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From Epilepsy to Empowerment

Starr Phipps endured years of stigma in school due to epilepsy. A non-medication treatment reduced the number of seizures she experienced.

March 29, 2021 By Kate Ferguson

The daughter of a sharecropper, Starr Phipps was born two months prematurely with double pneumonia. Other health problems followed during her childhood, including lead and mercury poisoning, diabetes, multiple sclerosis and heart problems. Phipps believes that her mother’s exposure to the pesticide DDT during pregnancy caused these multiple illnesses. Then, at age 9, Phipps experienced her first seizure.

Unable to afford a specialist and unsure of what to do, Phipps’s parents were grateful when one of their daughter’s grade-school teachers, who had a son who suffered from seizures, offered to help. The teacher took Phipps to her son’s physician, who diagnosed her with epilepsy.

Phipps experienced seizures throughout her school years. Educators wanted to place her in special education classes, but she petitioned the court to allow her to attend regular classes. A judge ruled in her favor and with the help of a guidance counselor, she thrived. Phipps even became a cheerleader.

Many years later, in 2003, a doctor introduced Phipps, who was now an adult, to vagus nerve stimulation (VNS Therapy), a non-medication treatment designed to prevent seizures. The treatment involves implantation of a small device in the patient’s left chest area that sends mild pulses—via a thin thread-like wire that runs under the skin—to the vagus nerve at regular intervals throughout the day. The signals consist of a predetermined frequency that is intended to prevent seizures.

VNS Therapy helped Phipps gradually decrease the number of medications she took for epilepsy and become seizure-free.

Phipps, now 62, has not had a seizure in almost 15 years. She is a literacy instructor at the nonprofit Brunswick Literacy Council in Lawrenceville, Virginia, where she helped launch a support group for other people with epilepsy.

Here, she chats with Real Health about the chronic illness and its effects on her life through the years.

How has the perception of epilepsy changed since you were diagnosed with the illness?

I still see a lot of misconceptions about epilepsy, especially in the school system. I also see a lot of judgments being made about students with the condition. I was once one of those students who was misdiagnosed and misunderstood. Sometimes, it may have led to them being placed in special education when they shouldn't have been, and I still see some of that happening. Some attitudes haven't changed in a major way, which I think should have happened by now. I'm still seeing things that just shouldn't happen to a child who has epilepsy, so I don't see that very much has changed except that more awareness has been raised. But that's why I'm still out here advocating for safe schools for kids with epilepsy and the way students are handled after they experience a seizure.

What was it like for you going to school with epilepsy?

When I was not having a seizure, I could actually do my work at an accelerated rate. But it took a teacher who wouldn't let me fall between the cracks and a judge to make that decision for me. Also, I think the school system should handle kids with epilepsy the same way they would somebody who has ADHD or who are developmentally delayed. This should be the way they handle children who have other illnesses that are characterized by seizures, such as autism, or who are sometimes nonverbal.

After a seizure, my memory wasn't good, so I used a tape recorder. Back then, that was a way to help me remember information if I forgot. It's the same way that an individualized education program, or IEP, helps with speech or any function that may be affected by seizures. During a seizure, a child might fall and injure himself or even develop a physical deformity because of it, so all those things need to be taken into consideration. Assessment should not be based solely on a teacher being afraid when a child has a seizure then automatically labeling that youngster as being a danger to the other students.

Kids with epilepsy should first be evaluated by an epileptologist and other specialists—sometimes this can be a psychiatrist or a behavioral specialist—so that the child and family members can get a clear diagnosis. Then once a child gets that diagnosis, I think that child needs an IEP. For example, I tested in the 100th percentile when I was not having a seizure.

Individualized education programs are for any child who needs special education services, even those with epilepsy or ADHD.

As you got older, what was the hardest part of living with epilepsy?

I'd get the feeling that no one wanted me to be on my own. I experienced depression because of that. When I'd have a seizure, I could not manage the other illnesses I had. For example, in order for you to be well with your diabetes, you have to be able to manage it. I wasn't able to manage that or any of my other health problems because I would forget to take my medicine or would not remember whether I had taken it or not. No other issues debilitated me more than my epilepsy. When seizures happened, everything else went by the wayside.

In addition, I couldn’t take care of myself effectively. I wanted to leave home and go to college. I had aspirations of living with some normalcy, but getting a job and having a career, getting married, having a child—all those things were questionable. At that time, everybody’s hope for me was that I’d stay at home with my momma, so everyone sort of bucked me when I mentioned that those were the hopes I had for myself. My mother completely would not help me with anything. Her fear was that I would do all this and then come back home crying because nobody would accept me. She felt that the minute I would have a seizure, I’d be perceived as that weird person, that monster, and I’d come back home feeling defeated.

Of course, that didn’t happen. Plus, there wasn’t that much literature then. Now, there is so much material available. There are websites specifically about epilepsy, what it is and what treatments are available, such as VNS Therapy. Now, most states across the country are providing epilepsy-safe schools for kids. Back then, there wasn’t a lot of that going on, and there wasn’t a lot of advocacy. Now, there are support groups and meetings where your parents can go to learn about your epilepsy.

What did you learn about yourself from the experiences that you had?

My experiences taught me that I was not a weak person. I was strong. I learned about my illnesses and that if I was compliant with the treatments, I could do a lot of things that people thought I couldn’t. I also learned that I am not my epilepsy; I am a person with epilepsy, and it’s up to me whether I let that control my life. I learned that I could get married, and I could have a child. In the beginning, there was a lot of trial and error for me. But I learned that you need to do research; you need to ask questions; and you need to join groups with people who are like you. These are people who struggle with some of the same problems you have. Then you need to go back and advocate for those people who have fallen between the cracks because, once upon a time, you were going through the exact same thing they experienced. You’ve gotta go back, reach down and help pull somebody else up.

How has VNS Therapy helped you?

VNS Therapy helped me become more independent and develop a better relationship with my family members and friends. Now, they know that they can help me by swiping my device with a special magnet if I have a seizure and I am not able to do so. That was very empowering.

It also empowered me to help other people know that they can gain control of their lives. All the side effects that I was having from multiple medications stopped as we started to reduce those medicines. That led to me being able to petition the DMV for a driving permit. In the state of Virginia, you have to be seizure-free for one year.

The whole forecast of my life sort of went from gray to bright yellow. Now I think in terms of possibilities and not hopelessness. VNS Therapy helped me deal with depression and see myself as a strong, powerful person who could help other people who, like me, were suffering. It’s always empowering to be able to help someone.

What motivated you to launch a support group for people with epilepsy?

I told a friend of mine with epilepsy, who also lives in Emporia, that there were a lot of people reaching out to me for information. In this area, we’re resource deficient, so I suggested to her that we should start a support group for people so we can address some questions and issues people have about epilepsy. I said we could have people come in and speak to help individuals find the resources that they need. That’s how we started it.

The YMCA in Emporia gave us the space. Before that, the group met in my doctor’s offices. We would have meetings once a month on Mondays after 5 p.m. We would also have other special programs, like an epilepsy fair. We do that at the fire department. We have police officers come in and other people who need to learn about epilepsy and how to deal with people with epilepsy.

I have even been tasered because I had a seizure and was just lying on the ground. The police just automatically assumed I was a vagrant, or maybe an alcoholic, because when they were telling me to get up, I wasn’t able to move. A lot of police officers and fire department workers and even emergency squads are not really clear about what to do in those situations. I even wore a bracelet that said I had epilepsy, but they didn’t look at that.

A lot of times we just try to bridge the gap between the police department and emergency technicians—who sometimes will know about VNS Therapy—to educate them about the medicines and the treatments that are available now. In addition, we also educate them about things they shouldn’t do when dealing with a person with epilepsy.

Sometimes, we have doctors come in and talk about epilepsy treatments. Now, the big thing is advocating for seizure-safe schools across the country. Virginia has now voted for epilepsy-safe schools. I’m glad I was a part of that. We’re trying to get state assemblies involved in a lot of issues, such as safe housing for people with epilepsy. There is still so much to do.

One last thing to say to people is that they need to reach out and use all the resources that are available. My advice is to find out about your epilepsy and what could possibly help you have a better quality of life.