

## A Closer Look at Seizures: Ryan's Story

*We want to thank Ryan's mother, Shari, for sharing Ryan's story with us.*

In April 2012, Ryan was at the group home getting ready for a day program [when he had his first seizure]. This seizure lasted 90 seconds and this is what the nurse noted as his symptoms: "Pale, eyes turning to left, slumped forward, both arms trembling." He returned to baseline after the seizure. The home called it a Petit Mal seizure.

A few months later, he had another seizure. This seizure lasted 50 seconds and this is what the nurse noted: "Staring spell, slow, flushed, upper extremities became cool to the touch. Twitching of the lips. Return to activity engaged in prior to seizure."

The next one was a few months later, and lasted about 120 seconds. The nurse noted: "Violent shaking of entire body, staring spell, shallow, ashen, cyanotic, unresponsive drowsiness, return to activity engaged in prior to seizure, complaints of headache, maintained safe environment, contacted nurse, contacted Emergency Services, sent to emergency room via ambulance. Precipitating Factors: None to note. Had just finished programs and shower. The home called this one a Grand Mal seizure."

The doctor was wonderful with Ryan. She understood that he wasn't a candidate for a monthly heart monitor to "try" to catch a spell, because he would never have kept it on. She compared his EKG from one at birth and it showed a pattern where it slows down. She determined that it was the vesovegal reaction causing Ryan's blood pressure to drop and hence less oxygen was going to the brain, causing seizures.

Ryan began Keppra in October 2012. We then worked with the dosage until we found the right fit for Ryan. It was given twice a day and he had it rechecked with a neurologist a year later. It was determined to keep him at the same dosage, which seems to be working (knock on wood).

Ryan can feel a seizure coming on. He begins by taking his hands and putting his fingers together, and stares at them. His skin gets pale and mottled. He then becomes unresponsive. The trigger that I've noticed before Ryan has a seizure is that it's usually after a feeding and he has been moved either from his wheelchair to bed or to shower. The staff at the group home now feeds him after his shower instead of prior.

We learned things to do that help Ryan when a seizure starts to come on. The best thing I've found to do is to put him in bed and elevate his legs to bring his blood pressure back up (per his cardiologist). I have tried preventing the seizures a few times while visiting him. He will be





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playing with his blocks and then starts to do the finger thing. I try to stimulate him by taking his hands, kissing them, his arms and cheeks to try to get his attention and bring his blood pressure up. I've done this a few times and it has worked.

The treatment at the group home where Ryan lives and at our family home is the same. The staff monitors that he won't choke on saliva if he is frothing at the mouth and now they elevate his legs. They also talk to him and tell him that they are there with him during the seizure. I think that really helps him because I think he would be scared not knowing what is going on.

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