

The USC Aphasia Lab Newsletter

Research and Community News for People with Aphasia, Their Families and the Rehabilitation Professionals Who Work with Them



The 2023 Aphasia Community Event- A Big Success!

WRITTEN BY KATIE BEMAN &
EMILY HUCKABY



We were so excited to host our favorite event of the year back in April. We came together at Segra Park to hear from speakers, build community, and strengthen our connection with each other. Fun was had by participants, their families, and USC Aphasia Lab researchers and students. Our speaker this year was Simon Barton. Simon's presentation was entitled, "Him, That Person, and Me." It was impactful, encouraging, and full of humor!

APHASIA COMMUNITY EVENT 2023
SIMON BARTON

<https://www.youtube.com/watch?v=9mxHo10Xd0c&t=13s>

We loved having "The Slow Road to Better" podcast hosted by members of the Stroke Comeback Center in Virginia join us from afar through a recorded video. Check out some of their podcast episodes where they share stories of adapting to life after stroke or brain trauma: <https://strokecomebackcenter.org/community/our-podcast/>

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Exciting News!!

The Camino In Memory of Aaron

WRITTEN BY GEORGE COLLINS

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“Better to have a short life that is full of what you like doing than a long life in a miserable way”.

Aaron - Feb 11, 2019

Aaron died on June 11, 2022. He was 46 years old.
He had a heart attack while he was hiking the Camino de Santiago.

He started in France and ended his journey in Spain.
Camino Frances or The Way of St. James is an ancient pilgrim path that leads to Santiago de Compostela. The Camino has been the most popular Christian pilgrim route in the world for over 1000 years. People from all over the world come to hike the Camino de Santiago to reflect on their lives, challenge themselves, unplug from the world, or connect with God.

Aaron was a great friend. We had been friends for over 21 years.
He was a PA at OrthoCarolina in Charlotte, NC. Aaron wanted to hike “The Camino Frances” for at least 10 years. It all started when he saw the movie “The Way” with Martin Sheen. He dreamed about the Camino.

Aaron died on June 11, 2022 at 8:00 am - 8:30 am between Torres del Rio and Viana, Spain.

Aaron lived. Unsatisfied with simply existing, he lived. He was so kind and good. The “mayor” of Charlotte. He knew everyone. He had so many friends.
Aaron was passionate about his work as a Physician Assistant. He loved helping all of his patients. He found his work very rewarding. Aaron loved exercise. He was a marathon runner; enjoyed CrossFit and lifting weights. He loved to travel all over the USA and the world.

At his funeral, I said to Shellie, "I'm going to hike the Camino Frances in one year in memory of Aaron."

But...

I needed someone to go with me. Aphasia makes it much harder for me to take on a big trip. In addition, I don't know any Spanish, making things even harder. I was concerned whether or not I could handle the TSA, especially if there was a lot of background noise and people talking quickly. I was able to plan our schedule and figure out where we would stay, but I was worried about booking the albergues/hostels/hotels over the phone in another country!

I told my friend John all about my plans to hike the Camino for Aaron. John said, "I'll do it."

My wife Shellie encouraged me to pursue my goals and supported my quest to hike the Camino.

I exercise all the time. I ride my mountain bike about two hours a day and do weight training about three times a week. To train for the Camino, I switched to hiking about 50 to 60 miles a week and made sure to focus on elevation. John and I met up to hike in Asheville and Morrow Mountain, NC. The first day of the Camino has a total gain of 13 and half miles in elevation.

I had a year to plan, and even incorporated planning for my trip into my speech therapy goals. June 3rd finally arrived and we were hiking the Camino! Luckily, all our flights went smoothly. I loved the Camino. It was so quiet, so peaceful. The mountains are beautiful and the small medieval towns gave me the feeling I was going back in time.

In just one day, we made friends from all over the world. To name just a few, Edi (Switzerland), Monica (Spain), Yoko (Japan), Jenny (South Korea), Cari (Arizona), and Silvia (Colorado). Edi and I talked a lot. My slow pace, coupled with the fact that I don't use much slang, helped Edi, whose first language wasn't English. Many of those who I met found it much easier to talk with me! I also met Silvia on the Camino who is a Speech Therapist! That's crazy! That's the Camino. What a small world.

For eight days, John and I walked in Aaron's footsteps along the Camino. We enjoyed beautiful scenery, quiet moments in nature, connecting with new friends, indulging in Spanish food and wine, and pushing ourselves physically. On June 11th, we reached the spot where Aaron died. I had a Camino shell for him. I laid the shell over a pile of rocks stacked high. I cried. It was a powerful moment I'll never forget. I am grateful that I got to be there for Aaron to honor his memory a year after he passed.





The Camino was magical and a life changing experience. I simply cannot wait to return. I have already recruited my sister to go with me next year.



When I returned home, Aaron's wife, Amanda Hewitt shared: "Thomas and Miriam from Italy. Last June they were on their honeymoon and walked the Camino with Aaron for 4 days. They were tragically with him during his last earthly minute. In true divine intervention and full circle of life, Thomas and Miriam welcomed a baby boy on June 11th...named Aaron. Exactly one year to the date of his namesake's untimely passing, this sweet miracle enters the world. "Benvenuto piccolo Aaron. Ti vogliamo bene" *English - Welcome little Aaron. We love you.*



Change the Narrative

WRITTEN BY LESLIE CAMPBELL

Almost a year ago, I met a man who has taught me about love, patience, and mutual respect. Shawn and I met online, and within 2 days we had so much in common that we had to meet in person. When he began to tell me about his life before and after the stroke, living with aphasia, roller derby, and his love of life, I was mesmerized and smitten. As Shawn and I got to know each other, we fell head over heels in love with each other, in fact, because of his aphasia, Shawn blurted those three words out multiple times before either of us were absolutely ready to say them. He was a little embarrassed about that, but I found it endearing because his heart always spoke with sincerity.

When we moved in together a few months ago, I assumed the role as his caretaker in a way by helping Shawn keep his activities organized and keeping a journal as a timeline, it comes easy for me to help him through life, and we have always been on the same page. As Shawn and I began to melt our routines together, I began to understand his condition more and more, and I find that I am still learning new things.

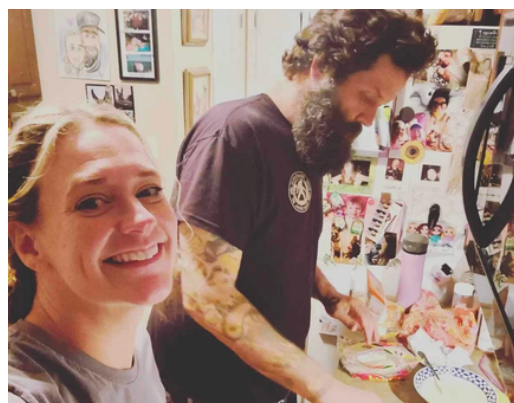
After a week of dating Shawn, I decided I would write in my journal again, something I have done my entire life to help me with understanding my innermost thoughts. One night, I told Shawn about my journal and that our relationship was the main subject in what I had written, and we decided that I would read what I wrote to him so he could relive those moments with me again. As I was reading, we started to realize that he didn't remember some of the moments as I described them, so we started to talk about each day in detail, and it helped jog his memory a little. It was that first night of reading to Shawn that I decided I would keep a timeline and continue writing every day as we grow in our relationship since it seemed to help him so much because of his aphasia. By the time we got to our first month anniversary, we had read and reread our first month's story together and the tradition had begun.



I am still writing every day, however, I changed the narrative to me talking to Shawn instead of to the journal and I make sure that I include everything I can remember in the writings so that it is honest and true to each day. I don't want the past to be jaded, so I am sure to include the imperfect days as well as the perfect ones. There have been some days where life gets in the way and I am too drained to write, but I try to not to get too far behind so that I can be sure that I don't miss anything because of my own memory.

I will also utilize my calendar and messages to help me make sure I get some of the details right. I believe that keeping this journal has helped Shawn with his memory, and as we get older, it will only help more. I am committed to continuing this tradition and will help him remember all of the days prior as we grow old together, it is a fun way to remind ourselves of how remarkable our lives are and how much love has been exchanged.

Aphasia is not who Shawn is, rather a condition he has adapted to living with. Like many other people, I had not heard of aphasia before meeting Shawn, and immediately after our first date, I began to research aphasia and I have learned a lot. I now have a better understanding of what it is like for him day by day, and I am always learning something new. I will always be open to trying new things to help make Shawn's life a little easier and we both want to spread awareness so that more people understand the gentleness and patience necessary for anyone dealing with a brain injury.



Anything But Cinderella

WRITTEN BY EMILY HUCKABY AND JAMES JETT



As part of continuing support for our Aphasia Community, the drama group, "Play on Words," put on their Spring show at the end of the Spring Semester. This group is headed by Dr. Dirk den Ouden, associate professor and researcher in the USC Aphasia Lab, alongside Peter Duffy, head of the Master's in Theatre Arts program at USC. The purpose of this drama group is to provide individuals with Aphasia a space to playfully work on strengthening their language and communication skills in a lot of different ways.

This year the show was titled "Anything But Cinderella," and was a comedy show where each individual with aphasia had a chance to tell their personal story. Telling the story of Cinderella is frequently used in Aphasia research. So, the play poked fun at no one wanting to tell the Cinderella story, while all the while actually telling the story of Cinderella. When asked what he wanted people to know about the play, one of the drama club participants, James Jett, said, "This is the second play for the Theater Play. The Aphasia Drama Club can help the brain get better for standing/sitting/walking/running and play the words. Each person had a story on the play: Cinderella (Buffy), Three Little Pig and Bad Woof (Woody), Casa Blanca (Marcus), James Bond (Van), The Prince (Charles) and Star Wars (James). In the fall we should be back rehearsal start again playing for the new theater play."

James also mentioned that his favorite part is "The Favorite part is atmosphere with all the friends and having fun." Inside Carolina followed the drama group and put together a story and video about the play and the participants' experience. A link to that video can be found by following this link:

https://youtu.be/-IP4_YaLT-k?t=265

If you would like to watch the show, a video of "Anything But Cinderella" can be found on Youtube by following this link:

<https://youtu.be/Fj4v54AcE5U>

For more info reach out to
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Gillian



Melanie



Welcome New Lab Members!

Miya



Gillian, Melanie, Miya, and Danielle are all graduate students in the Speech-Language Pathology program at USC. They joined our amazing team of GA's in the Aphasia Lab this summer. Our GA's play an instrumental role in scoring our assessments for our research studies, helping with our community events, newsletter, and social media accounts.

Danielle



Shine Your Light

WRITTEN BY ALLISON CROXTON

They say a picture can say a 1,000 words. There are so many ways we can express what we find meaningful in life. Since having his stroke and retiring from his work as a physician, Steven Brantley has taken the time to explore his abilities in creative expression. His appreciation for the beauty of creation shines through in his works of art. Thank you, Steven, for being an example of how to live with graceful acceptance of what is and finding ways to focus on the Life's beauty in the midst of great challenges.



The USC Aphasia Lab

Communication Sciences and Disorders
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Exciting news!!

A new study is starting in the lab, named **HOPES!** The title of the study stands for “Health Outcomes Predict dEmentia in Stroke” and will investigate the long-term cognitive changes during aphasia recovery. HOPES aims to better understand the role of modifiable and unmodifiable risk factors that may contribute to cognitive impairment and post-stroke dementia.

We are recruiting previous POLAR participants and a loved one or caretaker for this study. The HOPES team looks forward to working with you!

Please contact Erica Swierski (ericags@email.sc.edu; 803-777-0812) if you are interested in participating.



The HOPES Team
(Erica, Allie, Natalie, Mary, and Lisa)

We hope to hear from you soon!

Care Partner Support Group

We would love your feedback on starting a caregiver/care partner support group here at USC. If you are interested, please help us by filling out the survey by clicking the link provided or by scanning the QR code. Thank you!

<https://redcap.healthsciencessc.org/surveys/?s=LA78LRYAMEMXKYYJ>

