

Why We Can't Wait To Find A Cure



By Larry Falivena

I was diagnosed with ALS in 2017.

It took several years for my doctors to confirm I had the disease. Yet that slow process still didn't fully prepare me for the day I heard the news.

The truth is, I don't know when I'll lose the ability to do the small things I used to take for granted. I don't know if or when the day will come that I'll be unable to tell my family just how much I love them.

But I do know this: even in the face of a global pandemic, we can't wait to pursue the treatments and a cure that will end ALS. The people living with and working to end this disease aren't quitters. They're fighters to the last breath.

ALS ASSOCIATION

Greater Sacramento Chapter

Roll Up Your Sleeves

For my part, I wanted to do something with my family that could make an impact in the fight for a cure. After meeting with The ALS Association's CEO [Calaneet Balas](#) for the first time, we came up with the idea to visit every Major League Baseball stadium as a way to raise awareness of the disease I live with and to share the stories of others affected by ALS. Dubbed The Iron Horse Tour as a nod to Lou Gehrig—the baseball player first diagnosed with ALS in 1939—it's one way I tried to make a difference.



Another was joining [The ALS Association's Board of Trustees](#).

The ALS Association's leadership ensures voices like mine are a major and regular part of conversations and decision making.

That's true at every level of our organization. As Chapter leaders Jen Hjelle and John Hedstrom mentioned in their recent post, we're always [looking for people to serve](#).

We're Fighting on Every Front

Before I retired, I worked with several nonprofits. When I look at how The ALS Association invests and allocates its resources, it's clear to me that we are a high impact organization. Just look at one recent example. When the New England Journal of Medicine announced last



month that a drug developed by Amylyx Pharmaceuticals showed promise in clinical trials, the Association acted immediately to call on the company and the FDA to figure out how to get this treatment to people with ALS as quickly as possible. We know that people with ALS can't wait another two to three years for additional phase 3 testing. By the way, that research was supported early on by The ALS Association with ALS Ice Bucket Challenge money. We fund promising research, and we work with our partners to get treatments across the finish line.

That matters. Because we can't wait for this pandemic to be over to get up and continue the fight in our own ways. I know enough about the science to know we're not going to find a cure overnight. I'm also living with ALS, so I personally share in the urgency and sense of frustration that things aren't happening fast enough. I want the research to move quickly and my disease to progress slowly. We all do. Everyone in the ALS community is impatient for a cure.

It's the combination of research, care services, and advocacy that will defeat ALS. We have a duty to explore every avenue available.

You Are Helping Us Find a Cure

Before his diagnosis, Lou Gehrig played 2,130 consecutive games of professional baseball. That doesn't happen without a relentless attitude and a broad skillset that gives you a number of ways to win.

The same is true of The ALS Association. We're investing in a number of ways to defeat ALS. And you are helping to find a cure when you help out in any way you can.

If you're the [young girl](#) who donates the hard-earned coins in her piggy bank, you're helping us find a cure. If you're the [energetic researcher](#) throwing yourself into ALS genomic research to discover life-extending treatments, you're helping us find a cure. If you're a volunteer supporting a walk for the brave families in your community living with ALS, you're helping us find a cure. If you've messaged your elected official through our [Advocacy Action Center](#), you're helping us find a cure.

If we're going to beat this thing, we have to be relentless.

We can't wait until this is over.

Larry Falivena is a member of The ALS Association's Board of Trustees. This is the final post in a series where ALS Association leaders share their perspective on the urgent need to advance our mission during the current pandemic, and the ways you can get involved.