

Things for Patient Advocacy Groups to Keep in Mind About Pharma



1. We want to be an advocate for your organization and for your patient community.

Information helps us do that. Established metrics or key performance indicators that you can share with us from your programs are super helpful as we translate the return of investment to our senior leadership and pitch to receive budget for your events, awareness activities, and community support tools. This can be evidence in various ways, such as case studies, audience reach to a particular segment, social media community size and influence, etc.

2. The more notice you can give us on future funding support opportunities, the better.

When it comes to sponsorship for programs throughout the year, it's helpful for pharma to understand a patient advocacy group's needs and priorities, even if it's an idea not formally defined or formed into a proposal, so that they can submit and plan for that budget allocation 4-5 months before the start of the new fiscal year (companies may budget up to a year in advance). Some pharma companies begin their fiscal year in July while others begin in January. It's a good idea for PAGs to ask about budgeting and timing as you begin conversations and get to know one another. Even though we may want to, it can be challenging to fulfill sponsorship requests that pop up in the middle of the year because our budgets are already tied to specific initiatives or services.

3. The decision-making process can be long.

There are several reasons as to why it may seem drawn-out to get a decision around sponsorship, material development, approvals, etc. In such a heavily regulated environment, multiple departments within a pharmaceutical company may need to approve materials (i.e., clinical development, legal, clinical operations, compliance, communications, commercial development, marketing, etc.) depending on the use and audience (i.e., education for patients and their families or health care professionals.) Even in the most streamlined of companies it can take a while.

4. There can be internal stops and starts, slowing down, and then moving quickly. When we come to you asking for things quickly, it is not a lack of consideration for your time.

There are many factors that go into investment decisions at pharmaceutical companies, looking at scientific, regulatory and market considerations. Pharma is always doing the delicate and difficult job of determining which assets are most likely to make it to patients. We know that in so many indications, patients are waiting. Yes, we are accountable to our investors, but we also feel accountable to the communities we are tirelessly working to serve. We want to give potential therapeutics the best shot at reaching and helping patients. This unfortunately can mean making really hard decisions. Sometimes studies (and spending for a particular therapeutic program) are paused until therapeutic area leadership and strategy teams determine the best way to proceed to develop a meaningful, safe, and effective new therapy. Then they are greenlighted, and it's full speed ahead as quickly as possible.

5. We always appreciate when you let us know if you're connecting with other people at our company.

One of our challenges is aligning within a large company across multiple functions who are eager to engage with patient organizations for different purposes of awareness-building. We will do our best to ask if you're engaging with folks in commercial, R&D, patient advocacy and policy, and medical affairs. We're also always happy to explain how our role or function works within the larger drug development process.