Advocacy Groups: Enhancing Relationships and Patient Recruitment

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Report Overview

This report provides qualitative insight on advocacy groups' relationships with the pharmaceutical industry. The report explores their current philosophies toward clinical trials, provides recommendations and best practices for encouraging patient participation in trials, and identifies opportunities to partner (or build on existing partnerships) with the industry.

What you will learn in this report

- The type of relationships advocacy groups desire with industry, including: involvement in clinical trial design, collaboration on patient recruitment, and role in connecting patients to industry
- Advocacy groups' concerns with encouraging clinical trials, including: the need to remain neutral, patient education, and trial burden on patients
- Recommendations and best practices for delivering messages to patients and families about clinical trials

How you can use this report:

- Uncover proven strategies to more effectively enroll patients in your rare disease/difficult-to-recruit trials
- Learn to optimize communication strategies to ensure an "all inclusive" approach to relationship management considers all key players (advocacy groups, patients, caregivers, and investigators)
- Develop strategies to anticipate, discuss, and mitigate advocacy group concerns and hesitations

Major Sections

1. Relationships with Pharma
   - Clinical Trial Design
   - Patient-Industry Relationship
   - Opportunities for Industry in Trial Design Process

2. Clinical Trial Focus
   - Clinical Trial Focus Spectrum
   - Concerns with Encouraging Clinical Trials
   - Website Focus on Clinical Trials

3. Clinical Trial Recruitment Practices
   - Clinical Trials 101 – Back to the Basics
   - Patient Registry
   - Recruitment Best Practices
   - Managing Relationships

4. Patient Advocacy Groups' Requests of Pharma
   - Low Trial Focus Advocacy Groups
   - High Trial Focus Advocacy Groups

5. Patient Advocacy Group Profiles

Methodology

In ISR's qualitative analysis, ISR conducted 40-minute telephone interviews with senior decision-makers at 10 US-based patient advocacy groups. The individuals interviewed hold a variety of roles within their organizations, but all are in a position to speak to their organization's philosophy on clinical trials, as well as their organization's broader relationships with the pharmaceutical industry.

MS National Multiple Sclerosis Society

AMERICAN LUNG ASSOCIATION® Fighting for Air

CHRISTOPHER & DANA REEVE FOUNDATION TODAY'S CARE. TOMORROW'S CURE.

Huntington's Disease Society of America

AMERICAN LIVER FOUNDATION Your Liver. Your Life.

alzheimer's association®

Parent Project Muscular Dystrophy LEADING THE FIGHT TO END DUCHENNE

NATIONAL HEMOPHILIA FOUNDATION *for all bleeding and clotting disorders*

American Diabetes Association®

MDA® **Muscular Dystrophy Association**

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Introduction

As ISR's research has revealed time and again, patient recruitment is one of the most difficult and time-consuming aspects of conducting a clinical trial. Though the biopharmaceutical industry utilizes a wide range of recruiting techniques, one that ISR believes has not been fully (or even adequately) leveraged is partnering with patient advocacy groups to encourage trial participation.

Patient advocacy groups are spread across the spectrum regarding how involved they are with clinical trial recruitment. All respondents posit that clinical trials are the way to move forward but many have yet to delve into playing a role in the recruitment process. There are various reasons why an organization may not have fully developed this offering so industry will have to tailor its approaches to individual advocacy organizations. The bright side is that advocacy groups already playing in this space are searching for continued and more involved partnering opportunities and organizations without processes in place for patient education and recruitment are open to discussing partnering options with industry.

This report sheds light on advocacy groups' relationships with pharma, current philosophies toward clinical trials, best practices for encouraging patient participation in trials, and opportunities to partner (or build on existing partnerships) with pharma.

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Best Practices

Advocacy organizations have developed some best practices and some unique ideas for clinical trial education and recruitment. These practices will be detailed here as organizations can learn from successful strategies of other advocacy groups and industry can learn where it can lend a hand to support these initiatives.

Delivery is Key

Respondents shared several best practices in terms of delivering messages to patients and families about clinical trials.

Repetition

Consistent Language

Audience Understanding

Impactful Message
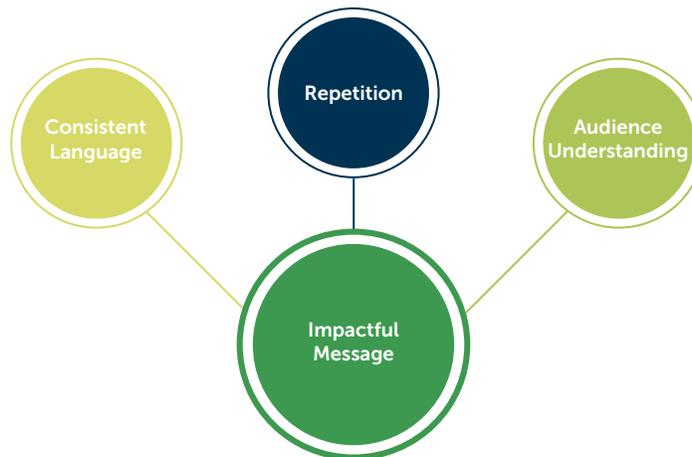
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Consistent Language

Consistency in language is critical. When messaging about key facts about a clinical trial, try to use the same wording as is used in other information about the trial from the sponsor company or CRO. This will help the patient to form a coherent understanding. Talk to PIs to understand how they talk about the trial with patients so a consistent message can be relayed to the patient community.
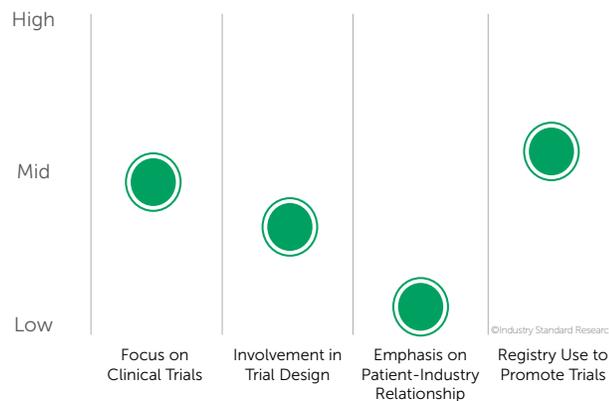
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Organization B

Spectrum Summary

High			
Mid			
Low			
Focus on Clinical Trials	Involvement in Trial Design	Emphasis on Patient-Industry Relationship	Registry Use to Promote Trials

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Relationship with Industry

The patient population for Organization B's disease focus is relatively small and our interviewee mentioned that pharma does not spend a lot of energy in this therapeutic area. For the trials that have taken place, this organization has had some collaboration regarding clinical trial design but on a rather limited basis. Our respondent relayed that the organization has a good clinical trial infrastructure and a high degree of expertise in the disease. This group would be eager and willing to collaborate with industry should industry decide to put more effort into researching this disease and its secondary issues.

Clinical Trial Focus and Recruiting Practices

The interviewee from Organization B would like to put more effort into educating patients about clinical trials, particularly because these patients tend to be leery of research. It has not put a great deal of effort into education as a high proportion of its money is funneled into research. The respondent believes that the pharma/biotech industry could help to develop good educational materials for patients that would explain that while a trial might not work for an individual patient, "a rising tide lifts all boats."

Organization B has a registry in which it tracks patients' disease progression and outcomes. The database is federally funded and is made available to researchers for

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