

# Advancing Research and Treatment for Frontotemporal Lobar Degeneration (ARTFL)

 [consortiapedia.fastercures.org/consortia/artfl/](http://consortiapedia.fastercures.org/consortia/artfl/)

## Research Areas



### Tool Development

Resource



### Biomarker Research

Drug

## At a Glance

- Status: **Active Consortium**
- Year Launched: **2014**
- Initiating Organization: **NIH Rare Disease Clinical Research Network**
- Initiator Type: **Government**
- **Rare disease**
- Location: **North America**

## Abstract

The Advancing Research and Treatment for Frontotemporal Lobar Degeneration (ARTFL) consortium is an integrated group of academic medical centers partnered with patient support organizations and dedicated to conducting clinical research in sporadic and familial frontotemporal lobar degeneration (FTLD) syndromes. ARTFL is funded by the National Institutes of Health (NIH) and is part of the Rare Diseases Clinical Research Network (RDCRN). Its operations are based at the University of California, San Francisco, and there are currently 14 clinical study sites in the United States and Canada.

## Mission

ARTFL's mission is to conduct clinical research to learn more about the different FTLD spectrum diseases to support the development of new therapies and diagnostic tools. It also aims to assist patients and family members to manage these diseases by connecting them with patient advocacy groups, expert medical care, support services, and new research opportunities in particular clinical trials.

The goals of this consortium are as follows:

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## Consortium History

October 2014: ARTFL funding by RDCRN announced

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## Structure & Governance

This consortium is part of the RDCRN, an initiative of the Office of Rare Diseases Research, National Center for Advancing Translational Sciences (NCATS). The RDCRN is designed to advance medical research on rare diseases by providing support for clinical studies and facilitating collaboration, study enrollment, and data sharing. Through the RDCRN consortia, physician scientists and their multidisciplinary teams work together with patient advocacy groups to study more than 200 rare diseases at sites across the nation.

Funding and scientific oversight for the RDCRN are provided by NCATS and 10 NIH components: Eunice Kennedy Shriver National Institute of Child Health and Human Development; National Cancer Institute; the National Heart, Lung and Blood Institute; National Institute of Allergy and Infectious Diseases; National Institute of Arthritis and Musculoskeletal and Skin Diseases; National Institute of Dental and Craniofacial Research; National Institute of Diabetes and Digestive and Kidney Diseases; National Institute of Mental Health; National Institute of Neurological Disorders and Stroke; and Office of the Director. In addition, patient advocacy groups provide funds for many of the projects.

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## Financing

The generous support of the NIH has provided ARTFL with the resources necessary to create this ongoing clinical research infrastructure.

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## Patent Engagement



ARTFL will establish a large cohort of patients with FTLD syndromes including corticobasal degeneration syndrome; primary progressive aphasia, including semantic variant and non-fluent variant; behavioral variant frontotemporal dementia; frontotemporal dementia with amyotrophic lateral sclerosis; and progressive supranuclear palsy. Healthy family members of patients with genetic causes of FTLD will also be enrolled.

Approximately 1,560 patients and family members will participate in on-site evaluations that will include medical exams, clinical assessments of cognition and functioning, questionnaires and surveys, and biological specimens. Patients and family members with familial FTLD syndromes may be followed longitudinally. Using the cohort data, ARTFL will conduct projects to discover new biomarkers for disease activity, standardize diagnostic criteria, and identify a large group of potential participants for clinical trials of new targeted therapeutic agents. Patients do not need to be enrolled in all studies to participate in ARTFL activities.

Additionally, RDCRN ARTFL maintains a Contact Registry for patients with FTLD and their family members to learn about ARTFL research studies they may be able to join. Participation is completely voluntary, and patients may choose to withdraw at any time. There is no cost to join the Contact Registry.

## Links/Social Media Feed

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Homepage

<http://www.rarediseasesnetwork.org/cms/artfl/>

## Points of Contact

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