

# Accelerated Cure Project for MS

September  
2017



*Accelerating research towards a  
cure for multiple sclerosis*

## Partner Spotlight - CISCRP

Medical advances made possible by clinical research regularly touch every person's life. More than half of all Americans are currently taking prescription medications and most Americans routinely use over-the-counter medications. Behind every treatment there are thousands of people that volunteered to participate in clinical trials. People don't usually connect medical advances, including these medicines, to clinical research and the dedication of research volunteers who made these developments possible. Clinical research is usually only discussed in a doctor's office when a patient is diagnosed with an illness. In addition, media coverage tends to focus on the negative occurrences in medicine, such as conflicts of interest among medical professionals or tragic errors resulting in harm to patients. This has created poor public perception of clinical research, and eroded the public's trust in its ethics and safety. The Center for Information & Study on Clinical Research Participation (CISCRP) is a Boston-based non-profit organization, founded in 2003, dedicated to changing this by raising awareness about the positive impact clinical research has on all of our lives and raising the level of public appreciation for the dedication of clinical research volunteers.



CISCRP offers a variety of resources, programs and services that provide a better understanding about clinical research and the role each party plays in the process. Doctors are often perceived as the heroes in medicine. While there are many outstanding physicians who provide excellent care to their patients, the fact that medical breakthroughs wouldn't be possible without the generosity of clinical trial volunteers is often overlooked. The [Medical Heroes program](#) recognizes clinical trial volunteers, or "Medical Heroes", for their gift of participation and increases awareness about clinical trial participation. Medical heroes are ordinary people who have chosen to give the gift of participation in clinical research despite possible risks. This gift profoundly contributes to the knowledge about the nature of disease, its progression and how to treat it; and ultimately benefits future generations.

[Studies show](#) that most clinical trial participants want to know the results of their trial, however almost none are given this information. Providing trial results can improve the transparency of clinical research, and help close the loop with patients. CISCRP's [Communicating Trial Results program](#) provides study volunteers with clinical trial results by creating and delivering summaries in everyday language. Volunteers in the medical community serve on an editorial panel that reviews these summaries to be sure that they are easy to understand, unbiased and accurate. With the help of this editorial panel, CISCRP "translates" the technical results of clinical trials into lay summaries. This provides ongoing communication with participants and keeps them informed about their study's results after it ends.

Finding a clinical trial can be confusing for many patients. [Search Clinical Trials](#) is a free service that CISCRP offers to help people find relevant clinical trials. CISCRP staff will search clinical trial listings and send the contact information for research studies to interested participants. They also offer free educational brochures that contain important information to consider about participating in clinical research and key questions to ask research staff before enrolling in a clinical trial. Patients providing an email address as a part of their clinical trial search can also receive a [quarterly newsletter](#) to help stay informed about CISCRP's programs, and clinical research in general.

CISCRP has an extensive library of [educational resources](#) intended to help the general public learn about clinical research and what it means to volunteer for a study. Their brochures provide basic information about clinical research, including patient protections,

and resources for potential research volunteers. Their educational videos, offered in a variety of languages, describe the clinical research process through real-life experiences of clinical research participants. CISCRP's library of resources also includes [The Gift of Participation: A Guide to Making Informed Decisions About Volunteering for a Clinical Trial](#), which is a complete resource for study participants. Written by the founder and chairman of CISCRP, it covers why participation in clinical research really matters, addresses what participation means and how it helps to advance medical science. This book also contains practical information on insurance coverage, compensation, and tax ramifications for clinical research volunteers. CISCRP also hosts the online community, [HealthUnlocked – Understanding Clinical Trials](#), that is dedicated to educating the public about and engaging them in clinical research.

CISCRP holds special events nationwide throughout the year. [AWARE for All](#) is a free program whose goal is to educate the public in making informed decisions about clinical research participation. AWARE events typically include free health screenings, informational exhibits, local physician and patient speakers, and a reception to honor clinical research participants. CISCRP sponsors [5K run & walk events](#) throughout the year to celebrate the people who volunteer for clinical research. CISCRP also hosts informative [webinars](#) on a variety of topics for both professionals and the public that share research findings, program updates, and educational presentations.

CISCRP does not recruit for clinical trials, rather they work to inform the public about clinical trials and why they might, or might not want to participate. Their programs recognize all of the men and women who participate in clinical research. Their participation not only advances our current knowledge about disease, but it improves medical knowledge for generations to come.