

March 2020 Newsletter



Food Allergies and Flares – Do They Go Hand in Hand?

With MS, the immune system misguidedly attacks the protective coating (the myelin sheath) surrounding nerves in the brain and spinal cord. Researchers have determined that both genetics and some sort of environmental trigger play a role in MS pathogenesis. In other words, in order for MS to develop, a genetically vulnerable person must be exposed to something in their environment. Many environmental factors have been investigated over the years, including Epstein Barr virus, smoking, vitamin D deficiency and allergies (among others). There is evidence that these same environmental exposures may be the driving force behind increased MS disease activity.

An allergic reaction occurs when the body's immune system attacks a foreign substance that typically doesn't pose a threat (an [allergen](#)). This can cause many unpleasant symptoms including sneezing, watering eyes, hives or shortness of breath (to name a few). A food allergy occurs when the body's immune system sees a certain food as harmful. Regardless of the type of allergy, even the smallest amount of an allergen can cause problems.



Food allergies have been a focus of MS research for decades. One [study](#), published in 1953, found them to be a contributing factor in MS disease activity. Investigators did skin scratch tests of over 2,200 patients with MS and found the severity of disease was related to specific allergens. When the offending substances were removed, MS symptoms often improved. Data showed the majority of individuals with severe MS symptoms had food allergies. Those with moderate symptoms reacted strongly to molds and fungi and those with mild MS symptoms were sensitive to pollens and chemical substances (medications).



A [2014 study](#) concluded food allergies may play a role in MS disease progression, specifically sensitivity to wheat and dairy products. Researchers studied blood samples from 400 donors of unknown health status, comparing them to samples from people with autoimmune diseases like MS. The blood samples were exposed to proteins from wheat and dairy, as well as proteins that occur naturally in the brain. They found that when the blood samples of people with autoimmune diseases were exposed to an increase in wheat or dairy, the level of [antigens](#) to attack cells in the brain also rose, suggesting that eating wheat or dairy products could possibly increase disease activity in those with MS.

[Investigators](#) from Brigham and Women's Hospital recently confirmed the connection between food allergies and MS. Researchers assessed 1,349 individuals with MS enrolled in the [Comprehensive Longitudinal Investigation of Multiple Sclerosis \(CLIMB\) study](#). Participants completed a questionnaire about environmental, medicinal, and food allergies. Researchers also collected clinical data on each participant's disease severity, including the total number of MS relapses, EDSS scores, MS severity scores and the number of lesions present on MRI. Results showed the total number of relapses was 1.3 times higher in people with food allergies than people with no known allergies, and those with food allergies were more than twice as likely to have disease activity on MRI scans. Subjects with MS who reported food allergies also had 27 percent more flares over the course of their disease than those with no known allergies. Interestingly, data suggest environmental and medication allergies do not have the same effect and EDSS/MS severity scores are not affected by these types of allergy.



A [recent study](#) shows that diet can influence the course of inflammatory diseases in two ways. Dietary factors can directly impact the metabolic process of inflammation in cells.



What you eat can also change the mix of “good” and “bad” bacteria in the digestive tract (the [gut microbiome](#)). A healthy digestive tract is populated by a great number of microorganisms living in balance. A disruption of this balance can have a significant impact on the chronic inflammation that occurs in diseases like MS by leading to the release of chemicals that stimulate

an immune system attack on the brain and spinal cord. The fact that researchers from Brigham and Women’s Hospital connected only food allergies (and not other types of allergies) to MS disease activity supports the theory that there may be a link between gut bacteria and immune system activity in neurological diseases.

More research is needed to confirm the link between food allergies and MS disease activity, as well as determine the underlying mechanism. This important work has the potential to lead to exciting new therapeutic strategies to minimize or possibly prevent relapses in people with MS. ACP’s mission is to facilitate impactful research efforts like this that are of prime importance to the MS community.



MS Sucks: Singing For a Cure – “The entire day and night was filled with so much love...”

[Lucky Boys Confusion](#) is an American rock band from Chicago. The band consists of lead singer Kaustubh Pandav ("Stubhy"), guitarist and vocalist Adam Krier, bassist Jason



Schultejann, and drummer Ryan Fergus. Since the group formed in the late 1990's, they have recorded several albums, including [Growing Out Of It](#), [The Soapbox Spectacle](#) and, most recently, [Stormchasers](#). Stubhy and Adam write the majority of the band's songs. Music plays a big role in Stubhy's life, it is one of his greatest passions. In his words, "I was a poet before I realized I had a gift for melody. It's my release, it's my outlet, it's my go-to when everything else is failing."

At the end of 2015, Stubhy noticed he was having difficulty walking, his leg started dragging and hitching. According to him, "I figured I needed to stretch it out, but that didn't help." He underwent extensive testing and tried a number of remedies over the next two years, including chiropractors, massage and physical therapy, to no avail. Eventually, Stubhy's neurologist ordered an MRI and found lesions on his brain and spinal cord. On Black Friday 2018, Stubhy was diagnosed with MS. The timing of his diagnosis was especially difficult as his wife was three months pregnant with their first child at the time. Fortunately, he is taking an effective MS treatment and is feeling better. Stubhy shares, "MS is with me everywhere I go, but I'm doing well. All my MRIs show there's no more progression. When I found out my MS treatment was working and I didn't have any more progression, I said the only thing that could be better right now relative to my disease would be a cure."

Stubhy wanted to do something to advance MS research toward a cure and help other people living with the disease. He decided to use his musical gift toward this end and organize a charity concert. After doing extensive research into possible beneficiaries, he decided to give the proceeds of the event to ACP. In his words, "I wanted to focus on a charity that is focused on research and cures... ACP is a



patient-founded organization fully focused on raising funds for a cure.” Stubby added, “It makes getting through this a little bit better knowing that you’re doing something that does some good for people. My dad was a real big philanthropist in his own right. He was really big into charity and donations, giving of his time more than anything else. I think I just picked up on that growing up, I just didn’t have a cause until now.”



[MS Sucks: Singing for a Cure](#) was held on Saturday, December 21st at the [Bottom Lounge](#) in Chicago. The event was split into two portions, with concerts in the afternoon and evening. Over 500 people enjoyed

performances by Lucky Boys Confusion and other groups like [AM Taxi](#), [Plain White T's](#), [Scissors](#) and [Ike Reilly](#), all of whom donated their time and talents. The evening concert featured raffles for prizes like [Riot Fest](#) passes, dinners around Chicago, as well as [House of Blues](#) and Bottom Lounge tickets. The proceeds from both concerts will support ACP’s work to accelerate research in MS to improve the health, healthcare, and quality of life for those affected by MS.

The concert raised an impressive total of over \$30,000, which far exceeded expectations. For Stubby, it was successful in other ways, too. He states, “People came up to me and said they were at the show because what I brought up made them realize they probably had something going on, too. I got a couple of people to go to neurologists, I got a couple of people to join me in the fight... In the MS community, they call me an invisible. If I’m walking down the street nobody would ever look at me and say, ‘Oh, he’s really sick.’ So that’s why I think it’s so important to tell people what’s going on. I’m fortunate I have this platform I can use to help people... Accepting MS as a part of my life has been pretty hard, but this wasn’t about me. I wanted to champion this celebration to raise awareness for other survivors that have it much worse than me... I hope to do this annually so don’t fret if you didn’t make this year’s concert!” The MS Sucks team is hoping to hold the 2020 concert in November. Stay tuned!





With ACP staffer, Lindsey Santiago, at the Bottom Lounge

The concert reached the hearts of many people in the MS community. Those in attendance felt the love and support that was the spirit of the event. According to Lindsey Santiago, Development Associate at ACP, “The concert was an amazing experience. It brought together so many groups of people from musicians, fans, those affected by MS, and so many more to all support a cause that is so important to Stubby.” Jennifer Kurz, photographer at the concert shares, "The ENTIRE day and night was filled with so much LOVE... you could literally feel the energy bursting from that entire building!!! It was overwhelming. This was one of my favorite moments of this entire year. Everyone coming together, whether it be volunteering your time or donating and coming out to support, is wonderful... I'll be honest, until my friend Kaustubh was diagnosed with MS last year, I didn't know much about it, nor did I realize how many lives are affected by this awful disease. I'm so proud of him for organizing this event and using his resources to help give back to a community that has supported him. I'm more than happy to have donated my time and photography, too.”

The MS Sucks concert had a tremendous amount of support behind the scenes. Alex Zarek and, as mentioned above, Jennifer Kurz donated their talent as photographers throughout the event. Alex also made two videos for the event, including this [recap](#) of the concert. The raffle was a resounding success thanks to the efforts of Anisha Gawriluk and Sam McHale. Anisha helped to secure raffle items and both she and Sam sold raffle tickets. Sam also helped organize volunteers for the concert and assisted with logistics the day of the event. We are grateful to all who helped to make the concert as successful as it was, both named and unnamed. We'd also like to thank [Genentech](#) for their generosity as sponsor, the Bottom Lounge for providing the venue for the event, [350 Brewing Company](#) for donating refreshments and [Car Con Carne](#) Podcast for hosting the show.

Funds raised from events like these help us to continue our work to improve diagnosis, optimize treatment, and find a cure for MS. If you have a favorite activity friends and family members enjoy doing or talents you would like to share, hosting a fundraiser is a great way to reach out to your community, raise funds for ACP and have fun while doing it. For more information on hosting your own fundraiser, contact Lindsey Santiago at lsantiago@acceleratedcure.org or (781) 487-0013.



March 2020 Research Spotlight

RESEARCH OPPORTUNITIES

iConquerMS™

A Research Study
EVERYONE
can join!

Real MS™ (Research Engagement About Life with MS)

In the summer of 2016, the iConquerMS initiative launched REAL MS, a longitudinal study of MS. REAL MS participants complete questionnaires online twice each year on a variety of subjects, including health history, diet, exercise and their experience with MS. An eighth round of REAL MS surveys are now available through the iConquerMS portal. Completing these surveys is one of the simplest ways you can accelerate MS research. The information collected will play a pivotal role in helping scientists and clinicians gain a better understanding of the health and quality of life over time for people with MS. REAL MS is just one of the many ways iConquerMS is facilitating research on topics of importance to people affected by the disease. If you are not already a member, please consider [joining](#) iConquerMS, the only people-

powered research network for MS. Already a member? Please [log in to your account](#) and complete your open surveys!



UsAgainstAlzheimer's

What Matters Most: Caregiving Challenges

Study Purpose:

Living with MS takes a toll on families due to both the intensity of care and long disease progression. This study will help shed light on how caregiving affects one's health and quality of life. We've partnered with a sister organization supporting families coping with Alzheimer's disease on a survey about the challenges and concerns of providing care to a loved one with MS. We will use what we learn to create new materials to educate caregivers about best practices, and resources for caregiving and self-care.

This Study Involves:

This study involves completing an anonymous survey. We'll use these data to better inform care practices and health care provider education. Let us know your biggest challenges, what resources or services you use or wish you had. What advice would you share with other caregivers?

Study Contact Information:

If you're interested in participating in this study, you can access the survey [here](#). Thank you for helping us make life better for all caregivers and their loved ones with MS!



New Year, New You

Study Title: Step for MS (Supervised versus Telerehab Exercise Program for People with Multiple Sclerosis)

Study Purpose:

New research shows that exercise is good for people with MS and may decrease symptoms and improve health and walking ability. An exercise study called *STEP for MS* will compare the outcomes of a 16-week exercise program conducted at home to a program conducted in a gym. The researchers conducting the study hope that the findings will make exercise and its benefits more available to people with MS who have problems walking.

This Study Involves:

Participants will exercise two times per week for about one hour each session for 16 weeks. A trained “coach” will help participants learn how to exercise and will provide encouragement throughout the program. Participants will take assessments before starting the program, two months into the program, at 16-weeks when the program ends, and at 6 and 12 months after starting the program.

Eligibility:

If you are between the ages of 18 and 65 years and you have Multiple Sclerosis you may qualify if you:

- Can **walk** but you have **some difficulty**, with or without a device
- **Do not exercise** regularly
- Have not had a **relapse** in the past month
- Can commit to **train 2 times a week for 16 weeks**
- Can **drive to study site** for assessments and potentially for exercise training

- Have reliable **internet access**

Participating Locations:

- Massachusetts General Hospital, Boston, MA (new site for the New Year!)
Contact: Dr. Plumer 617-724-3103/ PPlummer@MGHIHP.EDU
- Shepherd Center, Atlanta, GA
Contact: Erica Sutton at 404-367-1305
- Cleveland Clinic, Mellen Center, Cleveland, OH
Contact: Darlene Stough at 216-445-5877/ stoughd@ccf.org
- University of Colorado, Denver
Contact: Alexa Vareldzis: neurologyresearchpartners@cuanschutz.edu / 303-724-4644
- University of Alabama, Birmingham
Contact: Petra Silic at 205-975-1306/ petra09@uab.edu
- University of Georgia, Athens
Contact: Megan Ware at 423-260-5045/ megan.ware20@uga.edu
- Marquette University, Milwaukee, WI
Contact: Heidi Feuling at 414-288-6209/ Heidi.feuling@marquette.edu
- University of North Carolina, Chapel Hill
Contact: Rachel Keen at 704-877-5636/ rayray@live.unc.edu

For more information, please visit our

website: <https://www.iconquerms.org/welcome-step-ms>



A Study to Help Improve MS Clinical Trials

Study Purpose:

A pharmaceutical company (Sponsor) is conducting patient interviews with MS pediatric patients (10 - 17 years old) and their caregivers. The Sponsor will use the information collected during these interviews to improve the overall experience in clinical trials for MS pediatric patients and their caregivers.

This Study Involves:

These interviews will last at most 1 hour and will be conducted by an independent healthcare communications company, AXON Clinical Trial Services (AXON), on behalf of the Sponsor. AXON will share the information provided during the interviews with the Sponsor in an anonymized manner. This means that it will not include the name or any other personal information that could be used to identify the participants. The information provided will be used to write a report. During the interviews, MS patients and caregivers will be asked about what it is like to live with MS and about their perceptions of clinical trials. Participants will be compensated.

Study Contact Information:

If you're interested in participating in this study, please email MSPeds@axon.com, or call (416) 848-1464.