



CASE STUDY

Johns Hopkins and Answer ALS offer new hope to ALS patients

Patient medical data and artificial intelligence may hold key to new treatments

In 2014, Ed Rapp was on a run with his son in North Carolina when he noticed that every 15th step or so, one foot would catch.

"I thought, well, I had just come off a long flight," recalls Rapp, who at the time was based in Asia as a group president for a Fortune 100 company and had come home to visit family. But the next day it happened again.

So began a journey Rapp had never imagined he would take, first to a dreadful diagnosis and then to an inspiring destination that may help an untold number of others. Almost a year after that initial stumble, Rapp was diagnosed with amyotrophic lateral sclerosis, commonly known as ALS or Lou Gehrig's disease, a fatal progressive motor neuron disease that slowly robs patients of their ability to move, speak and even, in the end, breathe.

It is believed that as many as 400,000 people worldwide are living with ALS. There is no cure or effective treatment protocol, and very little is known about its cause. That may be about to change.

Challenge Harness big data and AI to search for answers – and treatments

Rapp and 1,000 fellow ALS patients are participating in Answer ALS, a revolutionary research program founded and run by Johns Hopkins and the Robert Packard Center for ALS Research.

Answer ALS is bringing together global research centers, leading technology companies, world-class researchers across an array of disciplines and ALS patients for one goal: leverage cloud computing, machine learning, an enormous amount of patient data, and a powerful, interactive data infrastructure with the ability to harness artificial intelligence – all to

help determine what causes ALS and identify potential treatments. Researchers will contribute to and have open access to the data research bank so that all can take advantage of one another's work. New leads and discoveries will be posted in real time, hopefully spurring new ideas and discoveries.

It all started with a symposium hosted by Team Gleason, the foundation created by former NFL player Steve Gleason, an ALS patient himself.

"If we truly want to have an impact on seemingly unsolvable diseases like ALS, Parkinson's, Alzheimer's and dozens of other diseases, large-scale coordinated and collaborative efforts are the best way to rapidly move forward," Gleason says.

"In 2014, Team Gleason brought the ALS community together and challenged clinicians and researchers to create a business plan to help end ALS," says Steve Gleason, who uses eye movements to type. "That plan is now Answer ALS. We didn't make that challenge lightly. The research community, coupled with organizational, industry and technology partners like Avanade, are delivering results based on that challenge. We haven't answered ALS yet, but we are closer than ever before."

Solution

A massive data repository and technology capable of processing research queries in hours, not weeks

Once the Answer ALS consortium selected Microsoft Azure as the backbone for the data research bank, Azure expert Avanade was selected to lead phase one of the project. Avanade began with a design-led workshop that focused less on technology and more on deciding what functionality was required, then prioritizing objectives.

“It was not a technical discussion,” said Michael Isaac, Avanade executive in the global data and AI practice, who led the workshop. “It was a ‘what do we need to accomplish’ conversation. We came out of that workshop with a clear, identified roadmap for how to proceed most efficiently.”

What the team needed, it turns out, was an Azure-based query engine capable of processing research queries

in hours instead of days or weeks – one capable of integrating the artificial intelligence (AI) and machine learning capabilities that will be added in later phases. Data security throughout was paramount.

Using agile methodology, Avanade built a powerful, secure system that allows researchers to use tools they are already familiar with, one that is ready by design to expand as the project continues to build momentum.

Researchers will be able to fully evaluate genetic information from each participating ALS patient and perform the most comprehensive biological analytics ever. This is possible by combining the data with RNA, protein and epigenomic analysis of the patients’ cells to yield a personalized database of thousands of petabytes of new ALS-specific information. The next phase will incorporate AI and machine learning to further speed and amplify research analysis, adding to the body of knowledge that one day will unlock the disease’s mysteries.

Results

A new template for medical research based on collaboration and AI data analysis

Participating researchers will share their insights, techniques, processes and ideas, a concept practically unheard of in medical research. Answer ALS believes that the results – gathered, analyzed and studied – will serve as the foundation for new clinical trials and new ways to subgroup participants that may lead to the development of successful treatment protocols.

“We are working on the cutting edge of science,” says Peter Warlick, vice president of corporate development for American Airlines, who was diagnosed with ALS in 2015. “The technology is a critical component. If the data isn’t accessible in a manner that data analysts can access it, the value of the work that preceded it is lost. The infrastructure is critical to drive accessibility and accountability.”

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Like Rapp, after his diagnosis Warlick selected Answer ALS for support. He launched a fundraising campaign, Aviators Against ALS, with a goal of using his contacts in the aviation industry to raise \$5 million to help fund Answer ALS work. His group achieved that goal in December 2018.

In addition to building memories with his family, he finds inspiration and meaning in his Answer ALS advocacy. "It's incredibly invigorating," he says. "It has helped give me purpose. A life without purpose is one that doesn't really exist."

"My ultimate objective is to change the prognosis for the future. It won't change mine. But with the new technologies, there is a higher probability of success than there has been in the past. I think we are demonstrating a new model for approaching medical research."

The project is already producing results. Sharing the Answer ALS data with a research group based in the Netherlands, scientists have identified a gene linked to ALS.

Since his first stumble years ago, Answer ALS has become a valued part of Rapp's personal journey, as well.

"I keep a list of the gifts of ALS," he says. "The courage of the patients, the caregivers, the doctors. ALS has opened my life to an entirely new world."

Ed Rapp, who now serves as chair of the Answer ALS Advisory Board, is realistic. "As I look at it personally, I have an open mind about what it means for me. If you find a pathway or subgroup, considering how long it takes to do the research, develop a protocol and get a treatment to patients, it will not happen in time to help me. I've never looked at this as a path to save me. I have always looked at it as something that can make a difference for the next generation."

About Answer ALS

The Answer ALS program was designed and implemented by Jeffrey Rothstein, M.D., Ph.D., founder and director of the Robert Packard Center for ALS Research. It was the direct result of a collaboration between the Packard Center and Team Gleason, the organization founded by former NFL player Steve Gleason after he was diagnosed with ALS. In 2014 Gleason and Team Gleason hosted a summit in New Orleans that brought together leading researchers, patients, caregivers and all ALS stakeholders for the first time in a single meeting. The call to action was to “think differently” and create a plan to ultimately end ALS in our lifetime.

The result was Answer ALS, now recognized as the single largest coordinated and collaborative ALS research project in the world. Under the leadership of the Packard Center, nearly two dozen institutions, 1,000 patients and trillions of data points will be key to the project that Answer ALS believes could discover different types of ALS subgroups and develop customized treatment protocols that could allow patients to live vibrant, full lives.

About Avanade

Avanade is the leading provider of innovative digital and cloud services, business solutions and design-led experiences on the Microsoft ecosystem. With 36,000 professionals in 24 countries, we are the power behind the Accenture Microsoft Business Group, helping companies to engage customers, empower employees, optimize operations and transform products, leveraging the Microsoft platform. Majority owned by Accenture, Avanade was founded in 2000 by Accenture LLP and Microsoft Corporation. Learn more at www.avanade.com

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North America

Seattle
Phone +1 206 239 5600
America@avanade.com

South America

Sao Paulo
AvanadeBrasil@avanade.com

Africa

Pretoria
Phone +27 12 622 4400
SouthAfrica@avanade.com

Asia-Pacific

Australia
Phone +61 2 9005 5900
AsiaPac@avanade.com

Europe

London
Phone +44 0 20 7025 1000
Europe@avanade.com