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For Immediate Release
**Les Turner ALS Research and Patient Center at
Northwestern Medicine Joins Answer ALS**

October 11, 2017 - Answer ALS is very pleased to announce the Les Turner ALS Research and Patient Center at Northwestern Medicine as the newest member of the single largest coordinated and collaborative effort to end ALS in the history of the disease - Answer ALS. The mission of Answer ALS is to build the most comprehensive clinical, genetic, molecular and biochemical assessment of ALS and make the data and research tools freely available to researchers to help bring an end to this disease.

“The Center is proud to be one of the eight academic institutions to join Answer ALS in the largest collaborative ALS study ever conducted, thanks to funding from the Les Turner ALS Foundation,” said Senda Ajroud-Driss, MD, Associate Professor of Neurology at Northwestern Medicine Feinberg School of Medicine and Director of the Lois Insolia ALS Clinic at the Les Turner ALS Research and Patient Center at Northwestern Medicine. “Our hope is, through these shared efforts, new therapeutic targets will be found, increasing the likelihood and speed in which a treatment for ALS will be discovered.”

This multi-organizational consortium is creating the most comprehensive collection of ALS data ever amassed, from an enormous sampling of 1,000 ALS patients in the United States. This collaboration uses big data sequencing efforts designed to uncover new ALS genes, which importantly leads to new therapeutic targets for researchers to go after in the fight against ALS. The more known therapeutic targets increases the likelihood that a treatment will be found. This research project also could potentially provide deeper understanding of Alzheimer’s, Parkinson’s and other neurodegenerative diseases. Sample collection and enrollment will begin shortly at the Lois Insolia ALS Clinic at the Les Turner ALS Research and Patient Center at Northwestern Medicine.

The Les Turner ALS Research and Patient Center at Northwestern Medicine joins seven other prestigious institutions in this project:

- Johns Hopkins University
- Massachusetts General Hospital
- Ohio State University
- Emory University
- Washington University
- Cedars-Sinai Medical Center
- Texas Neurology

Answer ALS originated as a result of the 2013 ALS Team Gleason Summit, which brought together leading researchers, patients, caregivers and advocates. The event was spearheaded by former NFL player Steve Gleason who lives with ALS and founded the ALS advocacy group, Team Gleason. The goal of the Summit was to create a plan to find a treatment or cure for ALS as quickly as possible.

“I’ve always said, to change the course of this disease, as a community, we would have to be bigger than ALS,” said Gleason. “I believe that if we commit to this effort, on this scale, we will have meaningful results in our lifetime.

A funding effort led by the Leandro P. Rizzuto Foundation and the Robert Packard Center for ALS Research has resulted in \$20 million raised for Answer ALS thus far. The initial stakeholder funders are the National Football League, the PGA TOUR, ALS Finding a Cure (a project of the Leandro P.

Rizzuto Foundation), Travelers, The Fishman Family and The Bari Lipp Foundation. In October 2016, American Airlines joined the effort by donating \$1 million to Answer ALS. The funding for the Answer ALS study being done at the Les Turner ALS Research and Patient Center is being donated by the Les Turner ALS Foundation.

To further advance its research and data efforts to an international level, in June 2017 Answer ALS announced a partnership with Project MinE and the NYGC's ALS Consortium to share its whole genomic sequencing data. In return, Project MinE USA will contribute results from its global genetic studies to further Answer ALS's objectives, in addition to lending its technical expertise in analyzing sequence data. This adds to the sequencing expertise already established and takes this initiative to an unprecedented level.

"Before being diagnosed with ALS, I used this philosophy during tough times in business," said Ed Rapp, former Caterpillar Group President and Chair of the Answer ALS Advisory Committee. "Have a clear definition of winning, pull together the right team of people, identify the key work streams that must be executed and drive a focused execution model." Rapp added, "And I believe the Answer ALS initiative employs that same philosophy."

People living with ALS who wish to be a part of the Answer ALS study or to learn more about Answer ALS, please visit www.AnswerALS.org

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