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**Job Title:** Project/Program Manager - Patient Programs – “Manager, Patient Programs”  
**Status:** Full-Time  
**Location:** Remote, with option to use offices in Cambridge MA, Aliso Viejo CA, and Washington DC  
**Last Revised Date:** May 2022

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**ABOUT GLOBAL GENES:**

Founded in 2008, Global Genes is a 501(c)(3) nonprofit organization that connects, empowers and inspires the rare disease community, with the ultimate goal of eliminating the burdens of rare diseases for patients and families everywhere. We provide hope and direction for the more than 400 million people affected by rare disease around the globe. We fulfill our mission by helping patients find and build communities, gain access to information and resources, connect to researchers, clinicians, industry, government and other stakeholders, share data and experiences, and stand up, stand out and become effective drivers of progress on their own behalf.

**ROLE SUMMARY:**

Patient and capacity-building programs is an essential team at Global Genes. The work is highly visible in the rare community. Education is produced and delivered by multiple avenues including live and online learning, video, live and recorded education and programs. Alignment of programming is vital for success in meeting the Global Genes mission.

This role requires a confident, poised leader who is a great listener that takes the time to understand the needs of the community and can shape delivery of tools and resources for optimal impact and scalability across rare disease worldwide. An ideal candidate is a project manager, a creative problem solver and a relationship builder who fosters confidence in Global Genes, both internally and externally. Attention to detail, communication, analytical and multi-project management skills are essential skills.

The **Manager of Patient Programs** is responsible for leading the programmatic delivery of education and learning to our community for maximum impact. This role provides leadership and direction to the team, navigating alignment across the organization and establishing clear priorities, processes and direction. Acting as a bridge, the role provides clarity and direction and internal and external communication to maintain alignment to goals. Direct team includes those responsible for developing content and resources for rare families and foundations of the RARE Foundation Alliance.

**KEY RESULTS:**

- Represent Global Genes, builds key relationships for long term growth and expansion
- Build and maintain team direction and adherence to priorities
- Ensure delivery of outstanding educational tools and resources
- Build and grow an outstanding team in alignment with mission vision and objectives
- Evaluate processes, making ongoing improvements with an eye toward global scalability

**RESPONSIBILITIES:**

The Manager of Patient Programs will act as the project manager for one or multiple organizational initiatives and will function as a leader and an essential member of team to carry out the duties required of the position which include but are not limited to:

- Drive the design and implementation of work plans and priorities with the team
- Set and manage to deadlines, priorities and timelines



- Make certain decisions are in alignment with organizational priorities and commitments
- Participate in cross-functional teams or assign members of the team to participate
- Track, measure and give individual and team feedback for team and individual development
- Continually coach direct reports for development and growth
- Work with marketing and communications to design and promote educational services
- Use financial data to make decisions and manage to or under budget
- Lead in forecasting and developing budget for functional area
- Actively gain and utilize community information to build success for the future

**QUALIFICATIONS:**

- Bachelor's degree from an accredited college or university required, advance degree and/or project management certification ideal
- Minimum of 3 – 5 years proven success in patient education or other life-sciences related areas
- Knowledge of issues facing rare disease patients and the broader community is preferrable
- Strong and demonstrated project management skills
- Experience in building initiatives and forming partnerships for health equity, diversity and inclusion programming a plus
- Non-profit advocacy, healthcare or life sciences experience a plus
- Exceptional analytical, problem solving and communication skills
- Exceptional professional style with a strong customer service approach
- Ability to lead and/or manage cross-functional teams, advisors and freelancers
- Strong passion for the rare disease community
- Self-starter with a proven commitment to excellence; results-oriented
- Role model in organizational skills, attention to detail and gaining accountability
- Comfortable working on a fast-paced remote team
- Bilingual or proficiency in multiple languages is ideal
- Proficient in Project Management platforms, Microsoft Suite, MS Word, Excel, PowerPoint, database management required (Salesforce preferred), Social Media platforms and other online tools for communication
- Ability to travel for meetings and conferences globally

**PERFORMANCE MANAGEMENT AREAS:**

- Core Values: Integrity, Authenticity, Respect, Creativity, Collaboration and Fun
- Competencies: Personal, People, Strategic and Position
- OKRs: Objectives and Key Results

**To Apply: Please email resume and cover letter to [humanresources@globalgenes.org](mailto:humanresources@globalgenes.org)**

*Equal Opportunity Employer committed to diversity in the workplace.*

The statements herein are intended to describe the general nature and level of work being performed by employees and are not to be construed as an exhaustive list of responsibilities, duties, and skills required of personnel so classified. Furthermore, they do not establish a contract for employment and are subject to change at the discretion of the employer.