

Submitter: Abigail Johnson
On Behalf Of:
Committee: House Committee On Education
Measure, Appointment or Topic: HB2529
To: House Education Committee
From: Abigail Johnson
Re: Support for HB 2529

My name is Abigail Johnson and wanted to share my story about my son, Alexander, who went into cardiac arrest in our home when he was just 6 weeks old.

Alexander had been acting more tired than usual and had been asleep all morning while my husband was getting ready for work, and I was getting our 3-year-old daughter ready to leave for preschool. I needed him to eat so I woke him up and attempted to feed him, but he refused and was extremely fussy. Suddenly, he let out a blood curdling scream that I will never forget the sound of. That was the beginning of the worst morning of our lives. He started to struggle to breath and his lips turned blue. I called 911 and we counted his slow and shallow breaths for the dispatcher as she worked on getting paramedics to our home. The dispatcher then told me I was going to need to start CPR. After 7 long minutes, paramedics, firefighters, and a police officer flooded my living room and took over CPR on Alexander. They hooked him up to the defibrillator and shocked him, but nothing happened. They shocked him a second time and I heard him make a small noise. I will never forget the kind police officer who was standing next to me looked at me and simply said "that's a really good thing." He was transported to the hospital and eventually the children's hospital where, after suffering another cardiac arrest event less than 24 hours after the first, he was later diagnosed with a genetic heart condition called Catecholaminergic polymorphic ventricular tachycardia or CPVT.

CPVT is a heart rhythm disorder. In CPVT, your heart beats too quickly when you exercise or feel extremely stressed. When your heartbeat speeds up, it's harder for your heart to pump blood through your body as it should. We later learned that the shock from the defibrillator, is the only thing that was going to save my son that horrific morning.

When we finally discharged from the hospital, we were given an AED. His AED goes with him everywhere. My son has since been incident free, but even with his medication regimen, it could happen again at any time, and we always have to be ready.

As horrifying as that morning was, our family was lucky that it happened the way it did. Most often, kids with CPVT do not present with the disease until they are older and in school, and without the passage of HB 2529, there is no guarantee that

schools in Oregon would know what do in the case of a student cardiac arrest. I'm writing today asking for your support for kids like Alexander and for your support of HB 2529.