

Biogen Idec turns to MyHealthTeam in successful test of social networks for enrolling MS clinical trial

By Ronald Rosenberg
CenterWatch Staff Writer

Social networks can provide not only a forum from which to learn about clinical trials, these communities—in which members share the same disease, personal profiles, stories and friendships—now also can motivate members to participate in trials.

That's what **Biogen Idec** found when it turned to **MyHealthTeams**, which creates communities of social networks for people with chronic conditions, and its MyMSTeam (multiple sclerosis). It asked members if they would like to be notified about clinical trials relevant to them. The response: 85% said yes.

"We were able to target the right group of people, a specific form of MS, known as relapsing MS, and it was personalized," said Javier Zambrano, M.D., director, Avonex/Plegridy and U.S. medical, neurology for Biogen Idec. "They were addressed directly in a personal manner, not in a massive communication that goes to everyone."

For most of Biogen Idec's trials, the average number of patients screened per week is six. Targeting a subset of MyMSTeam, 34 members were screened within the first 24 hours.

"This was incredible," said Zambrano, speaking at the recent **DIA** annual meeting in San Diego on a panel about social media in patient recruitment and how best to leverage the digital ecosystem. "We were not

expecting this response. People on my team were shooting me emails about how excited they were on the response of this pilot trial. Almost 800 patients decided to be screened and a lot of those patients were not even at the sites we specifically targeted. We ended up with 120 consenting and 66 patients who passed the screener."

He also acknowledged some of Biogen Idec's leaders were skeptical about using a social network in which participants shared their medical stories and provided extensive demographic information. The key question: Can social networks really help recruit patients for a specific trial?

"We wanted to test this type of recruitment to satisfy our leadership and to make sure it was viable and interesting if we used this tool," said Zambrano.

The ALLOW trial aimed to determine the proportion of relapsing MS patients who experienced new or increased flu-like symptoms when they change from one form of several drugs to another, and the incidence of adverse events.

For Eric Peacock, co-founder and CEO of MyHealthTeams, MyMSTeam is his fourth and fastest-growing social network for people living with a chronic condition looking to quickly find, communicate and connect with others like them. They also want to find local providers and businesses that can best help them.

"A major reason for our success, as a social network, is that the people in it are truly engaged and they interact," said Peacock, who also spoke on the DIA panel. "The most engaged patients are on social networks, not patient registries, databases, Google or health sites. It's important to communicate through the social network and be personal and transparent about money. So think beyond patient recruitment, target your outreach and deliver relevant information."

The result, he said, is faster recruitment of qualified patients, more engaged patients in and beyond the trials and a greater awareness of clinical research in the community.

Over two weeks, Biogen Idec sent two emails to MyMSTeam members, one post on the MyMSTeam web site and two posts on the MyMSTeam Facebook page.

The email, intended to pique members' interest in determining their eligibility, said many members had urged the MyMSTeam to share information about relevant MS clinical trials as they arose.

"We recently partnered with Biogen Idec to share news of the ALLOW study, which focuses on people with relapsing-remitting MS who currently are taking a standard interferon beta therapy such as Avonex (interferon beta 1b), Betaseron (interferon beta 1a) or Rebif (interferon beta 1a)," the email stated. "Find out if you are eligible."

myHealthTeams

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The final tally showed while 156 passed the screener to enter the trial, only 120 consented to be contacted and just 66 lived near a participating site. Then, 29 of the 66 dropped out for reasons ranging from their neurologists' disapproval of clinical trial participation to simply losing interest in the trial.

Overall, the 120 who consented represented 15% of the 800 social network members informed about the trial—well above the 2% to 5% consent rate from traditional recruitment methods, said Zambrano, acknowledging some “study hiccups with timelines” and logistical issues along the way.

Peacock stressed the importance of being precise when reaching potential participants in a social network, providing

information about trials relevant to them and being both transparent and personal.

“By personal, I mean ‘We are sending this to you because you fit this profile exactly,’” said Peacock. To be transparent, a sponsor should let patients know it is paying the social network to inform them of the trial, he said. “Be really clear and patients will love you for it. They are very wise to how this all works.”

That's been his experience with the three other MyHealthTeam groups. The first and largest is MyAutismTeam, a social network for parents of children with autism. Launched with 35 parents in California in June 2011, it has grown to more than 52,000 parents. MyBCTeam is for women diagnosed with breast cancer, followed by MyCrohn-

andColitisTeam. MyMSTeam is the newest and fastest growing, with an estimated 18,000 members.

Except for the autism team, more than 50% of registered members of these social networks are monthly active users, according to Peacock. By contrast, he said, many health web sites typically see 5% of users on a monthly basis.

A recent study by the Pew Research Center's Internet & American Life Project showed one in four internet users living with chronic conditions say they have searched online to find others with similar health concerns.

Email comments to Ronald at ronald.rosenberg@centerwatch.com.