

Accelerated Cure Project for MS

April
2018



Accelerating research towards a cure for multiple sclerosis

David Bexfield – “There is most definitely hope, never forget that.”

David Bexfield lives in Albuquerque, NM with his wife, Laura. He was diagnosed with multiple sclerosis (MS) when he was 37 years old. At the time, he was managing editor and co-owner of Nissan Sport magazine, with experience in journalism, advertising, and public relations. According to David, “I was a little bit of everything when it came to writing.” In his free time he enjoyed participating in a wide variety of sports, including tennis, basketball, baseball, soccer, and Frisbee golf. He was also an avid snowboarder, hiker and cyclist.



In the spring of 2005, Dave experienced some odd symptoms - flashes in his eyesight and tightness in his chest after exercising – and his doctors could not determine their cause. One recommended that he see a neurologist. In Dave’s words, “I did what most people do – “Uh-huh, sure,” and I went on living my life. I was feeling fine until one day in September. I was watching SportsCenter late at night ... my whole right side went numb and tingly.” David went to the ER that night and within an hour was told that he might

have MS. Once his diagnosis was confirmed in the spring of 2006, he started disease-modifying therapy (DMT), enrolled in a clinical trial and was monitored closely as part of the study. His MS symptoms were well managed for three years. In 2009 Dave's MS kicked into overdrive. He failed 3 FDA-approved therapies in just 6 months. According to Dave, "I was going downhill so fast. When you have MS you know the ups and downs and you know what downhill feels like. This downhill was a free fall. I knew it and I could feel it. Every morning I would wake up and another part of me would be lost ... I went from using the occasional cane, and I do mean occasional, to using a walker in 6 months and there was no respite. Even using the walker, I was struggling with that ... it was blindingly fast."

In 2010, Dave enrolled in HALT-MS, a hematopoietic stem cell transplant trial. In an effort to "reboot" their immune system, participants in HALT-MS received 6 days of high-dose chemotherapy, after which their own clean stem cells (collected before the



chemotherapy was given) were re-infused. The consent form for the study listed the odds of death potentially as high as 1 in 20. When asked about this risk, Dave states, "When I signed up for HALT-MS it truly was a rescue therapy for me ... All of the big guns available to me were gone, so it was stem cell transplant or bust." He underwent extensive testing and was accepted into the study by the narrowest of

margins. According to Dave, "I was almost too healthy when I applied to be in the trial. When I got in I was almost too sick." Dave participated in phase II of HALT-MS and experienced dramatic improvement in his MS symptoms. For the first 4 years after the transplant Dave's MS was quiet. In Dave's words, "The benefit started up pretty darn fast. Within a couple of months I was able to walk 700 meters unaided ... eventually my best day was a three-mile hiking day ... but, by year three and a half or four I could tell my body was starting to slow down a little bit and some numbness was starting to creep back into my feet." Today, walking without aids is once again a challenge for Dave and he uses a scooter and a wheelchair for distance. Reflecting on his experience, Dave says, "The trial saved my life. It did so many things for me. I have absolutely zero regrets going in to it. And I still feel good, it's just lately my legs have been just wiped out from underneath me."



After five and a half years of no MS medications, Dave restarted DMTs and he participated in a clinical trial testing an add-on therapy to keep his disease in check. He is also a firm believer in exercise as a form of treatment. For him, exercise and DMT have been a winning combination. When asked about his exercise regimen, “Ever since I turned 30 I’ve been working out every day pretty vigorously for an hour. Twelve to thirteen years since being diagnosed with MS, my workout routine is still pretty consistent. I take a day off each week. For the most part it’s an hour to an hour

and a half of decently heavy cardio and lots of stretching ... I do strength, upper body and lower body. I often will go to the gym, but not all the time. I’ll also do cardio, seated cardio, following exercise videos. I just modify whatever exercise video my wife is doing to make it work better for me. We often work out together. It keeps it fun for me and it’s an entertaining way to stay fit.” Dave’s exercise regimen helps him manage his MS symptoms. In his words, “If I don’t exercise for a week, the fatigue fog starts to roll in and it can get really challenging ... but, if I get in a good, hard workout it usually keeps the fatigue at bay. Exercise research has shown that is generally true. It might not work for everybody, but for many people it does, and it works for me.”

Dave and his wife love to travel. Together they’ve visited over 50 countries and crisscrossed the world. Of late Dave travels with a wheelchair and a pair of forearm crutches. When talking about their travels, he says, “It’s been really fantastic, I’ve discovered there are a lot of ways you can make travel work, even in areas that are, for the most part, inaccessible. You have to be careful and you have to plan a little bit more, but you can go to places that you thought you could never possibly go ...



My favorite destination is almost certainly the last destination I was just at, because that means I got out there and I did it and it immediately becomes near and dear to my heart.”

Dave founded [ActiveMSers](#) a few days before his MS diagnosis. According to Dave, “I knew that freight train was coming, so I said ‘let’s do this’ and I started ActiveMSers.” Dave reasoned if he was having trouble adjusting to his “new normal”, other people in a

similar situation would be, too. In his words, “When I got diagnosed I did what most people do when they find out they have some disease that has no cure yet – I hopped on the Internet and I read every single thing that was published at that time ... After losing lots of sleep and really gaining no information and getting more and more depressed, I figured there had to be a better answer out there ... I wanted something that was fun, that was optimistic, that would be motivating and inspiring and I had the toolset to do it.”



Today ActiveMSers is a community for people living with MS to share their active passions. It is designed to help, motivate and inspire those with MS to stay as active as possible—physically, intellectually and socially—regardless of physical limitations. The website offers reviews of the latest MS aids, advice on MS exercises, inspirational stories of people with MS doing extraordinary things, and many helpful tips on living with MS. ActiveMSers also hosts a web forum for people with MS to connect, a blog in which Dave writes about his experience with MS, and publishes a free newsletter. Dave also works to encourage those with MS through social media. He shares, “I’m on the typical social media channels ([Twitter](#), [Facebook](#), and [Instagram](#)). In coming weeks I’ll also be on [YouTube](#). I’ll start doing weekly, hopefully funny, little YouTube videos ... It’ll be awesome, they’ll be short and they’ll be fun.”

To date ActiveMSers has helped hundreds of thousands of people with MS from around the world by offering valuable information and uplifting encouragement. Dave’s motto is “Be active, stay fit and keep exploring,” a sentiment that he most certainly lives up to. He says, “I’ve made it my goal to practice what I preach, faithfully exercising most days—stretching, cardio, strength.” When asked what he enjoys most about ActiveMSers, Dave states, “I’ve got too many favorite parts. I love interacting with my MS friends, I love the creativity and the freedom to write what I want to write ... I like that I can just be myself.”



Dave is an active member of the [iConquerMS](#) community and serves on the Network’s Engagement Committee. In his words, “iConquerMS means that we finally have a patient voice in research and, as patients, as people with MS, we have a lot more power than we think. iConquerMS allows us to use that power and get us closer and ideally

faster to a cure for this disease.” Referring to MS research in general, “I’ve been to a lot of research conferences and the amount of research that’s been coming out with MS has been outstanding. It’s been jaw dropping ... I’m really optimistic and hopeful about the future with this disease ... I have secondary progressive, that’s a really tough time of the disease to treat. I’m excited that new treatments are coming out for that. I see new research on myelin repair. Any sort of repair treatment is encouraging and I do think there is some future in stem cell transplantation and stem cell therapy, too. I don’t necessarily think it’s the Holy Grail, but I do think it can be a valuable part of treating this disease.”

Dave has been described as living with a “stubborn defiance of MS.” He stays strong physically through exercise, and psychologically through his sense of humor. He states, “I’m funny with my friends, with my wife, with all of my MS colleagues and followers. I think humor just kind of lightens up the day and allows you to move forward with a smile on your face instead of a scowl.” With an optimistic attitude, Dave doggedly works to spread hope and inspiration to people with MS. In his words, “There’s most definitely hope, never forget that.”

