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Answer ALS: Announcement

Researchers Share Unprecedented Milestones

October 11, 2017 - Last week at the 2017 Annual NEALS Meeting, Answer ALS researchers presented updates on the initiative to the ALS research community. Those updates included some unprecedented efforts in the strategy to find answers and solutions to ALS.

“When Answer ALS was envisioned and ultimately organized, we wanted the entire research community, academic and commercial to have rapid access to our data, tools, results and resources,” said Jeffrey Rothstein, Answer ALS Executive Director and Director, Robert Packard Center for ALS Research, Johns Hopkins University. “This is the first major release of Answer ALS biologicals and the first of many public releases to come,” he continued.

With a mission to build the most comprehensive clinical, genetic, molecular and biochemical assessment of ALS, Answer ALS is not only rapidly meeting that goal, but also openly sharing those results to the global research community.

“Releasing these samples to the broader ALS research community provides a critical resource for researchers in the field,” said Clive Svendsen, Answer ALS Co-Director and Director, Board of Governors Regenerative Medicine Institute, Cedars-Sinai. “The cells can be expanded indefinitely and are linked to their clinical data and eventually a wealth of molecular data being generated by Answer ALS.” Svendsen added, “And, this only represents the first few lines from the 1000 being created”

Milestones announced by the Answer ALS Research Team:

- 34 well defined ALS iPSC cell lines released through the Answer ALS iPSC repository website
- Over 27,000 serum, blood and CSF samples released to the global ALS research community
- 564 currently enrolled in the Answer ALS study
 - 82 participants completed all 5 visits
 - 146 have completed 4 visits
 - 361 are beyond the 1st visit
- The Answer ALS App to monitor patient participant motor, speech, breathing and cognition progression is now available
- The Les Turner ALS Research and Patient Center at Northwestern Medicine announced it has joined Answer ALS as the 7th clinical site in the nation

Answer ALS is a multi-organizational consortium creating the most comprehensive collection of ALS data ever amassed from an ultimate sampling of 1,000 ALS patients in the United States.

Merit Cudkowicz, Answer ALS Co-Director and Chief of Neurology and Director of ALS Program, Massachusetts General Hospital, added, “To answer some fundamental questions about the cause and heterogeneity of ALS, it is critical to have detailed, high quality clinical information

linked with biofluid samples and iPSC lines. Through this amazing Answer ALS partnership between patients, foundations and researchers, these data, samples and cell lines are now available for researchers. Broad and fast access will accelerate research to finding new treatments. We encourage investigators globally to access these data and samples.”

To learn more about Answer ALS or if you are living with ALS and interested in being part of the study, please visit www.AnswerALS.org.

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