

# March 2021 Newsletter



## Emily and Oscar's Powerful Mission

[Pediatric MS](#) isn't common. According to a [2020 literature review](#), it affects approximately 2 to 10 percent of people with the disease. Nevertheless, when a child or teen is diagnosed with MS, the entire family is significantly impacted. A minor with the disease may struggle with disability, which often takes an emotional toll and has social implications at a time when relationships are typically of utmost importance. This, in turn, affects family members as they watch their loved one cope. The vast majority of MS research focuses on the adult MS population. Further study is needed to better understand the safety and effectiveness of MS treatments in this age group, the overall impact of pediatric MS and determine the best ways to help families affected by the disease. Resilience, strength and compassion all ring true in one amazing young lady who has graciously navigated the challenges of MS as a teen. She is now following her heart and using her insight and networking skills to directly help others walking a similar path. She is also joining in ACP's efforts to expand MS research to better understand their journey.



Emily Blosberg's father was diagnosed with MS in 1998, when she was 2 years old. In the summer of 2010, when her family went on a road trip to Washington DC, Emily struggled with the heat more than her father. Her parents found that odd, but figured she just wasn't

drinking enough water. A few months later, she noticed a sensation in her right hand, like she was wearing a glove (and she wasn't) and this sensation spread to her entire body. Her skin became so sensitive that wearing clothing hurt. She experienced a number of other puzzling symptoms over the next 14 months, including loss of balance, problems with her vision, fatigue, and headaches. Emily spent much of 8<sup>th</sup> grade going to doctor's visits, physical and occupational therapy. She was diagnosed with MS in November 2011, when she was 15 years old. High school was a challenge as Emily was only able to attend half of her classes in person. However, her dad was a strong role model on how to live life with MS and not let it get in the way. She completed the rest of her classes independently in order to graduate on time with her class and recently graduated from college with a degree in Communications.

When Emily learned of her MS diagnosis, she blamed herself. She shares, "I was getting a lot of attention. People were sending me cards and gifts. I basically had my mom's undivided attention for an entire year. I was honestly enjoying it... When I started to get better, part of me wished that something would happen so I could get that attention again." Emily's support system is largely her family. In her words, "Before my diagnosis I had some very strong friends in middle school. Afterward they all sort of trickled off. I wasn't in school, they weren't seeing me very often and they all continued doing their own thing." Emily longed to meet other teenagers with MS. About a year after she was diagnosed, she learned of 4 teens with MS in Sioux Falls, SD (all going to the same doctor). Emily connected with the teens on Facebook and, in a group chat, they decided to meet for breakfast one Saturday morning. Emily and her father drove 5 hours to spend the weekend in Sioux Falls. They formed a strong bond that weekend and created a [video](#) with a powerful message, "We're regular teens, we have MS, we have this thing in common."

After this momentous weekend, Emily started searching the Internet for teenagers with MS and created a Facebook page for them to meet. She put a map on her bedroom wall. Every time she found a child or a teenager with MS, she added them to the map. She introduced any that were relatively close to each other, so they'd know there was someone else their age with MS nearby. Emily shares, "I didn't want anyone else to feel that loneliness



that I felt. I created that support for other kids because I didn't want them to feel like they had to search as hard as I did to find it. I want it to be there for them, easy to find so when they do need help, they can find it with the click of a button." This was the beginning of [Mr. Oscar Monkey](#), a nonprofit organization that supports children and their families on their journey with MS.

Emily is a long-time volunteer for the National MS Society. She states, "As long as I could hold a pom-pom in my hand, I was cheering people on at the finish line of their bike rides and walks." Emily describes herself as a very "crafty person." She loves to knit but, when she was first diagnosed with MS, the feeling of yarn running across her fingers was too painful. Still wanting to do something with her hands, she switched to making sock



monkeys and sold quite a few to raise money for the Society. One day she decided to make a sock monkey for herself out of a pair of orange hunting socks and named it Oscar. She brought Oscar to a number of Society events and eventually created another [Facebook page](#) so

people could follow what Oscar was doing. After a couple of months, her followers started asking if Oscar could visit them. In response, Emily created Oscar's Buddies to go out into the world to be a friend to anyone who requested one. Emily sent her first one in December 2015 and has sent almost 500 to families around the world since then. She encourages families to post pictures of themselves with their buddy so others can see that they are part of a community, in hopes of bringing everyone together. Emily shares, "We have some kids that bring their monkey to their doctor appointments. They tell their doctor how their monkey is feeling, which really takes the pressure off of them. They feel safer communicating that way... We've made them MRI-friendly, so they can take them into the MRI machine with them."

Emily stays in tune with the pediatric MS community and creates fellowship opportunities through Mr. Oscar Monkey that help families living with the disease connect across the nation and the world. For the past three years on President's Day weekend, families have come together at Oscar's Buddy Bash (a family camp) to share a long weekend of fun, fellowship, stories, education, and laughter. Kids with MS, parents and



siblings split into groups periodically throughout the weekend for the opportunity to ask each other questions and have relevant discussions. Emily's sister often leads the sibling discussion. In Emily's words, "Recognizing that MS affects the whole family is so important. The parents enjoy being able to get together, ask questions and share with each other. It's important for the siblings to have that connection as well. My sister often faces the guilt of being the healthy child. It helps her to be able to share that with the other siblings and have them understand what it's like to have a sister with MS... Everyone comes as strangers, but it becomes such a tight knit group." Unfortunately, the Buddy Bash was cancelled in 2021 because of the pandemic, but Emily hopes it will be an annual event in the future.



Mr. Oscar Monkey held their first Teen Camp in the summer of 2019, with 25 campers in attendance. Some of them were college-aged kids with MS that served as role models for the younger campers and answered questions about life with MS after high school. Emily shares, "This group of kids truly became a family that week." Because of the pandemic, Oscar's teen camp was [virtual](#) in 2020. Emily sent "camp in a box" to 40 campers around the world. Each box contained a Camp Quarantine 2020 t-shirt, postcards for campers to send to each other, a roll of toilet paper, a facemask, Apples to Apples cards, a small painting canvas, a tabletop cornhole game, some snacks and a tealight candle for a campfire. The group had camp over Zoom one night, played Apples to Apples virtually and painted their canvases together.

Emily holds a Zoom call twice a month for teenagers with MS or a similar diagnosis, which has been a wonderful way for campers to stay connected. She states, "We have new kids joining almost every call. We started with just our 25 campers and we now have over 50 attending." Oscar also hosts weekly calls for kids 12 and under whenever there is a need. Anyone interested can find information on how to join these calls on the Mr. Oscar Monkey [website](#). Half of the campers are high school seniors who, according to Emily, still want to be a part of the Oscar community. In response, Emily is planning a young adult retreat for when the pandemic is over to provide an opportunity for them to continue to connect with each other.



Emily's goal for 2021 is to start a scholarship fund through Mr. Oscar Monkey, offering fifteen \$1,000 scholarships to high school seniors. She explains, "Many scholarships require students to be registered for a minimum number of credits in order to be eligible...12 credits can be really hard to handle for a student with MS. We want to take that credit

requirement away. If you're registered in a class at college, that's amazing. You're continuing your education, you're working around your MS, we want to support you."

When asked what her greatest joy is with Mr. Oscar Monkey, Emily states, "Oh my gosh, everything. Every time I talk with the kids, I'm re-energized... One teenager and her family drove from MI to attend the Buddy Bash in 2019. She was 17 at the time, just diagnosed 4 months before. Her parents were excited about the opportunity to connect with other people, maybe learn a little bit. She was very bitter the whole drive there. By Saturday (the second day) her dad was in tears because he had not seen her smile since she was diagnosed in November. And she was smiling. In 2020, she and her family came back to Buddy Bash and there was a girl her age, newly diagnosed just a couple of months before with a pretty negative outlook on life. The two of them spent time together that weekend and are absolutely best friends now. Things like that motivate me... These kids are my world. I will continue to do everything I can for as long as I can. As long as there are kids that still need it, I'm not going to stop."

With the support of a PCORI Engagement Award, iConquerMS will be expanding enrollment to include children and teens with MS and their loved ones. Through this effort, families will be able to contribute valuable data to shed light on many aspects of living with pediatric MS, help steer the future direction of MS research and may one day play a role in unlocking the answer to a cure. Emily is co-leading this project with ACP's CEO, Sara Loud. In her words, "It's important to create a place that recognizes pediatric MS as a relevant part of our world and makes sure pediatric voices are heard. Recognizing that kids' needs are so different than adults with MS and exploring that more. What can be helpful and what should be done within the pediatric MS community...In my personal opinion, I think kids hold the key to curing MS. If you think about environmental triggers, the number of things a 6-year old



has been exposed is so much smaller than a 35-year old. Even just that little piece. Having research opportunities in pediatrics will benefit the entire MS community.”

In closing, Emily shares perspective gained from working with the kids at Mr. Oscar Monkey, “There’s a stigma out there and it’s a challenge that we face when trying to reach out to kids. Admitting and recognizing that they have MS is a huge challenge for a lot of our kids because they don’t want to be sick. Parents will reach out on their child’s behalf, but they’re not ready yet. It’s a lot to digest. If they get involved in something like this, they’re admitting that they have the disease.” Something to keep in mind in our recruitment efforts moving forward. When asked what advice she would give to a child or teen that is considering joining the iConquerMS community, Emily said, “I would say join



A Research Study  
**EVERYONE**  
can join!

because, first of all, you’re part of a very strong and supportive community, and also you have the potential to help so many other people.” We are grateful for Emily’s advocacy toward the pediatric MS community and her insight as we work toward including this important population in iConquerMS.