

Hello Black-n-Blue Ball Friends!

Spring is here and while I have been enjoying the sunshine, warmer temps, and only having a quarter of my sophomore year left, I am bummed that I'm not gearing up to see your smiling faces at the Black-n-Blue Ball again this year. I can vividly remember being up on stage twelve years ago, seeing all of these new faces, smiling up at me, and I had no idea how MDA and all of you would change my life in so many ways. The Black-n-Blue Ball quickly became one of my favorite MDA events to attend because of the incredible people that I would get to see year after year, and it has become like an awesome family reunion.

My first Black-n-Blue Ball was in 2009 when I was almost 4 years old, and when I rolled into the Wisconsin Center, my first thought was WOW, this is amazing! That's also when I got my first "tattoo" and for the first time I saw a video about MDA Summer Camp. Hearing a bunch of older kids talking with Miss Jann about Summer Camp made me so excited to go when I got older, especially once I saw the horseback riding and Harley Rides. Two years later the day came for my first ever week of MDA Summer Camp, and I soon learned why it was called "the best week of the year" because it truly was.

Thanks to sponsors and donations made by all the amazing people that attend the Black-n-Blue Ball I was able to start Spinraza, the first drug to treat Spinal Muscular Atrophy (SMA), in the fall of 2017. It has truly changed my life, leading to hugs, happiness, and hope. While the COVID-19 pandemic has changed everyone's life, one of the most challenging things that I had to deal with during this time was how to get my life-changing drug. Since Spinraza is administered intrathecally, I had to go to the hospital to get my Spinraza shot. But being in the middle of the pandemic, it was becoming unsafe for me to even go to the hospital anymore. Luckily, I talked with my doctors, and found out that I could pivot from Spinraza to Evrysdi, a second new drug that had just been approved to treat SMA. I am now on Evrysdi full-time, which I take once a day through my feeding tube, and I feel stronger than ever! I am so grateful for the amazing friends of the Black-n-Blue Ball because I wouldn't be feeling so strong and healthy right now without not only one but TWO new drugs that help me be the best version of myself everyday. Thanks to Black-n-Blue Ball, my MDA friends, and especially the donors for becoming an amazing support system and helping me live longer and grow stronger.

Love you, muah!

*Reagan I Whoff*

