FTD Disorders Registry Tutorial

FTD DISORDERS
REGISTRY

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

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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

Questions: manager@ftdregistry.org

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.

✓ I have read and agree to the Terms and Conditions

✓ I have read and agree to the Privacy Policy

Questions: manager@ftdregistry.org

FTD DISORDERS REGISTRY

Verifying Your Account

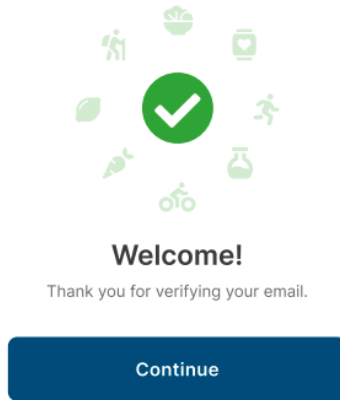You will receive an email from the Registry to verify your email address.

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.

Check your email

We sent you an email with instructions on how to complete your sign up

If you do not see an email in your inbox, please check your spam or junk folder

✉ sample@mail.com

Resend email

I've verified my email

Back to create your account

Questions: manager@ftdregistry.org

FTD DISORDERS REGISTRY

Verifying Your Account

Welcome!

Thank you for verifying your email.

Continue

Email verification expired

Please click resend email to generate a new verification link.

Resend Email

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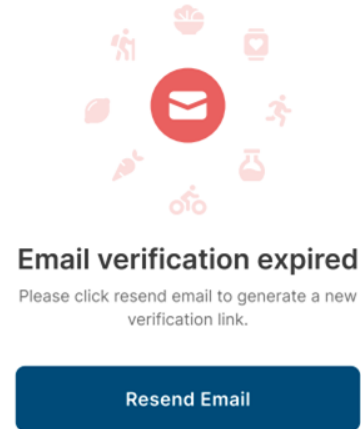
For your security, your verification email will expire after X days.

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.

Welcome

Please sign in to access your account

Email

Password

Reset password

Sign in

FTD DISORDERS REGISTRY

Reset Your Password

Reset password

Please enter your email address to
reset your password

Email

Send reset email

Back to sign in

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

Then select **Send reset email.**

FTD DISORDERS
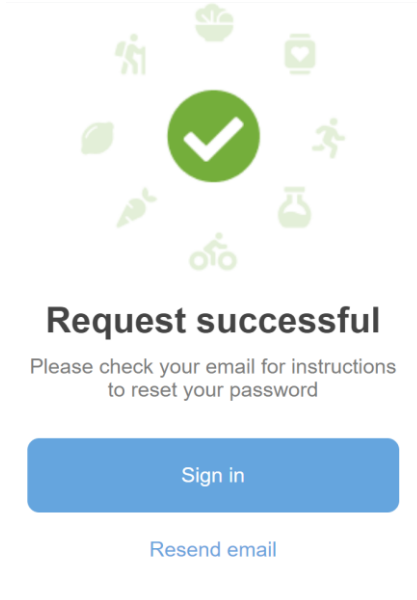**REGISTRY**

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.

Request successful

Please check your email for instructions to reset your password

Sign in

Resend email

FTD DISORDERS REGISTRY

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:
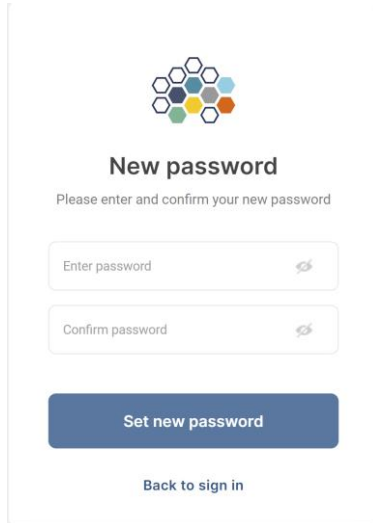
Reset password

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

Thank you,
Registry Manager

FTD DISORDERS REGISTRY

Reset Your Password

On the **New password** page, please create a new password for your account.
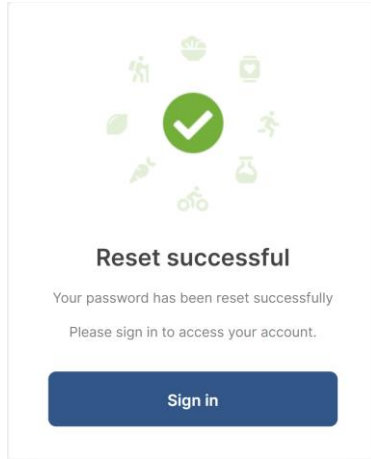
When **choosing a password**, remember your password must follow these requirements:

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

FTD DISORDERS REGISTRY

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.

Reset successful

Your password has been reset successfully

Please sign in to access your account.

Sign in

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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

Welcome

Tell us more about yourself so we can present you with options to participate.

Date of birth

Pick a date

Country

Select country

State or province

Select

Save & Continue

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Questions: manager@ftdregistry.org

Personalizing Your Account - Your Interests

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

Personalizing Your Account - Types of FTD

Your Interests

What would you like to receive information about? (Check all that apply)

- ☐ Behavioral variant (bvFTD), Pick's Disease, or Frontotemporal dementia (FTD)
- ☐ Progressive supranuclear palsy (PSP) or Richardson syndrome
- ☐ FTD with motor neuron disease (also called FTD-ALS)
- ☐ Primary Progressive Aphasias (PPA)
- ☐ Corticobasal degeneration (CBD) or corticobasal syndrome (CBS)

Save & Continue

Which FTD disorders would you like information about.

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Questions: manager@ftdregistry.org

Personalizing Your Account - Genes

Your Interests

In some cases, FTD disorders can be inherited. What would you like to receive information about? (Check all that apply)

- [ ] General information about genetics and FTD
- [ ] GRN
- [ ] MAPT
- [ ] C9orf72
- [ ] VCP
- [ ] TARDBP
- [ ] CHMP2B
- [ ] SQSTM1
- [ ] UBQLN1
- [ ] TBK1

Save & Continue

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

Questions: manager@ftdregistry.org

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Personalizing Your Account - Types of Information

Your Interests

Some people want information for themselves, sometimes people want information to share with others. What types of information would you like? (Check all that apply)

Please send me information for:

- [ ] Someone diagnosed with FTD
- [ ] Care partners / caregivers for persons diagnosed with FTD
- [ ] Family members of persons diagnosed with FTD
- [ ] Friends of persons diagnosed with FTD
- [ ] People who provide support or care for someone diagnosed with FTD
- [ ] Healthcare providers
- [ ] Scientists or other research stakeholders

Save & Continue

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.

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.

About the registry

What is the registry?

The Research registry will provide you with educational materials and resources as well as research opportunities that match your diagnosed FTD phenotypes, plus you will be helping contribute to FTD research by completing questionnaires.

Do I have to participate?

If you prefer to not answer questions and instead want to learn more about FTD, the Contact Registry will also provide you with educational materials and resources personalized for your FTD diagnosis. Continue should take us to the registry selection.

Can I enroll multiple people?

If you know or have additional people you would like to enroll in FTDDR, you will have the opportunity to do so on the Homepage

Next

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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).

Registry Options

Thank you for creating an account with us. As a registry participant, you will receive personalized information about research and resources. Would you please also contribute to research by sharing your experience (e.g. participating in surveys, sharing data)?

✓ **I am interested in sharing my experience and participating in research**

○ I prefer to receive information only at this time

Save & Continue

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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.

How satisfied were you with the registration process?

○ Very Dissatisfied   ○ Somewhat Dissatisfied   ○ Neutral   ○ Satisfied   ○ Very Satisfied

Tell us: What did you like or not like?

Enter notes

Skip   **Send feedback**

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Questions: manager@ftdregistry.org

Research Participant Profile

Relationship to FTD

Please choose which best describes you. Your answer will help us determine your eligibility for research.

Remember FTD spectrum disorders can include:
- behavioral variant FTD (bvFTD)
- primary progressive aphasias (PPA)
- progressive supranuclear palsy (PSP)
- corticobasal degeneration (CBD)
- FTD with motor neuron disease (also called FTD-ALS)

○ A person diagnosed with FTD disorder, answering for myself

○ Legally authorized representative for a person diagnosed with FTD disorder

✓ **A caregiver, care partner, or biological family member answering based on my insights**

○ None of these relationships apply to me

Save & Continue

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.

Questions: manager@ftdregistry.org

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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.

Your relationship to diagnosed FTD

Please enter the information of the person diagnosed with an FTD-spectrum disorder

What is your relationship to the diagnosed person?

☑ Biological family member

☑ Care partner / caregiver

Is the diagnosed person you cared for currently living?

✓ Yes   No

Save & Continue

Research Participant Profile - LAR

Who is the person diagnosed?

Please enter the information of the person diagnosed with an FTD-spectrum disorder

Participant First Name

Enter first name

Participant Middle Name (Optional)

Enter middle name

Participant Last Name

Enter last name

Participant Date of Birth

Select date

Save & Continue

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.

Questions: manager@ftdregistry.org

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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.**

Diagnosed FTD Conditions:

Please choose the diagnosis that relates to you or the person diagnosed in your life. Your answer will help us determine your eligibility for research.

Check the option that applies

- [ ] Frontotemporal dementia (FTD)
- [ ] Behavioral variant (bvFTD)
- [ ] Progressive supranuclear palsy (PSP)
- [ ] FTD with motor neuron disease (also called FTD-ALS)
- [ ] Primary Progressive Aphasia (PPA)
- [ ] Semantic variant PPA (svPPA)
- [ ] Logopenic variant PPA (lvPPA)
- [ ] Non-fluent / Agrammatic variant (nfvPPA, PPA-G)
- [ ] Corticobasal degeneration (CBD) or corticobasal syndrome (CBS)
- [ ] Richardson syndrome
- [ ] Pick's disease
- [ ] Unsure of FTD type
- [ ] FTD suspected, but no formal diagnosis

Save & Continue

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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.

Questions: manager@ftdregistry.org

Personal Information

You indicated you are a caregiver answering for yourself, please enter YOUR information below, not the information for the person diagnosed.

First Name

Enter first name

Middle Name (Optional)

Enter middle name

Last Name

Enter last name

Phone (Optional)

Enter phone

Street Address (Optional)

Enter street

City (Optional)

Enter city

ZIP Code

Enter zip code

Save & Continue

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Research Participant Profile - Consent

Please review and sign your consent to join research

Registry Consent Form

Consent

The consent form explains the study including the risks and benefits of participation.

◆ REQUIRED   Review & Sign ›

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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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.

Consent accepted

Thank you for signing your study document(s)

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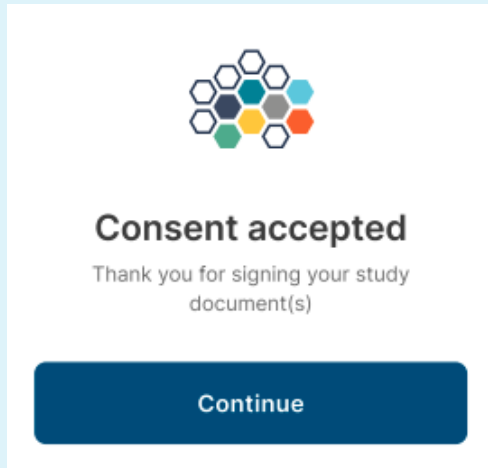
If you decide not to consent at this time you will be asked why you chose not to consent.

There is no right or wrong answer.

Answering this question will help the Registry understand barriers 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.

Questions: manager@ftdregistry.org

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.

Questions: manager@ftdregistry.org

Research Participant Profile - COMPLETE

Your profile is complete when you see this image!
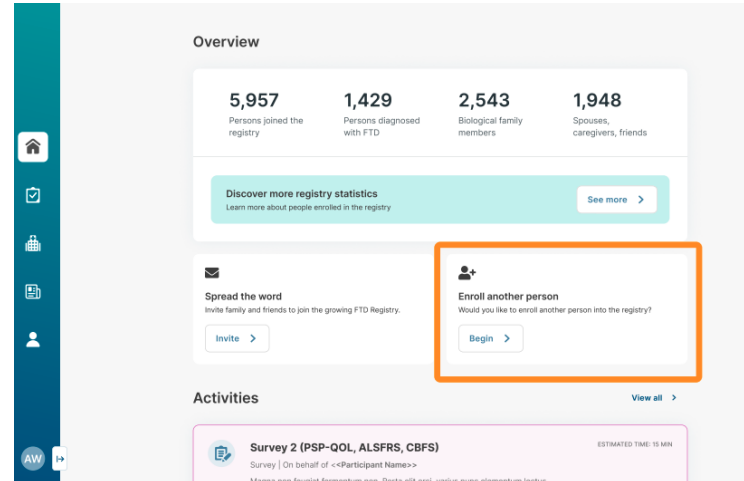
You will automatically be logged into the portal where you can view information, complete activities, learn about additional research opportunities and more.

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.
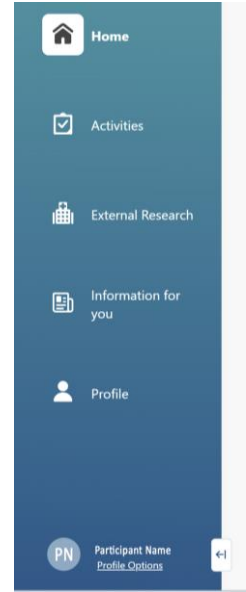
Account Navigation
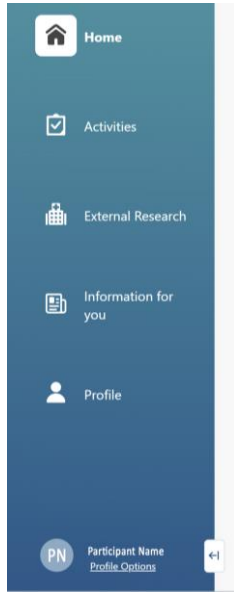
Once the navigation tool is open, you can access:

- 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.

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.

Filter External Research Opportunities

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

External Research

Search

No records to displa...

Filters ✕

SPONSOR

☐ Bluefield Project
☐ University of Chicago - Healthy Aging & Alzheimer's Research Care Center
☐ UCSF Dyslexia Center supported by NIH
☐ Digital Medicine Society (DiMe)
☐ University of California San Francisco Memory and Aging Center
☐ University of Miami - Alzheimer Disease Related Dementia Studies
☐ Yale PET Center

FOLLOW-UP STATUS

☑ All
☐ Contacted
☐ Ineligible
☐ Enrolled
☐ Declined
☐ Unreviewed

RESEARCH OPPORTUNITIES

☑ All
☐ Suggested for me

Questions: manager@ftdregistry.org

FTD DISORDERS
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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.

Questions: manager@ftdregistry.org

Filter Information for You

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

Questions: manager@ftdregistry.org

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.