

I am an attorney, head of the WVU Alumni in Charleston and life-long West Virginian at 34. I grew up in Charleston, and earned three degrees from WVU over 8.5 years in Morgantown. My family and I have performed work for Governor Justice before and during his governorship, I am on the state rehabilitation council (of which I was a product of) and I helped pass the law that provided genetic screening for my form of muscular dystrophy, Spinal Muscular Atrophy. For 25 years, sans the pandemic, we have ran a charity golf tournament that has raised money for research and treatments for my disease.

But I am first and foremost a disabled person. I accept that and view it as a privilege to work and serve my state as a productive citizen. I have Medicaid as secondary insurance to assist somewhat on my Home Healthcare Costs through WV Choice, which means I have a person coming in each day to assist in my life functions.

I am writing regarding **Evrysdi**, a oral genetic therapy for Spinal Muscular Atrophy, my disease. Spinal Muscular Atrophy, or SMA, is a disease that, at the Type I level, used to go unnoticed and often caused SIDS. My type, Type II, is one of four types, each varying greatly in the effect, but the same result: an inability to build muscle due to a mutation that doesn't allow one to create proteins to build and preserve muscle.

Previously, we had our hopes set on an invasive treatment, Spinraza, which would've required spinal fluid injections every 2-3 months, some anesthetized, and port maintenance. In November 2018, we discovered, while on the operating table, that my body was inaccessible for treatment.

Despite this traumatic revelation, we held out hope for a less-invasive, more-direct treatment. We maintained my health, lowered my workload to slow any deterioration and further atrophy, and then, during COVID, kept me away from public exposure and limited my contacts because of one word: HOPE.

Evrysdi, due to be FDA evaluated in May 2020, was that hope. This appeared to be the only form of treatment that would work for someone like me, and this hope guided our resolve during the pandemic to give ourselves an opportunity to increase my potential for a healthier life.

Evrysdi's approval process was delayed until August, but ultimately approved. I began my treatment on December 3, 2020. Now, nearly 2.5 months later, I can say my results are remarkable and life-changing. My ability to manipulate my body exponentially increases every week. I can now open a bag of chips and brush my own teeth. My body shows definition and structure that provide physical benefits in my breathing, vocalization and balance, but mental and emotional health—I fit myself more, and I now dream of a future that is no longer filled with pain and barriers, but progress and opportunity.

Not everyone's experience will be like mine. But I wanted you both to hear what this drug has done for me, my family, and my community here. Our 34-year journey to give people like me a better chance at owning their Hope has finally started, and it is in thanks to Evrysdi.

Feel free to contact me in anyway (and I am not writing in my capacity as an attorney!).

Sincerely,

Eric Arnold

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