



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

STRATEGIC PLAN

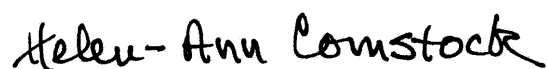
Letter from the Chair

In the seven years since I founded the Association for Frontotemporal Dementias (AFTD), the Association has grown from an all-volunteer organization funded by my \$1,000 donation to a non-profit with a professional staff of four and a budget of three-quarters of a million dollars. AFTD has surpassed even my ambitious dreams of an organization that would fund much-needed research and support and advocate for those coping with frontotemporal dementias. I believe our success to date can be credited to tireless board members, generous donors, smart management and the creation of strategic partnerships, but a great part must also be attributed to luck. Our biggest asset has been the commitment of our constituents: the families, physicians, researchers and other friends who share our belief that no family should have to face this diagnosis alone, nor hear that there is no hope.

Today, significant progress is being made in research, awareness and even advocacy, and we are gaining momentum in the quest to fulfill our mission. Scientists have discerned many of the genes and pathologies that characterize FTD; a growing number of caregivers are hosting awareness events, creating local support groups, and volunteering to share their story with the broader world; and FTD is among the small number of rare diseases that qualify for Social Security benefits under the Compassionate Allowances program.

Certainly, the bulk of our task still lies ahead of us. Too many families struggle for a diagnosis or face what that diagnosis means with minimal support. While researchers learn more each day, too many questions remain unanswered. I invite each person reading this Plan to join us, to commit in some way to creating a new, brighter future for our families and realize AFTD's vision of *A world where FTD is understood, effectively diagnosed, treated, cured and ultimately prevented.*

Wishing us all new hope for tomorrow,

A handwritten signature in black ink that reads "Helen-Ann Comstock". The signature is written in a cursive, flowing style.

Founder and Chair, AFTD

February 10, 2010

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AFTD Strategic Plan 2010-2013

Executive Summary

The Association for Frontotemporal Dementias (AFTD) was founded in November 2002 and fostered through its early development by an all-volunteer group of caregivers who knew intimately the need for greater focused attention on the needs of people with frontotemporal dementia and their families. During the following four years, the Board established an international Medical Advisory Council, attended FTD scientific conferences, created a website with information for caregivers, established a toll-free HelpLine and phone support group, awarded its first research grants, hosted symposia on FTD and caregiver dinners, and hired its first employees.

Since 2006, AFTD has grown to an organization with a Board with members throughout the United States and a professional staff that has served more than a thousand families navigating the tortuous path of diagnosis, treatment and care of someone with frontotemporal dementia. From its inception, AFTD also has been instrumental in bringing together researchers, caregivers and policy makers to focus on and advance research toward the cure of FTD. Significant milestones in research include the formation of AFTD's partnership with the Alzheimer's Drug Discovery Foundation in 2007, and the completion of a strategic analysis of international research funding for the frontotemporal dementias in 2009.

In recognition of a period of tremendous organizational growth and building upon this solid foundation, AFTD conducted a strategic planning process in 2009 to chart a course to strengthen our growing system of support and to accelerate progress toward the cure.

The Association for Frontotemporal Dementias (AFTD) is a non-profit organization whose mission is to:

- Promote and fund research into finding the cause and cure for the frontotemporal dementias;
- Provide information, education, and support to persons diagnosed with frontotemporal dementias (FTD) and their families and caregivers;
- Educate physicians and allied health professionals about FTD and how to improve patient care;
- Bring about greater public awareness of the nature and prevalence of the frontotemporal dementias and the needs of those who are coping with them;
- Advocate with public officials and to promote public and private programs that provide appropriate, affordable and high-quality long-term health care and social services ;
- Facilitate the international exchange of ideas.

Reaffirming our mission, we envision a world where the frontotemporal dementias are understood, effectively diagnosed, treated, cured and ultimately prevented.

In this vision, FTD is widely recognized by the public. The medical community is familiar with FTD, enabling patients to obtain accurate diagnosis and appropriate care. Genetic testing with counseling is readily available.

Prevention and cure are a reality. The Association for Frontotemporal Dementias will be the “go to” organization for caregivers and healthcare professionals concerned with FTD, enabled by effective regional networks and guided by a respected Medical Advisory Council. We envision an organization that is compelling and successful. AFTD will be: an organization with which others want to collaborate, a model for FTD organizations around the globe and the umbrella for the international exchange of ideas.

The following are AFTD’s Strategic Priorities for 2010 to 2013:

Strategic Priority 1: Promote and fund research for diagnosis and the cure. Accelerate progress toward accurate diagnosis and the cure by leveraging strategic partnerships to accomplish the following: establishment of a formal network of FTD centers of excellence, increased participation in brain donation, and identification of key biomarkers for FTD.

Strategic Priority 2: Support and enable patients, families and caregivers. Serve as the nexus of an extensive network of support, ensuring accessibility of support groups, information, education and counsel for each family faced with FTD.

Strategic Priority 3: Educate physicians and healthcare providers to better serve FTD patients and families. Develop educational modules in partnership with key professional educational organizations, thereby equipping doctors, nurses and long-term caregivers with the knowledge and capabilities to provide quality care and accurate referrals to FTD patients and their families.

Strategic Priority 4: Create public awareness of FTD and associated realities. Accelerate fulfillment of AFTD’s mission by creating a set of branded materials and disseminating them throughout professional and community networks across the United States and Canada, and spreading this message to the public via an annual, branded national awareness event

Strategic Priority 5: Systematically advocate for care and the cure of FTDs over a broad network of stakeholders. Create and foster the necessary infrastructure, relationships and processes to advocate effectively for a robust system of support for FTD patients and their families.

Strategic Priority 6: Fund AFTD’s growth by securing and expanding a sustainable donor base. Develop a broad and sustainable income stream that will enhance our ability to expand support services for patients and caregivers and accelerate the path to the cure.

Introduction

Our Mission

The Association for Frontotemporal Dementias (AFTD) is a 501(c)(3) non-profit organization whose mission is to:

- Promote and fund research into finding the cause and cure for the frontotemporal dementias;
- Provide information, education, and support to persons diagnosed with frontotemporal dementias (FTD) and their families and caregivers;
- Educate physicians and allied health professionals about FTD and how to improve patient care;
- Bring about greater public awareness of the nature and prevalence of the frontotemporal dementias and the needs of those who are coping with them;
- Advocate with public officials and to promote public and private programs that provide appropriate, affordable and high-quality long-term health care and social services;
- Facilitate the international exchange of ideas.

Our Values

AFTD's values are centered on knowledge, positive action, collaboration, respect, dignity and compassion. These form the foundation of how we work.

The Charge

2008 found AFTD in its "adolescence" as a non-profit organization. Fueled by an expanding base of donors and guided in great part by serendipity, we had grown from an all-volunteer organization to one with professional staff, programs, and annual goals and budgets. Each new activity and program initiated was bringing us in contact with more professionals and families, thus widening our circle of donors, potential partners and those for whom AFTD's ability to fulfill its mission was not merely an organizational mandate, but an urgent and very personal need. It was against this backdrop that fate, in the form of an unanticipated gift from an extremely generous donor, brought us an opportunity to pause, assess critically the organization AFTD had become, and chart a thoughtful, proactive course for the next three to five years.

Our Vision

Reaffirming our mission, we envision a world where frontotemporal dementia is understood, effectively diagnosed, treated, cured and ultimately prevented.

In this vision, FTD is widely recognized by the public; the medical community is familiar with FTD, enabling patients to be diagnosed early and accurately, cared for appropriately, and accepted by a wide range of health care facilities; appropriate genetic testing with counseling is readily available; and medical advances provide effective treatment and, ultimately, a cure and prevention.

We envision AFTD to be the “go to” organization for caregivers and healthcare professionals concerned with FTD, enabled by effective regional networks and guided by a respected Medical Advisory Council. Because of our existence, upon diagnosis all families will be given accurate information about FTD and patients, and families and professional caregivers alike will have an organization to turn to for resources, information and support. We see AFTD to be compelling and successful – an organization with which others want to collaborate, and a model for similar organizations around the globe, while serving as the umbrella for the international exchange of ideas.

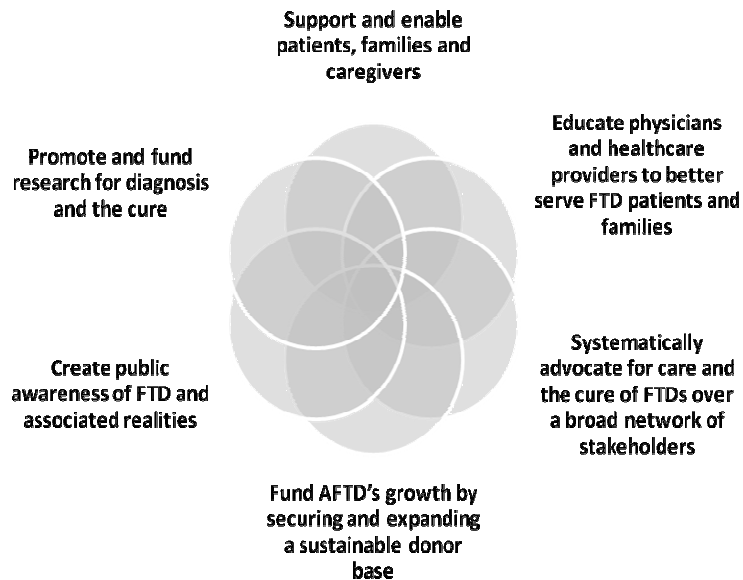
The Planning Process

In early 2009, a strategic planning committee comprised of AFTD Board and staff engaged in systematically planning AFTD’s future. We began by considering AFTD’s impact to date in fulfilling its mission, the current and future needs of its stakeholders, and the role that AFTD might play in fulfilling these needs and ultimately achieving our vision. We specifically assessed the organization’s strengths, weaknesses, opportunities and threats and drafted a vision for the future. We emerged with a list of strategic goals, and assigned the standing committees of the Board the task of further development and prioritization of these strategic goals.

In June 2009, the Board of Directors convened in Los Angeles for its annual meeting. During an additional day and a half committed to planning, the Board re-committed to the full breadth of AFTD’s mission, and approved an official vision statement and six strategic priorities to guide AFTD’s activities and resource allocation for the next few years. The following several months were allotted for the Board committees to construct an implementation plan and define the key assumptions and necessary resources for each priority.

The Plan

The resulting plan, approved by the AFTD Board of Directors November 6, 2009, provides a four-year work plan organized around six interlocking priorities:



For each priority, we have articulated a desired result, have decided “how to get there” by selecting specific goals, and have made it actionable by defining specific objectives, milestones and outcomes. The plan reflects this methodology, and provides a blueprint for more detailed annual planning.

Underlying and enabling the fulfillment of these goals is the continued effective leadership and governance on the part of AFTD’s Board and staff. We will specifically focus on leadership and organizational development during 2010 in anticipation of transition to the next stage of our growth as a more mature organization.

Through this plan, AFTD is re-committing itself to two themes that provide the foundation for all of our activities: *Care* and *The Cure*. *Care* deals with the system of services and information that AFTD provides to caregivers and patients. *The Cure* focuses on the combination of research, training and information dissemination that will speed capabilities for diagnosis, treatment and prevention of the frontotemporal dementias.

This plan represents the beginning of a process, rather than its completion. AFTD’s strategic plan is a working document, to be tested, amended and altered as unanticipated opportunities—and no doubt challenges as well—present themselves. We have and will continue to use it as a framework to guide the setting of goals and budget allocation each year, as well as to track our progress.

Critical Success Factors

The planning process brought focus to a set of critical success factors, which AFTD's leadership will manage and assess on an ongoing basis, to ensure successful implementation of this Strategic Plan.

- AFTD leadership must invest in Board recruitment in order to secure a seamless transition from the founder and initial Board to a renewed and expanded Board which, guided by our founding values, continues to advance the AFTD mission.
- The organization must invest significant energy in establishing and expanding the volunteer grassroots network. Well-trained and -equipped Regional Coordinators, and effective communications between the national office and these volunteers, will enable a consistent message that can produce maximum impact for awareness, advocacy and fundraising.
- Efficient progress toward the cure will require leveraging key assets and partnerships. These include: access to scientific and medical expertise (AFTD's Medical Advisory Council); development of a comprehensive research database (the International Strategic Analysis of Funding for FTD); leveraging of existing infrastructure (the Alzheimer Disease Centers); and engagement of major donors and other strategic partners, as they are identified.
- Establishment of win-win strategic partnerships is a critical strategy for achieving success across all six priorities. Key partners include families, researchers, clinicians, government, educators, peer organizations and other private and public funders.
- Success is dependent upon a broad, sustainable funding base. Development of this base will require expanded staff, time, expertise and infrastructure.

Our Commitment

This has been a journey of deep thought and self-realization for the Board and staff of the Association for Frontotemporal Dementias. The loved ones lost to FTD have been a significant presence with us throughout the planning process, and we recognize that our essential working norms- ***to gain insight; think expansively; be self-aware, communicate deeply; and be flexible***- are the very qualities and abilities that our loved ones have lost through FTD. This is a poignant reminder of just how precious these abilities are and highlights the great tragedy of FTD.

We have emerged recommitted to our mission and energized to work on behalf of all those who live and work with FTD each day. Indeed, you will find that this plan is proactive and aggressive: We hold the promise and the means to build a brighter future in our own hands.

Strategic Priority 1

Promote and fund research for diagnosis and the cure

Desired Result

AFTD accelerates progress toward accurate diagnosis and the cure of FTDs.

Strategies for Diagnosis and Cure with Supporting Objectives:

- Build infrastructure to become THE knowledge center for FTD and create an agenda to drive research forward
 - Form a Research Committee
 - Create part-time Research Director position
 - Continue to maximize valuable resource we have in the MAC
 - Collect information: Strategic Research Analysis, ADRC Survey
 - Analyze the data, identify scientific challenges, identify priority goals and define strategies to achieve each
 - Host Workshop every 18 months to evaluate research agenda on an ongoing basis
- Form a subcommittee of scientific advisors to take the lead on each strategic initiative/priority (influence but do not own these committees)
 - Create, build and maintain key relationships
 - Clarify the role AFTD should play in the international conference
 - Focus on three priorities:
 - Brain Donation: facilitate relationship and effective communication between researchers and families to encourage participation in brain donation
 - Establishment of FTD Cores within the ADRC network
 - Biomarkers: Motivate and focus the global research community to speed efficient path to the cure
- Invest our grant dollars to have the greatest strategic impact
 - Fund proof-of-concept research to catalyze drug development programs
 - Fund pilot research projects (basic and clinical)
 - Establish a recurring two-year Fellowship, awarded on alternate years

Resources

- Hire a part-time director of research in 2010 to strengthen connection with the research community and to direct strategic investment of AFTD's grant dollars
- Raise significant funds to sponsor the Strategic Research Analysis, scientific workshops and grant programs listed above on an ongoing basis
- Advocate for funding of major research initiatives by larger funding partners (e.g., NIH, Alzheimer's Drug Discovery Foundation, and Consortium for FTD Research)

Measurable Outcomes

- New partnerships and opportunities reflecting that AFTD is recognized as a knowledge center
- Progress relative to identified priorities: brain donation, establishment of FTD centers and biomarkers
- Increased funding for FTD research

Strategic Priority 2

Support and enable patients, families and caregivers

Desired Result

AFTD serves as the nexus of an extensive network of support, ensuring accessibility of information, education and counsel for each family confronting frontotemporal dementia.

Strategies for Support

- Grow in numbers served, enabled by increased staff facilitating a growing network of support
- Address the specific information and support needs of identified sub-populations within the FTD community
- Develop key relationships that will extend reach to individuals and families in need

Objectives

- Expand AFTD Helpline service to ensure response within one business day for phone and e-mail inquiries.
- Expand access to local caregiver support groups with a minimum target of one in each state/province and major metropolitan area. Groups operate independently, but receive assistance with networking, resources, materials and education from AFTD.
- Continue provision of three existing telephone support groups for caregivers unable to access in-person support; expand number of groups to meet unique needs or pilot new services.
- Expand Caregiver Respite Financial Assistance to decrease caregiver burden and engage additional families.
- Assess needs and provide support to currently underserved groups, particularly the newly-diagnosed, young adult caregivers, and families with children and teens.
- Develop partnerships to pilot projects for targeted populations; promote and disseminate the most effective products.

Resources

- Immediately add a full-time program coordinator to AFTD staff to expand services
- Later, add a full-time counselor to caregiver support staff to enhance accessibility and breadth of services
- Invest proportionally in infrastructure (IT, etc.) to enable growth of the support network

Measurable Outcomes

- 200 new caregivers and 2400 new contacts per year, building from current 850 caregivers and 6450 contacts
- Increase number and diversity of populations served
- Proportional increase in volunteers engaged in AFTD's mission due to expanded number of people served
- Number of caregiver respite grants

Strategic Priority 3

Educate physicians and healthcare providers to better serve FTD patients and families

Desired result

AFTD partners with key professional educational organizations to develop multiple avenues for professional education, thereby equipping doctors, nurses and long-term caregivers with the knowledge and skills to serve FTD patients and their families.

Strategies for Professional Education

- Connect health care professionals with essential information
- Educate physicians and healthcare providers to better serve FTD patients and families
- Establish AFTD as the central information source for training of health care professionals

Objectives

- Provide access to essential introductory information for priority health professionals (physicians, nurses, long-term care providers) via AFTD website
- Expand relationships with professional educators within priority health fields to fully understand the challenges, best methodologies and potential partnerships for creation and effective delivery of in-depth, accredited continuing education modules.
- Identify opportunities to leverage AFTD resources to have maximum impact and create higher standards of professional knowledge and care.
- Design and pilot a basic curriculum for each audience
- Conduct outreach to the target audiences to motivate and increase utilization of available education materials

Resources

- With the addition of a full-time program coordinator, AFTD's program director will concentrate on furthering these professional training goals
- Partnership with individuals or organizations from multiple health care areas with training capabilities
- Partnership and collaboration with FTD centers of excellence

Measurable Outcomes

- Number of professionals reached, content on healthcare professional section of the website, number of publications/ talks to professionals
- Number of online CME course offerings and number of professionals trained
- Number of health care professionals registered with AFTD, quality and quantity of web hits and content

Strategic Priority 4

Create public awareness of FTD and associated realities

Desired result

The fulfillment of AFTD's mission- care and cure- is accelerated through formalized, branded materials that are effectively disseminated throughout professional and community networks across the United States and Canada, culminating in a national awareness campaign to drive advocacy and fundraising.

Strategies for Public Awareness

- Formalize branding and develop materials.
- Distribute the message and materials throughout the FTD network
- Build national recognition for AFTD and FTD awareness

Objectives

- Create a set of multi-use, professional quality materials for use across all program areas; launch *Faces of FTD* at 2010 Annual and International Conferences
- Expand visual media and web-based efforts to increase awareness of FTD and AFTD; explore partnerships for production of a sponsored film piece
- Pilot the distribution of the materials through the regional network of volunteers
- Based on pilot learning's, identify how to systematically establish and distribute message and materials through multiple channels, both professional- and community-based
- Build relationships and knowledge to support a national awareness campaign

Resources

- Create and fill a staff position for marketing/communications in 2010
- Engage Board Awareness committee expertise, effective graphic designer and printer to support development of professional materials
- Leverage International meeting in Oct 2010 in Indianapolis to gain traction at the national level

Measurable Outcomes

- Quantity and quality of publications available through AFTD website and in hard copy
- Number of volunteers engaged in network, leadership coverage by region, number of Board members attending outreach events (e.g. regional conferences), quantity of marketing materials distributed throughout the community
- Number of media inquiries and articles published
- Generation of AFTD's own, proactive awareness campaign

Strategic Priority 5

Systematically advocate for care and the cure of FTDs over a broad network of stakeholders

Desired result

AFTD has the necessary infrastructure, relationships and processes to advocate effectively for a robust system of support for FTD patients and their families.

Strategies for Advocacy

- Build infrastructure for an effective advocacy program
- Develop key relationships that will support all advocacy efforts
- Embark on AFTD's first major advocacy campaign

Objectives

- Develop, engage and train leadership for FTD advocacy within the Board and extending to a vibrant grassroots network
- Develop an advocacy agenda based on the priority needs of FTD patients and families, and the professionals who support them
- Establish appropriate communication vehicles and technology to mobilize our constituent base

Resources

- The heart of advocacy will be a fully populated and trained regional volunteer network guided by knowledgeable and engaged Board leadership
- AFTD will benefit from the experience of peer organizations with more mature advocacy programs
- When appropriate, AFTD will partner with peer organizations to accomplish common agendas

Measurable Outcomes

- Number of Board members and volunteers engaged in advocacy
- Number of visits to policy leaders by Board members and volunteers
- Process established for prioritizing and evaluating issues, opportunities and partnerships
- Identification of priority issues
- Successful change on identified priority issues

Strategic Priority 6

Fund AFTD's growth by securing and expanding a sustainable donor base

Desired result

AFTD has a broad and sustainable income stream that will enhance our ability to expand support services for patients and caregivers and accelerate the path to the cure.

Strategies for Sustainable Funding

- Connect with, serve and grow support from donors at every giving level, each year.
- Effectively respond to major donor opportunities
- Identify key granting agencies and establish relationships, priorities and goals to maximize potential support

Objectives

- Set and pursue specific fundraising objectives derived from a match between AFTD's strategic priorities and donors' needs and interests
- Routinely follow and refine a year-round solicitation and cultivation schedule
 - Develop and utilize a branded message and professional presentation materials
 - Establish effective fundraising systems, maximizing the use of technology for online solicitation and collection and recording of donor information in a robust database
 - Develop additional mechanisms for donor support, to include planned giving, scheduled giving, bequests, and matching gifts

Resources

- Ensure continued strong leadership from Board members for cultivation and solicitation of major prospects
- Expand staff time for support of grassroots events
- Hire a Communications Director by mid 2010

Measurable Outcomes:

- Increased dollars raised
- Increased number of donations at each level
- Growth in the size of gifts from established donors
- Enhanced mechanisms for giving
- Growth in number of institutional donors, grants written, connections made, and dollars raised from institutions

APPENDIX A

AFTD Strategy Snapshot

Strategic Priorities:

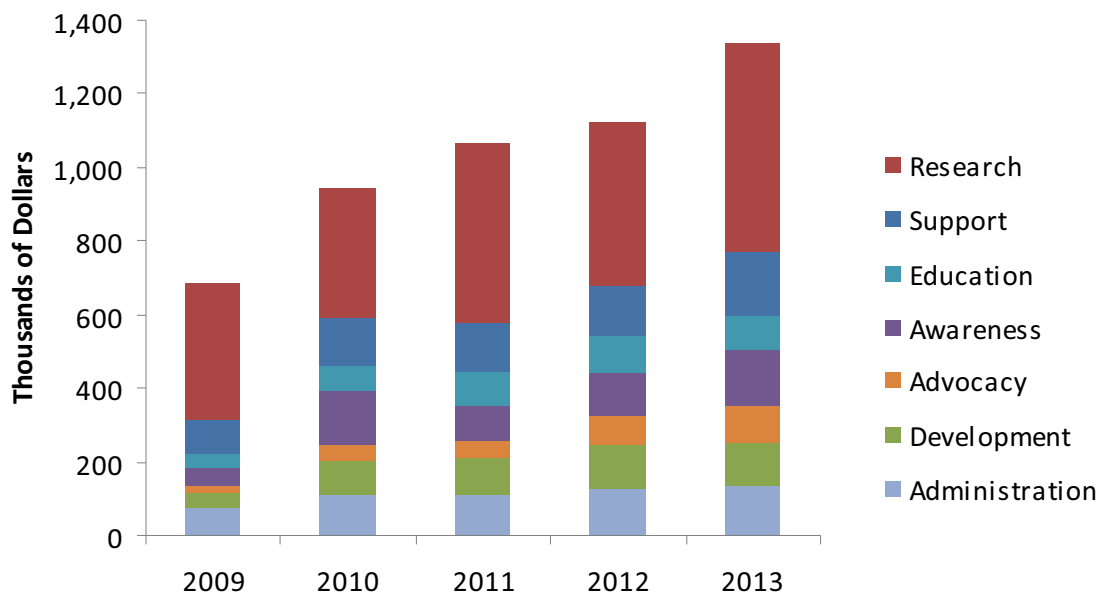
1. Research: Promote and fund research for diagnosis and the cure
2. Support: Support and enable patients, families and caregivers
3. Education: Educate physicians and healthcare providers to better serve FTD patients and families
4. Awareness: Create public awareness of FTD and associated realities
5. Advocacy: Systematically advocate for care and the cure of FTDs over a broad network of stakeholders
6. Funding: Fund AFTD’s growth by securing and expanding a sustainable donor base

Supporting Goals:

Research	Support	Education	Awareness	Advocacy	Funding
<p>Build infrastructure to become THE knowledge center for research relevant to FTD and create an agenda to drive the research forward</p> <p>Motivate and focus the global research community to speed efficient path to the cure</p> <p>Invest our grant dollars to have the greatest strategic impact</p>	<p>Grow in numbers served, enabled by increased staff facilitating a growing network of support</p> <p>Address the specific information and support needs of the identified sub-populations within the FTD community</p> <p>Develop key relationships that will extend reach to individuals and families in need</p>	<p>Connect health care professionals with essential information</p> <p>Educate physicians and healthcare providers to better serve FTD patients and families</p> <p>Establish AFTD as the central information source for training of healthcare professionals</p>	<p>Formalize branding and develop materials</p> <p>Distribute the message and materials throughout the FTD network</p> <p>Build national recognition for AFTD and FTD awareness</p>	<p>Build infrastructure for an effective advocacy program</p> <p>Develop key relationships that will support all advocacy efforts</p> <p>Embark on AFTD’s first major advocacy campaign</p>	<p>Connect with, serve and grow support from donors at every giving level, each year</p> <p>Effectively respond to major donor opportunities</p> <p>Identify key granting agencies and establish relationships, priorities and goals to maximize potential support</p>
Leadership Transition and Governance					

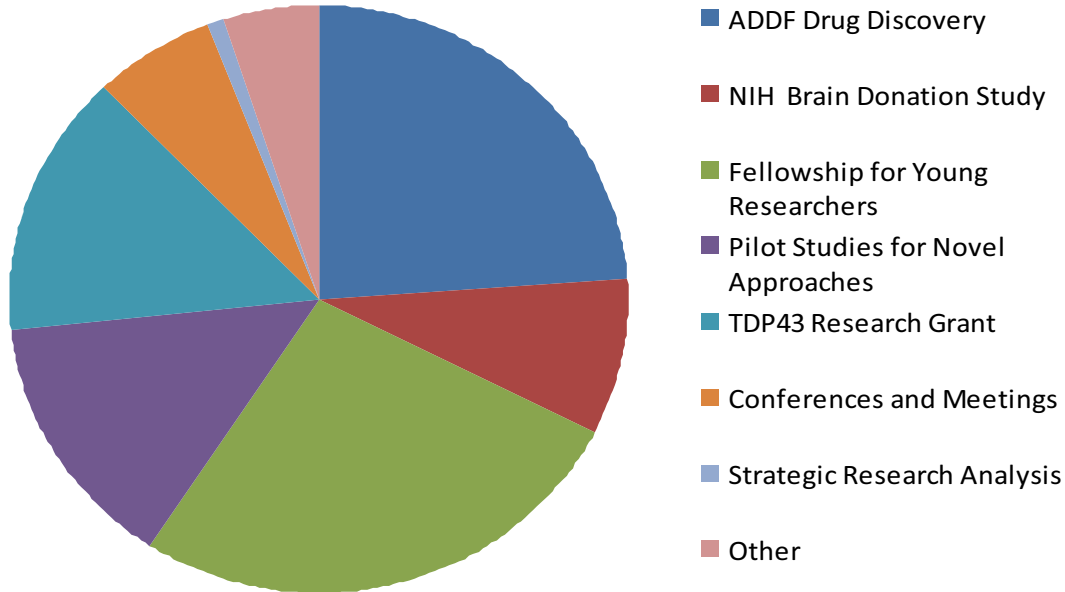
APPENDIX B

AFTD Financial Plan 2010 – 2013



This chart provides an overview of projected expenditures, broken down by strategic priority. The plan calls for an increase in total annual spending from \$690,000 in 2009 to \$1,360,000 in 2013. Research comprises up to 50% of the total budget throughout the plan, and is detailed on the next page. This graph distributes the 2-year research fellowships evenly across the years in which they are paid out.

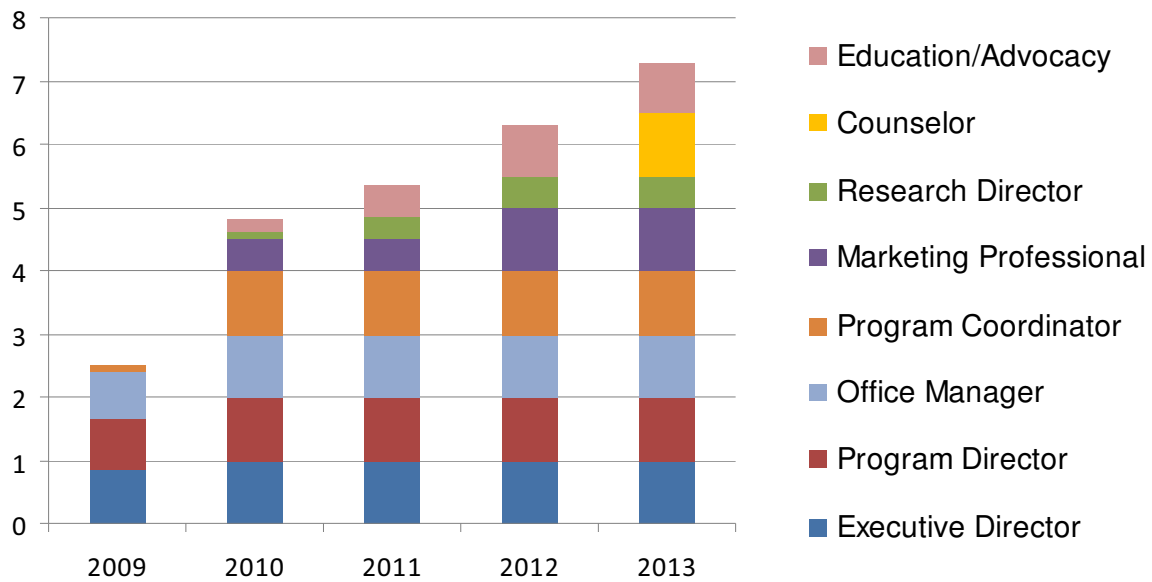
2009 Research Expenses



The 2009 research spend detailed in this chart includes a balance of activities necessary to advance the cure: drug discovery, brain donation, fellowships to encourage scientists to enter the FTD field of study, and targeted research projects to address key issues (e.g., TDP-43). The Strategic Research Analysis – in combination with technical conferences and meetings – guides and enables all involved with FTD research to collaborate and maximize the impact of precious research dollars.

APPENDIX C

AFTD Staffing Plan



This plan calls for an increase in total paid staff from two-and-a-half to seven full-time equivalents over a four-year period. This chart demonstrates the staffing plan broken down by function.

APPENDIX D

Timeline of AFTD's development

November 2002 – Founding of AFTD. Convinced of the need for an organization dedicated specifically to improving the lives of families coping with FTD and advancing research into treatment and a cure, and encouraged by caregivers and researchers alike, Helen-Ann Comstock founded AFTD. She organized a Board of Directors comprised of current and former caregivers and one neurologist to guide the new organization. Founding Board members were: Constance Drayton, Tess Parrish, Lisa Radin, Joyce Shenian, Kent Jamison, Helen-Ann Comstock, Robert Potamkin, Joseph Becker, Robert Kemp, and Lawrence Shor.

January 2003 – First meeting of the AFTD Board of Directors in Philadelphia, Penn., with Jordan Grafman, Ph. D., NINDS, as medical advisor. The Medical Advisory Council, comprised of leading researchers, clinicians and health care professionals working in FTD, was established as a critical partner in the organization's mission.

April 2003 – Helen-Ann Comstock was invited to speak at the 4th International Conference on FTD in Lund, Sweden, about the founding of AFTD and its mission. This announced the organization to international researchers and clinicians.

June 2003 – Board member Kent Jamison designed and launched AFTD's website to increase **education and outreach to caregivers**. The organization's first newsletter, edited by board member Tess Parrish, followed in early 2004.

July 2003 – **Advocacy** by Helen-Ann Comstock and her son Earl resulted in a mandate for FTD research to be included in the Senate Report to accompany the Labor HHS Appropriations bill.

July 2004 – FTD Symposium for researchers and caregivers was held immediately prior to the 9th International Conference on Alzheimer's disease in Philadelphia, Penn. It was arranged by Drs. Murray Grossman, Virginia M.-Y. Lee, Bruce Miller, John Trojanowski, and John van Swieten, with caregiver activities coordinated and supported by AFTD. AFTD awarded the first travel grants to six caregivers from the United States and Canada. AFTD also hosted a caregiver dinner and a reception for board members, conference speakers, and AFTD Medical Advisory Council members.

February 2005 – The AFTD office was established in Philadelphia with Martha B. Meyers hired as its first employee. One year later, Catherine Pace-Savitsky was hired as AFTD's first Executive Director. Both worked on a part-time basis.

July 2005 – AFTD's first **research grant** was awarded in the amount of \$35,000 to Eileen Bigio, M.D., Northwestern University, Feinberg School of Medicine, Chicago, Illinois.

September 2005 – The toll-free HelpLine started to provide **information and support** to caregivers. Board members responded to HelpLine messages. In November 2005, AFTD started a telephone support group and connected a network of FTD caregiver support groups across the United States and Canada.

September 2006 – AFTD was a major sponsor of the 5th International Conference on FTD in San Francisco, California.

January 2007 – Together with National Institute of Neurological Disorders and Stroke (NINDS) and National Institute on Aging (NIA), AFTD sponsored a workshop in Miami, Florida for leaders in the field to assess the state of FTD research and treatment.

May 2007 – In the wake of researchers' identification of TDP-43 as the common protein linking FTD and Amyotrophic Lateral Sclerosis (ALS), AFTD and the ALS Association co-sponsored a conference for caregivers in Philadelphia.

July 2007 – AFTD formed a partnership with the Alzheimer's Drug Discovery Foundation (ADDF) to **fund the first grants for FTD Drug Discovery**. AFTD embarked on a three-year campaign to raise \$300,000, which is matched by \$600,000 from ADDF and is awarded over a three-year period to researchers working toward discovery of the first treatments for FTD.

February 2008 – Susan Dickinson was hired as AFTD's second Executive Director

June 2008 – The first Annual AFTD Public Meeting was held in Baltimore, Md., and attended by nearly 100 caregivers, family members and friends. AFTD also published its first annual report.

September 2008 – AFTD was a sponsor of the 6th International Conference on FTD in Rotterdam, The Netherlands. AFTD also co-organized a meeting with international caregiver organizations. AFTD hired Sharon Denny as its first Program Director.

October 2008 – FTD was included as one of just 50 rare diseases in the Social Security Administration's new Compassionate Allowances program, under which patients with a diagnosis of FTD receive expedited review of their applications for Medicare.

January 2009 – AFTD awarded the first FTD Postdoctoral Fellowship. This two-year fellowship was funded by a generous gift from the Laden family.

March 2009 – AFTD created a pilot Caregiver Respite program to provide financial assistance grants for caregivers. The initial start-up donation of \$10,000 was used within the first month.

July 2009—AFTD's website is expanded as a platform for wider use of Internet technology for outreach and education.

August 2009 – AFTD moved to its own offices and expanded to a full-time staff of three: Executive Director Susan Dickinson, Program Director Sharon Denny, and Office Manager Michelle Leahy.

November 2009 – AFTD's Board of Directors voted to adopt the organization's first strategic plan.