Position Title: Director/Senior Director, Patient Advocacy

**Department:** Corporate Affairs

Reports to (title): VP, Corporate Affairs

**Location:** Boston, MA **Date:** November 2019

#### **About Catabasis:**

We are a team of experts from multiple disciplines who have come together driven to bring hope and life-changing therapies to patients and their families.

At Catabasis Pharmaceuticals (NASDAQ:CATB), we are excited about our lead program edasalonexent, an NF-kB inhibitor in development for the treatment of Duchenne muscular dystrophy (DMD). Edasalonexent is an investigational oral small molecule that is being developed as a potential foundational therapy for all patients affected by DMD, regardless of their underlying mutation. In DMD the loss of dystrophin leads to chronic activation of NF-kB, which is a key driver of skeletal and cardiac muscle disease progression. Our global Phase 3 PolarisDMD trial is evaluating the efficacy and safety of edasalonexent for registration purposes. Edasalonexent is also being dosed in the open-label extension trial GalaxyDMD. In our MoveDMD Phase 2 trial and open-label extension, we observed that edasalonexent preserved muscle function and substantially slowed disease progression compared to rates of change in a control period, and significantly improved biomarkers of muscle health and inflammation. The FDA has granted orphan drug, fast track, and rare pediatric disease designations and the European Commission has granted orphan medicinal product designation to edasalonexent for the treatment of DMD.

### Summary

- Build upon Catabasis' overarching global patient advocacy and patient community strategy. Develop
  a comprehensive and transformational engagement plan including defining, standardizing and
  executing best practices for patient advocacy and patient community engagement across the
  continuum of drug discovery and commercialization.
- Develop meaningful relationship engagement with global patient advocacy and professional organizations
- Remain abreast of new developments that have an impact on the function
- Define and deliver on clear metrics to measure advocacy efforts
- Share with the patient advocacy and patient community Catabasis' patient-centric philosophy and mission to bring hope and life-changing therapies to patients and their families
- Through understanding of the patient journey, increase the patient perspective in Catabasis decision making
- Support the building of a leading patient advocacy organization that is well-respected by the patient community, collaborators and advocacy partners

### Responsibilities

## **Advocacy Strategy**

• Contribute to the development of the overarching global strategic plan and holistic company philosophy around patient advocacy engagement and collaboration

- Liaise with key internal stakeholders to define the current and build the pre-commercialization and commercialization advocacy strategy
- Assess landscape and capabilities of patient advocacy and professional societies and prioritize collaborations 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
- Represent Catabasis at global patient advocacy events and present our edasalonexent and pipeline programs
- 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 proactive, strategic and sustaining
- 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.

### **Patient Voice**

- Leverage patient insights learned from the patient community and serve as internal consultant to champion and further incorporate patient perspectives into all appropriate initiatives, including disease education programs, clinical trial design, research collaborations and patient services.
- Act as the organization's ambassador for the patient perspective. Further enhance the patientcentric mindset at Catabasis and identify opportunities for organization members to learn more about patient and family experiences and perspectives.

### **Sponsorship Management**

- Manage budget and direct advocacy-related requests for funding (charitable donations, sponsorships, fundraiser and disease awareness events), providing recommendations to the review committee
- Ensure all advocacy funding requests are reviewed according to compliance policies
- Effectively manage patient advocacy budget and track financial support

### Requirements

Successful candidates will have the following:

- Strong track record of building successful relationships between healthcare corporations and patient advocacy organizations
- Undergraduate degree required
- 8+ years of "progressive" industry/relevant professional experience; 4+ years of patient advocacy experience.
- Understanding of relevant regulations and guidelines such as FDA, EMA, Pharma, GDPR, 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
- A self-starter with a high energy level and a passion for working with the patient advocacy community. Ability to work in a fast-moving, dynamic, small-company environment
- Ability to anticipate and effectively resolve conflict, mitigate risks and forge consensus among diverse parties
- Strong team player able to prioritize efforts and manage internal and external stakeholder expectations
- Excellent oral and written communication skills, strong leadership skills, self-motivated, and a teamplayer
- Travel: 40%+ (domestic and international with weekend involvement).

This is an opportunity to join our select team that is already leading the way in the Pharmaceutical/Biotech industry. Apply today by emailing <a href="mailto:careers@catabasis.com">careers@catabasis.com</a> and learn more about Catabasis' unwavering commitment to bring hope and life-changing therapies to patients and their families.