

GIVING A POWERFUL VOICE TO THE ALZHEIMER'S COMMUNITY

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The Pulse of the Community

Two years ago, UsAgainstAlzheimer's set out to close a glaring knowledge gap in science and research that has existed since the disease was first identified more than 112 years ago – the needs of patients and their caregivers. That was the year the A-LIST launched.

The goal of the A-LIST is to create a standing cohort of people affected by this disease who are willing to share insights through survey to improve clinical trial design and guide scientists toward treatments that matter most.

This group provides a powerful patient voice for those living with Alzheimer's and those caring for them. And the valuable, scientifically rigorous insights gained will help guide researchers, regulators, policymakers and the health care community, as well as accelerate the search for treatments and cures.

The A-LIST is part of a broader effort called AD-PACE, a ground-breaking patient/caregiver-led collaboration among industry, government agencies and advocates that will deliver new insights to researchers, regulators and payers.

Since its founding, the A-LIST has relied on partnerships, celebrity spokespeople, and social media to recruit and engage members. Today, there are more than 6,000 A-LIST members, a number that is growing rapidly. And already, the A-LIST has fielded 11 surveys, which generated more than 17,000 responses. Among them:

“The hard reality is that no matter what I do for my husband and my mother, Alzheimer's will win out. The A-LIST is our way of inviting others to validate their personal experiences, help other families in crisis know they are not alone and that together we can help accelerate meaningful research for a cure.”

Meryl Comer

A-LIST Engagement Lead and Caregiver

- “Pulse of the Community” focused on what was most distressing for those diagnosed and their caregivers.
- “What We Expect From Doctors” explored doctor-patient interactions.
- “CMS Feedback” looked at what was important to patients and caregivers in terms of support systems.
- “What Matters Most” is a multiyear survey designed to provide insights into treatment-related needs, preferences and priorities. In other words, which treatments would be most meaningful to patients and caregivers.
- Several “What Matters Most” surveys have already been conducted, including one focused on Home Health Care needs, information needs, technology usage, faith communities, and clinical trial participation.

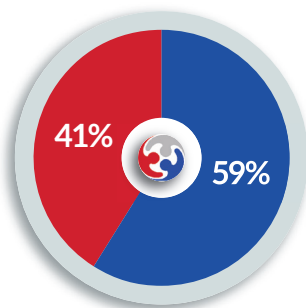
FINDINGS OF “WHAT MATTERS MOST: CLINICAL TRIAL PARTICIPATION”

The clinical trial survey, fielded in collaboration with the Alzheimer’s Association Trial Match®, included 2,500 caregivers and 600 people who received an Alzheimer’s diagnosis. The goal is to get a better picture of the reasons – logistical or trial related – patients give for not participating in clinical trials and learn about the experiences of those enrolled. It also looked at why those who volunteered weren’t accepted. The data will help the scientific community focus on ways to improve participation in trials going forward.

Some of the key findings:

- Among those diagnosed with Alzheimer’s, 59% said they hadn’t volunteered to participate in a clinical trial.
- The top logistical hurdles cited for not volunteering were: finding a trial was difficult; lack of information; trial site was too far away.
- The top trial-related reasons cited were: testing is too invasive and fear of side effects.

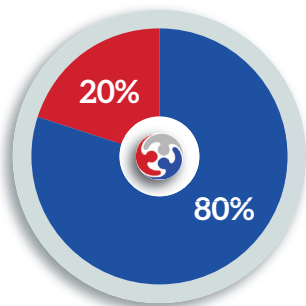
HAVE YOU VOLUNTEERED TO PARTICIPATE IN A CLINICAL TRIAL?



Of the 41% who had volunteered, nearly 80% said they weren’t accepted.

- The top reasons for not being accepted were: did not meet criteria or they don’t know.

WERE YOU ACCEPTED INTO THE CLINICAL TRIAL?



■ Yes ■ No

Of the 19.5% who were accepted, most rated their experience as positive.

- On a scale of 1 to 7, where 7 is completely satisfied, the average was above a 5.
- Reasons cited for being satisfied: good results, great follow-up, professional support, medical attention, and being treated with dignity.
- Those who weren’t satisfied cited poor results, less feedback than they expected, or participation was abruptly canceled.

The findings among the caregivers surveyed were similar. The top logistical hurdle keeping their loved ones from volunteering for clinical trials was difficulty finding one, and the top trial-related reason was testing was too invasive.

It also found that nearly a third of caregivers didn’t know why their loved ones weren’t accepted into clinical trials.

Caregivers whose loved ones were accepted also gave the experience high marks – averaging above 5 on the same 7 point scale.

In addition, the survey asked more than 600 people who haven’t been diagnosed with Alzheimer’s or aren’t caregivers about their likelihood of volunteering in clinical trials. On a scale of one to seven, the average was over 5.

One of the big challenges researchers face is getting enough volunteers for clinical trials. By getting a better understanding of the impediments to volunteering, the concerns about tests, and the need for better communication among Alzheimer’s patients, researchers will be better able to overcome these obstacles and get trials underway.

George Vrandenberg
Chairman, UsAgainstAlzheimer’s

THE TAYLORS

Six years ago, Geri Taylor was diagnosed first with MCI, and later Alzheimer's disease. As a 45-year health care professional with a family history of the disease, she had seen signs of the approaching disease. Thus she was not surprised by the diagnosis, but, despite her forewarnings, her husband Jim was caught off guard. He describes "going into his cave" for two weeks of solitude, feeling depressed after Geri's diagnosis.

Today, they are leading advocates and activists for developing a positive attitude and living fully in the mild and moderate phases of the disease. Speaking frequently to large and small audiences, Jim quotes a Chinese proverb: "The bird does not sing because it has the answer. The bird sings because it has a song." Here's Jim and Geri's story from their perspective:

“Geri and I are not researchers, or physicians, but we believe ours and every voice matters in the struggle against this disease. So we sing our song. We have no answers.”

Jim Taylor

“But we share our lived experience hoping that the insights we have gained in meeting this disease head on with a positive outlook might help others find answers to their questions.”

Geri Taylor

We all need to find a venue to be heard; our voices, our songs, our insights, our individual and collective experiences can be mighty in their impact when channeled through the appropriate tool. The A-LIST is designed to give patients, care partners, and advocates a voice. The A-LIST enables us to be heard by the people and institutions that want to hear from us. It is so empowering to be heard, to stand up and make a difference—individually and collectively!

Among those who need and want to hear from us are those in the drug development and approval process, both the pharmaceutical companies and the FDA. Billions of dollars now flow annually into Alzheimer's drug development. How should that research be prioritized? What's most important? Whose priorities matter most? What are those priorities? The FDA and pharmaceutical companies want to know the answers to these questions and that's really good for us!! What's most important to the person with the disease: driving as long as possible, understanding what they are reading, maintaining verbal communication?

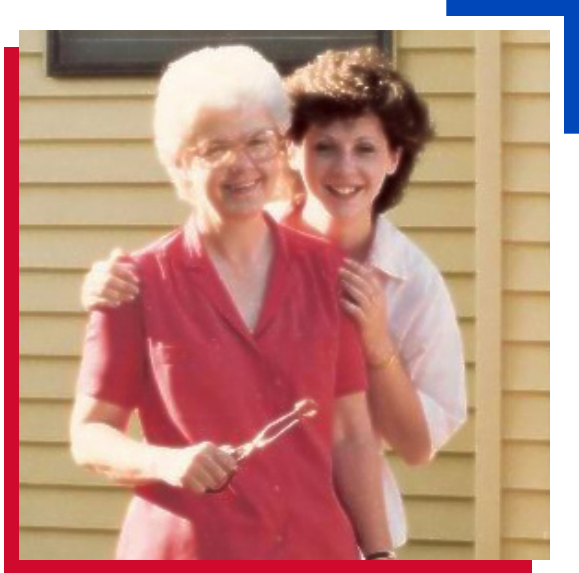
By continual communication and surveys within the Alzheimer's community, the A-LIST will become the leading tool for reliable information about our attitudes, experience and preferences; while giving us the opportunity to be heard; to sing our songs!



ANN NAPOLETAN

My mom was my person, always ready with a comforting hug, a willing ear, or a shoulder to cry on. Her intuition was on point; she knew when to offer advice and when it was best to just be there to quietly lend support. Together we celebrated small victories, important milestones, and life changing moments, and when heartbreak struck, she was there to pick me up.

Mom worked hard at a career she loved, and she did everything one should do to plan and prepare for a well-deserved, worry-free retirement. As that time approached, she dreamed of volunteering with children, spending leisure time gardening and enjoying the outdoors, traveling, and relishing time with beloved friends.



What we couldn't have imagined was that life had another plan. She retired at age 62, and shortly thereafter we began noticing subtle changes that eventually grew more pronounced. Initially, we attributed this to what seemed like a normal adjustment period; transitioning from a busy routine to days with little structure and less opportunity to interact with others. Instead of embracing this new chapter, she became increasingly withdrawn.

In time, we learned that nothing about these changes was normal. I knew very little about Alzheimer's then, but I could see my strong, independent, resilient mother becoming more isolated and losing the confidence and spirit that once defined her. We grew accustomed to the fact that from that point forward, we wouldn't know what the next day, or even hour, would hold. By the end, seeing a simple smile wash over her face, even if short-lived, was like hitting the lottery.

It's easy to wonder how life might have been different if not for Alzheimer's. This disease and our journey left me a changed person. I'm not

sure I'll ever feel the depth of joy that I once did. Conversely, I'm grateful for the lessons learned along the way and the precious moments Mom and I shared until she drew her last breath. Although her ability to communicate verbally faded early on, we found other ways to connect on a deeper level than I knew possible. Not even Alzheimer's could take away her true essence.

Now I want to ensure that our experience can make a difference to those who will come after us. I refuse to believe it was all for naught, and that's why the A-LIST is so important to me.

“My voice and our story have meaning; being part of a group that ensures my opinions are heard by researchers is empowering. I can help change the landscape of Alzheimer's research, treatment, and patient care. That won't bring my mother back, but it gives our journey purpose and helps me keep her legacy alive and well.”

MARTHA VILLANIGRO-SANTIAGO

Thankfully, my sister and I were with our mother when her doctor revealed mom's Alzheimer's diagnosis. Being together was the only comfort we could offer her. As far as we knew, my mother was the first one in our family to have Alzheimer's and none of her friends were living with this disease. At that moment my long and frustrating journey began as I sought positive news concerning the lives of Latinos living with Alzheimer's.

After my mother was diagnosed with Alzheimer's in 2013, I assumed the role of her caregiver. I quickly learned that as Latinos, and as a caregiver, we would face greater challenges in identifying the resources for ensuring her quality of life. I immediately began researching statistical information and experiences from other Latino families living with the impact of Alzheimer's. On the one hand, I discovered that Alzheimer patients would likely need to depend on unpaid caregivers to help them live with this disease. On the other hand, repeatedly I read that there was little or no

medical research based on the hardships faced by caregivers and their loved ones with Alzheimer's.

“ The statistics clearly established that in comparison to Whites, Hispanics were 1.5 times more likely to develop Alzheimer's yet the statistics and references to studies on Alzheimer patients did not include the experiences of Hispanics diagnosed with this disease nor of their caregivers. ”

I was delighted to learn about the A-LIST network for patients and caregivers of persons suffering from Alzheimer's. I finally discovered a resource offering vital data and updates regarding the prevention of Alzheimer's based on the information from those caregivers advocating for loved ones with this disease. Based on the long and diverse list of partners at the A-LIST network, I confirmed that the research collected and distributed by this Network was centered on the needs of both culturally diverse patients' and caregivers. Specifically, the A-LIST network consists of a variety of Advisory Councils, including Diversity; Patients & Caregivers; and Registries/ Clinical Trials. Upon following the easy steps for joining the network, almost immediately you are sent a survey to provide your perspective about a current issue for Alzheimer's patients and their caregivers. Simultaneously, your participation is added to the collection of data that will be used to consider future research trials, preventive electronic devices and other projects aimed at increasing available alternatives for the prevention and the cure of Alzheimer's.

As medical professionals, health organizations and academic institutions continue searching for answers that contribute to the prevention and cure of Alzheimer's, I gladly joined patients and other caregivers as a member of the A-LIST Network. There is strength in the number of caregivers willing to devote their daily lives to improving the lives of their loved ones suffering from Alzheimer's. The A-LIST Network nurtures that strength and makes it accessible to others in the campaign to facilitate a path to a cure.



LORETTA VENNEY

When dementia invades your family, as it did mine when my mom was diagnosed, you just feel so alone. You have no idea where to turn first or where to find good information. Thankfully, along came the A-LIST, which I believe is an important resource for those with dementia and their caregivers. It means everything to me because it allows me to have a meaningful voice. We are provided with surveys where we can say what matters most to us, both in caregiving itself and in clinical trials. We also have the opportunity to listen to podcasts for the most up-to-date information. We are allowed to read clinical trial results so we know what's happening now, and what will be happening in the future. I'm so grateful for the A-LIST, a place where I know I can turn, where I never again will feel alone.

