

Accelerated Cure Project for MS

March 2018



*Accelerating research towards a
cure for multiple sclerosis*

RealTalkMS – “News, Views, Interviews and Breakthroughs”

[RealTalkMS](#) is a weekly podcast well worth listening to for anyone who is affected by MS. Hosted by Jon Strum, it provides a platform to stay up-to-date on the latest information about multiple sclerosis. Jon packs a wealth of information into each 30-minute podcast. He covers a wide range of topics, from groundbreaking MS research to legislation surrounding healthcare issues. RealTalkMS also features interviews with neuroscientists, MS activists, MS caregivers and others who work to improve the quality of life for those living with MS. Two recent guests on the podcast were Dr. Robert McBurney and David Gwynne of the Accelerated Cure Project. In this [episode](#), Robert and David talk about some of ACP’s major initiatives and ways that you can be a part of MS research. In addition, the RealTalkMS website features a list of helpful [MS resources](#) for those living with MS. According to Jon, “My goal is simple – to keep our conversation going until there’s no longer a need to talk about multiple sclerosis, except in the past tense.”



Since its inception 6 months ago, RealTalkMS has gained an audience of over 2,000 listeners. Jon’s podcasts are intended to benefit people with MS, their caregivers, family members and friends, but everyone will find interesting content when they tune in. According to Jon, “I started the podcast in the beginning of October and I was hopeful that somebody would want to listen to it. I’m amazed at how fast it’s growing. I think it helps everybody understand at least a part of the MS journey a little bit better.”

Jon and his family have had a difficult journey with MS. His wife was diagnosed with secondary progressive MS in 1997. Prior to her diagnosis, she was an avid cyclist, riding her bike 40 miles every day. Within a few short years, she became a quadriplegic, no longer having the use of her arms or legs. Her MS has continued to progress, affecting her vision, cognitive abilities, her ability to swallow and even speak. In Jon's words, "What we've gone through has been incredibly difficult. I try to be involved because my hope is that maybe through the work that I and a zillion other people out there try to do every day, maybe one less family will go through what we did."

Jon has his finger on the pulse of MS research through his role as a lay member of the Scientific Steering Committee of the [International Progressive MS Alliance](#), a growing global initiative to end progressive MS. The Alliance, founded by a number of international [MS organizations](#), awarded \$15 million dollars

INTERNATIONAL
PROGRESSIVE MS ALLIANCE

CONNECT TO END PROGRESSIVE MS

in research grants in the last year to support promising MS research around the world. This level of international participation and collaboration is unprecedented and holds great promise for groundbreaking discoveries. The Scientific Steering

Committee oversees the peer review process of projects and recommends projects for funding. Jon states, "Through my participation in the Progressive MS Alliance, I'm able to hear firsthand some of the amazing research going on right now. The lay members of the committee are there to represent the interest of families that are living with progressive MS and to make sure that, when we're talking about science and research, it has a really constructive application at the end of the day... Part of the reason I started the podcast is that I'm hearing about all of the amazing science going on, information that makes me personally hopeful, and I want to share that. I thought if I could break this information down into easily understood language, a podcast might help other people living with MS feel as hopeful as I do."

Jon is an active member of the [National MS Society's MS Activist Network](#). As such, he has discussed healthcare issues that are of prime importance to the MS community with legislators and advocated for change. Earlier this month, at the [Public Policy Conference](#) in Washington, D.C., Jon spoke with elected officials from California about things like access to affordable medication and transparency in prescription medication pricing. In Jon's words, "... if not life and death, and sometimes they are, these are certainly quality of life issues that are profound." Jon's deep involvement in MS advocacy was part of his inspiration to launch RealTalkMS. According to Jon, "When living with MS so many of the things that happen to you are out of your control, but deciding that you're going to advocate on behalf of yourself and your own self interests – that's 100% within your control. And, when you exercise that power, it feels great. We use the podcast to not only provide information, but also to make listeners aware they can play an active role in advocating on their own behalf. Personally, I find that incredibly empowering. So, I would think that others would be equally empowered."



When asked what he enjoys most about his podcast, Jon states, “There’s not a part I don’t love. It’s provided me with a wonderful opportunity to meet some of the people who are leading the charge when it comes to research or activism or legislation or whatever we happen to be talking about that week. It’s put me in touch with the individuals who are the heroes of the story. I also enjoy the emails that I receive from people who seem to like what I’m doing or want to let me know that a particular episode meant something to them.”



Each year, the month of March is a time to raise awareness about multiple sclerosis, to educate more people about what life with MS can be like, and to help those that suffer from it. RealTalkMS is packed with information and inspiration for people living with MS. Its podcasts are interesting and easy to understand, a perfect resource to share this month and beyond.