

# Yeah...

I'm here to **Fight This Disease.**

## **THE AFTD - TEAM**

**a grassroots fundraising toolkit for the Special Forces  
taking on Frontotemporal Degeneration**



The Association for  
Frontotemporal Degeneration  
*Opening the gateway to help and a cure*

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# A WORD FROM OUR FEARLESS LEADER

Dear AFTD Supporter,

Thank you for your interest in hosting a grassroots fundraising event on behalf of The Association for Frontotemporal Degeneration. You are now part of The AFTD-Team...a group of “special forces,” dedicated to raising awareness of frontotemporal degeneration (FTD) as well as funds for research into treatment, prevention and eventually a cure.

We are so grateful for people--like you--who have been touched by the devastating effects of FTD in one way or another, and yet find the courage, strength and drive to give of themselves so that others may one day never have to hear the words: “You have FTD.” As much as this disease takes away, it also deeply binds together the families and friends of those affected. Know that you are not alone in this fight.

The following packet is a toolkit with information about FTD and suggestions to help you organize and plan your own fundraising event for AFTD. The information provided here is meant to be a guide and an offering of suggestions. Feel free to plan an event that best suits you.

Our vision is to live in a world where FTD is understood, effectively diagnosed, treated, cured and ultimately prevented. With your help, determination and commitment, we can work towards making this a reality. Every step you take to raise funds and awareness of FTD gets us one step closer to a cure. We thank you for your initiative, concern and support, and we’re proud to welcome you to The AFTD-Team.

Yeah...we’re here to Fight This Disease.

Best,



Susan L-J Dickinson, M.S.  
Executive Director, AFTD

**THE AFTD - TEAM**

# HOST AN AFTD FUNDRAISER!

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**Welcome to The AFTD-Team!** You are joining an elite group of special forces, driven by a common goal of funding research, care, treatment and ultimately a cure for FTD.

**We are grateful to have your support!** AFTD is a small but mighty organization, and our impact multiplies with each new member of The AFTD-Team who shares his/her story and hosts a fundraiser.

**Our staff is dedicated to providing support and resources** to all those affected by FTD, whether directly or indirectly. For additional information on FTD and fundraising, please visit *The AFTD-Team* section of our website.

For fundraising support or questions, please feel free to contact Angie Maher, Communications & Marketing Manager at [amaher@theaftd.org](mailto:amaher@theaftd.org).

**Thank you again for your support!** Your commitment to organizing and hosting an AFTD grassroots fundraising event will make a huge impact on our ability to fund care and a cure.

## OUR MISSION

The Association for Frontotemporal Degeneration (AFTD) is a non-profit organization whose mission is to:

- **Promote and fund research** into finding the cause, therapies, and cures for frontotemporal degeneration
- **Provide information, education and support** to persons diagnosed with an FTD disorder, and for their families and caregivers
- **Educate** physicians and allied health professionals about frontotemporal degeneration and how to improve patient care
- Bring about greater **public awareness** of the nature and prevalence of frontotemporal degeneration and the needs of those who are coping with it
- **Advocate** with public officials and promote public and private programs that provide appropriate, affordable and high-quality long-term health care and social services.
- **Facilitate** the international exchange of ideas.

# ABOUT AFTD

The Association for Frontotemporal Degeneration, a non-profit organization, was founded (as the Association for Frontotemporal Dementias) by Helen–Ann Comstock in 2002. The organization is the product of her experience as an FTD caregiver and collaboration with scientists, physicians and other caregivers who echoed the need for increased attention to these devastating diseases.

In nine years, AFTD has gone from a fully volunteer-run organization to a paid staff of six full-time employees. The organization has given more than \$1 million to FTD research. Since 2009, AFTD has given out \$90,000 in respite grants to caregivers in need of a bit of relief. Comprised of FTD caregivers who fully understand the needs of the FTD community, the AFTD Board of Directors works closely with a Medical Advisory Council that boasts some of the premier researchers and clinicians in the FTD field.

While there is currently no treatment or cure for FTD, AFTD offers an array of resources for the education of the general public, those affected and their caregivers. AFTD provides four telephone support groups and facilitates a network among the independent groups across the country and in Canada. Each year, AFTD hosts an annual caregiver conference where families can convene to learn about the latest in science as well as caregiving techniques. AFTD's website ([www.theaftd.org](http://www.theaftd.org)) offers a host of resources, from medical sites to books on FTD. AFTD believes that for our families knowledge is power, since many general practitioners have never heard of FTD.

## QUICK FACTS ABOUT FTD

Frontotemporal degeneration (FTD), also commonly referred to as frontotemporal dementia, frontotemporal lobar degeneration (FTLD) or Picks disease, is a disease process that causes changes in behavior and personality, language and/or motor skills, and a deterioration in a person's ability to function.

FTD is distinct from other forms of dementia in two important ways:

- Onset of FTD often occurs in the 50s and 60s; the average age of diagnosis is about 60, which is a full 10 years before the average Alzheimer patient is diagnosed. Thus, FTD can affect work and family in a way dementia in older patients does not.
- The hallmark of FTD is a gradual, progressive decline in behavior and/or language (rather than memory). As the disease progresses, these deficits cause significant impairment in social and/or occupational functioning and result in an increasing dependency on caregivers.

FTD affects an estimated 50,000 Americans.

Currently, there are no treatments to slow or stop the progression of FTD. However, research is advancing and initial clinical trials are underway.

The course of the disease ranges from 2 to as long as 18 years with an average of 8 years from the onset of symptoms.

# IDEAS FOR FUNDRAISERS

In determining what kind of event to host, you are limited only by your imagination. If you are a creative genius who loves a good themed event, take your idea and run with it! If you have a strong desire to raise money for AFTD but need an easy 1-2-3 event, that's OK, too. AFTD has put together a list of ideas to get your juices flowing and start you on the way to creating a successful and fun fundraiser. These are just a few ways you can help raise funds and/or awareness for AFTD and FTD research. We encourage creativity...feel free to think outside the box and create your own fundraising event.

- Movie night
- Car wash
- Bake sale
- Candy sale
- Fashion show
- Cocktail party
- Gallery opening
- Dog wash
- Garage sale
- Pet sitting
- Dance-a-thon
- Read-a-thon
- Bowl-a-thon
- Rock-a-thon (rocking chairs)
- Tailgate party
- Talent show
- Silent and live auction
- Used book/CD sale
- 5K/Road race
- Triathlon
- Marathon
- Cycling/Bike-a-thon
- Aerobics/Spinning/Yoga
- Horseback riding
- Mountain climbing
- Golf tournament
- Casino night
- Baseball game
- Walk-a-thon/5K
- Travel vouchers
- Picnic
- Gift wrapping
- Barbeque
- Cook-off
- Music concert
- Poker night
- Garden/House tour
- Scavenger hunt
- Wine and cheese party
- Karaoke night
- Coffee house talent show
- Email/Letter campaign
- Lemonade stand
- Masquerade party
- Volleyball/Basketball/Ping-Pong/Tennis tournament

**Be creative...bring some of yourself into your event. Your enthusiasm will be contagious, and your fundraising will be easier than you thought it would be!**

# PLANNING YOUR AFTD EVENT

## Getting Started

### **Decide on what type of fundraising event to have.**

Host an AFTD event that best suits your interests and the time you have available to commit to the event. Think about whether you envision a large community-based event, a smaller event in your front yard or even just emailing a letter to friends and family. Determine how much time you will need to plan your event when setting your event date. Based on your answers, decide whether you need to recruit community support or enlist additional volunteers. Take into account any costs that you may need to incur, and think about getting sponsors to underwrite those costs. Because AFTD is not managing these events, we cannot legally incur any costs for them. Remember to make it manageable to your abilities, budget and goals!

### **Pick a date and location.**

Decide where you want to have your fundraising event. Consider a location that works well for your event, like your front yard or a community center. After you choose a location, you will need to determine whom to contact in order to receive permission to hold event there. If it's a private location, such as a supermarket or shopping area, speak with the business owner or manager. If it is a public location, such as a park or school, inquire with the town or other public agency that manages the location.

### **Register your event.**

Contact Angie Maher at [amaher@theaftd.org](mailto:amaher@theaftd.org) or 267.514.7221 x2530 to register your fundraising event. You will need to complete a third-party fundraising form, which can be downloaded from our website. You will be able to create your own personal fundraising webpage through AFTD (this module should be available in October/November 2011).

If you are having other activities or serving refreshments at your fundraising event, you will need certain supplies. Formulate a plan for how supplies will be donated or bought and who will be responsible for the supplies on the day of the event. Also, make sure to thank your donors and/or sponsors!

## Begin the Planning

### **Set Your Goals**

Set a fundraising goal based on how much money you would like your event to raise. Plan how you will raise that money -- through donations, event sponsors, raffles, business sponsorships, your fundraising page, etc.

### **Develop a Plan for Your Fundraising Event**

Create a plan for your event. Determine what supplies you will need for your fundraising event, and if you will get these donated or underwritten. Determine if you will need volunteers to help you with donations, setting up, running the event, and cleaning up. This is a great area to include friends, family, schools and businesses. Establish how many volunteers you will need and how you will recruit them.

Identify volunteer responsibilities. Base these roles and responsibilities on your volunteers' availability and skill levels. For example, if you have volunteers who are very creative, ask them to create promotional signage or event invitations. We recommend utilizing your volunteers to help during every phase of your fundraising event!

# PLANNING YOUR AFTD EVENT (CONT.)

## Get the Word Out

### Promote your fundraising event.

- Let local media such as radio, newspapers, magazines, and television stations know what you are doing. Use the sample press release on Page 10 as a base for creating your own event-specific media release. This should be sent 2-4 weeks in advance of your event, depending on the media outlet.
- Utilize social media to promote your event. Post your event on Facebook, and tweet about it on Twitter. Social media is free and a quick and easy way to let family and friends know about your event!
- Create flyers to post at local convenience stores, libraries, and other public places that have bulletin boards, especially if your event is unique or something that the public might enjoy (runs, walks, bowling, etc.) If you belong to a place of worship, ask if you can place a blurb about your event in the bulletin or newsletter.

## FUNDRAISING TO THE MAX

If you're going to fundraise, why not try to maximize your efforts, right? Here are a few tips for increasing donations and making your fundraiser a super success.

### Take it to the Web

When your fundraising event has been approved by AFTD, you will be given an online fundraising page. (This function will be available in October/November 2011.) This page can be used to invite people to attend your event and to take online donations for your event. Online fundraising makes donating to your event quick, easy and convenient for people. It's also a great way to spread the word about your event through social media. Just cut and paste the link to your Facebook or Twitter pages.

If you need additional instruction or have questions about creating or using your fundraising page, contact Angie at [amaher@theaftd.org](mailto:amaher@theaftd.org).

### Can They Match It?

This is a fantastic way to increase your donations! Ask family and friends if their places of employment have a Matching Gift Program. Many workplaces offer to match an employee's generous donation; some even do a 2:1 or 3:1 match, making that donation go even further. If donors are unsure about their workplace policy on matching gifts, direct them to their Human Resources office.

### Put Their Name on It!

If you have the opportunity for corporate sponsorships (e.g., hole sponsors for a golf tournament, ads for a program, team t-shirts, etc.), invite companies to be a sponsor for your event. Charge a set fee and then advertise the company name/logo appropriately. Many companies are happy to support a good cause in exchange for some publicity!

# SAMPLE FUNDRAISING LETTER/EMAIL

Dear (personal salutation or general, such as “Friends”),

(Share your personal story and connection with FTD.)

On (date), I will be (state activity and event). My goal is to raise (\$ insert amount) in support of AFTD.

**The Association for Frontotemporal Degeneration (AFTD)** is a not-for-profit organization founded in 2002 to advocate for more funding into the causes and treatments of frontotemporal degeneration, as well as provide caregivers and patients with a dependable source of accurate, reliable information and support.

Please join me in my efforts to raise money and awareness to support the work of AFTD so that we can move forward in our quest to find a cure for this devastating disease. You can visit my personal fundraising page at (insert web address here).

Thank you for your support!

Sincerely,

(insert name)

Learn more about AFTD by visiting their website at [www.theaftd.org](http://www.theaftd.org).

# SAMPLE THANK YOU LETTER/EMAIL

Dear (insert name),

I would like to thank you for your generous contribution of \$(amount). Your support of a cause that is so important to me and other families affected by FTD helped raise \$(insert amount raised) for AFTD's ongoing programs.

Your contribution will enable AFTD to provide both help and hope for families affected by this life-changing disease: Help in the form of support groups, educational conferences and caregiver respite grants, and HOPE by funding research to better understand the causes of FTD and to promote drug discovery for the first FTD therapeutics. With your help, we are working to realize our vision of a world where FTD is understood, effectively diagnosed, treated, cured and ultimately prevented.

Thank you for supporting my efforts to make a difference in the lives of those affected by FTD.

Sincerely,

(insert name)

# SAMPLE PRESS RELEASE



## Media Release

Contact: [Insert name, phone and email of contact person]

For Immediate Release

[Date]

### [YOUR NAME/GROUP] to [FILL IN ACTIVITY] to Raise Funds for The Association for Frontotemporal Degeneration

[City, ST] -- [Your name or group] of [your town] will [fill in activity: hold golf tournament, run race, sell candy] on [date] to raise funds for The Association for Frontotemporal Degeneration (AFTD).

[Name] aims to raise [dollar amount] or more to enable the AFTD to continue aggressively funding research to find treatments and a cure for frontotemporal degeneration (FTD). [Name] is a member of The AFTD-Team, the organization's project for supporting grassroots community fundraisers working to raise funds and awareness for FTD research.

"I chose to [activity] as part of The AFTD-Team because [fill in your reason], and I wanted to do something personally to further AFTD's work. They are funding cutting-edge research to bring meaningful advances in treatments and eventually a cure to people affected by this disease," said [Name].

FTD is a rare disease, affecting approximately 50,000 nationwide. It is a debilitating form of dementia that affects the frontal and/or temporal lobes of the brain. FTD strikes people in the prime of life--typically between ages 50 and 60--and erodes their ability to speak, move and/or behave within social norms. There is no known cure for FTD. Current treatments mask symptoms but do not alter or slow disease progression. For those affected, getting a correct diagnosis is challenging, as many physicians are unfamiliar with FTD.

The Association for Frontotemporal Degeneration envisions a world where FTD is understood, effectively diagnosed, treated, cured and ultimately prevented. For more information about AFTD or frontotemporal degeneration, visit [www.theaftd.org](http://www.theaftd.org) or contact Angie Maher at [amaher@theaftd.org](mailto:amaher@theaftd.org). For information on [activity], please visit [insert your fundraising URL here].

# # # #



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"We love it when a plan comes together."

# HOW TO HANDLE EVENT EXPENSES

The issue of handling the expenses associated with putting on a fundraiser can be a little confusing, so we've taken the guesswork out of things in an effort to make easier for you, our gracious fundraisers!

As we stated before, AFTD is not managing this event; therefore, we cannot legally incur any costs for them. However, **AFTD can offer the following items to you as a fundraiser in soliciting sponsorships:**

- *A Letter of Intent:* This is a customized letter that AFTD's Communications & Marketing Manager will write for you to use in soliciting sponsorships as well as in-kind donations of goods/services. This letter will be written on AFTD letterhead, mention your name/event/date, and state that we are a 501(c)3 organization.
- *AFTD logo:* You may use the AFTD logo (which will be emailed to you after your event has been approved) on flyers, posters, websites...however you'd like to promote your event. There are some guidelines to be aware of when using AFTD's logo. These guidelines will also be emailed to you. Please email a sample of your materials to amaher@theaftd.org for a final check before printing/distributing. Using the AFTD logo will add to the credibility of your event and let potential sponsors know you are indeed raising funds on behalf of AFTD.
- *Our IRS letter,* which documents AFTD's 501(c)3 status as an organization.
- *An official thank you letter on AFTD letterhead* to any company or organization who donates goods/services to your event.
- *An official thank you letter on AFTD letterhead* to any individual/organization whose donation is made payable to "AFTD."

Contributions in cash or that do not come directly to AFTD can be used to offset the event expenses; at the end of the event, AFTD will send an official letter on AFTD letterhead acknowledging the donation of the cumulative balance that you forward to us.

If getting sponsors is not an option, you may also elect to maintain all your receipts for any out-of-pocket expenses you incur on behalf of the event benefitting AFTD and use them as a tax deduction at the end of the year.

Should you have additional questions regarding expenses, please do not hesitate to contact Angie Maher at amaher@theaftd.org.

# DONATION INFORMATION

## Checks

Checks should be made payable to the “**Association for Frontotemporal Degeneration.**” Donations made payable to “AFTD” are tax-deductible. Donations made directly to the Association for Frontotemporal Degeneration (AFTD) will receive an acknowledgement letter; otherwise, it is the responsibility of the event host to acknowledge donations.

## The AFTD-Team Online Donations

Friends and family of grassroots fundraisers like you can make online donations directly to your personal webpage that is affiliated with your event. This feature will be available in October/November 2011.

## Credit Cards

Credit card donations are accepted online at [www.aftd.org](http://www.aftd.org) or by calling the office toll free at 866.507.7222. Advise your donors to let us know they are supporting your efforts so we can credit your event with the gift.

Send all monies (be sure to include your name and event information) immediately following your fundraising event to:

**Association for Frontotemporal Degeneration  
Radnor Station Building 2  
Suite 320  
290 King of Prussia Road  
Radnor, PA 19087**



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