

EMMA: Young girl is fighting (and overcoming) obstacles every day

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highly addictive Methadone and Ativan that had been keeping her sedated for the first four months of her life.

And the medical community in Boston and Providence still had no idea what made little Emma so sick.

The following spring, Boston Children's Hospital contacted Shannon and David to offer genetic testing in an effort to determine the source of Emma's ailments. For the next year, they performed a process known as whole exome sequencing (looking at the exome at the atomic level), which is when researchers sequence all the protein-coding genes in a genome, first by selecting the subset of DNA that encodes proteins, then by sequencing the DNA itself.

The result? In 2014, Emma was diagnosed with Wiedemann Steiner Syndrome (WSS).

The Gray family had their answers. Except they didn't.

"One of the hardest things about this diagnosis is that doctors have no idea what they are dealing with," said Shannon. "We find ourselves having to explain the syndrome to them."

WSS is incredibly rare. Shannon, a teacher, and David, the captain of Engine 4 in Bristol, had to do what we all do when we need to know something about something — they Googled it.

Disease has a name — WSS

They found that WSS was originally described in 1989, and it can cause developmental delay, feeding challenges, short stature, and low muscle tone. There is no cure, though children can benefit from supportive therapies including physiotherapy, speech therapy, supplementary nutrition and special education.

The Grays also found a Facebook group which, at the time, consisted of five families with WSS children.

In the four years since Emma's diagnosis, the Facebook group has grown exponentially, with about 200 members (roughly 400 children have been diagnosed with WSS worldwide.) Families exchange information about developments and therapies, and meet at conferences. In 2015, a group of WSS moms, Shannon among them, banded together to form the WSS Foundation (www.wssfoundation.org). She also serves as the Facebook page administrator.

The Grays have learned a lot from interacting with other families; one thing is that WSS symptoms present on a spectrum and Emma seems to have been spared some of the more severe challenges faced by other WSS children. She's a very friendly, high-energy, curious little girl who only (barely) breaks from her "job" taking orders and wiping down tables at Destiny's Diner long enough to pose for a photo.

A family fundraiser — Sept. 15

"We owe a lot to them," says Shannon of Paul and Donna Diniz, who own Destiny's. They have been the driving force behind several WSS fundraisers, including the one coming up on Saturday, Sept. 15, which also happens to be International WSS Awareness Day. On that day there will be a clamboil fundraiser, organized by Shannon and crew at Destiny's for the WSS Foundation at the VFW Hall on Hope Street. There will be raffles, auctions, beverages, and plenty of clams, chowder and

clam cakes. There will also be a kid's meal option of chicken fingers and fries.

Tickets are \$30 for adults, \$10 for kids. Proceeds will go to fund research (rare diseases like WSS don't get funding by pharmaceutical companies) and a regional gathering of WSS families.

These days, Emma is getting ready to start first grade with teacher Jillian Lafazia at Colt Andrews School. Despite the past six years of countless appointments, therapies, and surgeries, Shannon and David have been told that the sky's the limit for Emma, and her developmental pediatrician says she will be able to graduate high school and go on to college, if that's what she chooses to do.

"She will do it when she's good and ready," said David.

"That's right," laughed Shannon. "She's so determined. You can't tell her she can't do something."

The Grays remain grateful to both the larger community of Bristol and the smaller community of Destiny's, which have rallied around them in support of Emma since the day she was born. "During those four months, this town embraced us in so many ways," said Shannon.

Emma is probably too young — and certainly too busy — to appreciate this sense of community the way her parents do, but another of Destiny's hard-working employees, waitress Chris Sevigny, perhaps said it best:

"Emma? She's everybody's kid."

To reserve tickets for the Sept. 15 clamboil, contact Shannon Gray at 401/837-4764 or email tchrgray14@aol.com.



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