Learning From the Patient Community

Catalyst is committed to improving the lives of people living with rare and debilitating neuromuscular diseases. How do we go about this? We start with the patient community because we know that understanding their true experiences and needs will help us make the greatest impact. The perspective we gain from the community guides our decisions and shapes how we move forward.

Catalyst Engagement

Our patient engagement team is the champion within Catalyst for the community voice and leads external communications with advocacy organizations. From supporting efforts to educate and raise awareness for key patient issues to spreading the word about clinical trials to developing and sharing educational programs and materials, our team is continually keeping community feedback and insights top of mind. Our team also works hard to connect individuals and families impacted by rare diseases with each other, or with support organizations, whenever appropriate.

We welcome an open dialogue and encourage organizations to come to us with opportunities to collaborate.

The mission of our patient engagement team is simple: Build and sustain trusting relationships with families and advocacy organizations to address rare disease issues and create opportunities to make a difference in patients’ lives.
Patient Advocacy Relationships

When people take an active role in their healthcare and participate in research, they may improve their own health as well as the health and lives of others. That’s why we’ve cultivated strong partnerships with advocacy organizations. We are proud to support their missions to educate, improve understanding, increase awareness, connect people with similar rare diseases together, and empower individuals and families.

Guiding Principles

To ensure that our relationships with patients and patient organizations are thoughtful and transparent, we rely on the following principles:

• We recognize and respect the autonomy of our advocacy partners and seek to reinforce their independence and integrity. We will not place our interests above theirs.

• We will not request or expect a patient organization to promote a Catalyst Pharmaceuticals product.

• We will be open and transparent about the objectives and scopes of any collaboration with patient organizations.

• We will respect and guard the privacy of all personal information and data we may receive from patients and patient organizations. We will only release information if given consent.

• We strongly encourage patient organizations to pursue and establish multiple funding sources.

• We will acknowledge Catalyst’s support and sponsorships of such organizations.

Charitable Contributions and Sponsorships

Catalyst is proud to support patient advocacy organizations and programs that improve the lives of those with rare neuromuscular disease. We have established a formal process to review and consider charitable requests from qualified non-profit organizations related to the disease communities we serve. For more information and application requirements, email our Patient Engagement team at PatientEngagement@catalystpharma.com.