

# A Patient-Focused Approach to Rare Diseases – Connecting with Multiple Stakeholders

In order to successfully commercialize a rare disease product, manufacturers must consider the needs of multiple stakeholders. Adding to the challenge, each stakeholder may have unique needs. This creates increased complexity when marketing a therapy in the rare disease space, but also offers multiple opportunities to engage, connect, and build relationships at a level that does not exist in other disease states. Below are some of the critical stakeholders and their respective needs.

## Patients and Caregivers

There are as many as 7,000 rare diseases and only 5% of these have known treatments.<sup>1</sup> Furthermore 50% of rare diseases touch children.<sup>1</sup> Engagement, education, and support are often needed for multiple stakeholders, including patients, parents, family members, and caregivers. Manufacturers need to develop multiple mediums for delivering information, such as mobile engagement, webinars, apps, websites, instructional videos, brochures, and support groups, to successfully reach as many stakeholders as possible.

Perhaps even more important to this stakeholder group is addressing treatment concerns once a therapy has been prescribed. Offering support services such as financial support, compliance and adherence programs, patient assistance, and clinical nursing support, is critical in the marketing of these therapies. Nurse visits in the home for self-administered products can be an important step in making a patient and the caregiver team comfortable with the respective treatment regimen. HUB providers can serve as an important partner to offer and coordinate all of the services needed along the treatment journey. Case managers form strong bonds with patients, family members, and caregivers, and often prove to be invaluable members of the treatment team.

## HCPs

Healthcare professionals (HCPs) often need assistance with navigating the barriers to therapy. There is an opportunity for HUB service providers to assist with the coverage, adherence, and financial challenges that are often inherent to rare disease therapies. These support services are paramount to a patient



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initiating therapy as well as adhering to the prescribed treatment. HUB service providers that offer high touch “white glove” services create special connections with patients, caregivers, and family members as they partner together to navigate treatment journey challenges and develop strategies to adhere to the requirements established by the prescribers. This partnership is critical to ensuring patients are adherent to the treatment plan and achieve the best possible outcome.

Each step after the therapy is commercialized may present a unique challenge and “hand-holding” for the provider can dramatically increase speed to therapy for the patient. HUB service providers specialize in providing support throughout the treatment journey. Clinical Nurse Educators are also an important resource that can connect with HCPs at a professional level and provide clinical nursing support and disease education.

## Advocacy Groups

Advocacy groups are often where patients, family members, and caregivers start and offer manufacturers an invaluable partnering opportunity. These groups serve as an engagement channel for local activities, disease specific educational forums, as well as fund raisers. Advocacy groups are also a medium to connect patients with advocates and other patients who may be facing similar challenges. Further-

Once a therapy is commercialized, support is needed to help all stakeholders understand access to therapy, payer coverage, navigate the prior authorization process, procure the therapy, attain financial support for the patient, and deliver the selected therapy to the patient.

more, by connecting with other patients or advocates, individuals feel less isolated, gain a better understanding of symptoms, and learn tips to manage their symptoms. Patients can also learn how to recognize signs of disease progression and strategies for partnering with their healthcare team. When manufacturers support patient advocacy groups they learn the best ways to connect with patients, family members, and caregivers. The time and effort that manufacturers invest in these groups is well spent as there is an opportunity for connectivity that doesn't exist in other channels and these relationships become critical to targeting smaller patient populations.

The special considerations and the multiple stakeholders that are part of the rare disease patient journey create challenges for brand teams, but also present tremendous opportunities for these teams to provide value as well as connect with patients, family members, and caregivers. <sup>PV</sup>  
*Editor's Note: <sup>1</sup> National Organization for Rare Disorders (2016). Rare Disease Facts. Retrieved from [http://cdn.rarediseases.org/wordpresscontent/wp-content/uploads/2014/11/NRD-1008-Fact-Sheet\\_5.pdf](http://cdn.rarediseases.org/wordpresscontent/wp-content/uploads/2014/11/NRD-1008-Fact-Sheet_5.pdf).*

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