

Fall 2019

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Patient Highlight: Mary Dilts

Mary Dilts is one of our wonderful patients here at the Fulton Center. She was diagnosed with ALS in November 2016. In the past three years, Mary and her husband, Woody, have been very active in the ALS community, including participating in research and advocacy efforts.

Participating in ALS Research

“At first, I had hopes that I may get the one miracle drug that would cure all of us. I also knew if I did not directly benefit, that my body and disease may benefit others in the fight. If people with ALS don’t participate, then a cure will never be found. I would like to think that even this part of my life can somehow help others someday.

The people I have worked with during the research trials have been wonderful. So kind and personable. I am not a patient or subject but a human. I believe the people make all the difference in making the decisions to do it again. They are friends helping me and others look for a cure. I found out after a year that I had a placebo in one of my trials. But I do understand that without placebo, you do not get a true reading of the drug that’s being tested. I have had ALS almost three years now, so I don’t qualify for some trials, but any that I do qualify for I want to be part of. I am fortunate that I am mobile with my wheelchair and still strong enough to participate.”

Advocacy in the ALS Community

“My husband and I had the awesome privilege of going to Washington, DC for



Patient Highlight: Mary Dilts continued

the ALS Advocacy Conference 2019. I was able to meet so many wonderful people there. One young lady sitting behind me has had ALS for three years. She just turned 33. Another couple invited me to sit with them at their table while they celebrated his birthday. I met some people I communicate with online. We are all connected with this disease. A dear, sweet young lady came to DC to tell her story of how her father fought and lost his battle with this disease. We heard speakers that are working tirelessly on our behalf for fundraising, research, and getting the message that we are here and need a cure. The highlight was going to the Capitol to tell our story to congresspeople and senators. What an honor to speak for all of you who couldn't travel there. My husband shared from the perspective of husband and caregiver. This tough guy of mine wept like a baby advocating for me and you.

My husband and I just celebrated our 50th wedding anniversary. Our two grown children and their spouses along with five of our six grandkids, were able to celebrate with us. Our lives probably like yours, have had many storms and all of them as scary at the time as ALS is now to us. We have accepted Jesus Christ as our personal Lord and Savior--He never promised to sugar coat our lives but to help us through the storms. We had plans and dreams that did not include ALS, but now that ALS is a reality, I want to continue to help and serve Him and others. The minute I step out of this failing body I will be in heaven with Him."

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 is currently enrolling patients.

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

NEALS Meeting

The 18th Annual NEALS Meeting was recently held in Clearwater Beach, Florida on Oct. 2-4, 2019. Many people from the Fulton Center and the Barrow Neurological Institute Clinical Research Organization were able to attend. A few had the opportunity to present and lead trainings, including Dr. Bowser, Dr. Ladha, Meghan Hall, Gale Kittle, and Daphne Westgate. This meeting brought together so many people in the ALS research community, including hundreds of researchers, clinicians, and industry partners -- all people whose efforts support the goal of learning more about ALS and discovering better treatments for patients.



Physical Therapy at the Fulton Center

With October being National Physical Therapy Month, it is important to remember the significance of physical therapy in ALS patients. We are very thankful to have Deborah Taylor as the ALS Clinic's physical therapist. She has been with the Fulton Center since it opened in 2014 and works extremely hard to make sure her patients receive the best care.

Physical therapy (PT) is available to patients with ALS at each clinic visit to the Fulton Center. Physical therapy addresses safety and functional training, instructs in range of motion (ROM) and stretching exercises, and instructs in gait and fatigue management. Physical therapists also work closely with the occupational therapists (OT) in the clinic.

The physical therapist will educate patients on proper techniques in transfers, including lift training with a sling, ROM exercises, and gait training. The use of equipment to increase safety and reduce fatigue is also discussed. The equipment can include a shower chair, elevated toilet seat, rails, and braces. Equipment should help patients be active in the home, as well as the community. When the time comes for a patient to

utilize power mobility, the physical therapist can perform an evaluation and assist with the process.

Occasionally, patients are able to go to an outpatient clinic for physical therapy. These visits should have specific goals to make patients more comfortable, as well as provide instructions to family about care. Home health is available when our patients have a change in function and families and caregivers need more instruction in the home for care.

Our goal is to educate our patients and make sure that they have the tools they need to live as safely and independently as possible. We want our patients to enjoy life and continue with their activities at home and in the community.

ALS Symposium

The 4th Arizona ALS Symposium was held at the University of Arizona in Tucson on Sept. 27-29, 2019. This event is an excellent opportunity for ALS researchers and clinicians to share ideas, collaborate, and discuss current research. Dr. Fen-Biao Gao from the University of Massachusetts was the keynote guest speaker and gave an overview of disease pathogenesis caused by the C9orf72 repeat expansion using patient-derived stem cells differentiated into neurons and fly models of the disease. In addition to this keynote lecture, several researchers and clinicians from Barrow Neurological Institute presented updates on their clinical advancements and laboratory research projects. They included two of our junior ALS faculty, Drs. David Medina and Nadine Bakkar, and our neuromuscular fellow, Dr. Bill Jacobsen.

The presentations highlighted the diverse and interdisciplinary research that is being conducted in

Arizona on ALS, from basic cellular and molecular disease mechanisms, to drug design and the development of voice tracking software for measuring ALS disease progression. The symposium included a poster presentation from all of Arizona's ALS trainees (undergraduate students, PhD students, and postdoctoral fellows), providing them with a unique opportunity to discuss their research with established ALS clinicians and researchers. The ALS Association Arizona Chapter generously donated poster awards to the best three poster presenters: congratulations to Dr. Lucas Vu (postdoctoral fellow in Dr. Bowser's laboratory, BNI), who won first place, and Stephen Moore (PhD graduate student in Dr. Sattler's laboratory, BNI) and Erik Lehmkuhl (PhD graduate student in Dr. Zarnescu's laboratory, UA Tucson), who won second and third place, respectively.



Tossin' Away ALS

On Saturday, Nov. 23, the nonprofit organization Tossin' Away ALS will hold their 6th Annual Cornhole Tournament. The event registration costs \$90 per team, which also includes lunch, t-shirts, and shaved ice. There are plenty of activities for the whole family, even for those who do not play in the tournament, including food trucks, raffle prizes, music, tailgate games, and more! The funds raised from this event goes towards helping ALS patients and their families create memories and enjoy fun experiences together. In the past, Tossin' Away ALS has been able to help families go to amusement parks, attend sporting events, and even visit out-of-state family and friends.

Please visit the Tossin' Away ALS website to learn more about the event and to register: www.tossinawayals.com/



6th Annual Cornhole Tournament

Location:
178 E Commonwealth Ave.
Chandler, AZ 85225

Time:
9am-12pm

In Your Face ALS Pie Challenge

Watch Dr. Ladha and Fulton ALS Center staff get pied in the face for the ALS Association's In Your Face ALS Pie Challenge!

Link:

bar.rw/piechallenge

Find Us On Facebook!

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

Find us at:

[Gregory W Fulton ALS Center](#)



Tips for a Patient Considering ALS Research

Mary Dilts, who has been a part of multiple ALS clinical trials at the Fulton Center, gave a few of her tips for patients considering participating in research:

- 1** Remember that **if you have been diagnosed less than two years**, you have access to more trials than others.
- 2** Read all the trial information and **give it a chance**.
- 3** If you can't complete the trial, **your care with the doctor will never be affected**.
- 4** If you live a little farther away, **many trials pay for mileage**.
- 5** **Some trials have a little compensation**, not that you choose the trial for that!
- 6** **You will be under a doctor's care**, so you will be monitored a little more often.
- 7** Try and look at it as a **help for all**.

Upcoming Events

Saturday, November 2 - Walk to Defeat ALS with the ALS Association

Friday, November 22 - Passport to a Cure Gala with the Muscular Dystrophy Association

Saturday, November 23 - Tossin' Away ALS Cornhole Tournament

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

Tucson Patients, Caregivers, Family and Friends

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

Where: Our Savior's Lutheran Church, 1200 N Campbell, Tucson, AZ 85719

Tucson Caregivers

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

Where: Our Savior's Lutheran Church, 1200 N Campbell, Tucson, 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



Gregory W. Fulton
ALS Center