

HOW TO GET STARTED

Thank you for your interest in mitoSHARE! To help you through the onboarding process, follow this step-by-step guide and you will be on platform in less than 10 minutes. We want to make sure every mitoSHARE participants knows how to navigate the key components of the registry. The most important fields to complete inside your registry account are the **Proxy Settings** and completing your **Member Profile**. By updating your contact information inside your Member Profile and enabling Proxy Settings will allow us to contact you with personalized content. To get to these settings start with step 1!

1. Select appropriate account type on <https://www.umdf.org/mitoshare-registry> - Click JOIN LUNADNA!



Welcome to LunaDNA

Who are you creating an account for?

☒ MYSELF

☐ A MINOR

☐ AN ADULT

I am an adult over the age of 18 able to manage my own account.

JOIN LUNADNA

Already a member? Link an existing account: [Log In](#)

2. Create your Account- Enter email address, password, Country of Residence, and DOB to get started!



Welcome to LunaDNA

Welcome to the mitoSHARE Registry!

Email Address*
registry@umdf.org

Confirm Email*
registry@umdf.org

Create Password*
.....

Confirm Password*
.....

☒ Between 8 and 100 characters

☒ Lowercase letter

☒ Uppercase letter

☒ Number

☒ Special character

United States

January

1

1980

Date of Birth

JOIN LUNADNA

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3. **Two- Factor Authentication-** Enter your cell phone or Google number to set-up your Two-Factor Authentication. Note you will use two-step authentication every time you log in to mitoSHARE.



Set Up Your Two-Step Authentication



Please enter your phone number below to add an additional layer of security.

SEND CODE

Notice:

Since your LunaDNA account can be used to access all of your shared health and DNA data, we require two-step authentication to ensure you are actually who you say you are. When you log into your account, we will use your phone number to send you a text message as an additional authentication step. Your phone number is your personal data, and as such will be protected in accordance with our privacy policy.

4. **Consent-** Confirm your consent agreement to participate in research presented by UMDF (mitoSHARE) as well as LunaDNA. Our registry participants have the right to control their own data, share their data, and participate in mitochondrial research to ultimately find avenues to better health.



With your consent, we can drive new discoveries


- Your data never leaves LunaDNA without your permission
- You can delete your data or revoke your consent at any time
- Your personal information is never shared without permission
- All research has oversight to protect participants
- LunaDNA does not sell data for advertising, marketing, or any other purpose

Read the full LunaDNA Consent ▾

By clicking **CONFIRM**, you are agreeing to be legally bound by the above terms, including the [Privacy Policy](#).

CONFIRM CONSENT

[I DON'T WANT TO CONSENT RIGHT NOW.](#)

[DOWNLOAD CONSENT](#) 

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5. **Demographic Data-** As part of the account creation, you will be asked to complete the demographic questions below.

The screenshot shows a web form titled "Help us learn more about you" from Luna DNA. The form explains that demographic information is vital for researchers. It contains two main sections: "Sex (biological)" and "Ethnicity (check all that apply)".

Sex (biological)

- ☐ Female
- ☐ Male
- ☐ Intersex
- ☐ None of these describe me
- ☐ Decline to answer

Ethnicity (check all that apply)

- ☐ American Indian
- ☐ Alaska Native
- ☐ Central or South American Indian
- ☐ Asian
- ☐ Black, African American, or African
- ☐ Hispanic, Latino, or Spanish
- ☐ Middle Eastern or North African
- ☐ Native Hawaiian or other Pacific Islander
- ☐ White
- ☐ None of these describe me
- ☐ Decline to answer

At the bottom of the form are two buttons: "SKIP FOR NOW" and "UPDATE PROFILE".

6. **Proxy Settings-** As a mitoSHARE member you have control over your data. You will be asked if you would like us to have access to your contact information as well as any contributed data inside mitoSHARE. Please know having access to your contact information is vital for us to be able to notify you of new studies.

The screenshot shows a web form titled "With your permission, your registry can do more with your data." from Luna DNA. The form explains the benefits of providing access to contact information and individual data for research.

By providing access to your **name and email address**, your registry can contact you directly.

By providing access to **your data**, your registry can do more for research.

The form contains two checkboxes:

- ☐ Allow mitoSHARE Registry to download my **contact information** (name and email address)
- ☐ Allow mitoSHARE Registry to download my **individual data** for their own purposes

At the bottom of the form are two buttons: "SAVE MY PREFERENCES" and "SKIP FOR NOW".

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7. **General mitoSHARE Study-** Our introductory demographic and diagnostic survey presented to all of our registry participants. This study seeks to capture standard demographic and diagnostic data to help better understand general aspects of the affected individual's everyday life and health to better characterize mitochondrial disease.

The screenshot shows a web interface for the 'General mitoSHARE Study'. At the top, a teal banner reads 'Contribute Data, Earn Shares'. Below this, a white card contains a welcome message: 'Welcome Registry Participant! On behalf of the entire UMD family welcome to our new patient registry, mitoSHARE. mitoSHARE is THE place to participate in mito-focused surveys and research studies that will capture your mito disease story in the form of data that ultimately moves the needle on therapeutic development. Your sharing shows you care. Thank you.' Below the message, a red text line states: 'This survey is for ADULTS (18 years of age and older) only.' The main content area is divided into two columns. The left column has a red warning icon and text: 'YOU MUST COMPLETE THE FOLLOWING REQUIREMENTS TO ENROLL IN THIS STUDY'. Below this, it says 'Age Restriction' and a 'QUALIFY' button. The right column has a line graph icon and text: 'STUDY INSIGHTS COMING SOON'. At the bottom, a white card shows a checklist item: 'mitoSHARE Demographics and Diagnosis Survey' with a red 'INCOMPLETE' status and a note: 'Age Restriction required'. Below this, an orange banner with a warning icon says: 'Participation Requirement not met. You need to complete the Age Restriction participation requirement.'

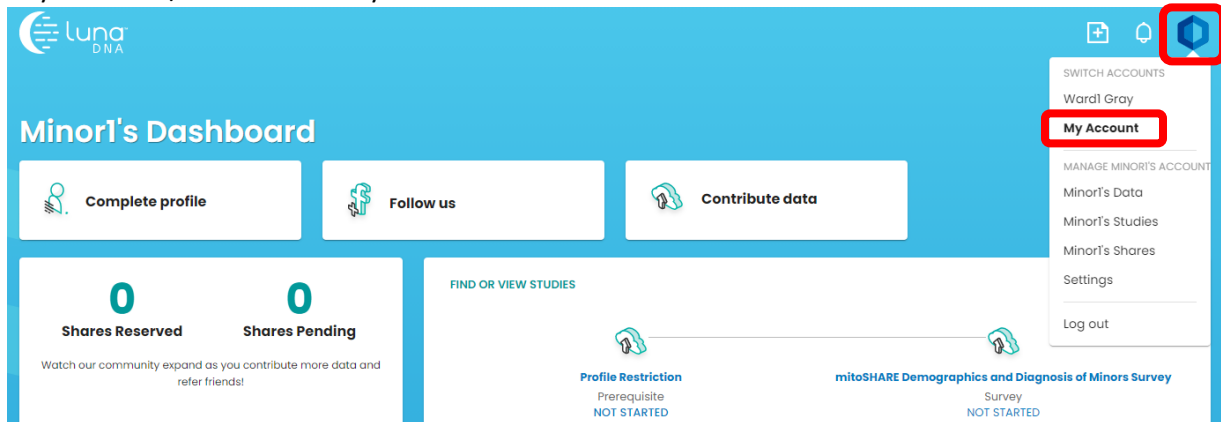
8. **Update Member Profile-** Please complete all Member Profile and Contact Info fields that are not prepopulated from account creation. This will allow our Registry Coordinator to keep you apprised of any new surveys and studies available on platform.

The screenshot shows the 'Settings' page of the Luna DNA platform. On the left, a teal sidebar contains the 'Settings' title and a list of options: 'Member Profile', 'Contact Info', 'Privacy', 'Security Settings' (with a checkmark icon), and 'Delete Account'. The main content area is titled 'Member Profile' and features a 'CHANGE' button with a circular arrow icon. The form is divided into two sections. The first section, 'Current Legal Name', has three input fields for 'First Name', 'Middle Name', and 'Last Name'. The second section, 'Information at Birth', starts with a checkbox labeled 'My birth name is the same as my current legal name'. Below this, there are three input fields for 'First Name', 'Middle Name', and 'Last Name'. Further down, there are three more input fields: 'Birthdate' (with a pre-filled value of '05/19/1988' and a 'MM/DD/YYYY' hint), 'City of Birth', and 'Country of Birth' (a dropdown menu).

9. **Minor/Ward Account Creation-** For the Guardians/Caregivers that are creating a profile on behalf of their child/ward, please create their account first before creating your own. After creating their account, you will be automatically pushed into the General mitoSHARE Minor Study. After completing this survey (on behalf of your minor/ward), you will have to go to the top right icon and select My Account. Selecting My Account will lead you the Consent for agreeing to participate in research allowing you to create your own account. Once you have created your own account you will

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be automatically see the General mitoSHARE Study for yourself. Please complete the survey at onboarding on behalf of your minor/ward as well as yourself.



If you don't create your own account in the same session as you did your minor/ward or you get kicked out due to inactivity and you have to log back in, you will have to find the General mitoSHARE Study yourself. Logging back into the system you will select MY DASHBOARD.



Where would you like to go first?

Available Users

Ward1

MY DASHBOARD

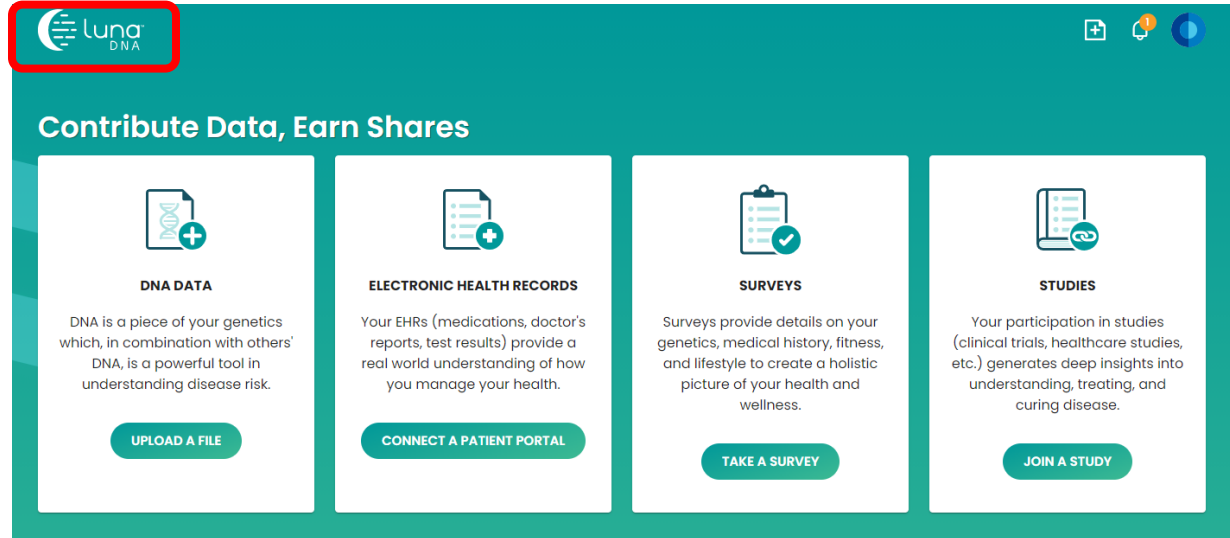
WARD DASHBOARD

- Share your own data for research
- Review tasks and notifications for both accounts

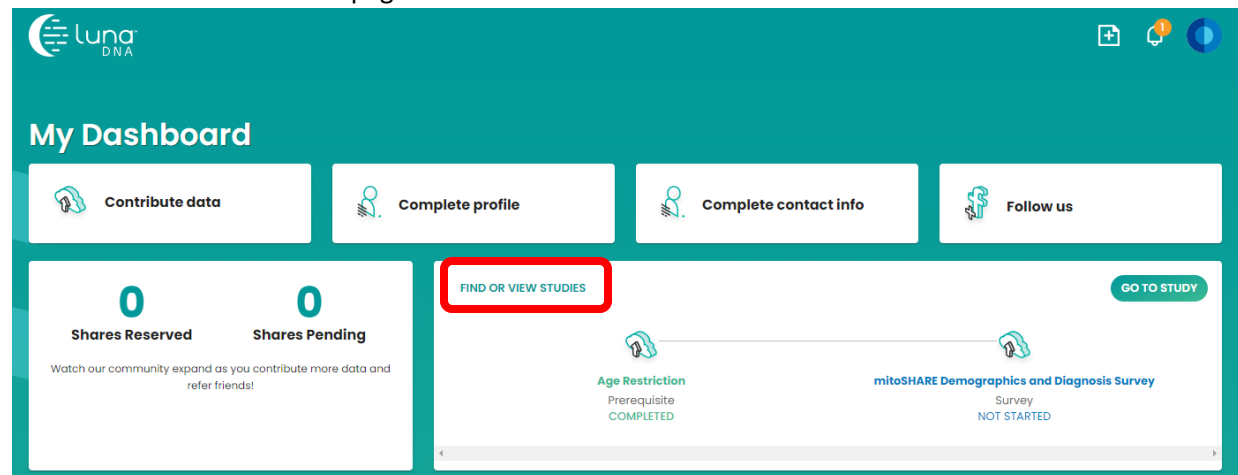
- Add data to your Ward's account
- Confirm how you are contacted for studies related to your Ward

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Complete your account creation. Once you have entered all the required fields to creating your account, you will see the Contribute data, Earn Shares landing page. On this page select the LunaDNA logo in the upper left corner of the screen. This will lead you back to your main dashboard.



Once you are viewing your dashboard, select FIND OR VIEW STUDIES. You will be able to access all of LunaDNA and mitoSHARE's studies on this page.



Select General mitoSHARE Study under mitoSHARE Registry Studies and complete the survey.



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To avoid this lengthy onboarding process, please create both minor/ward accounts as well as your guardian/caregiver account in the same session.