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**Presentation:** *FTD Disorders Registry: A patient and caregiver registry to advance science*

- A registry is an electronic database of information about individuals with a specific disorder or medical condition. Registries are often created by patient groups, researchers, or medical professionals to collect information into a central location.
- The purpose of FTD Disorders Registry is to improve our understanding of FTD disorders, increase awareness, and facilitate additional research.
- To participate you must be an individual diagnosed with an FTD disorder, or a family member, caregiver, or friend of a person diagnosed with one of the FTD disorders.
- The FTD disorders are: behavioral variant FTD, the primary progressive aphasia (PPA), progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), and FTD-ALS.
- The FTD Registry is both a **Contact** and **Research** Registry. It is designed to collect information from people diagnosed with FTD, their caregivers, family members and friends to study all aspects of life with these devastating diagnoses so scientists and clinicians can better understand them.
- **Contact Registry** enrollment allows you to receive the latest FTD news, research updates, and notifications about studies. International enrollment in the Contact Registry is Welcome and Encouraged!
- **Research Registry** participation requires that you are at least 18 years of age and a resident of the US or Canada (Alberta, Saskatchewan, Newfoundland and Labrador currently excluded).
  - You must sign an Informed Consent to participate in research.
  - Research participant information is made anonymous or de-identified for privacy.
  - Registry research allows you to participate in online surveys, questionnaires, and other data collection tools.
  - Registry data may help speed up research to find and test potential treatments, and facilitate other medical advances to improve the outlook for individuals diagnosed with FTD disorders.

**Join the Registry, Tell your story, and Advance the Science.**



IN THE WORLD OF FTD, **EVERY STORY** ADVANCES THE SCIENCE. *Starting with yours.*