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Testimony in Support of House Concurrent Resolution 14
Going before the House Committee on Healthcare
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I support the resolution currently before the committee, which would designate March 26, 2015 as Purple Day in Oregon, in support of expanding awareness of epilepsy in our state. Epilepsy has been defined as two or more unprovoked seizures, more than 24 hours apart, but it's so much more complicated than that simple definition. Terms and conditions are always being refined, in an effort to better understand, and bring better understanding to this disease.

Until my own daughter Rachel had her first seizure, almost 12 years ago, I had never seen anyone experience a seizure, or was aware of anyone in my life who lived with epilepsy. Those first few weeks were a whirlwind of tests, doctors, medications, and many unanswered questions. Rachel is one of the 30% of epilepsy patients who do not respond well to medication, and whose seizures are considered medically refractory.

I was fortunate to have found, in those first weeks of fear, a lot of support online at the Epilepsy Foundation's parent support forums. I didn't know anybody locally that I could speak to, and there were no local support groups to whom I could turn. Understanding and support are critical to coping with a condition like epilepsy, especially when you realize that each day is its own adventure. Living with refractory epilepsy means that all events, including family gatherings, holidays, and special occasions are penciled in on the calendar. Plans change at a moment's notice, if your child or loved one has a seizure. Maybe they'll recover quickly, and you can carry on, but maybe they'll experience a more serious seizure, and you'll be taking a ride in an ambulance, and then stuck in the ER for hours.

Events like Purple Day not only validate the experiences of people with epilepsy, but give a visual opportunity to open a dialogue with folks who may not understand what epilepsy really is. I know it gives my family a big boost when we go out on Purple Day, and see other families and individuals wearing purple in support of better awareness. Creating an official Purple Day in Oregon can only widen that awareness, and create more opportunity for education about everything from first aid to proper medical treatment, and rights of the disabled in education and the workplace.

Thank you for considering this important piece of legislation, and recognizing what it means for a segment of the population that is working hard to come out of the shadows.