

The UofSC Aphasia Lab Newsletter

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

A Letter from Dr. Julius Fridriksson, Director

Dear All,

This past year has been very difficult for so many and brought unprecedented challenges associated with the COVID-19 pandemic.

Although we are not out of the woods yet, it feels like things are slowly getting better as more and more people get vaccinated. As you may know, the Aphasia Lab has been closed for in-person clinical activities and research for over a year.

It is with much excitement that we will be opening back up and anticipate that persons with aphasia will be coming back to the lab starting in May. Likewise, I am pleased to share with you that our aphasia groups will start in person this summer. Although we hope to continue with our virtual aphasia group, we anticipate having our in-person aphasia groups back to pre-pandemic activities at full capacity. At the beginning of the pandemic, we were very fortunate to be able to switch from in-person groups to virtual groups and our very own, Lynsey Keator, deserves all the credit for keeping our groups going online.

In spite of all the bad news associated with COVID-19, there were some reasons to also rejoice during this past year. One very



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Stay Connected with the Lab

Website: <https://web.asph.sc.edu/aphasia/>

Facebook: <https://www.facebook.com/StrokeRecoveryProject/>

A Letter from Dr. Julius Fridriksson, Director (Cont.)

positive development was that the National Institutes of Health approved funding of the Center for the Study of Aphasia Recovery (C-STAR) for another five years. Many of you participated in our treatment studies during the past five years. Much of that work was a part of C-STAR and we have even more treatment studies starting soon as a part of this project. For example, next month we will be starting a new treatment study that compares the effectiveness of in-person aphasia therapy to online therapy. Of course, our studies only work if we can find enough people like you to participate. As always, our aphasia treatments are free-of-charge and you can contact Dr. Leigh Ann Spell (see next article) if you are interested in participating. During the past five years of the C-STAR project, we were able to learn a lot about aphasia therapy. As you know, aphasia varies a lot from one person to the next with regard to severity and symptoms. As a result of our research in C-STAR, we now understand better what kinds of aphasia therapy work best for individuals with different kinds of aphasia. We also have a much better idea about who is most likely to benefit from aphasia therapy and what we can expect with regard to treatment response. These kinds of results help speech-language pathologists better tailor their treatments to maximize aphasia recovery for each individual. We are working to share these results among the clinical community so it can benefit as many individuals with aphasia as possible. Again, without your involvement and commitment to our studies, none of this would be possible.

It is with much gratitude that I thank you all for participating in our research and I hope to see as many of you as possible now that we are opening the Aphasia Lab back up!

Sincerely,
Julius

We are Starting a New Clinical Treatment Study this Summer!

Dr. Leigh Ann Spell, Associate Director



We are excited that our Center for the Study of Aphasia Recovery (C-STAR) grant was renewed for another five years. We will start enrolling participants in this new study, called **TERRA (Telerehabilitation for Aphasia)**, in May of 2021. The study will include 6 weeks of daily speech-language treatment. Participants will be randomized to receive treatment either in-person or online. All baseline and follow-up assessments (including MRI scans) will be completed in-person, in

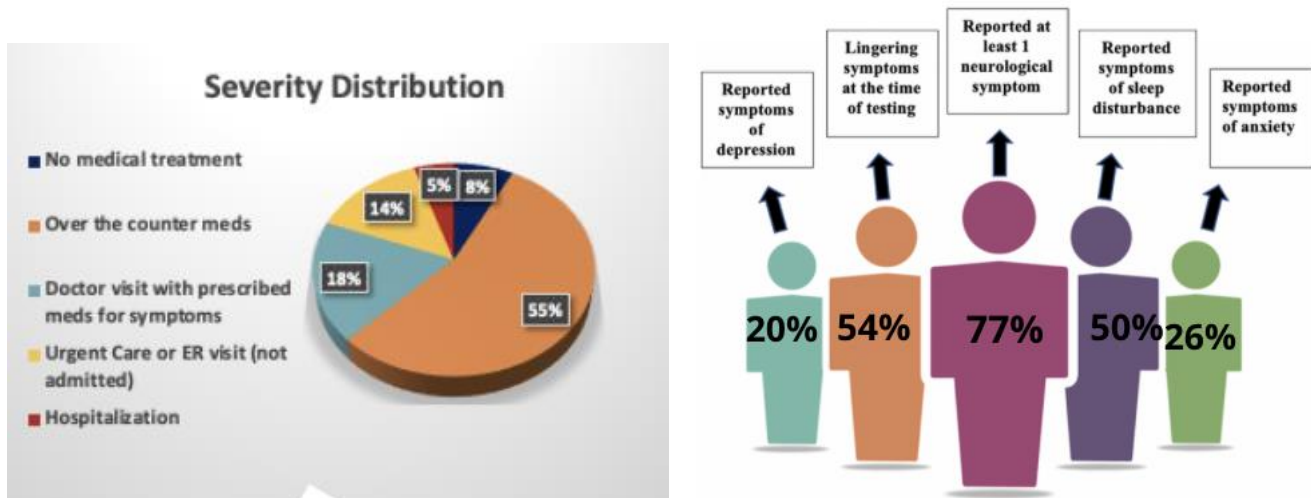
A COVID risk mitigation plan is in place to protect all participants coming to the UofSC Aphasia Lab and the McCausland Center for Brain Imaging. Eligible participants will be between 21-80 years old, have sustained a left-brain stroke at least 12 months ago, use English as their primary language, be able to have an MRI brain scan, and have adequate auditory comprehension and verbal expression skills to participate in specific therapy tasks. If you or a family member with aphasia is interested in participating, please contact Dr. Leigh Ann Spell: 803-777-2693 or SpellL@mailbox.sc.edu.

Exploring the Effects of COVID-19

Aging Brain Cohort (ABC) Research Team

At the beginning of the COVID-19 pandemic, we assessed the effects of social isolation associated with COVID-19 on quality of life (QoL) in a cohort of adults ages 60-80. We were interested in the relationship between age, socioeconomic status, physical activity, physical health, mental health, and isolation-induced changes in QoL. A total of 62 participants from our Aging Brain Cohort (ABC@UofSC) completed a series of questionnaires similar to what they completed previously before the pandemic. The isolation period was during the ‘shelter-in-place’ order issued for the state of South Carolina. In total, 51 participants (82%) experienced decreases in QoL, while only 11 participants (18%) showed an increase in perceived QoL. We found that individuals with higher scores at baseline (more physically active and better QoL) experienced greater decreases in QoL. QoL was correlated with participant age (higher age related to lower QoL) but was not related to socioeconomic status. Even a short bout of social isolation (1 month) can have significant effects on health and well-being, at least among older individuals. Many ways people coped was by connecting with family and friends through social media, virtual calls and meetings.

We recently completed enrollment for our study looking at the negative effects of COVID-19 on the brain, cognition, language and social-emotional health. We collected data from 120 participants who were at least 28 days recovered from COVID. The study included an online set of questionnaires, virtual testing, and an MRI scan. By this point, many of us are familiar with the common symptoms of COVID. In addition to those symptoms, our participants also reported experiencing at least 1 neurological symptom (77%), lingering symptoms at the time of testing (54%), sleep disturbances (50%), anxiety (26%), and depression (20%). Difficulty in word finding is one of the more common complaints from recovered COVID-19 patients with lingering neurological symptoms. There is still much to be explored relating to COVID-19 and the ABC research team at UofSC is excited to continue understanding the effects of the pandemic.



Connecting Through The Aphasia Ambassador Program

Marsha Ryninger, Newsletter Editorial Board Member



In the last newsletter we introduced The Aphasia Ambassador program. I think, like so many new things, one does not fully know how a new program will affect people. However, In the short time since the beginning of the Aphasia Ambassador program there have been an increase in connections, not just in our area, but from coast to coast.

Recently, a hospital Chaplain on the West Coast inquired about aphasia so that she could more effectively help stroke patients in her field of influence. When she contacted the UofSC Aphasia Lab, she was connected with Ambassadors who gave her information and insight to help direct her patients toward their recovery.

Another connection story comes from New York. We (my husband Marcus and I) had the privilege of speaking with a young man whose mom had recently had a stroke. In his words, here is his story and how he became acquainted with the Ambassadors:

"Immediately after hearing my mom's stroke would result in aphasia, I started to research the Internet. A lot of the information was pretty basic about different types of aphasia. My goal was to learn more about the treatments that result in the best outcome for aphasic patients. I came across the USC Aphasia Program and read their entire website's information. In addition to the information on the website, I found the videos posted to YouTube to be very informative (and encouraging). From there I spoke with Dr. Leigh Ann Spell to learn more about the programs available at USC. She mentioned the Ambassador program and asked if I would like to speak with one of the Ambassadors, I jumped at the opportunity. Leigh Ann connected me with Marsha and Marcus and we spoke for the first time about two weeks after my mom's stroke. At that point my family was still very emotional and in shock. Given the COVID restrictions not being able to see her at the hospital made it more difficult. Talking to Marsha and Marcus was amazing in two aspects: emotionally it helped to know that there's a support network and secondly it was encouraging to see Marcus's progress. Since our call we have kept in touch as my mom has come home and started her outpatient therapy. I'm incredibly grateful to Marsha and Marcus for their time and support through these difficult times. The Ambassador Program at USC is a great resource for patients and caretakers."

Authors note: Anyone can be an Ambassador and connect with others. If you have a story to tell and can share hope, you have helped someone.

UofSC Aphasia Lab Increases Online Presence

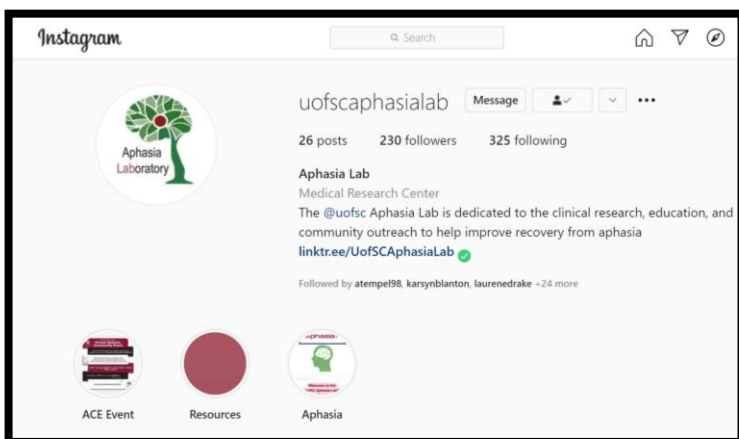
Anne Elise Nicoladis, Graduate Assistant

This spring, The UofSC Aphasia Lab created our first Instagram account and YouTube Channel, and we have been revamping our Facebook page and website. We hope to use these online platforms to reach more people with aphasia, their family members, and professionals. You can find us on Instagram by searching UofSCAphasiaLab. On Instagram, we post about our research, current events, and our participants! Most recently, we shared videos of our aphasia ambassadors. Instagram and Facebook are great places to learn about upcoming events or find interesting stories about aphasia, lab members, and participants.

There are other accounts related to aphasia on Instagram too! I recommend @SingAphasia, @AphasiaRecoveryConnection, @AphasiaIreland and @AphasiaCafe. You can find us on YouTube by searching for “UofSC Aphasia Lab.” Currently, you can watch the 2021 Virtual Aphasia Community Event (ACE), Dr. Fridriksson’s Lab Update from January, and The Aphasia Ambassador’s video. Then, head over to the C-STAR YouTube Channel to watch some performances from Play On Words: An Aphasic Drama Group and watch C-STAR lectures from world renowned aphasia researchers. We plan to continue adding to our YouTube Channel, so that you can watch any events you could not attend live and so that others with aphasia can watch videos to learn about The Aphasia Lab and what we do!

Another part of increasing our online presence is creating videos with the help of The Carolina Agency, a UofSC student-run marketing group. Did you see the fantastic promotional video for the 2021 ACE Event? The Carolina Agency helped us create that, and currently, two more videos are in the works—one general video about the Aphasia Lab and one video about our Tablet Loaner Program. Thank you to our participants who met with Lynsey Keator and me to record testimonials about the lab. To anyone who would like to be in a future video, please let Dr. Spell know.

We plan to continue to use our website and social media accounts to spread awareness about the Lab and our programs for people with aphasia. How can you help The Aphasia Lab’s Online Presence? Follow us online! Comment and Like our posts and tell us know what you think! Share our posts to your profiles! Let’s Connect!



What is an Aphasia Drama Group?

James Jett, Newsletter Editorial Board Member

One program offered through the Aphasia Lab is *Play on Words*, a drama group founded by Dr. Dirk den Ouden and Dr. Peter Duffy. Here is an interview with some of the members of *Play on Words*: **1. Before you had aphasia, did you act in any plays? If yes, tell me about it.**

James Jett— Second Grade for Elementary and I was the character for “Old King Cole” Judge with the longest lines (about 150 lines)

Woody Thompson - 1978 Home Coming Clemson Tigerama, 30,000; Drama “SuperHeros” - Va. Tech , 20 people, “Woody” Thompson - Chairman!

Dirk-Bart den Ouden, PhD - I don't have aphasia, but I did do a lot of drama in high school and college, and some directing after college. I studied in London, England, for a year, and while I was there, I played the plant in Little Shop of Horrors, a German innkeeper in a Dracula musical, and King Theseus in a Greek tragedy, among others. So, pretty varied!

Van Gullede – Yes, many years ago, high school and college

Anja Derry – I am not a person with aphasia, but prior to joining group, I had acted in a play in elementary school. I played a lead character and it was actually a really fun experience!

2. Why did you decide to join the aphasia drama group?

James - Volunteer (voluntold, LOL), but I have been very great experience and joking around.

Betsy – It will help me talk better

Buffy – Aphasia 🤔😅😂😭😭😭 Drama!!! Because you are, “JUST”

Van - I thought it would be enjoyable.

Marcus – I wanted to try something new and different. I knew that if I can't like it, I would drop out. I stayed because it was fun and the good group of people made it more fun.

3. What is your favorite thing about the aphasia drama group?

James - Having fun with the group and see all of them

Woody - Sports / Comedy

Betsy – It will help me talk better

Dirk - I like it when we crack up about some of the outrageous characters that visit us in our improvisations!

Buffy - Aphasia, Dirk, and Peter!!!!!!! I love the Drama!!!

Van – Watching the participants

Anja - I love playing the improv games because everyone has such a great sense of humor. It has been such a mood booster for me getting through grad school!

Marcus – We help each other. I think even the non-aphasia people are help. Being in drama gives me a way to express myself more freely.

If interested, please contact: Dirk-Bart den Ouden, PhD, 803-777-9241 denouden@sc.edu



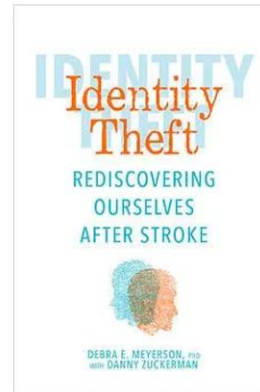
2021 Aphasia Community Event

Jane Stratton, Graduate Assistant

IDENTITY THEFT: REDISCOVERING OURSELVES AFTER STROKE



Debra Meyerson & Steve Zuckerman
Co-founders & Co-Chairs of Stroke Onward



Last March, the Aphasia Lab at the University of South Carolina held their annual Aphasia Community Event for people with aphasia, care partners, professionals and other interested individuals. Over 160 people registered for this virtual event, which consisted of a presentation by Debra Meyerson and Steve Zuckerman, a performance by *Play on Words: An Aphasic Drama Group* and exciting raffle prizes!

Debra Meyerson is the author of *Identity Theft: Rediscovering Ourselves After Stroke*, a memoir she wrote with her husband, Steve Zuckerman, and son, Danny Zuckerman, after experiencing a stroke in 2010. During the presentation, Debra and Steve discussed Debra's journey of recovery, specifically her emotional journey; how "stroke is a family illness;" Debra's experience with aphasia; the concept of identity; and the process of writing their award-winning book. Additionally, Debra and Steve spoke about founding *Stroke Onward*, a non-profit organization with the mission "to provide stroke survivors, families and caregivers with more resources to help them navigate the emotional journey to rebuild their identities and rewarding lives" (strokeonward.org).

The community event concluded with a performance by *Play on Words: An Aphasic Drama Group*, made up of people with aphasia, students, and members of the UofSC faculty. The performance was filled with lots of talent, creativity, and laughter. You can learn more about this wonderful group on page 6!

Thank you to everyone who made this event possible, including Debra Meyerson and Steve Zuckerman, *Play on Words: An Aphasic Drama Group*, the Howard family, Stroke Onward, The Carolina Agency, Constant Therapy and the Aphasia Lab community.

The recorded video of the Aphasia Community Event is available on the UofSC C-STAR website <https://cstar.sc.edu/lecture-series/> and on the C-STAR Lecture Series YouTube Channel

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What's Happening in the Aphasia Lab?

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