

impact

2014 Annual Report
July 2013-June 2014



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

rare disease, powerful resources

The Association for Frontotemporal Degeneration (AFTD) is the leading nonprofit organization devoted to Frontotemporal Degeneration (FTD).

FTD brings with it progressive behavioral and personality changes, loss of language and/or motor skills, and eventual inability to function. AFTD's mission is to:

- **Promote** and fund research into finding the cause, therapies and cures for FTD.
- **Provide** information, education and support to those diagnosed with an FTD disorder, their families and caregivers.
- **Increase** public awareness of the nature and prevalence of FTD and the needs of those coping with it.
- **Educate** health professionals about FTD and how to improve patient care.
- **Advocate** with public officials and 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.



Kids and Teens Website

Working with people diagnosed with FTD, their families, caregivers, clinicians and researchers gives AFTD a unique vantage point for helping our community meet profound challenges. In 2014, we introduced powerful new resources, including a website for kids and teens with families affected by FTD. It offers a reassuring place where young people can ask questions, find answers and compare experiences with peers. They can also share their poems, short stories, video diaries and other creative works. See www.AFTDkidsandteens.org.

impact

Dear Friends,

As I note AFTD's accomplishments this past year, one word comes to mind: *impact*.

More than a decade of groundwork laid by dedicated volunteers and staff is producing real change.

For the first time, FTD became recognized as a national priority within the National Alzheimer's Plan to cure dementia by 2025. We are leveraging this exciting milestone in our quest for expanded services for our families and increased funding for research.

We published the *FTD Research and Drug Development Landscape*, the first comprehensive overview of FTD research, compiled and written by AFTD's Scientific Director, Nadine Tatton, PhD. This will guide our priorities and resource allocation, as well as help attract vital industry investment in FTD drug discovery.

Children and teens who have a parent with FTD face especially heart-wrenching challenges. In response, AFTD launched AFTDkidsandteens.org, where kids can learn about FTD in their own language and practice coping skills. Most importantly, it's a place where they can share stories—in words, art, or video—and know that they are not alone.

Other important milestones have come from generous donors. These include AFTD's first million-dollar gift, as well as the creation of our first named fund, the Susan Marcus Memorial Fund for clinical research. Such donations enable us to have a bigger impact, sooner.

FTD Awareness Week helped educate people nationwide about this rare disease.

Finally, we organized the first FTD Awareness Week. Members of our community in 25 states and five Canadian provinces celebrated by hosting 56 local Food for Thought events. Each bore the individual style of the host, and each helped to educate about this rare disease.



Of course, we owe these accomplishments to so many people within this generous community who have contributed their time, talent, and treasure. Whether you are a donor helping another receive respite, a caregiver sharing your story to ensure a legislator puts a face to FTD, or a volunteer spreading awareness so that the next family will encounter a more understanding world, know that you are making an impact on the future.

With warm regards,

A handwritten signature in blue ink that reads "Jary Larsen".

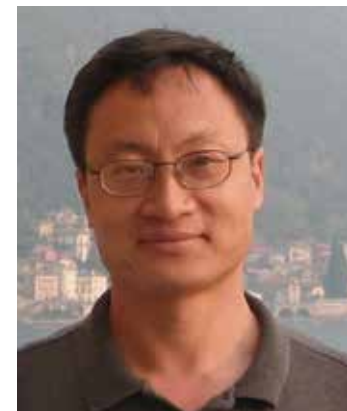
Jary Larsen, PhD
Board Chair

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researching FTD mechanisms in nerve cells



**Fen-Biao Gao, PhD, and
the “disease in a dish”**

Dr. Fen-Biao Gao, Professor of Neurology at the University of Massachusetts School of Medicine, co-leads the new FTD Induced Pluripotent Stem (IPS) Cell Consortium. The Consortium takes stem cells from skin biopsies of FTD patients and induces them to become nerve cells with the same gene mutation and pathology seen in the brain—effectively “a disease in a dish.”

Cell lines studied to aid in drug development include *GRN*, *MAPT* and *C9ORF72* gene mutations, the three leading causes of autosomal dominant FTD.

“There is so much excitement in FTD research, now especially with the *C9ORF72* gene mutation that is shared with ALS,” says Dr. Gao. “We have made great strides in the last few years.”

research

In 2014, FTD joined Parkinson's disease, ALS, and Huntington's disease as the fourth disease represented in the NIH Consortium to create IPS cells and ensure that these exciting new tools are available to all researchers. AFTD is a member of the public-private partnership that leads this initiative.

Grants. AFTD's tradition of awarding grants to projects and applicants deemed the best by a rigorous peer review process continued, with the 2014 Pilot Grant going to Emily Rogalski, PhD, at Northwestern University to develop and test a model for internet-based speech therapy to improve quality of life and access to care for PPA patients. Current AFTD Postdoctoral Fellow Catarina Silva, PhD, continued her work at Harvard to develop stem cells as a model for FTD disease. Finally, in the 7th year of AFTD's partnership with the Alzheimer's Drug Discovery Foundation, FTD Drug Discovery grants were awarded to two researchers. Jeff Rothstein, MD, PhD, at Johns Hopkins Medical Center is developing a novel therapeutic approach for the *C9ORF72* mutation that can cause FTD and ALS, as well as biomarkers to track the impact of this

approach. Donald Lo, PhD, at Duke University is using a novel brain slice model to identify molecules that can halt spread of tau protein pathology.

Meetings. In November AFTD was proud to partner with the ALS Association to co-host a scientific workshop on the *C9ORF72* mutation. Later that same month we co-sponsored "Establishing therapeutic efficacy in familial FTD," a meeting which convened clinicians from 21 different countries who follow families with an identified FTD gene mutation. Many of these investigators met for the first time at this conference, and the groundwork was laid for rich global collaborations going forward.

Publications. Finally, this spring AFTD was proud to publish the *FTD Research and Drug Development Landscape*, the first comprehensive view of the current state of knowledge of FTD. The document highlights both the tremendous excitement being generated by FTD science, as well as the gaps that remain along the path to drug development. We are using this important resource to guide AFTD's own priorities as well as to reach out to potential industry partners to stimulate investment in FTD research.

Each year, AFTD invests about one-third of every dollar in the science that will drive discovery and development of accurate diagnosis and the first therapeutics for FTD.

Emily Rogalski, PhD, received the 2014 AFTD Pilot Grant for her Web-based speech therapy project.



respite and travel grants



Art and Helen Granzeier

Art Granzeier lives outside Chicago where he cares for his wife, Helen. Helen was diagnosed with FTD in 2007, and since then has lost all communication skills. Art used his 2014 Comstock Caregiver Respite Grant to pay for adult day care to help provide the full-time attention and supervision necessary for Helen's well-being and safety.

"As my wife's primary caregiver for the past six years, the advice to caregivers to 'take care of yourself' has become very real to me. This is especially true as the disease progresses and the care becomes more consuming in time and psychic energy."

Joe McKeown

Joe McKeown is president of the McKeown Foundation, which has contributed to the AFTD respite and travel grant program for the past three years. The McKeown family knows from personal experience how challenging caring for a loved one with dementia can be, and their funding helps families affected with FTD cope.



support

AFTD understands the challenges that FTD presents to patients and their families, and works hard to develop unique resources and information that will improve quality of life for those living with FTD every day.

Over the past two years, the number of people contacting AFTD's Helpline has increased 60 percent, reaching an average of 160 per month. Each inquiry receives a personal and detailed response and includes information on the growing number and variety of resources available to our community.

In 2014, AFTD increased the budget for the **Comstock Caregiver Respite** program to \$70,000, which enabled us to assist 98 families with respite and 34 to attend an FTD education conference.

Eleven new **FTD support groups** started, which raised the total number of groups in the US and Canada to 82; five of these are telephone support groups directly run by AFTD. The organization hosted quarterly

web trainings for the group leaders, each featuring an FTD clinical expert lecturing and answering questions on a specific aspect of FTD management.

The AFTD **Kids and Teens website** was launched in April 2014. Within the first three months more than 2,000 people from 10 countries visited the site, which provides a place for young people to share their experience via original artwork, poetry, or videos.

AFTD's Annual Education Conference in White Plains, NY, on March 14 reached a new high in participation, with 244 attendees, including 34 people with FTD. Colleagues from Columbia University anchored the clinical and research presentations while Robert Bazell, former Chief Medical Correspondent for *NBC Nightly News*, gave the keynote address.

We continue to explore ways to understand and meet the needs of individuals who have been diagnosed with FTD: the AFTD telephone support group **for persons diagnosed** is active and well-received; this year's education conference included two presentations from patients; and this spring, reorganization of AFTD's website included introduction of a section called "I Have FTD."



Amy Eissler, Volunteer

Amy Eissler is one of AFTD's many wonderful volunteers. She was on the team that developed the Kids and Teens website, has written for the newsletter, and is a Food for Thought volunteer liaison.

Amy's father and his siblings all had FTD. "I want to help give support to those who have been affected by this awful disease. If I had known of the support systems out there as I watched FTD take my dad from me, I think I would have been able to view and handle the situation better."

sharing first-hand strategies

Ron and Sally Kinnamon

For 38 years, Ron was a nonprofit executive and board member who gave speeches and presentations around the world. Sally, a retired Nurse Practitioner, is chaplain of the neurosurgical service of a large hospital. When Ron was diagnosed with primary progressive aphasia several years ago, they combined their skills and energy in a new way. As they adapt to changes in Ron's communication, they model and teach the value of individualized speech-language strategies and good-natured teamwork. They have presented to small groups and at large FTD education conferences.



Rebekah Wilson, MSW

Rebekah Wilson was a core member of the planning team for AFTD's 2014 education conference. Her work in dementia hospice care, assisted living settings and five years running an FTD caregiver support group has given her a deep respect for individuals and families facing FTD. Rebekah's experience and commitment to advancing care in FTD contributed to an event that featured practical, field-tested strategies for managing care.

education

AFTD's **Partners in FTD Care** program, which provides accurate, comprehensive and cutting-edge information on care strategies, continued to produce quarterly newsletters with clinical case studies and recommended interventions for healthcare professionals.

Topics included: understanding semantic PPA, assessing pain, managing incontinence, and managing aggressive behavior. This year an additional feature was added called, "What to do about..." which provides specific, practical strategies that professional or family caregivers can use.

In FY 2014, AFTD continued a **rich tradition of collaborating** with other organizations to

present information on FTD to professionals across the spectrum of aging services:

- In August we partnered with the National Institute on Aging and Administration for Community Living to present a webinar on Younger Onset Dementia that reached an audience of 600 registrants.
- In January we participated in an educational presentation to the program directors of all Alzheimer's Association chapters in the US.
- In April AFTD lectured to more than 80 administrators and staff from Arden Courts, a company that operates specialized dementia care facilities in the Eastern US.

AFTD collaborates with a growing number of partners each year to educate healthcare professionals about FTD, with a goal of speeding our way toward accurate diagnosis and effective disease management and treatment.



***Brianna Sullivan, MPH,** performed an analysis of data from the HelpLine and applied the Social Ecological Model as a tool to help AFTD better understand our community's health needs. Brianna will present these results in a poster presentation to clinicians from around the world at the 9th International FTD Conference in October 2014.*



Max Portnoy's Catch-a-Thon

Max Portnoy used his Bar Mitzvah service project to honor his grandfather, Rabbi Hershel Portnoy, and help find a cure for the disease that is slowly taking his grandfather away from him.

Max hosted a three-hour Catch-a-thon, where he and his classmates and friends from Little League raised money with every toss of the ball. The event brought in over \$18,000 and boosted awareness through press and online coverage, including a prime-time segment on local ABC affiliate, WJLA.

"Well, I love baseball and my grandfather, so I thought it would be fun if I combined the two so I could play baseball to help my grandfather," says Max.



awareness

Volunteers continue to be the lifeblood of AFTD's ability to spread awareness about this rare disease. In FY 2014, more than 175 volunteers engaged with the organization by hosting awareness events, visiting nursing homes and day programs, speaking to groups of clinicians and researchers, facilitating telephone support groups, and providing data entry, graphic design or general office support.

This spring AFTD hosted a **Leadership Summit**, which brought together 11 lead volunteers from across the country for a day of training and brainstorming.

In October, AFTD sponsored the first-ever **FTD Awareness Week** with the **Food For Thought** campaign. Families and clinics across the US hosted an array of unique events, from line dancing in Delaware to a *Downton Abbey* tea party in Texas to a virtual recipe-sharing

event online. When all was said and done, there were 56 events in 25 states (and five Canadian Provinces), each of which succeeded in educating one more community about FTD.

In February, 15 families honored their loved ones by joining AFTD's third annual **With Love** campaign. This virtual event provided each caregiver with a webpage on which they could share photos and stories, and then eblast a message to friends and family, urging them to learn about FTD and support AFTD's work toward care and a cure.

Throughout the year, volunteers hosted individual grassroots events, including an antique car show in Baltimore, MD, and golf tournaments in California, Connecticut, Florida, Illinois and Ohio. A total of **109 events raised more than \$364,000** and garnered press about FTD in several media markets

across the US. FTD or AFTD made the news more than three dozen times this year, with stories featured online, in print, on TV or on radio. Whether stories get national or local attention, each helps spread the word about this disease.

Awareness is the key to everything our community needs to accomplish. When neighbors, physicians, professional caregivers, political representatives and news reporters all understand this especially cruel form of neurodegeneration and what it steals from our loved ones, we will be a good way down the road to our goal.

*For a Food for Thought event, **Gail Andersen** (center, in red shirt) had a Kona Ice Truck come to her Ohio home to give kids an opportunity to contribute to AFTD. Gail's husband died of FTD in 2012.*





“Adaptation
to Early-Stage
Nonfluent/Agrammatic
Variant
Primary
Progressive
Aphasia:
A First-Person Account”

Joanne Douglas, PhD

Joanne Douglas has a PhD in Molecular Microbiology and was a professor at The University of Alabama at Birmingham (UAB) in the field of human gene therapy. She also has primary progressive aphasia (PPA). Since her diagnosis, Joanne has been determined to share her experience and the strategies she has learned, to help others understand this rare disorder. Joanne has contributed articles to AFTD’s website, but one driving goal was to improve understanding of PPA among her peers in academia. Despite the painstaking process of writing now with PPA, Joanne realized her goal in February 2014 when her first-person manuscript on her experiences was published in the *American Journal of Alzheimer’s Disease and other Dementias*.

advocacy

As a result of a workshop AFTD co-hosted at NIH in 2013, as well as tireless advocacy on the part of AFTD volunteers and staff, in April 2014, for the first time FTD research and care priorities were included in the **National Plan to Address Alzheimer's Disease** (NAPA). The fact that FTD is now recognized as a priority at the national level is a key tool that AFTD Board members and volunteers are working to leverage into increased research dollars and improved services for our families.

AFTD wrote a **Guidance for State Alzheimer's Plans** which volunteers have used in 10 states to advocate for FTD priorities to be included in dementia plans at the state level, as well.

In October, Representative Patrick Meehan (R-Pennsylvania) inserted remarks into the

Congressional Record in recognition of the first FTD Awareness Week.

AFTD's Executive Director was invited by the National Institute of Neurological Disorders and Stroke (NINDS) to speak at their annual Nonprofit Forum on effective strategies for organizations to collaborate with NIH.

AFTD nominated two candidates who were successfully appointed to the Medicare Evidence Development & Coverage Advisory Committee of the **Center for Medicare and Medicaid Services**. This committee will play a critical role in determining whether emergent technologies and treatments for FTD are reimbursed by the government and private insurers.

Finally, AFTD and leaders on our Medical Advisory Council continue to work with our peer organizations to advance the cause of patients and families living with any dementia or neurodegenerative disease.

Our community is leading the way to send the message that dementia is a multi-faceted disease that can occur at a young age and begin with symptoms unrelated to memory. AFTD is working hard to ensure that this message is heard in Washington, DC and other seats of power, where decisions about research funding and services are made.



*In May, AFTD Board members **Paul Lester** (left) and **Popkin Shenian** met with **Senator Kay Hagan** (D-North Carolina) at her office on Capitol Hill.*

AFTD's generous donors

*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.*

1,000,000+

Anonymous

100,000+

Anonymous

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*AFTD Board members **Beth Walter** and **John Whitmarsh** with **Robert Bazell** at AFTD's Annual Education Conference in White Plains, NY. Mr. Bazell, former Chief Medical Correspondent for NBC Nightly News, gave the keynote address, "Making Yourselves Heard."*

AFTD's generous donors

1,000+ (continued)

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*Food for Thought host **Brandee Waite**
and the members of "Team Bev"
gathered for brunch after participating
in a local half marathon and 5K.*



appreciation

Each of these grassroots events and fundraisers raised \$1,000 or more during FY 2014.

Overall, 109 events across the country raised awareness and more than \$364,000. AFTD sincerely thanks all who accepted the challenge to bring FTD awareness to their hometowns and raise funds to support AFTD's mission.

1st Annual "Josh for the Cure" Golf Outing and Dinner
Don Pierce

Always on My Mind- In Loving Memory of John Kretekos
Laura Kaplan

Aramco Houston Half Marathon in Memory of Carol Tilotta Sumrall
Angela Kimble & Sean Cain

Body of Work
Amanda McDorman

Doing My Best for Bill
Anders Fehon

George F Sidoris 8th Annual Memorial Golf Outing
Christine Sidoris
George S. Sidoris

Highlands High School class of '63 Reunion

Hiking the Appalachian Trail
Brandon Cline and Katherine Vance

In Memory of Arnette Lester for Research
Paul Lester

In Memory of Paula Scott
Christine and Mikaela Hamilton

Max's Catch-A-Thon
Max Portnoy

Memory Lanes: Bowling to Strike Out Pick's Disease
Casey Greemore

Our Dad's Greatest Race
Eric Zuckerman
Jennifer Zuckerman Moran

Quest for the Cure
The Walter Family

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

Riverdale Country School Walk-a-Thon 2014
Olivia and Jason Goldring

Riverdale Country School Dance-a-Thon 2014
Olivia and Jason Goldring

The Robert M. Hatfield Foundation, Inc. Golf Outing

Running for FTD Research
Maja Murphy

The Silver Lining- FTD Research in Honor of Dr. Seth Reice
Traci Connor

Shoot for Scooter
Scaggs & Sealfon families

Strong Body Strong Mind
Deanna Angello

Untouchables Car Show
Mike Kipp

Food For Thought

Gail Andersen
Lucy Carter
Deborah Dolan
Susan Eissler
Debbie Fenoglio
Tracy Foye
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Cheryl Johnson
Kelley Klein
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Walking the Walk 2014

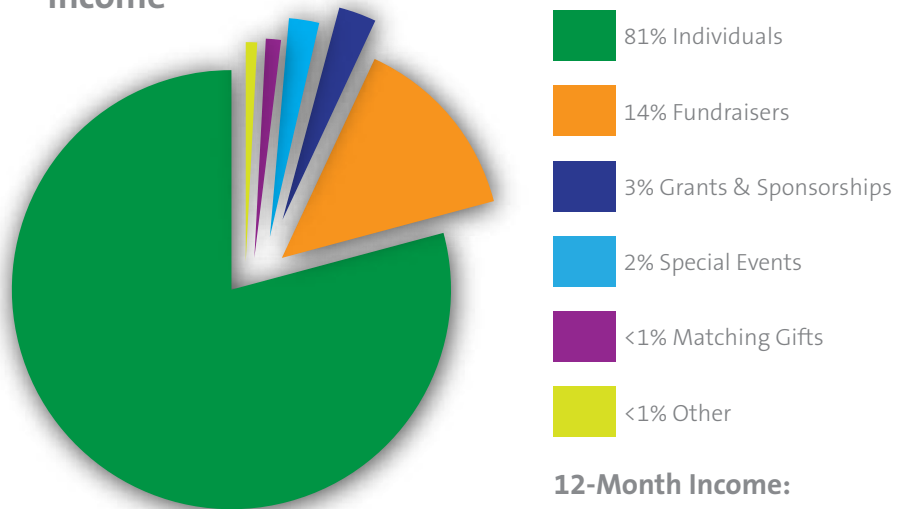
Susan Dickinson
Pam Lamaina & Chris Devine
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Colin Whitmarsh, Sarah Sozansky and Chris Moyer

With Love

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Team Alice
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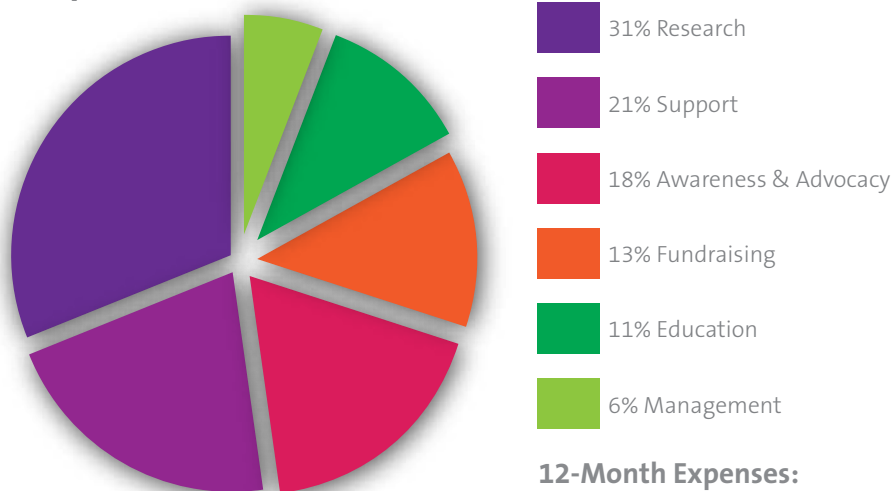
statements of financial position as of 6.30.2014

Income



12-Month Income:
\$2,693,906

Expenses



12-Month Expenses:
\$1,373,013

Assets

Cash & Prepaid Expenses	\$1,796,942
Certificates of Deposit	\$ 600,099
Contributions Receivable	\$ 100,000
Equipment	\$ 9,743
Security Deposit	\$ 6,289
Total Assets	\$2,513,073

Liabilities and Net Assets

Current Liabilities

Accounts Payable	\$ 14,557
Total Current Liabilities	\$ 14,557

Net Assets

Unrestricted	\$1,300,640
Temporarily Restricted	\$1,197,876
Total Net Assets	\$2,498,516
Total Liabilities and Net Assets	\$2,513,073

outlook

IMPACT: to affect; influence; change; alter; transform

As you read this annual report, we are already well into the new fiscal year, which we meet with energy and hope. Highlights will include: the 2nd annual FTD Awareness Week and Food for Thought campaign, October 5-12; a scientific workshop to explore the overlap between FTD and ALS genetics in Washington, DC, on November 14; and the 9th International Meeting on FTD in Vancouver, British Columbia, October 22-25.

Thanks to the passion and dedication of our growing community, AFTD's national role in advocacy, research, education and awareness continues to grow. Accomplishments of the

past year become tools that will enable us to keep momentum building. FTD's recognition as a priority in the NAPA national plan will add urgency to advocacy for increased research funding and expanded services. The comprehensive *FTD Research and Drug Development Landscape* will help make the case to the pharmaceutical industry that this rare disease merits investment. And the success of a growing national awareness campaign will speak volumes to all. The FTD community is here and making an **impact!**

This year the AFTD Board and staff will also build a strategic plan to guide investment of our resources over the next 4-5 years. Certainly, our major donors, fast growing in numbers, will be much-appreciated partners as we craft the roadmap for this work.

Finally, I invite you to join AFTD at our 2015 Annual Education Conference in San Diego on April 24, 2015. You'll hear research updates as well as the latest in caregiving strategies, and get a vital opportunity to interact with others who share in this journey. Together, we will continue to celebrate our impact as we work toward *a world where frontotemporal degeneration is understood, effectively diagnosed, treated, cured and ultimately prevented.*

Best wishes,



Susan L-J Dickinson, MS
Executive Director



Together, we work toward a world where frontotemporal degeneration is understood, effectively diagnosed, treated, cured and ultimately prevented.

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