Building a Future Free of FTD

2020 Annual Report

July 2019–June 2020
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Dear Friends,

I hope my letter finds you reading this from a place of safety and well-being. I know that for so many of you, this pandemic has compounded an already challenging FTD journey. AFTD is here to help – and we dedicate ourselves every day to providing the latest resources, information, and support to help with growing day-to-day challenges. Whatever your situation today, please know that you are not alone.

What unites us today is a fierce determination to make things better for the next family. Most importantly, what unites us today is a sense of hope. That spirit guided Helen-Ann Comstock when she and like-minded volunteers founded AFTD in 2002, and it guides every aspect of our work today. With support from our donors, AFTD is transforming hope into action.

With your support, AFTD provides help for the journey. Last year, the AFTD HelpLine responded to a record number of 2,546 calls and emails, and more than 493,000 people found information and targeted resources through our theaftd.org website. A total of 105 AFTD-affiliated volunteers now lead support groups across the country, with an additional seven offering phone support groups. And while it wasn’t possible to convene our Education Conference in person in spring 2020, a powerful online webinar series drew more than 630 people to learn vital information, gain important resources and hear new perspectives on the FTD journey, from expert clinicians and people and families affected.

With your support, AFTD is accelerating research. Through partnerships with the Alzheimer’s Drug Discovery Foundation and the Diagnostics Accelerator, we are funding leading-edge research targeting biomarker development and promising approaches to therapeutics. Notably, evidence of a genetic overlap between FTD and ALS has provided a unique opportunity to advance hope for families that carry the C9orf72 mutation. A new partnership with Target ALS has resulted in funding for six research teams that will work to develop and validate biomarkers, which are critical to diagnosis and monitoring disease progression, as well as for developing potential treatments for both FTD and ALS.

With your support and our engagement, FTD is becoming more recognized by both health professionals and families around the world, thanks in large part to the hundreds of AFTD volunteers, family members, care partners and friends who are speaking out about this disease to raise awareness. Local media channels are highlighting the journeys of persons diagnosed and caregivers. And 575 volunteer-led AFTD grassroots events last year brought new attention to the needs of all impacted by FTD, while raising vital funds to drive AFTD’s mission.

None of us expected this road to be easy, and few could have anticipated the impact 2020 would have for so many of us. But as I consider the years ahead, the resilience and courage you’ve all shown by being part of this mission gives me a profound sense of hope – that together, we will build a future free of FTD.

Sincerely,

David Pfeifer
AFTD Board Chair
Raising awareness is fundamental to improving the lives of people living with FTD today, as well as advancing research towards a cure tomorrow. The strong foundation of FTD awareness that we are building will carry us to a future when FTD is known, understood and effectively diagnosed.

During the 2019 World FTD Awareness Week, AFTD joined its partners in the World FTD United coalition to invite people to share their FTD journeys through an interactive world map, hosted at theaftd.org. In just one week, 228 people from 231 cities throughout 21 countries participated, spurring greater awareness and highlighting the need for improving resources in communities across the world.

Last fall, the New York Times featured three AFTD awareness ads, illustrating the devastating effects of an FTD diagnosis. With help from AFTD volunteer Jody Zorn, we turned a national spotlight on the impact of FTD and pointed millions of readers to the help and support our organization offers for families affected.

Increasingly, mainstream media outlets are sharing personal journeys about living with FTD. The story of Lee Holloway – who is living with bvFTD and whose wife Kristin is an AFTD Board member – was featured in the May 2020 issue of WIRED. The in-depth article highlighted the many complex challenges that evolve as this disease progresses, and the intensely emotional journey for many families.

In January, AFTD Board member Jary Larsen, PhD, spoke to the Boston Globe about his brother’s bvFTD diagnosis in 2006. In the subsequent article, Dr. Larsen strongly advocates for families to participate in research, which he believes is crucial to advancing better diagnoses and potential treatments.

Dan Keuning helped to raise FTD awareness by speaking frankly with his local NBC affiliate about his diagnosis.

Local news stations across the country featured thoughtful interviews with caregivers and persons diagnosed with FTD, bringing crucial attention to the need for improved diagnosis and support. Dan Keuning, who was diagnosed with bvFTD in 2018, shared his personal journey.
with an NBC affiliate in Denver. Additionally, AFTD Ambassador Deb Scharper shared her experiences as an FTD care partner with a CBS affiliate in Iowa. These and other interviews are helping to raise crucial awareness about FTD on the local level.


I hope that by advocating and raising awareness I can be a part of normalizing living with dementia for everyone who is affected,” says Aisha Adkins, whose mom was diagnosed with FTD in 2013. Aisha is committed to increasing the public’s understanding about FTD, and she hopes to build a future with more support for those diagnosed and their care partners, particularly young adults such as herself. “AFTD’s network of support has been so important – being able to connect with others who understand the nuances of FTD is a great asset as a young caregiver,” she adds.
This year saw AFTD’s work to provide information, resources and support become even more essential for the families we serve. In March, AFTD added a “COVID-19 and FTD” section to our website. Written by FTD experts and AFTD staff, this robust collection of strategies and practical advice has helped our community adapt to our changing world.

The AFTD HelpLine is often the first point of contact for people in their FTD journeys. Throughout the year, AFTD staff responded to 2,546 emails and phone calls with guidance, information, and resources tailored to the needs of people facing FTD. AFTD’s website drew more than 493,000 visitors, seeking the latest news, resources and support. And our monthly e-newsletter Help & Hope highlighted FTD news, provided updates about FTD research and AFTD events, and shared advice from medical experts for persons diagnosed and care partners.

In March we published Walking with Grief: Loss and the FTD Journey, a 48-page “roadmap” designed to help families navigate the grief that can accompany every aspect of life with FTD. Walking with Grief draws from interviews and discussions with dozens of people with FTD, care partners and family members.

Last year, AFTD awarded 252 Comstock Grants to assist with the complex needs of people in our community. Through the Respite Grant, care partners can schedule time and services that are beneficial to their well-being, while the Travel Grants help subsidize the costs of traveling to FTD-related conferences. The AFTD Quality of Life grants provide those living with FTD assistance to purchase equipment, support or access to services.

Finding FTD support locally is easier than ever through AFTD’s website. People seeking help can now search within their state for support groups, medical centers, useful resources, and ways to get involved. And our network of AFTD-affiliated support group volunteers continues to grow. There are now 105 volunteers leading groups safely online and in-person in communities across the country.
Finding Support: FY 2018 to FY 2019

U.S. States with Support Groups
Led by AFTD-Affiliated Facilitators

39

↑21%
Members of AFTD’s Facebook Group
6,300 total

Website visitors
↑56%
493,790 total

↑18%
Members of AFTD’s Facebook Group for Young Adults

“Grief changes you – it’s there from day one of this journey,” says Elaine Rose, whose husband was diagnosed with FTD and passed away in 2012. As a support group volunteer and contributor to AFTD’s Walking with Grief, published in March, Elaine is committed to helping others navigate the profound changes that come with an FTD diagnosis. Elaine found that listening to others’ stories while helping to write the booklet was its own kind of therapy: “Working with AFTD and hearing others share their journeys gave me permission to grieve the changes in myself and the changes in relationships around me.”
Advancing vital research to better understand the biological basis and progression of FTD has always been central to AFTD’s mission. With the support of our generous donors, passionate advocates, and committed Board, we are advancing the science targeting FTD.

A new and dynamic collaboration between AFTD and Target ALS recently invested $5 million to fund six research partnerships, bringing together researchers from the biotechnology-pharmaceutical industry and academia. Now that we know both FTD and ALS can be caused by a shared mutation of the C9orf72 gene, this unique partnership supports groundbreaking research to identify biomarkers and potential therapeutic targets, develop compounds for clinical trials, and determine specific technologies that can better detect disease progression and the efficacy of therapeutic interventions for these related conditions.

Since 2005, AFTD has supported early-career investigators through our annual Pilot Grants, which provide funding for innovative studies in the field of FTD research. These investigators, in the early stages of establishing an independent research program, are given the opportunity to build a strong foundation on which to continue their work further into their careers. Additionally, the AFTD Postdoctoral Fellowship program is essential to enriching the field of FTD research by supporting the next generation of talented and ambitious investigators studying neurodegenerative diseases.

TreatFTD, a $10 million grant-making initiative between AFTD and the Alzheimer’s Drug Discovery Foundation (ADDF), is designed to bring both novel and repurposed treatments into clinical testing for FTD and related disorders. Two new studies were funded in December 2019. One is testing the safety and efficacy of a pharmaceutical approved to treat Parkinson’s disease, for people with bvFTD. The second study is testing a non-invasive brain stimulation approach called transcranial Alternating Current Stimulation (tACS), to determine whether it can improve behavior and brain activity for people with FTD.

In November, AFTD and ADDF announced a major investment of $1.2 million to the Bluefield Project to Cure FTD through the Diagnostics Accelerator program, which aims to fast track the development of diagnostic tests and novel biomarkers for early, effective detection of distinct but related dementias.

Launched in 2016, the FTD Biomarkers Initiative is a multi-year initiative designed to spur biomarker discovery and validation. In the second round of awards, AFTD funded a three-year, $1.1 million study investigating the role of neuroinflammation as it relates to neurodegenerative diseases, potentially leading to the development of a test.
that could accurately determine disease progression and help to assess disease-modifying therapies.

Since 2007, the AFTD’s Accelerating Drug Discovery for FTD, in partnership with ADDF, has been supporting research to discover and develop pharmaceutical interventions targeted for treating FTD. Our 2019 award recipient, Dieter Edbauer, MD, will study the efficacy of an antibody injection to treat protein aggregation caused by a mutation in the C9orf72 gene, a leading cause of neurodegeneration.

**Awards and grants**

**Basic Science Pilot Grant** – Andrew Arrant, PhD, University of Alabama at Birmingham (US)

**Susan Marcus Translational Research Pilot Grant** – David Butler, PhD, Neural Stem Cell Institute at the Regenerative Research Foundation (US)

**TreatFTD** – Giacomo Koch, PhD, Santa Lucia Foundation (Italy); Emiliano Santarnecchi, PhD, Harvard Medical School (US)

**Basic Science Postdoctoral Fellowship** – Ming-Yuan Su, PhD, University of California, Berkeley (US)

**Clinical Research Postdoctoral Fellowship** – Oriol Dols Icardo, PhD, Institut de Recerca de l’Hospital de la Santa Creu i Sant Pau (Spain)

**Accelerating Drug Discovery for FTD** – Dieter Edbauer, MD, German Center for Neurodegenerative Diseases (Germany)

**Diagnostics Accelerator** – Rodney Pearlman, PhD, The Bluefield Project to Cure FTD (US); Judith Steen, PhD, Boston Children’s Hospital (US)

**FTD Biomarkers Initiative** – Tammaryn Lashley, PhD and Kerstin Sander, PhD, University College, London (UK)

The recipient of the 2019–2021 AFTD Postdoctoral Fellowship for Basic Science, Ming-Yuan Su, PhD is examining a C9orf72 protein complex, which is involved in key aspects of cellular functioning, to better understand the ways in which FTD and ALS progress and develop, potentially illuminating the path to future drug development for the treatment of both diseases. Receiving an AFTD fellowship “has been a prestigious opportunity for me,” she said, and I am very honored that AFTD supports my work and has allowed me and my institution to share our expertise with the people who are affected by FTD and the whole scientific community.”
FTD education is vital to ensuring that persons diagnosed, care partners and families impacted by this disease have better access to support, accurate diagnosis and high-quality care. AFTD works every day to provide reliable information, through print and digital media, to educate the public, healthcare professionals and policymakers.

In response to COVID-19, AFTD moved its 2020 Annual Education Conference online. *The AFTD Education Conference: Webinar Series* was hosted between April 7 and May 7. With the support of generous sponsors and presenters, we featured five webinars delivering content relevant to both FTD and the pandemic.

Over the course of the series, 634 unique viewers tuned in to gain insights on care strategies for persons diagnosed with FTD in a changing world, tips to help manage caregiver stress, the current state of FTD research, practical daily care advice from the perspective of someone diagnosed with FTD, as well as how AFTD is continuing to build a future free of the disease.

During the past year, AFTD published three *Partners in FTD Care* newsletters, aimed at both healthcare professionals and care partners, delivering guidance on such topics as medications and FTD, palliative care options and resistant behaviors in persons diagnosed.

We continue to expand the AFTD Educational Webinar series, in which FTD clinicians and researchers offer in-depth insights and expert advice. Last year, webinars addressed the clinical experience of persons with overlapping FTD and ALS symptoms, as well as the distinct symptoms of corticobasal syndrome and corticobasal degeneration.

Through our education outreach initiative, AFTD staff works closely with volunteers to initiate conversations about FTD with healthcare professionals, using materials and resources developed by staff in partnership with FTD experts. Opening this dialogue is imperative to creating and improving a network of care and support for families affected by FTD in communities throughout the United States.
Sisters and AFTD Ambassadors Joanne Linerud and Susan Meagher began volunteering with AFTD after their mother, who was diagnosed with FTD, passed away in 2016. They are similarly passionate about creating connections with and supporting families who are affected by FTD, and to increasing awareness about the unique challenges it presents. “I really enjoy building a network of resources and support in my area so that no one is left to do this on their own,” Joanne said. As Ambassadors, both sisters look forward to developing contacts with healthcare professionals, service providers, researchers and care partners to ensure everyone knows about this disease and the array of resources AFTD provides.

“I want to pay it forward for others who will need help and I want to be a part of what drives the whole mission forward,” Susan said.

Prior to the pandemic, our volunteers proudly represented AFTD at public events throughout the country, bringing FTD education with them wherever they went!
volunteers and the AFTD-Team

The momentum AFTD has made toward building a future free of FTD is due in large part to the passion, resilience and determination of our volunteers. Whether engaging with healthcare professionals to advance knowledge of FTD, leading support groups to help guide others on this journey, hosting informational meetings within their communities to raise awareness, or fundraising in support of AFTD’s work, volunteers are at the core of what we do every day. Despite the extraordinary challenges brought about by the COVID-19 pandemic, more than 310 volunteers drove our mission forward over the past year, maintaining vital connections and providing mutual support during a time of increased isolation.

Launched in November 2019, our new AFTD Ambassador program will further expand FTD awareness through targeted outreach and networking with local health providers, businesses and community members, engaging them as stakeholders in improving resources, support and care. To date, we have trained 13 volunteers to be Ambassadors, and they work closely with AFTD Volunteer Coordinators Jeni Cardosi and Annamarie Given.

In fall 2019, our flagship Food for Thought campaign brought together care partners, family members, friends and neighbors over good food and drink to increase FTD recognition and raise vital funding in support of AFTD’s mission. Last year, 52 hosts held 47 events in 25 states, raising nearly $161,000!

Timed to coincide with Valentine’s Day, the With Love campaign encourages people affected by FTD to share their stories of love and memories with friends and family, far and wide. The campaign continues to grow – in February 2020, with the generous support of The Mike Walter Catalyst Fund and The Rainwater Charitable Foundation, a record 41 people raised $74,337 in honor of their cherished loved ones.

Nicole DeLeve of Kansas representing AFTD

Volunteer Amy Shillady made and sold candles to support AFTD’s mission!
For many AFTD-Team members, running or walking on AFTD’s behalf is an expression of their strength, hope and determination. Throughout 2019, 240 runners and walkers raised $81,295, proudly sharing AFTD’s mission with thousands of their fellow competitors.

When COVID caused races to be canceled around the country, AFTD quickly found a unique outlet to continue bringing volunteers together. In April 2020, we partnered with the mobile app Charity Miles and encouraged people to walk, bike or run in support of AFTD. In our first three months on the app, 633 participants joined and began tallying up the miles and donations, reaching an astonishing 73,711 miles; and with the generous sponsorship of The Mike Walter Catalyst Fund, they raised $48,467.

No matter the occasion or scale, every opportunity taken by our driven volunteers increases the public’s understanding of FTD and the effects this disease has on so many families. We could not do it without you!

Before signing up for Cincinnati’s Flying Pig Marathon, Abrar Tanveer, above, whose father had FTD, would never have considered himself a runner, let alone a marathoner. But he committed himself to the race, both as a personal goal and to raise awareness and support for AFTD’s mission. “AFTD understands this disease doesn’t just affect one person but affects the entire family – it’s a resource for everyone,” Abrar said. John Kammerer, below, decided to run the same race to honor his father, who is currently living with FTD. Like Abrar, he fundraised on behalf of AFTD, and both young men were surprised to learn that they had attended the same high school. “It’s been great to build a friendship with Abrar and share something positive with him while going through this,” John said. While they were unable to compete in this year’s race, both have continued training and look forward to someday seeing each other at the finish line.

Pictured: Daniel Hare, middle left; Maggie Sepesy, middle right; Norma Morrison, bottom.
Thank you to all of the AFTD-Team members who walked, ran or biked to support AFTD’s mission through the Charity Miles app!
AFTD Named Funds honor or memorialize a loved one. Established with a minimum donation of $25,000, AFTD Named Funds are among AFTD’s most generous gifts. Named Fund donations advance the science of FTD and improve 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

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

The Mimi Fund
Established by her loved ones

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

The Holloway Fund for Help and Hope, in Honor of Lee Holloway
Established by the Holloway Family

Laden Memorial Fund
Established by the Laden Family

Susan Marcus Memorial Fund
Established by Larry and Jillian Neubauer

The Suzy Fund
Established by the Newhouse Family

Shepherd/Stowell Fund In Honor of Care Partners
Established in tribute to all Care Partners and Caregivers

The Mike Walter Catalyst Fund
Established by the Mike Walter Family

AFTD is grateful to everyone who provided support for our mission over the last year. We rely on donations like these to advance FTD research, bring support to families, and raise awareness of this disease.

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Rostair Foundation
Mr. Steven Rulison
Mrs. Jo-Ann Rulison
Mr. Ronald Sakoda
Mr. Mike Sangiacomo
Mr. Tom Saponas/Saponas Foundation
Mr. & Mrs. Nik Sathe
Ms. Beth Schatman
Lauren & Max Seibald
Allison & Mark Sellon
Mr. Donald B. Shackelford
Anna Marie & Robert F. Shapiro
Ms. Beth Sharphey
Ms. Amy Shirland
Mr. & Mrs. Mike Shmerling
The Siegel Family Fund
Ms. Bonnie Sirkin
Mr. David Skahill
Mr. Thomas Stark
Mr. Ryan Steglich
Mr. Brian Stromh
Strong Foundation of New York
A.G. Sulzberger
Mr. Gary R. Surprenant
Tabacco, Lavallee, Heffelfinger, Seaver, Barenbaum P.C.
Over the past year, the AFTD-Team flexed their creative muscles and displayed their passion and energy by hosting an extraordinary 623 grassroots events and Facebook fundraisers. Together, they shared information, educated the public, and raised more than $789,000 in support of AFTD’s mission. (All events listed here brought in $1,000 or more, with the highest-raising events in each category listed first.) AFTD thanks the incredible AFTD-Team for their efforts.

**Independent Events**

Brian Rose, Danny Hedaya, Michael Stowell and Kathy Mele

1st Annual Driving Hope Golf Tournament

George Sidoris and Christine Sidoris

13th Annual George F. Sidoris Memorial Golf Outing

Paul Lester

12th Annual Letters for Arnette

Rob Radtke

Google Giving Week

Lauren Massarella and Michelle Anderson

Hallowpalooza

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*S Denotes $1,000 or more given through recurring donations in FY2020*
Aabbrar Tanveer
Flying Pig Marathon
Jason Strohm, Brian Strohm
and Tracy Ortiz
Run Like Mike
Michael Stowell
2nd Annual Buffalo Trace Charity Open
Deb Scharper
3rd Annual Crusade for a
Cure Golf Tournament
Jacquelyn Breneman
IMO Tom Breneman
Brian Delaney
1st Annual Mary Jo Opening
Dominique Fabich
and Amanda Dawson
Local Heroes
John Kammerer
Flying Pig Marathon
Matthew Hatfield
Robert M. Hatfield 9th Annual Quest
for the Cure Golf Tournament
Cortney Walker Rohr
The Walker Family Golf Tournament
Brian Fox
Cornhusker Auto Wash
Becky Tinsley
IMO Bryan Tinsley
Lauren Rowans
IMO Timmy Rowans
Team Al
2020 Disney Princess
Half Marathon
Moretti and Marcy Families
4th Annual CWM Golf Outing
Paul Petras
Stone Steps 50K Trail Run
Joel McNulty
9th Annual Al McNulty Benefit
Cindy Odell
Custom Ink Hats
Brian Fox
Softball Fundraiser
Brian Strohm
Rock the Parkway
Suzanne and Calvin King
4th Annual “Tami Sue”
Golf Outing & Party
Amy Shillady
Soy Candles
Nicole DeLeve
Tyler’s Troopers
Food for Thought
Steve Bellwoar
Lisa Nolte
Terry Walter and Beth Walter
Elisabeth Lynch and Renee Faller
Emily Anderson and Nanci Anderson
The Pang Family
Taylor Long & Steven Long
Ryan Windhorst
Karen Hosley
Bonnie Shepherd and Catherine Sharpsteen
Nicole DeLeve
Elizabeth Soriero
Diane Cole
Via Facebook
Tanya Steel
Vicki Axe
Lisa Anne
Bob Beede
Lisa Shochat Ades
Noah Axe
Liz Furse
Alejandro Bolivar-Cervoni
JoAnne Duffy Kinyon
Brenda Thornburgh
Becky Tinsley
Shelley Fischel
Michele Moretti
Ilene Kaplan
Lori Preder
Phyllis Jonaitis
Sheryl Lebauer
Whitman
Kim Pandolfi
Halima Amjad
With Love
Faith Ott
Bonnie Shepherd
Scott Rose
Colleen Quinn
Kali Tormoen
Maria Kent Beers and Michelle Fiori
Victoria Tinsley
Jillian Condran
Kimberly Sullivan
Chu
Natalie White
Gina Alderucci
Susan Illis
Kristin Pursley
Melissa Fisher
Race Season
Team Jack Attack
Tamara Blankestijn
Josef Pohl
Anne Collins
Hodsdon
Martha, Bo and Alison
Popkin Shenian
Joe Fischel
Brian Strohm
Barbara Todd
Team Mamma Fish
Patti Del Mamma
Sabrina Solorzano
Laura Kupsch
Morganne Hodsdon
Fenoglio Family
Racers
Tara Huzinec
Bridget Graham
Lucas Rogers
Kacy Kunesh
Sherry Harlass
Via Facebook
Tanya Steel
Vicki Axe
Lisa Anne
Bob Beede
Lisa Shochat Ades
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Morganne Hodsdon
Fenoglio Family
Racers
Tara Huzinec
Bridget Graham
Lucas Rogers
Kacy Kunesh
Sherry Harlass
financial reports  fiscal year ending 6/30/20

Statement of Activities

Revenue and Support

<table>
<thead>
<tr>
<th>Revenue Source</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>$7,481,677</td>
</tr>
<tr>
<td>Special Events</td>
<td>$1,916,356</td>
</tr>
<tr>
<td>Investment and Other Income</td>
<td>$263,201</td>
</tr>
<tr>
<td><strong>Total Revenue</strong></td>
<td><strong>$9,661,234</strong></td>
</tr>
<tr>
<td><strong>Total Expenses</strong></td>
<td><strong>$7,857,293</strong></td>
</tr>
<tr>
<td><strong>Change in Net Assets</strong></td>
<td><strong>$1,803,941</strong></td>
</tr>
</tbody>
</table>

Expenses

- 55% Research
- 14% Education & Support
- 12% Awareness & Advocacy
- 10% Fundraising
- 9% Management & General

Statement of Financial Position

Assets

<table>
<thead>
<tr>
<th>Asset Type</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash &amp; Cash Equivalents</td>
<td>$7,698,944</td>
</tr>
<tr>
<td>Contributions Receivable</td>
<td>$10,894,890</td>
</tr>
<tr>
<td>Investments</td>
<td>$5,183,886</td>
</tr>
<tr>
<td>Other Assets</td>
<td>$110,863</td>
</tr>
<tr>
<td><strong>Total Assets</strong></td>
<td><strong>$23,888,583</strong></td>
</tr>
</tbody>
</table>

Liabilities and Net Assets

<table>
<thead>
<tr>
<th>Liabilities</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accounts Payable &amp; Accrued Expenses</td>
<td>$189,482</td>
</tr>
<tr>
<td>Deferred Revenue</td>
<td>$640,000</td>
</tr>
<tr>
<td>Research Grants Payable</td>
<td>$1,831,754</td>
</tr>
<tr>
<td>Payroll Protection Program Loan</td>
<td>$300,500</td>
</tr>
<tr>
<td><strong>Total Liabilities</strong></td>
<td><strong>$2,961,736</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Net Assets</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Net Assets without Donor Restrictions</td>
<td>$5,284,684</td>
</tr>
<tr>
<td>Undesignated</td>
<td>$4,959,454</td>
</tr>
<tr>
<td>Board Designated</td>
<td>$10,682,709</td>
</tr>
<tr>
<td><strong>Total Net Assets</strong></td>
<td><strong>$20,926,847</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Total Liabilities and Net Assets</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Liabilities and Net Assets</strong></td>
<td><strong>$23,888,583</strong></td>
</tr>
</tbody>
</table>

The Association for Frontotemporal Degeneration is a 501(c)(3) organization.

HelpLine: 866.507.7222 or info@theaftd.org | Office: 267.514.7221

2700 Horizon Drive, Suite 120, King of Prussia, PA 19406
In a challenging year for so many, I want to share a message of hope with you. Hope that we can put this pandemic behind us soon. Hope to advance AFTD’s mission and realize our vision – to the benefit of so many families.

Hope starts with AFTD’s donors and volunteers, each of you helping to build a future in which FTD is comprehensively understood, accurately diagnosed, and effectively treated. Your commitment provides hope for a world in which this disease is cured – and even prevented. Your dedication brings that reality closer day by day.

With your help, AFTD has grown to become a global leader in the fight against FTD. Today, more than 105 AFTD volunteers provide vital support groups for other families facing FTD, so that no one faces this journey alone. Together, we raise our voices to advocate for improved resources. Together, AFTD’s Ambassadors and hundreds of other care partners, family members and people with FTD drive education and awareness, sharing FTD stories through local and national media outlets to ensure that the most common form of dementia under 60 is more widely known year to year.

Together, we invest in and drive groundbreaking research that could dramatically change the landscape of diagnosis and treatment for FTD. A growing number of innovative biopharmaceutical companies are set to advance clinical trials for FTD therapies—trials that will be driven by the passion of the families who enroll. And our partnerships – with the Alzheimer’s Drug Discovery Foundation (ADDF), Target ALS, and ADDF’s Diagnostics Accelerator – are funding work that could move the needle for not only FTD, but other forms of dementia and neurodegenerative disease. Researchers and health professionals targeting FTD have adapted to new and difficult working conditions this year with poise, creativity, and determination.

I am proud to share with you that this coming March, AFTD will be hosting a virtual Patient Focused Drug Development meeting with representatives from the FDA. I hope that you’ll join us as we bring voices from our community to ensure that the research priorities of all whom we serve inform the FDA’s understanding of this disease as it considers approval for potential treatments.

While my message is one of hope, I want to acknowledge the losses experienced by our families this year. There are many for whom the future we seek will arrive too late. AFTD’s Board and staff dedicate our work to the memory of those who have been lost, and we carry it forward in honor of the people and families struggling today. Your experience does not go unwitnessed – and your voices and your passion drive our unwavering commitment to realizing a future free of this disease.

With warm wishes for the holidays and the year ahead –

Susan L-J Dickinson, MSGC
AFTD Chief Executive Officer
AFTD leadership

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Jeff Thompson
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Brittany Andrews
Fundraising Coordinator
Jeni Cardosi
Volunteer Coordinator
Annamarie Given
Volunteer Coordinator
Emma Tomasetti
Development Coordinator
Emily Bradley
Development Assistant
April Scott
Administrative Assistant
Elizabeth R. Young
Executive Assistant
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.