

Accelerated Cure Project for MS

November 2017



*Accelerating research towards a
cure for multiple sclerosis*

Funding ACP's mission

While there are many different types of for-profit businesses and as many business models, people are generally comfortable with the idea that a for-profit business funds its operations through the sales of products or services or something similar. From the outside looking in, it can be more challenging to determine how a non-profit sustains operations. While the truly curious can review our annual financial reports on our website, we thought an article summarizing the funding sources that fuel our operations, including donations from individuals, might be an interesting read.

As highlighted in our [September newsletter](#), the Accelerated Cure Project (ACP) has built valuable resources, such as the ACP Repository and iConquerMS™, to accelerate research into multiple sclerosis (MS). Improving the lives of people affected by MS with better diagnoses, treatments, and a cure has been our focus since we were founded in 2001. We are grateful for the generosity of our partners and individual donors who have provided the means to establish ACP's programs. These programs require sustaining funds, of course, so that they can continue to impact the pace and quality of research being done in MS today.



The [ACP Repository](#) is an important source of biological samples and clinical data for researchers studying MS and related demyelinating diseases. The costs associated with maintaining the Repository include sample storage and distribution fees, hosting for our extensive database, and salary support for scientific operations, business development, and sample and data distributions. In order to recover some of these costs, ACP charges a modest cost recovery fee for samples and data, adhering to a two-tiered [pricing policy](#) with different cost levels for academic and industry partners. Our cost recovery fees are modest in comparison to other sample sources and are designed to ensure that good research into MS can be done in a cost effective manner. Donations from individuals can also be a key source of funding for the Repository as some donors specifically request their donations be applied to research activities. A donor can take great pride in knowing their dollars have supported the ACP Repository, a key resource accelerating MS research.

Our people-powered research network, [iConquerMS™](#) has been built and maintained to date through a contract with the [Patient-Centered Outcomes Research Institute](#) (PCORI). Some of the costs associated with iConquerMS include the technical infrastructure, communications activities, and salary support for member engagement, research activities, business development, and operations. In the coming year, under the current contract, PCORI's support for iConquerMS will be phased out and end in September 2018. As a vital and critical resource for MS research, particularly in the area of research being done on topics of greatest importance to people affected by MS, we have a sustainability task force focused on identifying potential sources of funding for iConquerMS to ensure its continued operations. As with the Repository, there is a cost recovery policy in place with modest fees outlined for academic and industry users of iConquerMS. Other sources of funding for iConquerMS may include funds from advocacy organizations, foundations with an interest in people-centered research, and sponsorships from industry partners for specific events such as our annual Leadership Summit, a gathering of the MS stakeholders who govern iConquerMS. iConquerMS is unique in the area of MS research with its governance by members of the MS community and its truly people-centered and people-powered approach to research. Individual donors who are passionate about ensuring that people affected by MS, and their interests, preferences and priorities for research, are central to the MS research agenda, are also a key part to ensuring the sustainability of iConquerMS.

ACP receives funding from industry or advocacy partners for both scientific and non-scientific grants. Scientific grants are awarded for specific science-related projects.



For example, the [National MS Society](#) and [EMD Serono](#), among others, provided grant support in the past for the [MS Discovery Forum](#) and the [OPT-UP Program and Clinical Study](#). Non-scientific grants, or sponsorships, are awarded for other projects. For example, the ACP newsletter is funded in part by sponsorships from [Biogen](#) and [Teva Pharmaceuticals](#). Other projects for which ACP may seek industry sponsorships for in the future include adding podcasts or data visualization to iConquerMS. ACP is always looking for grant opportunities (both scientific and non-scientific) to fund its programs.



Donations from individuals, which cover ACP's operating costs, are a vital source of funding. There are [numerous ways](#) to make a donation. Because ACP is a 501(c)(3) charitable organization, donors may be entitled to a tax deduction for their contribution. One-time or recurring donations, large and small, are welcomed and important to ensure we are able to fulfill our mission. For supporters whose

companies host giving campaigns, funds can also be directed to ACP through the [United Way giving program](#) and other programs such as [Give with Liberty](#). Donations can be made in memory of a loved one, or in honor of an important event, such as a wedding or birthday. ACP can set up donor pages (dedicated online pages) that make collecting these kinds of gifts easier. Donors can also make a significant gift posthumously. Bequests allow individuals to make larger gifts than they could during their lifetimes.

Many corporations offer [Matching Gift Programs](#) for charitable contributions. These programs can increase the size of donations by contributing some additional amount for every dollar that is donated to an approved charitable organization. For those who shop online, Amazon will donate 0.5% of the value of purchases made on [Amazon Smile](#) to ACP. Shopping through Amazon Smile for both your everyday and holiday shopping can make a significant impact for ACP. A donation button was recently added to the [ACP Facebook page](#) for those who prefer to do their giving via social media. Of note, on [Giving Tuesday](#) (11/28) Facebook will waive all fees and the [Bill & Melinda Gates Foundation](#) will match all



donations, up to \$2 million. Anyone interested in making a donation via Facebook is

encouraged to do so early on Giving Tuesday in order to take advantage of this wonderful benefit!

Not every donation is in dollars. Volunteers from all over the world have donated their time and talents to ACP. ACP is also guided and overseen by our all-volunteer [Board of Directors](#). For some supporters of ACP, raising money through independent fundraising



events is the perfect blend of interest, expertise, and passion for ACP's mission. Marion Leeds Carroll produces the [Music to Cure MS concert](#) every October, and Kemp Jaycox holds his [annual Walk to Cure MS](#) in the fall. Others have hosted a

wide variety of such events in the past, including rowing events (Patrick Curley), running events (Eliza Duddy), and cross-country events (Libby Nichols and Maddy Chambers). The Medeiros family hosts an annual party to benefit ACP. In addition, Rick Szczepanski raises money for ACP through his [scholarship fund](#). We, at ACP, are extremely grateful for the time, talent and effort these volunteers devote to organizing and participating in fundraising activities. At ACP, we are happy to offer assistance to the volunteers that run them. If you would like additional information about donating, setting up a dedicated donation page, or if you have an idea for your own fundraising event, please contact Lindsey Santiago by phone (781) 487-0013, or by email lsantiago@acceleratedcure.org.

While ACP is continually seeking to expand corporate philanthropy, we rely on general donations (both large and small) and the altruism of our volunteers to continue our work at ACP. A major donation can finance a specific project, as can a number of smaller donations. All contributions, regardless of amount, enable ACP to achieve its mission to improve diagnosis, optimize treatment outcomes and find a cure for MS. We give thanks for the generosity of all of our donors and volunteers, and look forward to your continued support in the future.

