



## **A Look Back at Over \$16 Million in Research Grants Awarded During 2018**

### ***Investments are Accelerating Innovation and Progress Toward a Cure***

It's ALS Awareness Month, and The ALS Association remains steadfastly committed to funding the most hopeful research around the world that could lead to effective treatments and a cure for ALS.

Since the ALS Ice Bucket Challenge soaked the world almost five years ago, we have tripled our annual research budget.

More than \$108 million has been committed toward our mission, including over \$89 million that has been committed to worldwide research collaborations, since 2014. In 2018 alone, we awarded more than \$16 million (\$16,079,742) in funding to support 47 new research projects in nine countries\*.

To see a complete list of the research we have funded since the ALS Ice Bucket Challenge, [click here](#). For a list of all the grants we fund, [click here](#).

Our global research program, the largest private philanthropic source of ALS research funding worldwide, has led to some of the most promising and significant advances in ALS research since its inception in 1985.



“Our research is leading to new treatments and technologies for people with ALS and leverages more investment in ALS research by other organizations, such as NIH,” said Dr. Neil Thakur, executive vice president of mission strategy for The ALS Association. “We’re proud of our awardees and the people with ALS who participate in research studies. Each of them has accepted a challenge that will lead us to a better understanding of ALS, to more effective treatments, and eventually, to a cure.”

Our research grant portfolio includes the Lawrence and Isabel Barnett Drug Development Program, the Milton Safenowitz Postdoctoral Fellowship Program, the Clinical Management Program, the Investigator-Initiated Multi-Year Program, the Starter Grant Program, the Clinical Trials Program, the Biomarker Program, and Strategic Initiatives.

The **Investigator-Initiated Multi-Year Program** supports projects in a broad range of subjects within the ALS research space for periods up to three years. This program requires strong preliminary data. Thirteen grants totaling over \$3 million (\$3,055,000) were awarded during calendar year 2018\*.

**Investigator-Initiated Starter Program** awards are given to investigators who are entering the field of ALS, investigators who are senior fellows about to set up independently, or pilot studies by experienced investigators in any discipline. These one-year awards do not require strong preliminary data but must emphasize innovation, scientific merit, feasibility, and relevance to ALS. Ten grants totaling over \$570,000 (\$571,501) were awarded during calendar year 2018\*.

Nine ALS **Biomarker Awards** totaling more than \$680,000 (\$682,518) were awarded during calendar year 2018\*. The biomarker discovery grant program develops objective measurements of ALS and disease progress. It addresses an urgent need for ALS biomarkers to improve diagnosis, assess whether drugs successfully hit their target (indicating success during drug development and clinical trials), and track disease progression over time.

The biomarker initiative was formed under the ALS Biomarker Consortium, in partnership with ALS Finding A Cure (ALS FAC), the CREATe Consortium, Muscular Dystrophy Association (MDA), Northeast ALS Consortium (NEALS), and The Robert Packard Center for ALS Research.

The **Clinical Trials Program** funds the early phase (phase I and phase II) clinical development of novel, high-potential treatments for people with ALS. Three grants totaling over \$1.7M (\$1,744,000) were awarded during calendar year 2018\*.

The awardees were **Dr. Stanley Appel** at Houston Methodist Neurological Institute (“Expanded population of regulatory T-Cells (EPAR T-Cells) for people with Amyotrophic Lateral Sclerosis”); **Dr. Sabrina Paganoni** at Massachusetts General Hospital (“Expanded population of regulatory T-Cells (EPAR T-Cells) for people with Amyotrophic Lateral Sclerosis”); and **Dr. Steven Perrin** with ALS TDI/Analexis (“Clinical development of AT-1501, a humanized antibody targeting CD40LG, in ALS patients”).

The **Clinician Research Training Fellowship** is given in partnership with the American Academy of Neurology (AAN) to a clinician fellow dedicated to accelerating ALS research. One grant totaling \$150,000 was awarded during calendar year 2018\*.

The **Clinical Management Grant Program** funds research for improving the clinical, psychological, and social management of ALS, focusing both on people with ALS and their caregivers. Four grants totaling over \$775,000 (\$777,477) were awarded during calendar year 2018\*.

**Strategic Initiative awards** address research gaps and infrastructure to make all ALS research more collaborative and efficient. Many of these projects feature large collaborative efforts among industry and academic partnerships. Seven grants totaling over \$4 million (\$4,150,250) were awarded during calendar year 2018\*.

The **Lawrence and Isabel Barnett Drug Development Program**, named in honor of Lawrence and Isabel Barnett, has enabled the development of novel therapeutics that are currently in clinical trials for ALS and related neurological disorders.

The program has been instrumental in fostering academic-industry partnerships and contributed to the explosion in companies, small and large, entering the ALS field. The 16 contracts awarded during

calendar year 2018\*, totaling nearly \$4.5 million (\$4,448,996), continue this pioneering effort to develop novel therapies against the disease.

The **Milton Safenowitz Postdoctoral Fellowship Program** encourages and facilitates promising young scientists to enter and remain in the ALS field. This program was founded in 2004 by the Safenowitz family through The ALS Association Greater New York Chapter, in memory of Milton Safenowitz, who died of ALS in 1998. The program awarded grants to five postdoctoral fellows totaling \$500,000 in 2018.

**To see the specific research grants awarded by The ALS Association for each of these programs during calendar year 2018\*, visit our ALS Ice Bucket Challenge Progress page [here](#).**

*\* THE ALS ASSOCIATION'S ANNUAL FISCAL YEAR RUNS FEBRUARY 1-JANUARY 31. THE GRANTS HIGHLIGHTED IN THIS ARTICLE WERE AWARDED DURING CALENDAR YEAR 2018 - JANUARY-DECEMBER 2018.*