

The value of partnering with a patient advocacy organization in clinical trial recruitment in sarcoidosis

Purpose: Patient advocacy organizations build unique relationships with their patient communities by serving as a key resource at the time of diagnosis and beyond. This is especially true in rare diseases like sarcoidosis and the Foundation for Sarcoidosis Research (FSR). FSR has observed key strategies that not only engage patients, but that increase access to research opportunities and therefore accelerate therapeutic discovery.

Background: Sarcoidosis is an inflammatory disease characterized by the formation of granulomas in one or more organs of the body and is estimated to impact between 150,000 and 200,000 individuals in the U.S.. Black individuals not only experience the highest prevalence, but also the greatest disease burden, and yet are vastly underrepresented in clinical trials. FSR's Ignore No More campaign found that 85% of Black individuals with sarcoidosis surveyed felt clinical trials were worth the risk, yet 61% said they'd never been invited to participate by their doctor. This highlights a need for additional awareness and educational activities, and attention paid to patient-reported barriers to participation. FSR is uniquely positioned to provide strategic patient engagement to maximize effective clinical trial enrollment and design through our SarConnect Program (Figure 1).

Methods: Clinical trial enrollment statistics were collected through partner reporting and feedback. Content engagement for FSR social media, newsletters, our clinical trial indicator list, and registry communications were provided through platform metrics.

Results: The average trial duration, including the enrollment period, in rare disease is a little less than four years, yet our latest clinical trial partners completed enrollment through FSR engagement with trial durations below 2.5 years. Additionally, to address statistics indicating up to 50% of research sites enroll one or no patients, FSR referred nearly 1,400 potential participants to these partnered clinical trials, all of which achieved complete enrollment. These efforts in particular featured lessons learned from the Ignore No More campaign that led to patient decision-making and empowerment messaging. Regarding specific outreach, social media messaging received up to 7% click through rates (compared to industry standards of 0.75%-2%). Communication by email reached over 56,000 members of the sarcoidosis community, with content shared through the Registry receiving 86% more engagement than content shared in the general community newsletters (43% and 23% respectively). These high-engagement efforts resulted in hundreds of successful patient referrals and demonstrate the strength of partnering with patient-partnering organizations like FSR. Lastly, FSR drives opportunities to address the barriers facing sarcoidosis clinical trials and increase engagement with clinicians, nurses, and coordinators such as through the Advancing Sarcoidosis Clinical Trials and Research Workshop, which was held in November 2023 and included 28 specialists, industry partners, and other stakeholders.

Conclusions: Collaborations with patient advocacy organizations by clinical trial sponsors maximizes patient engagement in both protocol design and trial participation. FSR's insights into patient preferences on therapeutic interventions and clinical trial participation will expand when we host a Patient-Focused Drug Development meeting on October 28, 2024.