



ALS Association Contributes \$3.3 Million to Fund Groundbreaking Genome-Sequencing Database

A global, centralized, cloud-based repository of ALS genetic data is being assembled with funding from The ALS Association. This is the first such repository of its kind.

Much of the research aimed at finding a cure for ALS is in the area of genetics. Such work requires genomic sequencing, a process whereby individuals' genes are mapped in a way that can be compared to the genes of others who do not have ALS in an effort to identify variations that may be factors in the development or progression of disease.

Numerous labs across the country, many funded by The ALS Association, are working in the genomic space studying various aspects of the disease. These labs generate an enormous amount of data requiring immense storage capacity and high-end computing capabilities. As a result of these financial and infrastructure requirements, the ability to share the raw, unprocessed data with each other has not been feasible. Further, subtle differences in the extensive processing of the data could cause problems in comparing data from different centers.

This situation presents a great opportunity to accelerate research by creating a centralized, cloud-based repository of ALS genetic data. The repository will reprocess all the raw sequencing data so that it is treated identically. This process is called "data harmonization" which will yield cleaner, more consistent, and more reliable results.

The repository will store the data in the cloud allowing researchers around the world access to a wealth of sequencing data to study ALS genetics without the massive infrastructure previously needed. Additionally, by deploying the cloud's computing power, scientists can analyze the data using innovative

methods in hopes of uncovering novel findings in ALS genetics. The next frontier of ALS genetic research is uncharted territory and will take a lot of computing power to tackle.

“By providing access to this data and processing power, the repository will essentially enable ‘crowdsourcing’ of ALS genetics,” said John Landers, Ph.D., co-leader of the project.

“It will allow researchers worldwide to have immediate access to a large pool of data. Besides geneticists and neuroscientists, people outside the field might try to tackle parts of the ALS puzzle. Engineers, chemists, mathematicians, and programmers might find solutions others never thought to consider. The more people who are involved, the sooner we may find new genetic variations that contribute to the disease or potential methods of treatment. This central repository will provide an outstanding way to advance our understanding of ALS to the next level,” Landers added.

The \$3.3 million grant from The ALS Association will fund cloud storage, cloud computing, and the genomic sequencing of 3,000 people living with ALS. The Atlanta chapter of The ALS Association is contributing an additional \$100,000 to the project.

The creation of a central repository was conceived by three researchers well-known to The ALS Association:

- John Landers, Ph.D., University of Massachusetts Medical School
- Jonathan Glass, M.D., Department of Neurology & Pathology, Emory University
- Bryan Traynor, M.D., Ph.D., National Institute on Aging, National Institutes of Health