



Fulton ALS Newsletter



Issue 1 | Date: July 8, 2019

Bike for MS

On May 30, Dr. Jeremy Shefner, Chair of Neurology, started his 4,295-mile long bike ride from Bar Harbor, Maine to Seattle, Washington. While he is biking from coast to coast, Dr. Shefner is raising funds for Bike the US for MS and Barrow's MS program. Currently, Dr. Shefner has completed a little over half of his journey!

You can follow along Dr. Shefner's ride at jeremybikes.blog/.



Basic Science Research at the Fulton Center

Basic science and translational research are an important component of the Fulton ALS Center, providing new insights into disease mechanisms, new targets for drug development, and new ways to treat and monitor the effectiveness of drugs in clinical trials. Our research team includes senior faculty, junior faculty, fellows, PhD students, undergraduate students, high school students and staff members. Our senior scientists, Dr. Bowser and Dr. Sattler, are recognized leaders in ALS research.

Within our laboratories, the use of patient derived stem cells provides ways to study motor neurons from patients, learning about the disease process and providing the opportunity to perform drug screens with motor neurons generated from sporadic or familial ALS patients. We use animal models of ALS to test new methods to deliver drugs into the nervous system and if these drugs slow disease progression prior to moving these drugs to human clinical trials. We also completed and published one of the first studies in ALS using artificial intelligence programs to gain new insights into disease mechanisms.

The Fulton ALS Center is also home to a national biorepository for biofluid and tissue samples collected from ALS patients. Scientists from around the world use these samples to advance ALS research. We have also used these biofluid samples to discover biomarkers of ALS that are being used to create new diagnostic tests for ALS and ways to monitor disease progression.

If you are interested in learning more or would like to schedule a tour of the labs, please email Robert.Bowser@DignityHealth.org.

Bite Nite

On June 15, the Arizona Chapter of the ALS Association held their 10th annual Bite Nite at the Arizona Biltmore. This year, the event raised over \$408,000!

Bite Nite is a fundraising event that brings together the ALS community including patients, caregivers, health professionals, families, and friends-- all people who want to see a future free of ALS. Local restaurants serve mini dishes for everyone while guests enjoy live entertainment. The event also includes a live auction, silent auction, and plenty of fun activities for everyone to participate in while raising funds for an important cause.



Dr. Bowser and Dr. Ladha were both honored at Bite Nite.

Patient Highlight

Nancy Byler was diagnosed with ALS in 2004. She has lived with the disease for 15 years, which is very atypical, as the average life expectancy is 2-5 years after diagnosis. Nancy and her husband, Chuck, make the trip to Phoenix from Twin Falls, Idaho every month to attend ALS clinic and research appointments at the Fulton Center.

She is currently enrolled in one of Barrow's research trials that targets her specific gene mutation, SOD-1, which is linked to familial ALS. Despite her ALS diagnosis, she has a very positive attitude and considers herself "one of the lucky ones" because of her slow progression.

Nancy has seen the ALS community come a long way in the past 15 years and continues to participate in efforts for furthering ALS advocacy and research.

Thank you for being such a wonderful advocate in the ALS community, Nancy!



ALS Advocacy Day

On June 8, The ALS Association began their annual ALS Advocacy Conference in Washington DC. 650 attendees from ALS Association chapters around the US came to connect, learn, and advocate. On June 11, conference attendees went to Capital Hill and met with their local legislators to share their stories and legislative asks including:

1. Waiving the 5-month waiting period for people with ALS to receive their Social Security Disability Insurance benefits
2. Opposing the Centers for Medicare and Medicaid Services decision to include noninvasive ventilators in the Competitive Bidding Program
3. Providing \$10 million in appropriations to continue the National ALS Registry and Biorepository at the CDC
4. Providing \$20 million in appropriations to continue the ALS Research program at the Department of Defense
5. Providing \$41.6 billion in appropriations for the National Institutes of Health to continue funding ALS research, along with many other diseases



The Arizona Chapter of the ALS Association

If you would like more information on becoming an advocate, please visit <http://www.alsa.org/advocacy/> to learn more about ways to get involved.

ALS Clinic Team: Social Worker

The role of the social worker in the ALS Clinic is to guide and support ALS patients and caregivers through the different phases of the illness. The initial meeting allows the social worker to establish a relationship with the patient and family and together they prioritize the immediate concerns and challenges that need to be addressed. The meeting will also involve a comprehensive psychosocial assessment. The following areas are included in the social worker's assessment: medical history leading to first ALS clinic appointment, patient and family emotional status, home care needs and arrangements, patient and caregiver support, financial concerns, work status and accommodations, eligibility for Social Security Disability, short term and long term disability, advance directives, status of health insurance, spiritual beliefs and support, eligibility for community supports and Veteran's Administration benefits.

The social worker maintains contact with the patient and family between appointments as concerns arise and need to be addressed. Referrals to community agencies and programs are offered as needed. Short term counseling is provided and referral to community mental health providers for long term counseling is also facilitated.

Dawn Magid is the social worker for the ALS Clinic at the Fulton Center. She provides so much support to those living with ALS and those touched by the disease. The Fulton Center is very thankful to have her as part of the wonderful ALS Clinic team!

Clinical Research Updates

Biogen 261AS101

Biogen 261AS101 is a Phase 1 study to evaluate the safety and tolerability of BIIB100 in ALS patients. The Fulton Center will be enrolling patients soon.

BIO 3

BIO 3 is a biomarker study which aims to look at different features of ALS by using standard outcomes measures, but also utilizing cognitive assessment and biofluid collection during an 18-month period. This study will also help expand our biorepository. The Fulton Center will continue enrolling patients through December 2019.

Biogen 233AS101 Part C

Biogen 233AS101 Part C is the 3rd part of this study, which will be the fixed dose of BIIB067. To be eligible to screen for this study, you must have familial ALS with an SOD-1 mutation. This study is currently enrolling patients at the Fulton Center.

Speech Analysis

Speech Analysis is an observational study that will be looking at the use of speech and language measures to detect cognitive changes in patients with ALS. This study is currently enrolling at the Fulton Center.

ALS Post-Mortem Tissue Bank

The ALS Post-Mortem Tissue Bank collects post-mortem tissue (spinal cord, muscle, and brain tissue) from both people with ALS and people without ALS. This tissue bank will support ALS research efforts by strengthening collaborations in the research community and providing information to better understand the disease. The Fulton Center is currently enrolling patients in this program.

If you have any questions about participating in clinical research at the Fulton Center, please visit our website at:
www.barrowneuro.org/patients-families/find-a-clinical-trial

Diamondbacks ALS Awareness Night

On July 19, ALS Awareness Night will be held at Chase Field for the Arizona Diamondbacks and Milwaukee Brewers game! The Arizona Chapter of the ALS Association, the Arizona Chapter of the Muscular Dystrophy Association, and the ALS Therapy Development Institute have all teamed up with the Arizona Diamondbacks to put together this awesome night. ALS Awareness Night recognizes the bravery and strength of ALS patients and their families, while honoring those who have passed. The pre-game activities, which include the reading of Lou Gehrig's Speech and Ceremonial First Pitch, will begin at 6:00pm.

Ticket Information

To purchase tickets, please go to www.dbacks.com/barrow.

Promo Code: Barrow

A portion of every ticket purchased through this offer will be donated to Barrow Neurological Institute.

Please contact Joanna Imperial for any special seating needs at 602-462-4113 or email jimperial@dbacks.com.

Follow the Fulton Center on Social Media!



The Gregory W. Fulton ALS and Neuromuscular Disease Center is now on Facebook!

Find us at:

facebook.com/gregorywfultonalscenter

Upcoming Events

Saturday, July 13- Tuscon Caregiver Skills Training with the ALS Association

Friday, July 19 6:00pm- ALS Awareness Night at Chase Field

Friday, August 16- Saturday, August 17- Weekend to Remember Family Staycation with the ALS Association's Youth Program

Saturday, August 24- Phoenix Caregiver Skills Training with the ALS Association

Friday, August 30- Fill the Boot Northern AZ with the Muscular Dystrophy Association

Saturday, September 7- Teen Adventure Day with the ALS Association's Youth Program

Saturday, September 28- Tuscon Muscle Walk with the Muscular Dystrophy Association

ALS Association Support Groups

Call 602-297-3800 or email info@alsaz.org to confirm schedule and location .

West Valley Patients, Caregivers, Family and Friends

When: 2nd Thursday of each month from 1:00pm-3:00pm

Where: Church of Arrowhead 7902 W Union Hills Dr. Glendale, AZ 85308

East Valley Patients, Caregivers, Family and Friends

When: 2nd Tuesday of each month from 1:00pm-3:00pm

Where: Mesa Baptist Church (Room B-3), 2425 S. Alma School Rd. Mesa, AZ 85210

Phoenix Caregivers

When: 3rd Tuesday of each month from 5:30pm-7:30pm

Where: Contact ALSA for location.

Phoenix Survivors

When: 3rd Wednesday of each month from 5:30pm-7:30pm

Where: 360 E. Coronado Rd. Suite 140 Phoenix, AZ 85004

Tuscon Patients, Caregivers, Family and Friends

When: 1st Thursday of each month from 12:00pm-2:00pm

Where: Our Savior's Lutheran Church 1200 N Campell. Tuscon, AZ 85719

Tuscon Caregivers

When: 3rd Thursday of each month from 1:00pm-3:00pm

Where: Our Savior's Lutheran Church 1200 N Campell. Tuscon, AZ 85719

Northern Arizona Patients, Caregivers, Family and Friends

When: 4th Monday each month from 12:30pm-2:30pm

Where: VA Hospital Building 161 (room 145) 500 Highway 90. Prescott, AZ 86313

[Click here](#) for more details on support groups.