FTD Disorders Registry Tutorial

Welcome to the FTD Disorders Registry tutorial.

This tutorial will describe what to expect during the sign up process.

Do you prefer learning by video?
Watch our Walk-Through Webinar here.

Questions: manager@ftdregistry.org

FTD DISORDERS REGISTRY

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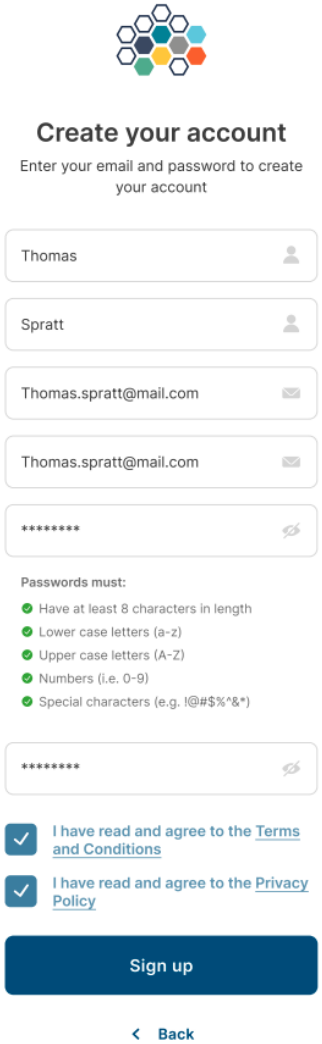

Creating Your Account

You can create an account by entering your first and last name, email address and password.

Already a Registry participant?
Please use the **same email address** associated with your account. Using this email address will link your accounts.

When **choosing a password**, remember your password must follow these requirements:

- ✓ both a lower case and upper case character,
- ✓ at least one number,
- ✓ one special character, and
- ✓ having at least 8 characters

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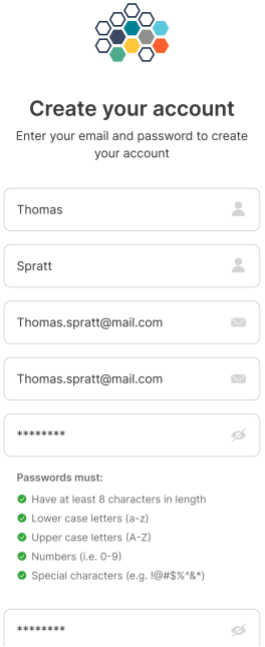
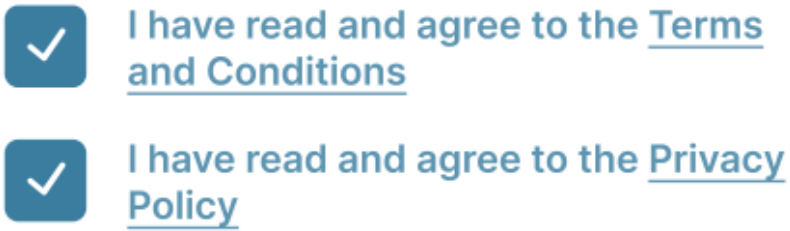


Creating Your Account

ItYou are required to **agree to the Registry's Terms and Conditions and Privacy Policy** to create your account.

These policies cover how your privacy and data will be protected.

Please **click on the links** to review these policies and **check** the two blue boxes to confirm that you have read and agree.



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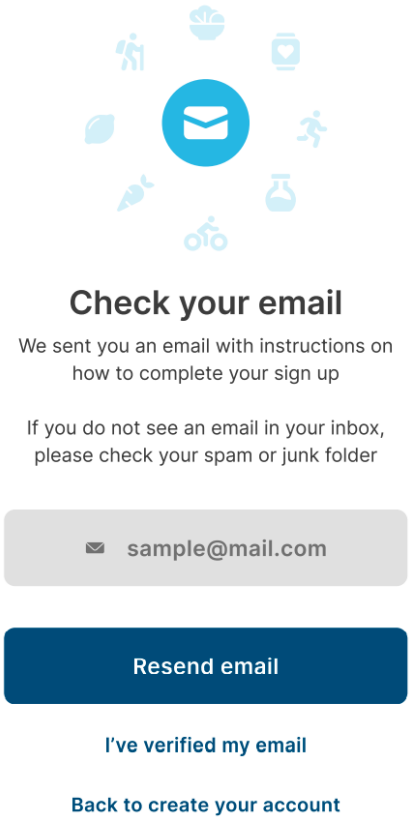

Verifying Your Account

You will receive an email from the Registry to verify your email address.

Click on the link in this email to verify your email address.

Verifying your email confirms that the email attached to your registry account is correct and belongs to you.

If you do not see this email, please check your spam folder. If you do not receive the verification email within 15 minutes, please check that your email address is correct and then click the blue resend email button.

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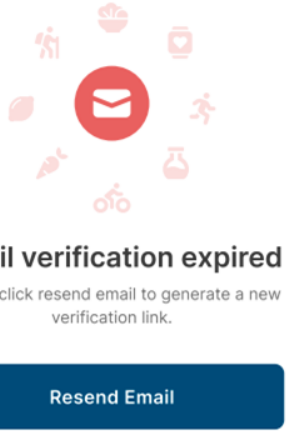
Verifying Your Account

You will know that your email has been successfully verified when you see this screen.

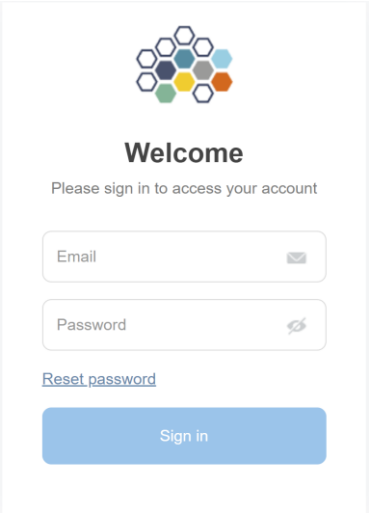
Simply press the blue continue button to finish creating your account.



For your security, your verification email will expire after X days.

If you see this message simply click the “resend email” button on the screen and you’ll receive a new verification email.

Reset Your Password



You can reset your password by clicking on the **Reset password** link at the bottom of the login screen.

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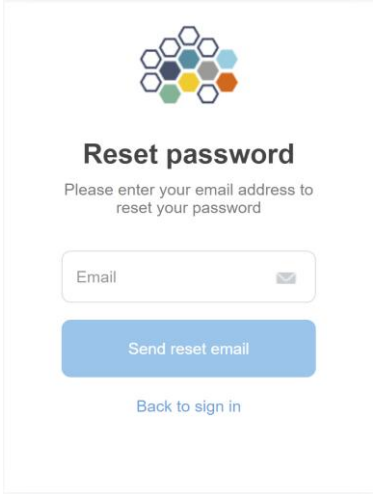
Reset Your Password



On the **Reset password** page, please enter the email address associated with your account.

Then select **Send reset email.**

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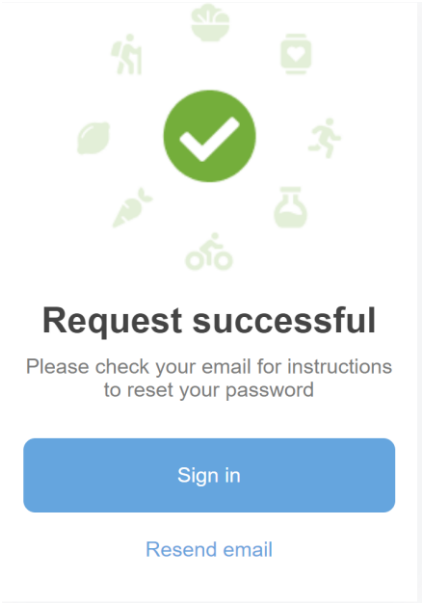
Reset Your Password



You will know that your request to reset your password has been successful when you see this screen.

Then open your email to receive the link to set a new password.

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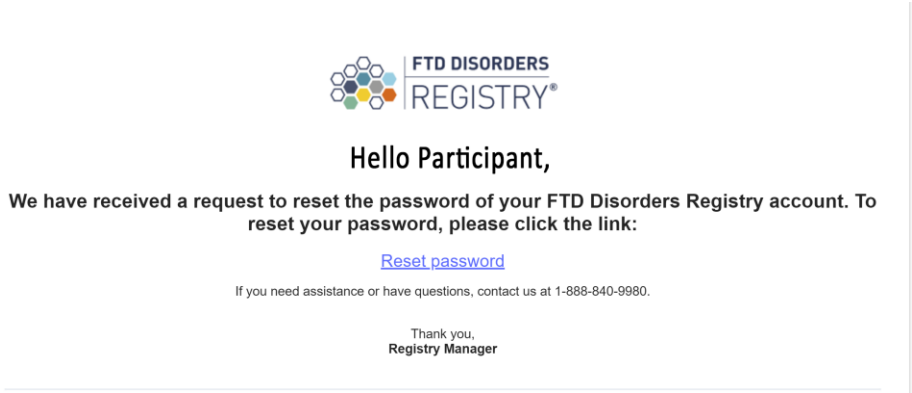
Reset Your Password

Open the email and click the **Reset password** link to return to the FTD Disorders Registry.



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Hello Participant,

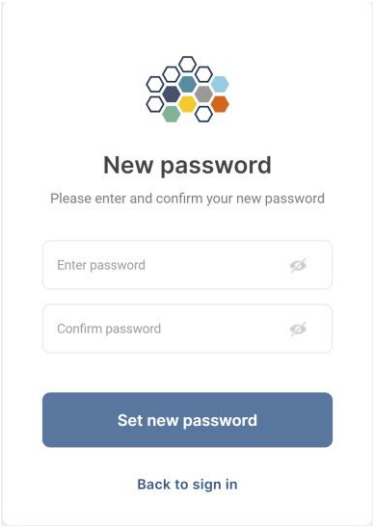
We have received a request to reset the password of your FTD Disorders Registry account. To reset your password, please click the link:

Reset password

If you need assistance or have questions, contact us at 1-888-840-9980.

Thank you,
Registry Manager

Reset Your Password



On the **New password** page, please create a new password for your account.

When **choosing a password**, remember your password must follow these requirements:

- ✓ both a lower case and upper case character,
- ✓ at least one number,
- ✓ one special character, and
- ✓ having at least 8 characters

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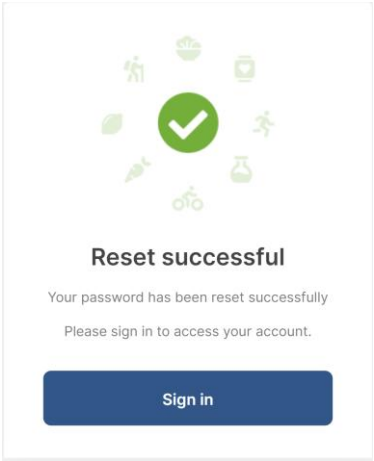
Reset Your Password



You will see this screen when your new password has been accepted.

Then click **Sign in** to return to the login screen.

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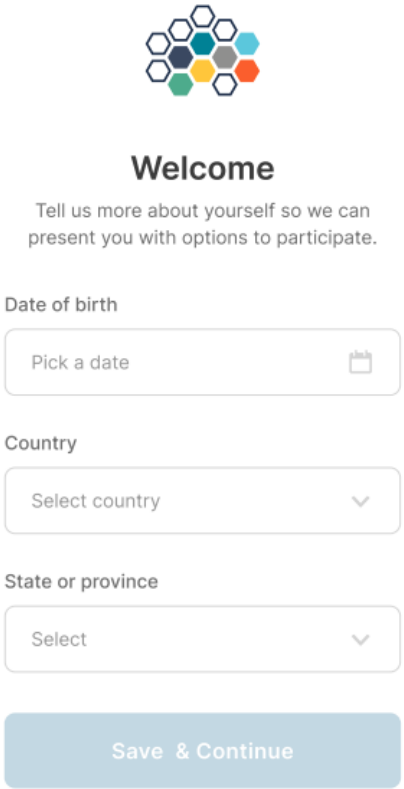
Personalizing Your Account

Once your email has been verified your Registry account has been created.

The next few screens will collect information about you to:

- determine your eligibility for research
- provide you with information of interest



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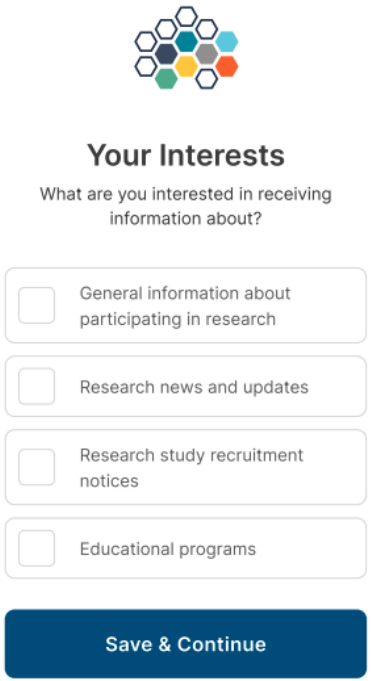
Personalizing Your Account - Your Interests



Next you will be asked about what types of information you would like to receive.

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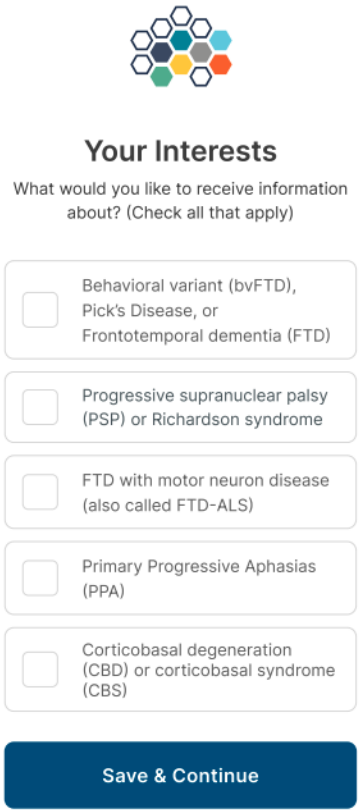
Personalizing Your Account - Types of FTD



Which FTD disorders would you like information about.

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Personalizing Your Account - Genes

Please select the genes associated with FTD disorders that you are interested in.

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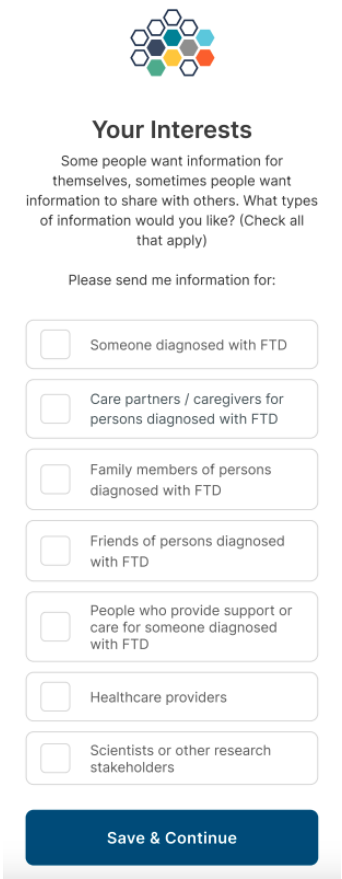
Personalizing Your Account - Types of Information



What types of information you would like?

Your selection on this page does not need to reflect your personal relationship to FTD but simply reflects your interests.

Based on your selections in this section your registry account will highlight information and resources related to your interests.

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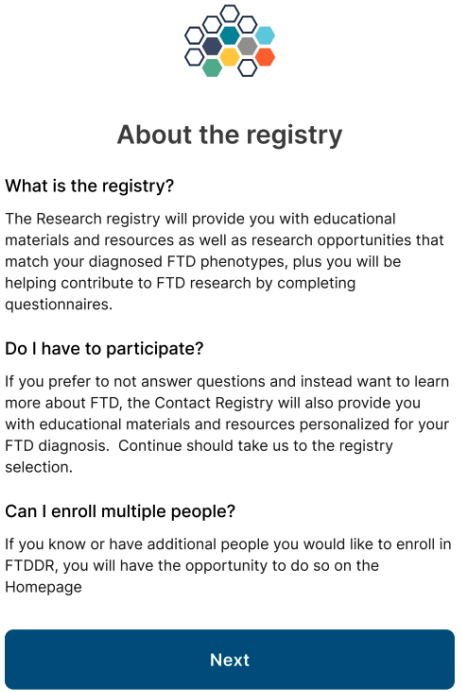
Questions: manager@ftdregistry.org

About the Registry

All registries are databases that contain information about a certain group of people. The FTD Disorders Registry includes people impacted by FTD (diagnosed, caregiver, relative).

As a participant you will be provided with information and resources about FTD. You may also be invited to participate in research that is being conducted by the Registry or other researchers.

Your participation in research is optional.



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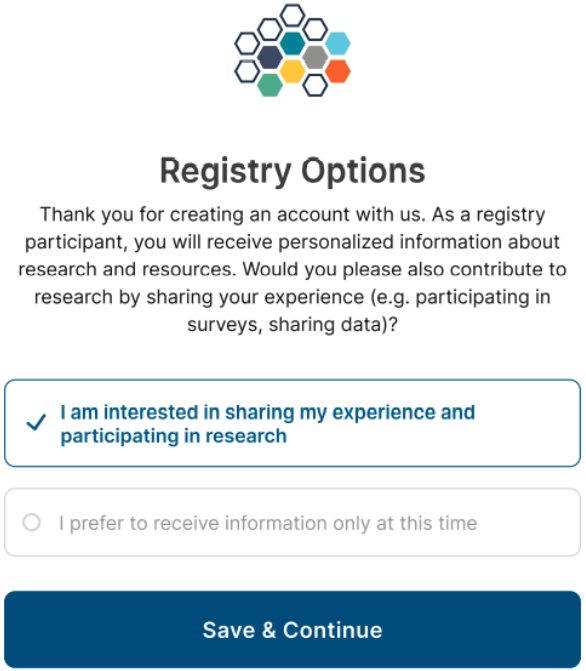
Questions: manager@ftdregistry.org

Joining the Research Study

As a reminder all Registry participants will receive resources and information about research opportunities. Research registry participants will be asked to complete surveys to advance our understanding of FTD disorders.

You will only see this page if you are eligible based on your age and country (indicated earlier in the process).



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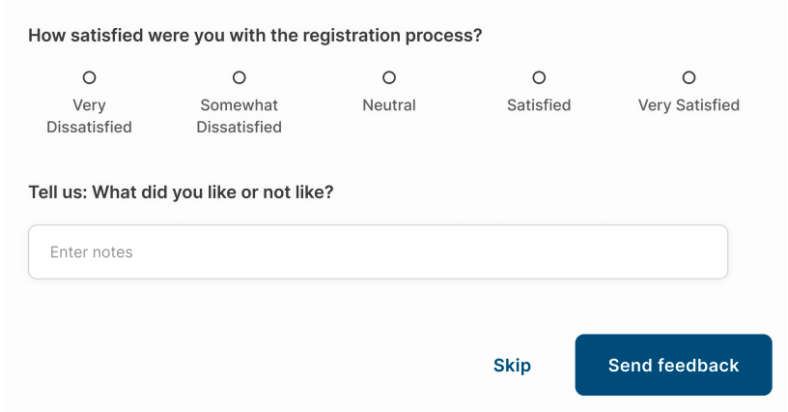
Registration Feedback

If you selected
“I am interested in information only at this time”

you’ll be asked for feedback on the registration process and then your account creation process will be completed.



If you selected
“I am interested in sharing my experience and participating in research”

you’ll be asked for additional information to create your research participant profile.

Even if you indicate an interest in research, you will be given an opportunity to change your mind later in the process.

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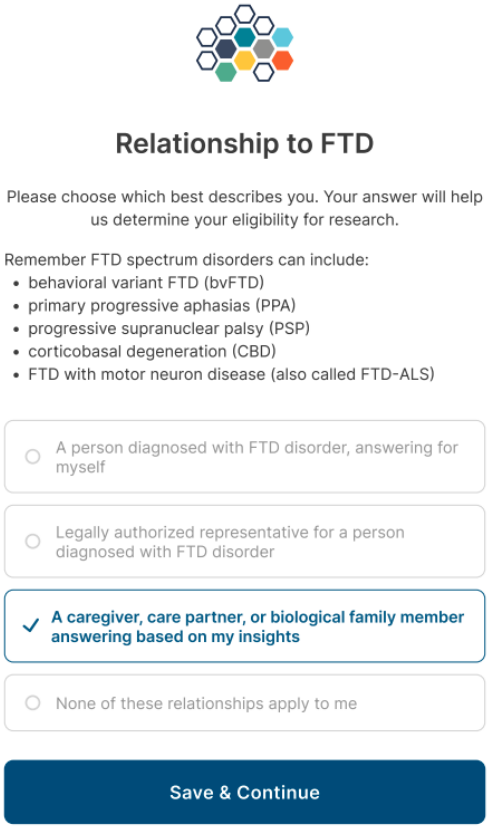
Questions: manager@ftdregistry.org

Research Participant Profile



To create your research participant profile we need to understand your relationship to FTD.

When making your selection, please remember that participants will be asked questions **from their personal perspective** based on their relationship to FTD. For example, caregivers will be asked about their experience as a caregiver.

Legally authorized representatives (LARs) are individuals who are legally empowered to make medical decisions on behalf of another person. If you are a LAR and a caregiver and you would like to create a research account on behalf of the person diagnosed and a caregiver account, you will be given the opportunity to do that later in the registration process.

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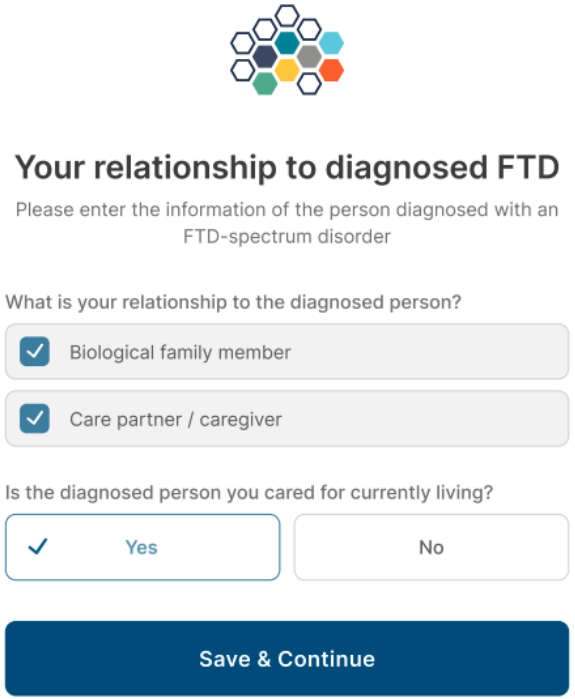
Research Participant Profile - Caregiver, Biological Relative

If you indicate that you are a caregiver/care partner or biological relative, you will be asked to clarify which relationship(s) apply to you. **You may select more than one relationship.**

We invite caregivers to participate whether the person diagnosed is alive or deceased.



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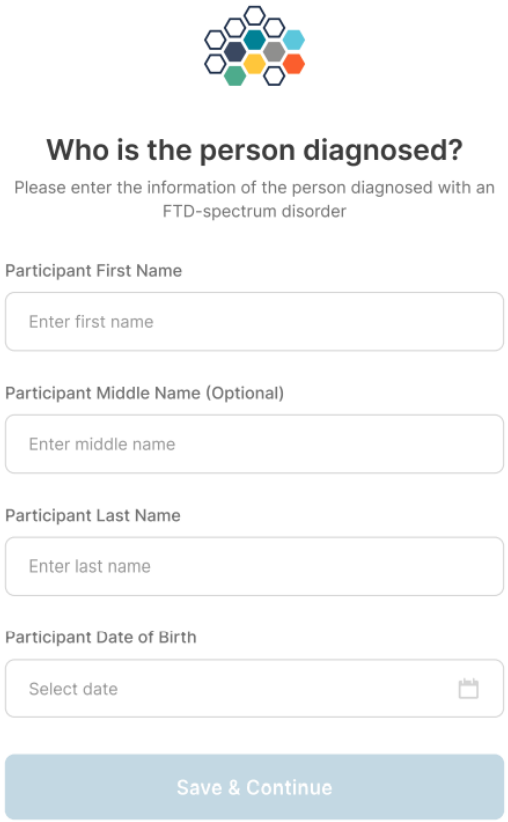
Research Participant Profile - LAR



If you are a legally authorized representative (LAR) for a person diagnosed with an FTD disorder, you will need to provide information about the person you are a LAR for.

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Research Participant Profile - Diagnosis

Although you were asked earlier what types of FTD you were interested in receiving information about, in this section you will be asked specifically for **your FTD diagnosis or the diagnosis of the person with FTD in your life.**

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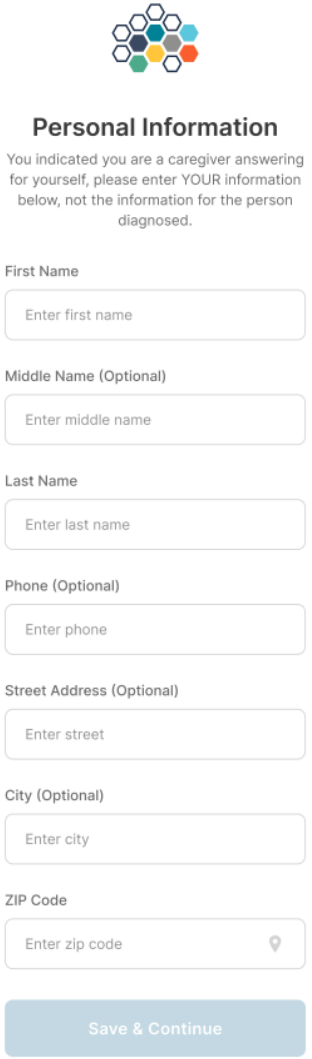
Research Participant Profile - Personal Information

ALL individuals will be asked to provide their mailing information and phone number.

Although the majority of communication will be through the portal and email, this information is important in case we need to reach you.



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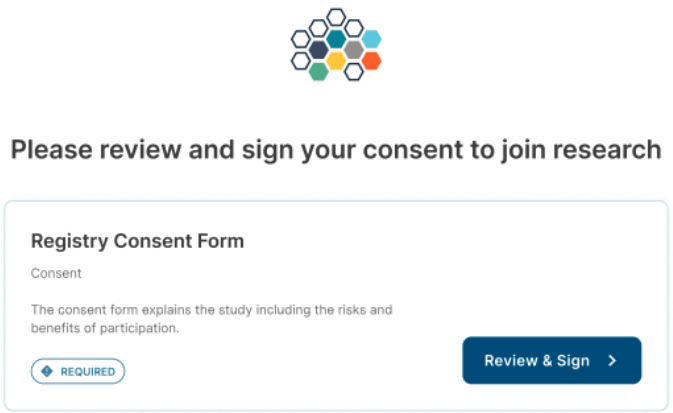
Research Participant Profile - Consent



A research consent form explains what will happen as part of the research study you are considering participating in. By clicking the Review and Sign button a **consent will open in another window**. **You will be given the chance to read the consent form and indicate your consent in this new window.**

The FTD Disorder Registry values your participation and your contribution to our understanding of FTD, however, there is no obligation to participate and there is no penalty for deciding not to participate.

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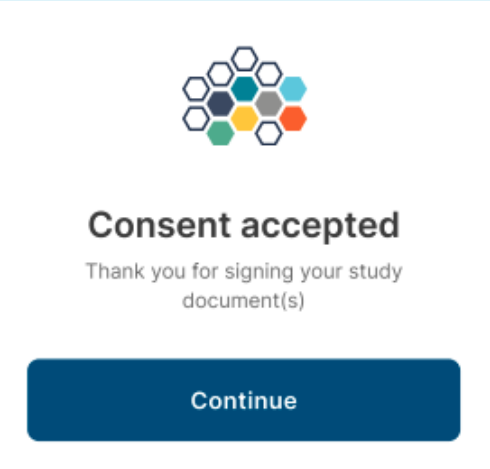
Questions: manager@ftdregistry.org

Research Participant Profile - Consent

If you choose to consent to participate in research, you will know your consent has been received when you see this image on your screen.



If you decide not to consent at this time you will be asked why you chose not to consent.

There is no right or wrong answer.

Answering this question will help the Registry understand challenges to research participation or areas that we can improve our information.

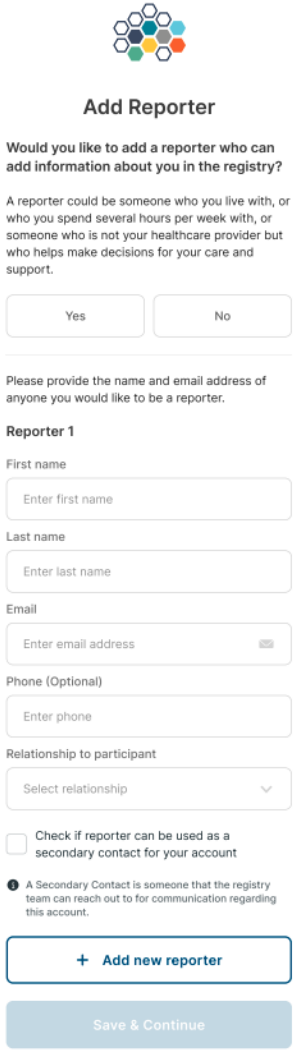
You can also change your mind and consent at a later time from within the Registry portal.

Research Participant Profile - Reporters

The FTD Disorders Registry Research Program allows individuals diagnosed with FTD to add reporters to their account.

By answering questions about the person who invited them, reporters can provide valuable information about the disease experience from their unique point of view.

Reporters will receive an email invitation, set up an account and will be asked questions about the person who invited them. Reporters will not be asked questions about themselves.



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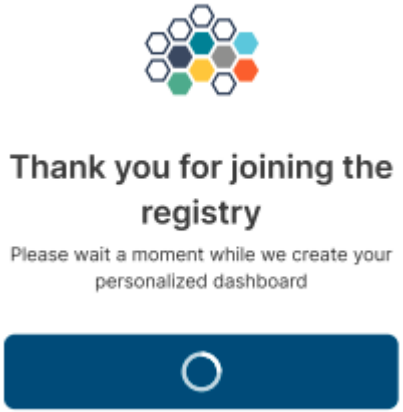
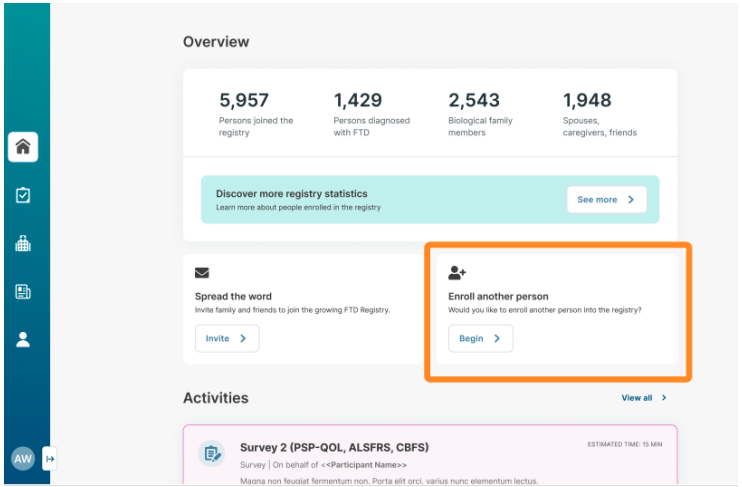
Research Participant Profile - COMPLETE

Your profile is complete when you see this image!



You will automatically be logged into the portal where you can view information, complete activities, learn about additional research opportunities and more.



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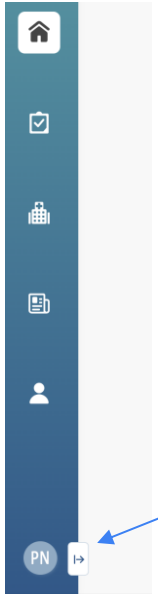
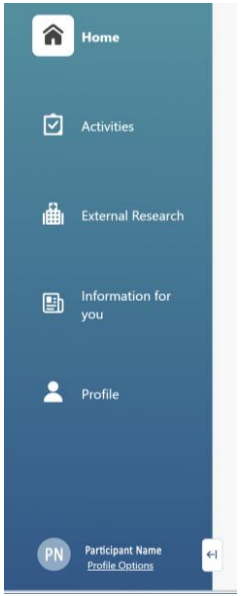
Account Navigation



Account Navigation tools can be found on the bottom left of your dashboard. To open them, click the small arrow next to your initials.

Open navigation.



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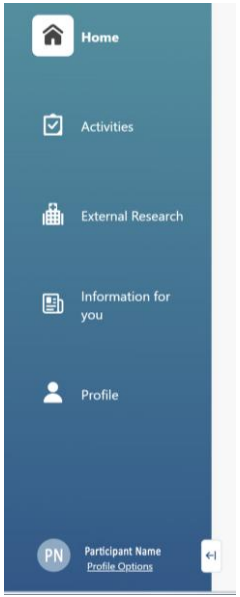
Account Navigation



Once the navigation tool is open, you can access:

- Your Activities
- External Research Opportunities
- Information for you
- Your Profile

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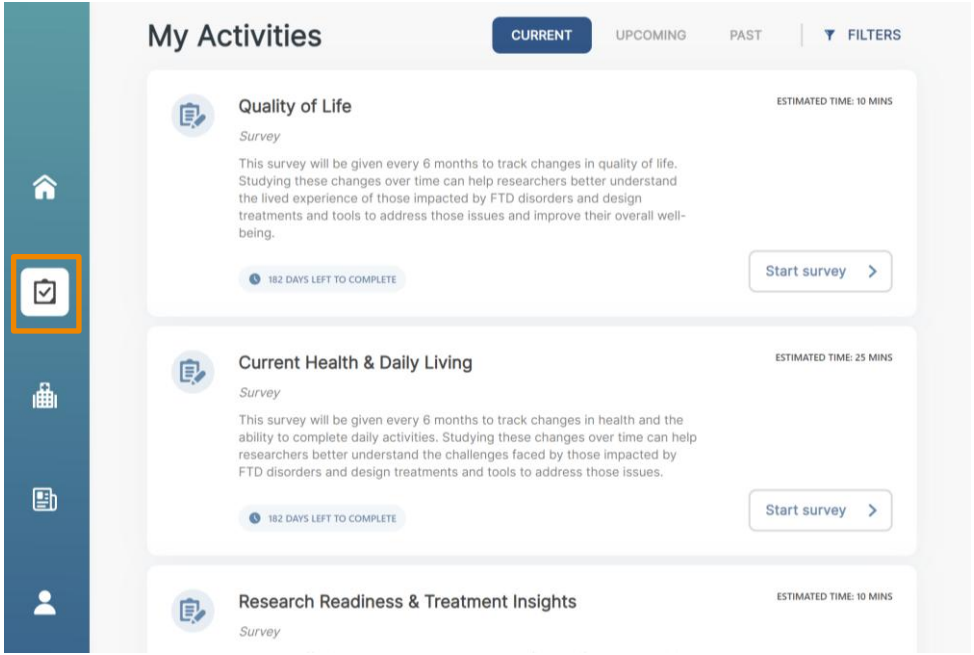
My Activities

Click on the Clipboard icon on the navigation bar to access the activities assigned to you.



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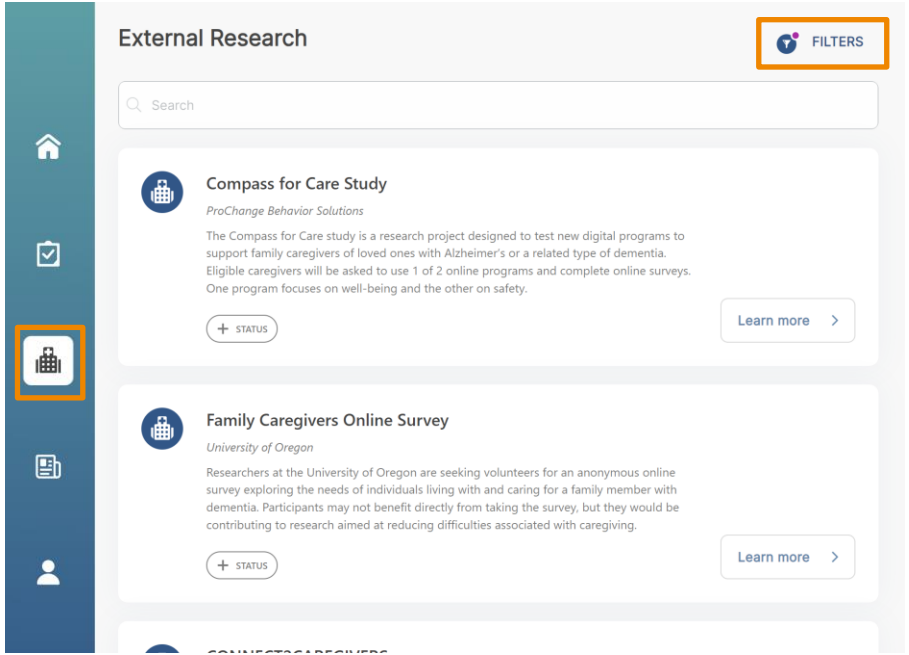
External Research Opportunities

Click on the hospital icon on the navigation bar to access external research opportunities.

To filter external research opportunities based on your interests, click on the **FILTERS** button in the top right corner of the dashboard.



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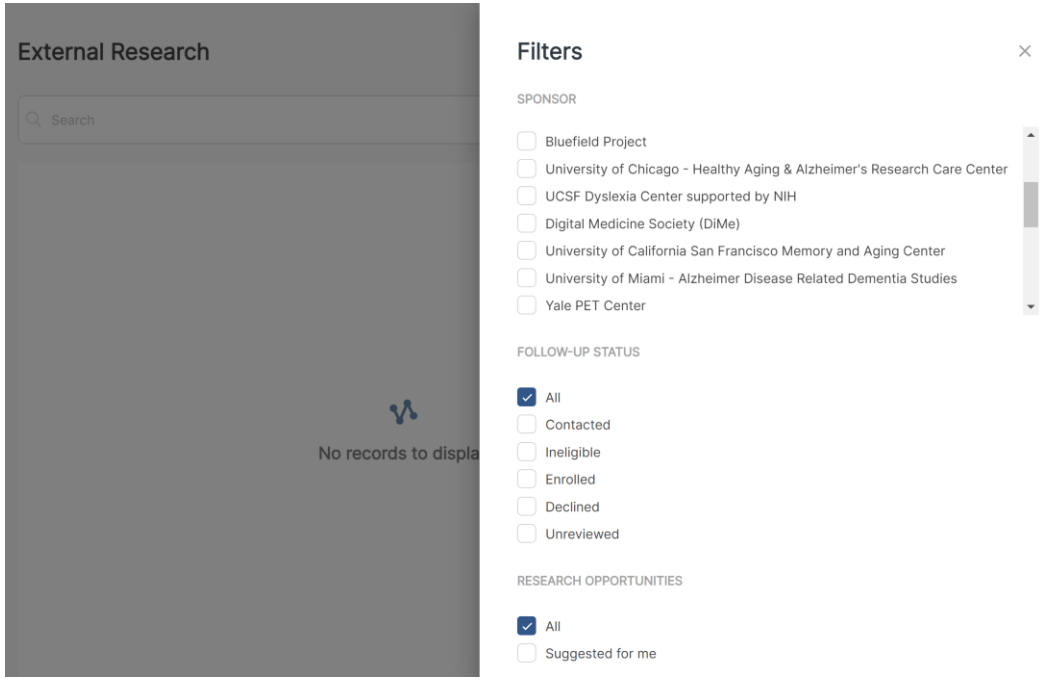
Filter External Research Opportunities

Check the boxes to broaden or narrow your list of external research opportunities.



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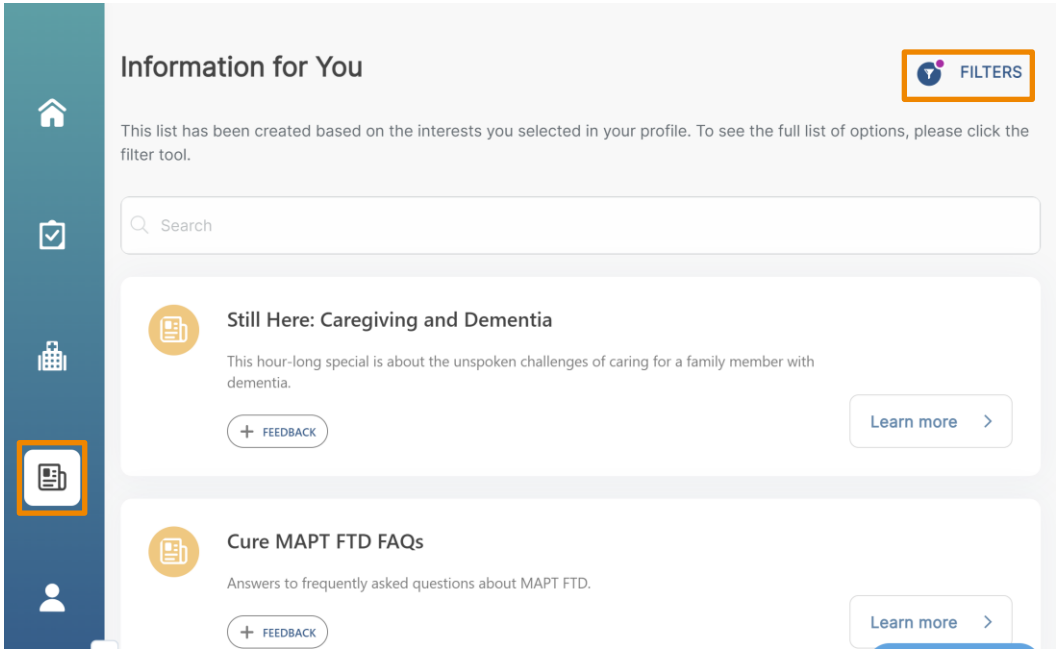
Information for You

Click on the newspaper icon on the navigation bar to access the Information for You page of educational resources tailored to your interests.

To filter Information for You based on your interests, click on the **FILTERS** button in the top right corner of the dashboard.



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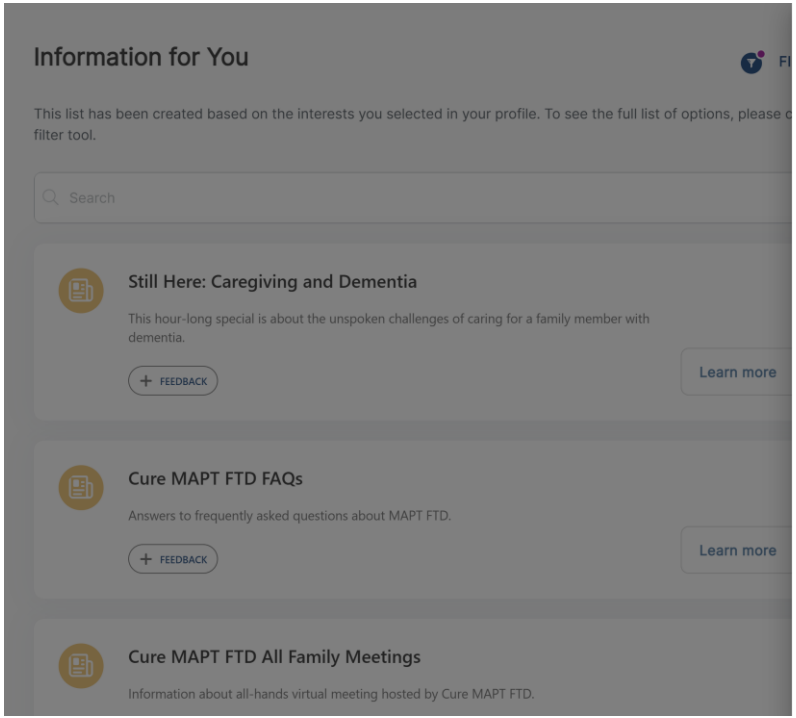
Filter Information for You

Check the boxes to broaden or narrow your list of Information for You interests.



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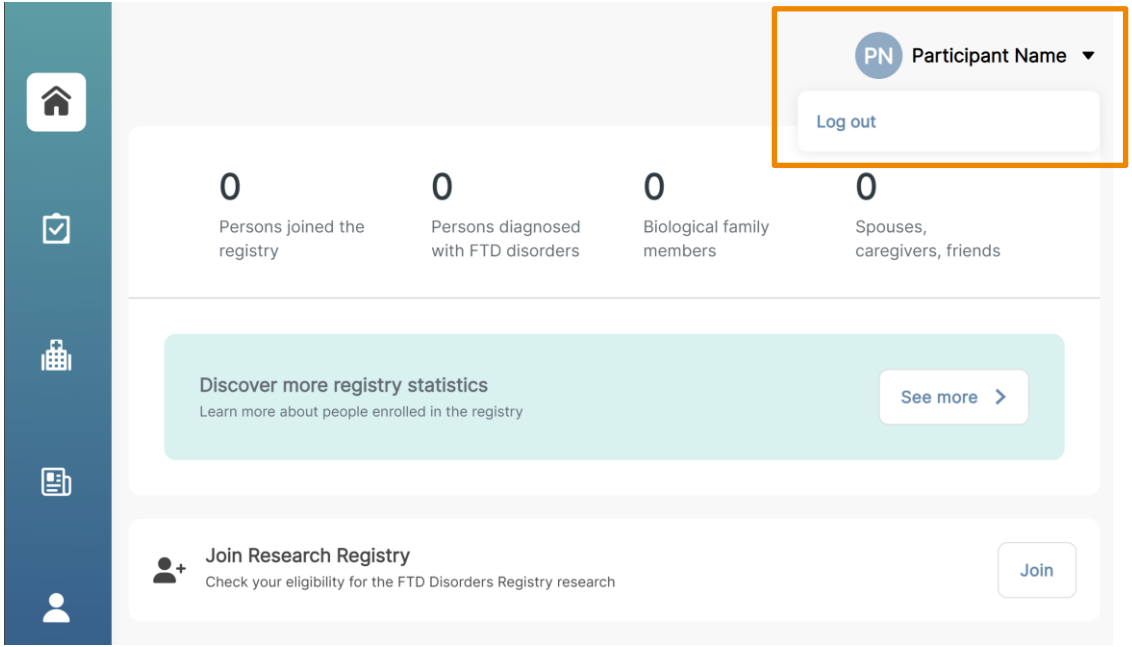
Log Out of Your Account

To log out of your account, click on the arrow next to your name in the top right corner of the dashboard.

Then click **Log out** from the dropdown menu.



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