

## My Clinical Study Experience with Focused Ultrasound

By Gregg Ley

I've have lived my whole life in a small town in Georgia. My wife Cathy and I have two grown children, Rachel and Thomas, and four grandchildren, Zack, Cody, Kinsey and Austin. I'm 58 years old. I make my living fixing TVs, radios, stereos and other home electronics. My brother, Billy, is my partner in the business. Our grandfather started the radio repair business in the 1930s when radios first came out. He took a correspondence course and opened the repair shop in his country store. My dad took over the business when he got out of the signal corps in 1946.

I have a condition called “essential tremor.” It makes my hands shake like Parkinson's disease. I couldn't write, I couldn't solder wires, I couldn't even drink a glass of tea because my hands shook so badly. My right hand was the worst and that was the problem because I'm right-handed. I'm a people person, but I couldn't be me. I didn't want to be around people because they were always asking me what's wrong. Fighting this thing all day just left me exhausted, so I was no use to anybody when I got home. It's hard when you lose the ability to do what you've always done.

I met Dr. Ryder Gwinn and his team when I was literally the last person accepted into the essential tremor study at the Swedish Medical Center in Seattle. Dr. Gwinn and his team convinced the team at INSIGHTEC (who invented the technology) to let me be the last patient because they had already told me they would do the procedure.

It was a miracle that I found out about the study at all. My wife Cathy is a beautician. Janie, one of her clients and our friend, read a book by John Grisham called “The Tumor.” The book mostly talked about using something called “focused ultrasound” to treat brain tumors, but it mentioned other conditions, including essential tremor. Janie knew my hands shook — it's a small town — so she told Cathy about it.

Cathy went online and found out about the clinical trial. We called or emailed ALL of them. Of the locations in the United States, four were full or did not reply, one said we live too far away, and one — Brigham and Women's Hospital in Boston — did put me on the list but I was number 30. Finally, Amanda at Swedish Medical Center helped get me in there. Everybody we talked to there treated me with respect and acted like they truly wanted to help me.

Dr. Gwinn explained that I would be in an MRI machine during the procedure so they could watch what was happening to my brain. I had to be fully conscious so they could talk to me and ask me to draw lines and spirals with my right hand after each treatment. They just did my right hand. They put a “halo” on my head with 1,024 ultrasound wave emitters that they could focus on a pinhead-sized spot in my brain. I was in that machine for four and a half hours.



Gregg and his wife, Cathy,  
in Seattle

After 16 treatments, my right hand was completely steady — as different as night and day. I had a one-week follow-up, so Cathy and I toured Seattle, rode the ferry, went to Bellingham, and just enjoyed my new life. I was able to sign a receipt. I know that sounds small, but it was huge to me. I hadn't been able to do that in years. The day after we flew back, I went back to work. Everyone says my whole attitude seems different.

I'm a religious man, and I thank God every day. Things just fell into place, one after the other. It's a miracle that our friend read the book and thought to tell my wife about it; one week later and it would have been too late to get into the study. It was a miracle that Dr. Gwinn and his team fought to get me into the study, and a miracle that INSIGHTEC let me in. It's a miracle the treatment worked at all. There were a lot of people praying for me. Everywhere I looked, God was involved. Even looking back now, I can't believe all of this happened to me. Dr. Gwinn didn't save my life, but he saved the life God gave me to live.

Thank you, Janie, for reading the book, Cathy for doing the research, Dr. Gwinn and your team for doing the surgery and giving me my life back, Swedish Medical Center for doing the trial at your hospital, INSIGHTEC for creating the technology, and thank you, Lord, for making everything fall into place.

*Prepared by Norman M. Goldfarb, Editor of the Journal of Clinical Research Best Practices. Contact him at 1.650.465.0119 or [ngoldfarb@firstclinical.com](mailto:ngoldfarb@firstclinical.com).*