
Patient Perspectives of Disease-Modifying Therapies for Alzheimer’s Disease

Applications from the [GSA KAER Toolkit for Brain Health](#)

Momentum Discussions Podcast from the Gerontological Society of America

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Host:

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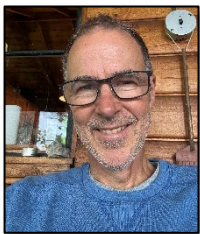
Gerontological Society of America



Guests:

Tracy Collins

Person living with early-onset Alzheimer’s disease



Scott Hardy

Care partner to Tracy

Announcer:

Welcome to the Gerontological Society of America’s Momentum Discussion, where we explore groundbreaking topics in the field of aging.

Jen Pettis:

Welcome to this GSA Momentum Discussions podcast episode titled *Beyond the Diagnosis: The Lived Experience with New Alzheimer’s Treatments*.

We’re grateful to Eisai for their support of this podcast episode.

My name is Jen Pettis, and I'm the Director of Strategic Alliances at GSA. I'm pleased to serve as the host for today's Momentum Discussion. Today's conversation focuses on disease-modifying therapies—such as monoclonal antibody treatments that lower amyloid in the brain—and the hope they offer for slowing the progression of Alzheimer's disease.

During this episode, we'll hear from Tracy Collins, who lives with early-onset Alzheimer's, and her care partner, Scott Hardy, about what it's like to choose amyloid-lowering therapy and experience the treatment journey. We have a remarkable opportunity to learn from them as they live this journey every day.

Welcome, Tracy and Scott.

Scott Hardy:

Hello.

Tracy Collins:

Thanks for having us.

Jen Pettis:

To start today's discussion, Tracy, please share with our listeners a bit about your journey to the diagnosis of early-onset Alzheimer's disease.

Tracy Collins:

I was widowed at 46, and I had a 12-year-old, a 9-year-old, and a 7-year-old. That was a trauma. Then, when I was 51, I had a meningioma brain tumor. That was surprising, but it explained many of the memory issues I was experiencing. They removed it, and a meningioma is one of the brain tumors that can be surgically removed.

Even after that, I was still having cognitive issues at work. I would walk into a room, see an instructor, then walk into another room ten minutes later and have the exact same conversation with him.

That's when Scott decided we really had to investigate further. Doctors put me on ADHD medications, but that didn't work. Finally, we did a spinal tap, and that was definitive for Alzheimer's. That wasn't a surprise, since I have a family history of the disease. That whole process took a couple of years and required a lot of adjustment.

Jen Pettis:

And Tracy, how old were you when you were finally diagnosed?

Tracy Collins:

I was diagnosed at 52, and because I was 52, I was too young for any clinical trials—you had to be 55.

Jen Pettis:

You have since started receiving disease-modifying therapy. I'd love to hear from both of you about how you made that decision together.

Tracy Collins:

I was still young, and it felt like everything else in my life was still very physical and active. I really needed to be a mom and take care of my kids. If I couldn't work and couldn't be there for them, that wasn't an option.

The challenge was that, because of my age, the insurance company denied coverage three times. My neurologist finally went head-to-head with them, and I've now passed my two-year mark on the medication.

Scott Hardy:

From my standpoint, it was an easy decision. We were eager to take advantage of this new drug as it was nearing final FDA approval. As Tracy said, with three kids and so much to live for, wanting to extend Tracy's quality of life made complete sense.

Given her diagnosis and the initial testing to make sure there were no risks of brain bleeds—a known risk with this therapy—she tested fine for that. We're very grateful the neurologist was able to convince the insurance company to cover it. Overall, it's been a positive experience.

Jen Pettis:

The infusions are every two weeks, correct? How have you managed logistics?

Tracy Collins:

I'm really fortunate. I live close to my primary care offices and go to an infusion center in Portland called Local Infusions. The people there are wonderful. I call it my "spa day."

They give you coffee, you recline in a soothing room, and you can watch TV, listen to music, or sleep. They have great snacks. It doesn't feel clinical or like a hospital; it feels more like a living room. The staff is just wonderful.

Jen Pettis:

Do you get to know other people receiving treatment there?

Tracy Collins:

Not really. It's pretty private. I don't usually see the same people, maybe a quick hello while getting coffee, but mostly you're in your own room.

Jen Pettis:

It sounds like they've created a great environment to receive treatment.

Scott Hardy:

It really is. And we're lucky it's only a 20–25-minute drive. Many people don't have access to infusion centers that are close to home. We're fortunate to have insurance coverage and access to care, but many people don't.

Jen Pettis:

Advocacy around access is incredibly important. Before we talk more about advocacy, can you share how treatment has impacted your daily life, independence, and quality of life?

Tracy Collins:

When I was first diagnosed, I was still working, so I had to manage my schedule around treatment. After I retired later that year, I had more flexibility. It's not really an inconvenience.

I go to the gym and to my infusions. During them, I relax. People often ask if I can tell whether it's working or if I feel clearer. I like to say that after infusions, I feel better, but it's not like you suddenly wake up with a clear brain.

What it gives me is peace of mind. I know I'm doing something that may help slow progression, and that matters to me.

Scott Hardy:

I'd echo that. It's not a panacea; it's not a cure. It slows progression, but progression still happens. The comfort comes from knowing it's helping. Otherwise, daily life is still daily life, with all its ups and downs.

Jen Pettis:

I understand you're also making a film called *Racing AI*. Tell me about that.

Tracy Collins:

Earlier in my career, I worked at Philips Electronics in Amsterdam on global PR. My boss there, Anya, became a close friend. When my late husband took his life in 2015, she flew over for the funeral. We've stayed close ever since, traveling back and forth between the U.S. and Holland each year.

Her husband, Konrad, is an avid cyclist. The year before my diagnosis, he cycled in the Alps. When I was diagnosed, he decided he wanted to do an Alzheimer's ride from Portland, Oregon, to Portland, Maine. I told him, "You're not going without me."

Scott's brother works in the film industry and wanted to document the journey, and that's how the project came together.

Scott Hardy:

Konrad wanted to bike across the country to raise funds in Tracy's honor. None of us could bike 100 miles a day with him, so my brother and I decided to film the journey instead.

We traveled in a VW Eurovan, camping along the route. The Alzheimer's Association helped connect us with chapters across the country, allowing us to meet communities, host events, and talk with people along the way. Even strangers at campsites approached us because our van was covered in Alzheimer's awareness signage.

The film is really about Tracy's story—her grit, optimism, hope, and love. People were deeply moved by her courage. We even kept a "hug counter" because so many people wanted to hug her. We plan to submit the film to the Sundance Film Festival in 2027. We have about nine months of editing and interviews left.

Jen Pettis:

When did the ride start and end?

Scott Hardy:

We started on August 9 and finished on World Alzheimer’s Day, September 21, in downtown Portland, Maine. We ended with an arrival ceremony at The Orange Bike brewery—fitting since Konrad rode an orange bike, and orange is the national sports color of the Netherlands.

Tracy Collins:

The ride was transformative, but also the hardest thing I’ve ever done. We moved to a new campground every day and lived in a van with three guys. I was constantly losing my glasses. I cried every morning and laughed every night.

Eventually, I told them, “Let me help. Let me do something.” I had ideas that we used for the rest of the trip, and it became a learning experience for all of us.

Jen Pettis:

Before we wrap up, what support systems have been most valuable to you?

Tracy Collins:

I have a wonderful support group of people with early-onset Alzheimer’s. We met every Monday, and some of them even came to the end of the ride. Technology makes connections possible in ways previous generations never had.

Scott Hardy:

For me, it’s unquestionably the Alzheimer’s Association. They connected Tracy to her support group, provided resources, and enabled advocacy. We’ve attended the AIM Advocacy Forum in Washington, DC, twice, and Tracy has met lawmakers like Senator Susan Collins because of their support. They provide community, relationships, and events like the Walk to End Alzheimer’s. If Alzheimer’s has touched your life in any way, I strongly encourage reaching out to your local chapter.

Jen Pettis:

Thank you both so much for joining me today. This has been a wonderful conversation, and I know our listeners will find inspiration in your story and in *Racing Al*. We look forward to helping you spread the word when the film is released.

Scott Hardy:

Thank you. We really appreciate the opportunity and the support from GSA.

Announcer:

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