

# Provider

LONG TERM & POST-ACUTE CARE

## Dementia Groups Draft Volunteers For Clinical Trial 'Bullpen'

1/28/2016

Two of the world's leading anti-Alzheimer's groups are joining forces to recruit an army of people to help develop the cure for what has become a global pandemic.

Global Alzheimer's Platform and Brain Health Registry say they want to get 40,000 people signed up for clinical trials of anti-dementia drugs over the next few months. Beyond that, they want to create a vast "bullpen" of people who are ready to pitch in any time a drug company needs to test its latest efforts against a disease that now affects some 130 million worldwide.

"The first person who is cured of Alzheimer's is going to be cured in a clinical trial," says George Vradenburg, founder of Global Alzheimer's and a former member of the congressionally appointed Long Term Care Commission. "No one company can do this, because they don't know when they're going to have a drug to test. But as an industry, there's no reason we can't have a bullpen of people who are ready, willing, and able to help out—'When you want us, give us a call.'"

### 'We've Got To Be More Respectful'

As it stands, it can take up to two years just to recruit enough people to run a clinical trial, Vradenburg tells *Provider*. The goal is not just to create a pool of willing volunteers, but to keep those volunteers engaged, continually.

"You do your clinical trial, the people who didn't make it into the trial go home and don't get contacted again. And even if you're selected, you go home when it's over and don't get contacted again," Vradenburg says. "We've got to be much more respectful of the enormous amount of time people are spending in clinical trials."

Vradenburg doesn't blame the drug companies—after all, they never know, moment-to-moment, when they'll have a drug ready for testing. But volunteer recruitment "will become a choke point if in fact we don't do a much better job," he says.

### Black Disease, White Cure

The groups are trying a variety of different methods—traveling plays, panel discussions, social media, even radio ads during Super Bowl week—hoping to urge people to get off the bench and get involved in the anti-dementia efforts. One special focus is on recruiting minorities, Vradenburg says. African-Americans, for instance, are somewhere between two and three times more likely to develop dementia than white Americans, but the percentage of black people in clinical trials is "somewhere in the low single digits," Vradenburg says.

“If we only have whites in clinical trials, we may be developing medicine that only works for white people,” he says.

It’s a tough job: Many African-Americans still taste the bitter (and embittering) memories of cases such as Henrietta Lacks, whose cancerous cells were harvested, cloned, and manufactured without her consent, and the infamous Tuskegee Study, in which black men were denied treatment for syphilis so that researchers could watch what happened.

The advanced marketing to get African-Americans into clinical trials is well-timed, well-judged—and essential, says Ralph Chittams, a D.C.-based civil rights activist.

“The black community will never forget Tuskegee, but that doesn’t change the fact that we must participate in these studies,” he says. “This is too important of a discussion not to have. We do need to have more underrepresented minorities participating in clinical trials. There is no downside to that.”

### **Florida Signs Off On New Caregiving Guide**

In other dementia-related news, the Florida Department of Elder Affairs has just signed off on a new Alzheimer’s care guide for long term care companies. The guide, written by the National Certification Board for Alzheimer Care, is designed to be part of a hybrid training program for direct care workers.

The certification board’s course runs eight hours. Thanks to Florida’s decision, caregivers can use those eight hours toward their state-mandated continuing education credits in the Sunshine State.

<http://www.providermagazine.com/news/Pages/2016/0116/Dementia-Groups-Draft-Volunteers-For-Clinical-Trial-'Bullpen'.aspx>