

Kids Do Get MS



My husband and I had the opportunity to go on Capitol Hill and speak to more than 30 congressional members and staff, who were gathered to learn more about a topic close to our hearts: pediatric MS. Together with the Director of Partners Pediatric MS Center and Associate Professor of Neurology at Harvard Medical School, Dr. Tanuja Chitnis, we helped shed light on a diagnosis that affects an estimated 8,000 to 10,000 children and adolescents, including our son Sean.

Sean's symptoms started when he was just 7 years old. He was dizzy, off balance, and had slurred speech. We took him to the emergency room, where - during the course of a weeklong stay in the intensive care unit - a battery of tests was performed and a diagnosis of Acute Disseminating Encephalomyelitis (ADEM) was made. I remember reading about ADEM and the mention of MS, but I never thought twice about it since we had heard that "kids don't get MS."

Sean was symptom-free for three years until we once again found ourselves at the hospital where an MRI showed lesions in his brain consistent with MS. A painful spinal tap confirmed the diagnosis... we were devastated. As a neonatal intensive care nurse, I knew very little about MS. Thankfully, the Children's Hospital of Philadelphia was getting their MS center up and running, and we were able to meet our neurologist, Dr. Amy Waldman.

Unsure how long Sean's next relapse might last, we began seriously considering what therapies were available. None of the current MS therapies are approved by the FDA for children, and of course the four medications approved for adults with MS at the time were all injectable — not exactly kid-friendly. The most difficult part was telling Sean that he was going to have a shot every week. We would do something special on injection day, like a

movie or a special dinner. He was always such a champ; he never complained. I gave the injections to him until his senior year in high school when he began using a self-injector to prepare for college. Sean's proud that he has only missed one week of medication over the last nine years. I think in his mind, as long as he takes his medicine, he will not flare and end up back in the hospital. So far so good!

Early on we went to National MS Society events, anxious to meet other parents and kids that truly understood our situation. We needed reminding that we were not alone. We heard one thing over and over from parents, "My doctor said that kids don't get MS." My hope is to squash that myth so that more money, more grants and more pediatric centers for MS can exist across the country.

Sean is a true success story and we could not be more proud. He has not been hospitalized since he started on a disease-modifying therapy and his MRIs have been stable over the last five years. He does well in school, is active as a runner, and just started his sophomore year of college focused on finance and accounting. We've been involved in Bike MS: City to Shore since his diagnosis and have raised \$80,000 to date as Team Taylor. We will ride until a cure is found. Sean even designed our team jerseys!

From the ACTRIMS-ECTRIMS research conference in Boston, to the halls of the Dirkesen Senate building, to Bike MS events, pediatric MS is coming to light. Learn more about pediatric MS in this [Momentum Magazine article](#). Or [contact your members of congress to urge support for MS research funding](#) - specify your focus on pediatric MS in your note!

Editor's Note: Patty Taylor's son, Sean, began experiencing symptoms at the age of 7 and was officially diagnosed with pediatric MS three years later. The MS movement has become a family affair for the New Jersey family; their Bike MS team has raised more than \$80,000.

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