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patient



Executive Director

Generation Patient

Remote

Salary: \$125,000 - \$140,000

The Organization

Generation Patient represents the 25 million+ young adults with chronic and rare conditions. Over the last few years, Generation Patient has led more than 650 peer support meetings for its community of young adult patients, published multiple peer-reviewed publications, and driven policy and advocacy campaigns focused on clinical trial representation, patent reform, and increased oversight of pharmaceutical advertising on social media. The organization primarily leads reform efforts in the United States and has a growing international profile.

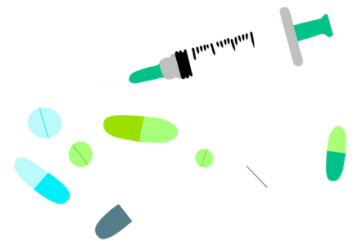
Generation Patient was established as a nonprofit in 2018, with roots dating back to 2013, with an initial focus on young adults living with inflammatory bowel diseases (IBD). Since its inception, the organization has expanded its mission to represent young adults with all chronic and rare conditions (i.e., lupus, arthritis, sickle cell, diabetes, epilepsy, among others). Today, Generation Patient, with an annual budget of \$750,000, is supported by four staff members and contractors, with plans to expand its team over the next two years to meet growing demand. The team is fully remote with staff members located across the country.

Generation Patient has established itself as a leading voice in patient advocacy, disability justice, and access to medicines movements, forging impactful partnerships and coalitions both in the U.S. and internationally. Generation Patient's advocacy is pragmatic and evidence-based, working across the political spectrum to advance policy solutions. With strong foundation support, the organization maintains full independence by declining all private health-industry funding, including from the pharmaceutical, insurance, and PBM sectors. This refusal of private health-industry funding is core to Generation Patient and ensures accountability and integrity for the young adult patients the organization represents.

The Position

Generation Patient is at a pivotal transition point as its founder moves out of the Executive Director role. The organization seeks its next Executive Director to bring it into a new phase of impact. The Executive Director will oversee all aspects of the organization, sustain and scale impact, and remain committed to the young adult patient community that Generation Patient proudly serves. Leveraging Generation Patient's deep-rooted partnerships with peer organizations and its strong relationships with funders and policymakers, the next leader will ensure a future for our patient community. They will oversee direct support programming and strategically drive systems-level change across healthcare and research.

Partnering with the Board of Directors, the Executive Director will act as the organization's primary external spokesperson, fundraiser, and advocate. They will be responsible for leading Generation Patient's programs and policy work, and will oversee operations, finance, human resources, and fundraising. The Executive Director's role is to drive community-informed strategic direction and to oversee partnerships and collaborations that enable Generation Patient to achieve its mission of elevating young adult patients on national and international platforms. As Generation Patient continues to work with global partners, the opportunity to serve as Executive Director arises at an exciting time to expand its impact for young adult patients worldwide.



Strategy & Organizational Leadership

- Collaborate with Board, staff, and others to cultivate an environment that upholds Generation Patient's mission, which is rooted in its dedication to inclusive, accessible standards of operation and an ongoing pursuit of quality improvement.
- Partner with the Board and staff to define an organizational strategy with measurable goals.
- Assess the current team and organizational structure, clarifying roles and responsibility and closing gaps.
- Support board recruitment, development, and governance.
- Maintain financial oversight and ensure compliant operations, including annual budget and audit.



Fundraising & Sustainability

- Lead funder engagement and stewardship efforts, diversifying philanthropic support through multi-year foundation partnerships and the establishment of an individual giving strategy.
- Bring strong financial and operational judgement to budgeting, forecasting, and grants management.
- Partner with the Board on a cohesive, multi-year fundraising strategy grounded in the organization's vision.
- Evaluate and ensure financial viability of new initiatives, considering the organization's evolving needs and priorities.

Policy & External Relations

- Set policy priorities and collaborate with the Policy Director and the Policy Manager to shape and implement impactful policy goals.
- Build relationships with funders, government officials, and community groups to build support and partnerships and to advance key policy initiatives.
- Serve as chief spokesperson and ambassador with funders and partners.

Programs Oversight

- Ensure peer support programming aligns with evolving community needs; expand program visibility through effective communication strategies.
- Bridge peer support and policy work and build pathways for community engagement across the organization.

The ideal candidate for the Executive Director position possesses the following competencies:

Drives Vision & Purpose

Painting a compelling picture of the vision and strategy that motivates others to action.

Manages Ambiguity

Operating effectively, even when things are not certain, or the way forward is not clear.

Resourcefulness

Securing and deploying resources effectively and efficiently.

Balances Stakeholders

Anticipating and balancing the needs of multiple stakeholders.

Action Oriented

Taking on new opportunities and tough challenges with a sense of urgency, high energy, and enthusiasm.

Financial Acumen

Interpreting and applying understanding of key financial indicators to make better decisions.

What we are looking for:

- Deep commitment and connection to the mission of Generation Patient.
- Experience leading and developing a team; nurtures collaboration, accountability, and professional development.
- Demonstrated experience bringing in funding from both foundations and individual donors.
- Strong skills in policy analysis and understanding of complex policy and legal documents; background in health policy or patient advocacy is valued.
- Strong verbal and written communication skills; comfort representing the organization in one-on-one and group conversations, as well as presenting to larger groups.
- Analytic and problem-solving skills; ability to strategically align Generation Patient's work according to community needs and the external environment.
- Able to work efficiently and independently as well as collaborate effectively with others.
- Proven emotional intelligence and conflict management expertise; strong interpersonal skills.
- Comfortable operating in a small, nimble organization and making confident decisions amid ambiguity.
- Experience with board member recruitment and engagement
- Previous experience working with young adults.
- Location in or near the DC/Northeast region is a nice-to-have.



Work Environment

Position is remote. Work environment is based on a personal home office. Must be willing to have availability outside of 9-5 p.m. EST for international work and to accommodate West Coast staff when needed.

Physical Demands

Sitting or standing at a desk, working with a computer, including many hours of screen time and virtual meetings.

Travel Required

National travel 1-2 times a month for organizational and partner events, policy, and fundraising meetings, speaking engagements.

Work Authorization/Clearances

Will require a background check for work with young people around sensitive topics.

Our Commitment to Diversity, Equity, & Inclusion

Generation Patient is an equal-opportunity employer. We value collaboration, respect, empathy, accountability, and independence. We encourage people who have been young adult patients themselves, those experienced with chronic and rare diseases, and/or those who have cared for people with chronic disease to apply.

Compensation and Benefits

Salary

\$125,000 - \$140,000

Benefits

- Monthly healthcare stipend (\$750) to support employees' medical coverage
- Employer-paid dental, vision, and short-term disability insurance for employees
- Paid time off, including vacation and sick/safe leave
- Paid holiday schedule, including major federal holidays and year-end holidays

If you are interested in this position, please [click here](#). All applicants will receive an email confirming receipt of their application.

We encourage candidates of all backgrounds to apply even if you do not meet all of the qualifications outlined above. If you are selected to move forward for an initial screening call, we expect you to hear from us by September.

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[Submit an application](#)