Accelerated Cure project for multiple sclerosis

Accelerating research towards a cure for multiple sclerosis

Partner Spotlight - Smart Patients

Smart Patients is a unique online community where members and their families dealing with a variety of illnesses can learn from each other about treatments and challenges by sharing questions and concerns. While providing members a safe environment to interact, this connected network also helps the healthcare system learn from all participants in order to serve them better. They do this by providing clinical providers and researchers with an opportunity to ask the Smart Patients community important questions and receive their feedback.

The founders of Smart Patients, Gilles Frydman and Roni Zeiger, believe that tapping into the knowledge created by networks of engaged people can significantly improve healthcare. They recognize the wisdom gained by individuals as they live with their disease as a great resource and created a high quality forum for members to share their expertise with one another. This same forum also serves as a connection with the scientific community so that researchers have access to patient patterns and insights in order to determine the causes and improve treatment of diseases. The original focus of Smart Patients was in
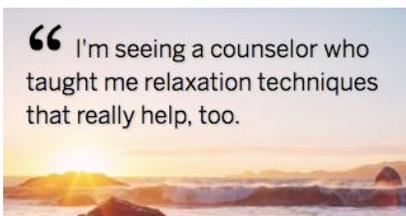
> **❝** I find the stories on this site absolutely amazing. The strength, courage, and love come through.

oncology but they have since expanded to working with people affected by many different diseases. Patients, family members, friends, patient advocates, and survivors are all part of the Smart Patients community. Members learn from conversations and can help each other on a wide variety of topics, including treatments and side effects, where to find help, how to cope with disease, end of life, research and clinical trials.

> " The site and its members have helped me more than I could ever express.

Smart Patients differs from other social communities in a number of ways. With Smart Patients there is no marketing or advertising, and members need not worry about social listening or web scraping. Protecting the privacy of participants is paramount as described in their Privacy Policy. Smart Patients asks for explicit permission from members before sharing any information that identifies individuals with partners such as medical centers or pharmaceutical companies. HIPAA guidelines are used to remove identifiable information (for example, names, locations, or email addresses) before it is shared. The Smart Patient privacy policy describes how anonymous information may be gathered and used.

Smart Patients communities are identified by disease or condition. New members are invited to join a community where they will receive help and advice from other patients and caregivers who have experience with their condition. After joining a community, participants can see conversations started by other members of their community and join in any that interest them. Conversations on topics that span

> " I'm seeing a counselor who taught me relaxation techniques that really help, too.

disease boundaries, such as fatigue and caregiver stress, can be viewed by members of many disease communities so that patients can also learn from people with other diseases about these common topics.
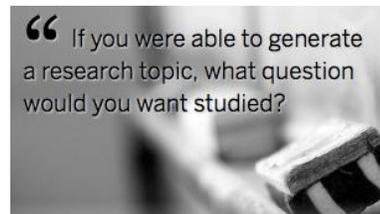
Sometimes members of Smart Patient communities need help with difficult or misunderstood topics during their conversations. In order to facilitate these interactions, Smart Patients offers "Ask the Expert" sessions in which experts in the topic of interest are invited into a community to answer questions. These sessions can complement what patients learn from their

> " That really helps me know what to expect and plan for post-infusion.

health care team and help them prepare questions for their next appointment.

Clinical trials are a way for researchers to test promising new drugs and treatments, and gather information about their safety, effectiveness, dosage, and side effects. Many treatment options, especially for cancer and multiple sclerosis, are available only through clinical trials. Smart Patients believes that clinical trials should be incorporated into care options where appropriate, not just a last resort. They try to make it easier for participants to learn more about trials by having conversations about them. The Smart Patients website includes a clinical trial search engine that makes it easy for members to find trials, track clinical trials that are of interest, and discuss them with the community.

The Accelerated Cure Project is collaborating with Smart Patients by connecting the iConquerMS™ portal with the Smart Patients MS community. Through iConquerMS, researchers can connect with people with MS and also receive data collected via the iConquerMS portal in order to gain a better understanding of the patterns of multiple sclerosis and gain insight into its disease process. iConquer MS also offers its members the opportunity to provide input on future areas of research. The Smart Patients MS community connects people with MS with each other to share, interact, and learn from each other in a safe, supportive environment. This powerful collaboration not only addresses the needs of people with MS, but also extends the ability of iConquerMS to connect researchers with patterns and insights to figure out the causes of MS, determine who will respond best to various treatments, and find new and improved treatments for the disease.

The potential benefits of people sharing information with each other are profound. Smart Patients' mission is based on the belief that individuals become experts in their conditions and this knowledge can be an important resource to improve healthcare. They provide a supportive, safe environment for participants to interact and learn from each other. This interaction offers members reassurance that they are not alone. Smart Patients also helps the healthcare system learn from patients by connecting patients and caregivers.