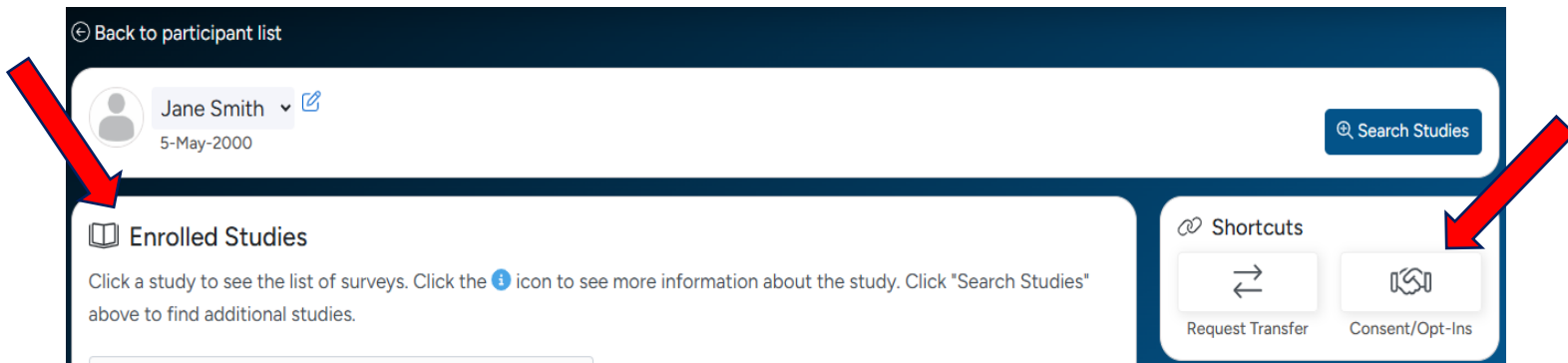
View Responses and Reports

- 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.

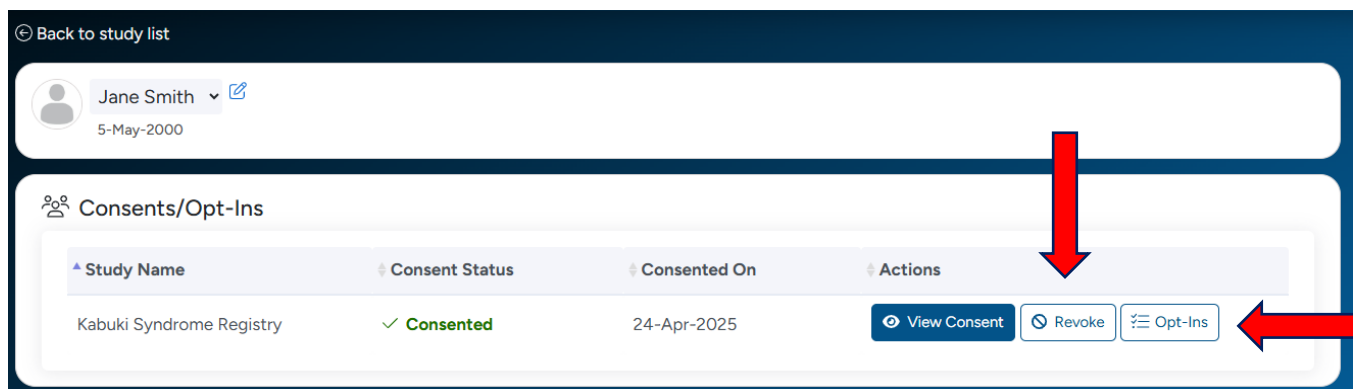


View Consent and Opt-Ins

- 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”.

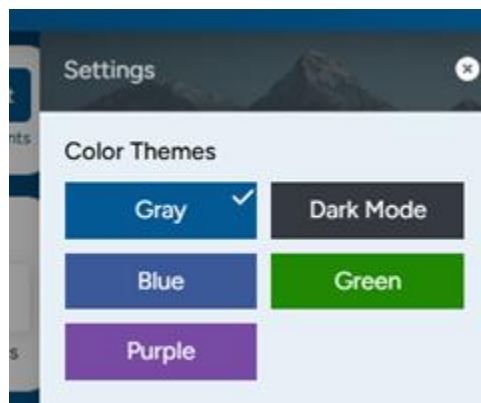


Dark Mode Settings

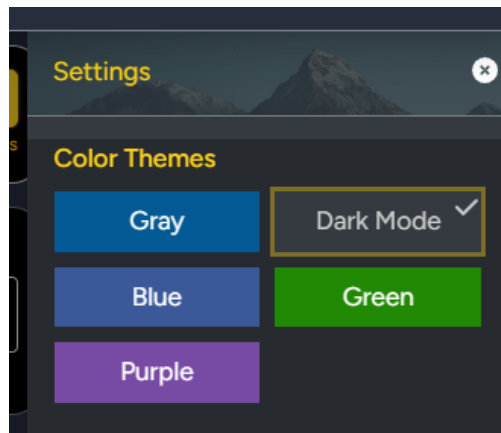
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

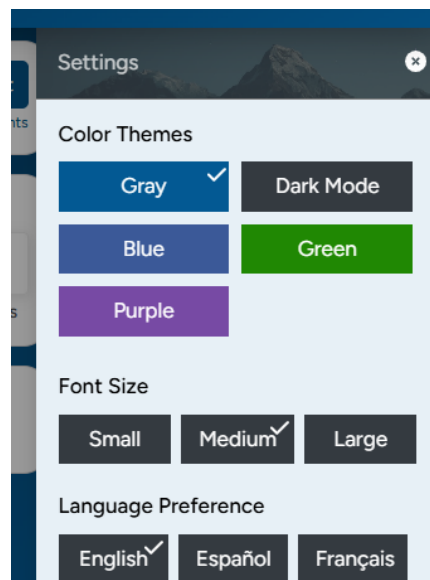


Display Settings

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



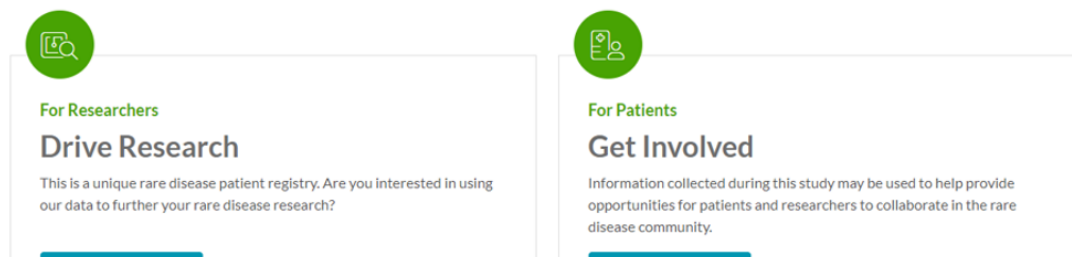
- Step 2: Select a color theme, a font size, or language preference.

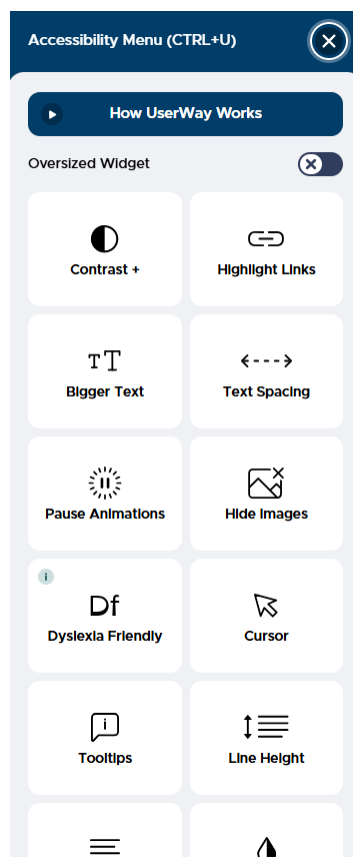


- Step 3: Exit the Settings menu, and your selection will be saved.

Microsite Visibility

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

 A screenshot of a web form titled 'Have a question?'. The form is set against a light background with a dark blue header. The header contains a home icon and the text 'Home', and a question mark icon with the text 'Help'. The main content area has a title 'Have a question?' with a close button. Below the title is 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.' Below this text are two input fields: 'Inquiry Type *' with a dropdown menu showing '-- Select Inquiry Type --', and 'Message *' with a text area containing the placeholder 'Your message'. At the bottom of the form 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



All Things Kabuki
allthingskabuki.org

Contact

All Things Kabuki

E-mail

registry@allthingskabuki.org

IRB E-mail

info@northstarreviewboard.org

Social Media

