AFTDnews

AFTD's 2021 Education Conference Offers Resources, Support, Hope



AFTD's 2021 Education Conference, held on May 13 and May 14, took place entirely online, with more than 1,200 registrants from around the world taking the opportunity to find help and share hope.

For those unable to watch the conference live, most sessions from this year's

Education Conference were recorded and can be viewed at aftdconference.org.

Dr. Tia Powell, author of Dementia Reimagined: Building a Life of Joy and Dignity from Beginning to End, opened the Education Conference with her session, "Transforming

Funded by the

the Culture of Dementia Care."

Dr. Powell, the director of the Montefiore Einstein Center for Bioethics at the Albert Einstein College of Medicine, spoke about steps

> necessary to deliver the most efficient, high-quality care to persons diagnosed, emphasizing the need to adequately

train, support, and compensate professionals who provide dementia care.

"The pay for people [working] in dementia is poor," she said. "At the same time, there's a growing need. There are more and more people, not fewer, getting dementia."

(Continued on page 4)

INSIDE THIS ISSUE

Spotlight on
Rita Choula2
News Briefs2
Summer Appeal3
Education Conference4
New AFTD Grants5
Donations 6-7
Global Conversation on FTD8
NYS Advocacy Day8
Helping Hands9
Volunteers9
The AFTD-Team10-11

ALLFTD Study Recruiting Participants to Help Further Understanding of FTD

Find help and share hope online: Most of the sessions

from AFTD's 2021 Education Conference are available to

watch at aftdconference.org.

ALLFTD, the North American consortium of FTD-focused research centers, is recruiting participants in a longitudinal study that aims to examine how FTD progresses and presents itself over the long term to better prepare for clinical trials.

Rosen of the University of California, San Francisco (UCSF). Drs. Boeve and Rosen are members of AFTD's Medical Advisory Council.

Launched in 2020, ALLFTD combines two

More participation will allow researchers to better understand the natural FTD history, develop biomarkers, and create an FTD clinical trial network.

FTD - f c research
A d v a r

FTD-focused research studies:
Advancing
Research and
Treatment for

Frontotemporal Lobar Degeneration (ARTFL) and Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects (LEFFTDS).

(Continued on page 5)

National Institutes of Health, ALLFTD biomarkers, and create at comprises 18 site centers that enroll persons diagnosed with a variety of FTD-related disorders and syndromes. The cooperative study is co-directed by Dr. Brad Boeve of the Mayo

Clinic and Drs. Adam Boxer and Howard

Spotlight on...Rita Choula, AFTD Board of Directors

Before Rita Choula's mother died last October following a decade-

plus journey with behavioral variant FTD last year, she told her daughter to do two things: be bold and take risks. Choula says that her mother's advice will guide her tenure on the AFTD Board, which began earlier this year.



Rita Choula

"That [advice] is so applicable to the work we are doing at AFTD," Choula said. "AFTD is a small – but powerful

and mighty – organization. I [couldn't] turn away from this. I can't have walked this journey and have gone through what my family

went through to turn my back and say, 'it's over."

Choula said that she is motivated to help further AFTD's mission due to her family's struggle to obtain a correct diagnosis for her mother, Theresa Bryant. Neurologists originally diagnosed Bryant with Alzheimer's. But Choula, Director of Caregiving at

the AARP Public Policy Institute in Washington, D.C., knew enough about the disease and its symptoms to question that assessment. Bryant was finally diagnosed with bvFTD at age 60, and died at 72.

The family's inability to get an accurate

early diagnosis "took away a lot of opportunity for us to just be with her," Choula said. "So much of our journey

Working with fellow AFTD Board members "is a passion for me, to be able to turn and give back so that other families don't have to walk down that same journey."

was me figuring it out and having to educate professionals on it."

Reflecting on her personal and professional experiences in dementia caregiving, Choula said that the chance to join AFTD's Board is an "opportunity and a calling" she could not ignore. "This is a passion for me, to be able to turn and give back so that [other families] don't have to walk down that same journey – or that journey doesn't have to be as difficult as mine was."

She also aspires to continue conversations that center the perspectives and experiences of Black, Indigenous, and people of color (BIPOC) and other underrepresented identities among the community AFTD serves.

"It's about elevating BIPOC leaders within these caregiving communities

and engaging with diverse professional organizations to make sure they're aware and are able to send their messages out," Choula said. "I

want to continue sharing the stories of diverse individuals and families that are living with FTD. If we don't know certain things, we don't know how to engage. If we're asking people to share their story and we want to develop and build a welcoming family, we have to welcome all."

AFTD News Briefs

AFTD to Begin Strategic-Planning Process

AFTD staff and Board have begun the process that will result in a new organizational Strategic Plan, which will guide AFTD's work and establish our priorities beginning in July 2022. Numerous stakeholders and experts, many of whom have lived experience of FTD, will contribute to its development. The most recent AFTD Strategic Plan, which took effect in January 2019, has lent clarity to AFTD's work in our mission to improve the quality of life of people affected by FTD and drive research to a cure; it is available to download under the About Us tab on theaftd.org.

AFTD Welcomes New Ambassadors

In December 2019, AFTD launched a new volunteer leadership position: AFTD Ambassadors, who represent AFTD within a defined geographic area, working to raise awareness, educate, and build connections at the local level. For the first time since establishing this role, the Ambassador team is expanding! Our newest Ambassadors are Dr. Jerry Lazarus (NC), Dawn Ducca (MI), Marc Toles (MI), Dawn O'Gara (MA) and Susan Eissler (TX). AFTD's Ambassador team now totals 14 dedicated individuals across 12 states. We are grateful to all our Ambassadors for their time, energy, leadership, and commitment to supporting AFTD's mission.



Finding Support and Giving Back

"AFTD is helping more people understand what it is like to live with FTD, and giving hope to the people who need it."

- Reverend Randy Ledbetter, FTD care partner

Randy and Bobbie Ledbetter in 2019

In 2015, Bobbie Ledbetter, an early childhood educator for nearly four decades, began to have trouble recalling familiar words and phrases. Her husband Randy remembers a psychologist saying she simply needed to brush up on her vocabulary skills. "As someone who had been a teacher for 40 years, her vocabulary was not the issue," Randy said. "She used to get upset with me for finishing her sentences, but it became something I need to do."

Word-finding and memory lapses grew concerning enough for Bobbie and Randy to seek medical advice. In 2018, when Bobbie was 75, a neurologist diagnosed her with the logopenic variant primary progressive aphasia form of FTD.

"After Bobbie's diagnosis, the neurologist told us that there was nothing we could do about her condition. There was no way to stop what was going to happen," Randy said.

Determined to understand more about his wife's diagnosis, Randy used AFTD's website

to help him prepare for their future. He is now a member of a support group in the Houston, Texas area.

"We talk about what we are experiencing, and I learn what to possibly expect from this disease," Randy said of his support group. "It is nice to be with others who are going through a similar experience, and to know you are not alone."

He also uses resources such as AFTD Educational Webinars and recorded sessions from our 2021 Education Conference to help him better understand how Bobbie's disease might progress, and how to best continue to support and care for her. "AFTD can educate people on what it is like to live with FTD, and help others become more aware of what people like my wife and I are going through," he shared.

As a care partner and monthly donor, Randy is all in to #endFTD: "I give to AFTD because I want to help the organization that is supporting me as I support and care for Bobbie."

Will you join Randy 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 today, you can join a growing number of volunteers and donors who are helping to bring forward a world with compassionate care, effective support, and a future free of FTD.

Simply use the enclosed envelope or visit theaftd.org and click on the Donate+ button at the top of the page.

Education Conference (Continued from page 1)

Dr. Adam Staffaroni, a FT neuropsychologist at the Cli University of California San (ar Francisco's Memory and Aging Ad Center, used his session to provide "Updates on Major FTD Research Pe Initiatives" He talked about why

Initiatives." He talked about why natural-history studies of FTD, such as ALLFTD, are so important for understanding how the disease progresses over time, and for helping to shape (and recruiting potential participants for) treatment trials.

Additional featured speakers included Dr. Elizabeth Finger of Western University, who discussed emerging and current FTD clinical trials, as well as Dr. Chiadi Onyike, director of the

FTD and Young-Onset Dementias Clinic at Johns Hopkins University (and a member of AFTD's Medical Advisory Council). Dr. Onyike's presentation, entitled "Cultural Perspectives in FTD," summarized emerging efforts to understand FTD across global geography and diverse cultures, and the many challenges in this work.

A wide range of leading FTD experts and researchers provided a global audience with the latest information and resources.

To effectively ensure that all impacted by FTD receive the diagnoses and care they need, Dr. Onyike said, "we need language and cultural translations of clinical measures to make that happen. We

need to understand the geographic distribution of syndromes as well as the larger population and genetic risk factors; that's going to be crucial for screening."

The Education Conference featured 18 sessions, including four breakout sessions on each day, with over 30 speakers total. AFTD's recently chartered Persons with FTD Advisory Council led two sessions. The conference also encouraged audience participation via live, interactive polls, Q&As, and community chat sessions.

Visit aftdconference.org to watch select sessions from the Education Conference.

AFTD thanks the following sponsors for their support of the 2021 Education Conference

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AFTD Announces New Drug Discovery Grant and Postdoctoral Fellowship Recipients

AFTD has recently announced new awards supporting research to advance the science of FTD and, hopefully, hasten a future free of this disease.

Since 2007, AFTD and the Alzheimer's Drug Discovery Foundation have partnered to fund the Accelerating Drug Discovery in FTD grant program, which supports preclinical research on promising new or repurposed drugs to treat FTD. For 2020, the recipients of the Accelerating Drug Discovery for FTD awards are Wen-Hsuan Chang, PhD, and Anna Orr, PhD.

Dr. Chang, the Head of Research for AcuraStem Incorporated, a California-based biotechnology company, will test to see whether blocking a specific enzyme will increase the clearance of damaged or misshapen proteins, such as tau and TDP-43, to prevent them from accumulating and potentially causing FTD. Meanwhile, Dr. Orr, an assistant

professor of neuroscience at Cornell University, will work to improve a group of compounds developed by her team that block free radicals that can trigger protein accumulation and inflammation in brain cells – a potentially promising new approach to treating FTD.

New AFTD-funded research points to promising new approaches to treating the disease, as well as detecting it early in the disease process.

AFTD has also awarded three 2021-2023 Holloway Postdoctoral Fellowships. The recipients are Daniel Okobi, MD, PhD, of UCLA; Hijai Regina Shin, PhD, of the University of California, Berkeley; and Matthew Nolan, PhD, of Massachusetts General Hospital.

Dr. Okobi will use miniature microscopes implanted in the brains of mice with an FTD-associated mutation to image brain pathways in the animals, allowing him to detect subtle abnormalities that

represent the earliest signs of the FTD disease process. Building on work carried out by former AFTD Postdoctoral Fellow Dr. Ming-Yuan Su, Dr. Shin will devise strategies for the development of drugs that restore normal lysosome function in C9orf72-associated FTD. Finally, Dr. Nolan will use gene editing, stem cells,

and animal models to advance our understanding of the role of RNA binding proteins in FTD, and seek to identify and evaluate new drugs as potential treatments for TDP-43–associated FTD.

For over a decade, AFTD Postdoctoral Fellowships have funded the next generation of FTD researchers during the critical final phase of their training. Thanks to generous support from the Holloway Family Fund, established earlier this year by AFTD Board member Kristin Holloway, AFTD has updated and expand this program, demonstrating our commitment to maintaining the pipeline of promising early-career investigators.

ALLFTD Study Recruiting (Continued from page 1)

Dr. Adam Staffaroni, a neuropsychologist at UCSF's Memory and Aging Center, provided updates on ALLFTD's progress during AFTD's 2021 Education Conference that took place in May. While ALLFTD has succeeded in its initial efforts in enrolling participants, researchers are looking to

increase involvement in the study, Dr. Staffaroni said. (The FTD Disorders Registry is a partner to ALLFTD, supporting recruitment and remote data collection.)

The COVID-19 pandemic impacted ALLFTD's recruitment, slowing new enrollment and reducing in-person evaluations. A gradual easing of restrictions has allowed researchers to resume their efforts. More participation allows investigators to understand the natural FTD history, develop biomarkers for diagnosis and prediction, identify new genes and mutations associated with FTD, and create an FTD clinical trial network.

The study's recruitment plan is split into a longitudinal arm and a biofluid-focused arm. The former aims to enroll 1,100 participants. Participants and a study partner will go to their designated site for two to four visits per year. Participation includes getting

Participants will also be able to answer questionnaires via the new ALLFTD app; take cognitive, motor, and language assessments; and submit speech and language samples.

blood drawn, undergoing neurologic examinations, a brain MRI, and completing questionnaires.

The biofluid-focused arm of the ALLFTD study, which is seeking 1,000 participants, allows for enrollees to complete their participation in a single visit to a research site. It will primarily consist of symptomatic FTD participants, although asymptomatic family members will be considered on a case-by-case basis. Participants in

this arm will also have their blood drawn, undergo neurologic examination, and complete questionnaires.

Enrollees in the longitudinal arm of the study will be able to use the new ALLFTD mobile app to submit data. Participants will also be able to answer

> questionnaires via the app; take cognitive, motor, and language assessments; and submit speech and language samples.

"The app will provide us with additional data that can't be captured in a typical annual visit," Dr. Staffaroni said. "By being able to administer these tests more frequently, we're going to get a more reliable estimate. We think [it will] help us be more sensitive to the earliest changes of the disease and allow us to collect some novel information, like step count."

Visit allftd.org to learn how to participate in the ALLFTD study.

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Gifts received from February 1, 2021 - June 30, 2021

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Global Conversation on FTD to Highlight World FTD Awareness Week

World FTD Awareness Week, a week marked by individuals and organizations sharing FTD education and information across the globe, will take place September 26 through October 3, 2021.

This year, World FTD Awareness Week will be highlighted by the Global Conversation on FTD, a video presentation featuring persons diagnosed, care partners, health professionals, and researchers from around the world talking about how FTD has affected them – as well as some of the reasons they have hope for a future free of FTD.

The video will be broadcast online

in multiple time zones during World FTD Awareness Week. Visit theaftd.org/world-ftd-awareness-week-2021 to learn more.

In the U.S., the beginning of World FTD Awareness Week will coincide

The Global Conversation will feature the voices of those whose lives have been touched by FTD.

with the launch of Food for Thought, AFTD's signature grassroots fundraising and awareness campaign. Food for Thought event hosts tell their stories, making people personally aware of FTD, while incorporating food and raising funds to support AFTD's mission.

This year, for health and safety, AFTD will emphasize virtual gatherings and other creative responses. However – if local and state guidelines permit and hosts feel personally comfortable doing so – Food for Thought hosts may also choose to host a small inperson gathering.

World FTD Awareness Week is organized each year by World FTD United, an international coalition of FTD-focused organizations of which AFTD is a member. Visit worldftdunited.net for more information.

New York State to Recognize FTD Awareness Week 2021

AFTD staff and members of our community joined several New York state senators on June 2 for a virtual lobby day in support of a resolution to recognize this fall's upcoming World FTD Awareness Week.

The resolution's sponsor, Sen. Michelle Hinchey of New York State's 46th district, led the lobby day. Sen. Hinchey's father, the late in U.S. congressman Maurice Hinchey, died of FTD-related complications in November 2017.

Since her father's diagnosis, Sen. Hinchey has worked to raise public awareness about FTD. "When [my father] passed I felt it was incredibly important for me to pick up his mantle and be a voice for working families and

our communities," she told AFTD when she announced her State Senate run in 2019. She was elected the following year and took office in January 2021.

New York has officially adopted Hinchey's resolution, proclaiming September 26 to October 3 FTD

New York State Senator Michelle Hinchey – whose father, U.S. Rep. Maurice Hinchey, had FTD – introduced the resolution that recognized Sept. 26 to Oct. 3 as FTD Awareness Week.

Awareness Week in the state. It aligns with the recognition of World FTD Awareness Week, which comprises events, activism, and engagement focused on raising FTD awareness across the globe. [See above for more information.]

To raise awareness of FTD and

World FTD Awareness Week, AFTD Advocacy Manager Matt Sharp, MSS, and Senior Director of Advancement Ben Freeman spent the June 2 lobby day virtually meeting with the staff of five senators who sit on the State Senate Health Committee: Sens. Rachel May, Peter Oberacker, Phil

Boyle, Kevin Thomas, and Health Committee Chair Sen. Gustavo Rivera.

Persons impacted by FTD also joined the lobby day proceedings. Sheryl Whitman, who is living with primary progressive aphasia (PPA), and her sister, Jill Whitman, spoke with the staff of Sen. Rivera, who represents their home district, while AFTD volunteer Peter Bee spoke with Sen. Thomas's staff about being an FTD care partner to his wife, Marianne.

Giving a Hand to Our Helping Hands! AFTD's Persons with FTD Advisory Council

"We are passionate about the people with this disease having a voice," said Amy Shives, speaking on behalf of the AFTD Persons with FTD Advisory Council, of which she is an inaugural member.

"We're passionate about the fact that we are still very bright and very able, as our group proves."

Since 2020, the Council has helped to ensure that the insights of people living with FTD are considered in the development of AFTD's policies, programs, and services. Before the Council was officially chartered last year, AFTD relied on an informal "Think Tank" of persons diagnosed to inform its work.

"AFTD has given me a very rare opportunity to work with like-minded people for betterment and to push the mission forward. Sometimes it's not easy but knowing that I have a tribe and that we move [the mission] forward together, it gives me hope for tomorrow," said Teresa Webb, Council co-chair.

Historically, Council members say, the perspectives of persons diagnosed have been underrepresented or even ignored in discussions about FTD – something they are working to rectify. "I think



it's important that people know what it's like living with this disease" from a firsthand source, Council member Anne Fargusson said.

AFTD Advocacy Manager Matt Sharp said that formalizing the Council was "an important step forward for AFTD to include the perspective of those living with this disease in our work."

For many of the members, joining the Council has provided a sense of purpose, working with AFTD to help create a better future. Jennifer Lee, who joined the Council in June, shared that "being

proactive with the [Council] allowed me to focus on that work while looking at the positive side of everything rather than sitting there and waiting for the sky to fall."

Lee continued: "If someone has FTD, they should volunteer – because who better to volunteer than somebody who lives with it every day? Through your own experiences, you can share with others what works for you and what could work for them."

For member Steve Perlis, the Council has been valuable source of connection. "I feel like I've found a home," he said. "These are not just colleagues — these are friends.

"Telling [our] stories is a good starting point for raising hopes and resurrecting the dreams that people like us have for being useful, productive, and relevant in today's world," he added.

AFTD Updates COVID-Related Volunteer Guidelines

Whether you are considering volunteering in support of AFTD's mission for the first time, or you are one of the 500+ passionate volunteers who have already made the choice to share your time and talents, we want to share how AFTD plans to lead and coordinate volunteer activities and events in the coming year.

The health and safety of AFTD volunteers – and the safety of all volunteer-activity participants – is a priority! As states continue to reassess their approaches to managing the COVID-19 pandemic, and as more people get vaccinated, AFTD has determined that targeted in-person volunteer activities can move forward, based on a volunteer's own sense of safety, and their activity or event's

compliance with evolving local, state, and federal guidelines.

We know that for some, virtual engagement will remain preferable, whether due to personal safety, challenges of traveling, or challenges

Targeted in-person AFTD volunteer activities can move forward, based on a volunteer's own sense of safety, and their activity or event's compliance with evolving guidelines.

of taking part in in-person events while navigating FTD. AFTD will continue to develop and support a mix of virtual, in-person, and hybrid events to meet the different needs of our full range of volunteers and community members.

Moving forward, AFTD will be offering a

growing number of in-person activities and events, contingent on local, state, and federal guidelines. AFTD's Volunteer Coordinators are available to discuss options and talk through opportunities with you.

We appreciate our strong national network of volunteers, and we're grateful for the impact that a community that is all in to #endFTD can achieve. We can't wait to connect with many of you in person, and to bring this mission to others in local communities across the country, and beyond.

Visit theaftd.org/get-involved/volunteersnetwork to learn about AFTD's current in-person and virtual volunteer activities and fundraising opportunities.

THE AFTD-TEAM



Going the Distance: Jason Nagin participated in an Olympic Distance Triathlon in the Hudson Valley in memory of his grandmother, who passed away from FTD; in honor of his mother, who is currently living

with FTD; and in support of AFTD's mission. The event included a one-mile swim, followed by a 28-mile bike ride, and then a six-mile run. Jason fundraised prior to the event and raised \$60,475 to support AFTD's research initiatives.

An Un-fore-gettable Time: The 10th annual Quest for the Cure Golf Tournament was hosted by the Robert M. Hatfield Foundation on November 13, 2020, at the Bardmoor Golf and Tennis Club in Seminole, Florida. This year the event raised \$9,114 for AFTD's mission, increasing the annual tournament's total amount raised to \$72,264.

Moving Miles: James

Staten, recently diagnosed with PPA, wanted to take part in the AFTD-Team's 2020 Race Season, but due to the pandemic, most races were canceled or postponed. This year, James is looking forward to joining the AFTD-Team for races in Denver, Philadelphia, and Dallas. Since he began fundraising in



December 2020, James has raised \$7,376 for AFTD's mission.

Honoring Donald: Bob Powers hosted a letter-writing campaign in honor of his husband, Donald Clement, who is currently living with FTD and recently moved into a care facility. Bob's letters shared about his time in the Peace Corps and Donald's passion for architecture. He also spread FTD awareness and helped to further AFTD's mission with \$5,000 in gifts from family and friends.

Perfect Pairing:

The Jackie Pang Fund hosted a virtual wine tasting experience through Old York Cellars on May 7, 2021. Family and friends indulged in an interactive, one-hour wine and chocolate pairing via Zoom, guided by a certified sommelier and wine educator. The event was a success,



bringing in \$2,649 to further AFTD's mission.

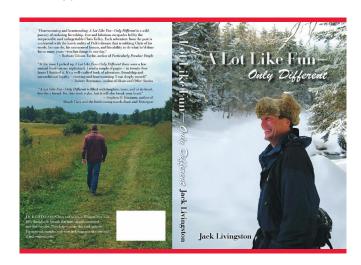


Biking in the Clouds: Blake Ovard hosted the Cloud Gravel Invitational, a gravel biking event. Bikers could traverse distances of 50 to 90 miles with an option to bike 200 miles in three days, while elevation gains ranged from 4,600 to

19,600 feet! Participants were asked to donate in support of AFTD's mission, and the event raised \$1,228.

The Adventures of Two Friends:

Author Jack Livingston published the book *A Lot Like Fun* – *Only Different*, featuring stories of his adventures with his longtime friend Chris Kelley. Chris is currently living with FTD, and Jack is donating a portion of proceeds from each copy sold to support AFTD's mission. So far, he has raised \$992.



A Big "Thank You" from AFTD's Staff!

AFTD is very pleased to announce that this past fiscal year (July 2020 – June 2021) was the most successful yet for our Grassroots Events Program, raising over **\$808,000** for our mission. While the year had its many complications, our fundraising volunteers remained dedicated to bringing attention to this disease and the journey endured by families affected.

Shortly after the pandemic started, we introduced new virtual fundraising opportunities – including our partnership with the Charity Miles app – that grew the AFTD-Team and let members support the mission we all share while still responsibly social-distancing. Our largest annual campaign, Food for Thought, went virtual, allowing hosts to get immensely creative while keeping safety at the forefront. Meanwhile, some AFTD volunteers took

the initiative and organized the #FTDhotshotchallenge, a social-media campaign that became the most successful independent event to benefit AFTD's mission to date.

To AFTD's fundraising volunteers – thank you! Thank you for logging miles on the Charity Miles app, for showing off your culinary skills by hosting a Food for Thought event in the fall, for sharing stories of love for February's With Love campaign, for braving the #FTDhotshotchallenge, and for planning and implementing creative events of your own.

On behalf of AFTD Special Events Manager Bridget Graham and AFTD Fundraising Coordinator Brittany Andrews, we want to thank all our fundraising volunteers who are driving AFTD's mission forward!



AFTD-Team members have shown incredible dedication to supporting AFTD's mission and making the FTD journey easier for the next family by logging miles using the Charity Miles app. Thanks to your passion and drive, you have helped us to secure gifts from two generous sponsors this spring and summer.

In May, Alector sponsored members' miles at \$1/mile, resulting in a \$10,000 donation to AFTD's mission. And in July, miles were

sponsored by The Jackie Pang Fund, also at \$1/mile, resulting in an additional \$10,000 donation to strengthen AFTD's support programs. More than 1,400 AFTD volunteers are active on Charity Miles and helped achieve each \$10,000 donation in less than two weeks.

Thanks to our sponsors and our volunteers who created pledge pages through the app, the AFTD-Team has raised over \$110,000 through Charity Miles since April 2020!







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