

Volume XI, Issue 1 Spring 2014

AFTD Kids and Teens Our Children Are Not Alone by Amy Eissler

Explore. Learn. Connect.

These three powerful words are used to describe the mission of a new resource designed to meet the unique needs of children and teenagers who have a parent or loved one with frontotemporal degeneration (FTD). In an effort to provide these youths with the information, community and support they need, The Association of Frontotemporal Degeneration (AFTD) is excited to announce the launch of a new website "AFTD Kids and Teens" (www.aftdkidsandteens.org).

"FTD is a progressive disease with many variants, creating lots of changes at home for families and loved ones. AFTD Kids and Teens offers kids a chance to explore and learn on their own terms.



www.aftdkidsandteens.org

Through the site they can develop some comfort with the situation, recognize they are not alone and find empowerment to cope, " said Sharon Denny, AFTD program director.

Two parallel sites

In order to provide age-appropriate information that is relevant to a range of young visitors, the website is split into two separate sites--a site designed for kids (roughly ages 4-11 or 12) and a site designed for teenagers (roughly 13 and up). While the site is designed to be explored independently by children, not all children will be interested in or ready for all the information at once. A Letter to Parents, available through the home page, encourages parents to preview the site to decide how best to introduce it to their child.

The basic structure of both sites is similar. Each includes five sections

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AFTD Receives \$1 Million Gift

he Association for Frontotemporal Degeneration (AFTD) is pleased to announce receipt of a \$1 million donation to support research. The gift, which comes from an anonymous donor who is a long-time supporter of AFTD, will accelerate the association's strategic investment in science that will lead to the first effective therapies for FTD.

"We are tremendously grateful for this vote of confidence," noted Jary Larsen, Ph.D., AFTD board chair. "It is especially important to have knowledge of this gift as the Board of Directors undertakes strategic planning over the next six months to develop and implement AFTD's goals for the next five years."

In accordance with the donor's wishes, AFTD will work with experts on our Medical Advisory Council to explore ways to leverage this contribution, using it to create initiatives that attract and engage new funding partners and researchers for the cause. In so doing, AFTD will build upon a tradition of leadership in research funding which includes seed funding for pilot studies and a two-year Postdoctoral Fellowship, as well as partnerships that have produced a national clinical FTD database, an IPS cell repository, and a drug discovery program that has funded seven years of promising translational research (see page 5).

Spotlight On... John Whitmarsh, Ph.D., AFTD Board of Directors

ike many spouses of people with FTD, when John Whitmarsh first started noticing personality changes in his wife he attributed them to a problem with their relationship, not a problem with Barbara's health. During that time, one of her best friends stopped spending time with her and a coworker refused to continue working with her, but it wasn't until their kids expressed concern after a Christmas spent at home that John began to realize there might be a medical issue at hand.

With this new concern in mind, John asked Barbara to see a doctor, but she refused for months. When she finally agreed, she went through numerous physicians, tests, and an initial diagnosis of Alzheimer's disease. Finally, a neurologist recognized the initial signs of FTD on an MRI that had been performed two years earlier, when Barbara was still functioning well in her highly demanding position at the National Institutes of Health.

After Barbara's diagnosis, the Whitmarsh family was featured in a segment on the NBC Nightly News with Brian Williams. John says that when AFTD approached him about the segment, "I immediately said yes with the hope that sharing our story



John Whitmarsh, Ph.D.

would help others and accelerate research into FTD. In my view, we need to work to distinguish FTD from Alzheimer's disease for health professionals and lay audiences."

John found great comfort in his support group, and it was the group's leader, former AFTD Board member Joanne Sackheim, who sparked his interest in joining the Board of Directors. "I felt that my research and administrative experience in science would enable me to make significant contribution to the goals of AFTD," said John.

Having worked for NIH himself, John has a strong focus on the research currently being conducted and is optimistic about the advances that AFTD's recent increase in funding could bring. "To date we have had very little money to work with and yet have made remarkable impact," said John. "My goal would be to use the funding to leverage more funding, and to continue to focus on enabling outstanding young scientists to devote their careers to FTD."

AFTD NEWS BRIEFS

Join Us in Vancouver this October! Researchers and clinicians from around the world will convene for 3 days at the 9th International FTD Conference, October 23-25, 2014. AFTD is helping to organize a one-day symposium for caregivers, which will be Friday, October 24. To register: www.ftdvancouver2014.com.

New Support Groups - Seven new support groups have been formed, in: Peoria, IL, Harris County, TX, Puget Sound area, WA (this is an informal group), Seattle, WA, Toronto, ON, Los Angeles, CA and Fairfax, VA. For a complete list of support groups, visit the regional page on AFTD's website.

Best Practices in FTD Care - AFTD's Partners in FTD Care Yahoo Group is an on-line forum for professional and family caregivers interested in practical approaches to FTD symptoms. Expert clinicians and caregivers share effective strategies for care management at home and in residential facilities. www.groups.yahoo.com/neo/groups/PartnersInFTDcare/info

Food for Thought volunteer liaisons are needed to help lead this year's campaign! As AFTD representatives, liaisons maintain contact and provide support to hosts who are organizing a Food for Thought event. If you would like to learn more, please contact Kerri Barthel, volunteer manager, at kbarthel@theaftd.org.

Do you want to help make a difference in the lives of those affected by FTD? Have you considered volunteering with AFTD? Various fun and rewarding opportunities are available. Contact your regional coordinator volunteer to learn more. Click on your state through the following link to find your regional coordinator. www.theaftd. org/support-resources/us-regions.

See you in San Diego! AFTD's 2015 education conference will be at the Doubletree Mission Valley on Friday, April 24, 2015. Mark your calendars and watch our website for additional information over the coming months.

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AFTD's 2014 Education Conference & Annual Meeting

n Friday, March 14, 248 people attended AFTD's education conference and annual meeting in White Plains, NY. This was the largest attendance to date for the event, which was designed to inform and engage the broad community of those affected by FTD: family caregivers, health professionals, people diagnosed with the disease, and young adults with an affected parent.

AFTD Board Chair Jary Larsen, PhD, welcomed participants and encouraged everyone to learn from experts and network with others who understand the challenges they face. The morning featured an overview of FTD and developments in research by Dr. Edward Huey, assistant professor of psychiatry and neurology at Columbia University's College of Physicians and Surgeons. Jill Goldman, MS, CGC, genetic counselor at Columbia University Medical Center's Taub Institute and Nadine Tatton, PhD, AFTD scientific director, addressed genetic research and the critical role it plays in advancing understanding of the diseases and development of potential treatments.

Susan Dickinson, AFTD executive director, started the afternoon with an overview of AFTD's growth and accomplishments over the past year. Olivia Goldring, 18, who lost her mother to FTD in 2012, delivered a moving

description of her experiences and why she was eager to be involved with AFTD's newest resource, the AFTD Kids and Teens website (see article page 1).

The afternoon focused on approaches to care management and coping. It included an opportunity for participants to select one of five breakout sessions to dig deeper into a topic of particular interest, and a panel discussion with a former caregiver, current caregiver and person with FTD.

Robert Bazell, adjunct professor at Yale University and former NBC chief science and health correspondent, was the final speaker and gave the keynote address entitled "Making Yourselves Heard." He provided examples of how to engage media to help promote awareness of the disease and impact care, and addressed questions from the audience.

Thirty-four people diagnosed with FTD attended this year's conference and two participated as speakers. An informal lunch meeting brought together 25 young adults who have a diagnosed parent and who want to share support and get more involved with AFTD.

Prior to the start of the conference, pharmaceutical company TauRx hosted an informational meeting on the role of tau protein in FTD and Alzheimer's disease. About 100 people attended



AFTD Conference 2014

the meeting in which Dr. Joel Ross and Dr. Richard Holub answered questions about the science and a clinical drug trial of the compound LMTX in behavioral FTD. The study is currently recruiting at sites across the U.S. For more information on the study visit www.clinicaltrials.gov.

Following the conference nearly 200 people stayed to network and connect with others at a dinner reception. Feedback from the day reflected deep appreciation for the chance to be together with people who share a commitment to addressing FTD. One caregiver captured the feeling expressed by many: "Not only did I get a better picture of everything AFTD is doing, but I really was struck by how powerful and inspiring it was to be surrounded by others who are involved in the FTD community."

Slides from the plenary sessions and a downloadable version of the conference booklet, including material from each breakout session, are available on AFTD's website under "Past Caregiver Conferences". The 2015 conference will take place on Friday, April 24 in San Diego.

Special THANKS to our Conference Sponsors!

alzheimer's ?







TauRx Therapeutics science, medicine, innovation

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Dr. Marsel Mesulam Awarded the Potamkin Prize



Dr. Marsel Mesulam

r. Marsel Mesulam, Chair of the AFTD Medical Advisory Council and Director of the Cognitive Neurology Alzheimer's Disease Center at Northwestern University, Chicago has been named as the 2014 Potamkin Prize winner. The Potamkin considered Prize is foremost award for dementia research and recognizes major

contributions to the understanding, prevention, treatment and cure of FTD, Alzheimer's and related diseases.

Dr. Mesulam was the first to recognize primary progressive aphasia as an independent form of dementia in the 1980s. "It was not all that long ago when the terms 'dementia' and 'Alzheimer's' were used synonymously and when memory loss was considered an invariant feature of dementia," he said. "This is no longer the prevailing opinion. We now know that there are multiple diseases that can cause dementia without Alzheimer's pathology or memory loss."

The Prize is sponsored by the American Academy of Neurology (AAN) and the American Brain Foundation through the philanthropy of the Potamkin family. Dr. Mesulam will receive the award at the annual meeting of the AAN in Philadelphia this April.

Research Opportunities on the AFTD website

ndividuals interested in participating in clinical research for FTD now have an important new resource. The AFTD Research webpage contains a subsection titled "Participate in Research," which for the first time lists four active clinical trials.

TauRx, Inc. is sponsoring a phase 3, multi-site trial for behavioral variant FTD patients to test the new drug LMTX in a year-long study. A 3-month study testing the FDA-approved drug Nuedexta is recruiting FTD patients with pseudobulbar affect at Drexel University College of Medicine, Philadelphia. An NIH-sponsored clinical trial is currently recruiting

patients with the *C9ORF72* gene mutation for a 3 year longitudinal study to gather natural history data. On the west coast, a 10-week study is testing the FDA-approved drug Nimodipine in *GRN* mutation carriers at the University of California, San Francisco.

In this same section of the website persons diagnosed with FTD and their family members can find valuable information on the different types of research studies as well as questions to ask and how to decide if a certain research study is right for you. Bookmark this site and plan to revisit it often over coming months, as we continue to flesh out this important information.

Call for Proposals: 2014 AFTD Pilot Grants

he new Pilot Grant-Request for Proposals (RFP) is now posted on the AFTD website. From its inception in 2005, the Pilot Grant program was designed to support highly innovative clinical and basic science research in FTD. Last year our grant competition attracted 42 proposals from both national and international applicants. We welcome projects that

advance our understanding of behavioral variant FTD, primary progressive aphasia, supranuclear palsy, corticobasal syndrome or FTD-ALS. The program is designed to seed original projects with the goal of generating preliminary data toward a larger grant application to the NIH or other public or private agencies concerned with FTD.



2014 Drug Discovery Awards





Donald Lo, Ph.D.

Jeff Rothstein, M.D.

FTD is proud to announce the recipients of our 7th annual grant program which is run in partnership with the Alzheimer's Drug Discovery Foundation to advance drug discovery in FTD. Jeff Rothstein, M.D. of the Johns Hopkins School of Medicine and Donald Lo, Ph.D. of the Duke University Medical Center were each awarded \$150,000 to support their medical research efforts.

Dr. Rothstein works with stem cells grown from the skin of ALS and FTD patients who have the *C9ORF72* gene mutation. With funds from a 2013 FTD Drug Discovery award, his group recently discovered, and was able to treat, the toxic effect of *C9* RNA (ribonucleic

acid) byproducts in nerve cells grown from the C9 stem cells (For more on the advances from last year's award, go to www.sciencedaily.com/ releases/2013/10/131016123022. htm). Dr Rothstein has identified biomarkers that would show if these new treatments can inactivate the C9 gene and help bring this potential new therapy to clinical trial. Dr. Rothstein is developing these markers in partnership with Pharmaceuticals (Carlsbad, CA). "We are very excited about the new findings from Dr. Rothstein's group and are eager to continue our investment in the use of FTD pluripotent stem cells for drug discovery," said Nadine Tatton, Ph.D., Scientific Director for AFTD.

Dr. Lo has developed a new way to screen drugs for neurological diseases that uses a thin slice of rat brain to quickly test hundreds of potential drug therapies on reducing or stopping tau protein-based nerve cell death. Dr. Lo is interested in drugs that would affect a type of RNA called micro-RNA. Micro-RNAs act like control switches for the coordinated expression of many genes, and when they don't work properly can lead to neurodegenerative diseases like FTD. Micro-RNAs are the newest leading edge of drug discovery in neurological diseases. Dr. Lo is working in partnership with Regulus Therapeutics (San Diego, CA) which has created custom drug libraries to be tested with Dr. Lo's brain slice assay.

Help fund FTD Drug Discovery!

Thanks to our partners at the Alzheimer's Drug Discovery Foundation every \$1 you give this spring will produce \$3 toward a cure for FTD.

Visit www.theaftd.org today to be a part of the promise.

Donations Honor Loved Ones Gifts received from Oct. 16, 2013 - Mar. 15, 2014

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In lieu of flowers...

Families who wish to direct memorial donations to AFTD are encouraged to call our office. AFTD can mail you donation materials, or you can download them from the AFTD website. All donors will receive letters of acknowledgement and families will receive a list of donors. To contribute electronically via our website, go to www.theaftd.org.

AFTD Kids and Teens (Continued from page 1)

that prioritize information, guidance and create a resource for children because examples of how others cope. In addition to providing factual information about FTD, content focuses on the young person's experience of FTD and changes to expect at home, in school and within the family as the disease progresses. Interactive

pages give visitors the opportunity to relate to and share their own experiences with other kids and teens in similar situations, as well as tips and tools that may help them adjust to the struggles they may encounter having a parent with FTD. A final section gives visitors the chance to ask questions and offers suggestions on how to get involved, build awareness or participate in FTD fundraising events. It is also a showcase for those who

have done events of which they are proud.

Although the two sites have basic structure similarities, the detail and tone of content within each site is designed to be appropriate for the targeted audience. The kids' site introduces FTD topics and provides basic information around a fourth grade reading level. Fictional characters of a young boy and girl named Sophie and Connor serve as guides who model successful coping strategies and offer words of encouragement throughout the site.

The teens' site aims to cover specific FTD topics in more detail at a tenth grade reading level. Photos, quotes, and stories of teenagers who have parents with FTD are used throughout the site to give teenagers information that is both accurate and authentic that they can apply to their own situations.

A long-term goal

The need for a website to help kids and teens cope as they work through the illness with their families was first recognized in 2010 by AFTD's Task Force on Families with Children, a group of professionals and family caregivers who focused on exploring the needs of kids, teens and families with a parent with FTD. One of the Task Force's primary goals was to

at the time no other resources existed.

Information, ideas and input were collected from AFTD's Helpline, AFTD parent telephone support group, FTD support group members

and various other individuals. The Task Force did extensive research into the resources and approaches used to support children with parents who have debilitating illnesses. addition, anecdotal information was obtained from surveys of young adults who had a parent with FTD. All of this research was compiled in a report written by the Task Force in May 2011. In 2012 the Task Force began planning the website

money raising for

Catherine Pace Savitsky, leader of AFTD's telephone support group for parents, was engaged to manage and recruit a team of volunteers to develop

AFTD Kids and Teens offers kids a chance to explore and learn on their own terms.

the website. "Parents are desperate for resources specific to the needs of their children. I knew this website would be a lifeline for many kids and teens whose lives were being affected by a disease as unique and complex as FTD," Savitsky said.

Olivia Goldring, 18 years old, lost her mother to FTD in 2012. When her mother was first diagnosed with FTD, Goldring did online research to learn about her mother's illness. "I looked things up on Google, but was always led to medical pages which were far above my comprehension level. There were no resources that presented the information in a compassionate, understanding, and relatable way. What AFTD has made with the children and teens sites is all of the things I didn't find elsewhere." Goldring said.



Awareness activities hosted by kids and teens are featured on the site.

Kids helping kids

AFTD recognizes that children are resilient and have a tremendous amount of wisdom to share with each other. One of the most important aspects of the new website is the opportunity it gives children to share their stories and let their voices be heard. Sections titled "Kids Like Me" and "Get Involved" help provide the validation that children and teens desperately need when facing the difficulties that FTD presents.

After she and her three young children lost their father, and her husband, to FTD, Michele Van Son was eager to help develop content for the site. "It is my hope that one day my kids will log onto AFTD Kids and Teens and encourage other kids who are going through what they went through." Van Son said.

When asked about her hope for AFTD Kids and Teens and the impact it will have on youth Denny said, "Changing the feeling that no one understands is our main goal. There is tremendous solace and power in feeling understood."

AFTD is tremendously grateful to the following donors, who made the new site possible: Anonymous, Florence V. Burden Foundation, The Connecticut Frontotemporal Dementia Foundation, Inc., Olivia Goldring via Riverdale Country School 2012 Walk-a-Thon for Rachel, The Allen & Lola Goldring Foundation, and Son. Famil



AFTD's 1st Volunteer Leadership Summit a Huge Success!

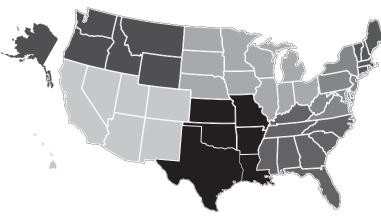
s a rare disease organization with nationwide reach, AFTD relies on lead volunteers to help represent the organization in communities

throughout the country. These volunteers are part of the AFTD team and play an important role inadvancing the mission..

On March 13, 2014, a year and a half after launching the volunteer program, AFTD sponsored its first-ever leadership volunteer summit. Eleven regional coordinators and key volunteers from across the country were in attendance. Some the topics presented for discussion included recruiting and organizing volunteers, well as

as managing volunteers, activities, and administrative tasks effectively. The volunteers learned critical new leadership skills and techniques, and

identified strengths to apply in their management roles. They shared strategies and brainstormed new approaches to try back home in their regions.



Connect with AFTD's regional coordinator volunteer in your region and find out how you can engage to advance the mission! Go to www.theaftd.org and search on "US Regions".

The summit offered the only opportunity to be together in person as a team during the past year. Everyone in attendance expressed appreciation for the

time spent collaborating. Jenny Hinsman, MidAtlantic regional coordinator said, "The leadership summit was an amazing time to meet with other regional

coordinators and to share ideas. I was particularly interested in othe discussion we had around outreach to universities to grow our volunteer base."

"I left the summit feeling very motivated as a leader after being surrounded by a community of volunteers all there for the same reason," said Rachael Baffa, Southwest regional coordinator. Charlene Martin-Lillie, Midwest regional coordinator shared, "I was so lucky to be a part of the leadership summit. It was fantastic to meet all of the other regional coordinators. It strengthened my dedication to AFTD and to supporting families impacted by this

devastating disease." As a result of the afternoon, the volunteers left feeling part of a team making a significant impact on behalf of AFTD.

Giving a Hand to Our Helping Hands! by Rachael Baffa

dvancing AFTD's mission requires the engagement of a growing number of wonderful volunteers across the United States. Based on individual interest, skill and availability, AFTD works diligently to match each volunteer with the work that needs to be done.

One of our many valued volunteers is Mary Black. Mary, currently residing in Philadelphia, lost her husband, Bernie (64), to FTD in 2012. She recalls that she was first introduced to AFTD as she struggled with the knowledge that Bernie's illness was growing progressively worse, and that keeping him at home was becoming less and less of an option. "I would call the AFTD Helpline, mainly to ask questions about nursing home placement," Mary recalled. Mary's journey with FTD was difficult on its own, but adding the stress of finding placement made it even harder. "It took two years. I did finally manage to get Bernie into

a stellar facility that took Medicaid. I wrote them several letters, and never gave up hope, even after being rejected three different times," stated Mary.



Mary with one of her ten grandchildren

Because Mary encountered such resistance from the nursing homes, she is now volunteering in AFTD's facility outreach program, which strives to educate staff at facilities about FTD.

"Some facilities don't accept anyone under 65," Mary said. "I want to advocate for nursing homes to be open to taking these much younger clients." Mary also provides office support when there are special projects and plans to represent AFTD as a community awareness representative at the upcoming Brain Health Fair in Philadelphia.

Kerri Barthel, volunteer manager, said that "Mary is always flexible and willing to make herself available to help. She is truly dedicated to advancing the mission of AFTD."

Mary's experience with FTD has been "a soul stretching journey. Watching it take over someone you love requires reserves of courage that you didn't know you had, but somehow, that courage will be there when you need it."

Rachel Baffa, whose father is affected with FTD, is a volunteer writer for AFTD.

"With Love" Campaign Raises \$50,000

FTD would like to thank all of our fundraisers, donors and matching donors for making year three of "With Love" a success!

Focused around Valentine's Day, "With Love" urges those whose lives have been impacted by FTD to share their stories of enduring love. This year's campaign featured fourteen different stories of love from many different perspectives- friends, spouses, children, grandchildren and parents. The "With Love" campaign page highlighted the story of Phyllis and Nancy, whose decades-long friendship was put to the ultimate test when Phyllis was diagnosed with FTD. Nancy faced the challenge head-on and committed to sticking by her friend and making the most of their time together.



"With Love" once again exceeded expectations and raised over \$50,000, including two generous matching gifts from Beth Walter and The Rainwater Charitable Foundation, bringing the grand total for all three years to over \$135,000.



Help Raise Awareness of FTD Put Your State on the Map!

What: AFTD's 2nd Annual "Food for Thought" Campaign: Make a meal and invite

family/friends, host a bake sale or engage a local restaurant to give back a portion

of a night's sales. Anything that involves food and a little FTD education!

Volunteers are ready to guide you through the process.

When: Any day from October 5 - October 12, 2014: The more Food for Thought

events we have across the U.S., the better!

For complete details, visit AFTD's Food for Thought webpage:

http://www.theaftd.org/about/aftds-food-for-thought

THEATTIID -TEAM



Go to "What's New" on the AFTD website to view the ABC news coverage of Max's Catch-a-Thon

Max's Catch-a-Thon

Max Portnoy, of Bethesda, MD, came up with a unique idea for his charity project in conjunction with his Bar Mitzvah. Max decided to turn time spent playing the game he loves into an opportunity to honor his beloved grandfather and raise money to help end the disease that is taking his grandfather away from him. Max organized a three-hour catcha-thon to honor his grandfather and raise money

for AFTD. Max's grandfather is a former well respected rabbi and army chaplain, but now, due to the effects of FTD, he can no longer speak, has difficulty moving and can no longer play catch with Max. Over sixty people turned out for the event on March 23rd, which included raffles and food donated by



Max Portnoy and his "Zayde"

several local business. There was even a surprise guest: Max's grandfather Skyped in from his home in New York to greet all of the participants. Max's catch-a-thon raised over \$18,000 and was features on a local news website, as well on a prime time news segment on the local ABC affiliate.

Manasquan Turkey Trot

Brother-Sister duo Eric Zuckerman and Jennifer Zuckerman Moran marked the beginning of the holiday season by participating in the Manasquan Turkey Trot, a five mile race held in Monmouth County, NJ, in honor of their father. Their father, a former avid runner himself, is affected by FTD. The Zuckermans raised over \$7,000 for AFTD.

3rd Annual Robert M. Hatfield Foundation, Inc. Golf Tournament

The Robert M. Hatfield Foundation, Inc., led by Matt Hatfield, held its third annual golf tournament on November 11, 2013 in Saint Petersburg, FL. The tournament raised \$7,000 for AFTD.

The Silver Lining

Traci Connor's grandfather was a professor of biology and authored a book entitled *The Silver Lining: The Benefits of Natural Disaster.* He is currently diagnosed with FTD and Traci and family are trying to find the silver lining by raising funds for AFTD. Their fundraiser raised \$1,809 to support research.

Aramco Houston Half Marathon

Angela Kimble and Sean Cain teamed up to run a half marathon in memory of their mother, who died of FTD in 2011. Angela and Sean raised nearly three times their goal of \$500.

Join us in King of Prussia, PA May 18!

Inspired by so many generous grassroots fundraisers in the FTD community, the staff of AFTD will hit the streets for the third year in a row to raise funds and FTD awareness in our own community. Join us on May 18th at the King of Prussia 10 Miler and 5K. AFTD will provide a light breakfast and an opportunity to gather with other families, AFTD staff and members of the local medical community. Visit our Givezooks! page for more information. www.theaftd.givezooks.com/campaigns/aftd-and-friends-walking-the-walk-2014

Interested in putting together a team to participate in a race in your area? AFTD can help you find a race and solicit team members! Contact Liz at eneal@theaftd.org for more information.



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