

▶ Patient Advocacy

Biopharmaceutical companies are becoming more fully engaged with patients as well as patient advocacy groups. Millennium's head of patient advocacy, Tom Sellers, discusses the barriers and opportunities that early engagement entails.



Tom Sellers

➔ **PV:** *What are the benefits to early patient engagement?*

➔ **PV:** *What has precluded biopharmaceutical companies from early patient advocacy engagement?*

SELLERS: I think in the past, the operating paradigm and the relationship between drug developers and the patients who ultimately took their medicines was viewed in mostly commercial or business terms. And biopharmaceutical companies valued the relationship late in the development continuum and from the perspective of the illness and not the patient.

There were also regulatory restrictions that the FDA has imposed — particularly around social media and how products can be promoted through any channel — that have not necessarily encouraged interaction between patients, physicians, and drug makers. That model has begun to change as companies are looking beyond “products that treat a disease” and view patients and patient advocacy groups as partners that can forge relationships as a platform for a shared vision with benefits for both patients and businesses.

Social media is one milieu that patients have clearly embraced and where the industry needs to enhance its presence if companies truly want to capture the attention and partnership of patients. Another is engaging patient advocacy groups in discovery and early-stage development.

➔ **PV:** *What are some of the ways or programs in which biopharmaceutical companies can engage patients?*

SELLERS: Companies can and should engage with patients around drug development, policy advocacy, and patient education. One of the most important areas for engagement that can most directly affect the course of a disease and its treatment is partnering around the design of and recruitment for clinical trials. Getting the patient perspective and a clearer understanding of what questions clinicians should be asking, assisting in active patient recruitment to ensure study validity, as well getting input in developing the correct trial protocols are important elements of any active engagement. In addition, patient groups are becoming more involved in funding and supporting

early-stage discovery and clinical development, particularly for rare diseases to leverage their research experience.

More and more patients are becoming key influencers of regulatory policy and reimbursement decisions for new therapies. Helping companies understand how healthcare policy impacts a patient and comprehending it from the unique perspective of the patient is critical. Developing a reimbursement strategy without listening to or understanding the patient voice is fighting only half the battle and companies should enlist patient support to help regulatory bodies and payers understand the impact on patients before making decisions that impact patients' access to care.

Finally, patients look to patient advocacy groups as a trusted source of information about their disease and often about treatment options. Supporting patient education programs is an important way to receive feedback from patients.

SELLERS: Patient groups have been a widely untapped resource for drug development. Companies can find great value in partnering with patient groups at virtually every stage of development. More patient groups are developing bio-banks, patient-led research networks, and patient registries. Patient groups provide many different channels for patient education and outreach, including clinical trial recruitment or adherence programs. Advocacy by patients is becoming more important as regulators and funders such as the FDA and NCI look to patient groups for input. Relationships with patients and patient group provides an opportunity for the creation of a shared vision that highlights opportunities that are mutually beneficial.

By changing the perception of industry and leveraging partnerships/collaborations built on mutual respect, companies can enhance their reputation and differentiate themselves in the eyes of current and potential beneficiaries. **PV**

Creating a Patient Connection: A Selection of Advocacy Organizations

» National Health Council

The National Health Council is made up of more than 100 national health-related organizations, divided into five membership categories: patient advocacy organizations; professional and membership associations; nonprofit organizations with an interest in health; business and industry; and associate members.

▼ For more information, visit nationalhealthcouncil.org.

» National Organization for Rare Disorders

The National Organization for Rare Disorders (NORD) is a federation of health organizations dedicated to helping people with rare orphan diseases and assisting the organizations that serve them.

▼ For more information, visit rarediseases.org.

» National Patient Advocate Foundation

The National Patient Advocate Foundation is a national nonprofit organization providing the patient voice in improving access to, and reimbursement for, high-quality healthcare through regulatory and legislative reform at the state and federal levels. NPAF translates the experience of millions of patients who have been helped by its companion, Patient Advocate Foundation, which provides professional case management services to individuals.

▼ For more information, visit patientadvocate.org.

» Patient Advocate Foundation

Patient Advocate Foundation (PAF) is a nonprofit organization that provides professional case management services to Americans with chronic, life-threatening, and debilitating illnesses. PAF case managers serve as active liaisons between the patient and the insurer, employer, and/or creditors.

▼ For more information, visit patientadvocate.org.

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