



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”.

The screenshot shows the 'Registration' page for the ACD platform. At the top, it says 'Featuring' followed by the ACD logo and the word 'Registration' in a large, bold font. Below the title is a progress bar with five steps: 'Terms & Conditions', 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. The 'Terms & Conditions' step is currently active, indicated by a blue bar under the label. The main content area contains a paragraph explaining the purpose of the Terms of Use and Privacy Guidelines, followed by a section titled 'Acknowledgements' with four checkbox items. At the bottom left, there is a link to 'Return to login', and at the bottom right, there is a blue 'Next' button.

Featuring

ACD
ASSOCIATION FOR
CREATINE DEFICIENCIES

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 the 'Registration' page for the Association for Creative Deficiencies (ACD). The page features the ACD logo at the top, which includes a DNA helix icon and the text 'Featuring ACD ASSOCIATION FOR CREATIVE DEFICIENCIES'. Below the logo is the word 'Registration' in a large, bold font. A progress bar at the top indicates the current step: 'Contact Info' is selected and highlighted in green, while 'Terms & Conditions', 'Notifications', 'Review & Submit', and 'Confirmation' are in grey. The form contains the following fields: a dropdown menu for 'Country of Residence *', two text input fields for 'First Name *' and 'Last Name *', and a text input field for 'E-mail *'. At the bottom left, there is a link 'Return to login'. At the bottom right, there are two buttons: 'Previous' and 'Next', with 'Next' being highlighted in green.

- 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 'Registration' page for the Association for Creative Deficiencies (ACD). The page features the ACD logo at the top, which includes a DNA helix icon and the text 'Featuring ACD ASSOCIATION FOR CREATIVE DEFICIENCIES'. Below the logo is the word 'Registration' in a large, bold font. A progress bar at the top indicates the current step: 'Notifications' is selected and highlighted in green, while 'Terms & Conditions', 'Contact Info', 'Review & Submit', and 'Confirmation' are in grey. The form contains a question: 'I am interested in NORD contacting me regarding available studies. *'. Below the question are two radio button options: 'Yes' (selected) and 'No'. At the bottom left, there is a link 'Return to login'. At the bottom right, there are two buttons: 'Previous' and 'Next', with 'Next' being highlighted in green.

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

Featuring
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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](#)

- 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.

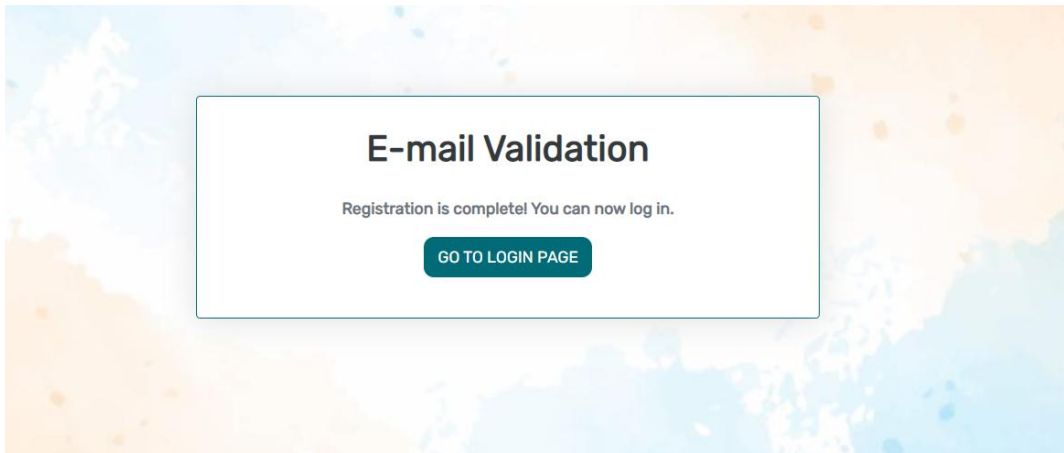
Password

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](#)


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



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

IAMRARE®
LOGIN

e-mail

password 

Keep me logged in

[➔ LOGIN](#)

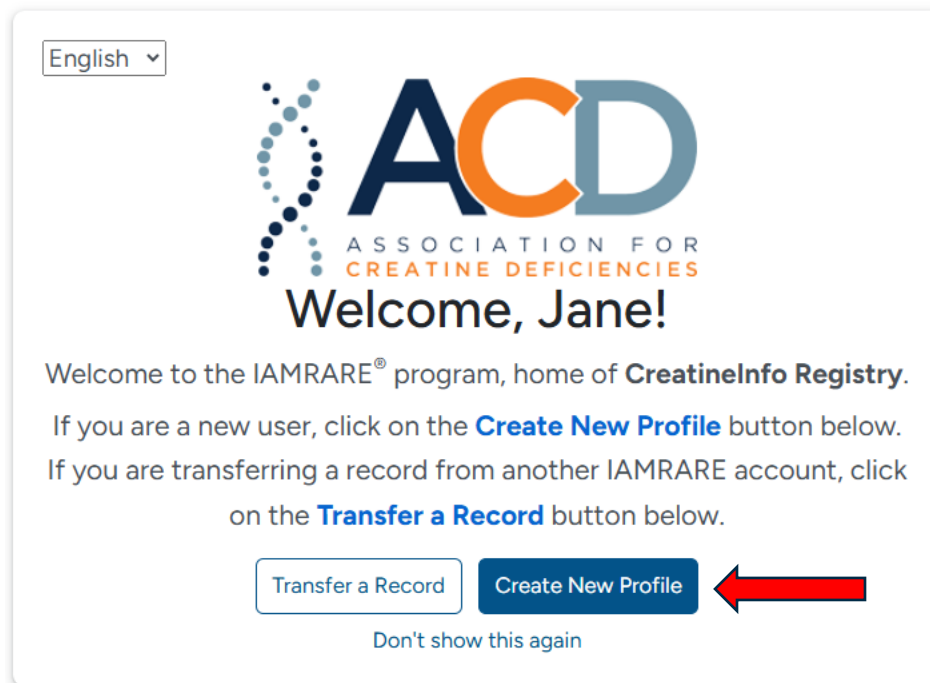
[⚠ Forgot Password](#) [+ Create an Account](#)

By logging in, you agree to NORD's [Privacy Policy](#) & [Terms and Conditions](#)

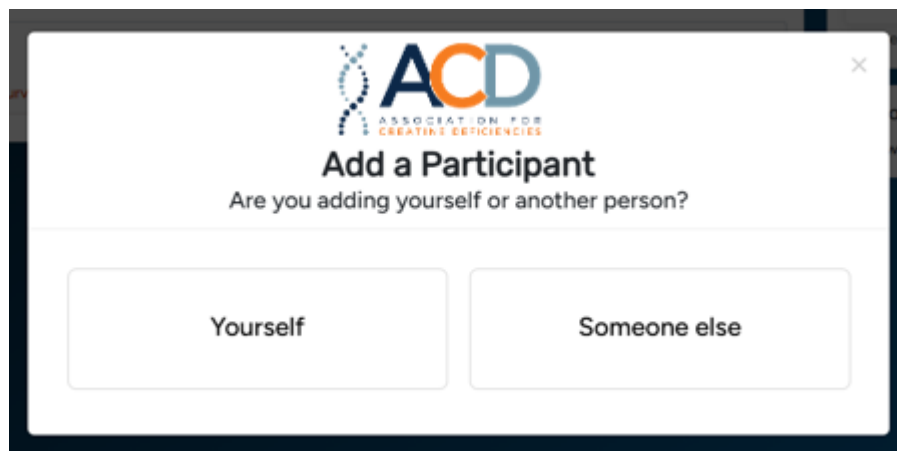


Add a Participant

- 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 [X]

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 * ⓘ** [Calendar Icon]

Sex Recorded on Birth Certificate * ⓘ [Dropdown]

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

Country of Birth * [Dropdown] **City/Municipality of Birth ***

What Is Your Relationship to ? * ⓘ [Dropdown]

Profile Image
 OR
No image selected

Consent to the Study

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

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Thank you for registering your first participant!
Would you like to consent to participate in the **CreatineInfo 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 CreatineInfo Registry


Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with cerebral creatine deficiency syndromes (CCDS) 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 CreatineInfo Registry

Adult Consent

Consent to Participate in The CreatineINFO Registry and to Allow Your Data to be Shared for Future Research

Title: CreatineINFO Registry

Principal Investigator: Heidi Wallis, Executive Director, Association for Creatine Deficiencies

Phone: +1(801)893-0543

Email: heidi@creatineinfo.org or registry@creatineinfo.org

Sponsor: Association for Creatine Deficiencies (ACD)

Key Information


You are invited to take part in a research study for individuals with cerebral creatine deficiency syndromes (CCDS). We hope that this form will help you decide whether or not to participate, but you can also call or email the study staff at the contacts above if you have any other questions.

Things you should know:

We are doing this research to understand patient and caregiver experiences with CCDS, to help support the development of treatments.

If you choose to participate, you will be asked to:

Previous Next



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.

You will be asked to acknowledge that:

- You have read the consent form and have no further questions about the Registry and your participation;
- You wish to provide personal data to the Registry for the purposes of the Study;
- You allow for your data to be used for future research, and
- 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 CreatineINFO Registry. After signing, a copy of the consent form will be emailed 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 CreatineINFO Registry have been answered to my satisfaction and I understand the purpose of the Registry and the risks of participation.

Previous

Next

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

Consent to CreatineInfo Registry

Jane Smith

X

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 CreatineInfo Registry

Select Opt-Ins for this study

- Interest in hearing about other studies from **Association for Creatine Deficiencies**
- Interest in hearing about relevant clinical trials
- Interest in donating specimens or DNA (biobanking) for future research
- New surveys
- Registry updates
- ACD community events

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 are navigation links for Home, Help, Settings, and a user greeting 'Hi, Jane!'. Below this is a welcome message 'Good Afternoon, Jane!' and 'Member since Mar 24, 2025'. A '+ Add Participant' button is in the top right. The main section is titled 'Participants' and contains instructions: 'Select a participant to view their studies. Click on the "Add Participant" button above to add a participant.' Below the instructions is a list of participants, with 'Jane Smith' (5-May-2000) and '10 pending surveys' highlighted. A red arrow points to the '+ Add Participant' button. To the right, there are 'Shortcuts' for 'Request Transfer' and 'Consent/Opt-Ins', and a 'Notifications (0)' section.

- Step 2: Click on the appropriate study.

The screenshot shows the 'Enrolled Studies' section for Jane Smith. At the top, there is a 'Back to participant list' link and a 'Search Studies' button. The main section is titled 'Enrolled Studies' and contains instructions: '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.' Below the instructions is a list of studies, with 'CreatineInfo Registry' (English) and '10 pending surveys' highlighted. A red arrow points to the 'CreatineInfo Registry' study card. To the right, there are 'Shortcuts' for 'Request Transfer' and 'Consent/Opt-Ins', and a 'Notifications (0)' section.

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

The screenshot shows the 'CreatineInfo Registry' study details page. At the top, there is a 'Back to study list' link and a 'Search Studies' button. The main section is titled 'CreatineInfo Registry' and contains instructions: '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.' Below the instructions is a list of surveys, with 'CreatineInfo Registry' (English) and '10 pending surveys' highlighted. A red arrow points to the 'CreatineInfo Registry' study card. To the right, there are 'Shortcuts' for 'Request Transfer' and 'Consent/Opt-Ins', and a 'Notifications (0)' section.

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 'CreatineInfo Registry' page for Jane Smith. It displays two completed surveys: 'Getting Started' and 'Caregiver Contact Information', both completed on 24-Mar-2025. For each survey, there are buttons for 'View Responses' and 'Reports'. Red arrows point to these buttons. The top navigation bar shows 'Jane Smith' and '5-May-2020'. A 'Surveys' section indicates '8 pending' surveys. Filter buttons for 'All (10)', 'Complete (2)', and 'Pending (8)' are visible.

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. It features a search bar labeled 'Search Studies' and a 'Shortcuts' section with buttons for 'Request Transfer' and 'Consent/Opt-Ins'. A red arrow points to the 'Consent/Opt-Ins' button. The top navigation bar shows 'Jane Smith' and '5-May-2020'. A 'Back to participant list' link is visible in the top left.

- 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. It displays a table with the following data:

Study Name	Consent Status	Consented On	Actions
CreatineInfo Registry	✓ Consented	24-Mar-2025	View Consent Revoke Opt-Ins

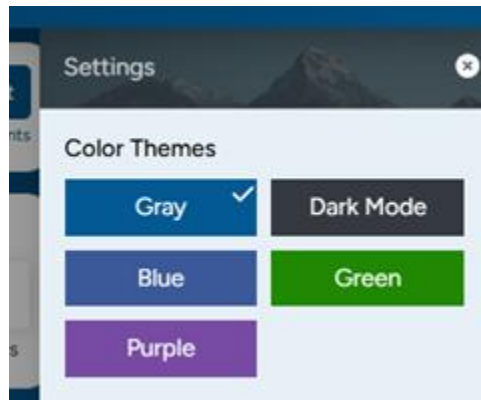
Red arrows point to the 'View Consent', 'Revoke', and 'Opt-Ins' buttons in the Actions column. The top navigation bar shows 'Jane Smith' and '5-May-2020'. A 'Back to study list' link is visible in the top left.

Dark Mode Settings

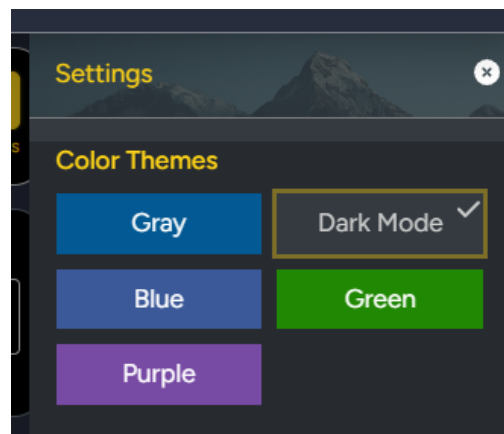
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

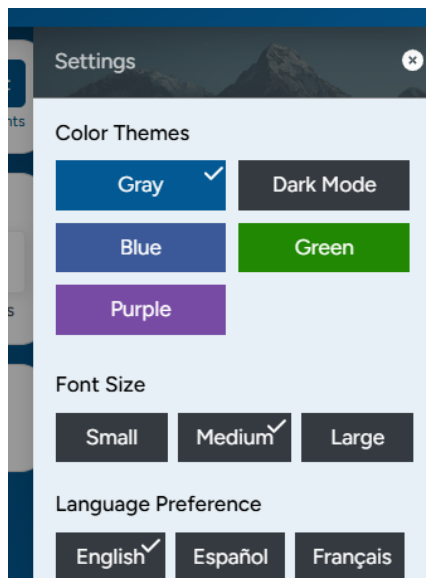


Display Settings

- 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 (creatineinfo.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?

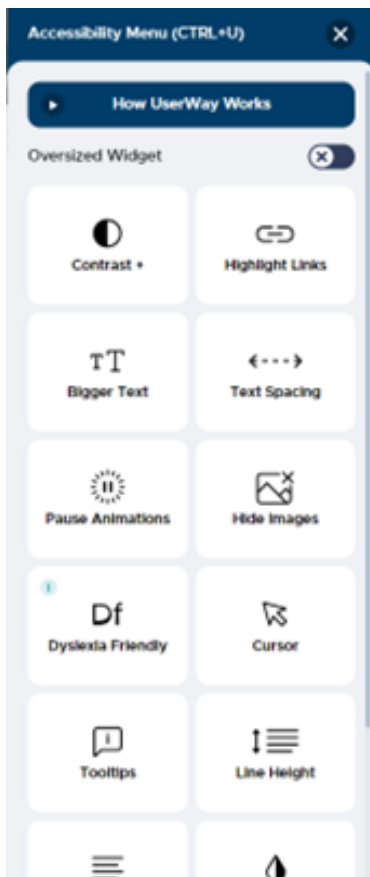


For Patients

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.

The image shows a "Have a question?" dialog box. At the top, there are "Home" and "Help" navigation options. The dialog box contains the following 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 is a dropdown menu for "Inquiry Type *" with the placeholder text "-- Select Inquiry Type --". Underneath is a text input field for "Message *" with the placeholder text "Your message". At the bottom, there 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.

The image shows a dashboard on the left with four panels. The first two panels each contain a 'View Responses' button with a notification icon and a 'Reports' button. The third and fourth panels each contain a 'Take Survey' button with a pencil icon. To the right is a contact information card for the Association for Creatine Deficiencies (ACD). The card features the ACD logo, the organization's name, and the website creatineinfo.org. It lists contact details for Emily Reinhardt, including a phone number (+1 (801) 893-0543) and an email address (registry@creatineinfo.org). It also provides an IRB email address (info@northstarreviewboard.org) and social media icons for Facebook, Twitter, and Instagram.

View Responses 1

Reports

View Responses 1

Reports

Take Survey

Take Survey

ACD ASSOCIATION FOR CREATINE DEFICIENCIES

Association for Creatine Deficiencies

creatineinfo.org

Contact

Emily Reinhardt

Phone

+1 (801) 893-0543

E-mail

registry@creatineinfo.org

IRB E-mail

info@northstarreviewboard.org

Social Media

[f](#) [t](#) [i](#)