FISCAL YEAR 2021 STEWARDSHIP REPORT

Gregory W. Fulton ALS and Neuromuscular Disease Center



↑ Shafeeq Ladha, MD, is the director of the Gregory W. Fulton ALS and Neuromuscular Disease Center.

VER 20,000 PEOPLE in the United States, and 175,000 people worldwide, are living with amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease.

The Gregory W. Fulton ALS and Neuromuscular Disease Center at Barrow Neurological Institute, led by Shafeeq Ladha, MD, is a model for offering comprehensive care within a single center, while providing access to advanced clinical trials and world-class research. While scientists do not yet know what causes ALS, and there is no cure for the disease, scientists at Barrow have been working tirelessly to perform cutting-edge research that investigates biomarkers and uses artificial intelligence (AI) to track disease progression and uncover associated genetic mutations. The Fulton ALS Center is an ALS Association Certified Treatment Center of Excellence.



telemedicine visits

outpatient clinic visits

active clinical trials

BARROW NEUROLOGICAL INSTITUTE BY THE NUMBERS





CLINICAL IMPACT

77,600+

total number of patients seen at Barrow annually

22,200+

telemedicine visits

5,700+ brain and spine surgeries



11

research fellows and visiting scholars from Brazil, Columbia, India, Ireland, Pakistan, Russia, Thailand, and Turkey

PROGRAM ACCOMPLISHMENTS

The Fulton ALS Center saw that many patients were overwhelmed with the amount of information given to them during clinic visits. Dr. Ladha proposed the development of an online information resource center that could be used to help ALS patients better understand the disease, how it is managed, and what can be done at home to help them. In the first half of 2021, the Fulton ALS Center created a series of user-friendly informational handouts and developed the electronic hardware needed to deploy the content to patients.

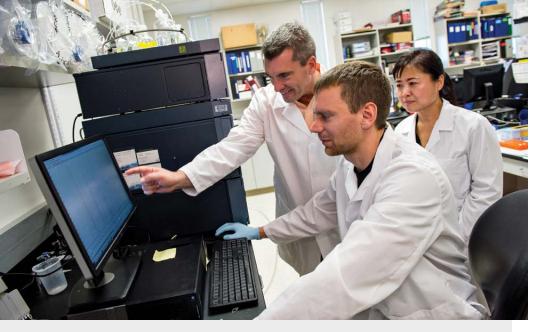
As a part of its mission to educate and train the next generation of the world's leading neuroclinicians, Barrow welcomed Bill Jacobsen, MD, to the Fulton ALS Center team. Dr. Jacobson completed both his neurology residency and a fellowship in ALS and neuromuscular diseases at Barrow.

RESEARCH ADVANCES

In addition to unsurpassed clinical care, the Fulton ALS Center has a robust clinical and basic research program. ALS research at Barrow is led by Robert Bowser, PhD, deputy chief scientific officer and John and Betty Van Denburgh Chair in Neuromuscular Disease, who has pioneered efforts to discover and validate biomarkers for ALS. The ALSA-BIO3 biomarker study collected clinical data, MRI data, and bio-fluids (cerebral spinal fluid and blood) from motor neurons to enter into a national biorepository used to aid therapy development for ALS.

Dr. Bowser and Fredric Manfredsson, PhD, were awarded a highly competitive two-year grant from the Department of Defense (DOD) to continue their collaborative research on a novel treatment for ALS. Their research aims to target specific inflammatory cells involved in ALS and "flip" them from causing cell death to become more neuroprotective. The research funded by the DOD builds off of Dr. Bowser's previous research on chitinases, which are associated with chronic neuro-inflammation. He found that they occurred in higher levels in people with ALS, but also in cells that control inflammation in nervous tissue.

Rita Sattler, MSc, PhD, is working on identifying disease-causing mechanisms for patients with ALS, frontotemporal degeneration (FTD), and other neurodegenerative diseases. Most of these diseases have overlapping pathogeneses, (processes by which a disease develops) so uncovering mechanisms for one disease may enable scientists to draw parallels to the other diseases and develop therapeutic interventions that could be applicable to multiple patient populations.



Robert Bowser, PhD, is working to identify biomarkers that may lead to more precise diagnostic tools for earlier detection of ALS, to accurate selection of patients for particular drug treatments, and the ability to monitor the impact and efficacy of treatments.

ON THE HORIZON

The Fulton ALS Center will continue developing the online platform for ALS patients by creating instructional and informational videos. Once complete, the videos will go live and the online platform will be available to Barrow patients. Eventually, the team would like to open up platform access to ALS patients, caregivers, and organizations across the country.

The Fulton ALS Center has started enrollment for the Target ALS Biomarker Study and the EIM At Home Study, which are new, multicenter studies originating from the ALS research team at Barrow. The Target ALS Biomarker Study will collect cerebral spinal fluid and blood samples from ALS patients at the time of diagnosis and as the disease progresses in order to identify biomarkers, enable early diagnosis, and track the effectiveness of potential treatments.

Dr. Ladha will serve as the co-lead for Regimen E in the Healey Platform Study. The Healey Platform Study simultaneously tests different drugs for their effectiveness in ALS patients. Regimen E will assess a new compound called trehalose to see if it can slow disease progression. The COURAGE-ALS study, which is a large, multicenter phase 3 study, investigates the effectiveness of a compound that can enhance muscle contraction in the weakened muscles of ALS patients. Additionally, Dr. Ladha and Dr. Bowser received support to develop and build a large clinical database that will capture information on ALS patients at Barrow, and then link it with biomarker data and whole genome DNA data in hopes that the dataset can provide new insight into how DNA and biomarkers can help scientists understand ALS disease progression better.

BARROW NEUROLOGICAL INSTITUTE BY THE NUMBERS



RESEARCH

320+

active research studies

791

patients enrolled in clinical trials

\$11.7 MILLION

in federal research grant support



DONOR IMPACT

\$28 MILLION

total distributed to Barrow Neurological Institute, including:

\$21 MILLION

designated to specific centers/programs

\$5 MILLION

for basic, clinical, and translational research

\$1.7 MILLION

for endowed research chairs



The Gregory W. Fulton ALS and Neuromuscular Disease Center at Barrow Neurological Institute is the largest center of its kind west of the Mississippi.

THANK YOU FOR YOUR SUPPORT

We are so thankful for your partnership in bringing the best treatments available for ALS patients to the Gregory W. Fulton ALS and Neuromuscular Disease Center at Barrow. Your generosity has truly allowed us to build a beacon of hope for ALS patients, where they know they can experience the best care, have access to cutting-edge research, and feel empowered as they battle this awful disease. Our incredible team has made great strides in both clinical care and research over the past year, despite the challenges presented by the pandemic. This would not have been possible without your support.

On behalf of the entire team at the Gregory W. Fulton ALS Center at Barrow, thank you for your generosity and dedication.

With Gratitude, Shafeeq Ladha, MD Ira A. and Mary Lou Fulton Chair in Motor Neuron Diseases Director, Gregory W. Fulton ALS and Neuromuscular Disease Center

The mission of Barrow Neurological Foundation is simple: to be the catalyst of our donors' passion for transformation by providing the resources for Barrow Neurological Institute to achieve its mission of saving human lives through innovative treatment, groundbreaking research, and by educating the next generation of the world's leading neuroclinicians.

