


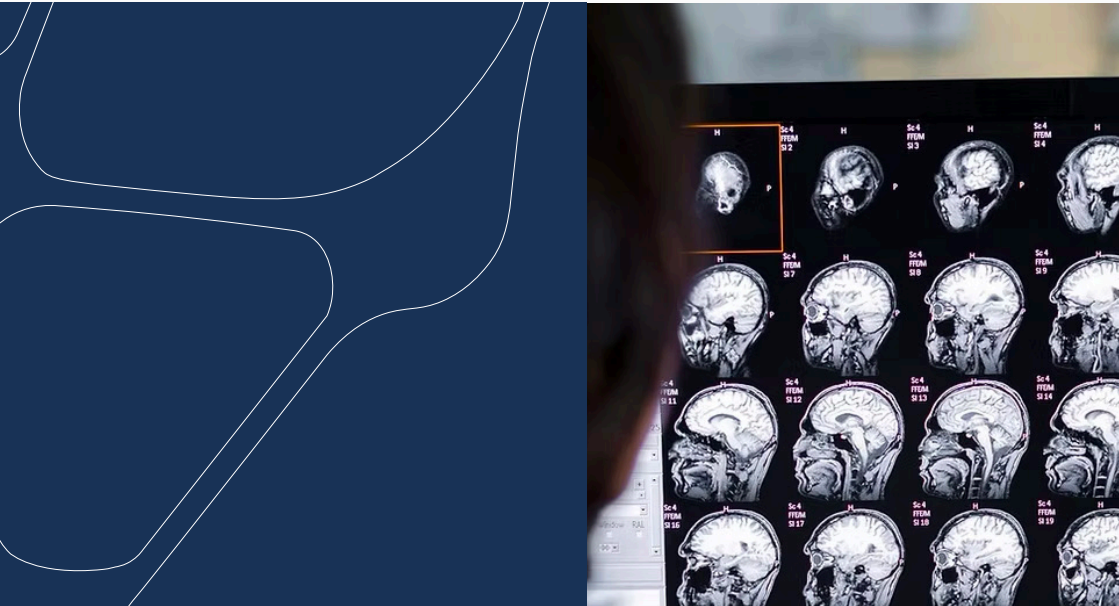
 [predictftd.eu](https://predictftd.eu)  
 [@PREDICTFTD](https://www.youtube.com/@PREDICTFTD)  
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# Accelerating the Validation of Predictive Liquid Biomarkers for Frontotemporal Dementia Diagnosis and Subclassification



## PREDICTFTD NEWSLETTER 01



Funded by  
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## About

Why PREDICTFTD?

### Debilitating effect on patients and their caregivers



#### Robust Two-Stage Validation Approach

Phase I validates biomarkers and algorithms on a cohort of genetic and autopsied cases and phase II assesses biomarker value for diagnosis of all FTD patients and at-risk pre-symptomatic mutation carriers.



#### 11 Geographically Diverse Cohorts

We combine 11 geographically diverse cohorts of sporadic and familial FTD with retrospective and prospective longitudinal liquid biopsy samples and extensive clinical and behavioural data.



#### Multimodal Clinical & Liquid Biomarker Data

We are the first to use multimodal clinical and liquid biomarker data to train an AI-algorithm as a diagnostic tool.

About FTD

Frontotemporal dementia (FTD) has a debilitating effect on patients and their caregivers and leads to substantial economic costs.

15-30%

Familial FTD

15-30% of patients have familial FTD caused by known pathogenetic mutations.

70-85%

Sporadic FTD

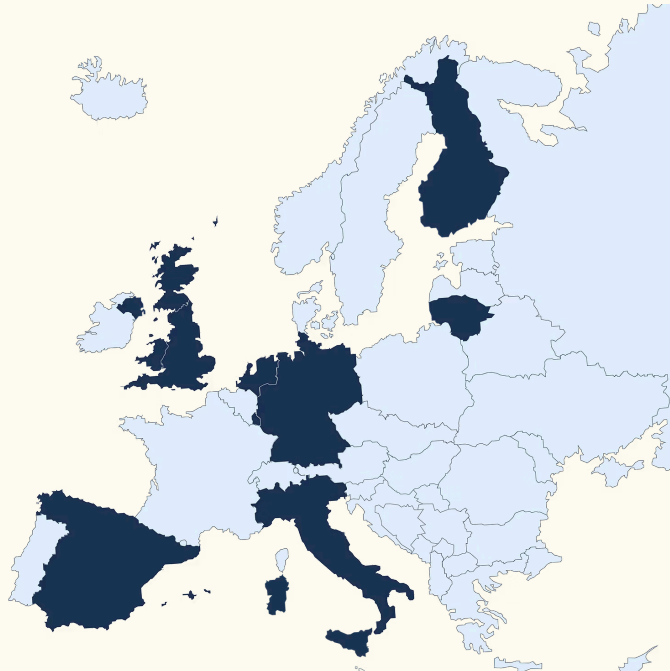
For the other 70-85% of patients, termed sporadic FTD, diagnosis is slow (~3.6 years) with frequent misdiagnosis due to clinical, genetic and molecular heterogeneity.

# Consortium


Who

## The diversity brings a wide range of perspectives to the project

This includes experts and institutions from Finland, Germany, Italy, Lithuania, Luxembourg, the Netherlands, Spain, and the United Kingdom, each contributing their unique knowledge and innovation to our collaborative efforts.



# Public Involvement Board



**To support meaningful Public Involvement, [Alzheimer Europe \(AE\)](#) has set up the PREDICTFTD-PIB at the beginning of 2025. In partnership with the project partners, AE will conduct Public Involvement activities ensuring that all the research conducted within the project is informed by people with lived experience.**

The PREDICTFTD-PIB is currently composed of a diverse group of 7 people from 4 different countries: United Kingdom, Ireland, Finland and Malta. This diversity is also reflected in their lived experiences. Alzheimer Europe and the project partners have

already started working with the PREDICTFTD-PIB and are looking forward to more fruitful discussions with its members. Their contributions will be essential for the research activities conducted by the consortium.

Why is Public Involvement important?

## Active and meaningful contribution

Public Involvement is based on the right of people living with a condition to have a say in the research that directly affects them. People with a neurodegenerative disease leading to dementia can actively and meaningfully contribute towards several aspects of the research process by bringing their lived experiences, perspectives and priorities, from which researchers can benefit too.

Read more

[Public Involvement Board discuss different aspects of a Frontotemporal dementia diagnosis Members](#)

# FTD Awareness Week

Why Awareness Week

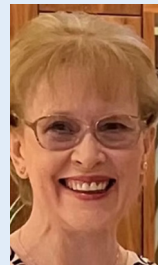
## Breaking the stigma, fostering understanding, and pushing for earlier, more accurate diagnoses

September 21st-27th marks FTD Awareness Week, a time to raise awareness of a condition that often goes unnoticed and is misunderstood. Behind every diagnosis of frontotemporal dementia (FTD) is a personal story of resilience, struggle, and love. Sharing these experiences is vital to breaking the stigma, fostering understanding, and pushing for earlier, more accurate diagnoses. Real FTD experiences are also essential for the PREDICTFTD project.



### Stephen Kennedy

"I no longer take small moments for granted. Every day, I try to accept what I cannot control and find light, even in uncertainty. Though FTD changes many things, it doesn't erase the love I feel or the value I bring to those I care about. I'm still here, day by day. Simple joys, like a shared laugh, mean more than ever to me now."



### Margaret McCallion

"I socialise with family and friends, as well as enjoy singing and music. I am an active member of the Scottish Dementia Working Group & the European Working Group of People with Dementia, where we affect changes to working practices. FTD does not define who I am."



### Carmel Geoghegan

"If we had received an explanation at the point of diagnosis, we would have had a more positive life experience. Mum's change in personality, behaviour and language at times was unreal. Information is key to quality of life for all affected."

## Website

### The [PREDICTFTD website](#) is now live!

Website, where you can find:

- Mission to accelerate the validation of predictive liquid biomarkers for frontotemporal dementia (FTD);
- Subscription to the newsletter and stay updated on news, events, and results;
- Consortium and our public involvement approach;
- How we're working together to enable earlier and more accurate diagnosis of FTD—paving the way for tailored care and treatment;
- Visit us at: <https://www.predictftd.eu/>.

## Dissemination Material

Find material for downloading, printing and sharing.

[Logo](#)

[Roll-up](#)

[Leaflet](#)

[and more](#)



# Meetings and Dissemination Events

23rd January 2025

## Day 1 of the Project Kick-Off Meeting

What an exciting and productive start to our PREDICTFTD journey today! Day 1 of the Project Kick-Off Meeting was focused on partner introductions and aligning our goals as we laid the foundation for this project.

A huge thanks to all our incredible partners for joining us onsite in Rotterdam, kindly hosted by coordinators Harro Seelaar and Laura Pruyin from Erasmus MC. Your energy and ideas are invaluable, and we can't wait to continue this journey together!



24th January 2025

## Day 2 of the Project Kick-Off Meeting

Another successful day of collaboration at the PREDICTFTD Project Kick-off!

On Day 2, we continued discussing work packages, biomarker details, and AI model generation. These sessions laid a strong foundation for advancing biomarker-led diagnostics and AI-driven solutions in dementia research.

A heartfelt thank you to our amazing partners for their dedication and contributions!

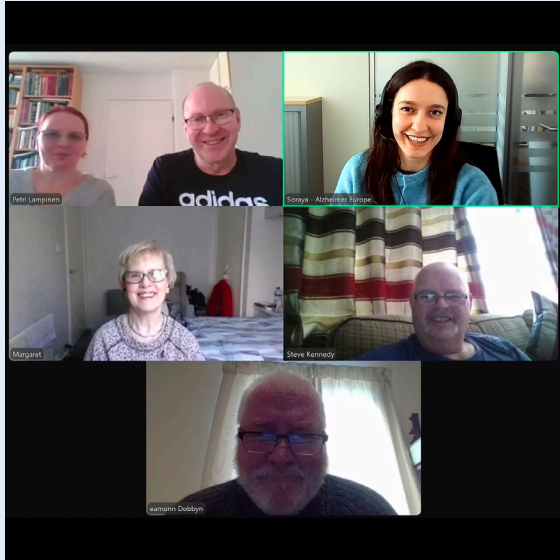


10th April 2025

## Public Involvement Board Meeting Online

On 10 April, the members of the newly-set-up PREDICTFTD Public Involvement Board (PREDICTFTD-PIB) gathered online. This consultation was attended and facilitated by Soraya Moradi-Bachiller, Public Involvement Officer at Alzheimer Europe.

During the consultation, members of the PREDICTFTD-PIB were asked about the barriers and challenges they faced getting the diagnosis of Frontotemporal dementia and how this situation could be improved in their own country. There were also discussions about the post-diagnostic stage, which focused on understanding the consequences of receiving a diagnosis of Frontotemporal dementia and the kind of information and resources to which people have access immediately after the diagnosis. Although the situation has improved in the past ten years and varies depending on the country, members explained that there is still a widespread lack of knowledge and awareness about this specific type of dementia.



6th-8th October 2025

## Alzheimer Europe Conference

The PREDICTFTD project participated in the 35th Alzheimer Europe Conference titled "Connecting science and communities: The future of dementia care", taking place on 6-8 October 2025 in Bologna, Italy.

Connected with colleagues, shared insights, and explored the future of dementia care together.

