
Raising Awareness of Alzheimer's

MMG and the Alzheimer's Association team up to increase awareness and understanding of Alzheimer's clinical research.

By Nancy Mulligan

There are currently more than five million people in the US living with Alzheimer's disease, and half a million new cases are expected this year alone. This is a critical time for Alzheimer's research – there are dozens of drugs under evaluation in phase II and III clinical trials and not enough volunteers to fill the studies. In response, the Alzheimer's Association retained MMG to launch the Clinical Studies Initiative – a campaign to increase awareness of and participation in Alzheimer's research. Initially launched as an eight-month pilot program, the Initiative's goal is to test specific strategies and tactics to determine the most effective ways to increase research participation at sites in selected pilot markets.

The Clinical Studies Initiative is currently being piloted in five cities – Indianapolis, Tulsa, San Francisco, Providence, and Atlanta. In each of these communities, MMG, the Association, and the local chapters teamed up to explore existing outreach efforts and to develop new ones aimed directly at raising clinical research awareness. Because Alzheimer's doesn't just affect the person living with the disease, but also their loved ones, the campaign is aimed at raising awareness throughout the community, focusing on patients, caregivers, and physicians.

Working closely with the local Alzheimer's Association chapters, MMG created a task force of physicians and researchers in each of the pilot cities to raise research awareness for professionals dealing with Alzheimer's patients. The task force members are featured in brochures, posters, and radio and TV public service announcements, lending a personal aspect to the outreach in each community. The goal of this is to encourage discussion and education about current Alzheimer's research, including local opportunities to participate in clinical studies, while emphasizing the crucial need for new volunteers.

To reach further into each local physician community, MMG developed a series of continuing medical education (CME) events about Alzheimer's disease and current research options. Physician education is crucial to increasing study enrollment, as physicians are the first and most trusted source of health information for the target patient population and their caregivers. Increasing physician support for Alzheimer's clinical trial participation, while providing them with access to information on currently enrolling studies, is a central part of the Initiative.

In addition, MMG added a grassroots element to the Initiative with community ambassadors who are actively working to raise Alzheimer's awareness in the pilot sites. These ambassadors work within each community's local framework to host informational forums and lunch-and-learn sessions, and recruit local partners in awareness activities with organizations such as AARP, the local Council on Aging, Area Agency on Aging, and Senior Action Council. Although each community lends itself to different

local partners, the goal of the ambassadors is consistent throughout: to raise awareness of Alzheimer's clinical research through in-person education and communication.

All of the outreach efforts of the Initiative are geared toward spreading the word – as far and as wide as possible – about the many current research opportunities and the critical need for research volunteers.

“Alzheimer's disease is reaching epidemic proportions,” says Dr. William Thies, Alzheimer's Association Vice President for Medical & Scientific Relations. “Recruiting clinical study volunteers has become a serious impediment to developing better treatments and preventions for Alzheimer's. The next generation of experimental drugs now being studied is showing great promise. With more than 100 sites conducting Alzheimer's disease research in this country alone, we need a steady stream of volunteers to ensure that studies will be completed in a timely manner.”

Thies also notes that the prevalence of the disease could triple by 2050 unless researchers learn how to prevent it, treat it effectively, or find a way to cure it.

Meeting challenges head on

The task of recruiting volunteers for experimental drug studies is always challenging. Among the general population, less than 0.08 percent has ever participated in a clinical trial. The reality of Alzheimer's disease brings added challenges with which many other areas of research may not have to contend. For example, many people with Alzheimer's disease are undiagnosed, particularly in the early stages of the disease, while others remain in denial even after their condition has been confirmed.

In an online survey conducted by MMG and the Alzheimer's Association of researchers in the pilot communities, nearly three-fourths of respondents reported that it is somewhat or very difficult to recruit participants into Alzheimer's research studies.

Most clinical studies for Alzheimer's require the participation of a caregiver as a condition of enrollment, an obligation that can place an additional burden on someone who may already be operating under significant time constraints. Also, the nature of the disease presents unique challenges for informed consent and ongoing participation. Caregivers and family members, faced with deciding whether to enroll a loved one into a clinical study, often find the subject to be too overwhelming to contemplate.

Even with these challenges, there are potential benefits to volunteers: the possibility of receiving an experimental drug, access to study-related medical care at no cost, and the opportunity to make an important contribution to the search for a cure. Rigorous FDA guidelines and study-specific data safety and monitoring committees serve to monitor and protect study participants.

Pilot market snapshot

Oklahoma will see a 19 percent increase in Alzheimer's disease in people aged 65 and older from 2000 to 2010. Media coverage in Tulsa, as in all five pilot communities, has helped tremendously in spreading the word about the Initiative and its local goals. The ABC, CBS, and FOX affiliates produced news items on the Initiative, as did several area community newspapers including Tulsa World, and the Trinity Broadcasting Network.

Community outreach in Tulsa also showcases the Initiative's success. Local healthcare organizations, the Tulsa Area Agency on Aging, several large local churches, and the Jewish Federation of Tulsa have all distributed materials promoting the Initiative. AARP Oklahoma sent a blast fax and distributed

educational materials to its members state-wide.

The community ambassadors in Tulsa attend local health fairs and co-ordinate promotion of the Initiative through local organizations, senior care facilities, and support groups. In addition, they have made presentations to public and professional audiences, including Family and Children's Services and the Department of Health.

Broad-based results

Similar success is being achieved in the other four pilot communities. To date, media coverage in all five cities has appeared in publications with a total circulation of nearly two million, and on broadcast TV and radio news programs with audiences totaling more than three million. More than 100 local events and presentations have activated a core group of advocates and healthcare professionals to the cause of increasing participation and referrals for local Alzheimer's research.

"I felt so fortunate to be part of the pilot initiative," remarks Elizabeth Morancy, Executive Director of the Alzheimer's Association's Rhode Island Chapter. "We have excellent relationships with research sites in the Providence area, and we were able to leverage those with the enormous output of materials, events, media, and advertising provided by the initiative – and our phones have been ringing off the hook. It's like people suddenly woke up and said – there is something I can do!"

About MMG

While MMG regularly supports individual studies on behalf of commercial clients and government research institutes, the company also has proven experience in supporting category-wide recruitment. For the National Institute of Diabetes and Digestive and Kidney Diseases, MMG developed and managed several national, multi-study programs supporting recruitment for diabetes research in children, adults, and families. For the National Cancer Institute, the company's first client in 1987, MMG created a centralized nationwide call center supporting recruitment and information referral services for more than 150 studies. NCI continues to refine this model to support cancer research in the United States.

About the Alzheimer's Association

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support, and research. Nationally and through nearly 300 chapters located in communities across the US, the Association provides core services to families and professionals, including information and referral, support groups, care consultation, education, and safety services. The Association directly supports clinical research with a research portfolio of more than \$21 million annually. It supports all research into Alzheimer's and related conditions through its literature and outreach.

About the author

For 15 years, **Nancy Mulligan**, Vice President of MMG's CNS Therapeutic Area, has directed recruitment and retention campaigns, health communications programs, community outreach projects and training programs for pharmaceutical companies, nonprofits, and government agencies. She directs adult and pediatric studies in bipolar, schizophrenia, depression and anxiety for pharmaceutical and government clinical trials. She was a strategic consultant for the landmark Step-BD bipolar study and the TADS study for NIMH.