



Participant User Guide


Register for an Account

- Step 1: Select the appropriate Account Type. If you need more information to help you choose, click “Not sure? Help me choose”.
 - If you have a diagnosis of Metachromatic Leukodystrophy (MLD), select **Participant Account**.
 - If you are entering information for someone else who has Metachromatic Leukodystrophy or you have Metachromatic Leukodystrophy and are also entering information for yourself, select **Caregiver Account**.
 - If you are entering information for a Metachromatic Leukodystrophy patient who has passed away, select **Caregiver Account**.

A screenshot of the registration page titled "Select Account Type". At the top, it says "Featuring" above the Cure MLD logo. Below the logo, the title "Select Account Type" is centered. There are two main options presented in boxes: "I have a rare disease, condition, and/or diagnosis. Participant Account" and "I am a family member or guardian of someone with a rare disease. Caregiver Account". At the bottom left, there is a link "Return to login" with a back arrow icon. At the bottom right, there is a link "Not sure? Help me choose.".

- Step 2: Read the Terms and Conditions and Privacy Policy and attest to the statements provided. When you are finished with this page, click “Next”.

Featuring




Caregiver Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

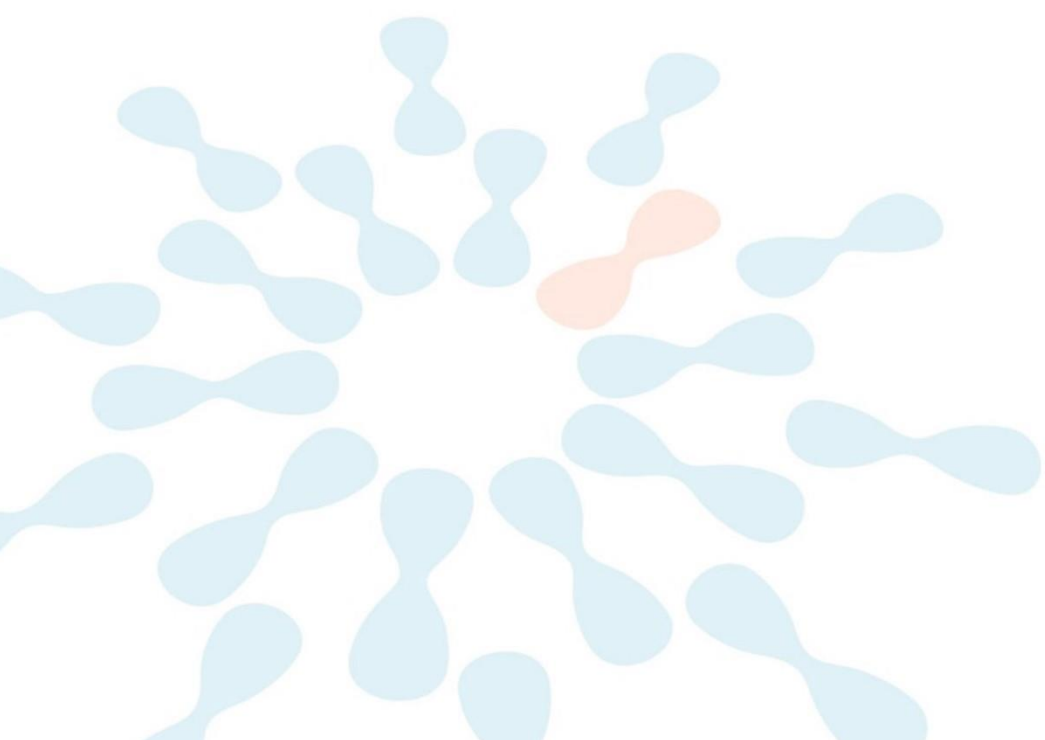
Below are links to the IAMRARE Terms of Use and Privacy Guidelines. The purpose of these documents is to outline your rights and responsibilities when using the platform. These documents include: 1) Standard policies for all studies on this platform, 2) A privacy statement that details how your data can be used, 3) Information outlining the unacceptable uses of the platform, and 4) Information about how to address questions and issues.

- 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 3: Enter **your** personal information in the spaces provided. When you are finished with this page, click “Next”.



Featuring



Caregiver Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

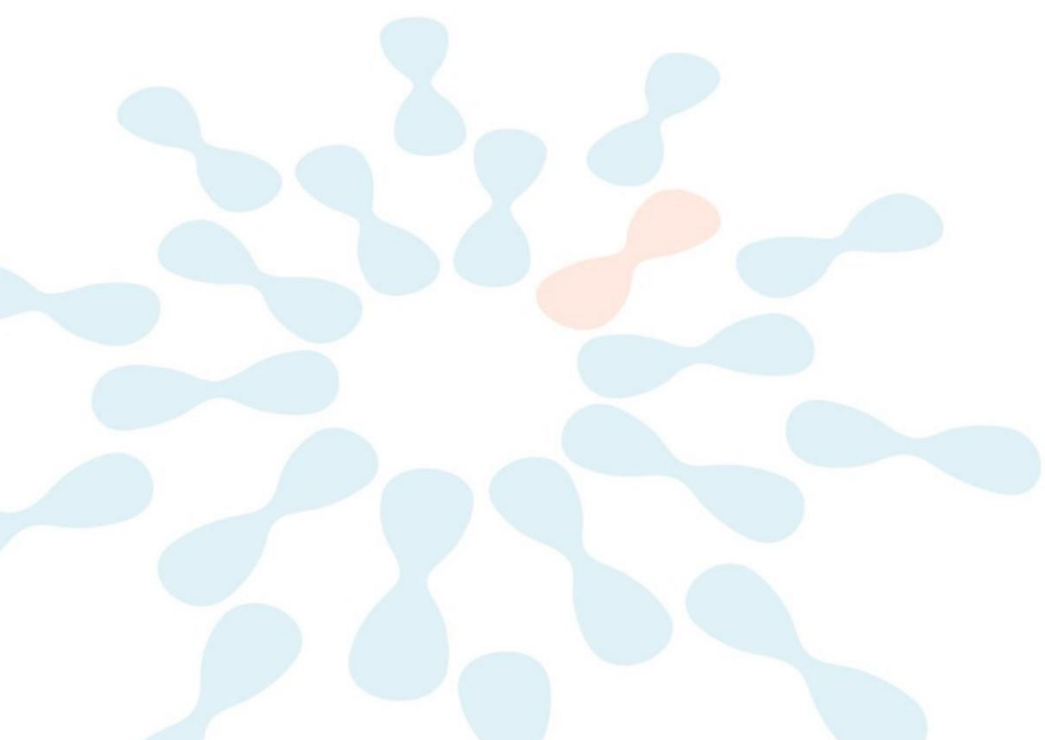
Country of Residence *

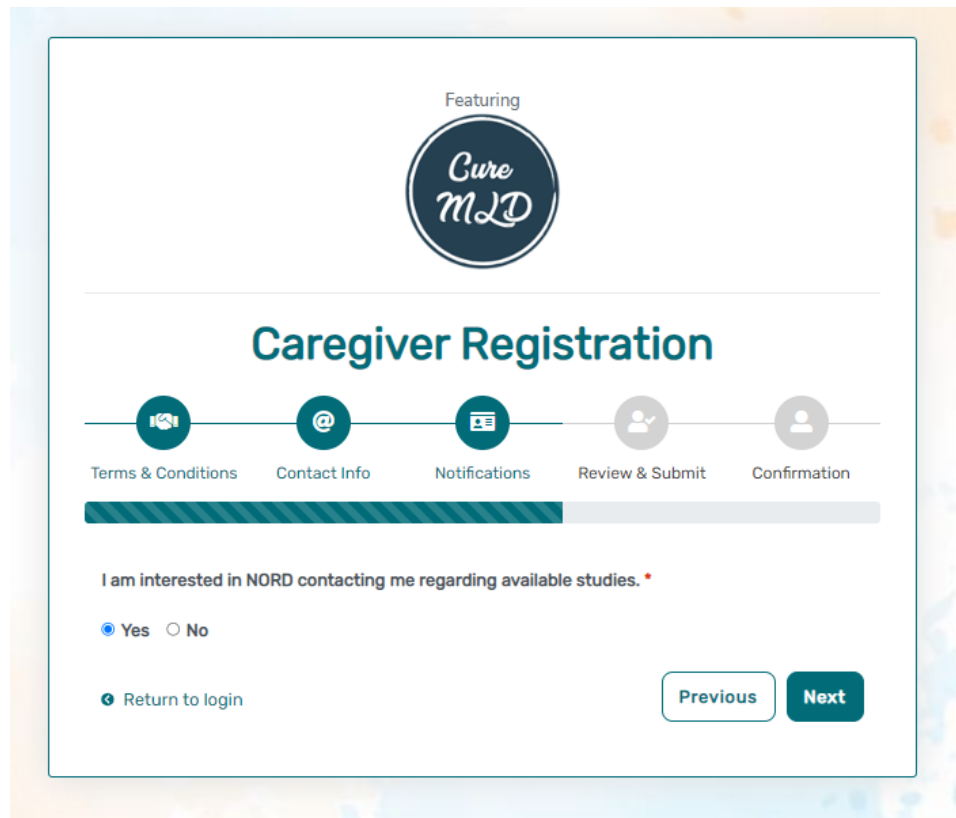
First Name * Last Name *

E-mail *

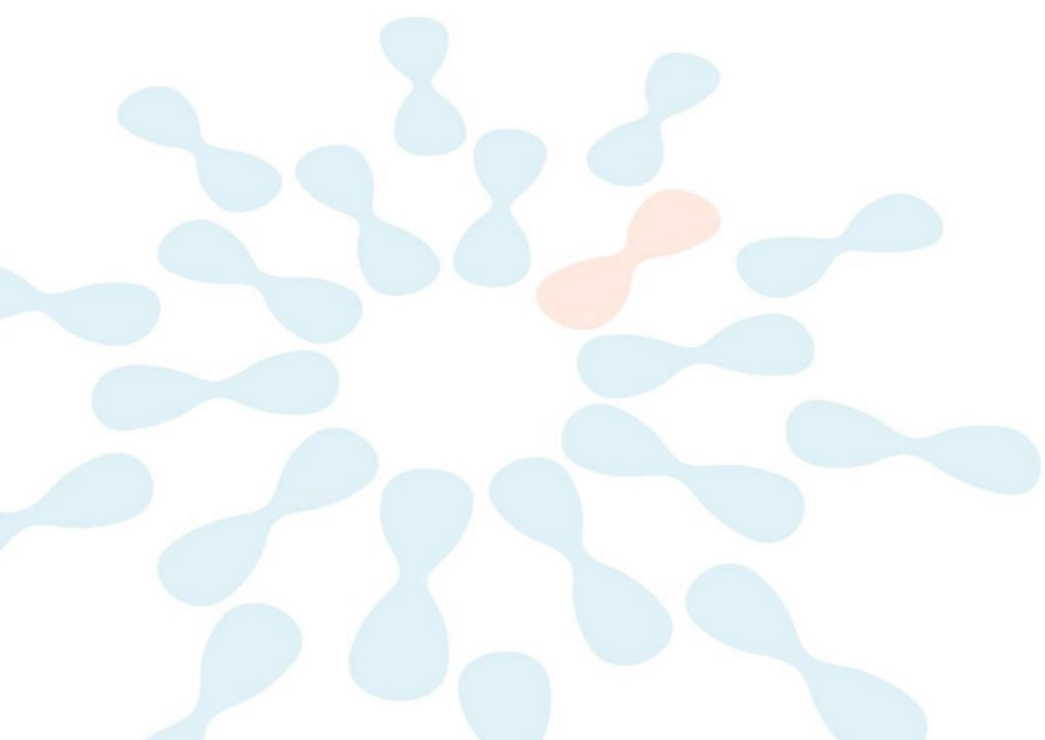
[Return to login](#) [Previous](#) [Next](#)

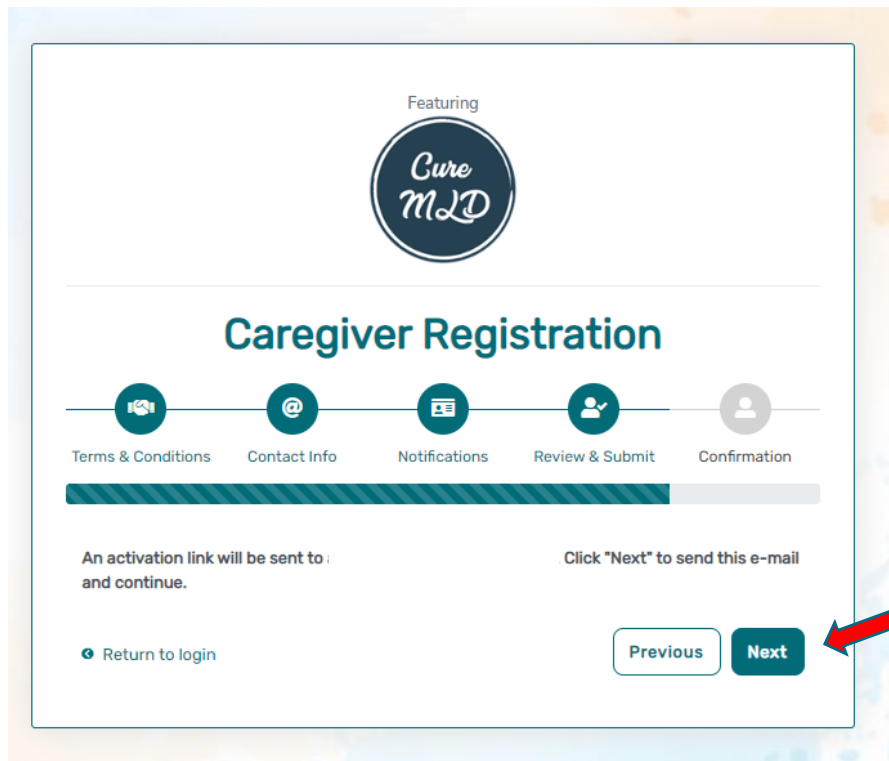
- Step 4: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.



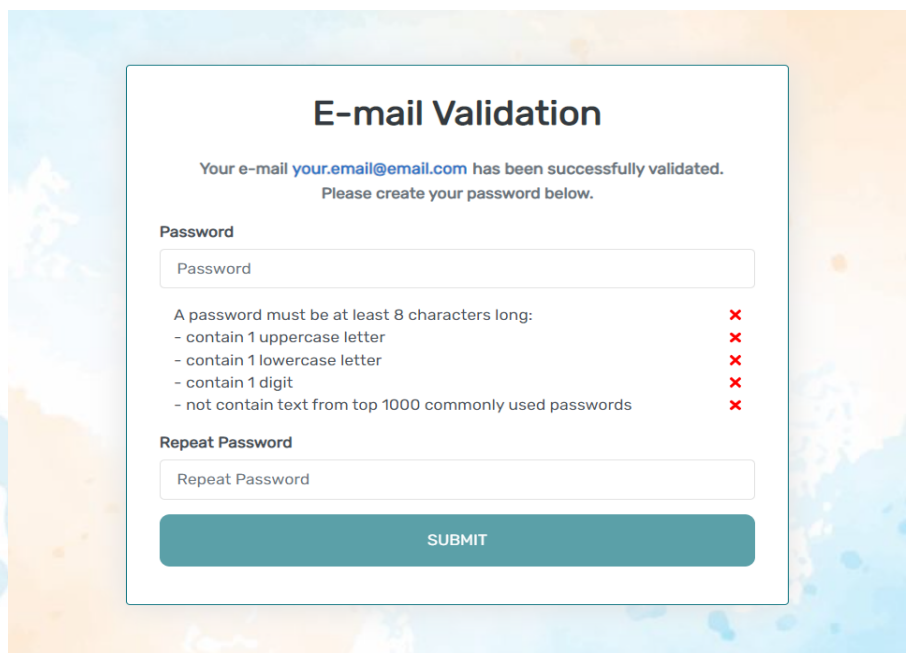


- Step 5: Select “Next” so that an activation link is sent to your e-mail to complete registration.

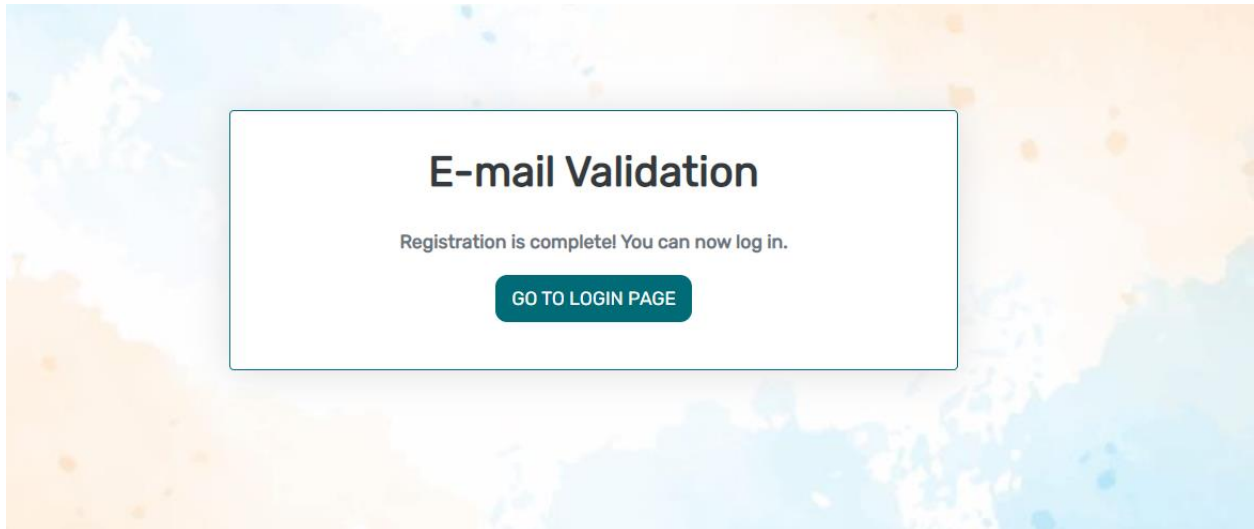




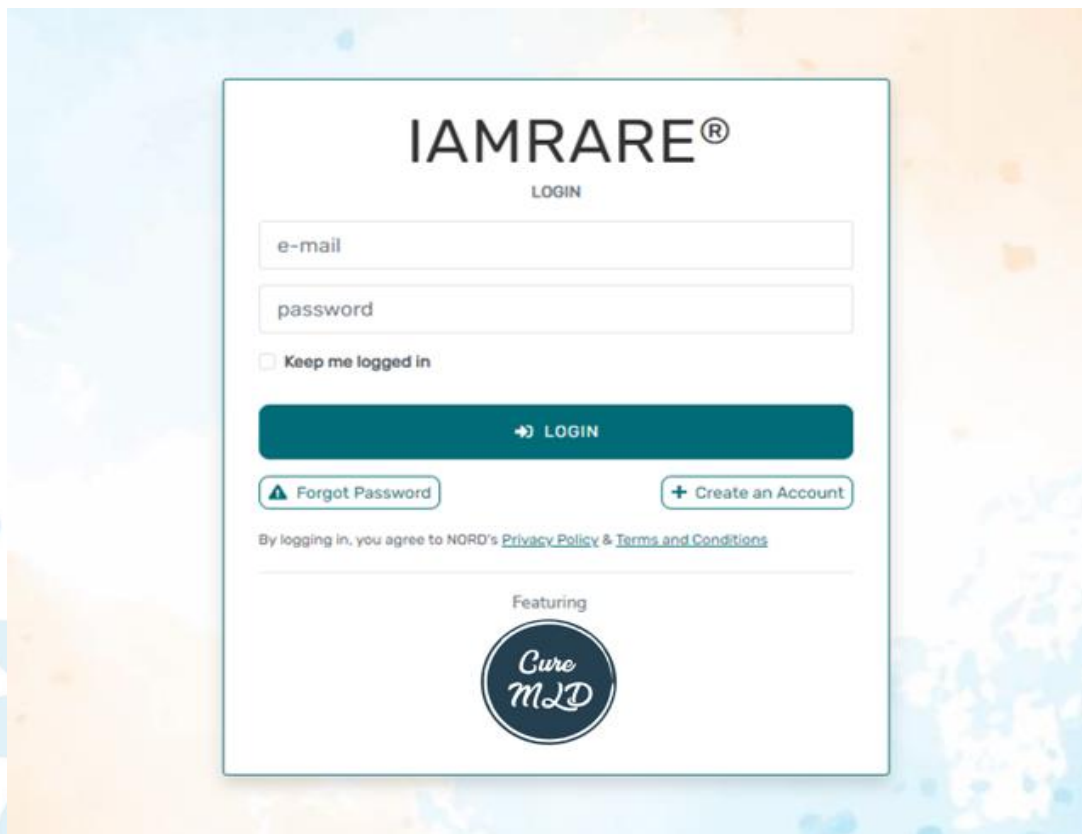
- Step 6: Click the link you are sent via e-mail. Please check your Spam folder if you do not see the e-mail. You will be taken to the following screen in a new tab within your browser. Set your password and click “Submit”.



- Step 7: Your validation is now complete. Select “Go to Login Page”.

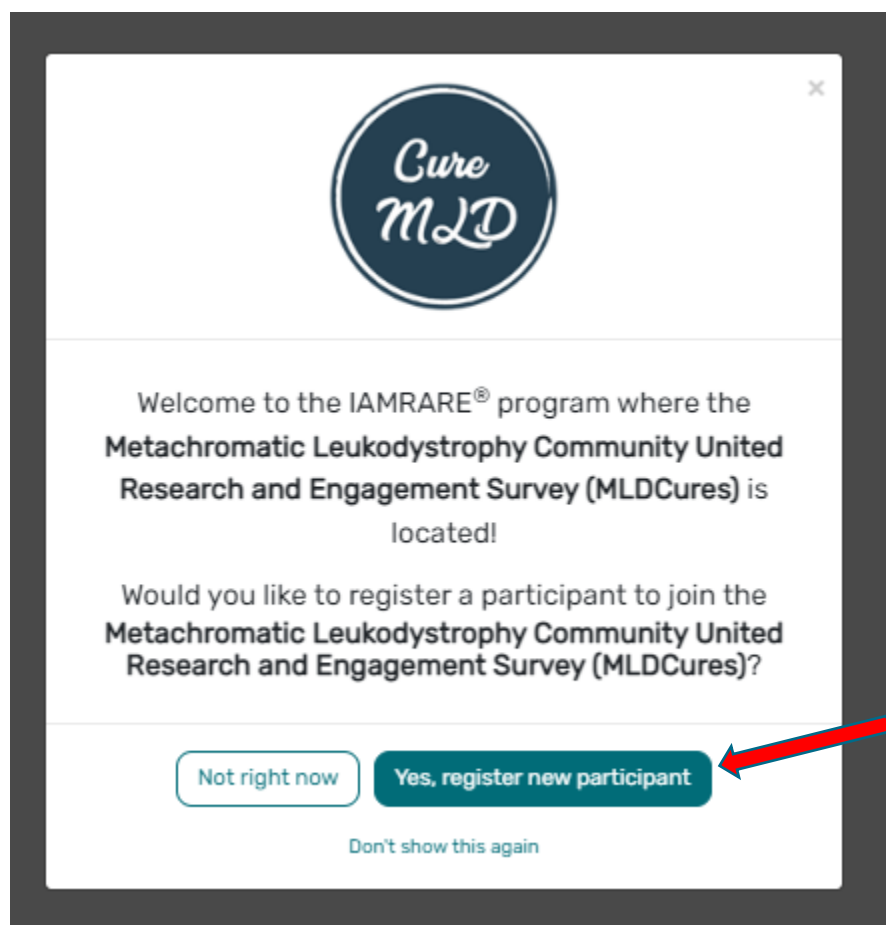


- Step 8: Log in using your new e-mail and password.

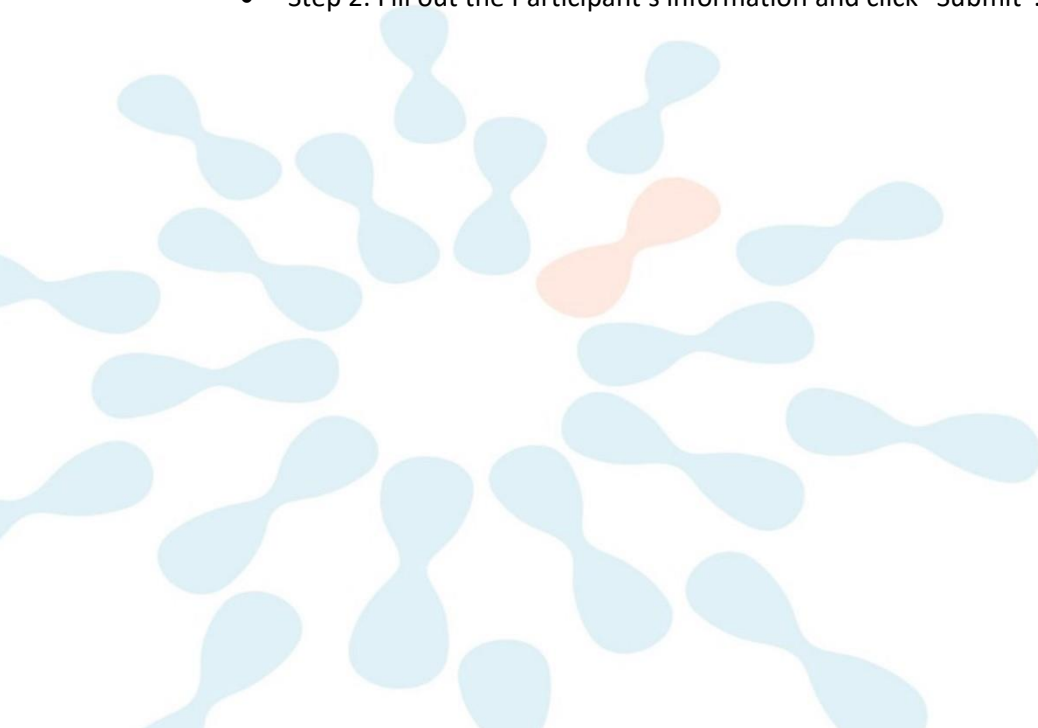


Add a Participant

- Step 1: To start, click Yes, register new participant.



- Step 2: Fill out the Participant's information and click "Submit".



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 *

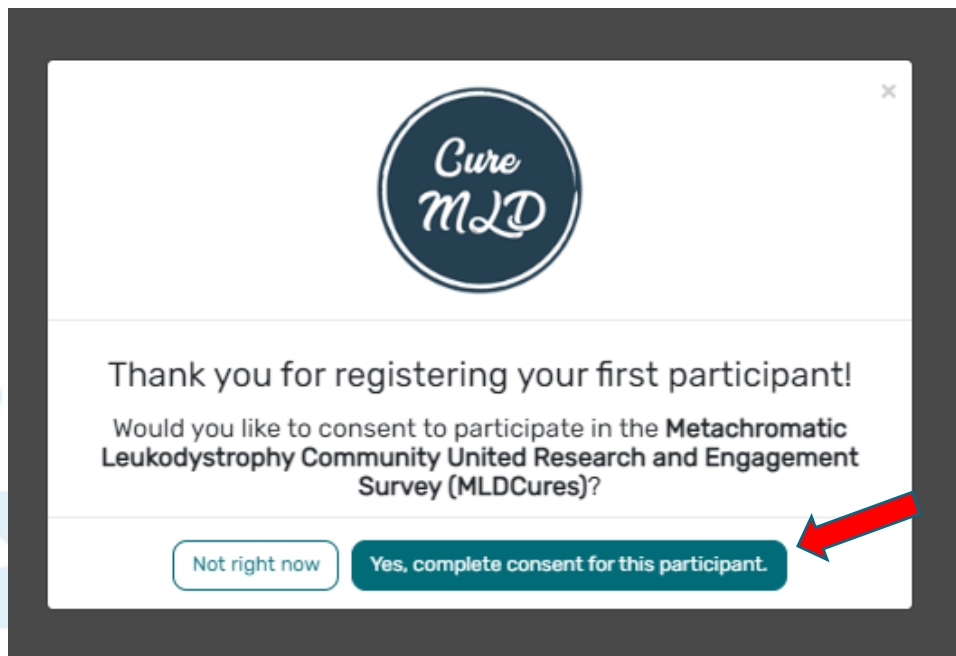
Country of Birth *

City/Municipality of Birth *

What Is Your Relationship to ? * 

Consent to the Study

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



The image shows a consent dialog box with a dark border. At the top center is the Cure MLD logo, which consists of the words "Cure MLD" in a white, cursive font inside a dark blue circle. Below the logo, the text reads: "Thank you for registering your first participant!" followed by "Would you like to consent to participate in the **Metachromatic Leukodystrophy Community United Research and Engagement Survey (MLDCures)?**". At the bottom, there are two buttons: "Not right now" in a light blue button and "Yes, complete consent for this participant." in a dark teal button. A red arrow points to the teal button. The dialog box has a close button (an 'x') in the top right corner.

- Step 2: Scroll down and read through the consent form thoroughly. Once you finish reading, 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 “Continue to Opt-Ins.”

Consent to Metachromatic Leukodystrophy Community United Research and Engagement Survey (MLDCures)

• You cannot reach the research team.
• You want to talk to someone else about the research.
• You have questions about your rights as a research subject.

Do not sign this form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Authorization

I have read (or someone has read to me) this Consent and Authorization Form to provide data for future research purposes and have decided to donate the Study Participant's data to MLDCures. The general purposes of survey participation, details of my and the Study Participant's involvement, and possible risks and inconveniences have been explained to my satisfaction. I understand that I will receive an electronic copy of this consent/authorization form.

Because of the way data is collected and saved, to participate in this study, the Participant or person agreeing must be willing to agree to permitting data to be shared as described. If you cannot agree to this, please do not participate in the study.

Please reference the following sections of the consent form for details on how data collected in this study will be used.

- How Study Participant Data Gets into the Survey
- How Study Participant Data is Stored and Used for Future Research
- Confidentiality
- Voluntary Participation and Withdrawal
- Privacy Rights

I have read this consent document and have no further questions on behalf of the Study Participant, regarding participation in the MLDCures survey.

I give permission on behalf of the Study Participant to provide research data to MLDCures only for the purposes described above. The Study Participant's data will be used as described in the consent form.

I give permission on behalf of the Study Participant to provide research data that has been pseudonymized to MLDCures for future research within recognized ethical standards for scientific research.

I understand that by providing my consent on behalf of the Study Participant to participate in the MLDCures survey, I am not automatically sharing the Participant's or my individual Personally Identified Information with the Children's Hospital of Philadelphia (CHOP) MLD natural history study. If I am willing to share the Study Participant's and my information with CHOP, I will be required to opt-in to sharing my information in a separate survey within the MLDCures study.

I have explained the study to the Participant to the extent feasible according to the Study Participant's ability to understand, and to the degree possible, the Participant has given their consent to participate in this study.

[Continue to Opt-Ins](#)

- Step 3: Select your opt-ins, then click Save and Review.

Opt-Ins for Metachromatic Leukodystrophy Community United Research and Engagement Survey (MLDCures)

Select Opt-Ins for this study

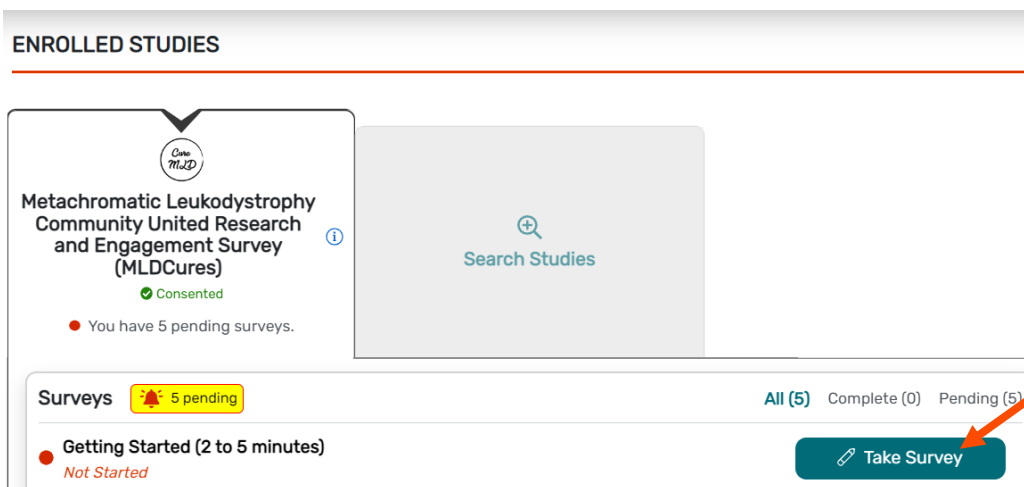
- Interest in hearing about clinical trials you may be eligible for
- Interest in donating specimens or DNA (biobanking) for future research
- Support from [Cure MLD](#) Ambassador / Care Coordinator
- If eligible, I have interest in receiving [Cure MLD's](#) merchandise that would be sent via electronic or postal mail
- Interest in hearing about family conferences and events run by [Cure MLD](#)
- Support from other Patient Advocacy Groups
- For US Residents: If eligible, I would like to receive a thank you token that would be sent via electronic or postal mail.

[Save and Review](#)

- Step 4: Download a copy of your consent, or click Close to continue.




- Step 5: You will now have access to start taking surveys.



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.

ENROLLED STUDIES



**Metachromatic Leukodystrophy
Community United Research
and Engagement Survey
(MLDCures)** ⓘ

✔ Consented

● You have 4 pending surveys.

Search Studies

Surveys 🔔 4 pending All (5) Complete (1) Pending (4)

✔ Getting Started (2 to 5 minutes) <i>Completed on 14-Mar-2023</i>	View Responses ⓘ
	Reports
● Participant Profile (10 to 12 minutes) <i>Not Started</i>	Take Survey
● Diagnosis (10 to 12 minutes) <i>Not Started</i>	Take Survey

