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Dear Friends,

During my time as AFTD Board Chair, I have formed powerful bonds with countless people whose lives – like mine, and those of my family – have been changed forever by FTD. But although we were brought together by the challenges, grief and loss that FTD inflicts, hope is what made us into a thriving, dedicated community. “Sharing Hope,” the theme of this annual report, underscores the most profound part of AFTD’s mission: accelerating the day when families are no longer devastated by this disease.

That day will only come when we fully understand FTD; hence, research is critical. Over the past year, AFTD has provided funding for a broad range of innovative research proposals, allowing talented investigators in the U.S. and abroad to examine the causes of this disease and to test out potential treatments and therapies.

Among the general public, too few today know how completely life-altering an FTD diagnosis can be. Our hope is that AFTD’s pioneering study on the economic and social impact of FTD, published last November in Neurology, brings this fact into the light. Among other sobering statistics, the study shows that the economic burden FTD imposes on families is nearly twice that of Alzheimer’s.

The more who know about FTD, the greater the hope for a breakthrough in the fight against it. AFTD’s 2017 series of public service announcements emphasized that not all dementias are the same, with the tagline “Think It’s Alzheimer’s? Think Again. Think FTD.” The short film VJ & Chuck offered an intimate portrait of a marriage as FTD forever disrupts lives and families. You can find all these videos on our YouTube channel, www.youtube.com/TheAFTDorg, and I hope you share them far and wide.

Last year more than 340 AFTD volunteers personally shared hope, hosting Meet & Greet events throughout the country and continuing to grow our network of in-person support groups. And nearly 2,300 people seeking information, advice and assistance from AFTD’s HelpLine received a personal response from our staff – which continues to grow, providing help and sharing hope with more people each year.

As our community expands, so too does the generosity of those who back our mission. Notably, AFTD was honored by the creation of the David Geffen Fund, a 10-year commitment that will contribute $2 million annually for our mission. I’d like to thank the David Geffen Foundation and the Samuel I. Newhouse Foundation for generously contributing to this fund.

Hope is the reason I choose to devote my time to AFTD, and I am heartened by how it continues to be shared and amplified throughout this community. Much work remains, but I hope you share my sense that a better future is closer than ever.

Sincerely,

Gail Andersen
AFTD Board Chair

“Hope is the reason I choose to devote my time to AFTD.”
In May, the 12 Barz Band performed at the annual Battle of the Biotech Bands in Boston – and chose AFTD to be their charity recipient. The band – whose members include representatives from Yumanity Therapeutics, Biogen and other biotech companies – rocked out to Chicago and Stevie Wonder songs, and raised more than $15,000 on AFTD’s behalf while spreading awareness of FTD.

Raising FTD awareness is central to AFTD’s mission. Awareness promotes public understanding and helps families get accurate diagnoses for their loved ones. Awareness alerts health professionals to the realities of FTD, and it can even spark new research. Over the last 12 months, members of our community have bravely chosen to share their stories. AFTD is grateful for your resilience and your courage, and is honored to partner with you in telling the story of FTD.

VJ and Chuck Anastasia welcomed filmmaker Joseph Becker of ThinkFilm, Inc., into their home to document VJ’s FTD journey. The resulting short film, VJ & Chuck, powerfully shows how VJ’s 2013 diagnosis of primary progressive aphasia has changed every aspect of their lives. Narrated by longtime AFTD volunteer Teresa Webb, VJ & Chuck premiered in November and has been viewed by thousands on AFTD’s YouTube channel.

World FTD Awareness Week 2017 took place from September 24 through October 1, 2017. AFTD marked the occasion by joining forces with our international allies in the World FTD United coalition to raise awareness around the globe; ten countries representing four different continents participated. In the U.S., AFTD again placed two full-page awareness ads in Sunday issues of the New York Times, thanks to the support of a generous donor. Designed by volunteer Jody Zorn, the ads urged readers to rethink their take on dementia: “Think It’s Alzheimer’s? Think Again.”

That tagline also appeared in six public-awareness videos produced by AFTD in partnership with Discovery Inc. Each video featured a prominent AFTD community member.
member, such as actress Martha Madison and sports broadcaster Wes Durham. These brief videos can be found through AFTD’s YouTube page, findable on the site under theAFTDorg. We hope you’ll share our video resources with your friends, family members and colleagues.

The hiring of AFTD’s first Online Community Coordinator has significantly bolstered our social network impact. Between June 2017 and June 2018, AFTD’s Twitter followers grew by 34%, while the number of Facebook followers went up 52%.

Finally, you may have noticed that AFTD now offers a new logo, tagline and new resources. In April 2018 we rolled out a completely redesigned website at www.theaftd.org. Designed with the marketing firm Teramark, the site built on a process consulting caregivers, persons diagnosed and other volunteers. It is designed to allow people and families affected to more easily access the information and resources they need, and to more easily make connections with others, as they seek to Find Help. Share Hope.

Actress Martha Madison and sportscaster Wes Durham appeared in AFTD’s “Think FTD” series of PSAs.
For many facing FTD, whether as a care partner or a person diagnosed, finding help and support for their journey can be an extraordinary challenge.

AFTD’s HelpLine – the only such resource devoted exclusively to providing information and guidance about FTD – remains a vital first point of contact. Last year, our staff responded to nearly 2,300 phone and email inquiries, answering with compassion, urgency and the type of straightforward information families dealing with FTD need. Our e-newsletter Help & Hope began providing information for both care partners and people with FTD on a monthly basis.

We continue to expand our national network of support. Last year, 80 AFTD-trained and -supported volunteers – including health professionals and care partners alike – led targeted support groups in 32 states. Many have recently recommitted to lead their groups for an additional two years. Eight remote AFTD-affiliated groups provided a safe space online or by phone, offering support that can reach underserved rural areas.

AFTD volunteer support group facilitators offer one of the few available resources designed specifically and exclusively for people whose lives have been touched by FTD. They offer vital opportunities for problem-solving, resource sharing and emotional support between people facing a common experience, and chip away at the isolation far too common for families navigating an FTD diagnosis.

Last year, AFTD awarded 180 Comstock Grants to members of our community. AFTD recognizes the need for care partners to look after their own well-being, and offers Respite Grants that can be used to arrange respite care. Travel Grants, to subsidize the costs of travel, lodging, registration fees and/or respite care for travel to FTD-related conferences, are also available.

Last year AFTD piloted a new Comstock Grant. Developed with invaluable input from AFTD’s Think Tank – a group of persons diagnosed with FTD that meets regularly to help further our mission – the AFTD Quality of Life Grant represents the only organized program designed to empower those living with FTD to purchase equipment, services or supports that they could not otherwise afford. The pilot was a success, and we are now in the process of rolling out additional Quality of Life Grants to deepen the support we provide for people living with FTD.
Support means feeling like they’re part of a community and making connections to others going through the same thing.”

- Gary Radin
AFTD Volunteer
AFTD continues to be a global leader in funding cutting-edge FTD research. The ongoing partnership between the scientific community, AFTD and our generous donors has the potential to produce remarkable scientific breakthroughs, helping to further our understanding of this disease – and create hope for a world without it.

AFTD funded and co-wrote a study detailing the economic and social burden that FTD inflicts on families. Published in the peer-reviewed scientific journal *Neurology* in November, our economic burden study shows that FTD wreaks a yearly financial toll of roughly $120,000, and can reduce household income by as much as 50 percent.

Over the past year, AFTD funded the research of several promising investigators in the U.S., Canada and Europe. These awards include the first grants awarded through our TreatFTD initiative, which promotes innovative approaches to FTD clinical drug trials.

AFTD also awarded our first-ever pilot grant for nonpharmacological therapies and tools for FTD, the latest addition to our ongoing Pilot Grant program. A return-on-investment analysis of this program proves that it gets results: From 2005-2016, AFTD awarded $955,000 in Pilot Grant awards, resulting in more than $7.5 million in follow-on funding.

In October, AFTD convened the initial grantees of the FTD Biomarkers Initiative to update the Scientific Advisory Board as well as AFTD staff and Board members on their progress in identifying biomarkers for FTD. Later, we awarded an additional Biomarker grant to researchers leading the ARTFL clinical program at the University of California, San Francisco.

AFTD held its biennial meeting of the FTD Treatment Study Group (FTSG) in March, convening representatives from 27 pharmaceutical and biotech companies, along with government regulators and academic researchers, to identify and formulate creative responses to the challenges of getting the first drugs approved for use in FTD.

A year ago, in March 2017, AFTD and the Bluefield Project to Cure Frontotemporal Dementia launched the FTD Disorders Registry, the first online database to compile the self-reported experiences of people affected by FTD and to match them with research and clinical trial opportunities. One year after its launch, the Registry had already attracted more than twice its original registrant goal.

Median household income 12 months before an FTD diagnosis is in the $75-99K range. AFTD's study on the economic burden of FTD shows that 12 months later, median income falls to around $50K.
In June, AFTD awarded its first-ever Pilot Grant for Nonpharmacological Therapies and Tools to Dr. Lauren Massimo, an assistant professor at the University of Pennsylvania’s FTD Center. Dr. Massimo is using the grant to convene a team of neuropsychologists and smartphone app developers, who will work on an app that will help persons diagnosed overcome apathy, “a common and highly debilitating symptom for people with FTD,” she says. The app will use alerting mechanisms to signal persons diagnosed to perform a customized range of activities, including grooming, exercising, completing household chores and taking prescribed medications. The AFTD Pilot Grant award “allowed this team to come together,” Dr. Massimo said. “Without an award from AFTD, this app would not happen.”

“Awards and grants

**AFTD Biomarker Awards** – Adam Boxer, MD, PhD, and Howard Rosen, MD, University of California, San Francisco (US)

**The Susan Marcus Memorial Fund Clinical Research Pilot Grant** – Haakon Nygaard, MD, PhD, University of British Columbia (Canada)

**Basic Science Pilot Grant** – Todd Cohen, PhD, University of North Carolina, Chapel Hill (US)

**Nonpharmacological Therapies and Tools for FTD Pilot Grant** – Lauren Massimo, PhD, CRNP, University of Pennsylvania (US)

**TreatFTD Fund Grant** – Barbara Borroni, MD, University of Brescia (Italy)

**Accelerating Drug Discovery in FTD** (in partnership with the Alzheimer’s Drug Discovery Foundation) – Thomas Kukar, PhD, Emory University (US); Steven Finkbeiner, MD, PhD, J. David Gladstone Institutes (US)
education and advocacy

Educating members of the public, the medical community, and state and federal legislatures about FTD is central to achieving AFTD’s mission.

Unique among other U.S. organizations, we produce substantive, medically accurate, FTD-focused resources for healthcare professionals and families. Over the last year, three new installments in our Educational Webinar series brought attention on the FTD Disorders Registry, the genetics of FTD, and two promising brain-stimulation technologies that researchers hope can be used in assessing and treating FTD.

AFTD’s Partners in FTD Care initiative produced three new, highly informative newsletters, focusing on ALS with FTD, accurate diagnosis, and apathy, a common symptom. Two new members of the Partners advisory committee are now bringing additional clinical and community-care experience to the creation of new issues, strengthening an already highly knowledgeable group.

The 2018 AFTD Education Conference took place in Chicago in April, drawing 341 attendees from 37 states and Canada for a powerful day of information, support and networking. Drawing from the experiences of AFTD’s Think Tank, an advisory group of persons diagnosed, the conference was specifically designed to be more inclusive of all attendees.

AFTD Volunteers Amy Bouschart-Callea and Frank Callea welcome attendees to the 2018 AFTD Education Conference.

Education Conference attendees took part in breakout sessions on improvisational theater (this page) and positive care strategies (opposite).
On Capitol Hill, AFTD continued its strong advocacy on behalf of persons diagnosed and their families. Our staff worked closely with Sen. Charles Schumer’s office to draft language to be included in a key congressional report encouraging the National Institutes of Health (NIH) to expand its FTD clinical research network. Working directly with staff from the U.S. Defense Department, AFTD helped to get FTD included for funding through the Peer-Reviewed Medical Research Program. These were key wins for our community.

In October 2017, AFTD sponsored the National Alzheimer’s Project Act’s summit on dementia care, held on the NIH campus, ensuring that the care needs of people with FTD were addressed. AFTD allies Sharon Hall and Teresa Webb spoke at the summit and served on stakeholder panels, where they helped guide federal research priorities in dementia care and services from the standpoint of a care partner and person diagnosed, respectively.

The Very Reverend Tracey Lind was diagnosed with primary progressive aphasia in 2016, leading her to step down from her prestigious position as Dean of Trinity Episcopal Cathedral in Cleveland. She has chosen to be completely transparent about her diagnosis, both “to give it meaning and purpose” and to “destigmatize this dreaded disease by speaking about it from the inside out,” as she said during her Keynote Address at the 2018 AFTD Education Conference.
Volunteers provide the vital energy and momentum that drive AFTD’s mission. We are grateful for every volunteer – and the myriad ways they demonstrate resilience and resolve to make a difference.

During the last 12 months, 340 active volunteers led the charge in bringing AFTD’s presence to local communities across the country. They held fundraisers, led support groups in 32 states, led table settings at community events to spread awareness, performed outreach to educate staff at local facilities, and hosted Meet & Greet events in cities from Seattle to Mobile to Fargo.

Our 11 highly committed Regional Coordinator Volunteers helped stimulate volunteer activity in each of their regions. AFTD recognized these individuals, along with our invaluable AFTD-affiliated support group facilitators and other key volunteers, at our annual Volunteer Leadership Summit, held immediately prior to our 2018 Education Conference in Chicago.

Volunteers inform AFTD’s work on a daily basis. An all-volunteer Think Tank, comprised of persons diagnosed with FTD, helps us to better serve, include and empower these vital constituents. A devoted committee of healthcare professionals helm the Partners in FTD Care initiative, enabling us to offer the most up-to-date information on FTD care and management. More people continue to step up and give generously of their time and effort each year.

AFTD volunteers who host or participate in a grassroots fundraising event become members of the AFTD-Team, dedicated to fighting this disease. Last year, during our flagship fundraising campaign, Food for Thought volunteers raised more than $178,000 – a new record – and spread FTD awareness, all while providing delicious meals for friends, loved ones and community members. A total of 63 Food for Thought events took place in 34 states!

With Love, a campaign centered around Valentine’s Day, raised more than $52,000 from a record 29 hosts, while the AFTD-Team Race Season raised more than $68,000 during 2017. Races – and fundraising – continue in 2018!
For people who have FTD in their lives, there is no substitute for connecting with others who understand. For that reason, AFTD encourages and supports volunteers who host Meet & Greet events. Jerry Horn of Alabama organized one of the 14 Meet & Greets held last year, bringing people together to talk about their experiences, learn about resources and exchange information. “Meeting people who understand FTD is invaluable,” he said. “Forging these bonds is such an important part of the FTD journey.”

Meeting people who understand FTD is invaluable.”
named funds and donors

AFTD Named Funds honor or memorialize a loved one. Established with a minimum donation of $25,000, Named Funds are among AFTD’s most generous gifts, with donations advancing the science of FTD and improving care and support for people currently living with the disease. AFTD is proud to recognize these individuals and their families for their contributions.

The Dr. Lawrence Albert Memorial Fund
Established by Mrs. Kathi and Mr. Peter Arnow

Kevin M. Harvey Memorial Fund
Established by The Connecticut Frontotemporal Dementia Foundation, Inc. via the Harvey Family

Susan Marcus Memorial Fund
Established by Mr. & Mrs. Lawrence Neubauer

Laden Memorial Fund
Established by the Laden Family

The Suzy Fund
Established by the Newhouse Family

The Mike Walter Fund for Research
Established by the Mike Walter Family

The Mimi Fund
Established by her loved ones

The Michael E. Fenoglio, MD Memorial Fund
Established by the Rocky Mountain Surgeons Consortium

AFTD relies on donations to fulfill our mission of advancing research, raising awareness and providing support. We are immensely grateful to all who have strengthened AFTD with their generosity over the last year, and we look forward to continuing these partnerships.

1,000,000+
David Geffen Foundation
Samuel I. Newhouse Foundation Inc.

100,000+
Discovery Inc.
Katherine Farley & Jerry Speyer
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Emma & Mackenzie Strathy
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Nan & Stephen Swid

AFTD Regional Coordinator Volunteer Deb Scharper and a friend at the First Annual Crusade for a Cure Golf Tournament
donors

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Mrs. Terry L. Walter
Gretchen Beidl & Michael Willner
Ms. Candace Young

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AFTD CEO Susan L-J Dickinson speaks at AFTD’s second annual Hope Rising Benefit in New York
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Shirley Young, Chair of the US-China Cultural Institute

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FTD Research Community

At Hope Rising (left to right): AFTD CEO Susan L-J Dickinson, AFTD donor Donald Newhouse, journalist and TV host Paula Zahn, Sen. Charles Schumer (NY)
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Mrs. Joan C. Zlotnick
fundraisers

The AFTD-Team was out in full force over the past year, hosting 245 grassroots events and bringing more than $432,000 to support AFTD’s mission! The events listed on this page each raised more than $1,000. We are incredibly appreciative of our volunteers for their determination and drive, and we share in their hope that one day we will live in a world free of FTD.

**Independent Events**

George & Christine Sidoris  
12th Annual George F. Sidoris Memorial Golf Outing

Paul Lester  
11th Annual Letters for Arnette

12 Barz Band  
Battle of the Biotech Bands

Debbie Baumgartner  
3rd Annual John E. Baumgartner III Golf Tournament

Deb Scharper  
1st Annual Crusade for a Cure Golf Tournament

Pam & Matthew Hatfield  
Robert M. Hatfield 7th Annual Quest for the Cure Golf Tournament

Sharon & Rod Hall  
2018 FTD Calendar

Diane Cole  
Chuck’s Celebration of Life

Cindy & Ken Brunner  
Wooden Bowl Sales

Dawn Zeremba  
Evine Social Media Campaign

Suzanne & Calvin King  
2nd Annual ”Tami Sue” Golf Outing & Party

Matt Pelton  
Hiking the AT for AFTD

Rachel Lower  
”I Love You, Mom”

Anonymous  
”Help Save the Brain” Shirts

Jon Moretti  
2nd Annual CWM Memorial Golf Outing

Juliet Bornia  
Big Sur Marathon

Kaj Malden  
In Memory of Jacqueline Malden Phelps

Kaitlyn Heffron  
Hiking the PCT for AFTD

Amy Shillady  
Soy Candle Sales

Lucy Carter  
House Restaurant Event

**Food for Thought**

Steve Bellwoar  
Cathy Sperrick

Bonnie Shepherd  
Terry Walter

Deanda Welch  
Kathy Ritchie

Molly Trimmer  
Chuck Anastasia

Ryan Windhorst  
Lucy Carter

Katrina Hellman  
Joan Harper

Rachel Castellanos  
Diane Cole

Mary Beth Mixdorf  
Shirley Gordon

**Race Season**

Team Jack Attack  
Frank Callea

Daniel Ranti  
Joe Fischel

Marisa Lutz  
Patti Del Guercio

Debbie Fenoglio  
Joe Pang

Kerry Verdi  
Stephanie Potter

Rachel Lower  
Susan L-J Dickinson

Karen Dalley  
Jane Carter

**With Love**

Emily Anderson  
Suzanne Dana

Kathryn Primeau  
Melissa Fisher

Zoy Kocian  
Jamie Hale

**Via Facebook**

Randee Curry  
Gary Johnson

Jamison Sep  
See Aytch

Cassie Jonaitis  
Randi Davis

David White  
Maggie Braun

Alyssa McCray  
Ashley Olhausen

Lorrie Cox  
Laurie Kozakiewicz
The Association for Frontotemporal Degeneration is a 501(c)(3) organization.
Every year, I pause to reflect on the honor it is to support AFTD’s mission and serve this community.

Throughout my tenure at AFTD, my daily work has been fueled by the stories I hear -- from persons diagnosed seeking medically accurate information; from care partners looking for practical advice; from researchers and healthcare professionals grateful for AFTD’s leadership in advancing FTD science.

Today, AFTD stands stronger than ever, more capable of providing help and sharing hope with all affected by FTD. Thanks to support from people like you, we stand poised to extend our reach even farther.

Over the next year, AFTD will continue supporting cutting-edge research into FTD’s symptoms, causes and, potentially, treatments. We will convene researchers investigating TDP-43, a protein whose accumulation in the brain is associated with the presence of FTD. Our research team will also award the second round of grants through our FTD Biomarkers Initiative, a program we hope will foster earlier and more accurate diagnosis.

In November, AFTD will sponsor the 11th International Conference on Frontotemporal Dementias in Sydney, Australia, with staff and Board members on hand to collaborate with global leaders in FTD science. The following March brings the Alzheimer’s Disease-Related Dementias Summit, hosted by the National Institutes of Health; AFTD is sponsoring that as well. And we look forward to uniting our own community on May 3, 2019 in Los Angeles, for the annual AFTD Education Conference.

Our staff will continue to share FTD information and education, both directly through the AFTD HelpLine and generally through Educational Webinars, newsletters and social media. The AFTD-Team, comprising volunteers who support AFTD with grassroots fundraising and awareness efforts, will further expand its presence. Look for us – or better yet, join us – at marathons in Philadelphia, Austin and Dallas.

I’m so proud of the work we’ve accomplished over the last year, and I look forward to serving this community in an even more comprehensive and profound way over the next year, and beyond: We will soon debut our ambitious, forward-thinking strategic plan for 2019–2022.

Thank you for sharing your support and ideas, your time and resources – and most of all, for sharing your hope for compassionate care, effective support and a future free of FTD.

Susan L-J Dickinson, MS, CGC
Chief Executive Officer
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AFTD values

Knowledge
Information is the key to unlocking the future we seek.

Compassion
We recognize the importance of finding others who understand.

Collaboration
AFTD connects a community. Together, we can end this disease.

Respect
We learn by listening, knowing the power of a single story.

Dignity
We strive to honor, help and empower all on this journey.
We envision a world with compassionate care, effective support, and a future free of FTD.