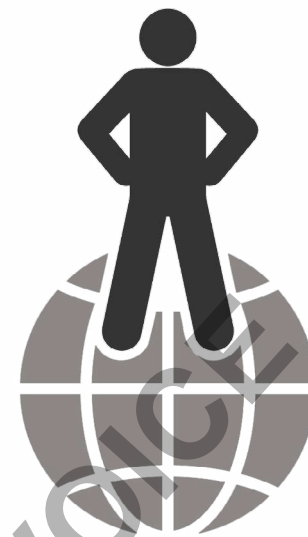




by Taren Grom

Chief Patient Officers and Advocates



More and more companies are elevating patient-facing roles to the C-Suite; as a result these key roles continue to expand and evolve.



JAYNE GERSHKOWITZ
Chief Patient Advocate
Amicus Therapeutics

THE NEW C-SUITE ROLE

The chief patient role is actually new compared with other C-suite industry positions. While many more companies are increasingly listening to patients and caregivers, I think this continues to be most evident in the rare disease space, where patient populations are so small that there needs to be an honest collaboration to address the legitimate concerns patients and caregivers have about their disease management and therapeutic options.

Throughout my healthcare and rare disease career, one of the bigger movements I've seen, especially driven by Amicus as a particularly patient-dedicated company, is the emphasis on being creative, connected and compassionate, and having a place at the table for patients from start to finish. As chief patient advocate, I've had the privilege of working with Amicus to help usher in a holistic approach of healing beyond disease, focusing on behaviors, and facilitating the company-patient-caregiver relationship into a cohesive, working unit.

PATIENT ENGAGEMENT

Patient engagement is only going to continue to grow in importance as we expand our industry further into personalized medicine. Giving people more access and control over their medical and health data — through genetic and diagnostic screening services such as genome sequencing, through data collection and sharing, AI, and more — is creating a community that is expected to become the most informed and involved generation of healthcare consumers and advocates. I see the chief patient advocate role becoming even more central to the overall purpose and strategies for achieving organizational goals across the rare disease space and into the broader pharmaceutical and biotechnology market. This role is poised to have a stronger influence across all aspects of the business and how we think about the entire spectrum of therapeutic development,

education and supportive services. It's not only about R&D and clinical research programs, but about the human experience of disease and improving that with myriad approaches.

Understanding rare diseases is more than just knowing how a disease comes about and progresses, it's also about the patient experience beyond their physiological health, i.e., how a disease impacts the day-to-day of the person living with a chronic, debilitating diagnosis as well as the entire family. As chief patient advocates, it will continue to be our responsibility to make sure that the concerns, unmet needs, and outcomes of patients and their families remain at the forefront of all organizational decisions that might influence the communities we're striving to help every day.

CREATING A JOURNEY

Understanding, connecting with, and inserting the patient perspective into the development of all our programs is really one of the driving aspects of my role as a chief patient advocate, and that of my team. We need to bring people along on an educational journey — both internally and externally. From start to finish, we want our patient community partners to understand what we're doing on a fundamental level, while informing us and sharing ideas to do things in a way that honors and makes sense to the lay community. Armed with this knowledge, we can keep them and their needs in our collective conscience and approach our work with an optimal sense of purpose, dedication and urgency.



KATHI HENSON
Chief Operating Officer,
Patient Services and Chief
Patient Officer
Eversana

A SEAT OF INFLUENCE

Patients rely on us not only to develop life-saving therapies, but also for help in developing strategies to ensure that they can access those therapies. The role of the chief patient officer (CPO) has significant influence across a pharma organization by

ensuring that the patient, arguably our most important stakeholder, is engaged in every phase of the precommercial and commercialization strategies of drug manufacturing. As a key senior leader, the CPO makes sure that the patient is kept at the center of key business decisions, the manufacturer truly partners with patients and patient organizations, and helps all team members within the organization understand how their role connects to the patient. By doing all these things, the patient becomes part of the organization's DNA and trust is ultimately built both internally and externally.

DRIVING COLLABORATION

Pharma has the opportunity to continue to be a leader in driving collaboration across all stakeholders — patient, payer, physician, and regulatory — as industry strives to continue to meet the needs of a rapidly changing environment. We must continue to push for advancements in and adoption of new technologies and financial models that incentivize patient care differently to make the shift from reactive care to proactive care. Fortunately, I believe we are starting to see changes in each of these areas, though more work is needed. Technology is enabling this to happen at a much more rapid pace by streamlining processes and allowing healthcare providers access to real-time patient data faster than ever before. Some examples include EHRs where IDNs have been drivers of adoptions, using digital tools to transform the way patients engage with education about their health condition as well as how providers connect with patients in the home setting, and wearables that give both patients and provider's better access to monitoring that can allow earlier intervention or diagnosis. Payers are starting to change incentives to focus on prevention of hospitalizations, prevention of chronic disease, as well as demonstration of outcomes for key high-cost therapies that can be curative. In addition, for the highest cost curative therapies we are also starting to see both manufacturers and payer's partner with value-based contracts. ^{PV}

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