

# LONG-TERM Living

## Gathering the gray cells

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By Pamela Tabar, Editor-in-Chief

It's official: I have donated my brain to science.

I signed up for the [Brain Health Registry](#) (BHR), an online platform whose mission is to collect health, medication and lifestyle data on thousands of healthy people and then track them over time in an attempt to learn how early onset dementia works and what signs should trigger medical intervention.

How many of us have said, "If only we knew how to detect dementia earlier," or "If only we knew what interventions worked best for early stages"? This is part of how we learn those answers.

The registry, led by Michael W. Weiner, MD, and Scott Mackin, PhD, both from the University of California—San Francisco, and Rachel Nosheny, PhD, neuroscientist and lead grant writer, has enrolled nearly 40,000 people since its launch in 2014 and hopes to double that number by the end of 2016. The effort has attracted nearly two dozen industry partners, including the Veterans Health Research Institute, the [Global Alzheimer's Platform Foundation](#) and several prominent medical schools.

It's crowdsourcing for brain data; medical research in the cloud. The data will be made available to those who want to pursue clinical trials to research new screening tools, learn what factors may help or exacerbate the progression of dementia, formulate new best practices and—above all—dig deeper into the almighty question of why some older people develop dementia and others do not.

Everyone who has been touched by Alzheimer's disease, Parkinson's disease or any other neurological condition should consider joining the BHR. Through participation, you are making a major contribution to research, yet it's free and painless. Yes, it took an hour or two to complete the preliminary registration questions, which are detailed for a good reason. But, you can stop anytime and come back later to finish them.

Once registered, you don't have to keep track of anything. The BHR system will send you an email once or twice a year to ask a few new questions or have you play a short online game. In the four months since I registered, the program has emailed me only once—my bank bugs me more often.

In addition to being a wellspring of data in the race for cures, the discoveries from the data pool have the potential to teach us a ton about the onset and pre-onset phases—the earliest stages of any disease when the symptoms are most difficult to notice and the exact diagnosis is most elusive.

At February's [Memory Care Forum in Austin, Texas](#), one of the prominent themes was the devastating impact of dementia on the family. Any research that leads us to better treatment protocols—everything from new drugs to new approaches to behaviors and progression awareness—is worth spending a few hours per year participating in the registry. What we learn someday could buy someone with dementia years of quality time.

Join the BHR at [www.brainhealthregistry.org](http://www.brainhealthregistry.org) and support the effort on Twitter at #GrayMatters.

It's a no-brainer.

<http://www.ltImagazine.com/blogs/pamela-tabar/gathering-gray-cells>