

AFTD Advocacy:

How to Recognize FTD Awareness Week in 2024



Securing an Awareness Resolution is a great way to raise awareness about FTD and AFTD. This toolkit serves to guide you through the process and provide the resources you may need to request that your state legislature or government official declare September 22-29, 2024, as FTD Awareness Week in your city, town or state.

WHAT IS A RESOLUTION?

A resolution or concurrent resolution is a non-legal declaration designating a period to commemorate an event or cause, or to honor an individual or group. An example of this is Congress declaring November National Family Caregivers Month. A resolution requires sponsorship and must be approved by the entire legislative body from which it is sought. A concurrent resolution requires sponsorship and passage in both the Senate and Assembly/House. Resolutions can be issued by governing bodies at any level and can be a great way to educate public officials and draw attention to FTD-related issues.

WHY REQUEST A RESOLUTION IN YOUR CITY OR STATE?

- Frontotemporal Degeneration (FTD) is often misunderstood and misdiagnosed. We need to build awareness of the complexity and diverse presentations of a disease that affects people between the ages of 21 and 80 with the largest percentage of those affected being between 45 and 64.
- Build closer working relationships with local, county and state officials.
- Increase policymaker's understanding that FTD is not the same as Alzheimer's disease.
- Increase AFTD & FTD Visibility—Any press or online visibility around a resolution can help build support and awareness of what AFTD has to offer to persons with dementia and their families.
- Advocacy can successfully shape public policies to increase research funding and develop and improve care, support and respite services.

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STEPS TO SECURE A RESOLUTION

- Step 1** Contact AFTD at advocacy@theaftd.org to let us know your plans to secure a resolution in your state.
- Step 2** Prior to September identify your state and local legislators in both houses (Senate and Assembly). Use www.usa.gov/state-local-governments to perform an easy search.
- Step 3** Find a sponsor(s). Research your legislators to see what kind of issues they tend to support and if they have an interest in dementia or health more generally. Identifying more than one sponsor, especially from both parties, will help with passing the Resolution.
- Step 4** Identify the deadline for filing resolutions and build out a plan of action accordingly. (See <https://www.statescape.com/resources/legislative/session-schedules/>)
- Step 5** Call, write or email the sponsor(s) you have identified and offer/attach the Model Resolution text.
You will find the sample email text and model resolution text below.
- Step 6** Follow up the written request with a phone call. Be prepared to answer questions about AFTD and how the Resolution will be used. AFTD's advocacy team can work with you on a press event/release, or formal presentation as requested by the sponsor(s).
- Step 7** Work with the sponsor(s) to finalize the Resolution language and introduce the bill.
- Step 8** Once the Resolution has been introduced, reach out to AFTD's advocacy team for support in mobilizing advocates in your area via email and social media to help get it passed.

Email advocacy@theaftd.org with any questions or for help along the way!

**** You don't have to work alone! We encourage you to find other people in your area who are passionate about obtaining a Resolution. Working with a group provides support and may expand the sponsor selections if members are from different constituencies.**

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SAMPLE OUTREACH EMAIL

The following email template is to provide you with language you can use when seeking a Resolution from your state or local officials for World FTD Awareness Week. Please feel free to copy/paste or edit as you like and be sure to personalize the letter and speak to your experience with FTD.

Dear [Legislator last name]:

I am a constituent who lives in [Town, State] and [I have / I have a loved one living with/ I had a loved one living with] Frontotemporal Degeneration (FTD). As an advocate with the Association for Frontotemporal Degeneration (AFTD), I am writing to ask for your help in sponsoring a Resolution in [City, State or Town] recognizing September 22-29, 2024, as FTD Awareness Week.

FTD is an underdiagnosed neurodegenerative disease that affects more than 60,000 people in the United States. FTD affects ages as young as 17 and old as 87 with the largest percentage of affected being under 65. It can impact behavior, decision-making, personality, language, and/or movement. The average life expectancy is 7 to 13 years. There are currently no treatments to slow the progress of this disease.

[Add 2-3 sentences about you, your family member, and your experience with FTD]

You can learn more about FTD at <https://www.theaftd.org/what-is-ftd/disease-overview/> and AFTD at <https://www.theaftd.org/>.

Establishing an FTD Awareness Week will help increase awareness and support for a disease that is largely misunderstood, misdiagnosed and underfunded. Similar efforts are underway in other states across the country. I urge you to sponsor a Resolution to declare September 22-29, 2024, as FTD Awareness Week in [City, State or Town].

I appreciate your attention to this request and will follow up shortly with a phone call.

Sincerely,

AFTD Advocate Name

Street Address

City, State

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SAMPLE RESOLUTION TEXT

(Text can be used as a starting point for other states)

MEMORIALIZING [Name of Governor] to proclaim September 24-October 1, 2024, as Frontotemporal Degeneration Awareness Week in the State of [Name of State]

WHEREAS, It is the custom of this Legislative Body to recognize official weeks that are set aside to increase awareness of serious health conditions that affect the lives of citizens of [Name of State]; and

WHEREAS, Attendant to such concern and in full accord with its long-standing traditions, it is the sense of this Legislative Body to memorialize [Name of Governor] to proclaim September 22- 29, 2024, as Frontotemporal Degeneration Awareness Week in the [Name of State], in conjunction with the observance of World FTD Awareness Week; and

WHEREAS, the Association for Frontotemporal Degeneration (AFTD) reports that Frontotemporal Degeneration (FTD) is a terminal and incurable neurodegenerative disease affecting the frontal and temporal lobes, causing impairments to speech, personality, behavior, and motor skills which constitutes a major public health concern; and

WHEREAS, It takes an average of 3.6 years from start of symptoms to get an accurate diagnosis of FTD with average life expectancy of 7-13 years after start of symptoms; and

WHEREAS, FTD may strike people between the ages of 21 and 80 with the largest percentage of those affected being between 45 and 64, rendering people in the prime of life unable to work or function normally; and

WHEREAS, FTD imposes average annual costs associated with care and living with the disease that are approximately double those of Alzheimer's disease; and

WHEREAS, FTD is identified in The National Plan to Address Alzheimer's Disease as a related dementia and included as a priority in the goals and strategies of the Plan to achieve the vision of a nation free of Alzheimer's disease and related dementias; and

WHEREAS, [Add clause here connecting an FTD Awareness Week to a State Alzheimer's Plan or similar document]

WHEREAS, FTD represents an estimated 5 to 15 percent of all dementia cases and is the most common form of dementia for people under 60 years of age; and

WHEREAS, approximately 40% of people with FTD have a family history of FTD or a related condition such as ALS, with about half of those found to have an inherited form accounted for by mutations in the Progranulin, C9orf72, Tau/MAPT and other rarer genes; and

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WHEREAS, FTD is often misdiagnosed as a psychiatric problem or other neurodegenerative disease because of the wide range of cognitive and behavioral symptoms and their young onset; and

WHEREAS, FTD often affects a person's ability to express emotions and to show affection and empathy for loved ones; and

WHEREAS, In the behavioral variant of FTD, a person's sense of social graces and appropriate behavior can be lost, and their personality may be significantly changed; and

WHEREAS, Furthermore, in the language variants of FTD (primary progressive aphasia), a person may have trouble producing speech and understanding grammar, lose the meaning of words or become hesitant in their speech, and may eventually become mute; and

WHEREAS, In the movement variants of FTD, a person may experience muscle weakness, falling, loss of balance, difficulty making speech, difficulty swallowing, or choking; and

WHEREAS, While there has never been a global epidemiology study of FTD, it is estimated that more than 60,000 people are affected in the United States today; and

WHEREAS, AFTD is the leading national organization exclusively focused on the spectrum of FTD disorders with a mission to improve the quality of life of people affected by FTD and drive research to a cure; and

WHEREAS, It is imperative that there be greater awareness of this serious disease, and more must be done to increase activity at the local, state, and national levels; now, therefore, be it

Resolved by the Senate of the [Name of State], the Assembly thereof concurring, That the Legislature proclaims the week of September 22 to September 29, 2024, inclusive, as Frontotemporal Degeneration Awareness Week; and be it further.

Resolved, That the Secretary of the Senate transmit copies of this resolution to the author for appropriate distribution.

The Association for Frontotemporal Degeneration
theaftd.org | HelpLine: 1.866.507.7222 | info@theaftd.org

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