Long overlooked, epilepsy resources coming to Stamford

By CHASE WRIGHT

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STAMFORD -- Epilepsy has changed the life of Sara Harris forever.

Even after multiple surgeries and a 10-hour procedure in which doctors removed a four by four millimeter portion of her brain, Harris, a 17-year-old girl with overwhelming confidence and a vibrant personality, is still having seizures.

The third most common neurological disorder in the United States, epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions.

According to the Epilepsy Foundation, seizures can last anywhere from a few seconds to several minutes and can produce a variety of symptoms including convulsions, loss of consciousness, blank staring and sudden jerking movements.

Harris has experienced them all, and while the surgery removed 95 percent of the problematic area and has helped make her seizures less pronounced, she's still unable to live the life of a normal teenage girl.

"It's been the hardest thing our family has had to endure," said her mother, Louise Harris. "No kid should have to go through what Sara has been through."

Yet many Americans do. According to the Epilepsy Foundation, more than 3 million people in the U.S. are currently living with the seizure disorder. At least 326,000 of those are children.

While the disorder adversely affects the quality of life for anyone who has it, epilepsy is often overlooked in government funding, said Linda Wallace, executive director of the Epilepsy Foundation of Connecticut. Funding from the State Department of Social Services has been continually cut from a high of $55,000 to $0 in the upcoming year. The Epilepsy Foundation of Connecticut is the only organization to provide support and social services to the more than 60,000 Connecticut residents living with epilepsy, said Wallace.

"There's no money in the budget for us next year and because of the deficit, I don't think it will come," said Wallace. She said the foundation will continue to lobby its cause in Hartford, but the money, which covers roughly 20 percent of the foundation's operating budget, will likely have to come from outside sources.

"We're just going to have to figure out a way to go on without it," she said.

Part of reason is that epilepsy often goes overlooked is because the disorder is still not a widely known, said Wallace. "It's a hidden disability," she said. "You wouldn't assume someone had epilepsy unless they told you otherwise or you witnessed them having a seizure."

The only hope for change, says Wallace, is to get people talking about their experiences with epilepsy. The foundation organizes monthly support groups in Milford, Middletown and Farmington, but due to the high concentration of epileptic patients in Fairfield County, Wallace is desperately trying to extend the foundation's reach to the Stamford area.

According to the U.S. Census Bureau, about one million, or one-third, of the state's population live in Fairfield County. At least 1 percent of those people have epilepsy, said Wallace.

"There are more people in Fairfield County who have epilepsy than in any other county in the state," she said.

The foundation has upcoming meetings with the North Eastern Regional Epilepsy Group (NEREG) so the two entities can figure out a way to provide a broader array of services to those living in the Stamford community.

The NEREG has taken steps of its own, said the executive director of Epilepsy Life Links, Ann Marie Bezuyen. The New York-based group will be opening its first Connecticut branch at 733 Summer St. in Stamford on April 1, she said. Life Links is the epilepsy advocacy extension of the NEREG and has been coordinating its efforts with the Epilepsy Foundation of Connecticut directly to bring a support group to

Stamford in the next few months, said Bezuyen.

The NEREG offers a full range of services for those with known or suspected seizure disorders, including clinical and diagnostic services, medical, surgical and dietary therapy, cognitive rehabilitation and educational support groups for patients and members of the community. NEREG will soon be bringing these services to its Stamford office, said Bezuyen.

Based on outreach to area physicians, the NEREG determined that there was a significant need for epilepsy services in the region, said Bezuyen. "We found our services would be most beneficial to residents in (the Stamford area)," she said. "I would think the services will be well received and heavily utilized by those residents."

Coming from Pound Ridge, N.Y., Louise Harris said she would much prefer utilizing services closer to home rather than having to travel to New York City or Northern Connecticut for visits to her daughter's doctors and support groups.

For Sara Harris, the distance isn't the issue; it's achieving a life of teenage normalcy. "I'm still limited to what I can do," she said.

For most teenagers, driving is considered the benchmark of their young lives. For Harris, getting behind the wheel will have to wait -- at least until her seizures stop altogether. She still has problems with mathematics and memorization, so college may have to wait as well.

"I still have a lot of goals of want to accomplish," she said. "My epilepsy has delayed a lot of them, but I won't let it stop me."