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FOR IMMEDIATE RELEASE

The ALS Association and The Tow Foundation Commit Additional \$6 Million to New York Genome Center

New Funding to Support Center for Genomics of Neurodegenerative Disease

Washington, D.C. (February 5, 2019) — The ALS Association and The Tow Foundation are pleased to announce their continuing support of the New York Genome Center’s (NYGC) [Center for Genomics of Neurodegenerative Disease](#) (CGND), in recognition of the substantial genomic research being carried out by NYGC scientists. The ALS Association has committed an additional \$3.5 million to the NYGC’s CGND, including a \$1 million commitment from the Association’s [Greater New York Chapter](#). [The Tow Foundation](#) in New Canaan, CT, has contributed an additional \$2.5 million gift.

Following the ALS Ice Bucket Challenge in 2014, The ALS Association invested \$2.5 million in the CGND to match a \$2.5 million gift from The Tow Foundation. The success of this unique three-way partnership between The ALS Association, The Tow Foundation and CGND in advancing research to develop new ALS treatments has resulted in this renewed support and commitment of nearly \$6 million in additional funding. To date, the joint gift to the NYGC CGND has contributed to sequencing and analyzing thousands of ALS genomic samples, while pairing this information with patient clinical history. This data has led to better understanding of ALS disease pathways and supported many new ALS gene discoveries using cutting-edge genomic technology and disease models. Through initiating and fostering many critical collaborations, ALS data sharing increased on a large scale, empowering an integrative worldwide approach to find effective treatments and a cure for ALS. Funding by The ALS Association will further the work of the CGND, led by its Director, Hemali Phatnani, PhD, as it combines the expertise of NYGC scientists and its global partners to translate its genomic research into innovative advancements in clinical care and accelerate the development of new ALS treatments.

“The ALS Association is proud to continue our support for the critical work the NYGC CGND is doing to reveal genomic patterns and pathways that help us better understand the complexities of ALS,” stated Calaneet Balas, President and CEO of the Association. “NYGC CGND has helped create a flourishing ALS big data

community focused on innovation and open data sharing. We look forward to seeing the many new discoveries that it will continue to generate.”

“We are very grateful to The ALS Association and the Tow Foundation’s ongoing support of our genomic research to discover new mutations and elucidate the mechanisms underlying ALS,” said Tom Maniatis, PhD, NYGC’s Scientific Director and CEO.

Since its inception, NYGC’s CGND has established itself as a prominent player in ALS genetics, leading the way in ALS gene discovery. It represents an important hub of ALS data collection and analysis, which fosters an ever-growing array of collaborative partnerships within the ALS community. The CGND’s ALS Consortium, a collaboration of clinicians, scientists, geneticists and computational biologists, has grown to 29 member institutions from around the globe. The data accumulated is shared at an unparalleled scale with ALS researchers globally, empowering an integrated worldwide approach to working toward effective therapies and a cure for ALS.

At the CGND, the goal is to sequence and analyze the genomes of several thousand clinically well-annotated ALS patient samples. Researchers utilize state-of-the-art clinical and functional genomics techniques and bioinformatics to discover new ALS genes, which represent new therapeutic targets and lead to a better understanding of ALS disease pathways.

Its pioneering work includes sequencing genomes and analyzing data from 1,000 ALS patients collected through [Answer ALS](#), which is openly shared with the global ALS research community. This new investment by The ALS Association includes \$450,000 in funding toward completing this massive whole genome sequencing effort, which continues its support and collaboration with Answer ALS.

About ALS

ALS is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. Eventually, people with ALS lose the ability to initiate and control muscle movement, which often leads to total paralysis and death within two to five years of diagnosis. For unknown reasons, veterans are twice as likely to develop ALS as the general population. There is no cure.

About The ALS Association

The ALS Association is the largest private funder of ALS research in the world. The Association funds global research collaborations, provides assistance for people with ALS and their families through our nationwide network of chapters and certified clinical care centers, and advocates for better public policies for people with ALS. The ALS Association builds hope and enhances quality of life while urgently searching for new treatments and a cure. For more information about The ALS Association Greater Sacramento Chapter, visit our website at www.alssac.org.

About The Tow Foundation

The Tow Foundation, established in 1988 by Leonard and Claire Tow, funds projects that offer transformative experiences to individuals and create collaborative ventures in fields where they see opportunities for

breakthroughs, reform, and benefits for underserved populations. Investments focus on the support of innovative programs and system reform in the areas of juvenile and criminal justice, groundbreaking medical research, higher education, and cultural institutions. For more information, visit <http://www.towfoundation.org>.

About the New York Genome Center

The New York Genome Center (NYGC) is an independent, nonprofit academic research institution focused on advancing genomic research. We are furthering investigation to translate genomic research into new treatments and therapies for patients with neurodegenerative disease, neuropsychiatric disease, and cancer, leveraging our strengths in whole genome sequencing, genomic analysis, and the development of new genomic tools.

The NYGC serves as a nexus for collaboration in genomic research for the New York community and beyond, building on the combined strengths of our faculty, member institutions, scientific working groups, affiliate members, and industry partners. Central to this commitment is an outstanding faculty who are leading independent research labs based at the NYGC and one of our member institutions. They also support the NYGC scientific mission and engage in research programs that support the NYGC and the wider scientific community.

Member institutions include: Albert Einstein College of Medicine, American Museum of Natural History, Cold Spring Harbor Laboratory, Columbia University, Hospital for Special Surgery, Icahn School of Medicine at Mount Sinai, The Jackson Laboratory, Memorial Sloan Kettering Cancer Center, New York-Presbyterian Hospital, The New York Stem Cell Foundation, New York University, Northwell Health, Princeton University, The Rockefeller University, Roswell Park Cancer Institute, Stony Brook University, and Weill Cornell Medicine. For more information on the NYGC, please visit: <http://www.nygenome.org>.