

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

September 28 - October 4, 2026



Proclamations can help increase the visibility of AFTD, expand awareness of FTD, and support the needs of persons with dementia and their families. This toolkit serves to guide you through the process and provide the resources you may need to request that your public officials proclaim September 28 - October 4, 2026, as FTD Awareness Week in your city, town, or state.

WHAT IS A PROCLAMATION?

A **proclamation** is a formal public statement by a public body of a person, group, or event that may not require a formal legislative vote. Proclamations are clerical procedures that are handled by a county or municipality council, or executives, such as a governor or mayor, via executive orders. They are often routine and can be simple to obtain.

WHY REQUEST A PROCLAMATION?

Awareness week proclamations are a great tool to begin or build upon working relationships with your officials. By starting this conversation with your legislators, you are building awareness of the complexity and diverse presentations of FTD and increasing policymakers' understanding that FTD is not the same as other dementias.

Proclamations result in increased visibility of both FTD as well as the resources and support that AFTD has to offer for persons with dementia and their families. They also have the potential to capture press that will expand your reach. Advocacy can successfully shape public policies to increase research funding and develop and improve care, support, and respite services.

September 28 - October 4, 2026 is World FTD Awareness Week!



STEPS TO OBTAIN A PROCLAMATION

Three Months Before FTD Awareness Week, September 28 - October 4, 2026

- 1 Contact AFTD at advocacy@theaftd.org to let us know your plans to get a proclamation in your state, city, or town.
- 2 For requests to **the Governor**, most states have a proclamation request form that can be found and filled out online. Most forms will ask you to include Proclamation Language which can be found below. If you are asked and able, request that you pick up your proclamation in person. For requests at **the local level**, send an email to your local officials using the sample email template found below. Be sure to include an attachment of the proclamation language found below.
 - a States may ask for the requesting organization (AFTD) and summary/background information regarding the organization. Please use the Requesting Organization Information below.
- 3 Follow up with a phone call or email if you have not received a response within a month of your request to your Governor and within two weeks of your request at the local level. It is not uncommon for the process to take several weeks.
- 4 Upon successful outreach, if your request was made at the local level, be prepared to answer questions about AFTD and whether you would like a formal presentation of the proclamation by a public official. If your request was made at the state level, be sure to request that you pick up the proclamation in person.
- 5 Pick up your finalized proclamation.
- 6 Please take a photo of your proclamation and/or presentation and share it with us at advocacy@theaftd.org. If you share your success on social media, make sure you tag us on Facebook @TheAFTD and Instagram @theaftd.
- 7 Be sure to send a follow-up thank you to your officials 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 FOR LOCAL REQUESTS

The following email template is to provide you with language you can use when seeking a proclamation from county and city/town 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 28 - October 4, 2026.

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 28 - October 4, 2026, 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 people 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/>.

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. Many states and cities have already adopted FTD Awareness Week Proclamations across the country.

If you or your staff have any questions concerning 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

Town and State

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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 advance accurate diagnosis, treatments, and a cure. Our organization 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.

SAMPLE FOLLOW UP TEMPLATE

Dear [Name],

I am writing to follow up on my request for your office to issue an official proclamation to recognize September 28 - October 4, 2026, 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 previously sent in a proclamation request as well as sample proclamation language to assist your office in composition of 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
Town and State

SAMPLE THANK YOU TEMPLATE

Dear [Name],

Thank you for your support of an official proclamation recognizing September 28 - October 4, 2026, as FTD Awareness Week. We believe that raising awareness for this rare form of dementia will help in diagnosis. On a personal level, this recognition is very special to me because [blank]. We are very grateful for your support.

Sincerely,

AFTD Advocate Name
Phone Number
Town and State

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SAMPLE PROCLAMATION LANGUAGE

WHEREAS, it is the custom of this Executive office to recognize official weeks that are set aside to increase awareness of serious health conditions that affect the lives of citizens of (Name of City/State); and to memorialize (Governor/Mayor) (Name of official); to proclaim September 28 - October 4, 2026, as Frontotemporal Degeneration Awareness Week in the State of (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; and that 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, and is the most common form of dementia for people under 60 years of age, 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 is identified in The National Plan to Address Alzheimer's Disease and recognized by the [Name of State Dept] as a related dementia and included as part of the vision of the nation and [State/City] free of Alzheimer's disease and related dementias; 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 28 - October 4, 2026, 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 2026.

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

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