

# Three-Year Strategic Plan 2015-2018

*AFTD will be at the forefront of stimulating and funding research until a cure for FTD is found. We will be a leader in creating and delivering novel resources and support as long as there are persons diagnosed with this disease.*

**STRATEGIC PLAN ADOPTED BY THE AFTD BOARD OF DIRECTORS  
DECEMBER 12, 2014**



# AFTD Strategic Plan 2015 – 2018

## Letter from the Chair

It has been five years since this organization crafted and adopted its first strategic plan. In the intervening years scientists have made tremendous strides in advancing understanding of this disease. Clinicians have crafted advanced criteria for diagnosis of the various FTD disorders. Government has invested in this rare disease at an unprecedented level. And industry has begun to turn its attention toward FTD, sponsoring programs for development and testing of the first FTD therapeutics. There has never been a more hopeful time for those of us dedicated to eradicating this disease.

At the center of these advances are the persons themselves diagnosed and those who love them. By sharing their stories, participating in research and advocating tirelessly these courageous people serve as the engine of this progress. AFTD is proud to sit at the interface of these professional and private communities, and over the past five years we ourselves have learned much about our business: how we can most effectively harness this engine to drive science, medicine and policy to meet both immediate and long-term needs of our families, while also translating technical advances into lay language to stimulate the funding, engagement and partnerships needed to reach our goals.

It is within this context that AFTD's Board, staff and advisors have crafted a plan for the next three years that is both aspirational and sound. This plan calls upon the strengths of all of these stakeholders, integrating and leveraging partnerships and assets to build upon current momentum and ensure progress that is both efficient and effective.

I call upon each person reading this plan to identify a role you can take on to help ensure our success. We welcome you as partners in this important work, and pledge to work tirelessly to realize a more hopeful future that includes accurate diagnosis, effective therapeutics, quality care and a more understanding world.

With belief in a better tomorrow,

A handwritten signature in blue ink that reads "Jary Larsen". The signature is written in a cursive, flowing style.

Jary Larsen, Ph.D.  
AFTD Board Chair

January 30, 2015

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## **Executive Summary**

In recent years successful programming and advocacy have produced unprecedented growth for AFTD and have propelled our organization— now in its 13th year— toward maturity. Fueled by passionate Board members, staff, volunteers and donors we have successfully implemented our first strategic plan, broadened our reach in all areas of our mission and expanded organizational capacity. Each of our initiatives brings us in contact with more professionals and families, and we are engaging with an increasing number of people for whom AFTD’s ability to fulfill its mission is not merely an organizational mandate but an urgent and very personal need. It was against this backdrop that, in the summer of 2014, AFTD’s Board of Directors determined that the time was right to pause, assess critically the organization AFTD was becoming, and chart a thoughtful, proactive course for the next three years.

The planning process included gathering information from a wide array of the organization’s stakeholders, distilling core learnings from recent experiences, revisiting our vision, mission and values statements and aligning organizational strengths and developmental needs with the important work that needs to be done. The result is a plan that relies upon AFTD’s proven strategies of leverage and collaboration to realize progress across all of our mission areas.

The 2015-2018 Strategic Plan is organized around five interlocking goals; the first three serve to align the different areas of our mission toward a future of improved diagnosis, care and understanding. The final two goals focus on strengthening the organization itself, to ensure that AFTD will have the capacity to work effectively on behalf of our community for years to come. Our strategic goals are:

- I. People will receive a timely and accurate diagnosis and have access to high quality medical care.
- II. Every person with FTD and their caregiver(s) will have access to high quality, effective support services.
- III. FTD will be commonly recognized and understood.
- IV. AFTD will diversify and increase its funding.
- V. AFTD will continue to mature into a sustainable organization with strategic and effective: leadership, marketing, technology and professional governance practices.

As a result of the strategic initiatives outlined in this plan, AFTD projects that over the next three years its income will nearly double, to \$3 million. Each year of the Plan, nearly 40% of funds spent will be focused on research to drive development of accurate diagnosis and therapeutics for this disease. An additional 25% of expenditures will be devoted to expanding effective support mechanisms and developing and piloting new, unique resources for our community. Significant resources each year will also be invested in raising awareness, advocacy, educating professionals and strengthening core functions of the growing organization.

The Board reviewed and adopted the 2015-2018 Strategic Plan at its meeting held on December 12, 2014. This document outlines the goals and strategies for January 2015 through June 2018. An action plan that details the timeline, tactics, measures and budget impact has also been developed and will be continually reviewed by the Board to guide and monitor implementation of the plan.

## **Introduction**

### **About FTD**

Frontotemporal degeneration (FTD) causes changes in behavior and personality, language and/or motor skills, and deterioration in a person's ability to function. FTD subsumes a variety of clinical diagnoses, including frontotemporal dementia (also known as behavioral variant FTD, or bvFTD), primary progressive aphasia (PPA), progressive supranuclear palsy (PSP) and corticobasal syndrome (CBS).

FTD is distinct from other forms of dementia in two important ways:

- FTD is a young onset dementia, with symptoms most often beginning between ages 45 and 65— a full 10 years before the average onset of Alzheimer's. Thus, FTD can affect work and family in a way dementia in older persons does not.
- The hallmark of FTD is a gradual, progressive decline in behavior, language and/or motor skills, with memory usually relatively preserved. As the disease progresses, these deficits cause significant impairment in social and/or occupational functioning and result in an ever increasing dependency on caregivers.

FTD affects an estimated 50,000 to 60,000 Americans. The prevalence worldwide is uncertain, with estimates of FTD amongst people ages 45 to 64 at 15 to 22 per 100,000. FTD may account for up to 10% of all dementia, and it is the most common dementia in those under 60 years of age. Because of the nature of its symptoms— and the expectation that a patient is often “too young” for dementia to be considered— FTD is routinely misdiagnosed as a psychiatric problem or movement disorder, such as bipolar disorder or Parkinson's disease. Alzheimer's disease is another common misdiagnosis. The course of the disease ranges from 2 to over 20 years, with a mean course of 8 years from the onset of symptoms.

Currently, there are no treatments to slow or stop the progression of FTD. However, research is advancing rapidly. In 2014 alone significant progress included: FTD being recognized as a national priority within the National Alzheimer's Plan to cure dementia by 2025; a \$30 million investment in FTD research by the National Institutes of Health (NIH); and initiation of clinical trials for FTD therapeutics. Momentum is building, and it is a hopeful time.

## **AFTD Vision, Mission and Values**

### **Vision**

We envision a world where frontotemporal degeneration is understood, effectively diagnosed, treated, cured and ultimately prevented.

### **Mission**

Our mission is to improve the quality of life of people affected by FTD and drive research to a cure.

We work every day to advance:

- **RESEARCH:** We promote and fund research toward diagnosis, treatment and a cure.
- **AWARENESS:** We stimulate greater public awareness and understanding.
- **SUPPORT:** We provide information and support to those directly impacted.
- **EDUCATION:** We promote and provide education for healthcare professionals.
- **ADVOCACY:** We advocate for research and appropriate, affordable services.

### **Values**

We value knowledge, collaboration, respect, dignity and compassion. These values are core to our ability to lead a network of caregivers, persons diagnosed, medical professionals and government to forge change that will deliver our mission and achieve our vision.

## **History and Landmark Achievements**

The Association for Frontotemporal Degeneration (AFTD) was founded in 2002 by Helen-Ann Comstock to advocate for increased funding into the causes and treatments for frontotemporal degeneration and to provide caregivers and persons diagnosed with a central place to find information and support. Originally founded as the Association for Frontotemporal Dementias, the organization changed its name in 2010 to reflect AFTD's responsiveness to people dealing with any of the FTD disorders, and because the word "degeneration" captured the essence of the FTD experience: a one-way journey of progressive loss. The organization is the product of Ms. Comstock's experience as caregiver for her husband with FTD and collaboration with scientists, physicians and other caregivers who echoed the need for increased attention to these devastating diseases.

One of the organization's first actions to advance research was to establish a Medical Advisory Council comprised of leading researchers, clinicians and health care professionals from across the U.S. and Canada. Together they created a culture of collaboration and excellence that has been a foundation for the organization's growth.

In the 12 years since its inception, AFTD has raised and donated more than \$2 million to FTD research. With a small but energetic staff, a dedicated Board of Directors of past or present caregivers and a top-notch Medical Advisory Council, AFTD has become the information and support resource for persons with FTD and their families. The following are examples of landmark accomplishments within each of our mission areas.

### **Research**

Over the past five years AFTD has invested approximately one-third of every dollar into science to drive development of accurate diagnosis and the first therapeutics for FTD. To the greatest extent possible this investment is leveraged via collaboration with a wide variety of public and private partners. The current high level of collaboration and emerging research on the biology of FTD suggest to many that successful therapeutics for FTD may lead the way to effective therapies for other neurological diseases, like Alzheimer's, Parkinson's and amyotrophic lateral sclerosis (ALS). AFTD research efforts include:

- Since 2005 AFTD's grant programs have awarded more than \$1 million in support of FTD Postdoctoral Fellows and pilot grants investigating novel ideas in FTD research.
- Since 2007 we have partnered with the Alzheimer's Drug Discovery Foundation (ADDF), which matches AFTD's investment 2:1 to fund research to develop the first therapeutics for FTD. Together, our two organizations have invested a joint \$2.7 million in FTD drug development.
- In 2010, AFTD partnered with NIH and academic researchers to design a national database that collects common data elements on FTD patients across the US and Canada.
- As a founder of the FTD Treatment Study Group (FTSG), AFTD works with academic researchers, industry and government stakeholders to stimulate collaborations that will accelerate FTD drug discovery.
- AFTD's 2014 publication of the comprehensive *FTD Research and Drug Development Landscape* is helping to stimulate industry interest. The same year saw NIH award an unprecedented \$30 million to fund four major FTD research initiatives. AFTD is on the oversight committee that will ensure coordinated development for three of these efforts.

## **Support**

Despite improved awareness, the experience of families facing FTD is still marked by confusion, frustration and isolation. AFTD provides accurate information, compassionate guidance and opportunities for members of our community to connect with each other:

- In 2014 AFTD staff responded in an individualized and timely fashion to more than 2000 HelpLine inquiries from caregivers, persons diagnosed and healthcare professionals (an increase of 17% over 2013).
- Each year AFTD's Comstock Caregiver Respite Program provides financial assistance that enables 100 families to obtain respite and 50 people to attend an FTD education conference.
- Through five telephone support groups and start-up assistance to an annual average of 10 new FTD face-to-face groups, AFTD reduces the isolation and improves coping skills among those impacted by the disease. We provide quarterly continuing education to the leaders of independent FTD support groups (84 groups in 2014) to strengthen this critical lifeline for caregivers.
- Launched in April 2014, the AFTD Kids and Teens website provides a place for young people to learn about the diagnosis and share their experiences via original artwork, poetry or videos. More than 2,000 people visited the site in the first three months.
- A new Facebook group for young adults in their 20s and 30s provides a vehicle for connection among peers. Less than a year since the group launched, more than 100 young adults have subscribed.
- In response to an increase in contact with persons who are diagnosed with FTD, we have developed a monthly telephone support group, content on our website and opportunities to participate in AFTD's annual education conference to help address their unique needs.

## **Education**

Educating healthcare professionals about FTD is critical to improving accurate diagnosis and effective disease management. Each year AFTD collaborates with nationally-recognized partners in medicine, nursing, rehabilitation, aging and community services to blend discipline-specific expertise with the Association's deep knowledge of the needs of those affected:

- In 2011, AFTD developed the Partners in FTD Care initiative, which relies on a multidisciplinary committee of experts and family caregivers to create case-based studies and intervention strategies that address challenges in FTD care. Over the past three years the number of healthcare professionals receiving these quarterly modules has doubled, to nearly 1400.
- AFTD staff and committee members co-author articles in peer-reviewed journals and present on dementia care, FTD behavior management, hospice and palliative care.
- AFTD has participated in national web-based training programs for professionals across the spectrum of aging services, including through the NIH Administration for Community Living and the national Alzheimer's Association.
- In 2014, AFTD presented a poster at the 9th International FTD Conference in Vancouver, B.C., which analyzed data from AFTD's HelpLine to articulate our community's health needs to clinicians and researchers.



## Awareness

Awareness is the key to everything our rare disease community needs to accomplish. Media coverage is growing, and recent highlights include:

- Production of *It Is What It Is*, a short film that documents four families' journeys with the disease (See this and other recent video work at <https://www.youtube.com/TheAFTDorg>).
- Coverage on CNN (2009), the front pages of both the *LA Times* and the *New York Times* (2012) and on *NBC Nightly News* (2013).
- Sponsorship of the first FTD Awareness Week in 2013, which was celebrated at *Food for Thought* events across the U.S. and Canada. In 2014, families and clinics across the country hosted 81 creative events in 36 states and Washington, D.C. (a 45% increase over the previous year) to increase local understanding of FTD. In 2015, FTD Awareness Week will go international, as it has been adopted by peer advocacy organizations in 10 countries.
- A growing network of more than 175 volunteers across the country host events, visit nursing homes and day programs, facilitate telephone support groups, hold exhibits at health fairs and conferences, and share their technical and creative skills in support of AFTD's mission. This volunteer corps is led by 11 volunteer Regional Coordinators who have taken on the special role of tapping and nurturing this grassroots energy.
- In 2014, creation of a Public Service Announcement by Discovery Communications, which was first broadcast on the Discovery Life channel on December 29th.

## Advocacy

AFTD is leading the way to give voice to the needs of people affected by FTD and ensure that policymakers recognize that dementia is a multi-faceted disease:

- In 2008, AFTD successfully advocated for the inclusion of bvFTD among the first diagnoses to qualify for disability benefits under the Social Security Administration's Compassionate Allowances program.
- In 2013, AFTD co-sponsored a meeting with NIH, which produced FTD research priorities that were adopted into the National Alzheimer's Plan to cure dementias by 2025.
- AFTD's *Guidance for State Alzheimer's Plans* has been used by constituents in 10 states to advocate for FTD priorities to be included in dementia plans at the state level.
- In 2014, two AFTD-nominated candidates were elected to an advisory committee for the Center for Medicare and Medicaid Services, which will play a critical role in determining whether emergent treatments for FTD are reimbursed by the federal government and private insurers.

AFTD will be at the forefront of stimulating and funding research until a cure for FTD is found. We will be a leader in creating and delivering novel resources and support as long as there are persons diagnosed with this disease.

## **2015 – 2018 STRATEGIC PLAN**

### **Overview**

The Strategic Plan outlined on the following pages is the product of six months' work by the AFTD Board, staff and advisors. During this process we collected input from a wide variety of stakeholders, recommitted to our vision, mission and values, and have taken stock of the organization's current programs. We have analyzed the drivers behind the organization's steep growth trajectory in recent years, as well as the work that remains in order to realize our ultimate vision.

The result is a plan that is both aspirational and grounded. Progressive and creative expansion of funding mechanisms is balanced by an aggressive investment plan, in which initiatives are coordinated across the full breadth of our mission areas. Over the course of this plan we project that AFTD's budget will nearly double, to \$3 million. We anticipate investing an increasing portion of the budget (approaching 40%) into research, with additional resources allocated to develop an increasing variety of support mechanisms and awareness initiatives overall. Strategies, detailed tactics and a financial plan will guide our daily work, which will be grounded in the values and culture AFTD has cultivated over the past 12 years. Should fundraising exceed expectations, we have identified initiatives that are ripe for accelerated implementation.

The 2015-2018 Strategic Plan detailed on the following pages is organized around five interlocking goals; the first three serve to align the different areas of our mission toward a future of improved diagnosis, care and understanding. The final two goals focus on strengthening the organization itself, to ensure that AFTD will have the capacity and funding to work effectively on behalf of our community for years to come.

## AFTD Strategic Plan 2015 - 2018

<b>Goal and Strategies</b> <small>**Denotes strategies to be accelerated, should funding exceed projections</small>	<b>Mission Area</b>	<b>Key Tactics</b>
<b>Goal I: People will receive a timely and accurate diagnosis and have access to high quality medical care.</b>		
Strategy 1: Be a lead partner in creating and maintaining an FTD registry designed to support disease research and trial recruitment.	Research	<ul style="list-style-type: none"> <li>• Form partnership with peer organizations to steward registry</li> <li>• Select appropriate IT platform</li> <li>• Brand and market registry to constituents</li> </ul>
Strategy 2: Activate and strengthen the FTD Treatment Study Group as a mechanism to promote collaborative efforts between academia, industry and government in order to fast track diagnosis, treatment and cure.	Research	<ul style="list-style-type: none"> <li>• Convene steering committee of representative stakeholders</li> <li>• Refresh mission, goals and brand</li> <li>• Host conference every 18 months</li> </ul>
Strategy 3: Expand AFTD's current research grant programs. **	Research	<ul style="list-style-type: none"> <li>• Continue and expand current grant mechanisms</li> <li>• Develop metrics to track impact of AFTD grant-making</li> <li>• New pilot grant for nonpharmacologic interventions</li> <li>• Develop new grant program to target specific gaps (e.g., biomarkers)</li> </ul>
Strategy 4: Conduct an economic burden study of FTD and publicize results to help make the case for continued investment by public and private funders.	Research	<ul style="list-style-type: none"> <li>• Study to be completed Q1 2016</li> <li>• Publish results in medical, policy and popular press</li> <li>• Present at 2016 International Conference</li> </ul>
Strategy 5: Continue to advocate for attention to and inclusion of FTD-specific issues within the National Alzheimer's Plan and similar state-level Alzheimer's plans and governing bodies.	Advocacy	<ul style="list-style-type: none"> <li>• AFTD representative at all National Alzheimer's Project Act (NAPA) meetings</li> <li>• Develop agenda of priority issues</li> <li>• Engage volunteers at federal and state levels</li> </ul>
Strategy 6: Expand AFTD's efforts to educate physicians and other health care professionals. **	Education	<ul style="list-style-type: none"> <li>• Expand on current Partners in FTD Care initiative</li> <li>• Overarching AFTD education strategy in place by June 2017</li> </ul>

<b>Goal and Strategies</b> **Denotes strategies to be accelerated, should funding exceed projections	<b>Mission Area</b>	<b>Key Tactics</b>
<b>Goal II: Every person with FTD and their caregiver(s) will have access to high quality, effective support services.</b>		
Strategy 1: Establish a network of AFTD-affiliated support groups across the U.S.	Support	<ul style="list-style-type: none"> <li>• Hire Support Services Manager</li> <li>• Develop program for leader recruitment and training</li> <li>• Establish best practices</li> </ul>
Strategy 2: Expand AFTD’s capacity to ensure responsive, high quality support and information for the rapidly increasing number of individuals making Helpline inquiries.	Support	<ul style="list-style-type: none"> <li>• Hire Program Assistant</li> <li>• Develop standard operating procedures (SOPs) for Helpline efficiency and quality assurance (QA)</li> <li>• Incorporate intern and/or volunteer(s)</li> </ul>
Strategy 3: Determine the most effective way for AFTD to design and facilitate support for persons diagnosed with FTD.	Support	<ul style="list-style-type: none"> <li>• Provide telephone support group</li> <li>• Assist caregiver groups with piloting support strategies for those diagnosed</li> <li>• Expand engagement with persons diagnosed and FTD/dementia self-advocacy leaders</li> </ul>
Strategy 4: Define and address the needs of distinct stakeholder groups within the FTD community.	Support	<ul style="list-style-type: none"> <li>• Promote and expand AFTD Kids and Teens website</li> <li>• Promote and expand Facebook group for young adults</li> <li>• Create additional phone groups to address unmet needs</li> <li>• Maximize use of technology to connect isolated stakeholders</li> </ul>
Strategy 5: Expand AFTD’s conference to accommodate growing numbers, distinct stakeholder group needs and changes in the external environment.	Support	<ul style="list-style-type: none"> <li>• Standardize planning procedures</li> <li>• Expand content for professionals and individuals diagnosed</li> <li>• Incorporate recruitment for registry and clinical trials</li> </ul>
Strategy 6: Strengthen and expand travel and respite grant program.	Support	<ul style="list-style-type: none"> <li>• Review program for QA and efficiency</li> <li>• Survey past recipients to ensure alignment with needs of stakeholders</li> <li>• Identify additional sources of funding</li> </ul>

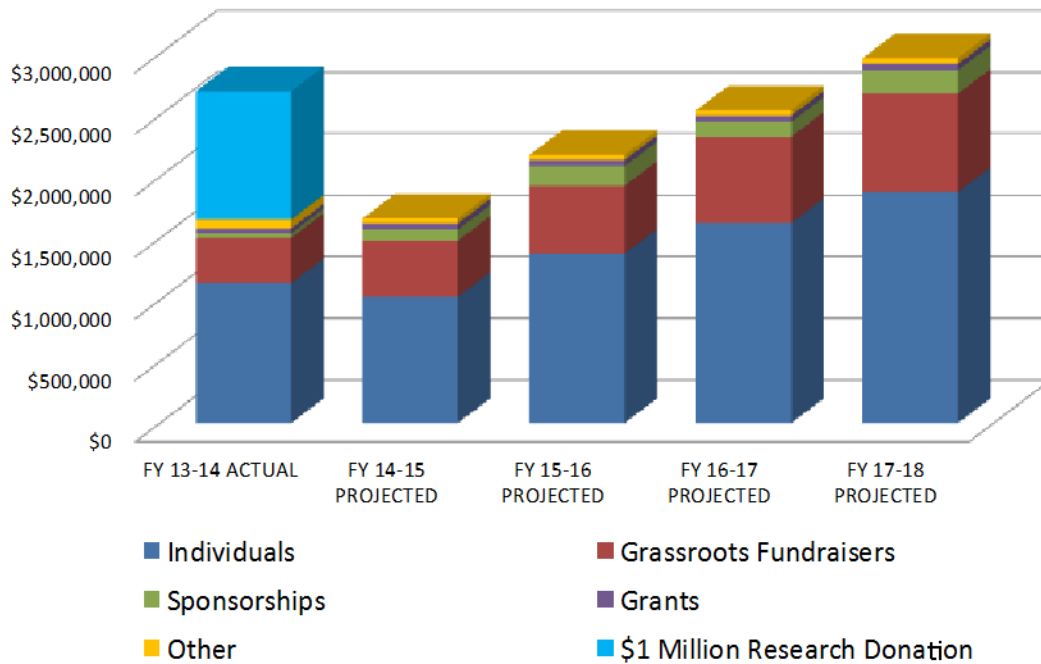
<b>Goal and Strategies</b> <small>**Denotes strategies to be accelerated, should funding exceed projections</small>	<b>Mission Area</b>	<b>Key Tactics</b>
<b>Goal III: FTD will be commonly recognized and understood.</b>		
Strategy 1: Expand stakeholder advocacy efforts with legislators.	Advocacy	<ul style="list-style-type: none"> <li>• Develop mechanisms to identify and engage volunteer advocates</li> <li>• Create toolkit for volunteers to meet with legislators</li> <li>• Incorporate technology to expand efforts</li> </ul>
Strategy 2: Strengthen and expand AFTD's grassroots events in order to reach a broad nationwide audience in a manner that is coordinated with both marketing and volunteer engagement.	Awareness	<ul style="list-style-type: none"> <li>• Expand FTD Awareness Week and <i>Food For Thought</i></li> <li>• Refresh <i>With Love</i> campaign at Valentine's Day</li> <li>• Establish a series of 5K walk/runs across the country</li> <li>• Expand use of social media</li> </ul>
Strategy 3: Design a public awareness campaign. **	Awareness	<ul style="list-style-type: none"> <li>• Benchmark with other rare disease organizations</li> <li>• Identify a national spokesperson</li> <li>• Develop relationships with select media representatives and outlets</li> </ul>
Strategy 4: Create and disseminate accurate information about FTD. **	Awareness, Education, Support	<ul style="list-style-type: none"> <li>• Redesign website</li> <li>• Continue to create unique resources that target identified needs</li> <li>• Maintain pool of experts for public comment and review of materials</li> </ul>

<b>Goal and Strategies</b> <small>**Denotes strategies to be accelerated, should funding exceed projections</small>	<b>Mission Area</b>	<b>Key Tactics</b>
<b>Goal IV: AFTD will diversify and increase its funding.</b>		
Strategy 1: Implement a cultivation, stewardship and solicitation strategy for AFTD's major donor program.	Infrastructure Funding	<ul style="list-style-type: none"> <li>Standardize cultivation, stewardship and solicitation practices</li> <li>Research donor capacity and document priorities</li> <li>Expand donor recognition strategies</li> </ul>
Strategy 2: Expand overall donor base.	Infrastructure Funding	<ul style="list-style-type: none"> <li>Segment donors by giving level</li> <li>Implement targeted communications for each level</li> <li>Design and implement cultivation processes to move donors up</li> </ul>
Strategy 3: Create, expand and market a menu of giving mechanisms.	Infrastructure Funding	<ul style="list-style-type: none"> <li>Expand Planned Giving program</li> <li>Market Monthly Giving program</li> <li>Cultivate and solicit major donors to increase numbers of Named Funds</li> </ul>
Strategy 4: Pursue corporate sponsorships of events, meetings and scientific programs.	Infrastructure Funding	<ul style="list-style-type: none"> <li>Create a comprehensive benefits package for sponsors</li> <li>Network among stakeholders to increase sponsor prospect list</li> <li>Showcase corporate sponsors on website</li> </ul>
Strategy 5: Implement a comprehensive proposal and reporting system.	Infrastructure Funding	<ul style="list-style-type: none"> <li>Create a case statement for expanded support</li> <li>Identify fundable programs and potential funding sources</li> <li>Engage a grant writer and pursue new requests</li> </ul>
Strategy 6: Engage Board members, staff and volunteers in the cultivation and solicitation of donors.	Infrastructure Funding	<ul style="list-style-type: none"> <li>Design and implement training program</li> <li>Provide robust support materials</li> <li>Recruit additional volunteers to support development initiatives</li> </ul>

<b>Goal and Strategies</b> **Denotes strategies to be accelerated, should funding exceed projections	<b>Mission Area</b>	<b>Key Tactics</b>
<b>Goal V: AFTD will continue to mature into a sustainable organization with strategic and effective: leadership, marketing, technology and professional governance practices.</b>		
Strategy 1: Continually invest in and strengthen the organization's leadership.	Infrastructure Governance	<ul style="list-style-type: none"> <li>• Ensure pipeline of Board candidates with key expertise</li> <li>• Implement comprehensive orientation and training program</li> <li>• Design succession plan for Executive Director, Board officers</li> <li>• Revise committee structure for efficiency of operations</li> <li>• Review Medical Advisory Council structure and procedures</li> </ul>
Strategy 2: Create an integrated, national and structured volunteer program that engages and supports an increasing number of volunteers in mission-critical ways.	Awareness Advocacy Support Education Research	<ul style="list-style-type: none"> <li>• Expand leadership training for Regional Coordinators</li> <li>• Integrate AFTD-affiliated support group leaders into volunteer program</li> <li>• Leverage technology to increase engagement with volunteers</li> <li>• Create new volunteer activities to align with priority needs</li> </ul>
Strategy 3: Create and implement uniform business practices that ensure quality across the expanding organization.	Infrastructure Business Practices	<ul style="list-style-type: none"> <li>• Benchmark with peer organizations for best practices</li> <li>• Develop SOPs to ensure QA of organizational practices as a whole</li> </ul>
Strategy 4: Ensure effective use of technology.	Infrastructure IT	<ul style="list-style-type: none"> <li>• Evaluate and revise or replace database to support our expanding activities</li> <li>• Assess current IT contract support</li> <li>• Create a policy to ensure robust hardware infrastructure</li> </ul>
Strategy 5: Update, streamline and standardize AFTD's messaging and brand.	Awareness	<ul style="list-style-type: none"> <li>• Hire Director of Development &amp; Communications</li> <li>• Identify stakeholder groups and best communication medium for each</li> <li>• Develop marketing strategy with key messaging</li> </ul>
Strategy 6: Develop strategic staffing plan to ensure organization's capacity to deliver the targeted goals.	Infrastructure Staff Development	<ul style="list-style-type: none"> <li>• Benchmark with peer organizations as we grow</li> <li>• Review and revise job descriptions on a regular basis</li> <li>• Evaluate key points of interface between positions to maximize efficiency</li> </ul>
Strategy 7: Keep the organization's Strategic Plan active and relevant.	Infrastructure Planning	<ul style="list-style-type: none"> <li>• Quarterly review of key metrics and progress vs. goals</li> <li>• Create annual goals and work plans</li> <li>• Begin new strategic planning process Q1 2018</li> </ul>

## FINANCIAL PROJECTIONS

### Income by Source



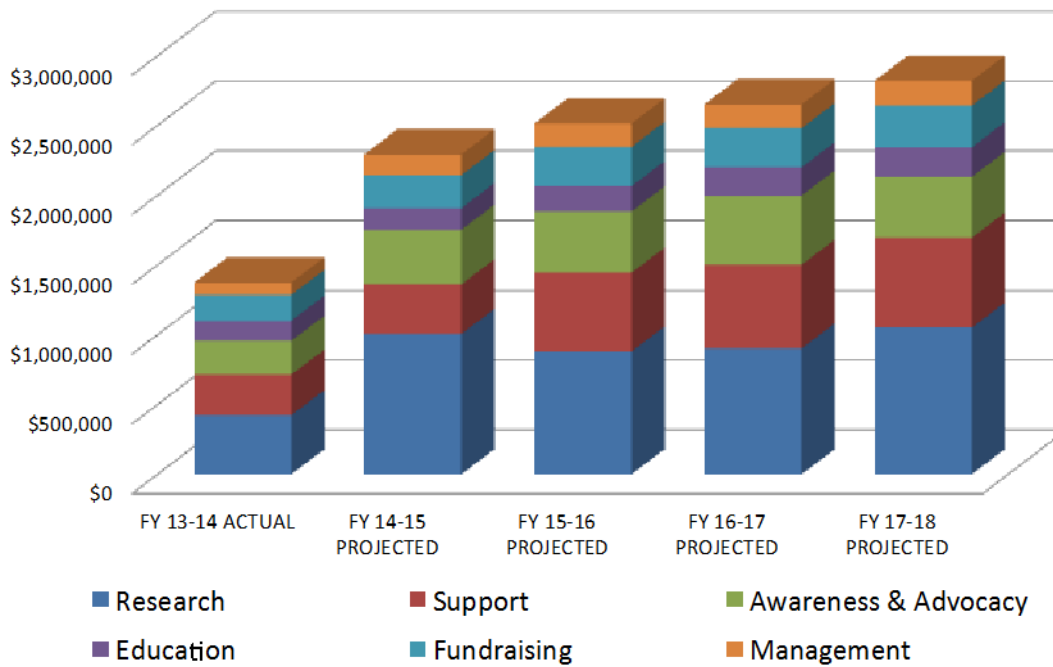
In FY 13-14, AFTD secured a one-time donation of \$1,041,570 to support the organization’s research efforts. The largest gift in the organization’s history to date, this donation has served as a catalyst for multi-year growth.

Over the course of the Strategic Plan’s implementation, AFTD aims to nearly double its *base* income (excluding the \$1M donation), to nearly \$3 million in FY 17-18. The majority of these funds will come from individuals via memorial donations and an increasing number of other giving mechanisms—such as named funds, planned giving and automated monthly donations. A growing proportion will be raised by constituents through grassroots events. These events can be unique fundraisers conceived by the individual or those hosted in conjunction with national AFTD campaigns such as *Food For Thought* and *With Love*. Increasing constituent interest and engagement in this area, built up through expanded grassroots fundraising expertise, has resulted in related contributions increasing by 95% from FY 12-13 to FY 13-14. Finally, we will seek to increase contributions from corporations and foundations via program grants and sponsorships for meetings and events.



## FINANCIAL PROJECTIONS

### Expenses by Mission Area

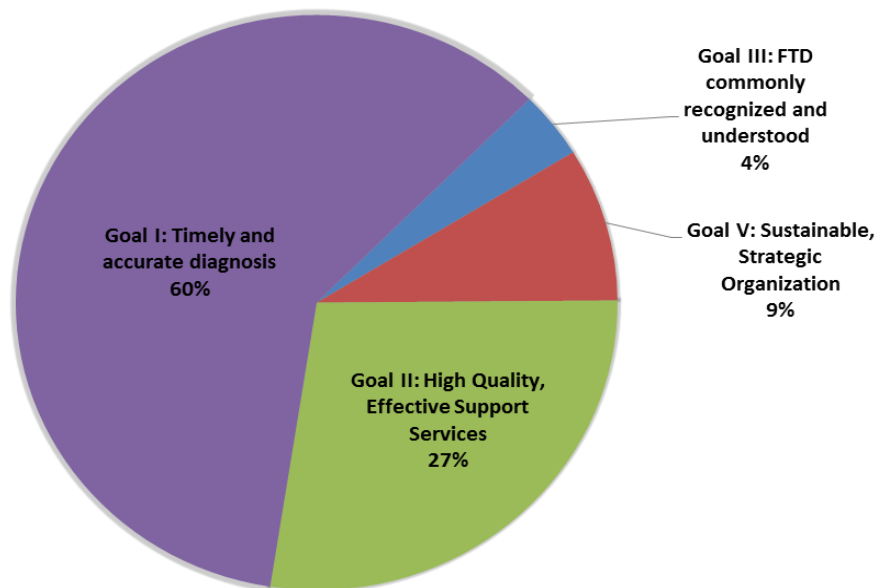


Expenses are projected to double from FY 13-14 to FY 17-18, approaching \$3 million. Investment in research initiatives is weighted toward the early years of the Strategic Plan to reflect spending of a \$1 million research gift received in March 2014 and creation of a Contact Registry in FY 14-15. Should income exceed projections, AFTD has identified specific initiatives within the Strategic Plan that are primed for accelerated implementation (see strategies marked \*\*). AFTD is committed to ensuring that the portion of budget spent on management and fundraising will not exceed 20% in any year, a goal AFTD has consistently met or exceeded.

# Investment Plan for Infrastructure and New Initiatives

*Investment of Additional Funds: FY 14-15 through FY 17-18*

Total expenses portrayed in the bar chart on the preceding page include base expenses to maintain existing programs, as well as an additional \$2.1 million investment in new initiatives and organizational infrastructure. *Goal IV: AFTD will increase and diversify its funding*, will deliver the funds to support investment in Goals I, II, III and V. The following pie chart portrays how this incremental multi-year spend will be allocated:

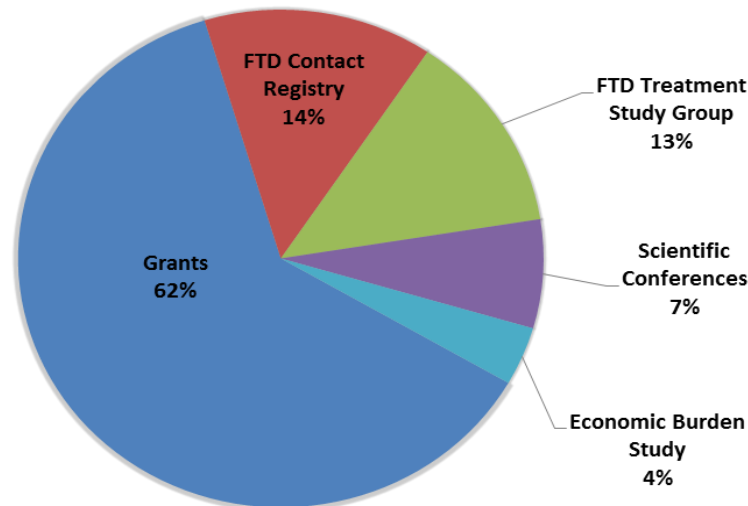


- **Goal I:** New initiatives in research, advocacy and education of medical professionals will drive discovery, policy and transfer of knowledge to clinicians in pursuit of accurate diagnosis and effective therapies for FTD.
- **Goal II:** AFTD will work to deepen our understanding of the most pressing needs within each of our constituencies and engage with these stakeholders to design and implement new and effective support strategies.
- **Goal III:** Increased investment in branding, messaging and advocacy will target policy leaders, media and the public at large in pursuit of increased awareness of FTD.
- **Goal V:** Strategic investment in leadership, a vibrant national volunteer network, marketing, technology and governance practices will ensure a strong infrastructure as AFTD continues to mature and expand.

## Total Projected Research Investment

*FY 14-15 through FY 17-18*

Total funds invested in both existing and new research programs—anticipated to exceed more than \$3.8 million over the multi-year period highlighted—will support five main initiatives:



- **Grant Program:** The Strategic Plan calls for increased investment in AFTD’s existing mechanisms of Basic and Clinical Pilot Grants, Postdoctoral Fellowships and the joint AFTD-ADDF Drug Discovery program. New funding mechanisms initiated within the next three years will include a third annual pilot grant to stimulate development of nonpharmacologic interventions, targeted funding of specific projects that will address key questions identified in AFTD’s *FTD Research and Drug Development Landscape* and increased investment in the development of biomarkers.
- **FTD Contact Registry:** A database of information entered by persons diagnosed and their family members to stimulate and support industry investment in drug development and clinical trials.
- **FTD Treatment Study Group:** A joint initiative among nonprofits, researchers, government and industry to stimulate collaboration that will speed efficient and effective advances in the development of diagnostics and therapeutics.
- **Scientific Conferences:** Each year, AFTD sponsors a number of meetings to convene researchers from a variety of scientific disciplines related to FTD. These meetings promote exchange of knowledge and collaborations that advance us toward a better understanding of the disease process and how best to intervene in that process, driving toward accurate diagnosis, effective treatments and a cure.
- **Economic Burden Study:** A study to quantify the financial burden FTD places on families and society as a whole. The results will be published in a variety of formats to support public awareness as well as advocacy for increased research funding and expanded services.

# AFTD STRATEGIC PLAN SUMMARY

## Vision:

We envision a world where FTD is understood, effectively diagnosed, treated, cured and ultimately prevented.

## Mission:

Our mission is to improve the quality of life of people affected by FTD and drive research to a cure. We work every day to advance:

- **RESEARCH:** We promote and fund research toward diagnosis, treatment and a cure.
- **AWARENESS:** We stimulate greater public awareness and understanding.
- **SUPPORT:** We provide information and support to those directly impacted.
- **EDUCATION:** We promote and provide education for healthcare professionals.
- **ADVOCACY:** We advocate for research and appropriate, affordable services.

## Values:

We value knowledge, collaboration, respect, dignity and compassion. These values are core to our ability to lead a network of caregivers, individuals diagnosed, medical professionals and government to forge change that will deliver our mission and achieve our vision.

## Goals and Strategies (Mission Deliverable):

<b>Goal I: People will receive a timely and accurate diagnosis and have access to high quality medical care.</b>	
Be a lead partner in creating and maintaining an FTD registry (Research)	Conduct an economic burden study of FTD and publicize results (Research)
Activate and strengthen the FTD Treatment Study Group (Research)	Continue to advocate for attention to and inclusion of FTD-specific issues within the National Alzheimer’s Plan (Research)
Expand AFTD’s current research grant programs ** (Research)	Expand AFTD’s efforts to educate physicians and other health care professionals ** (Education)
<b>Goal II: Every person with FTD and their caregiver(s) will have access to high quality, effective support services.</b>	
Establish a network of AFTD-affiliated support groups across the U.S. (Support)	Define and address the needs of distinct stakeholder groups within the FTD community (Support)
Expand AFTD’s capacity to ensure responsive, high quality information for Helpline (Support)	Expand AFTD’s conference to accommodate growing numbers, distinct stakeholder needs, and changes in the external environment (Support)
Determine the most effective way for AFTD to design and facilitate supports for persons diagnosed with FTD (Support)	Strengthen and expand travel and respite grant program (Support)
<b>Goal III: FTD will be commonly recognized and understood.</b>	
Expand stakeholder advocacy efforts with legislators (Advocacy)	Design a public awareness campaign ** (Awareness)
Strengthen and expand grassroots events in order to reach a broad nationwide audience (Awareness)	Create and disseminate accurate information about FTD ** (Awareness, Education, Support)
<b>Goal IV: AFTD will diversify and increase its funding.</b>	
Implement a cultivation, stewardship and solicitation strategy for AFTD’s major donor program (Infrastructure, Funding)	Pursue corporate sponsorships of events, meetings and scientific programs (Infrastructure, Funding)
Expand overall donor base (Infrastructure, Funding)	Implement a comprehensive proposal and reporting system (Infrastructure, Funding)
Create, expand and market a menu of giving mechanisms (Infrastructure, Funding)	Engage board members, staff, and volunteers in the cultivation and solicitation of donors (Infrastructure, Funding)
<b>Goal V: AFTD will continue to mature into a sustainable organization with strategic and effective: leadership, marketing, technology and professional governance practices.</b>	
Continually invest in and strengthen the organization’s leadership (Infrastructure, Governance)	Update, streamline and standardize AFTD’s messaging and brand (Awareness)
Create an integrated, national and structured volunteer program that engages and supports an increasing number of volunteers (All)	Develop strategic staffing plan to ensure organization’s capacity to deliver the strategic plan’s targeted goals (Infrastructure, Staff Development)
Create and implement uniform business practices that ensure quality across the expanding organization (Infrastructure, Business Practices)	Keep the organization’s strategic plan active and relevant (Infrastructure, Planning)
Ensure effective use of technology (Infrastructure, IT)	

*\*\*Denotes strategies to be accelerated, should funding exceed projections*

*AFTD envisions a world where frontotemporal degeneration  
is understood, effectively diagnosed, treated, cured and  
ultimately prevented.*



**The Association for  
Frontotemporal Degeneration**  
Opening the gateway to help and a cure