



AFTDnews

Newhouse and Holloway Gifts to Advance AFTD's Mission



Donald and Susan Newhouse

AFTD is grateful to announce the creation of two new funds, supported by generous gifts from Board members, that will help AFTD expand, innovate, and drive our mission to create a future free of FTD.

The Board members, Donald E. Newhouse and Kristin Holloway, have both had their lives unalterably affected by the disease, and are passionately

dedicated to making the journey easier for other families.

Mr. Newhouse created The Donald and Susan Newhouse Fund with a gift of \$20 million, the largest single donation in AFTD's nearly two-decade history. The Fund is named in honor of his late wife, who died of FTD, as did Mr. Newhouse's brother, Si.

Kristin Holloway has created The Holloway Family Fund, supported by an initial gift of \$2 million and with a plan to donate \$1 million each year for an additional eight years. The fund aims to further the understanding of FTD; drive basic, clinical and translational research; and accelerate the path toward effective treatments and cures.

The Donald and Susan Newhouse



Lee and Kristin Holloway

Fund will accelerate and deepen the organization's work across our mission areas of research, support, education, awareness, and advocacy. The gift is unrestricted, and will be allocated after planning by Board and staff. In its scope and generosity, it will empower AFTD to deepen and broaden the vision of our current strategic plan (available online at theaftd.org/strategic-plan).

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FTD Disorders Registry Announces Its First Strategic Plan

Since 2017, the FTD Disorders Registry has provided a secure, centralized platform for persons diagnosed, caregivers, and families to connect to research participation opportunities and share their day-to-day experiences of living with FTD. Each story advances the research of FTD to hasten treatment development.

The Registry (ftdregistry.org) now presents its first formal Strategic Plan, designed to expand its reach and continue providing value for participants and researchers. Four strategic pillars and goals inform the plan: Infrastructure, growth, partnering and collaboration, and sustainability.



**FTD DISORDERS
REGISTRY**

"This is an important moment for the Registry," said AFTD Senior Director of Scientific Initiatives Penny Dacks, PhD. "The Strategic Plan, developed in collaboration with our partners, allows us to evolve from a start-up into a long-term sustainable organization with a worldwide reach."

"The first pillar of the Strategic Plan involves creating a more robust infrastructure that includes genetic data," said Registry Director Dianna Wheaton, MS, PhD, CHES.

Dr. Dacks, who also serves as president of the Registry, added, "We're already HIPAA-compliant, but a technology upgrade is needed for the Registry to better reach international communities."

(Continued on page 8)

Spotlight on...Kristin Schneeman, AFTD Board of Directors

Kristin Schneeman began her relationship with AFTD in 2019, when she led a discussion on the concept of “patient-driven philanthropy” for the AFTD Board. Since then, she has served as a member of AFTD’s Research Committee, where she provided her expertise and insight on ways that nonprofits and other disease-focused organizations can have a greater impact on engaging the people and community they serve.



Kristin Schneeman

“I bring this broader perspective of how foundations are engaged in research and development that seemed like it could be useful,” she said. “I felt like I had something to offer to help [AFTD] move its mission along.”

Since 2005, Schneeman has been

Director of Programs at FasterCures, a Washington, DC think tank that is part of the Milken Institute’s Center for Accelerating Medical Solutions. Through her work, Schneeman and her team focus on how patient-driven philanthropy can act as a catalyst for accelerating change in the medical research ecosystem.

While Schneeman has worked

“I felt like I had something to offer to help [AFTD] move its mission along,” said Schneeman, whose father had FTD.

alongside other healthcare organizations, she was particularly drawn to AFTD because of her own connection to the disease: Her father, Dr. Peter Schneeman, died of FTD-related complications in 2007.

“My father had a diagnosis and we

[didn’t] know a whole lot more than that,” she said. “Now that we know what his situation was, we’re fairly confident that his mother and brother had the same condition, so we may have a familial variant.”

As an AFTD Board member, Schneeman hopes to continue to provide more of her professional knowhow to the organization while “filling in the gaps in the research landscape” to help further AFTD’s mission.

She is also eager to learn more about AFTD’s existing work in advocacy, education, and support for caregivers and persons diagnosed.

Historically, she said, AFTD has been “very thoughtful about its role and its approach in doing a lot of important things.”

Schneeman lives in Connecticut with her husband, Ezra Greenberg, and their daughters.

AFTD NEWS BRIEFS

AFTD Awards 2020 Pilot Grants

AFTD Pilot Grants – our longest-running funding program – provide critical support to early-career investigators and encourage them to become lasting contributors to FTD research. The 2020 Well-Being in FTD Pilot Grant was recently awarded to Allison Lindauer, PhD, of Oregon Health & Science University. Dr. Lindauer’s project will customize an existing telehealth program (STELLA) to address the unique needs of FTD caregivers, based on input from the caregivers themselves. Maria Catarina Silva, PhD (Massachusetts General Hospital), was awarded the 2020 Basic Science Pilot Grant to study a class of drugs that ramp up the process responsible for removing damaged or dysfunctional proteins, known as autophagy, to determine if – and how – they reduce the abnormal accumulation of the FTD-associated protein tau.

A Successful AFTD Virtual Volunteer Leadership Summit!

AFTD’s inaugural team of Ambassadors recently gathered with staff for a 4.5-hour virtual volunteer leadership summit. Volunteer expert and AFTD consultant Sheri Wilensky Burke facilitated the successful meeting. Kerri Keane, AFTD Volunteer Manager, said, “Time was well spent equipping our leaders as representatives to broaden and expand their reach across the country.” Some of the topics covered included strategies for achieving goals, building relationships, and having a positive impact during COVID-19. “It is a great feeling to know that I am part of a winning team of wonderful, caring people,” said AFTD Ambassador Jerry Horn of Alabama, while Ambassador Melissa Fisher of Oregon said, “I walked away inspired and feeling valued.”



"Raising awareness is so important to dispelling the assumptions about people with FTD – I wish for people to see my dad the way I see him."

Kristin Pursley, FTD care partner

Kristin Pursley describes her dad, Bryce, as "a modern Renaissance man." He loved co-directing and singing in his church choir with his wife, Karla; watching sports; and enjoying the outdoors with his family. Some of Kristin's favorite memories with her dad include swapping Carolina Panthers and UNC Tarheels game highlights, as well as soaking up the summer sun on the beaches of North Carolina.

Gradually, she started to notice concerning changes in his behavior and that her dad was becoming less interested in what had once given him so much joy. Shortly after leaving his career as a Senior Systems Programmer for a prominent North Carolina power company, Bryce was diagnosed with bvFTD at the age of 59. Determined to cherish every moment with him, Kristin moved in with her parents to help care for her dad.

"The first few years I was home with him, he would play piano music throughout the day," she said. "We sang a duet together before he stopped playing – I am so grateful for that."

For Kristin, being a care partner for someone with FTD is a journey of loss and grief, but also one that is filled with love and compassion. "I now understand what it is to miss someone so profoundly and deeply, even when they're right next to you," she says. "Being involved with AFTD allows me to feel engaged and be proactive in raising awareness on behalf of my dad."

Through AFTD, Kristin has found resources and participated in webinars to help her care for her dad, as well as a community that is advocating for all who are impacted by FTD. She hopes that with more awareness, persons diagnosed and their families will have increased access to high-quality support services, and that research will lead to an end to this disease.

As a care partner and AFTD grassroots event host, Kristin is all in to end FTD: "I chose to share my dad's story through AFTD's With Love campaign because I believe love is more powerful than any disease. I want to show how much my dad is loved, and to be an advocate for him and others who are affected by FTD."

Will you join Kristin in supporting AFTD's mission? Together, we can demonstrate the power of a community that is all in to #endFTD. By making a tax-deductible gift of any amount, you can help us to improve the quality of life of people affected by FTD and drive research to a cure. Simply use the enclosed envelope or visit theaftd.org and **click on the Donate+ button** at the top of the page.

AFTD Hosts Successful Externally Led Patient-Focused Drug Development Meeting

AFTD hosted an Externally Led Patient-Focused Drug Development (EL-PFDD) meeting on March 5, allowing persons diagnosed and current and former caregivers a valuable one-time opportunity to inform the development of federal regulatory processes for potential FTD therapeutics.

An estimated 550 people joined the interactive livestream, hosted by AFTD CEO Susan L-J Dickinson and James E. Valentine, who previously worked with the FDA.

“To the people and families from around the world who live the FTD journey every day, this meeting is for you,” Dickinson said during the meeting. “It’s your chance to ensure that the FDA understands the urgent need for FTD treatments, which symptoms you find the most

burdensome, and what you would want most from an approved therapy.”

EL-PFDD meetings help to ensure that the experiences, perspectives, needs, and priorities of persons affected by a specific disease are captured and meaningfully incorporated into the FDA’s drug-regulation process. These

The AFTD-led PFDD meeting featured live input from persons diagnosed, as well as current and former caregivers.

meetings help the FDA to understand what it’s like to live with a particular disease with an insider’s perspective of its symptoms and how they affect daily living.

The AFTD-led PFDD meeting featured live input from persons who are either diagnosed with FTD themselves or who are current or

former caregivers. Participants answered live FTD-related polling questions; many called in to share personal stories of themselves or loved ones. Viewers were also able to send in written comments about their experiences. (Visit tinyurl.com/AFTD-PFDD to learn more.)

Following the EL-PFDD meeting, AFTD will prepare a report summarizing these testimonies. Known as a “Voice of the Patient” report, these summaries are a key resource for FDA regulators to help better understand what people living with FTD and their care partners/caregivers most want to see in treatment options.

The Voice of the Patient Report will be publicly available on AFTD’s website for review.

AFTD thanks the sponsors of our Externally Led PFDD meeting:

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AFTD Convenes 2021 Education Conference

As this issue goes to press, AFTD is preparing our 2021 Education Conference. By the time you receive this newsletter, the conference will likely have just taken place.

Scheduled speakers at the 2021 Education Conference include Tia

Powell, MD, director of the Montefiore Einstein Center for Bioethics; Chiadi Onyike, MD, MHS, director of the FTD and Young-Onset Dementias Program at Johns Hopkins University; Adam Staffaroni, PhD, assistant professor in the Department of Neurology, Memory and Aging Center at the University of California San Francisco; and Elizabeth

Finger, MD, assistant professor of Neurology in the Schulich School of Medicine & Dentistry at Western University.

The 2021 Education Conference spanned two afternoons, May 13-14, and was held entirely online. For more information about the conference, and access to its video archives, visit theaftd.org/education-conference-2021.

Newhouse and Holloway Gifts

(Continued from page 1)

“To face an FTD journey is to fervently wish that no one should ever face one again,” said AFTD Board Chair David Pfeifer. “Don’s generous gift reflects the urgency of a community of thousands of donors and volunteers unwilling to accept the fundamental lack of treatments for FTD today.”

“As my Suzy would have wanted, I have committed myself to do what I can, so that others do not suffer as she did,” Mr. Newhouse said. “AFTD proved to be the most effective vehicle for carrying out my commitment, and my collaboration with this organization, and generous board members like Kristin Holloway, is a labor of love.”

The Holloway Family Fund will first fund an expansion of AFTD’s postdoctoral fellowship program. These fellowships seek to attract the best young minds in science to FTD, and inspire a new generation of researchers to dedicate their careers to advancing FTD science. An announcement is forthcoming for the 2022 Clinical Research Training Scholarship in FTD – the first award of its kind – funded by the Holloway

Family Fund and the American Brain Foundation in collaboration with the American Academy of Neurology.

“FTD has taken center stage in our family’s life since my husband, Lee Holloway, was diagnosed in 2017,” said Ms. Holloway. “Lee was a brilliant technologist and entrepreneur

Generous gifts from Board members Donald E. Newhouse and Kristin Holloway will help AFTD expand, innovate, and drive our mission to create a future free of FTD.

who excelled at building technical infrastructure to solve hard problems.

“It is vital to find better ways to support research and expand the medical community’s understanding of this disease so that FTD can be treated, and eventually cured,” she continued. “Focusing the fund on research was important to our family, and builds on Lee’s inherent gift to create solutions for tough problems.”

The Holloway Family Fund will also support an annual research summit to convene medical professionals and researchers, and encourage

collaboration around a specific, emergent issue. The first summit, envisioned for early 2022, will seek to accelerate development of digital biomarkers for FTD. The emergent field of digital biomarkers is harnessing advances in technology to enable researchers to collect physiological data via remote monitoring—like a smart watch or phone—and thus enable participants to provide more, real-life data without having to get to a clinic.

“Kristin’s role on AFTD’s Board – and her philanthropic commitment in establishing the Holloway Family Fund – reflect strong resilience and determination brought into action,” said AFTD CEO Susan L-J Dickinson, MSGC. “I’m hopeful that her gift will bring new awareness of FTD’s impact on the lives of so many.”

Mr. Newhouse said, “I draw inspiration from seeing Kristin and her family dedicate themselves so boldly to this mission, and I hope that it will encourage others who have seen loved ones impacted by dementia join us in bringing an end to the devastating form known as FTD.”

Those We Honor... Those We Remember

Gifts received from October 1, 2020 – January 31, 2021

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Donations in the name of a loved one bring help and support for families affected today – and hope for a future without FTD.

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Honor a Loved One or Remember Their Legacy

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FTD Disorders Registry (Continued from page 1)

“We need to cultivate, engage and retain new diagnosed persons and caregivers,” Dr. Wheaton said, referring to the second pillar – growth. “By the end of 2022, we want to double Registry enrollment, with a major outreach to underserved communities in the U.S. and across Asia and Africa.”

Pillar number three is an ambitious effort to enhance partnerships and collaborations, establishing the Registry as the global go-to resource for FTD researchers. “And achieving sustainability through long-term business planning is the final pillar

for expanding revenue streams and partnerships and ensuring longevity,” Dr. Dacks said.

The Registry has recruited more than 4,200 participants, providing them

Four strategic pillars and goals inform the plan: Infrastructure, growth, partnering and collaboration, and sustainability.

with information on research studies and clinical trials. But the Registry’s “most significant accomplishment,” Dr. Wheaton said, “is a collaboration with the ALLFTD Research Consortium.

Together we built a custom portal on the Registry website where patients now enroll in the five-year ALLFTD study.”

“Every success brings us one step closer to conquering FTD. We honor the courage of our community as they work with us towards a cure,” Dr. Dacks said.

Dr. Wheaton encourages anyone diagnosed with FTD, their current or former family members, caregivers, and friends to register and help contribute to the science of FTD.

Dr. Fauci Discusses COVID-19 Vaccine, Dementia Care with NAPA Council

Longtime AFTD volunteer Katie Brandt, MM, sat down with Dr. Anthony Fauci to discuss the importance of the COVID-19 vaccine as it relates to persons with dementia during a January 25 meeting of the National Alzheimer’s Project Act (NAPA) Advisory Council.

In their conversation, Dr. Fauci addressed concerns over any potential risks involved with people diagnosed with dementia in taking the vaccine. He explained that there are “likely not” any additional risk factors in persons with dementia outside of the expected side effects, such as inflammation.

“There’s very little significant inflammatory response after the first shot, considerably more after the boost” he said during the discussion. Nevertheless, he added, “I wouldn’t hesitate” to vaccinate a person with dementia just because “you’re concerned that the inflammation associated with the vaccine is going to be harmful to them.”

Brandt — co-chair of the NAPA Advisory Council and the Director of Caregiver Support Services and Public Relations at Massachusetts General Hospital’s Frontotemporal Disorders Unit — told AFTD that she felt it important to have Dr. Fauci

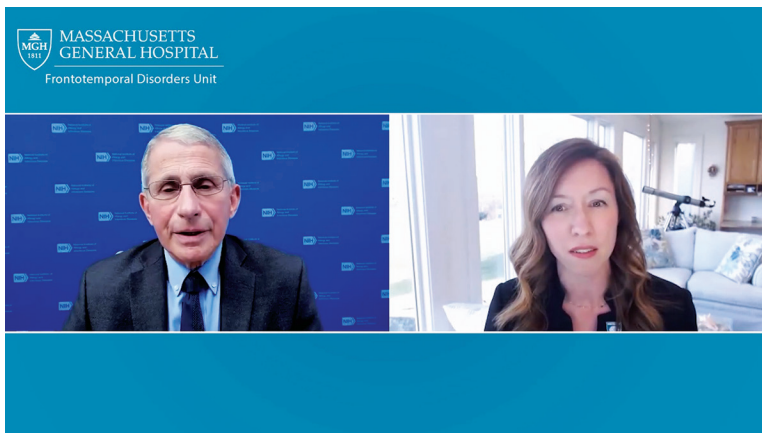
families about their goals of care, their values, and their loved ones’ values around taking vaccines.”

Brandt also noted some concerns she has heard in response to the rapid development of the vaccine, a point that Dr. Fauci addressed during the conversation.

“As Dr. Fauci spoke to, it’s because of the incredible advances in science in the past few years around vaccine technology, the incredible dedication, the money, and the time that was put into this -- that’s what propelled it forward at such an incredible speed,” Brandt said. “Never have people had to work at this

level to get something done.”

Brandt said she was “so appreciative” of Fauci for allotting time for the conversation. “Not only was Dr. Fauci so incredibly sharp and thoughtful about these big critical issues for our FTD and related dementia community — he was also incredibly generous and kind,” she said.



quell the concerns associated with taking the vaccine.

“In my work, I have noticed that there are caregivers who have hesitancy about it,” she said. “They are worried that it’s a new vaccine and questioned if will it make [their] loved ones’ dementia worse. I tried to think about how [I could] talk with

Giving a Hand to Our Helping Hands!

AFTD Volunteer: Dawn O’Gara

When Jim Tobin was finally diagnosed with bvFTD, his daughter Dawn O’Gara quickly realized that where they lived in central Massachusetts was bereft of clinical and caregiving resources.

“No one here had even heard of FTD,” Dawn said. “My family felt isolated and realized there must be other FTD families in the region who also needed a community to lean on. I decided to help fix the problem by volunteering for AFTD.”

Volunteering was second nature for Dawn, who had been a Girl Scout Leader and a Special Olympics coach. “Working with special-needs children taught me to look at the world from their perspective,” Dawn said.

Since becoming an AFTD volunteer, Dawn has worked to raise critical

awareness in her community, including ensuring FTD is part of the conversation in her local dementia-friendly community. She also recently appeared on Caregivers Solutions Info with Marcia Teele, an online show in which she shared her experience and advice on FTD caregiving.

“Many caregivers I speak with put up a good front, [trying] to stay strong for their loved ones,” Dawn said. “I draw them out to reveal their deeper truths and emotions and provide a safe place to feel human.”

Dawn has also served as a Food for Thought Liaison, supporting volunteers across the country as they plan and host events in support of AFTD’s annual Food for Thought campaign. “Dawn’s commitment and dedication inspired many to tell



Dawn O’Gara

their stories, raise awareness, and encourage funds for AFTD’s mission,” said Brittany Andrews, AFTD’s Fundraising Coordinator.

Recently, Dawn took on a new volunteer leadership position as AFTD Ambassador. “Before volunteering, I felt helpless confronting this relentless disease,” she said. “As an AFTD volunteer, I have learned that compassion, whether you’re providing it or receiving it, heals everyone.”

AFTD Appreciates Our Volunteers!

National Volunteer Appreciation Week was April 18-24, and we’d like to take this opportunity to express a heartfelt thank you to our volunteers! Not only do our volunteers generously devote their time, they share their experiences, knowledge, and wisdom with others on the FTD journey.

We especially thank them for stepping up in a year that has delivered unforeseen difficulties, particularly for those impacted by FTD. Throughout the pandemic, our volunteers continue to offer the gifts of connection, encouragement,

awareness, education, and leadership to ensure the next family receives the help they need.

We especially thank our volunteers for stepping up in a year that has delivered unforeseen difficulties, particularly for those impacted by FTD.

Thank you to our Ambassador team, leading the charge and diligently networking with local professionals and organizations.

Thank you again to those who hold spaces of comfort and compassion as support group volunteers and to those who bring people together for

connection through Virtual Meet & Greets, Zoom support, and volunteer orientation.

Thank you to everyone who has hosted a grassroots event, raising critical funds to support families and research into improved diagnosis and treatment of FTD.

Thank you to all who have shared their stories, spread awareness, and educated their communities about FTD and AFTD.

To everyone who drives AFTD’s mission through the gift of their time and talents, we say: Thank you.

THE AFTD-TEAM

With Love

In February, AFTD hosted the 10th anniversary of our annual fundraising and awareness campaign, With Love—an opportunity for our community to share their stories of love, bring awareness to this devastating disease, and raise crucial funds toward creating a future free of FTD.

To commemorate this milestone, we asked community members to share their stories in a creative way. 35 people responded by posting pictures with their loved ones, penning poems from the heart, singing songs inspired by the campaign, and detailing their FTD journeys and the love they've shared throughout the years. Through this year's campaign, With Love hosts raised over \$85,000 altogether!

AFTD would like to extend a heartfelt thank you to everyone who contributed to With Love's success this year. We are grateful for our two generous sponsors, The Mike Walter Catalyst Fund and The Rainwater Charitable Foundation; the hundreds of people who made donations; and, of course, our 35 fundraisers, who bravely shared their stories of love.

Anthony Cordasco*

Bonnie Shepherd*

Carol Almeranti*

Carrie Benton

Catherine Gardner*

Christe Konopitski

Dave Andrews*

Denise Parker

Niki Toscani & Mike Sininski

Hannah Moore*

Jessi Feaster

Jillian Condran

John Kammerer*

Julie Bak

Julie Kelly*

Karine Adalian

Kat Primeau*

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Steven Wilson

Susan Scarff

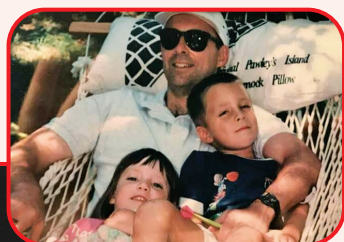
***Fundraisers that raised over \$1,000 for AFTD's mission.**

With Love 2021 Partners with "Remember Me" Podcast

Throughout the With Love campaign, we partnered with the Remember Me podcast series to help celebrate our 10th anniversary milestone and share the stories of our community members. Remember Me, created by Maria Kent Beers and Rachael Martinez (both of whom had a parent with FTD), features FTD stories with a focus on remembering individuals for who they were before the disease.

To kick off the collaboration, AFTD CEO Susan L-J Dickinson sat down with the two hosts to talk about AFTD's mission and community resources, as well as recent advancements in FTD research and ways to support and engage with AFTD.

We want to extend a sincere thank you to Sophia Werning, John Kammerer, Kimberly Sullivan Chu, and Scott Rose, for generously telling their stories on the podcast, and also raising \$12,000 together through the With Love campaign. We are grateful to hosts Maria and Rachael for their efforts and their collaboration in telling these stories of love.



remember me



The Big 1-5: The 15th annual George F. Sidoris Memorial Golf Outing was scheduled to be held on July 18, 2020 at the Lost Nation Municipal Golf Course in Willoughby, Ohio. While it ended up being canceled due to the pandemic, the Sidoris family did not stop there! Through a letter-writing campaign, they sold 15th anniversary edition "GFS Memorial" t-shirts, raising \$10,125 for AFTD's mission. This event is AFTD's longest-running grassroots fundraiser and has donated over \$244,000 to our mission in its 15-year history.

Letters for Arnette: Former AFTD Board Member Paul Lester hosted his 14th annual letter-writing campaign in memory of his late wife, Arnette. He sent both paper and electronic versions of his letter, with the help of our online fundraising platform Classy. After all letters were sent out, his campaign raised a total of \$10,856. Over the past 14 years, his letter-writing campaign has raised more than \$160,000 towards the fight against FTD.

Golden Anniversary: Barbara and Mike Todd were married on October 30, 1970. For their 50th wedding anniversary, Barbara asked family and friends to donate to their online fundraiser to honor their special day and to honor Mike, who was diagnosed with FTD five years ago. Through the fundraiser, they were able to raise \$7,898 for AFTD's mission.

Bar Mitzvah Project: To celebrate his Bar Mitzvah, Hunter Javeline wanted to complete a Chesed project—"Chesed" meaning "kindness" in Hebrew—and chose AFTD as the organization he wanted to support. Hunter's grandmother, Sheryl, had FTD and passed away in October 2018. Hunter's original goal was \$1,012 to honor his grandmother's birthday of October 12th. The fundraiser surpassed its original goal and raised \$4,523 for AFTD's mission.

Turning 30: Alejandro Bolivar-Cervoni requested donations online for his 30th birthday to honor his mother and remember his uncle who are/were both affected by young-onset dementia. He raised a total of \$3,668 for AFTD's mission.

Eroding Beauty: The Very Reverend Tracey Lind hosted a photo exhibit at Foothill Galleries in Cleveland Heights, Ohio, titled "Eroding Beauty: A Retrospective Photography Exhibit" from September 15 through November 1, 2020. She donated 10 percent of sales to AFTD, in coordination with gallery owner Michael Weil, and was able to donate \$2,280 through the exhibition.

Charity Miles - A Year in Review

In April 2020, we announced our partnership with the Charity Miles app as a response to the COVID-19 pandemic and a chance for members of our community to foster a virtual connection with our mission and each other. The smartphone app enables donations by tracking miles moved through daily workouts, and turns those miles into a fundraiser for AFTD.

We are incredibly grateful to the 990 AFTD-Team members who downloaded the app and made their miles matter, as they completed 366,000 miles by running, walking, biking, and hiking in their local communities.

AFTD would also like to extend our sincere gratitude to the three sponsors that supported our team members in the last year. In April and May 2020, The Mike Walker Catalyst Fund sponsored miles that members logged at \$1/mile, raising over **\$47,000** designated to AFTD's support programs and grants. In July, every mile logged was sponsored by Alector at \$1/mile, raising **\$20,000**. And lastly, throughout March 2021, Arden Courts sponsored the AFTD-Team for \$1/mile, to secure a donation of **\$10,000!**

Through the Charity Miles initiative, the AFTD-Team has raised over \$77,000 together! To all our team members logging miles, thank you for your continued support through this partnership.



Laura Gamberdella



Travis Gause



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