

AFTD Advocacy:

Secure a Proclamation in your State or City for FTD Awareness Week



Proclamations like resolutions can help support the needs of persons with dementia and their families, expand awareness of frontotemporal degeneration (FTD), and increase the visibility of AFTD. This toolkit serves to guide you through the process and provides the resources you may need to request that your public officials proclaim September 22-29, 2024, as FTD Awareness Week in your city, town, or state.

WHAT IS A PROCLAMATION?

A proclamation is an official public statement that may not require a legislative vote for approval. Proclamations are clerical procedures handled by clerks of the Senate, House, or county or municipality council. Executives, such as a governor or mayor, may issue proclamations via executive orders. They are often routine and can be simple to obtain.

Why Request a Proclamation?

- Increase policymakers' understanding that frontotemporal degeneration (FTD) is not the same as Alzheimer's disease.
- FTD is often misunderstood and misdiagnosed. We need to build awareness of the complexity and diverse presentations of a disease that affects people as young as 21 and as old as 80 with the largest percentage of those affected in their 40s to 60s.
- Build relationships with local, county and state officials.
- Increase AFTD & FTD Visibility—Any press or online visibility around a proclamation can build support and awareness of what AFTD has to offer to persons with dementia and their families.
- A request for a proclamation and publicity about the proclamation reminds policy makers of the need for public resources to address dementia issues.

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STEPS TO OBTAIN A PROCLAMATION

Three Months Before FTD Awareness Week, September 22-29

- 1 Contact AFTD at advocacy@theaftd.org to let us know your plans to get a proclamation in your state.
- 2 Decide what public body or office could best issue a proclamation: city or county council, either branch of the legislature, or the mayor or governor's office.
- 3 Send a proclamation request to the clerk of the legislative body you have selected. (If a state proclamation is desired, call the governor's office to ask who handles these affairs- send your request directly to them!) The model proclamation language below should be sent with this request.
 - a States may need to know who the requesting organization (AFTD) is and ask you to send summary/background information regarding the organization. Please use the Requesting Organization Information below.
 - b Please let us know what state, city or town you have applied for by emailing advocacy@theaftd.org.

Two Weeks Later

- 4 Follow up with a phone call if you have not received a response. Do not be upset if the clerk has not read your request letter, the clerk may be juggling multiple requests at once. Be prepared to answer questions about AFTD and whether you would like a formal presentation of the proclamation by a public official.
- 5 Finalize the proclamation text with your legislator and arrange a time when the proclamation may be picked up.
- 6 Please take a photo of your proclamation and/or presentation and share on social media. Make sure you tag us on Facebook @TheAFTD and Instagram @theaftd. Also, send the photo to advocacy@theaftd.org so we can celebrate with you and share your success!
- 7 Be sure to send a follow-up thank you to your legislators once you have received your proclamation! Please see thank you template below.

Be sure to use AFTD as a resource! Do not hesitate to reach out to advocacy@theaftd.org for any questions or concerns.

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SAMPLE EMAIL / FORM TEMPLATE

The following email template is to provide you with language you can use when seeking a Proclamation from your state or local offices for 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). To help others learn more about FTD and the devastating impact it has on families and friends, I would be grateful for your support in promoting FTD Awareness Week, September 22-29, 2024.

Recognizing this week is an excellent opportunity for (City / County / State / Town) to demonstrate its support for increasing awareness about FTD. As an advocate with the Association for Frontotemporal Degeneration (AFTD), we would be honored if you would sponsor an official proclamation to recognize 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 21 and old as 80 with the largest percentage of those affected under 65. It can impact behavior, decision-making, personality, language, and/or movement. The average life expectancy is 7 to 13 years. There is no cure and 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/>.

Attached is (sample proclamation text) which may help your office in writing the proclamation.

Proclaiming 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, cities, and towns across the country.

If you or your staff have questions about the request, the sample proclamation or FTD and AFTD, please let me know. I appreciate your attention to this request and will follow up soon with a phone call.

Sincerely,

AFTD Advocate Name

Phone Number

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REQUESTING ORGANIZATION INFORMATION

Requesting Organization: The Association for Frontotemporal Degeneration (AFTD)

Summary and Background of Requesting Organization:

The Association for Frontotemporal Degeneration (AFTD) is the largest national nonprofit devoted to providing resources to help families affected by FTD today, while advancing research to foster accurate diagnosis, treatments, and a cure. Our volunteer founded organization – driven by thousands of volunteers and donors – reflects a community's profound determination to #endFTD. With the FTD Disorders Registry, we are proud to partner with families, researchers, biopharma companies, state and federal policymakers, and health professionals across the country to improve care for people and families facing FTD.

While FTD is the most common young-onset dementia, too few medical professionals are aware of it. On average, it takes nearly four years to get a correct diagnosis. Unlike Alzheimer's, which is characterized by a decline in memory, FTD causes irreversible changes in personality, behavior, language, and/or movement, while leaving memory relatively preserved.

SAMPLE FOLLOW UP EMAIL TEMPLATE

Dear [Name],

I am writing to follow up on my request for your office to issue an official proclamation to recognize September 22-29, 2024, as FTD Awareness Week.

This week provides an excellent opportunity for (City / County / State / Town) to demonstrate its support for raising awareness about frontotemporal degeneration.

I sent sample proclamation language to help your office draft the appropriate proclamation. Please contact me if you have any questions.

Thank you for your consideration of this special request.

Sincerely,

AFTD Advocate Name
Phone Number

SAMPLE THANK YOU EMAIL TEMPLATE

Dear [Name],

Thank you for your support of an official proclamation recognizing September 22-29 as FTD Awareness Week. We believe that raising awareness for this rare form of dementia will help increase diagnosis rates and improve care and services for those living with FTD. On a personal level, this recognition is very special to me in honor of [family member's / friend's name] who [lives/lived] with FTD. We are very grateful for your support.

Sincerely,

AFTD Advocate Name
Phone Number

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SAMPLE PROCLAMATION LANGUAGE

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, 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

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

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SAMPLE PROCLAMATION LANGUAGE

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

NOW, THEREFORE, I, (Lawmaker's First and Last Name), (Lawmaker's Title) of the (State / City Name), do hereby proclaim the week of September 22 to September 29, 2024, as Frontotemporal Degeneration Awareness Week

IN TESTIMONY WHEREOF, I have hereunto set my hand and caused the Great Seal of the (State / City Name) to be affixed.

DONE at the (Capitol / Town Hall) in the (State / City) on this (Write Out Date) day of (Month) in the year 2024.

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

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