

# It Really Does Take a Village

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*Adam Todd and Megan Monica, ages 7 and 12, have never met each other, but they are part of an extended family—the epilepsy community. Both children are being raised by parents who definitely go the extra mile—not just for them, but for many other children and parents who are trying to navigate a path in the sometimes confusing world of health care, legal rights and education. Megan’s mother, Nancy, and Adam’s parents, Dale and Sara, share their stories.*

**T**he expression “it takes a village” is part of the vernacular by now, referring to how an entire community needs to pull together to raise a child. If you have a child with epilepsy, however, those words represent much more than a societal ideal, they literally define what it takes to create a seamless structure of support around a child.

## ACCIDENTAL ADVOCATES

Dale and Sara Todd’s son Adam was diagnosed with epilepsy when he was 3 years old. Adam was enrolled in preschool and was experiencing tonic-clonic seizures. If he had one in the morning, his parents observed that he was likely to then have a cluster of seizures. His parents knew administering Diastat would prevent the clustering and get him, as his father said, “some semblance of a quality of life for the rest of the day.” However, the school administrators “did not have a good comfort level for administering the Diastat.” So either Sara or Dale would have to go to the school, involving time and travel, to administer the medication.

When Adam entered public school, his parents developed an Individual Education Plan (IEP) for him and met with the school nurse who would, essentially, change

their lives. When Sara and Dale brought up the discussion of Diastat, they touched on the protocol from the previous school and the discomfort they encountered. The school nurse, Mary Vorwerk, immediately responded, “What’s the big deal?” Dale said, “You know, guys aren’t supposed to cry, but I looked at my wife and we welled up a little bit. Our eyes got wet because it was a comfortable feeling knowing that the school nurse was willing to embrace our son.”

Dale has become a visible and tireless advocate for his son. He said, “I’m one of these folks that’s always on the side of the underdog it seems. Well, life’s strange twist is, the underdog I’m fighting for is my own kid.” He acknowledged that he and Sara did not set out to become advocates. “We found ourselves in this position because nobody else was saying what needed to be said.” He hopes “through advocacy and research we can find the reason why my son continues to have seizures.” He also described his advocacy as a form of therapy and likened the constant uncertainty of whether Adam is going to have a seizure to a “detective story that we find ourselves in every day.” He added, “You know, you don’t have a real choice in it; you have to be an advocate.” Dale is working within his state of Iowa to recruit a pediatric epileptologist for the university and he also feels that school nurses should be an important part of a district’s employee base. He said, “We’d love to see nurses at every school.”

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Sara Todd is a nurse who initially did not know much about epilepsy aside from basic neurological information. She said, “Now I know more about epilepsy than I ever hoped to know.”

She added, “We have found we really need a support crew around us. If Dale and I were just doing this alone, it would really be hard. So we’ve cultivated the school nurse, our health secretaries and the teachers and I think our advocacy for Adam is contagious. I remember his first teacher that he had for pre-K—an awesome wonderful enthusiastic teacher. She said, ‘I got to tell you that I’m a little scared.’ She said, ‘If I fail this kid, I will quit teaching.’ She started out the very first day of school saying, ‘You know what? We’re going to talk about differences. We’re all different. Suzie has a



peanut allergy, so we can't bring any food in the classroom that has peanuts in it or peanut butter." She finished by saying, "Adam has seizures. Sometimes he might fall on the ground and shake, and that's just what's going on with him."

Sara says she feels like Adam's first teacher laid the groundwork for demystifying Adam's condition. She also emphasizes the importance of assembling a team, while acknowledging that there is no precise road map for that. She and Dale have arranged for a one-on-one associate for Adam, a physical therapist and respite care. She said as a nurse she knew these kinds of services existed but never imagined she would be eligible as a recipient. She said any feelings of guilt subsided when she and Dale realized, "we just need to get out." She said, "In spite of all this, Adam's got such a good little spirit."

Mary Vorwerk, Adam Todd's school nurse, is an RN who works for the Cedar Rapids Community School District. She recognizes the importance of having school nurses in school, based on firsthand experience. She said, "It's not putting on a Band-Aid at school anymore. There are a lot of health needs coming to school that we are involved with, more so than even 12 years ago. We do a lot of planning and writing individual health plans and protocols for children so that they can have a great experience at school and come to school just like anyone else."

She finds satisfaction in her job because, she says, "I walk out of work and know that I have done something in my job today to help a student access health care." She said, "Having school nurses in the buildings is a great asset to these students with health issues." She praised the involvement of parents like Dale and Sara and said, "Adam is a wonderful little boy. He is very inquisitive; he loves to learn and read books; he loves to be at school; and has quite a few friends who know him. He is just a great addition to our school community."

Sara Todd advises reaching out to places like the Epilepsy Foundation and to doctors. She says, "I think a lack of knowledge breeds fear. More information helps dispel the fears."

## THE LUCKIEST MOM IN THE WORLD

During delivery, Nancy Monica's daughter Megan suffered a cut on her head caused by a fetal monitor. The cut later became infected with *E. coli*, causing Megan to run a fever. Her parents rushed her to the hospital and she suffered a stroke in transit from the first hospital to the pediatric ICU hospital. She fell into a coma for about 3 weeks. When she was 6 months old she started having infantile spasms and Nancy called the National Organization of Rare Disorders. They sent her a packet on epilepsy and she called them back and said, "You sent me the wrong thing. My daughter has seizures, she doesn't have epilepsy." She explained, "That's how naïve I was in the beginning. I had no idea it was epilepsy."

Nancy's naïveté has long since been replaced by a wide-ranging knowledge of epilepsy and what her rights are as a mother of a daughter with epilepsy. She uses her

expertise not only as an advocate for her own daughter; she conducts clinical outreach services—seizure clinics—for the Epilepsy Foundation in North/Central Illinois for people with epilepsy who do not have access to specialized medical care. The clinics are geared for lower income people. She connects participants with top neurologists and support groups; develops IEPs and advises them on social issues such as employment and driving.

Nancy says the first thing she needed as a parent of a newly diagnosed child was "some little piece of hope to hang onto—that there was a possibility that my daughter was going to be OK." She wrote to *Exceptional Parent* magazine and was connected with another mom. She said, "Even though she is in California and I am here in Illinois, it just gave me someone to go through it with."

They are still in touch, 12 years later.



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As part of her clinical outreach work, Nancy assists parents on developing IEPs for kids. She requests:

- Extended time for assignments.
- Tests read aloud in a quiet area.
- Unlimited time for tests.
- Graphic organizers to break down information.
- Highlighted instructions in different colors to distinguish changes in tasks.
- Use of a calculator.

She also has special recommendations for the high school students she sees at her clinics that are having seizures for the first time as they go through puberty. She counsels them to apply for their IEP a year in advance of 11th grade, whether they intend to use it or not, because the IEP needs to be in place for a full year before a student can apply for accommodations for taking college entrance exams.

Nancy calls Megan her "little miracle." She says, "I just think I am the luckiest mom in the world because to our whole family she is like the glue that holds us together."

Nancy learned the hard way how to be an advocate for her child, but she is generous with what she knows so other parents, teachers and children don't have to travel the road alone.