

Gregory W. Fulton ALS and Neuromuscular Disease Center



AMYOTROPHIC LATERAL SCLEROSIS (ALS) is a devastating neurological condition that gradually robs patients of the ability to move their body, speak, eat, and swallow. Eventually, they can no longer breathe on their own and must depend on a ventilator. Meanwhile, all of their cognitive functions remain intact, so they are fully aware of what is happening. It is a terrifying disease for those diagnosed and a heartbreaking one for their friends and family.

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. While we do not yet know what causes ALS, and there is no cure for it, scientists at Barrow have been working tirelessly to perform cutting-edge research to change that narrative. The Fulton ALS Center is an ALS Association and Muscular Dystrophy Association Certified Treatment Center of Excellence.



10+

clinical studies



872

telemedicine visits



4,396

clinic visits

BARROW NEUROLOGICAL INSTITUTE BY THE NUMBERS



CLINICAL IMPACT

91,800+

total number of
patient visits

20,900+

telemedicine visits

5,500+

brain and spine surgeries



GLOBAL IMPACT

78

international
research fellows and
visiting scholars

RESEARCH ADVANCEMENTS

Last year, the Fulton ALS Center was involved in the development of a new drug treatment for the disease, which recently received approval by the Food and Drug Administration (FDA). The medication, Relyvrio, is the first ALS drug to receive FDA approval in five years.

Earlier this year, Dr. Ladha administered the first-ever gene therapy doses to an ALS patient in the history of Barrow. The treatment involves inserting a gene into motor neurons that produces a growth factor, which will hopefully slow disease progression. This will pave the way for more gene and cell therapy trials at the Fulton ALS Center. Dr. Ladha is also the principal investigator in a multicenter trial exploring the effectiveness of a new drug that may help motor neurons clear away some of the abnormal proteins that cause their early death.

Robert Bowser, PhD, the John P. and Betty Van Denburgh Chair in Neuromuscular Disease, is the principal investigator for the Target ALS Biomarker Study, which collects cerebrospinal fluid (CSF) and blood samples from ALS patients. These samples are entered into large biobank, so scientists around the world can use them as tools to develop new ALS treatments. Dr. Bowser and his team have also initiated studies to develop improved ways to measure the RNA binding protein TDP-43, which can cause familial forms of ALS, in blood and CSF samples from ALS patients.

Rita Sattler, PhD, is investigating the role of microglia in both ALS and frontotemporal dementia (FTD). During the disease process, microglia become destructive rather than protective. Dr. Sattler and her team aim to understand how microglia dysfunction impacts the health and survival of neurons, which could ultimately help scientists identify targets for future ALS and FTD drug therapies.

Jeremy Shefner, MD, PhD, is the principal investigator for two multicenter ALS clinical trials. The COURAGE-ALS study investigates the effectiveness of a new drug that has been shown to improve muscle force in patients with ALS. The second trial investigates a novel Sigma-1 receptor antagonist, as mutations in the Sigma-1 receptor have been linked as a possible contributing cause of the disease.

PROGRAM ACCOMPLISHMENTS

To help reduce patient and caregiver anxiety, the Fulton ALS Center set out to create an online ALS guide with information to help them better understand the disease and how it is managed. The team is now in the process of deploying the content to patients on tablets, which can be used in clinic while they wait to see ALS care team members.

The National Institute of Neurological Disorders and Stroke (NINDS) has formed a dedicated ALS Strategic Planning Team to identify the highest ALS research priorities. Barrow ALS scientists Dr. Bowser, Dr. Shefner, and Dr. Sattler were all selected for this specialized team, with Dr. Sattler serving as the steering committee co-chair. The team's focus will be on defining properties that will accelerate translational research toward novel ALS therapies, optimizing clinical research, improving quality of life for ALS patients, and identifying opportunities for research collaborations.

ON THE HORIZON

Dr. Bowser and Dr. Ladha are in the process of developing the Fulton ALS Database, a large clinical database that will capture information on Barrow ALS patients and link it with biomarker and whole-genome DNA data to help scientists understand disease progression better. After the online ALS guide becomes available to Barrow patients and caregivers, the team will look into allowing other ALS organizations to access the guide. Additionally, the Fulton ALS Center welcomed Sami Kaldawi, DO, and Clara Chow-Haws, MD, in 2022 as its new neuromuscular fellows.

FULTON ALS CENTER FUTURE NEEDS

- **Chair in neuromuscular diseases:** The new chair would allow the Fulton ALS Center to recruit a nationally known neuromuscular specialist to help build the non-ALS component of the program.
- **Collaborative research platform:** This would allow the Fulton ALS Center to leverage experts in engineering, data science, and artificial intelligence to make new discoveries under the guidance of Barrow ALS specialists. It would also allow for the comprehensive study of the relationship between ALS, Parkinson's disease, and Alzheimer's disease.
- **ALS research symposium:** The Fulton ALS Center would sponsor an annual ALS research symposium, bringing together respected clinicians and researchers from across Arizona to present their latest findings and work.
- **Outreach to rural Arizona:** As ALS advances, it becomes impossible for patients to travel long distances. The Fulton ALS Center would like to reduce this burden and allow patients access to expert care by creating monthly ALS/neuromuscular disease clinics located in rural and under served areas of Arizona.

BARROW NEUROLOGICAL INSTITUTE BY THE NUMBERS



RESEARCH

397

active research
studies

791

patients enrolled
in clinical trials

\$14 MILLION

in federal research
grant support



DONOR IMPACT

\$20 MILLION

total distributed to Barrow
Neurological Institute,
including:

\$3.5 MILLION

designated to specific
centers/programs

\$15.4 MILLION

for basic, clinical, and
translational research

\$1.5 MILLION

in endowments



↑ 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

Thank you for your support in helping the Gregory W. Fulton ALS and Neuromuscular Disease Center provide the best care and treatments available to ALS patients. Your generosity has allowed the Fulton ALS Center to become a beacon of hope for ALS patients; a place where they know they can experience compassionate care, have access to cutting-edge research, and feel empowered as they battle this devastating disease.

In addition to being an ALS Association Certified Treatment Center of Excellence, the Fulton ALS Center is also one of the most well-known and sought-after centers by both ALS foundations and pharmaceutical companies that are interested in clinical trial and therapy development. This would not be possible without your generous support.

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.

Barrow
Neurological Foundation

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