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!
2. **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.

3. **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.
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.
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.