

# The VOICE of FTD

FALL 2019

## World FTD Awareness Week 2019

September 22-29, 2019

*A week of events, activism, and international engagement*

This fall from September 22-29, 2019, World FTD Awareness Week will celebrate its fifth year. The week is to focus on what FTD is (frontotemporal degeneration), increase awareness, and provide education. It is an initiative of World FTD United, a coalition of several organizations throughout the world.

“The goal is for people to share their FTD stories, practical advice, resources, and messages of hope with others throughout the world, both to bring support and strength to each other and to let the general public know that not all dementia is Alzheimer’s,” said Matt Ozga, Communications Manager at the [Association of Frontotemporal Degeneration](#) (AFTD).

A week of events, activism, and international engagement, World FTD Awareness Week is held each year near the end of September or in early October.

Last year 179 people representing 167 different cities in 24 countries contributed their stories to the [World FTD Awareness Week map for 2018-2019](#). The map collects messages of hope, practical guidance and resources, and stories of families affected by FTD. You can share hope with others around the world by telling your story via the [2019-2020 World FTD Awareness Week map](#). Read a message or leave a message.

This year the Asociación de Demencia Frontotemporal de España will celebrate the week with presentations in three cities across that country, including:

- September 23 - Bilbao
- September 24 - Madrid
- September 25 - Barcelona

For more information on these events, check out the flyer on page 3.

### AFTD Takes a Bite Out of FTD

Food for Thought (FFT) is a grassroots fundraising campaign that supports AFTD’s mission and is held each year in conjunction with World FTD Awareness Week. FFT empowers people throughout the U.S. (and elsewhere -- events have also been held in the United Kingdom and Canada) to host events in which they bring people together to raise funds and spread FTD awareness. Anything can be a FFT event, as long as FTD and food are involved -- it could be a happy hour, a three-course home-cooked meal, or a pizza party.

AFTD launched its first annual “Food for Thought” initiative seven years ago in October 2013. That year, people in 25 states and five Canada provinces hosted 80 food events and raised approximately \$50,000 to benefit AFTD’s mission.

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**FTD Disorders Registry LLC**  
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[youtube.com/channel/UCQU8ZEx-eueiDPLIFXzfPQ](https://youtube.com/channel/UCQU8ZEx-eueiDPLIFXzfPQ)

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Since 2015, FFT has been organized around World FTD Awareness Week and went global with 20 international events in addition to 61 in the United States. Hosts worked to raise FTD awareness through activities, events, conferences, and various online social media campaigns. This year FFT kicks off with World FTD Awareness Week, and while many events are held during this first week, some are also scheduled for the following week.

In addition to FFT, other major AFTD grassroots fundraising campaigns include With Love (February) and the Race Season (year-round).

“Outside of these three branded campaigns, members of our community may choose to raise funds on behalf of our mission via Facebook fundraisers or independent events,” Ozga said.

During World FTD Awareness Week you can share a meal and provide FTD education with friends and family. You can Inform people about this disease, and to raise support for efforts to fight it.

Past Food for Thought events have included:

- Home-cooked dinners
- Bake sales
- Lemonade stands
- Champagne receptions
- Happy Hours
- Wine & Chocolate receptions
- Restaurant fundraisers
- Dessert Nights
- Silent Auctions
- Line Dancing
- Tea Party
- Online events
- Pizza parties

[Learn more about hosting an AFTD event.](#)



World FTD United organized the first World FTD Awareness Week in 2015. Currently, 15 countries are represented in the coalition: Argentina, Australia, Brazil, Canada, Columbia, France, India, Ireland, Italy, Germany, Spain, Switzerland, The Netherlands, United Kingdom and the United States of America.

Although FTD is the most common form of dementia for people under 60, far too few know about the challenges it brings for hundreds of thousands around the world. World FTD Awareness Week hopes to change that by increasing global awareness in order to hasten diagnosis, improve care and support options, foster research into potential treatments, and ultimately find a cure.

Links:

- [2019-2020 World FTD Awareness Week map](#)
- [Host an AFTD Event](#)
- [Learn more about FTD events in Spain](#)

**Join the Registry.  
Tell Your Story.  
Advance the Science.**

***“Together, we can make a difference!”***

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World  
FTD Awareness Week  
Del 23 al 29 septiembre 2019

## V SEMANA INTERNACIONAL DE LA DEMENCIA FRONTOTEMPORAL

Antes conocida como 'Enfermedad de Pick'

**Día 23 BILBAO** Salón de Actos BOLUNTA (Edificio BBK) C/ Ronda s/n. Desde 16:00 h.

Dra. Mónica Moyano / Unidad de Cuidados Paliativos. Hospital San Juan de Dios de Santurtzi (Bizkaia).  
"EL DUELO. APRENDIENDO A VIVIR LA PÉRDIDA".

D. Manuel Pérez Álvarez / Dpto. Neuropsicología UD. Equipo de Enfermedades Neuromusculares de la Universidad de Deusto.  
"ELA-DFT. AVANCES EN LA CARACTERIZACIÓN DE LAS ALTERACIONES NEUROPSICOLÓGICAS".

Dr. Javier Terán / Director científico de Laboratorios NUTILAB.  
"DHA PURO. SALUD Y PROTECCIÓN PARA EL CEREBRO".

Dra. María Ángeles Gómez Beldarrain / Neuróloga. Jefe del Servicio de Neurología del Hospital Galdakao-Usansolo.  
"DEMENCIA FRONTOTEMPORAL Y PROGRANULIN".

Dr. Manuel Fernández / Unidad de Valoración de la Memoria y Demencias. CAE OROITU (Getxo).  
Neurólogo BioCruces - Health Research Institute.  
"NUEVOS AVANCES EN LA DEMENCIA FRONTOTEMPORAL".

Dra. Elisa Blanco / Neuróloga. Hospital de Urduliz (Bizkaia).  
"FÁRMACOS EN DESARROLLO PARA LA DEMENCIA FRONTOTEMPORAL".

**Día 24 MADRID** Aula Francisco Grande del Hospital Universitario de la Fundación Jiménez Díaz. 16:00 h.

Dra. María Ruggiero / Neuróloga. Hospital Rey Juan Carlos I.  
"LA DEMENCIA FRONTOTEMPORAL, DESINHIBICIÓN Y APATÍA".

Dr. Pablo Agüero Rabes / Neurólogo. Unidad de Demencias del Hospital Universitario de la Fundación Jiménez Díaz.  
"LA DEMENCIA FRONTOTEMPORAL, SU MANEJO Y AVANCES".

Testimonio de un familiar de paciente con DFT.

**Día 25 BARCELONA** Sala de Actos Farreras Valentí del Hospital Clínic de Barcelona. C/ Villarroel, 170. 16:00 h.

Dr. Sergi Borrego / Neurólogo. Hospital Clínic de Barcelona.  
"CONOCIENDO LA DEMENCIA FRONTOTEMPORAL".  
"EL CUIDADO DEL PACIENTE CON DEMENCIA FRONTOTEMPORAL".

Dra. Raquel Sánchez Valle / Unidad de Alzheimer y otros trastornos cognitivos. Servicio de Neurología-ICN Hospital Clínic. IDIBAPS-Universidad de Barcelona.  
"AVANCES DE LA INVESTIGACIÓN EN LA DEMENCIA FRONTOTEMPORAL".

ORGANIZADA Y COLABORA:



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