The FTD Disorders Registry

Secure online database designed to be the ‘home’ of all individuals wishing to participate in FTD research

Community where you can share your experience of FTD to help us understand these diseases better and support the development of new treatments
**FTD Disorders Registry LLC**

**Fully independent entity** with the patient/caregiver registry as sole non-profit mission

- Founded March 2015 by AFTD & Bluefield Project for the Cure

- Funded by grants
  - AFTD
  - Bluefield Project
  - Rainwater Charitable Foundation’s Tau Consortium

- Oversight by Management Committee & Scientific Advisory Board
FTD Disorders Registry Format

- **Contact & Research** registry
  - Health outcomes research
  - Support clinical trial & research study recruitment

- Self-report, participant-entered data via online survey tool

- Curated, audited, & error checked

- IRB-approved & HIPAA-compliant platform
FTD Disorders Registry Research Tools

Surveys/questionnaires
  • FTD Disorders Registry intake surveys
    • Demographics
    • Disease impact
    • Research ready
  • ARTFL
    • Lifestyle questionnaire
    • Autoimmune history
    • Clinical trials
  • Additional surveys to be added
Why Join?

• Your experience can improve our knowledge of FTD, impact care, and help others

• Participating in research surveys will provide data to advance the science

• The Registry will be the go-to site to recruit for FTD clinical trials
FTD Registry Target Population

Who can Join?

- Persons diagnosed with FTD
- Current or former spouse, family members, caregivers or friends

**bvFTD**

**PPA**

**PSP**

**CBD**

**FTD-ALS**

FTD diagnosed person

Self-enroll or with helper

Biological family member

Spouse/Caregiver/Friend

AND NOW WE WORK TOGETHER

**I AM DIAGNOSED WITH FTD**

enrolling myself in the Registry or joining with help of a helper (e.g., family, friend)

**YES**

**I AM A FAMILY MEMBER (BIOLOGICAL RELATIVE)**

enrolling myself in the Registry

**YES**

**I AM A SPOUSE, CAREGIVER, OR FRIEND**

of a person who is/was diagnosed with FTD

enrolling myself in the Registry

**YES**
Join the Registry

• Share name & email
• ✅ email updates

Join the FTD Disorders Registry

Scientists are making real progress in our understanding of FTD, and every person’s story is vital. The FTD Disorders Registry invites people living with FTD, including caregivers, family, and friends, to join this critical movement towards a cure.

Join the registry. Your story can help lead us to a cure.

Still trying to decide whether to join? Visit the WHY JOIN or ABOUT THE REGISTRY tabs above for more information.

Please tell us more about yourself by choosing from the options below:

Family member (biological relative) of a person who is/was diagnosed with FTD

E MAIL

FIRST NAME

LAST NAME

ZIP/POST CODE

Year of Birth

I want to receive important FTD info, updates, and study opportunities via email.

Join THE REGISTRY
Research Registry

• Login account with password
• Informed Consent
FTD Disorders Registry Data & Privacy

• Registrant’s personally identifiable information (PII) masked with GUID

• Registry Director is *sole person with access to PII*

• Aggregate, de-identified data shared with the public via website, newsletters, publications

• Third-party access to de-identified data
  • Reviewed by Scientific Advisory Board & approved by Management Committee
Quality Assurance Testing & Phased Roll-out

• User testing
  • FTDDR staff
  • Target user groups

• Soft launch
  • December 15th 2016
  • February 24th 2017

• Grand public launch!!
  • March 26th 2017

Enrollment goal was exceeded in <24 hrs!!
Enrollment as of May 1st: 528
FTDDR Enrollment by Geographic Distribution

International:
- Canada
- Australia
- UK, Germany
- Netherlands
- Italy, Israel...

Locale

<table>
<thead>
<tr>
<th>Locale</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>U.S.</td>
<td>426</td>
<td>81%</td>
</tr>
<tr>
<td>International</td>
<td>102</td>
<td>19%</td>
</tr>
</tbody>
</table>
FTDDR Enrollment Statistics: 528 total registrants

**Category**
- Spouse/Cgv/Friend: 188 (35%)
- Biological Family: 273 (52%)
- FTD dx: 67 (13%)

**Participation Type**
- Contact: 259 (49%)
- Research: 259 (49%)
- Not validated: 10 (2%)
What Can We Do With the Data?

Tabulate who, where, how many…but goes beyond basic demographic characteristics

- Build a clearer picture of the impact of FTD from a patient, caregiver, and family perspective
  - May help us ask better questions, drive new hypotheses
- Assess research study/clinical trial feasibility
  - Patient-centric design & outcome measures
  - Facilitate recruitment
- Use the data to raise awareness, and advance research and facilitate advocacy throughout the FTD community
  - Partner and collaborate to make the FTDDR a key resource for all

➢ Your participation has the power to make a difference
FTD Disorders Registry: Thank You!

• Join the FTD Disorders Registry.
• Tell your story.
• Advance the science.

www.ftdregistry.org
www.facebook.com/EndFTDregistry
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