



## **Director, Patient Advocacy**

**Location:** Waltham, MA

**About Us:** At Nightstar, our mission is to maintain and restore sight in patients with inherited retinal diseases. We are a clinical-stage company focused on developing and commercializing a pipeline of novel and potentially curative, one-time retinal gene therapies for patients suffering from rare inherited retinal diseases that would otherwise progress to blindness, and, for which, there are no currently approved treatments.

**Job Purpose:** We are seeking a Director of Patient Advocacy to lead the development and execution of advocacy strategy including defining, standardizing and executing best practices for patient advocacy engagement across the continuum of drug discovery and commercialization. Liaise with key internal stakeholders to define and build the overarching advocacy strategy. Serve as an internal resource by identifying opportunities and developing action plans to support programs that help patients by addressing disease-specific challenges, increase disease awareness, decrease time to diagnosis and increase access to therapy.

### **About the role:**

#### **Advocacy Strategy**

- Contribute to the development of the overarching strategic plan and holistic company philosophy around patient advocacy engagement and collaboration.
- Assess landscape and capabilities of patient advocacy and professional societies and adjust accordingly based upon capabilities and alignment.
- Create and maintain therapeutic area tailored advocacy strategies and operational engagement that may include but are not limited to educational programs, disease awareness initiatives, advisory boards, patient speaker engagement, clinical trial awareness, and policy improvements.
- Support the development and deployment of strategic advocacy campaigns within assigned therapeutic areas.
- Ensure that strategic plans with external stakeholders align with overarching corporate goals.

#### **Relationship Management**

- Responsible for leading relationship development with key advocacy and professional societies to ensure productive ongoing partnerships based on shared patient- focused objectives
- Ensure relationships are strategic not just transactional.
- Drive presence at relevant advocacy organization events and meetings. Share key learnings with relevant internal stakeholders.

#### **Cross-Functional Collaboration/Alignment**

- Bring experience to contribute as a high performing team member to help build the company's new patient and professional advocacy relations function including assisting with departmental strategy development, planning, budgeting and portal development.
- Build strong, collaborative relationships with internal stakeholders and communicate accordingly. Ensure cross-functional collaboration with medical, brand, market access, government affairs,



health policy and other key stakeholders to optimally manage relationships to ensure alignment and effective execution of patient advocacy strategy.

- Participate in relevant team meetings to facilitate ongoing communication of advocacy activities and to ensure continued alignment.
- Work collaboratively with Alliance counterparts.

**Critical Competencies:**

- BS within scientific discipline
- 10+ years of "progressive" industry/relevant professional experience; 7+ years of patient advocacy experience
- Understanding of relevant regulations and guidelines such as FDA, EMA etc.
- Proven ability to demonstrate leadership skills and a track record of developing communications and advocacy strategies and campaigns
- Ability to serve as company ambassador with external stakeholders  
Ability to anticipate and effectively resolve conflict, mitigate risks and forge consensus among diverse parties

**Behavioral and Interpersonal:**

- Excellent oral and written communication skills, strong leadership skills, self-motivated, and a team-player
- Strong track record of building successful relationships between healthcare corporations and patient advocacy organizations  
Strong team player able to prioritize efforts and manage internal and external stakeholder expectations

**Contact:** Katherine Danyluk, Recruiting Coordinator

[careers@nightstartx.com](mailto:careers@nightstartx.com)

+1 (617) 481-1709