

Psychology Today

If We Only Had a Brain: Participate in a Clinical Trial Alzheimer's has consumed my family—now it's coming after me.

July 26, 2016

By: Greg O'Brien

I could wile away the hours

Conferrin' with the flowers

Consultin' with the rain

And my head I'd be scratchin'

While my thoughts were busy hatchin'

If I only had a brain

—"If I Only Had A Brain," Wizard of Oz, 1939

With apologies to the late Ray Bolger, the sinuous, peripatetic Scarecrow in L. Frank Baum's Wizard of Oz, for those of us with Alzheimer's—the early, middle and late stages—the disease is a ride over the rainbow. Our heads are full of stuffin'.

Early on the straw-like numbness comes and goes with the flick of a switch, as synapse fails its mark. Then, in the middle and later stages—beyond expression—blackout comes on like the night.

If we only had a brain.

Alzheimer's, which devastates all demographics, yet preys on blacks, Latinos and women, is a full throttle silence of the lambs, robbing the brain—initially in increments as passive as grass growing—of all memory, self, and resolve.

Hannibal can be stopped. But it will take the collective, driven, cerebral efforts of researchers, caregivers, the Congress, and the public at large to slay the demon. It starts with recruiting an army. Yet expect a Pyrrhic victory at the onset. I know the frontline well. Alzheimer's has consumed my family—my maternal grandfather, mother, paternal uncle, and father—and now is coming after me. I was diagnosed at 59. This is not your grandfather's disease.

"This is a battle we're going to win because we're going to lose so many along the way," says George Vradenburg, co-founder of Global Alzheimer's Platform (GAP) Foundation and UsAgainstAlzheimer's. A member of the World Dementia Council, the Council on Foreign Relations, and former senior executive at CBS, FOX and AOL/Time Warner, Vradenburg is a warrior in the fight against Alzheimer's, and as pragmatic as he is fierce.

“Research will give us some insights,” says Vradenburg, “but to develop state-of-the-art medicines to delay the symptoms of Alzheimer’s and ultimately stop the disease, we will need legions of individuals in clinical trials. The first person cured of Alzheimer’s will be in a clinical trial.

“This is just the beginning of the beginning of the fight; we have now engaged with the enemy, which has had its run of the field. We’ve hardly picked up our weapons, but we have begun to engage.”

To that end, Vradenburg, GAP Foundation president John Dwyer, and Dr. Michael Weiner, principal investigator of the [Brain Health Registry](http://brainhealthregistry.org) (brainhealthregistry.org), joined forces to develop the first ever survey conducted online by Harris Poll to determine how many Americans are willing to participate in Alzheimer’s clinical trials. The results, just released, are indeed encouraging, however, there is a clear disconnect, synaptic in its comparison, between those who have engaged in clinical Alzheimer’s trials, and those willing to do so, or consider it.

The [GAP Foundation](http://GAPFoundation.org) is hard at work connecting the dots that show clinical participation rates to date of less than 10 percent, and poll results confirming that 60 percent of Americans are willing or would consider participating in a clinical trial.

Among other key findings:

- 11 percent of American Millennials believe there is a cure for Alzheimer’s disease
- 25 percent of American families have/had a family member with Alzheimer’s disease
- 20 percent of Americans said they would definitely be willing to take part in a clinical trial; 39 percent said they would consider taking a test
- More than three in five Americans (62%) believe that Hillary Clinton will do more than Donald Trump to help in the fight against Alzheimer’s disease

Vradenburg talks about the failure to provide willing Americans more information and easier, far less intimidating tools for participation will be the difference between victory and defeat in this disease. In a snapshot, more than five million Americans have been diagnosed with Alzheimer’s, with an annual death toll of a half million—far beyond the body count of the Black Death of the 12th Century. The number diagnosed with Alzheimer’s is expected to rise to 7.1 million in less than 10 years, and to 135 million worldwide by 2050. Add to the toll, the tens of millions of caregivers who face decimating health challenges themselves, and more than \$230 billion in soaring health care costs, expected to rise to \$1.1 trillion within the next 34 years, and you have a word picture approaching Armageddon.

Who woulda thunk?

If we only had a brain.

“Alzheimer’s is a cancer-sized problem,” says Vradenburg, noting [Alzheimer’s](http://Alzheimer.org) is the sixth leading cause of death in the United States, the only such disease on the rise, and the only one for which there is fundamentally no cure.

And yet Alzheimer’s pales in comparison to cancer funding at the federal level, a 6-to-1 contrast. Cancer research funding totals more than \$6 billion annually, while Alzheimer’s research today is funded at about \$900 million, with prospects of a \$300-to-\$400 million increase in the Congress for the next fiscal budget—encouraging, but still far short of the mark to stop a disease the general public has difficulty grasping, is in denial, or just focused on the drive-by.

To take Alzheimer’s serious when encountering someone with the disease, many, stereotypically, seem to be anticipating something akin to the creepy out-of-this-world bar scene in the original Star Wars. Not

even close. The visual is more like the Michael J. Fox sitcom, "Family Ties." In Alzheimer's there are no scars from operations, no profound affects from chemotherapy. At a glance, at times, in the early stages, there are few visual manifestations to the naked eye. Still, you can't remove a brain.

I'm not advocating today for a single cent less to be spent on research for cancer, heart disease, AIDS, ALS, Autism, depression, or any number of vile illnesses. In fact, much more needs to be appropriated. I know the fears of cancer; I've been diagnosed with it, as well. I just want Alzheimer's to get its due.

So how do we win on the Alzheimer's front? By proactively taking a page from GAP's groundbreaking survey, and register free-of-charge at the Brain Health Registry to learn more about clinical trials. You don't have to be diagnosed with Alzheimer's to do so. It's been said that in the next 25 years there will be two kinds of people in the world: those with Alzheimer's and those caring for someone with the disease. The Brain Health Registry (BHR) gathers data from volunteers who have registered and completed questionnaires and cognitive tests on its website. BHR seeks to reduce the cost of patient recruitment for clinical trials through building a large online pool of potential, trial-ready candidates.

Just a few keyboard swipes could put this nation on the road to triumph over Alzheimer's. If you are experiencing memory loss that disrupts your daily life, seek help. Take the test.

As the Scarecrow sung on cue:

*"I would not be just a nuffin'
My head all full of stuffin'
My heart all full of pain
I would dance and be merry
Life would be a ding-a-derry
If I only had a brain"*

And yes, there is no place like home...

<https://www.psychologytoday.com/blog/pluto/201607/if-we-only-had-brain-participate-in-clinical-trial>