



### ANSWER ALS

# Answer ALS: New template for future medical research?

Research approach emphasizes open collaboration, data mining technology and AI

Combine a dreadful disease with no current cure, some of the top medical research centers in the world and the power of cloud computing, and what do you have? Answer ALS and a \$40 million bid to find the cause of and develop treatments for amyotrophic lateral sclerosis, commonly known as ALS or Lou Gehrig's disease, a progressive motor neuron disease that slowly robs patients of their ability to move, speak and even, in the end, breathe.

At the heart of Answer ALS, founded and run by Johns Hopkins and the Robert Packard Center for ALS Research, are world-renowned medical researchers, who are using new tools to delve into untold levels of biological analysis, and technology companies eager to stretch the boundaries of cloud computing, artificial intelligence (AI) and machine learning to bring new hope to ALS patients worldwide. The project requires a data system capable of storing and processing trillions of bits of data and a customized data query engine that allows researchers to quickly and efficiently access and analyze this never-before-gathered amount of cellular ALS information.

Avanade, which built the data query engine and interfaces that are enabling global research collaboration, spoke with Emily Baxi, Ph.D., executive director of the Robert Packard Center for ALS Research at Johns Hopkins, to take us to the front lines of this new approach to medical research.



# **Q:** What is different about the Answer ALS approach to medical research?

A: Today, we can interrogate cell function like never before. Answer ALS researchers are essentially building 1,000 profiles of ALS patients, constructed piece by piece using multiple sources of data, ranging from the patient's clinical history and genetics to information gathered by an app specifically designed to monitor speech and cognition, everything right down to the cellular biology of each patient's own motor neurons.

Using the power of AI and machine learning to integrate and analyze these profiles, we hope that Answer ALS will lay the groundwork to uncovering ALS patient subgroups and identify the most effective treatment strategies for each. This all amounts to big data. We are able to collect more information on ALS or any other disease than in the past. But it requires a convergence of talent and techniques.

# **Q:** Did that lead to Answer ALS's marriage of medical research and data technology?

A: As a neuroscientist, I know about neurons, but I don't know anything about storing or integrating data or applying AI to data. That is where this program has set a good example. Biologists are interfacing with computational experts and data analysts to understand the best way to wrangle this data, gather it in one place and build the tools to successfully work with the data in a way that is fast, effective and accessible to people who are less IT savvy but who can ask relevant questions about the biology. That is a huge part of what Avanade has helped us with.

In the end, the goal is to put multiple forms of data together to build a stronger, more complete, more enlightened picture of a particular disease type. What Avanade has done is bring everything together in the cloud, making the ability to query the data fast and efficient for researchers.

**Q**: Has this approach to combining medical research with the power of cloud computing been done before?

A: It is pretty new. Programs are starting to use similar approaches, but we are pushing the envelope. We are asking people to come together and join forces, apply their knowledge and figure out a meaningful way to compile and access more data than ever before.

Using machine learning techniques, we are trying to extract the true biology out of the massive data set so we can bring it back to the lab and work with it to get a good picture of what is happening, so we can then come up with new therapeutic approaches.

# **Q**: One core aspect of the Answer ALS approach is its commitment to open-source sharing. How did that come about?

A: We are asking scientists to do something that is becoming more common but has not been typical for us, which is to share. There's the race to get published, to be first to discover something. That creates an environment of secrecy, holding your cards close to your chest.

However, ALS is such a terrible, devastating disease and the problem is bigger than any of us. Our agreement up front was that any data that was produced would not belong to any individual institute, contributing to the work. It would all be open source, which is both different and huge for us. We think this approach has a good shot at cracking open ALS.





## **Q**: Could this template be used to help find treatments or cures for other diseases?

A: We think so. This approach, combining research and data technology in a powerful open-source infrastructure available to everyone could be applied to Alzheimer's, Parkinson's, multiple sclerosis or cancer or any other disease. We are asking questions that are particular to motor neurons and ALS. The same template could be used for any other cell type in the body.

#### Q: What have been the results so far?

**A:** Phase one is gathering all this information and making it available and usable. Phase two will enable more elaborate interrogation and validation of the data sets.

Even at this stage, other ALS researchers have looked at what we are doing and are building programs that will complement what we are doing. We also have made our data available to a project called Project MinE, based in the Netherlands. Project MinE's goal is to map the full DNA profiles of at least 15,000 people with ALS and to perform comparative analyses on the resulting data. We pooled our data and discovered a gene linked to ALS. That's just right off the bat. There is a lot more to come.

#### 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 is 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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