


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 participant knows how to navigate the key components of the registry. The most important fields to complete inside your registry account are the **General Information** and your **Demographics** fields. To get to these settings start with step 1!

- 1. Create an Account-** Enter your First Name, Last Name, E-mail address, Mobile Phone, and DOB to get started! Select if you are at least 18 years of age and where you are located. Don't forget to select what kind of mitoSHARE participant you will be, a patient, a caregiver, or someone who has lost a loved one to mitochondrial disease. You can select all that apply!



Request Access

Join us and get connected today!

Your Information:

This information will be used to create access credentials for the patient who will be accessing the platform themselves, or the caregiver/guardian who will be providing information on behalf of a patient.

Your First Name *

Enter Letters Only

Your Last Name *

Email *

Mobile Phone *

Enter Numbers Only

Your Date of Birth *

In order to proceed with your account creation, please acknowledge the following:

I am at least 18 years of age (or at least the Age of Majority in my State/Country)

I acknowledge that I am located in the United States; OR

I acknowledge that I am located outside of the United States, and that the information I am providing will be transmitted to the United States for account creation.

Please check all that apply:

Patient Participant
A Patient Participant is a person with a rare disease (already diagnosed or still on their diagnostic journey) who will be able to answer surveys and provide information about themselves.

Caregiver Participant
A Caregiver Participant will be able to answer surveys and provide information on a patient(s) with a rare disease, for whom they are the Parent or Legally Authorized Representative.

Person who has lost a loved one to a rare disease
This user will be able to answer surveys and provide information on a loved one with rare disease who is now deceased.

[PRIVACY POLICY](#) [TERMS OF USE](#) [GO TO LOGIN](#)

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- Terms of Use-** As part of the Across Healthcare Matrix platform, all mitoSHARE users are required to read and accept the TOU before joining the registry.

Terms of Use (TOU)

Please read and accept this agreement in order to gain access to this application. This agreement outlines how this application can be used and explains obligations and restrictions.

Matrix
Terms of Use
Last Updated December 23, 2021

These Terms of Use constitute a legally binding agreement made between you, whether personally or on behalf of an entity ("you") and Across Matrix, Inc. ("Matrix," "we," "us," or "our"), concerning your access to and use of our website and other technologies located at www.acrossmatrix.com as a component of your use of other hosted services (the "Service(s)"). Matrix is providing the Services as a service provider for a third party to whom we provide the Services ("Host Site"). You agree that by accessing the Services as part of your use of the Host Site, you have read, understood, and agreed to be bound by all of these Terms of Use. If you use the Services on behalf of a company or other entity, then "you" includes you and that entity, and you represent and warrant that you are an authorized representative of the entity with the authority to bind the entity to these Terms of Use, and you agree to these Terms on the entity's behalf.

IF YOU DO NOT AGREE WITH ALL OF THESE TERMS OF USE, THEN YOU ARE EXPRESSLY PROHIBITED FROM USING THE SERVICES, AND YOU MUST DISCONTINUE USE IMMEDIATELY.

PREVIOUS NEXT

- Informed Consent** – Informed consent is a critical part of research. The Informed Consent Form describes the goals of the registry, the types of data we intend to collect, the manner in which we collect the data, and how we plan to use the data to advance research in mitochondrial disease. You will need to review and agree to the terms of the Informed Consent Form in order to join the mitoSHARE registry.

Please complete our Informed Consent below.

Informed Consent

[Blank Consent Download](#)

Sponsor / Study Title:	United Mitochondrial Disease Foundation / "mitoSHARE: A Worldwide Patient-Populated Registry for the Study of Mitochondrial Disease Patients and their Caregivers"
Protocol Number:	mitoSHARE-001
Principal Investigator: (Study Doctor)	Phillip E. Yeske, Ph.D.
Telephone:	(412) 744-1065 (888) 900-6486 (24 Hour)
Address:	United Mitochondrial Disease Foundation 8085 Saltsburg Road, Suite 201 Pittsburgh, PA 15239

This form is for use in a research study that may involve participants who may or may not have the capacity to consent to take part in the study. When the participant cannot legally consent to take part, pronouns "you" and "your" should be read as referring to the participant rather than the person (parent/legal guardian, or legally authorized representative) who is signing and dating this form for the participant. In cases where the participant's representative gives consent, the participant should be informed about the study to the extent possible given his/her understanding. During the course of the study if the participant regains the capacity to consent, or if the participant turns the age of majority, informed consent will be obtained from the

PREVIOUS NEXT

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4. **General Information** – As part of the account creation, you will be asked to fill out the basic demographic criteria below. All data fields are required. The data fields will be used to create a GUID (Global Unique Identifier) for each of our mitoSHARE participants. To review the purpose of GUID's, please go to our Informed Consent Section “How is my data used for research?” Please remember to click “Save” before proceeding.

UNITED MITOCHONDRIAL DISEASE FOUNDATION.

Terms of Use ✓
Patient Informed Consent ✓
General Information

Demographics

First Name *
Middle Name
Last Name *

Suffix
Country *
Address Line 1 *
Address Line 2
City *
State/Province/Region *
Zip/Postal Code *
Date of Birth *
Phone *
Email Address
Preferred Language

Required field. Please enter Country
Required field. Please enter Address Line 1
Required field. Please enter City
Required field. Please enter State/Province/Region
Required field. Please enter Zip/Postal Code

PREVIOUS NEXT

UNITED MITOCHONDRIAL DISEASE FOUNDATION.

Terms of Use ✓
Patient Informed Consent ✓
General Information

Other Information

Race *
Ethnicity *
Gender At Birth *
Gender Identity *
Birthplace: Country *
Birthplace: State/Province/Region *
Birthplace: City *
Estimated Household Income *
Insurance Coverage for Patient? *
Clinician
Rare Disease(s) - Select all that apply *

Required field. Please enter Race
Required field. Please enter Ethnicity
Required field. Please enter Gender at Birth
Required field. Please enter Gender Identity
Required field. Please enter Birthplace Country
Required field. Please enter Birthplace State/Province/Region
Required field. Please enter Birthplace City
Required field. Please enter Estimated Household Income
Required field. Please enter Insurance Coverage
Required field. Please enter Rare Disease

CANCEL SAVE

PREVIOUS NEXT

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5. **Account (Patient/Caregiver) Dashboard-** Once you agree to the TOU, the ICF, and your patient and/or caregiver account has been created, you will land on your Dashboard. You will be directed into the Surveys/Studies tab of the registry, displayed green text below. Surveys/Studies will be the primary access point to any research opportunities available to you as mitoSHARE participant. Our introductory Diagnostic Intake Form is our main survey to complete. This survey captures information to understand the registry participant’s connection to mitochondrial disease and their diagnostic status so that additional relevant survey/study opportunities may be presented in the future.

The screenshot displays the 'Surveys/Studies' section of the mitoSHARE dashboard. At the top, there are two tabs: 'New/In-Progress' (active) and 'Completed'. Below the tabs is a table with the following columns: Surveys/Studies, Published On, Expiration Date, Time To Complete, Questions, and Status. Two surveys are listed:

Surveys/Studies	Published On	Expiration Date	Time To Complete	Questions	Status
Detailed Demographic Surv...	Mar 03, 2022		0 min	0	START
Diagnostic Intake Survey	Feb 28, 2022		0 min	0	START

Below the table, there is a 'VIEW: Category' dropdown menu. The left sidebar contains navigation options: Dashboard, General Information, Surveys/Studies (highlighted), Health Info, Symptoms and Activities, Insights, Journal, Messages, Documents, Sharing Center, Resource Center, and Contact Us. The top right of the dashboard shows 'English' and a user profile icon.