

Navigating the Complex Treatment Landscape of Chronic Rare Diseases as a Patient

Chronic rare diseases present unique challenges for patients and healthcare providers alike. Rare Disease patients often face significant barriers that complicate their treatment journey, which in turn impacts their ability to get to optimal treatment and management decisions. Interpreting and solving for these challenges is the first step in enabling better access and improved outcomes. By maximizing their understanding of the chronic disease landscape, pharmaceutical brands can more successfully develop and market treatments that truly meet the needs of this underserved population.



Common Barriers Faced by Patients with Chronic Rare Diseases

1. Adaptive Behaviors

Patients with chronic rare diseases often experience significant diagnostic delays and face complex medical journeys. By the time they receive a diagnosis, they often have developed entrenched behaviors as a means of adapting to their emerging symptoms (e.g., modifying how they perform activities of daily living to get to their desired outcome). Once patients become accustomed to such adaptive behaviors, it can be difficult to identify a need to adjust as patients become resistant to further change.





2. Learned Helplessness

By the point of receiving a diagnosis and getting treatment, many patients become accustomed to life with their condition and the decreased quality of life compared to life before symptom onset. They have learned to live with their symptoms, settling for minimal improvement or stability as they don't think it's realistic to strive for anything more. This often manifests in a lower willingness to look for new treatments and/or decreased motivation to work with their care teams to increase their quality of life.

3. Satisficing

Patients often settle for "good enough" treatments out of fear of worsening their condition by trying something new. This behavior, known as satisficing, results in patients avoiding new treatments that could potentially offer better outcomes due to the perceived risks and efforts involved in the switch/ addition.



4. Need for Control

Due to the rarity of their conditions, patients often find that the professionals they interact with have limited experience with their specific disease. This creates a dynamic where patients need to be proactive in researching and initiating conversations about new treatment options in order to get to optimal treatment outcomes and a need to be constantly advocating for themselves. Due to the high tendency for satisficing, they need to have a high need for control in order to be intrinsically motivated to do this research and initiate treatment discussions.





5. Feelings of Isolation

Low overall awareness of chronic rare conditions leaves many patients feeling lonely and unsupported. They struggle to connect with others, feeling like very few people if any are able to truly understand their experiences. As a result, patients with rare diseases often turn to support groups and online communities to find a sense of belonging and understanding unable to find such communities in their direct environments.



How BEESY Can Help

BEESY is dedicated to helping navigate these complex dynamics and enabling patients to strive for better outcomes by focusing on:



1. Faster Diagnosis and Reduced Adaptive Behaviors



Identifying key symptoms of adaptive behaviors leading to faster referral escalation and diagnosis: BEESY helps to identify and emphasize the importance of specific symptoms that can act as triggers for referral escalation, leading to faster diagnosis and reducing the development of entrenched adaptive behaviors.

2. Leveraging Moments of Urgency



Creating moments of urgency to increase the likelihood of treatment escalation: By identifying and creating moments of urgency during a patient's treatment journey, BEESY helps decrease satisficing behaviors and increases the likelihood of treatment escalation when it is the optimal outcome.



3. Understanding Emotional and Behavioral Landscapes



Elucidating patients' unmet needs and preferred outcomes: BEESY provides a deep understanding of the complex emotional and behavioral landscape impacting treatment and management of specific disease states. This insight allows for a deeper understand patients' unmet needs and preferred outcomes.

4. Bridging Patient-Doctor Disconnects



Reducing patient burden by identifying key disconnects: BEESY identifies key disconnects between patients and doctors and provides strategies to bridge these gaps, reducing the burden on patients to drive treatment conversations and research new options.

5. Maximizing Product Potential



Uncovering and speaking to the most motivating attributes: BEESY helps maximize a product's potential by identifying its most motivating attributes and developing strategies to effectively communicate these to both patients and doctors.



Schedule a meeting with BEESY today

TO LEARN WHY TOP BRANDS HAVE TRUSTED US TO ENHANCE THEIR UNDERSTANDING OF CHRONIC RARE DISEASE TREATMENT LANDSCAPES AND SUPPORT PATIENTS IN REACHING THEIR FULL POTENTIAL. LET BEESY GUIDE YOU IN MAKING A MEANINGFUL IMPACT IN THE LIVES OF PATIENTS WITH CHRONIC RARE DISEASES.

Learn more about how harnessing the power of understanding decision-making can advance your brand's goals.

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