



# Walking the talk for Dementia

## Walking the Talk for Dementia:

*Empowering Individuals, Diversifying Perspectives, and Unifying the Dementia Journey*

Santiago de Compostela, Spain - May 15, 2023 - The Walking the Talk for Dementia (WTD), took place from May 1st - 6th in Santiago de Compostela, Spain, bringing together approximately 70 participants, affectionately referred to as "pilgrims." These individuals embarked on a transformative journey, walking 40 km of the world's most renowned pilgrimage route, the Camino de Santiago.

The Camino de Santiago holds deep historical and spiritual significance, attracting pilgrims from all corners of the globe seeking self-discovery and enlightenment. WTD embraced this tradition, allowing participants to immerse themselves in the essence of the Camino, but this time with a single purpose: to build a better world for people with dementia.

According to global data from the World Health Organization (WHO), approximately 50 million people worldwide are living with dementia, and this number is expected to triple by 2050. Dementia affects individuals, families, and communities, posing significant social and economic challenges.

The 70 individuals who joined WTD represented a diverse group of distinguished researchers, healthcare professionals, advocates, and people living with dementia from nearly 30 different nations across the Americas, Europe, Africa, Asia, and Oceania.

"Walking the Talk for Dementia was an unforgettable experience. We came together from different corners of the world, united by our shared journey with this disease, to demonstrate our resilience and support for one another. The global support we received from scientists, researchers, physicians, and care partners was priceless. This experience fills my heart with immense joy, and I am sure I will forever hold it dear in my memories." - Laurie Waters, living with Alzheimer's in the USA.

Remarkably, the collective journey was enriched by the invaluable participation of eight individuals living with dementia from the United States, England, Ireland, Namibia, Singapore and Spain.

"The experience of Walking the Talk for Dementia has provided me with a safe and trusting space for mutual exploration and learning on dementia. We walked and we talked while remaining human and hopeful." - Desmond O'Sullivan, living well with dementia. Their personal experiences and insights added a profound depth to the event, fostering a deeper understanding and empathy for the challenges and thriving experiences by those living with a dementia diagnosis.

The immersive experience proposed by WTD proved to be an outstanding platform for breaking down hierarchical barriers and fostering a sense of equality among participants. By walking alongside each other, regardless of background or expertise, individuals engaged in conversations about living, working, and researching dementia, promoting empathy, compassion, and meaningful connections.

"We need to demonstrate that dementia is not the end, and that it is possible to experience joyful moments, as long as society adapts to support individuals living with dementia, rather than expecting them to conform. Walking the Talk for Dementia serves as a powerful example of how this transformation can take place." - highlights Fernando Aguzzoli-Peres, Co-founder of the project.

The journey spanned four days along the Camino, divided into 10 km segments, commencing in Sarria and culminating at the iconic Cathedral of Santiago de Compostela. The event also featured two days of a scientific symposium held at the 13th-century San Francisco Hotel, a historic monastery. As expected, after walking alongside the audience, the symposium speakers decided to alter their presentations and narratives, recognizing the power of this pre-conference immersion in enhancing audience engagement.

On the final day of the Camino, the WTD group was greeted by over 200 individuals from various parts of Galicia, the region encompassing Santiago de Compostela. Together, they walked the last 5 km of this extraordinary journey. Among the participants were individuals with dementia at different stages, family members, and professionals associated with the Federation Alzheimer Galicia.

REALIZATION:



Crónicos do Dia a Dia

[cdd.org.br](http://cdd.org.br)



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The primary objective of WTD was to diversify cultural, geographical, and social perspectives on dementia, shedding light on crucial topics such as diagnosis, lifestyle, public policies, and the optimization of existing resources. Notably, global organizations such as Alzheimer's Disease International and the World Health Organization have emphasized the urgency of collaborative efforts to address Alzheimer's disease and other forms of dementia.

Dr. Maria Teresa Ferretti, neuroscientist, co-founder, and Chief Scientific Officer of the Women's Brain Project, expressed her gratitude for being part of WTD, stating: "It has been an absolute privilege to be part of the WTD. This initiative has embodied what equity, diversity, and inclusion mean in research, bringing together patients, their families, scientists, doctors, nurses, researchers, political scientists, and much more, united against dementia. The event has been an eye-opener on current initiatives but also challenges in different countries. The Camino has been truly inspiring, and it has motivated me to initiate new collaborations with a broad spectrum of stakeholders."

The event was organized by two Brazilian organizations, Instituto Vovó Nilva and the NGO Crônicos do Dia a Dia, dedicated to mitigate challenges faced by individuals and families living with chronic diseases in Brazil. WTD received support from Alzheimer's Association, Atlantic Fellows, BrainLat, Alzheimer's Disease International, Sociedade Galega de Neurologia, European Brain Council, Global Brain Health Institute, FAGAL - Federación Alzheimer Galicia, AFundación, and FEBRAZ.

Participants regarded the event as "one of the most transformative experiences of their lives," impacting them both personally and professionally. The connections and collaborations fostered during WTD continue to thrive through virtual groups, contributing to research advancements and improvements in dementia care across borders. Kevin Quaid, living with Lewy body dementia, described his experience as a transformative journey: "It was a trip of a lifetime, a pilgrimage. Something in my wildest dreams I could never imagine happening. Five years ago, they were getting me ready for a wheelchair, and then this amazing thing happened. For me, it was a genuine miracle, and no matter how bad my Lewy Body Dementia gets, I may lose my memory, but I will never lose the feeling and the love I felt on this once-in-a-lifetime inner voyage with some of the most beautiful, amazing people the world has ever seen."

Link with Photos:

<https://drive.google.com/drive/folders/1zDX-mUK-li0c7EyCLx3qqI0jrY-lvS1N?usp=sharing>

Photo Credit: Max Schulte and Alex Kornhuber.

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