AFTD Request for Proposals 2015 - The Economic Burden of Frontotemporal Degeneration

Announcement date: Monday, December 22, 2014

This request for proposals is made by The Association for Frontotemporal Degeneration (AFTD) [http://www.theaftd.org/](http://www.theaftd.org/). FTD is a rare (defined as <200,000 diagnosed in the US) and typically young onset form of dementia that encompasses progressive degenerative changes in behavior, personality, language, cognitive skills and motor function.

**Deadline for submission of applications:** Friday, March 27, 2015
Grant Term Start Date: Friday, May 1, 2015
Seeking competitive proposals under a maximum cap of $90,000 (direct costs only)

Applications must be submitted electronically as a single PDF to: grants@theaftd.org

**Introduction**
The FTD disorders include behavioral variant FTD, primary progressive aphasia, progressive supranuclear palsy, corticobasal syndrome and FTD-ALS. Accurate diagnosis may take more than 3 years from the time symptoms first appear, disease progression is rapid and fatal, and persons affected live an average of 6-10 years after symptom onset (1). FTD typically affects families when the patient is at the peak of his/her earning potential and career path. Many patients lose their jobs because of FTD symptoms, and spouses become part- or full-time caregivers. A significant number of families have school age children residing at home, while others have young adult children providing caregiver support. Families are faced with high costs due to lost productivity, job loss, direct and indirect medical and non-medical expenses.

To our knowledge, the economic burden of FTD has not been established (2) but there is published literature on caregiver burden in FTD (3). An economic burden study will help inform policy makers, research funders and health professionals about the major cost drivers of FTD, as well as demonstrate the financial impact of the disease on families and on public programs. Moreover, it will make evident the necessity of allocating resources to effective and efficient treatment options for FTD where none now exist.


**Research Objectives**
The primary objective of this RFP is to capture the economic impact of FTD on patients, their caregivers and families; as well as on the healthcare system/community resources compared to non-FTD affected families in this age demographic in the United States. The successful applicant would be expected to create, develop and carry out an online survey of FTD patients and caregivers/family members, supplemented by telephone interviews and other methods to collect all relevant data. The secondary objective of this RFP is a systematic analysis of the peer reviewed literature to identify burden studies in other neurodegenerative conditions, including Alzheimer’s disease, Lewy Body dementia, Parkinson’s disease, ALS (Lou Gehrig’s disease), and Huntington’s disease to support a quantitative comparison of cost of illness with the FTD data findings. The successful applicant would ideally have experience in performing economic burden studies and understand and be sensitive to surveying patient and caregiver populations.

**Data**
The collected data will be de-identified and all interviewed subjects will read, agree and sign an informed consent with condition that they are providing information voluntarily and retain the option to withdraw from the study.
Proposal Submission and Research Plan
The following information must be included with the grant application:

1. **Cover page** – use form attached, please include signature of company/institution official supporting the RFP submission.
2. **A 200 word abstract** of the research plan in lay language.
3. **Research plan** of 4 pages maximum (single-spaced, 10pt font minimum) to include Specific Aims, Research Plan overview, Study Design and Methods. The proposal must include a detailed study design and methods for conducting the economic burden survey and analyzing the relevant literature to compare across other neurodegenerative diseases. An outline of proposed survey methods of patients, caregivers (family members) is required. Include methods for analysis and pooling data from the published literature. Include methods for handling individual caregiver data and patient data from Medicare and/or MEPS sources.
4. The research plan must include a timeline with anticipated completion dates of major milestones, and the projected completion dates for a final report and a final manuscript for submission to a peer-reviewed scholarly journal.
5. Anticipated challenges in collecting the data, organization and management issues, and strategies to meet those challenges should be included.
6. A plan for surveying human subjects, the proposed inform consent form to be used, and a description of how subject data will be de-identified for data analysis and publication purposes.
7. **Biosketch pages** - principal investigator (PI) and research team if applicable (may include postdoctoral fellow). The NIH biosketch format is suggested, 2 page maximum limit for each, to include role of the PI and (any) team members on the project and relevant expertise.
8. **Budget page** and justification, (indirect costs and institutional overhead are not supported). The budget will include a $3000 USD travel stipend to present study findings at the 10th FTD International conference in Munich, Germany, late August, 2016.
9. **Obtain Institutional Review Board (IRB) approval** as needed. Note that central IRB agencies may be used, such as Western IRB or Chesapeake IRB services.
10. **Conflicts of interest** – state any that exist.

**Deliverables**
1) A final report to AFTD, summarizing the data and financials – due no later than September 15, 2016.
2) A manuscript of the research study and analysis, suitable for submission to a scientific, peer-reviewed journal, no later than August 31, 2016.
3) Presentation of the data at the 10th International FTD conference in Munich, August 31-September 2, 2016 (oral or poster presentation).

Note: All public presentations of the data will acknowledge grant funding support by AFTD.

**Eligibility**
Applications will be accepted from faculty at accredited academic institutions, or employees of other non-profit or for-profit organizations with expertise in health outcomes research. The applicant is expected to perform as principal investigator on the study and design appropriate survey strategies, be responsible for all data gathering, performing data analysis with the expectation of a final report and manuscript submission to a scientific, peer-reviewed journal. Experience working with patients and caregivers with neurological diseases would be an advantage and/or publication history of economic burden analysis.

Applications will be reviewed confidentially by AFTD and a Scientific Review Panel selected from the AFTD Medical Advisory Council and external advisors where appropriate. The AFTD Board, upon recommendation from the Review Panel, reserves the right to make the final award decision.
AFTD RFP 2015 – Economic Burden of Frontotemporal Degeneration

COVER PAGE

PROJECT TITLE

PRINCIPAL INVESTIGATOR
NAME
TITLE
DEPARTMENT

Signature of PI ____________________________

PRINCIPAL INVESTIGATOR ADDRESS
INSTITUTION
DEPARTMENT
STREET ADDRESS
CITY
STATE OR PROVINCE
COUNTRY
ZIP CODE/POSTAL CODE
TELEPHONE
EMAIL

INSTITUTIONAL CERTIFICATION AND ACCEPTANCE

“I certify to the best of my knowledge that the statements contained within are complete and accurate and accept, on behalf of the institution, the obligation to comply with the terms of this grant award from AFTD. I further certify that I am authorized by the institution to make representations and accepted the obligation referred to herein, on its behalf.”

____________________________________
Official signing for applicant institution

PAYABLE TO:

Mailing Address for Checks

INSTITUTION:
DEPARTMENT:
STREET:
CITY:
STATE/PROVINCE, ZIP
CONTACT PERSON:
TELEPHONE: