

# November 2021 Newsletter



## An award-winning essay

[Pediatric MS](#) isn't common, affecting just [two to ten percent](#) of people with the disease. Nevertheless, when a child or teen is diagnosed with MS, the entire family is significantly impacted. [Mr. Oscar Monkey](#) is a nonprofit organization, founded by Emily Blosberg, that supports children and their



families on their journey with MS. They host regular retreats and Zoom calls that help children and teens living with the disease, and their families, connect across the nation and world. Emily recently started a scholarship fund through Mr. Oscar Monkey, offering fifteen \$1,000 scholarships to high school seniors with MS. Applicants were asked to write an essay about their MS journey, their involvement in the MS community and their post-graduation plans. Alivia Cook is the recipient of one of these scholarships, which was sponsored by ACP.

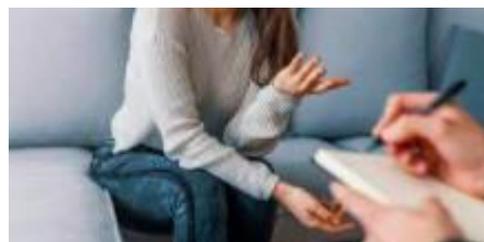
Alivia was diagnosed with MS in 2019, when she was a sophomore in high school. She had trouble with her vision for 2 weeks. In her words, "I woke up ready to start the second semester, but I could not see clearly. I had these black spots in my vision, it was as if I was looking through Swiss cheese." She went to an optometrist and an ophthalmologist, who

couldn't find anything wrong. Her mother thought it was just a migraine. However, when an MRI revealed she had lesions, she was diagnosed with clinically isolated syndrome. Six months later, the first day of her junior year, she experienced numbness in her right arm and leg and was rushed to the emergency room. She received a 5-day course of steroids and was diagnosed with MS while she was in the hospital. A month later, her neurologist started her on disease modifying therapy. According to Alivia, "When I took Gilenya my heart rate was too low and I had to spend another night in the hospital. They started me on Tecfidera about 2 weeks later and since then that's helped a lot."



At first Alivia tried to hide her diagnosis from her teachers and friends, "I tried to downplay my feelings about it, saying 'it's no big deal' or 'hey, it could be worse' because it's hard to tell the people you care so much for that you have a chronic illness. It was also hard for me to accept my new reality...In the beginning I missed a lot of school. I missed a week for my spinal tap. That was when I decided I had to be more open and honest. When I came back to school, my chemistry teacher said you don't have to tell me what happened. I just want you to know I'm here for you and I've got your back...Fortunately, I have a really good group of friends. I remember telling them about my diagnosis and one of my friends said, 'whatever it is, we can get through it together'. I think about that a lot. I know it was definitely rough on my friends but going through it with them was really good. It made it a lot better. I realized that I had a whole other community to support me. I know they'd be there to help me every step of the way."

When asked how her MS diagnosis made her feel, Alivia states, "It wasn't easy accepting my diagnosis. I think a lot of that was me pushing down my feelings about it. I felt sad for a long time because I was really confused. I had a hard time understanding what I had done wrong for this to happen. Anytime someone would ask me about it I would feel like I was about to cry. Even though I had all this outside support, my inside support system was not catching up. One of the social workers who saw me when I was in the hospital recommended that I start therapy. She said it helps a lot of children who are recently diagnosed with chronic illness to just talk it out in the first couple of months. Therapy has helped me a lot. It's



really nice to get a clear, unbiased perspective from someone who's not an immediate part of your life, like a parent or a friend. Over time it got easier and easier to talk about and one day it all just clicked and I felt a lot better. I started talking to my friends and family about my fears. Being bogged down with my thoughts about MS made me miss a lot; it removed me from the world. It was like I was hovering over everything but eventually my feet felt the ground and I took off running. I got back to school. It took me some time to catch up, but I got there. I got back into my sports, clubs and activities." Alivia shares that facing her MS diagnosis has taught her a lot about herself. "I'm more resilient than I thought I was. I've had a lot of setbacks with this and I get down about it sometimes, but I just pick myself up and brush the dirt off and I just keep going until I hit the next bump. Then I stumble a little bit and just pick myself back up and keep going."



Once Alivia came to terms with her MS diagnosis, she got to experience some of the greatest moments of her life. She received her second varsity letter in debate, went to prom with her friends, had a fantastic outdoor track season and took a memorable trip to Italy with her family and about a dozen fellow students from her school. She states, "It was really nice to have that break and immerse myself with new people and experiences." She is currently a freshman in college at Case Western University and would eventually like to go to medical school and specialize in pediatrics.

Alivia's family was also impacted by her diagnosis. In her words, "I have always had a small family, just me, my mom, and my grandparents. They were devastated at first but have been pretty strong. It was the hardest on my mom, she's a single mother and I'm her only child. We're pretty close and stuck together through it. My family is now doing everything they can to support me. My grandma comes to my doctor's appointments with me and makes her list of questions to ask the neurologist every time we go. My mom is always researching new therapies or new advancements in MS research."



Alivia didn't know any other kids with MS when she was diagnosed, but she did know three adults. In her words, "When they heard I had MS they started talking to me about

the different treatments and how MS has affected them in their lives. That was comforting to hear, but it wasn't as relevant to me because they were all diagnosed as adults." Alivia learned about Mr. Oscar Monkey about a month later. She shares, "I came home from school to find a package in the mail. It contained an orange sock monkey. I was still put off by my MS at the time. I thought, 'what did my mom do?' She was still at work, so I texted her and she sent me a link."



Alivia has attended Mr. Oscar Monkey's camps for the past two years and she periodically attends their calls. She states, "When I went to my first retreat, I wasn't at terms with my MS diagnosis and wasn't as open. I don't feel like I got as much going there as I could have if I went with a more open mind. Getting to know Emily, her family and the other children with MS allowed me to build up a community of people that I didn't know I was able to have, one that really understands what I've gone through. It gave me a new perspective on MS. The disease is so different for everyone. Everyone at Mr. Oscar Monkey refers to MS as snowflakes because we all have a different story. It's good to hear how other people experience some of the similar things you do. There was a girl who was recently diagnosed at one of the camps this summer and it was nice to talk to her because we had similar symptoms and she felt the same way I did when I was first diagnosed. It was kind of like looking at myself and I feel like I was able to help her. I also think it's been really beneficial for my mom to talk to other MS moms. She's gotten to know some that she met at the buddy bash and they're able to bounce ideas off of each other for similar problems."



When asked what she would say to a child or teen that was considering joining Mr. Oscar Monkey, Alivia replies, "I would say I was definitely hesitant at first. My mom forced me to go and it was a really good thing she did. The community that Emily has built up is truly amazing. I wish I had been more open and more involved earlier because the people you meet, Emily and her family, they care so much about each one of us. They really take the time to get to know you and make you feel supported."

They make you feel like part of their family.” According to Alivia, “MS is not something that anyone wants, it has taken a lot from me, but it also has given me much more. It has shown me a support system that spans across the country and has also brought my family and I closer and made us understand each other more. It gave me a new community to interact with, a new drive. I’m interested in going into healthcare, but I’ve also seen how Emily and the other MS kids advocate for public health and public policy specifically surrounding MS. I also think it’s given me a drive to advocate for people with chronic illnesses. Trying to find ways that I can do more for this community that has given me so much.”

The vast majority of MS research focuses on the adult MS population. Alivia states, “I think it’s important to find ways that children and youth can participate in research studies for MS. Many people say that kids can’t get MS. A lot of kids are misdiagnosed at first because the disease manifests itself so differently in children and adults. It’s necessary to be able to identify the different symptoms that children and adults might experience.” With the support of a PCORI Engagement Award, iConquerMS will be expanding enrollment to include children and teens with MS and their loved ones. Emily Blosberg is co-leading this project, lending the insight and experience she’s gained working with the children at Mr. Oscar Monkey. Through this effort, families will be able to contribute their insights, expertise, and valuable health information to shed light on many aspects of living with pediatric MS, help steer the future direction of MS research, and one day unlock the answer to a cure.

