

CASE STUDY

# Amicus Therapeutics Collaborates with Patients to Develop Medicines for Rare Diseases

How do you ensure vulnerable patients can continue to contribute to the development of therapies when traveling to an in-person event might put their health at serious risk? This was a question biotechnology company Amicus Therapeutics grappled with in early 2020 as the COVID-19 crisis unfolded.

The New Jersey-based company develops therapies for people living with rare metabolic diseases, including Batten disease, Fabry disease, and Pompe disease. As part of this important work, Amicus Therapeutics' Patient Advisory Board program connects patients and caregivers with Team Amicus as well as other members of the medical community and researchers to help expand knowledge about these diseases. The program also ensures that the patient perspective is built into every aspect of drug development.

With the COVID-19 crisis rapidly evolving, the company accelerated its use of BlueJeans Meetings so Patient Advisory Board members could participate in meetings from anywhere. This would help their safety while also allowing the company to gather the critical insights needed for its research.

## Gathering Critical Insights Virtually

Patient Advisory Board meetings had been a blend of virtual and face-to-face since the industry-leading program began in 2008. However, the company pivoted to virtual sessions in 2017, when unpredictable wildfires on the west coast raised questions about the safety of patients traveling to a meeting scheduled there.



**Industry:** Biotechnology

**Challenges:** Ensure safety of patients participating in its Patient Advisory Board (PAB) and focus group meetings during the COVID-19 crisis.

With most employees working remotely, wanted to remind employees of its mission.

**Solutions:** Stepped up use of BlueJeans Meetings to hold PAB meetings virtually.

Using BlueJeans Events, transitioned regular 'Lunch & Learn' sessions for team members to a 100% remote format.

**Results:** Transitioned to holding PAB meetings virtually, continuing to gather the critical patient insights needed for important research.

Through virtual 'Lunch & Learn' events, ensure employees remain connected with the impact the company has on the lives of patients and their communities.

“One of the great things about BlueJeans, even before COVID, was the interoperability with different platforms and devices. We could work in a conference room, we could work in a café, or we could work at our desk.”

– GARY LASASSO, DIRECTOR OF COLLABORATION EXPERIENCES & TECHNOLOGIES,  
AMICUS THERAPEUTICS

“We didn’t want to put people living with a rare disease in a potentially risky situation where timely return travel could be questionable, so we made it a two-day BlueJeans virtual event instead,” says Amanda Sowinski, Manager, Patient & Professional Advocacy, Amicus Therapeutics. “Since then, we’ve gained confidence that advisory board meetings that are virtual can be meaningful.”

“Since COVID-19 happened, BlueJeans has been great for enabling us to maintain that interaction with the patients and caregivers we partner with and continue to get their feedback. When travel isn’t an option — for whatever reason — it’s important to us that we can accommodate everyone.”

To ensure all Patient Advisory Board members were comfortable with the technology, Sowinski ran several practice sessions early in the process. As members are located around the globe, Amicus Therapeutics did not assume that English was everyone’s primary language. It also considered members’ varying degrees of familiarity with video conferencing technology. However, getting the hang of it didn’t take long. Everyone is now “very comfortable using it,” says Sowinski.

### Supporting the Work of Patient Organizations

The company also uses BlueJeans Meetings to regularly connect with the patient advocacy organizations it partners with. These organizations provide valuable support to patients, and work with doctors and researchers to develop treatments. They also deliver support, awareness, and education in the community.

While Sowinski used to connect with these nonprofit organization leaders on a quarterly basis, she’s been communicating with them more frequently since the COVID-19 crisis began.

### Inspiring Team Amicus to Excel

Helping employees around the world to remain engaged with the company’s mission while working remotely is critical to its continued success, as well as to maintaining its intensely patient-dedicated culture. To help connect with and inspire employees, the Patient and Professional Advocacy team broadcasts its regular ‘Lunch & Learn’ sessions via the BlueJeans Events platform to employees across the United States, as well as in Canada, Europe, Japan, and other countries around the world.

Before the pandemic, the company ran these sessions as hybrid events, with most employees attending in person. BlueJeans' Q&A and Raise Hands features enable remote employees to actively participate.

"We were a little nervous about going virtual, but it's been seamless," says Sowinski. "It has been easier to plan, and we often get even more questions than we used to in person when we passed around a microphone. BlueJeans' virtual Q&A feature has been great for getting people more involved — even if it's just people writing comments to thank our guests for sharing their stories."

The company has also launched a new online Mission Moment Library, with a selection of inspiring and informative videos featuring the realities faced by people living with rare diseases. These can be uploaded to BlueJeans Meetings and shared during internal or external meetings or company-wide events to keep employees connected with the purpose of their work and reinforce Amicus Therapeutics' extraordinary dedication to patients.

### **A Strong Foundation for Business Continuity**

According to Gary LaSasso, Director of Collaboration Experiences & Technologies at Amicus Therapeutics, the company's COVID-19 journey has been simpler than it might have been because BlueJeans was already in regular use to help facilitate communication and collaboration. "We didn't realize we were road-mapping for COVID-19," he says. "But it happened, and we were prepared for it."

"One of the great things about BlueJeans, even before COVID, was the interoperability with different platforms and devices. We could work in a conference room, we could work in a café, or we could work at our desk. We're still doing it the same way — that workflow hasn't changed."

Team members can also use BlueJeans as a bridge to other platforms such as Microsoft Teams. "For example, if I want to join a Teams meeting in a conference room, I can join it with BlueJeans Gateway," LaSasso says.

Amicus Therapeutics has also recently started working with BlueJeans Smart Meetings, which allows team members to capture meeting highlights and share notes with others using recordings. "The product road map at BlueJeans has been very innovative and continues to evolve, which is wonderful," LaSasso says.

#### **ABOUT AMICUS THERAPEUTICS**

Amicus Therapeutics is a global biotechnology company focused on discovering, developing, and delivering high-quality medicines for people living with rare metabolic diseases. Founded in 2002, the company prides itself on its patient-centricity. It advocates for patients and caregivers, and builds their perspectives into the design of clinical trials and other aspects of developing therapies. Amicus Therapeutics also supports patients and caregivers with the information and educational resources needed to understand the daily challenges of living with a rare, genetic disease.