

Alexandria Times

Saving a smile

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By Derrick Perkins

Lawrence Singer first met Brittany Leap when the Botox injections no longer kept her involuntary facial spasms at bay. Afflicted with a rare neurodegenerative disorder, the 12-year-old was tearing her mouth apart.

“[Her doctors] would Botox her muscles of mastication to keep her paralyzed, all of her face muscles paralyzed, because if you didn’t then she would have a repetitive movement all the time where she bit her tongue, bit her lip, her cheek,” Singer said. “She bit it to the point where these things were bleeding and knotty hard tissues. You can think of it like a callus; if something was rubbing something else all of the time and it became raw and hard and bleeding.”

About four years ago, the dentist with practices in Alexandria and Washington welcomed the Leaps into his office. They had been referred by doctors at George Washington University, and came looking for a new way to keep Brittany from uncontrollably gnawing on herself.

She was an “awkward” child, but independent, said her mother, Sandy. Though doctors assured the family she was fine, Brittany’s parents remained suspicious. They kept asking questions and got a shocking answer in February of 2006: Brittany suffered from neurodegeneration with brain iron accumulation, a disease not widely known, one without a cure and with few treatment options.

The disorder strikes roughly one to three people out of a million, according to the NBIA Disorders Association. Symptoms generally include muscle cramping, losing control over voluntary movements and loss of speech and eyesight. Those afflicted decline in quick bursts, followed by long periods of relative stability. Within months of the diagnosis Brittany, then 11, lost the ability to walk, eat and talk.

Within a year Brittany began to gnaw on her tongue, lips and cheeks. Doctors and dentists didn’t know what to do, Sandy recalls, especially after her daughter grew resistant to the Botox.

“She would literally tear her tongue up to pieces,” Sandy said. “We went to several dentists and they said, ‘We can’t help you.’”

For Singer, a man fascinated by puzzles, Brittany’s case was a once-in-a-lifetime challenge. Standard operating procedure called for the complete removal of her teeth, but Singer couldn’t bring himself to do it. Brittany had lost so much, he said, why take her humanity?

“My main goal was to save her teeth,” he said. “A lot of times they just end up taking the teeth out totally on these people, just to solve the problem. But I couldn’t do that to what was then a 12-year-old. I couldn’t take her dignity away.”

He kept Brittany on the Botox — at first — and began working on a solution. Using equipment and materials on hand, Singer crafted a device, which looks like a pair of clear retainers for both upper and lower teeth, to keep Brittany's bite open. At the same time, the custom equipment channels her tongue forward, straight out of her mouth and safe from her teeth.

It worked, but the job wasn't over. As Brittany ages and the disorder progresses, her spasms change. The now 16-year-old is a regular at his office. She may not have a "normal" life — there is no cure on the horizon — but she will keep her smile.

She's a trooper, said Sandy, and they'll soldier on.

"Every day, we try to make the best of it," she said. "Physically, she's dependent on everything, but mentally she's all there. She understands. That's probably the toughest part. She knows exactly what's happening every day. She just turned 16 this past Saturday. We celebrate every year because we just don't know."