

November 2020 Newsletter



Volunteers don't necessarily have the time, they just have the heart

- Elizabeth Andrew

Volunteers make a huge difference in ACP's ability to accelerate and advance MS research. We are grateful for hundreds of donated hours that support our work each year. This year has been filled with uncertainty and new hurdles to overcome, but our volunteers have risen to the challenge and found safe ways to help us with a wide variety of important tasks. Some have hosted fundraising events to raise money that enables the work that we do. Others are a tremendous help with administrative tasks and other projects. We are very grateful for these remarkable individuals who have freely given of their time and talents!

Volunteers



*They don't necessarily have the time;
they just have the heart.
Thank You!*

Kemp Jaycox has been living with MS since 2003. Each year, he organizes an annual walk to support ACP. Neighbors, family members and friends have gathered to participate in these walks in many beautiful places, such as Yellowstone National Park and the Canadian Rockies. On Saturday, October 10th, Kemp and his family raised over \$7,600 for ACP as they enjoyed a beautiful autumn day together walking through Rocky River Reservation, a local Metro Park in Cleveland. In Kemp's words, "The leaves were just beginning to



Kemp and his wife, Cindy Fink

change colors so the backdrop was really pretty. It was nice to see so many people using the park including cyclists, walkers, people picnicking and even fly fishing in Rocky River. Nature is a great antidote when the country is in the middle of a pandemic and political and social unrest during a presidential election year.” When asked what inspires him to raise funds on ACP’s behalf, Kemp responded, “I have always been drawn to the ACP for their focus on facilitating research. MS is a terrible disease that strikes most people in the prime of their lives. From my perspective, neurological diseases such as MS don’t get the attention and share of research dollars that other high-priority causes do, such as

cancer and heart disease. Therefore, I believe private individuals can step up to contribute financially to facilitate much-needed research... I am incredibly grateful for my family, friends and neighbors who support my walk! I am truly blessed to have a wonderful support network. This is my way of paying it forward to other people who suffer from MS and hopefully one day will benefit from research breakthroughs facilitated by the ACP and other valuable organizations.”

Marion Leeds Carroll is an experienced opera singer and stage director from Arlington, MA. She has lived with MS since 1988. As her MS symptoms grew, Marion began limiting her performances, concentrating

instead on directing and organizing concerts. Every year in October, Marion and a group of colleagues perform a concert to benefit ACP, featuring solo instruments, chamber-music ensembles and singers who perform a diverse repertoire of classical music. To keep everyone healthy and safe, this year’s concert is virtual, featuring [16 performers](#). Marion is one of the performers, chanting verses from Genesis, describing the birth of Isaac and the banishment of Ismael and his mother, Hagar. With the concert hosted this year on [YouTube](#), anyone, anywhere can join in the fun. Marion’s biggest challenge organizing a virtual concert was deciding how to give people a chance to join in. She shares, “Once I was introduced to YouTube Channels I knew how to run it... but although I hoped to be able to work with a virtual accompanist myself and then give advice to others, I ended up doing an a capella piece and performers found their own way to perform together.” Marion’s fundraising efforts this year have raised a growing total of over \$1,000. When asked what inspires her to raise funds on ACP’s behalf, she states, “I’ve



had a pretty mild case (of MS), but by 2000 I was showing permanent disabilities, and was looking for more help. It was not long after that I heard about what was then the Boston Cure Project and was very impressed by its attitude towards supporting researchers and encouraging them to help each other. When I read about ACP's founder's story - how he figured, 'I'm smart - I'll find a cure myself!' and eventually realized that he'd be better off using his own skills to support others who were using theirs to aim for a cure - I decided to use my own skills (in classical music) to support ACP, hoping I can help the team a little bit..."

Patrick Curley is a Certified Elder Law Attorney with Curley Law Firm LLP in Wakefield, MA and also donates his time and expertise as an ACP Board member. Over the last few years, he has turned his passion for sports into fundraising opportunities to benefit ACP. From 2014 to 2018 he raised money by paddling in the Essex River Race. For the past two years, climbing mountains has been his focus. In his words, "My son Alan and I had a great climb up Mount Monadnock last year. We considered hiking Monadnock again, but it is a very popular hiking mountain and we were worried about the COVID risks if there



were too many people on the trail not wearing masks. So, we decided to take the road less traveled and picked a less popular peak, Mount Gunstock in southern NH." Patrick's family raised over \$4,500 while conquering Mount Gunstock on Friday, October 23rd. He states, "Our kids happened to be off from school that day and we knew there would be no crowds on the trail. We

had the mountain to ourselves!" When asked what he enjoyed most about this year's climb, he shares, "Two things. First, hiking with my whole family felt great. They are with me through thick and thin on this journey and I love and appreciate them. Second, getting out into the woods and smelling the pine forest, seeing the different colored foliage, enjoying the silence of the forest, all of it is just amazing. I feel incredibly alive in the forest. That is especially true during this COVID crisis that makes you question even the air you are breathing. Our climb was invigorating." When asked what inspires him to raise funds on ACP's behalf, he states, "ACP is doing something no one else is. Its biorepository is accelerating research towards better treatments and a cure, while iConquerMS offers a vigorous community, both nationally and internationally, for those living with MS as well as people impacted by MS to work together with researchers and pharmaceutical companies to truly target research to the needs of our community."



Since 1997, the [Mary J. Szczepanski "Never Give Up" MS Scholarship Foundation](#) has been awarding scholarships to high school seniors and college students who have used their creativity and determination to raise funds for MS. Ten \$500.00 scholarships are awarded each year. This extraordinary program has touched the lives of many across the United States and is

constantly raising awareness about MS. We are grateful to the Szczepanski family and the students, who raised \$1,930 to benefit ACP this year.

Stubhy Pandav is the lead singer of the popular Chicago band, [Lucky Boys Confusion](#). After having symptoms for many years, he was diagnosed with MS in 2018. Stubhy is using his musical talent and connections to raise awareness about MS and funds to benefit ACP. In his words, “I realize how lucky I am to be born when I was because back in the 80’s, MS was a wheelchair sentence. So, it’s my turn to give back... I realize that I have a platform here where I can make at least a little bit of a difference.” Stubhy hosted the “[MS Sucks, Singing for a Cure](#)” concert on ACP’s behalf last year and hopes to host future concerts when it is safe to do so. In lieu of a concert this year, he plans to release a fundraising video. Stay tuned!



Our volunteers also help us with a variety of administrative tasks and other projects. ACP recruits many of its volunteers through postings on [Volunteer Match](#), a network that connects volunteers with opportunities that match their skills in the nonprofit sector. We are thankful for the individuals who have answered the call to volunteer at ACP. They all have different backgrounds and interests and volunteer their time and talents in different ways.

Corinne Rhode has worked in banking for 13 years and has since transitioned to photography, focusing mainly on travel and landscape photography. Corinne learned about ACP through Volunteer Match. ACP's posting caught her eye because she has friends with MS. Earlier this year Corinne helped put together information packets for people with MS and she helped write thank you cards to donors. More recently she gathered information on resources available in Virginia for a caregiver who needed help assisting her mother with mobility issues. When asked what she enjoys most about volunteering at ACP, she shares, "I've known people with MS so ACP and their work certainly holds a personal connection for me and the people at ACP are just so great to work with."

Betty Lapide also helps by writing thank you notes to donors. In her words, "It makes me feel useful and is something I can easily do from home." Betty is from a small town in western Pennsylvania and moved to Boston after college. She was an elementary teacher, grades 4-7, for 38 years. Betty loves to bake, garden, play MahJongg, have lunch with friends and exercise. She learned about ACP while doing online research after she was diagnosed with MS in 2007. When asked what she enjoys most about volunteering at ACP, Betty shares, "I really enjoy the connections with people who are so involved in MS research. Their knowledge and hard work are so appreciated by those of us dealing with the disease. It gives me hope."

Kelly Dutcher is a travel nurse recruiter with Host Healthcare. She was diagnosed with MS in August 2013. She shares, "Since my diagnosis I have always wanted to get involved in the MS community as a way to be a positive voice for others. I feel like there can be a lot of negative thoughts tied to an MS diagnosis and I hope that narrative can change... Everyone's experience will be different and sometimes we just need to learn it's ok to lean on each other for support and cheer each other on along our journey!" Kelly recently learned about ACP through MS staffer, Lindsey Santiago. She has been working on updating [ACP's LinkedIn page](#). In her words, "ACP doesn't have much of a presence on LinkedIn and there is a lot that can be accomplished there! LinkedIn is a huge platform that people use today and I think ACP can greatly benefit from a few minor tweaks." When asked what she enjoys most about volunteering at ACP, Kelly states, "I love that ACP is driving toward a cure because that is something I believe in and I believe that is achievable. The things that have been accomplished in just the last 5, 10 years in the medical world is already remarkable and makes me excited about what is just around the corner."

We'd also like to thank Elif Ozsen, a student at Rutgers who is working on starting an organization about neurological disorders, like MS. We're grateful for the Medeiros family, who have held annual fundraisers to benefit ACP since 2002. Unfortunately they had to cancel their event this year because of the pandemic. We also appreciate Nancy Feeney, who has assisted with past fundraising events and hopes to help Marion Leeds Carroll with hers in the future.

It's been a pleasure working with our volunteers this year. We appreciate the contributions they, and many others, have made in support of our work. Their efforts make a big difference in ACP's success. We strive for each of our volunteers to contribute in a way that they find rewarding and fun. 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. Please contact Lindsey Santiago by phone (781) 487-0013, or by email lsantiago@acceleratedcure.org. We make it easy to support ACP in this way! If you are interested in joining the ACP team as a volunteer, please contact Sara by email scloud@acceleratedcure.org! We would love to hear from you!

