

EPILEPSY FOUNDATION OF
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NEWSLETTER MARCH 2017

Meet the student-leader of the Purple Day event!



Come and join **Spreading Epilepsy Awareness (SEA)**, a student run organization at the University of Virginia, for our very first Purple Day event! It will be held at the UVA [amphitheater](#) on **Sunday, March 26th from 2-4pm**. There will be great food, games, live entertainment, and crafts for people of all ages! This is meant to be a fun and engaging event where everyone can come together and raise epilepsy awareness.

UPCOMING:

Good news! The Richmond Epilepsy Support Group will begin meeting again starting April 10, 2017. The new location is the Ginter Park Library located in Richmond. Meeting time is 6:00-7:30 PM. See epilepsyva.com/calendar.

45th Annual Hans Berger Clinical Neurophysiology Symposium. The annual Hans Berger Clinical Neurophysiology Symposium brings together physicians, technologists and medical professionals for practical updates in applying state-of-the-art electrodiagnostic testing in the clinical management of patients with epilepsy and related disorders.

May 22 - 23, 2017

The Hermes A. Kontos Medical Science Building
MCV Campus of VCU



Meheret Kifle is a third-year at University of Virginia pursuing pre-medical studies. She's a valuable member of the Epilepsy Foundation of Virginia team and the founder and president of Spreading Epilepsy Awareness (SEA).

"My first encounter with a seizure was the summer before I came to UVA. I was at my aunt's house watching a movie with my sixteen year-old cousin after an active day outdoors. I remember turning to ask him a question and instead of seeing his goofy face, feeling terrified and heartbroken. I jumped out of my seat but then I couldn't move a single step. I had a million thoughts running through my head. Why is he having a seizure? Does he have epilepsy? What should I do right now? Should I touch him and comfort him? Is he even conscious? Unable to answer any of these questions I frantically yelled for his older brother. Unlike me, his brother came into the room in a calm manner and went to his seizing brother's side. My efforts with EFVA, SEA, and the UVA Adolescent Epilepsy Clinic help me use my experience as a fuel to make a difference for those impacted by epilepsy."

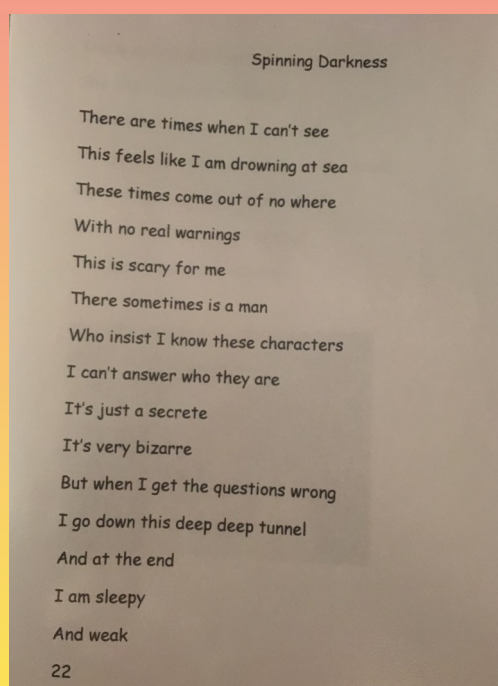
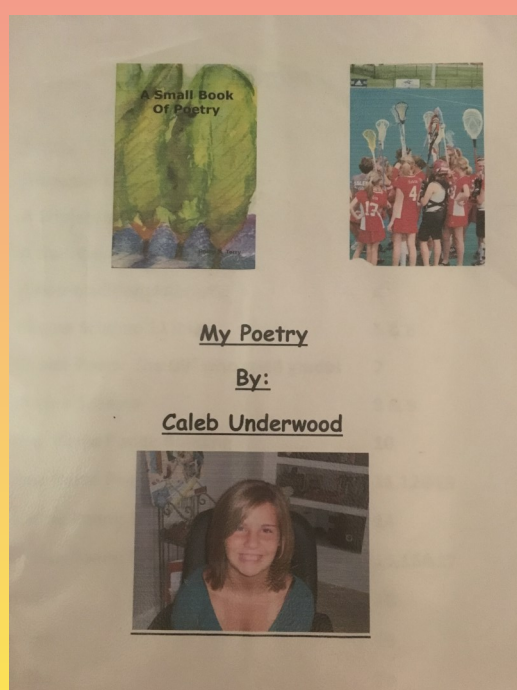


Telling Your Children You Have Epilepsy

Article by Tom McGranahan Jr. from blog "Different Brains". Visit at <http://differentbrains.com/>

Tom McGranahan Jr. was born in Richmond Va., the second oldest in a family of eight. Lives with wife Angela and 2 daughters, Mariah and Arielle. He has a Bachelor of Science in Business Administration. He was a member of Virginia State Board for People with Disabilities 6/95-6/99, and speaker at Department of Education's 3rd National Employment Conference 9/11/00. Exercises every other day at a gym and operates a residential painting business. He steadily perseveres to life's challenges – like writing this article – even after 50% of the language section of his brain was removed in his 4th brain operation.

Visit his website: <http://www.epilepsyintheopen.com/>



Caleb Underwood had epilepsy and would experience frequent seizures. For a school project in the 8th grade, she wrote a poetry book. In one poem, she writes about what she would experience right before a seizure. 14 months ago, she passed away from SUDEP. SUDEP stands for sudden unexpected death in epilepsy, and it is a fatal complication of epilepsy. SUDEP is the sudden, unexpected death of someone with epilepsy, who was otherwise healthy. In SUDEP cases, no other cause of death is found when an autopsy is done. Each year, more than 1 out of 1,000 people with epilepsy die from SUDEP. If seizures are uncontrolled, the risk of SUDEP increases to more than 1 out of 150. These sudden deaths are rare in children, but are the leading cause of death in young adults with uncontrolled seizures.

Until further answers are available, the best way to prevent SUDEP is to lower your risk by controlling seizures. For most people living with epilepsy today, the disease can be controlled with available therapies and good seizure-management practices including the support of an epilepsy specialist. And for people with the most severe types of difficult to control epilepsy, there are steps an individual can take to lower one's risk. These include taking medication as prescribed, limiting alcohol and leading a regular life.

For more information, visit <http://www.epilepsy.com/learn/impact/mortality/sudep>



Great volunteers preparing bikeride October 14, see epilepsyva.com and scroll down .

Below are five things that are common effort.

Healthcare updates

monly confused about the health overhaul

1. The GOP bill would replace the health law's subsidies with tax credits. Not really. The GOP bill would replace the Affordable Care Act's tax credits with different tax credits.

Under the ACA, people with income above the poverty line (about \$12,000 for an individual in 2017) and under four times the poverty line (about \$47,000) who buy their own insurance are eligible for advanceable, refundable tax credits. "Advanceable" means they don't have to wait to file their taxes, so the money is available each month to pay premiums; "refundable" means credits are available even to those with incomes too low to owe federal income tax. The ACA's tax credits are based on income and the actual price of health insurance available to each individual.

The GOP bill also has advanceable, refundable tax credits. They are based on different criteria, though. The Republican tax credits would increase with age (from \$2,000 for youngest adults to \$4,000 for older adults not yet eligible for Medicare), and would gradually phase out with income (starting at \$75,000 for individuals and \$150,000 for families). They would not vary by geographic region or the cost of coverage. And while older adults would get credits twice as large as younger adults, another change in the bill would let insurers charge those older customers' premiums that are five times as high. In the current law, the difference is 3-to-1.

There are actual subsidies in the ACA — they help people with incomes between 100 and 250 percent of poverty (\$12,060 to \$30,150 for an individual) pay their deductibles and coinsurance or copays. These subsidies are the subject of an [ongoing lawsuit](#) filed by the House against the Obama administration. Those subsidies would be repealed under the GOP bill.

2. The provisions of the health law that allow adult children to stay on their parents' health plans until they turn 26 and that prohibit insurers from rejecting or charging more to people with preexisting health conditions remain in the GOP bill. But even if Republicans had wanted to get rid of those provisions, they likely could not. That's because [the budget rules](#) Congress is using to avert a filibuster in the Senate forbid them from repealing much of the ACA that does not affect government spending.

3. This bill is one part of a three-part effort to remake the health law. This is true; Republicans continually refer to their health care effort as having three "buckets." One is the budget bill currently under consideration. A second is the power of [Health and Human Services Secretary Tom Price](#) to make administrative changes that would undermine the ACA. The third is follow-up legislation that would allow things like selling insurance across state lines and limiting damages in medical malpractice lawsuits. House Speaker Paul Ryan (R-Wis.) referred to that in a Thursday [press conference](#) as "additional legislation that we feel is important and necessary to give us a truly competitive health care marketplace."

The second and third parts are complicated. Changing federal regulations generally requires a cumbersome process of advertising the changes, soliciting comments and revising the rules. Controversial changes also can bring lawsuits and lengthy legal proceedings. In addition, any subsequent bills on the law would require 60 votes to pass the Senate because they would not be covered by the budget rules Republican are using for this first legislation. Republicans currently have a 52-48 vote majority in that chamber, and Democrats have so far been united in opposing the GOP's health changes.

4. The Affordable Care Act allowed states to expand Medicaid, whose cost is shared between the states and federal government, to everyone with incomes under 138 percent of poverty. Previously, eligibility was restricted to those in specific categories (primarily low-income pregnant women, children, seniors and those with disabilities). Because Medicaid was already a significant financial burden for states, the federal government offered to pay the entire cost for the expansion population for the first three years, eventually dropping back to 90 percent, which is still more than states get for traditionally eligible populations. The GOP bill would end new enrollment in that expanded program in 2020. It would continue to cover people who had already qualified — but since many people in Medicaid churn in and out of the program, the number of enrollees is likely to gradually decline.

But that's just the beginning of the Medicaid changes. The Republican bill would, for the first time ever, limit the amount the federal government provides to states for Medicaid spending. It would make payments based on the number of enrollees in each state and that "per-capita" cap is expected over time to shift more financial responsibility for the program to the states.