

# 2013

# ANNUAL REPORT

JULY 2012 – JUNE 2013



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

# MISSION



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

Dear Friends--It is with great pleasure and honor that I take the reins of this organization as its board chair, especially as we look back over a decade of important accomplishments and look forward to a new decade of hopeful progress.

—Jary Larsen, Ph.D. | Board Chair, Association for Frontotemporal Degeneration

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

In 2002, a former FTD caregiver with connections to scientists, physicians and other caregivers stepped forward with \$1,000 to start an organization that would come to be known as the Association for Frontotemporal Degeneration. The volunteer board of directors operated the nonprofit with the help of a Medical Advisory Council; they launched a website, created newsletters and set up a HelpLine for caregiver support.

Fast forward 10 years. AFTD has nine full-time employees, serves as the premier resource for caregivers and those affected with FTD, and works diligently with researchers around the world to fund and find a cure. AFTD educates care facility staff on how to care for an FTD patient when he or she enters the door, funds promising research in the lab and the clinic, and offers an education conference in a different region of the United States each year. AFTD continues to answer an ever-increasing number of HelpLine calls, provides caregiver grants to those in need of respite, and connects caregivers with others in their area as a local support system.

With a focus on dedication and determination, we have come a long way in a decade. Now, we look to the promising 10 years ahead with a committed team of staff, an expanding volunteer network that brings growing capacity to accomplish the work of

our mission and a real national advocacy initiative in the National Alzheimer's Plan Act, which includes FTD among the dementias to be cured by 2025.

Through amazing grassroots fundraising efforts of our community, the courage of caregivers to tell their stories to local and national press, and a strong, clear mission guiding the organization, AFTD continues to gain momentum as we strive toward care and a cure. I am proud and energized to lead this organization into a new phase of growth...and we hope you will be an important part of that.

With warm regards,

A handwritten signature in black ink that reads 'Jary Larsen' in a cursive, flowing script.

Jary Larsen, Ph.D.  
Board Chair



# RESEARCH

The Alzheimer's Drug Discovery Foundation is proud to partner with AFTD to foster FTD drug development. Over the course of our six-year partnership, we have seen FTD research emerge as a rich and productive area of inquiry, which is providing exciting insights into our understanding of all neurodegenerative diseases.

—Howard Fillit, M.D. | Executive Director, Chief Science Officer, Alzheimer's Drug Discovery Foundation



**Promote and fund research into finding the cause, therapies and cures for frontotemporal degeneration.**

**As we enter our second decade, AFTD is committed to ensuring that today's dramatic advances in the laboratory are translated efficiently and effectively into treatments and care for tomorrow. With growing capacity to affect this progress, we continue to fund promising research and form strategic partnerships that will result in meaningful advances and increased quality of life.**

AFTD continued to support FTD research with another year of funding awarded to impressive researchers with innovative projects. The fellowship award, which is granted to a promising post-doctoral candidate, received 28 applications from 21 institutions around the world. With an ever-increasingly impressive pool of candidates, AFTD awarded the fellowship to M. Catarina Silva, Ph.D., who works in the laboratory of Dr. Stephen Haggarty at Massachusetts General Hospital. Dr. Silva's research entails creating induced pluripotent stem cells from the skin cells of an affected person in order to better understand the biological process that leads to disease and kills the nerve cell.

In the realm of drug development, AFTD entered our sixth year of a joint program with the Alzheimer's Drug Discovery Foundation. Twenty-two grants totaling more than \$2.3 million have been awarded since the beginning of the partnership. This year, three

scientists investigating different disease mechanisms at work in FTD received a total of \$430,000 to fund their promising work.

AFTD sponsored several major conferences and symposia, including the 8th International Conference on FTD held in Manchester, UK in September 2012. AFTD hosted a welcome reception and full-day program for caregivers as well as a meeting of peer organizations from 11 different countries in the interest of fostering growth and encouraging collaboration across international lines. In October, AFTD co-sponsored a symposium with the ALS Association, enabling scientists to share their latest findings on the *C9orf72* mutation, which is emerging as the most common genetic change that can lead to FTD and/or ALS.

In May, AFTD was proud to co-sponsor a meeting at the National Institutes of Health to ensure inclusion of FTD as a priority in the National Alzheimer's Project Act. Attendees began crafting a plan that will guide national research efforts on non-Alzheimer's dementias (FTD, Lewy body dementia and vascular dementia) over the next 12 years. Five AFTD board members, four staff and more than two dozen FTD experts were among those who contributed to the recommendations and were present to comment upon priorities for research.



Dr. Howard Fillit is a key partner to AFTD in the FTD Drug Discovery grant program, run jointly by AFTD and ADDF.



# SUPPORT

As both a professional social worker and a family member of a person diagnosed with FTD, I am so impressed with your organization and how you reach out to and support your members.

–Anonymous



**Provide information, education and support to persons diagnosed with an FTD disorder, and for their families and caregivers.**

**Providing support to those affected with FTD and their families fulfills a vital part of our mission. Whether it's answering a HelpLine call or directing people to a support group, AFTD strives to help those seeking answers to their questions about FTD in compassionate and accurate ways.**

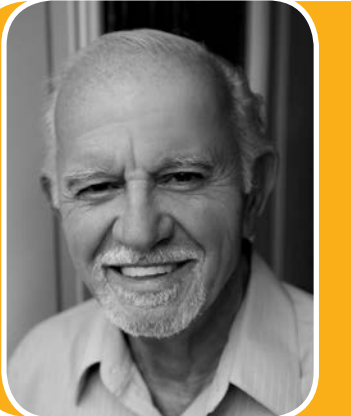
In the past year, AFTD has continued to raise the bar in providing support to our community. A dramatic expansion in funding for the Comstock Caregiver Respite program enabled award of respite grants to 90 caregivers. AFTD also awarded travel grants that enabled 16 people to attend caregiver conferences across the country. Staff responded to a record-number 1,637 phone calls and emails that came in to the HelpLine.

AFTD introduced two new publications, both of which meet critical needs for information within our community. *The Doctor Thinks Its FTD. Now What? A Guide for Managing a New Diagnosis* provides practical and concrete information for families at a very difficult and confusing juncture in their lives. More than 2,000 copies of the booklet on a new diagnosis were distributed within the first three months. In addition, AFTD partnered with the University of Pennsylvania on a booklet called *Understanding the Genetics of FTD. A Guide for Patients and Their Families*, which was published in September 2012. This resource explains

the role that genetics plays in some families with FTD and provides guidance for individuals who may want to consider genetic testing.

AFTD's annual education conference, held in Salt Lake City in April, attracted more than 200 caregivers, professionals and patients for the first time. Highlights of the program included an update on FTD research from Dr. Norman Foster of the University of Utah, two panel discussions that provided valuable perspective from caregivers and clinicians, and a performance of original music from students enrolled in a multidisciplinary course on dementia at the University of Utah.

AFTD continues to explore how the organization can help meet the needs of those who themselves are diagnosed with one of the FTD disorders. In Salt Lake City, 11 people attended a full breakout session for those diagnosed. Later in April, a small telephone support group began meeting monthly as a pilot program to find out more about the needs and desired support for this part of our community. In an effort to educate and empower families to understand emerging opportunities for engagement in research, AFTD held a training webinar in May on the topic of FTD clinical trials. This was the first of several planned webinars aimed at providing valuable information to families facing FTD.



Jim Rodgers, whose wife Elsie passed away from FTD, runs a support group in Pittsburgh, PA for caregivers.

# EDUCATION

It's been a pleasure to be involved with AFTD's initiatives to educate and support those in the healthcare field about FTD. I'm proud of the work that our committee does and see the impact of **Partners in FTD Care** within our memory care programs. This effort is clearly making a difference!

—Susan Hirsch, M.A. | Education and Development Specialist, HCR Manorcare



## Educate health professionals about frontotemporal degeneration and how to improve patient care.

**AFTD seeks to educate health professionals, academic centers and care facilities to improve the accuracy of FTD diagnosis, to expand knowledge of the disease and to provide compassionate care to those affected and their families.**

**Partners in FTD Care**, AFTD's initiative to educate community providers about FTD and how to better care for those affected, continues to grow. During the past year the program's quarterly newsletter was expanded, to include a case study, information on interventions and a practical tip sheet called "What to Do About..." that focuses on a new topic for each issue.

AFTD collaborated with professionals across a variety of healthcare disciplines to increase education about FTD. The National Adult Day Services Association broadcast a web training featuring AFTD to its members in January. AFTD Program Director Sharon Denny and several members of AFTD's Long-term Care Education Committee authored the article "Managing Differences: Care of the Person with Frontotemporal Degeneration" published in the *Journal of Gerontological Nursing*. AFTD also joined Drs. Edward Huey and Chiadi Onyike to present a short course on neurodegenerative diseases to an audience of approximately 50 psychiatrists at the American Psychiatric Association's annual meeting in May.

In conjunction with Northwestern University's Cognitive Neurology and Alzheimer's Disease Center and the National Aphasia Association, AFTD hosted a three-part webinar series on primary progressive aphasia for speech-language pathologists.

The organization initiated a pilot community outreach project involving 12 volunteers within the AFTD community who conducted visits to 41 care facilities with two main goals: 1) increase awareness of FTD and 2) increase recognition of AFTD as a resource for families and professionals. The project led to increased FTD awareness, information sharing, presentation requests and professionals joining **Partners in FTD Care**.

With consultation from the Medical Advisory Council, AFTD also expanded the Healthcare Professionals section of our website to include information on clinical features, diagnosis and pharmacological treatment in FTD with links to clinical criteria, and key research publications.



Lisa Gwyther, LCSW, Director, Duke Family Support Program, serves as an active member of AFTD's Long-term Care Education Committee.

# AWAWARENESS

Kudos to AFTD for landing such a nice piece on the national news. I never thought I would live to see the day. We have come so, so far. This is truly a great step forward in awareness.

—Kent Jamison | former AFTD Board Member, regarding the June 13th FTD segment on *NBC's Nightly News with Brian Williams*



**Bring about greater public awareness of the nature and prevalence of frontotemporal degeneration and the needs of those who are coping with it.**

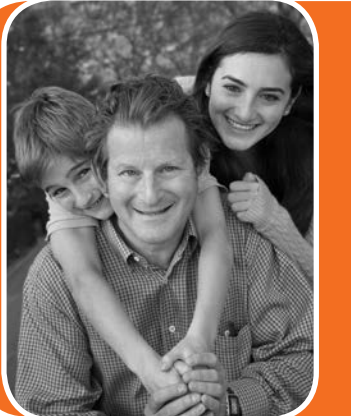
**Raising awareness is the foundation upon which all of AFTD's goals are built. When we raise our voices together as a unified community, we garner support for education, for research, for improved services. We speak out about this little-known disease for those who can no longer do so themselves.**

In the past year, AFTD took some vital steps in creating more awareness of frontotemporal degeneration. The organization celebrated its 10th anniversary with a formal event called "Care & Cure" at the Pyramid Club in downtown Philadelphia in October 2012. With almost 200 people in attendance from as far away as California and Canada, the event featured friends, food, a silent auction and a special video presentation of milestones and accomplishments of the first 10 years of AFTD's existence.

Possibly the most far-reaching piece of awareness that AFTD helped into fruition, a segment on FTD aired on *NBC's Nightly News with Brian Williams* on June 13. The piece, reported by former Chief Science and Health Correspondent Robert Bazell, featured AFTD Board Member John Whitmarsh and his affected wife Barbara, as well as AFTD Medical Advisory Council Member, Dr. Bruce Miller. The segment brought the term "FTD" into the homes of millions who had never heard of the disease.

This year, AFTD hired Kerri Barthel to the new position of volunteer manager. Under Kerri's leadership AFTD now has developed and implemented a formal structure, training and materials to engage and support volunteer efforts. By properly equipping and supporting volunteers, AFTD exponentially increases our awareness-raising efforts.

AFTD entered Year Two of both the Valentine's Day-centered "With Love" campaign as well as the "Walking the Walk" event in King of Prussia, PA. In February, with the backing from three matching donors, individuals shared their stories about FTD online and raised more than \$55,700 in 1.5 months' time. In May, more than 60 AFTD staff, friends of the organization and local supporters came to join or cheer on the AFTD-Team in the the King of Prussia 10-Miler/5K. Participants raised more than \$6,300, and AFTD received two awards from the event organizers for best team times in the 5K and the 10-miler. In the past year, 57 supporters across the United States have stepped forward to raise awareness of FTD while raising money to advance AFTD's mission by hosting fundraising events.



Brother and sister Jason and Olivia Goldring with their father, David. Olivia and Jason organized a walk at their school in memory of their mother, Rachel. The school raised \$9,000 in support of AFTD's mission.



# ADVOCACY

It's an exciting time to be advocating with AFTD on Capitol Hill. As a volunteer who has helped craft a Congressional resolution that would establish an official FTD Awareness Week in the United States, I'm proud of the steps the organization is taking to give a voice to those directly affected with FTD as well as their families.

—Shoshana Derrow | part-time FTD caregiver and former Health Legislative Assistant for Congressman Marion Berry (D-AR) and Counsel and Legislative Assistant for Senator Joseph Lieberman (I-CT)



**Advocate with public officials and promote public/private programs that provide appropriate, affordable and high-quality, long-term health care and social services. Facilitate the international exchange of ideas.**

**Accomplishing AFTD's mission requires advocacy – speaking out about patients' and families' needs, hopes and successes. As we create a growing network of supporters, the collective influence that we have on our policy makers and legislators will make a difference in the lives of those affected.**

In July 2012, AFTD Program Coordinator, Matt Sharp, addressed the advisory council for the National Plan to Address Alzheimer's Disease in Washington, DC to introduce the council to AFTD and offer our expertise and assistance with The National Alzheimer's Project Act (NAPA). NAPA is a major federal initiative to help prepare the nation for increased prevalence of Alzheimer's and related diseases such as FTD that will result from an aging population. The project involves 24 federal agencies working with public and private partners to achieve the goal of curing Alzheimer's disease and related dementias by 2025. Matt, along with other AFTD board members and community supporters, has attended and presented public comments at each quarterly meeting of NAPA since July 2012.

Last fall, AFTD Program Director Sharon Denny provided input to NAPA's Specific Populations Task Force on the needs and challenges of people with young-onset dementia. The task force released a report this past March summarizing the information they received from AFTD and other professional organizations

and translated their findings into action items for the second draft of the National Plan, released this past June.

AFTD has also been actively involved in several peer meetings with organizations such as National Organization for Rare Diseases, American Brain Coalition, the Social Security Administration and Rare Disease Legislative Advocates to add our voice to the issues that impact the FTD community. In February, AFTD joined with NORD and other rare disease organizations to commemorate the 30th anniversary of the Orphan Drug Act, which provides special accommodations for drugs in development for rare conditions for which there is no approved treatment. AFTD sponsored a message in March as part of an insert in the Washington Post titled "Because Not All Dementia is Alzheimer's," in which caregiver-advocate Katie Brandt shared the story of her husband, Michael, who lost his battle with FTD at the age of 33. In June, Katie spoke out again at a presentation of Michael's case to more than 80 neurologists at Massachusetts General Hospital. This marked the first time Mass General had ever included comments from a caregiver, and Katie's speech was met with a standing ovation.

Additionally, in an effort to draw national awareness to FTD, the organization has worked with a few key volunteers to craft a proclamation that will be submitted to Congress in the hopes of obtaining an official FTD Awareness Week.



Pop Shenian of Philadelphia is chair of AFTD's advocacy committee, which strives to bring the needs of those affected with FTD to legislators in Washington, DC.

# GRATITUDE

AFTD has the perfect balance of providing up-to-date information, funding research and supporting families. They help those with FTD and their loved ones to navigate the healthcare and information maze with the goal of enhancing quality of life and, one day, finding a cure!

—Kathi Arnow | former caregiver



**We are deeply grateful to all of the generous donors who partner with us each year to change the future for FTD families and the professionals who care for them.**

## \$100,000+

Anonymous

## \$50,000+

Anonymous

## \$20,000+

E. Muriel Allen

Peter and Kathi Arnow

Susan Laden

Philip H. Lovett

Lawrence and Jillian Neubauer

The Rainwater Charitable Foundation

## \$10,000+

Timothy Broer

Colonial Electric Supply

The Connecticut Frontotemporal Dementia Foundation, Inc.

Marcia Halligan

Lou Ruvo Center for Brain Health, Las Vegas

The McKeown Foundation

Mr. and Mrs. Edward Quinn

Dr. and Mrs. Sashi Reddi

Bonnie Shepherd

TauRx Therapeutics, Ltd.

Alice and Jim Taylor

Beth Walter

## \$5,000+

Gail Andersen

Michael Basla

Joseph A. Becker

Clare Hall

Helen Heibert

Lola Goldring

Mr. and Mrs. Dale W. Lutz

Mr. and Mrs. Douglas Morgan

Patricia Moser

Kevin O'Neill

Kevin A. Quinn

Mr. and Mrs. Edward J. Quinn, Jr.

Arthur Sommers

Southcoast Capital Corporation

## \$2,500+

Anonymous

Joseph Bellwoar

Bristol Myers Squibb Company

Susan Eissler

Giving Bean

Raymond Koenig

Legrand North America

Paul Lester

Joyce Shenian

The Community Foundation for the National Capital Region

Anthony A. Yoseloff

## \$1,000+

AmideBio ,LLC

Melissa and Paul Anderson

Anonymous

Dal and Carolyn Bagley

Kara Baldino

Mr. and Mrs. Stephen P. Bellwoar

Ted Beneski

Michelle Berliner

Bill's Best BBQ Sauce

Genevieve Black

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BP Foundation

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Armin Krueger

Francine Laden, ScD

Augusta Leininger



AFTD is in many ways an available life line, a port in a storm to me and my husband, who was diagnosed seven years ago. They support, guide and truly understand the challenges... AFTD is a resource for hope, direction and information. And we are most grateful!

-Sandy Karger | Caregiver



**\$1,000+** (cont'd)

- Mr. and Mrs. Eliot Levy
- Lighting Solutions
- Jaime Marcucci
- Adele Marcucci
- Mr. and Mrs. Kenneth Mayne
- Kathryn McAndrew
- Mary Lou McCammack
- Judith McLachlin
- The McLain Family Foundation
- Lauren McMahan
- Michael Mihalich
- Koren Miller and Manish Bhatt
- Musselman Volleyball Boosters Club
- Linda E. Nee, MSW
- Daniel Neuwirth
- Faye Olivieri & Ron Kozich
- Pfizer Foundation
- Picoma Industries
- Retail Properties of America
- Allison Riddiford
- Darlene Ryan
- Joanne Sackheim
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- Beth Schatman
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- Popkin Shenian
- Richard Silva
- Silverado Senior Living - SLC
- Flo Smerconish
- Jane Steffen
- Mr. and Mrs. Scott Strong
- Philip J. Swanson
- Synergy Electrical Sales, Inc.
- Shelly Taylor
- Christine Taylor-Stiller
- Tozour Energy Systems
- The Turner Foundation Fund
- Mr. and Mrs. Robert Vanderhye
- Mr. and Mrs. John Weicher
- Steven Weiss
- Wells Fargo
- Wheatland Tube Company
- John Whitmarsh
- Don Wood
- Jim Yahner
- YPO Forum I - Past & Present

**The following are grassroots events and fundraisers that each raised \$1,000 or more during FY 2013.**

**Overall, 57 events across the United States raised more than \$145,000. AFTD gratefully recognizes those who take the initiative to support AFTD's mission!**

**1st Annual Bob Hartman Food for Thought Benefit for Dementia Research**

**H'ArtSong**  
Anna Hill

**Riverdale Country School 2012 Walk-a-Thon for Rachel**  
Olivia and Jason Goldring

**Walking the Walk 2013**  
• Susan Dickinson  
• Hager & Mellor family  
• Caroline Waldeck

**1st Annual Golf Benefit Honoring Cheryl Whitcomb**

**Her Star**  
Justin Peavey

**Robert M. Hatfield Foundation, Inc. Golf Outing**

**With Love 2013**

**A Stolen Life**  
Mike Kipp

**Research Hike for FTD Corticobasal Syndrome**  
Jim Tabor

**Royce Bosselman Memorial Golf and Tennis Outing**

- Anita Bigger
- Lisa Bloom, Daniella Pessah & Jessica Pessah
- Debbie Fenoglio
- Melissa Goldstein
- Zoy & Kiley Kocian
- Lee and Susan Danis Giving Trust
- Amy O'Neil
- Tenney Smith
- Team Alice
- The Walter Charitable Foundation
- The Rainwater Charitable Foundation

**Cocktails for a Cause**  
Leifer family

**Paul Lester Letter Writing for Drug Discovery**

**Scout for Scooter**  
Scaggs & Sealfon families

**Emy Jo Bartus' Birthday Celebration**

**Raising Money for FTD Research in Honor of Jim Taylor**  
Ginny Scott

**Strong Body, Strong Mind**  
Deanna Angello

**George F. Sidoris Memorial Golf Outing**

**RI Marathon 2012**  
Russell Zomback

**Volley to End Dementia Night**  
Shawn Martz

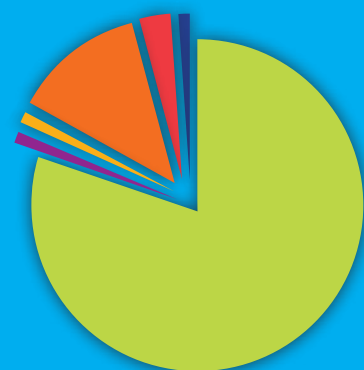
# OUTLOOK

As we close the doors on our first decade, we look forward to continuing the tremendous progress we've made in terms of advocacy, awareness, education, research and support. And that progress would not have been possible without the passion and commitment of a community who wants to help find care and a cure as much as we do.

—Susan L-J Dickinson | Executive Director

## Statements of Financial Position as of 6.30.2013

12-Month Income By Source  
\$1,245,938



- 76% Individuals
- 15% Fundraisers
- 6% Special Events
- 2% Grants & Sponsorships
- 1% Matching Gifts
- 1% Other

12-Month Expenses  
\$1,176,686



- 31% Research
- 21% Support
- 17% Awareness & Advocacy
- 13% Fundraising
- 11% Education
- 6% Management

### ASSETS

|                         |                    |
|-------------------------|--------------------|
| Cash & Prepaid Expenses | \$1,221,882        |
| Equipment               | \$12,333           |
| Security Deposit        | \$4,155            |
| <b>Total Assets</b>     | <b>\$1,238,370</b> |

### LIABILITIES

|                                  |                 |
|----------------------------------|-----------------|
| Accounts Payable                 | \$5,745         |
| Research Grants Payable          | \$55,000        |
| <b>Total Current Liabilities</b> | <b>\$60,745</b> |

### NET ASSETS

|                         |                    |
|-------------------------|--------------------|
| Unrestricted            | \$985,684          |
| Temporarily Restricted  | \$191,941          |
| <b>Total Net Assets</b> | <b>\$1,177,625</b> |

**TOTAL LIABILITIES & NET ASSETS \$1,238,370**

The upcoming year holds much promise for AFTD and our community. With the addition of a Volunteer Manager position, AFTD's influence now extends well beyond our nine employees in Philadelphia. Having eager supporters on the ground all across the United States multiplies our reach exponentially, as evidenced in our first-ever national FTD awareness campaign, Food for Thought.

During the first week of October 2013, members of the AFTD community across the United States and Canada will host events to draw attention to FTD using two common denominators—food and FTD education. From dinner in one's home to an office coffee break to working with a local restaurant to donate a portion of a night's proceeds, Food for Thought hosts will invite others to learn a bit about FTD while sharing some sort of edible delight. We will work hard to garner both local and national press coverage through this concentrated campaign to raise awareness of FTD.

In July, AFTD also hired Nadine Tatton, Ph.D. as our full-time scientific director. Under Nadine's leadership, AFTD will be able to devote more resources to stimulating research initiatives, including the Frontotemporal Degeneration Treatment Study Group.

The National Alzheimer's Plan Act (NAPA) provides the biggest opportunity for AFTD to make real progress in the realm of advocating for those affected by FTD. The plan seeks to cure Alzheimer's and related dementias—which includes FTD—by the year

2025. AFTD staff, board and volunteers have taken part in each quarterly meeting since the inception of the plan, giving public testimony and speaking on behalf of those with FTD. We will continue to take part in each upcoming NAPA meeting to ensure that the FTD community is represented and heard.

We invite you to take an active part in the AFTD community. Be a volunteer. Tell your story. Join a support group. Attend an education conference. Share words of encouragement with other caregivers. Host an event. Raise your voice in support of the many who have lost theirs to FTD... It will take all of us working together, but we **will** realize our vision of **a world where FTD is understood, effectively diagnosed, treated, cured and ultimately prevented.**

Best Wishes,

Susan L-J Dickinson, M.S.  
Executive Director



# VISION

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

## BOARD OF DIRECTORS

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**Michelle Leahy**  
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Communications Manager

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

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