Alzheimer's Patient Advocate Montminy Uses Voice to Influence Alzheimer's Treatments, Sees Hope in Future Treatments

By Alexander Diegel, Yashmin Karten, Joe Montminy and Sudhir Sivakumaran

When Joe Montminy was just 54 years old, he began noticing changes that impacted his ability to do his job. Routine work soon had him working nights and weekends to compensate for decreased productivity. He took prolific notes during meetings to remember not only action items, but details that he used to simply store in his memory.

It took another few years of experiencing this change in function before his Primary Care Physician sent him to a neurologist. Upon completing various tests, including a neuropsychological exam and MRI, his neurologist diagnosed Montminy with younger onset Alzheimer's disease (AD).

"The prognosis was very traumatic," Joe explained. "My neurologist said, 'You should retire today. There's a chance that you may not recognize your family in five to seven years and – on average — I had a 10-year life expectancy.' It was incredibly overwhelming. Fortunately, my progression has been slower than expected."

Six years later, Joe's resilience has allowed him to maintain his relationships. He advocates for those living with the disease and serves as a public speaker, including at C-Path's 2022 Neuroscience Annual Meeting. In addition to participating in global AD and related dementias conferences around the World, Montminy's advocacy work extends to State and Federal levels, as a member of the Massachusetts/New Hampshire Chapter of the Alzheimer's Association's Board of Directors, its New England Early-Stage Advisory Group and a former member of the National Alzheimer's Association's Board of Directors.

Joe at AAIC 2023 in Amsterdam, Netherlands, with CPAD Sr. Project Coordinator Eileen Priest

Montminy's reach and commitments go beyond those roles, and he is particularly proud of his work on the Advisory Council of the National Alzheimer's Project Act where he made a big impact working with a number of federal government agencies and non-federal partners.

"Being on the National Board of Directors and Advisory Council was a huge honor," Montminy explained. "The board role enabled me to speak at a lot of conferences, including the Alzheimer's Association's International Conference in Amsterdam, and get a lot of media exposure to ensure the research industry and drug development experts really understand what's important to those of us living with the disease. The advisory council role enabled me to work with other council members to make recommendations to the U.S. Secretary of Health and Human Services – as well as members of our U.S. Congress – on things that can be done to improve the lives of those of us living with dementia – and our families – in the US."

While advocacy and giving a voice to those living with the disease has been Joe's focus since his diagnosis, he has also seen firsthand the work and impact of what C-Path's Critical Path for Alzheimer's Disease (CPAD) consortium is doing to advance research and drug development efforts in AD and related dementias, with a vision towards improving the lives of millions of people in need.

"CPAD is helping the industry by developing tools that can help optimize clinical trial designs, identify individuals best suited for trials, and understand what are meaningful benefits for those diagnosed with early symptoms of AD. It gives the drug developers and regulators a perspective on why currently approved treatments are so important to us and what treatments will benefit us most based on what we want to get out of them. It's a very exciting time to be involved in this process. There are more Alzheimer's treatments coming that better attack not only the beta-amyloid protein buildup, but also the buildup of tau protein in the brain, that will slow the disease and improve the lives of those of us living with this disease."

To fulfill its mission of accelerating and de-risking development of safe and effective drugs, CPAD provides a unique pre-competitive framework. The framework allows for diverse stakeholders to come together on neutral ground to generate consensus on tools necessary for addressing unmet needs in AD drug development. One of the tools developed and endorsed by the Food and Drug Administration (FDA) under the Fit-For-Purpose mechanism is a novel quantitative model of AD that enables researchers to simulate clinical trials, which can in turn accelerate the time to test new drugs. As of August 2023, this tool, which is

based on CPAD's mild to moderate AD progression model, has been accessed by 152 approved users. Another clinical trial simulation tool, this one for pre-dementia stages of AD, received Letters of Support from both the FDA and the European Medicines Agency, and provides a way to simulate patient selection (based on an imaging test) for clinical trials.

Joe at AAIC 2023 in Amsterdam, Netherlands, with Project Manager Corissa Lau.

The past year has been a very exciting time to be part of the AD research and drug development efforts, where current advances not only bring hope to millions of people in need but also bring effective and meaningful therapies. Facilitated by advances in the scientific and clinical understanding of AD and the extraordinary levels of data-sharing by sponsors and academic institutions, CPAD is best positioned to generate advanced tools and solutions for the most pressing unmet needs, which years ago seemed far out of reach. Currently, AD progression to date, including more than 4,500 amyloid-positive participants across nine different studies from both industry and academia. The model integrates information about the natural history of disease and impact of disease or subpopulation characteristics on the rate of disease progression. In addition, CPAD launched a clinical trial simulation and bi-directional modeling platform, providing a way to interactively explore CPAD-developed disease progression models that feature various clinical outcomes and variables. The results may be predictive of disease outcome (e.g. age, sex, race), and a way to simulate disease progression in a placebo group in a hypothetical clinical trial.

In addition, CPAD is leading two pre-competitive working groups: The Tau PET Harmonization Working Group aims to validate a standardized scale to quantify tau protein deposition across cohorts and radiotracers used in neuroimaging, which will facilitate a generalizable evaluation across the disease continuum, from early to late stages. The Tau PET Surrogacy Working Group aims to evaluate whether tau protein deposition can serve as a reasonably likely surrogate endpoint in AD trials to support accelerated drug approvals.

Work like what is being done in C-Path's CPAD consortium helps advocates like Joe see a path towards a brighter future for the current and future generations of people diagnosed with Alzheimer's disease and related dementias.

"For individuals who are at risk of developing or who might receive an AD diagnosis, we now have more hope than ever before," he explained. "I'm just so excited with what has been accomplished. Organizations like CPAD and the Alzheimer's Association have helped get us to where we are today. There's so much happening to help everybody in different areas. It's the most exciting time ever for Alzheimer's research and treatment!"

Want to learn more about the CPAD-developed tools and life-changing work CPAD is doing? [Get in touch today](#)

CPAD's data repository and clinical trial simulation tools are freely accessible online:

- CPAD C-Path Online Data Repository (CODR): http://codr.c-path.org/
- Mild-to-Moderate AD Clinical Trial Simulator: https://c-path.org/ad-cts-tool-request/
- Hippocampal Neuroimaging-Informed Amnestic MCI Clinical Trial Simulator: https://cpath.shinyapps.io/predemctegui/

You can join the cause to advance drug developments in Alzheimer's and dozens of other therapeutic areas by supporting C-Path [here](#).