

Getting a grip on epilepsy

By DOROTHY SCHNEIDER

dschneider@journalandcourier.com

Stephanie Tolle has spent more than a decade searching for treatment options to contain -- and hopefully eliminate -- her epileptic seizures.

Tolle, of Indianapolis, has maxed out on many medications and discovered she was not a candidate for any surgical fixes. She can't drive and even had her bike privileges taken away because of the risk of her having a seizure.

When Tolle's doctor told her about a clinical trial through Indiana University, she was a bit skeptical.

"The fact that it was a study made me a little bit nervous," Tolle admitted, but added that she got more confidence in the trial after reading about it and looking at the school's neurology background.

So last August, Tolle went in for brain surgery and had a doctor implant one of the trial devices, called an RNS System. She's already seen improvements, such as having only three seizures last month, down from her monthly average of six to eight.

Epilepsy is a chronic neurological disease that affects more than three million Americans. Dr. Martha Morrell,

RNS System: How does it work?

The RNS System is an investigational device made up of tiny wires with electrodes. It includes a programmer for the study physician and a data transmitter for patients to provide information from a neurostimulator to the study physician.

The RNS neurostimulator is implanted within the skull by a study physician. The device is powered by a battery and contains a computer chip that detects and stores a record of the brain's electrical activity.

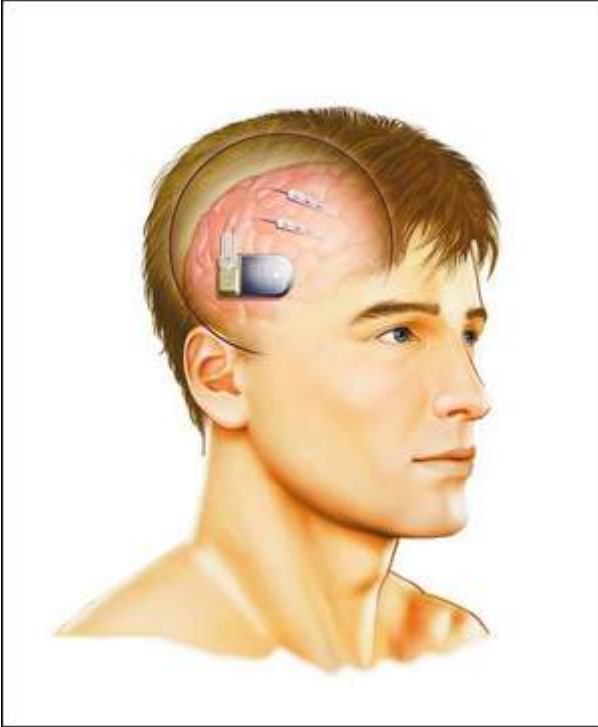
When the device identifies seizure activity, it attempts to suppress the seizure by sending electrical stimulation through the leads to a small part of the brain. The stimulation settings are selected so that stimulation cannot be felt.

This type of treatment is called responsive stimulation.

- To learn more or find out if you qualify for the clinical trial, visit www.seizurestudy.com or call (866) 904-6630.

related

- [What is epilepsy?](#)



(Illustration provided)

RNS System helps patients lower number and frequency of seizures.

chief medical officer of NeuroPace (which is sponsoring the clinical trial), said the new device offers hope to the 15 percent of epilepsy patients who can't be treated through medication or surgery.

"For these people, there just aren't any options," Morrell said.

The RNS System device detects abnormal electrical activity in the brain and then counters it by delivering small amounts of electrical stimulation. The system builds on existing technology used to treat Parkinson's disease.

Dr. Robert Worth, a professor of neurological surgery at IU's School of Medicine, said participants in the clinical trial have to make frequent clinic appointments to program the implant.

The patients also are asked to upload data from the device on to a private Internet site nearly every day. The data is then studied and adjustments are sometimes made to the implant to more effectively counter the seizures.

Tolle said her family reported she was grabbing for her face in some of the early seizures she had after the device was put in. But her doctors were able to lower the implants' output and correct it, she said.

Morrell said the results from the 122 people in the clinical trial so far are very promising.

The testing will continue for two more years and then hopefully the device will be approved by the Food and Drug Administration for general use, she said.

Tolle, who isn't even allowed to shower without supervision for fear of her safety, is optimistic about the new treatment option. She hopes to experience even fewer seizures and be able to lower her medication intake, since the drugs cause serious side effects such as periodontal disease and osteoporosis.

"I've lost a lot of my teeth from taking these medications for 15 years," Tolle said. "And at this point, the 80-year-old dad I take care of is losing his ability to drive. It would be great if I could go six months without a seizure and regain my right to drive."