A Decade of Discovery: How DABNI Is Transforming Alzheimer's Research in People with Down Syndrome

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Summary:

People with Down syndrome are genetically predisposed to develop Alzheimer's disease. The Down Alzheimer Barcelona Neuroimaging Initiative (DABNI) project was created in 2012 with the aim of studying, through different markers, the natural history of Alzheimer's disease in Down syndrome. Since then, the DABNI project has followed more than 1,100 adults with Down syndrome. This pioneering project has transformed how Alzheimer's disease is understood and managed in this population. The findings show that almost all people with Down syndrome will develop Alzheimer's if they live long enough. This study has led to major improvements in diagnosis, care strategies, and clinical trials aimed at prevention and treatment.

Background

People with Down syndrome are now living longer than ever before. Thanks to better healthcare, early interventions, and improved support, many individuals are living well into their 60s and beyond. But this success has brought new challenges. One of the most significant is the very high risk of developing Alzheimer's disease dementia. By age 40, almost every person with Down syndrome shows changes in the brain associated with Alzheimer's. Over time, most will go on to develop dementia, making Alzheimer's disease the leading cause of death in this population today.

The challenge

Alzheimer's disease is difficult to detect early in people with Down syndrome. Intellectual disability, communication difficulties, and other medical conditions such as epilepsy or sleep problems, may hide or confuse the first signs of cognitive decline. This can lead to late diagnoses and missed opportunities for support or treatment. Until recently, there were few long-term studies that followed people with Down syndrome over time to understand how the disease develops.

The DABNI project

Recognizing this growing need, the Hospital de Sant Pau and the Catalan Down Syndrome Foundation launched the Down Alzheimer Barcelona Neuroimaging Initiative (DABNI) in 2012. This groundbreaking program brings together clinical care and scientific research in a single setting. More than 1,100 adults with Down syndrome have taken part in the study. Many have returned for multiple visits over the years, creating one of the largest and most complete datasets in the world on Down syndrome and Alzheimer's disease.

DABNI is not only a research study, it is also a model of integrated care. Participants are evaluated regularly by a multidisciplinary team, including neurologists, psychologists, nurses, and social workers. Families are supported throughout the process, from initial evaluation through to diagnosis and care planning. Participants receive neurological and neuropsychological assessments, and many also undergo blood tests, brain imaging, sleep studies, and genetic analysis (Figure 1: participants in the DABNI cohort and Health Plan). This makes it possible to identify the disease early, even before any clear symptoms appear.

Main findings and impact

The main findings from DABNI are illustrated in Figure 2. Importantly, DABNI has shown that Alzheimer's disease in Down syndrome follows a predictable pattern. The disease starts silently, often in a person's 30s, with changes in brain chemistry and structure that can be detected through advanced imaging and biomarker testing. Symptoms like memory loss and confusion usually begin to appear in the 50s. Nearly all individuals with Down syndrome who live into their 60s will develop dementia, unless treatments can be found to prevent it. These findings have changed how doctors think about Alzheimer's disease in this population. It is no longer seen as a possibility, but rather as a stage of aging that is almost certain to occur.

The study has also revealed the importance of early warning signs such as sleep disorders and seizures. Many people with Down syndrome experience obstructive sleep apnea or sudden behavioral changes that may signal the beginning of Alzheimer's. DABNI has shown that tracking these symptoms can help identify individuals who are beginning to decline cognitively, even before traditional memory tests show a problem.

Another key finding from DABNI is that memory loss is often the first and most noticeable symptom of Alzheimer's in people with Down syndrome, just as it is in the general population. This has helped to update clinical guidelines and improve diagnosis. The team has also found that certain blood tests and brain scans can detect the disease long before symptoms appear. These tools are now being used in clinical trials of new medications designed to slow or stop the disease.

Beyond diagnosis and monitoring, DABNI has become a hub for international research. The study has produced over 100 scientific publications and is actively involved in global partnerships. These collaborations help ensure that people with Down syndrome are included in the latest Alzheimer's research and can benefit from new treatments as soon as they become available. This is a major step forward in a field where individuals with intellectual disabilities have often been left out of research and drug development.

What this means for families and professionals

For families, DABNI has made a difference by offering not just answers but also support. Families receive counseling after diagnosis and are guided through available resources, including legal, healthcare, and emotional support services. Caregivers can participate in support groups and educational workshops, helping them understand the disease and how to manage it over time.

As the project enters its second decade, the team behind DABNI is more committed than ever to pushing the boundaries of what we know about Alzheimer's in Down syndrome. With new technologies, more data, and growing international collaboration, there is real hope that the next decade will bring effective ways to delay or even prevent dementia in this population by enabling clinical trials.

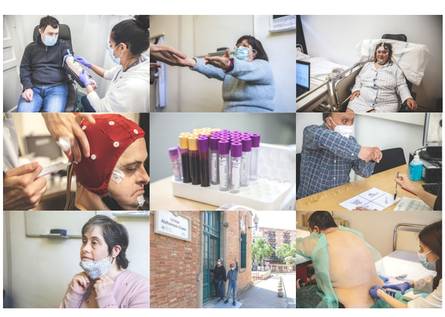
Conclusion

Alzheimer's disease in Down syndrome is no longer a mystery. Thanks to DABNI and other longitudinal cohorts, we now know when it starts, how it progresses, and what signs to look for. We have tools to detect it early and we are beginning to test ways to treat it. This progress is only possible because of the families and individuals who have chosen to participate, giving their time and trust to the research team. Their contribution is helping to build a future where aging with Down syndrome is not synonymous of Alzheimer's disease.

Take-home message

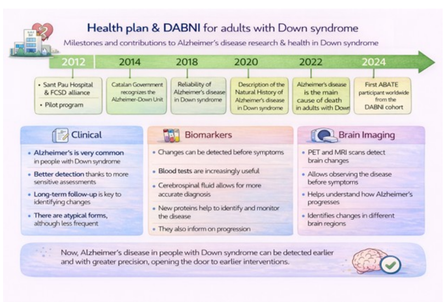
- Regular cognitive monitoring in people with Down syndrome from the age of 35 is essential for the prevention, early detection, and treatment of Alzheimer's disease.
- The DABNI initiative is a commitment to better care, better science, and a better future. It proves that with careful planning, compassion, and collaboration, we can meet the health challenges of today and prepare for the opportunities of tomorrow

Figure 1: DABNI participants in different clinical and research assessments.



The volunteers in the pictures have signed their consent to appear in them and have given permission for their their publication

Figure 2: DABNI's timeline including milestones and contributions to Alzheimer's disease research in Down syndrome



Reference

Videla L et al. The Down Alzheimer Barcelona Neuroimaging Initiative (DABNI) and its contributions to understanding Alzheimer's disease in Down syndrome: A decade of discovery. Alzheimers Dement. 2025 Jun;21(6):e70259. doi: 10.1002/alz.70259.