

A World Apart Our Fearless Leader

AFTD's **Food** for
Thought



**an FTD grassroots fundraising toolkit for
educators and eaters**



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

Radnor Station Building 2, Suite 320 • 290 King of Prussia Road • Radnor, PA 19087
www.theaftd.org • 267.514.7221 • 866.507.7222

A Word from Our Fearless Leader

Dear AFTD Supporter,

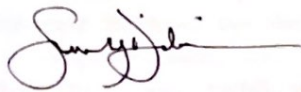
Thank you for your interest in hosting a grassroots "Food for Thought" event on behalf of The Association for Frontotemporal Degeneration. **Our goal is to have at least one person from each state and five people in Canada host an event during the first week of October** to maximize our awareness efforts and gain a collective sense of purpose...and hopefully get the attention of the media as well!

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 Food for Thought 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. And by participating in a Food for Thought event during the first week of October, you will be one of many members of our community who are raising a collective awareness of FTD across the U.S. and in Canada! We thank you for your energy, initiative and support.

Best,



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

HOST an AFTD Food for Thought Fundraiser!

Your Very Cool Tools

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Welcome to The AFTD-Team! As a Food for Thought event host, 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, known as “The AFTD-Team.”

We are grateful to have your support! AFTD is a small but mighty organization, and our impact multiplies with each Food for Thought host who shares his/her story and organizes an event.

Our staff is dedicated to providing support and resources to all those affected by FTD, whether directly or indirectly.

For fundraising support or questions, please feel free to contact the AFTD Food for Thought Volunteer Liaison assigned to you after you [submit your fundraising form!](#)

Thank you again for your support! Your commitment to organizing and hosting an AFTD Food for Thought 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 10 years, AFTD has gone from a fully volunteer-run organization to a paid staff of nine full-time employees. The organization has raised more than \$1 million for FTD research. Since 2009, AFTD has awarded \$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 diagnosed with FTD and their caregivers. AFTD provides four telephone support groups and facilitates a network of independent face-to-face groups across the U.S. and in Canada. Each year, AFTD hosts an annual caregiver conference where families can convene to learn about the latest advances in science as well as caregiving techniques. AFTD's website (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 little or no experience with 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 57, 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.

What is a Food for Thought Event?

An excellent question!

Food for Thought is a grassroots fundraising and awareness-raising campaign designed to rally as many supporters of AFTD as possible during the first week of October across the U.S. and Canada. Our collective effort to raise awareness will hopefully draw the media's attention and garner some great press for FTD.

As we all know, frontotemporal degeneration (FTD) is a life-altering disease for those affected as well as their loved ones. Yet it is little known and poorly understood. This campaign seeks to make more people aware of FTD while involving some food/drink and a little education. **Event hosts can have a dinner in their home, hold a bake/cider sale or engage a local restaurant to have a "Food for Thought" night out at their establishment.**

AFTD's Food for Thought Goal: To have at least one person in every state and five people in Canada host a Food for Thought event! And, as a little incentive, we're throwing out a challenge: the state that hosts the most number of events will get a page on AFTD's website dedicated to their Food for Thought stories for an entire year. Each organizer will get a picture and a short write-up about their Food for Thought event...and bragging rights until next October!

So...are you hungry enough to take a bite out of FTD? Ready to join people from Connecticut to California to Calgary who will share a meal and provide some FTD education with their friends and family (and hopefully the media)? If so, we want to hear from you. Simply fill out the [Food for Thought Event Form](#) on AFTD's website, and we'll get an AFTD Food for Thought Volunteer Liaison in touch with you. The liaison will be your primary point of contact to help answer any questions you might have.

We're looking forward to seeing what all of our voices together can do to raise awareness of FTD! **Don't sit this one out...we have a great opportunity to make a REAL difference and draw national attention to FTD. And it will be awesome for you to be able to say, "Yeah, I was a part of that...and I'm here to Fight This Disease!"**



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Food for Thought Fundraising Toolkit

Food for Thought Event Ideas

AFTD has put together a list of three Food for Thought event ideas. The details are outlined below for each of the fundraisers. Feel free to modify these ideas a bit to fit your taste and style. If the fundraiser can take place during the first week of October, that would be spectacular, as we hope to get many events happening during the same week to raise public awareness of the disease! We encourage creativity...feel free to think outside the box and create your own fundraising event as long as it involves food/drink to keep with the theme.

1. Host a Food for Thought dinner in your home.

This is probably the easiest of the three ideas presented here. Dinner is something that most of us have on a regular (or semi-regular) basis anyway...so go ahead and invite some friends to join you. Instead of a hospitality gift or a side dish, just ask your attendees to bring a check or make an online donation to AFTD! It's a great way to spend an evening with family and friends while sharing a bit about FTD and what your guests' support means to you. If you collect checks from your guests, send them all in one envelope to AFTD so we can accurately keep track of your fundraising efforts. Each guest who writes a check will get a personalized thank you letter (which should be kept for tax-deduction purposes) from AFTD. Online gifts will also be receipted...you may want to consider setting up a [Givezooks! fundraising page](#) to make it easy for your donors to give.

2. Hold a bake sale/cider stand (or the like) at your community center/fire hall.

Fall is a great time of year to hold a bake sale -- lots of apples, pumpkins and other great flavors to incorporate into pies, cakes and doughy goodness. A bake sale might take a little more coordination than a dinner at one's house. Check into your local community center or fire hall to see what rental fees may exist and if you can secure a date for sometime during the first week in October (a weekend day is probably best). Invite family and friends to help make items for the sale. Use the sample press release in this packet to help get the word out about the sale. Post your event on your Facebook page; ask others to share it.

While it's not lemonade season, children could get involved with a hot chocolate or hot cider stand. These drinks are perfect for cooler temperatures. Of course, adults may need to supervise, but people love supporting children who are raising money for good causes. Please check with your local government (if you have one) about any permits that might be necessary to have a stand. Having the stand in a high-traffic area would maximize your efforts...just remember that you need to be able to replenish your hot drinks from time to time, so you should have access to a stove or at least hot water.

3. Ask a restaurant to host an event for you.

Consider asking a restaurant in your community if they'd host a "Food for Thought" night during the first week of October. This was piloted a few years ago by a family in New York City. The restaurant donated the food, each attendee was charged a fixed price and guests enjoyed a good meal with some FTD education as well. You will need to work closely with the owner to iron out all details. Use the sample press release in this packet to help get the word out about the event. Post the fundraiser on your Facebook page; ask others to share it. If the owner is willing to advertise the event for you as well, that would also be helpful. For any specific questions on this option, please email Angie Maher at amaher@theaftd.org.

Planning your Food for Thought Event

Getting Started

Decide on what type of fundraising event to have.

Host a Food for Thought event that best suits your interests and the time you have available to commit to the event. Take into account any costs that you may need to incur. 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 event. Consider a location that works well for your event, like your home, 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 the 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.

Fill out the [Food for Thought Event form](#) on AFTD's website. AFTD staff will then assign you a Food for Thought Volunteer Liaison who will be your primary point of contact for any questions you may have while organizing your event. You can also create your own personal online fundraising webpage through AFTD by visiting <http://theaftd.givezooks.com>. This fundraising page would give people who cannot attend your event an opportunity to donate online. Setting up a Givezooks! page is easy and quick, and the software walks you through the set up step by step.



Planning Your Food for Thought Event (cont.)

Get the Word Out

Promote your Food for Thought sale or restaurant night out

- Let local media such as radio, newspapers, magazines, and television stations know what you are doing. Use the sample press release on Page 11 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. 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 form has been received by AFTD, you will be able to create your own an online fundraising page (visit <http://theaftd.givezooks.com>). 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, especially for those who may not be able to attend. It's also a great way to spread the word about your event through social media.

If you need additional instruction or have questions about creating or using your fundraising page, contact Liz Neal at eneal@theaftd.org.

Can They Match It?

This is a fantastic way to increase your donations! Ask family and friends if their employer has 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.

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) as a Food for Thought 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 mission 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.

Sample Thank You Letter/Email

(note: AFTD will also send thank you letters for any individual checks and online donations.)

Dear (insert name),

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

Your donation will enable AFTD to provide both help and hope for families affected by this life-changing disease: HOPE 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. Because of the generosity of people like you, we are able to work on realizing 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)



For Immediate Release
[Date]

Sample Press Release

Media Release

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

[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 bake sale/restaurant night out] on [October date] to raise awareness and funds for The Association for Frontotemporal Degeneration (AFTD).

[Name] aims to raise funds to enable the AFTD to continue aggressively funding research to find treatments and a cure for frontotemporal degeneration (FTD). [Name] is one of many individuals across the country and Canada raising awareness of FTD this week as part of AFTD's "Food for Thought" campaign.

"I chose to [activity] as part of Food for Thought campaign 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 may address 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 or contact Angie Maher at amaher@theaftd.org. For information on [activity], please visit [insert your fundraising URL here].

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How to Handle Food for Thought Restaurant Night out 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 form has been received) 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 your Food for Thought Volunteer Liaison 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 deductible to the extent your personal tax situation allows. Contact your tax professional for direction.

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" or "AFTD." Donations made payable to the organization are tax-deductible. Donations made directly to 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. Visit <http://theaftd.givezooks.com> to create your own online fundraising webpage. Automatic thank you letters will be sent electronically to all donors who give online with the amount of their name, address and amount of their donation on it for tax purposes.

Credit Cards

Credit card donations are accepted online at 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 Food for Thought 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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