

Making an Impact

SD RESEARCH UPDATE

From My Perspective: Phyllis Lachowyn



Phyllis Lachowyn shared her experience of participating in this research study. She has had SD for twelve years. I flew from Cleveland, OH, to Minneapolis arriving in the afternoon. After meeting Rebekah Summer and Dr. Mo Chen to fill out paperwork that evening, I participated in the program by having

an MRI of my brain. While in the MRI I was able to enjoy a view of a screen placed outside the MRI machine which showed very nice peaceful scenes. During this time Rebekah and Mo communicated with me through headphones that blocked most of the noise of the machine. During these communications I was asked to do both finger movements and speak "eeee". The team closely monitored me inquiring about my comfort while coaching me along. The 45-minutes went by pretty quickly and having the reassurance of Rebekah and Mo was comforting.

The next morning I went to a different building where the research was being done. I was placed in a comfortable recliner. There was a screen projecting images of my brain from the MRI which helped guide the researchers where to stimulate with the transcranial magnetic stimulation (TMS) coil. My muscle activity was monitored to measure my responses to different stimulations from the TMS coil placed near my head. We made measurements with the hand first. Then, Dr. George Goding inserted a thin wire through my neck into the larynx muscles. Once that wire was in, I was stimulated by the TMS coil again in a different spot on my head. It felt like a rubber band gently snapping me. It did NOT hurt! Dr. Kimberley (*pictured above with Phyllis*) and Mo took turns running the coil over different areas of my head.

At times there was much chatter from the staff about the reactions of the screen. Other times, there was no reaction. When the procedure was complete Dr. Kimberley told me that they did get some good data from the experiment, so I felt gratified by that. I do feel that this program will be very useful in furthering knowledge about SD. The staff involved in this research were very professional and caring.

The NSDA-funded project, "Pathophysiology of Spasmodic Dysphonia (SD)" being carried out by Teresa Jacobson Kimberley, PhD, PT and her team at the University of Minnesota is nearing completion. Data have been collected on over 30 people with SD and healthy control participants. Dr. Kimberley's study is investigating how the brain areas involved in vocalization are connected to one another, with the rest of the brain, and how those connections are different in people with SD vs. people without. "We know that people with SD have differences in how their brain works to generate movement of laryngeal muscles, but we don't yet know exactly how it is different from healthy people. This study is an important first step to using new imaging technology to help us understand how the connections are different" explains Dr. Kimberley. Understanding differences may lead to treatments that will modify brain connections and result in symptom improvement.

The Minnesota area SD community has been very supportive of the study, but in addition, numerous people have traveled far distances to volunteer. "I was excited about the opportunity to participate in this study, and happy that it's taking place close enough geographically for me to travel to take part in it. Up until now, I'd assumed the only way for me to contribute to SD research was to donate my brain after I die. But not so! The two sessions for this study (the scanning and the TMS) were fascinating. It reinforced for me the neurological nature of SD. It's gratifying to see the efforts of talented neuroscientists to understand the complexity of this condition. I'd encourage anyone who wants to move knowledge and treatment forward (and at the same time to get an inside glimpse into how this research is conducted) to volunteer. It was intriguing!" states study participant Jane Voglewede of North Dakota.

Importantly, the NSDA investment in this research allowed the collection of essential preliminary data that was used to submit a request for a grant from the National Institutes of Health. The grant is still in the review process, and awaiting notification at the time of publication.