FISCAL YEAR 2020 STEWARDSHIP REPORT

Gregory W. Fulton ALS and Neuromuscular Disease Center

BARROW Neurological Foundation

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

EVERY 90 MINUTES, someone learns they have Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease. ALS causes the death of neurons controlling voluntary muscle movement. One of the things that makes the disease so devastating is that as nerve cells die, patients lose the ability to walk, talk, swallow, and breathe, but the brain is unaffected so they are fully aware of what's happening to them. ALS affects as many as 30,000 people in the United States. About 10% of ALS cases are inherited; the other 90% have no clearly associated risk factors and no family history of the disease. ALS is incurable and current treatments focus on controlling symptoms and making the lives of patients as manageable as possible. Barrow Neurological Institute's Gregory W. Fulton ALS and Neuromuscular Disease Center is one of the few centers in the world that combines unsurpassed patient care and curative research. The Center is a certified treatment center of excellence as designated by the ALS Association.

Affects
175,000
people worldwide

Most common
in people
OVER 60

20%
more likely to develop
in men than women

BY THE NUMBERS

BEST HOSPITALS U.S.News NATIONAL NEUROLOGY & NEUROSURGERY 2020-21

CLINICAL IMPACT

100,878
BNI Clinic Visits

77,000+
Patients Treated

5,000+
Brain & Spine Surgeries

GLOBAL IMPACT

47
Visiting Scholars from Argentina, Austria, Brazil, China, Chile, Colombia, Germany, India, Italy, Ireland, Israel, Mexico, Pakistan, Philippines, Portugal, Romania, Russia, Spain, South Korea, Turkey, United Kingdom

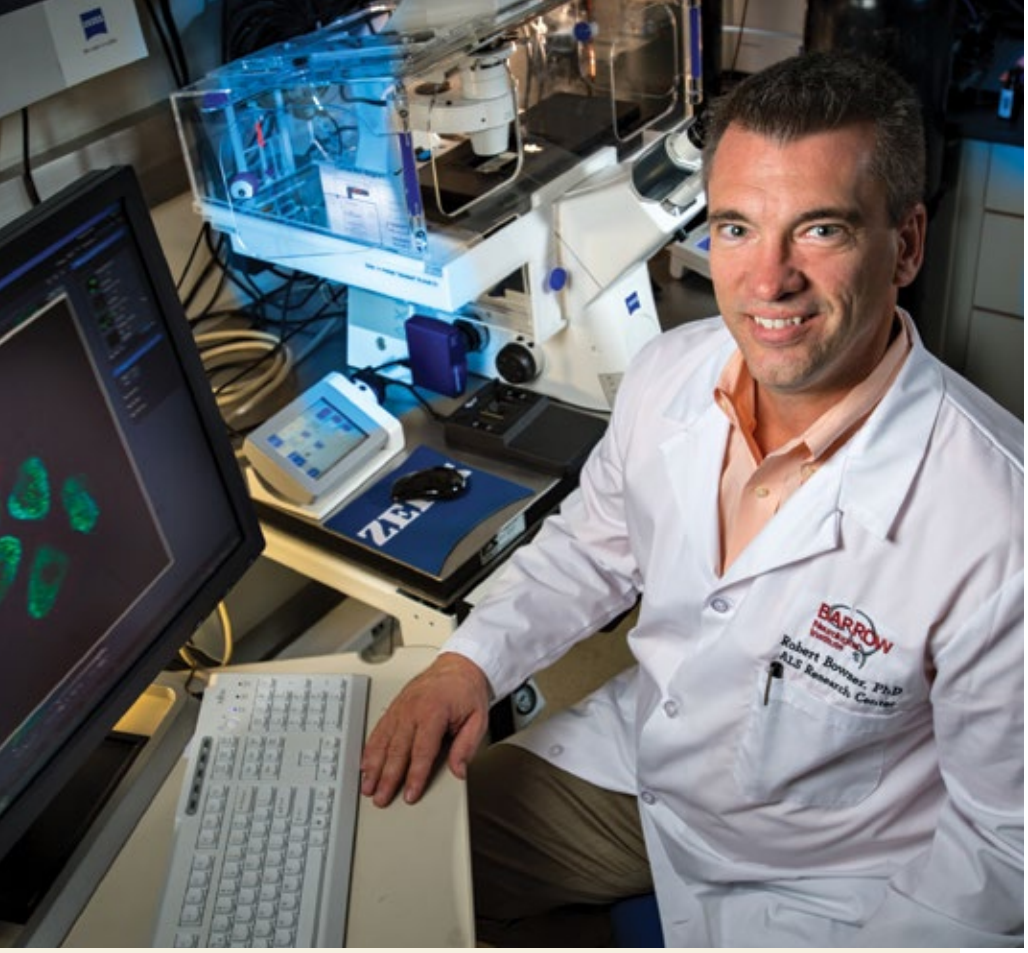
PROGRAM ACCOMPLISHMENTS

The Fulton Center has grown significantly in the last several years, becoming the largest ALS center west of the Mississippi River. Our physicians see five times as many patients today as they did seven years ago, and our scientists are conducting groundbreaking studies into the causes of ALS while working tirelessly on new treatments. Investigators teamed with IBM's Watson to identify five never-before-linked genes associated with ALS. Additionally, researchers have done pioneering work in using a patient's own stem cells to create individualized therapies. Multiple drug trials are underway at any given time, as pharmaceutical companies are attracted to Barrow because it is an ALS center of excellence.

COVID-19 presented many challenges for our vulnerable patient population. In our efforts to keep patients safer at home, the Center was able to adjust quickly and convert in-person clinic visits into telemedicine appointments. While COVID-19 did affect clinic operations, we were able to safely continue seeing patients for research visits and new study enrollments. Their visits were conducted remotely whenever possible. Despite the challenges brought to bear by the pandemic, 14 clinical trials for ALS enrolled 75 patients in FY20. One of the trials investigated a new drug for ALS. The trial showed evidence it could slow the progression of the disease.

RESEARCH ADVANCES

In addition to thriving patient care and clinical research programs, the Fulton Center has a robust basic research enterprise that includes the work of four independent scientists. Robert Bowser, PhD, has one of the most active ALS labs in the world. His work has identified a number of individual proteins and specific cellular pathways that are altered in ALS patients. Dr. Bowser's research seeks to develop diagnostic biomarkers for ALS and identify biochemical pathways that change early in the course of the disease. A collaboration with David Medina, PhD, used a preclinical model to prove it is possible to deliver a drug to the brain using a microscopic delivery system in order to preserve strength. The next steps involve expanding the work into clinical trials in people. Rita Sattler, PhD, is investigating how the dysfunction of neurons at the cellular level contributes to ALS.



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

In our efforts to find the next, best treatment for ALS, the Fulton Center will take part in several clinical trials in the coming year testing medications to slow the progression or ease the symptoms of the disease. The Center also will enroll patients in gene therapy trials to alter the course of the disease in the familial form of ALS.

Barrow is one of the coordinating sites for a worldwide collaboration to launch the first-ever platform trial for ALS accelerating the study of promising drugs. The consortium brings together a team of experts to rethink the design of early-phase trials for the disease, accelerate the path to effective treatments and increase patient access to trials. Barrow is the only participating site in Arizona supporting study operations and providing clinical monitoring and outcomes training for all participating sites.

BY THE NUMBERS

RESEARCH

1,377
Active Research Studies

959
Patients Enrolled in Clinical Trials

$11.3 MILLION
Federal Research Grant Support

DONOR IMPACT

$2.4 MILLION
Basic & Translational Research

$5.28 MILLION
Strategic Initiatives

$1.63 MILLION
Education and Fellowship Programs

$1.97 MILLION
Community Outreach Programs

↑ 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 to patients with ALS at the Fulton Center. Because of your generosity we are also accelerating scientific discovery and keeping our patients safer at home with telemedicine. We could not do it without you.

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

Barrow Neurological Foundation's mission 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, curative research and educating the next generation of the world's leading neuro clinicians.

BARROW
Neurological Foundation

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