

Resident launches campaign in aid of epilepsy



By Mark Pavilons

Whitney Goulstone is full of life and energy. It's almost as if she's holding back an avalanche of joy behind her smile.

But that's something relatively new for the Kettleby resident.

Whitney got her life back and that's a claim few can make. Her life changed, literally over night, after a challenging and rare surgical procedure that virtually removed the cause of her epileptic seizures.

Today, the mother of two young children has plenty of hugs to go around. And being part of her children's lives on a daily basis is all she really needs.

Just a couple of years ago, Whitney was bed-ridden waiting for her new lease on life. Suffering from chronic epileptic seizures for all of her adult life, she hit rock bottom, literally. Going against the odds, Whitney and her husband Richard opted for the delicate surgery, performed only a handful of times.

Fortunately for the Goulstones, the days are much brighter now.

Whitney's ordeal has not only changed her physically, but also in the way she looks at life. Something as simple as spending family time with Andrew, 5, and Lillian, 3, fills her with joy. For her, seizing the day is not just a catch phrase, it's the real deal. Time is precious and there's no time like the present. Reading bed-time stories and checking under the bed for monsters actually brighten her evenings.

Whitney no longer waits for the next seizure.

But, there was a time when seizures were part of her daily routine that prevented her from accomplishing many simple tasks.

She wore a helmet when out in public and as her seizures worsened, was confined to a wheelchair and then bed-ridden.

Her epileptic seizures originated from the right perietal lobe of the brain, which, unfortunately for Whitney, is not only uncommon, but presented medical challenges. There is an abundance of studies and evidence regarding temporal lobe-based epilepsy but only anecdotal information on Whitney's condition.

Whitney underwent a craniotomy to insert a grid and electrodes into her brain to monitor the pattern of her seizures. That was in the fall of 2010. Once enough data was collected, the surgical team was ready get to work. Whitney had a lesion of mostly scar tissue, the size of a tangerine, interfering with normal brain function. While the lesion was large, the surgeon removed it bit by bit, being careful not to damage any surrounding tissue.

Given the intricacies of her case, there was a risk she could lose her vision or be partially or totally paralyzed.

For Whitney it was "blind faith," and she literally placed her life in the hands of skilled neurosurgeon, Dr. Taufik Valiante.

While physicians don't like to use the term "miracle," Whitney was just that.

Since the November 2010 surgery, Whitney's life has never been the same "thankfully."

"I got my life back," she said. One of the first things she did was walk alone, unaided, on a busy downtown Toronto street to meet a friend for coffee. She remembers feeling free and liberated. She also remembers cooking meals and going apple picking with the family as simple pleasures that were once beyond her grasp.

Whitney has definitely been challenged. There's no denying that and there's no point in burying the bad memories. They're part of who she is.

Now, she's a bit of a crusader and has taken up the cause of helping to spread awareness and raise funds for epilepsy programs. She admits she has a "real need to give back."

She just launched Whitney's Wish, a campaign aimed at helping to raise \$5 million for the Epilepsy Monitoring Unit (EMU) at Toronto Western Hospital's Krembil Neuroscience Centre.

While Canada is a world-leader in epilepsy treatment and surgery, there aren't enough funds to help everyone. There's an estimated waiting list of 18 months to two years for beds at Western's EMU alone. Whitney's Wish hopes to double, even triple, the number of beds made available to patients.

It's estimated epilepsy affects one in 100 people and is one of the most prevalent neurological disorders. Some 300,000 Canadians suffer from the disorder.

Every penny counts and Whitney is extending a challenge to everyone to contribute. If they reach their goal, "this can change the lives of so many people," she said.

She wishes a Canadian celebrity would step forward to help spread awareness and offer a "face" to the cause.

There's still a stigma surrounding epilepsy. "It can and should be talked about," Whitney observed, adding "I have nothing to be ashamed of."

She's sending out the call for an athlete or just one famous person in Canada to step forward.

In the absence of celebrity umph, Whitney is more than happy to lead the charge.

An eight-minute video that chronicles Whitney's journey is posted on YouTube ? YouTube Video:

[YouTube.com/watch?v=W6HYSceEJVI](https://www.youtube.com/watch?v=W6HYSceEJVI)

This video has made the rounds, and has even become part of the curriculum at several U.S. and UK schools.

For more on Western's EMU and Whitney's campaign, visit www.tgwhf.ca/wish. You can find out more on the topic by visiting www.epilepsyork.org.

She's more than happy to answer any questions you may have. You can contact her directly at whitneygoulstone@gmail.com.

March is Epilepsy Awareness Month, and a time to rally support for this "silent disorder." March 26 is "Purple Day," when people in countries around the world are invited to wear purple and host events in support of epilepsy awareness.

For people like Whitney Goulstone, every day is purple.