

Director of Access Policy and Innovation

Sick Cells is hiring a Director of Access Policy and Innovation. This is a leadership role.

Organization Overview: Sick Cells is an advocacy nonprofit. The organization focuses on storytelling and policy initiatives to eliminate stigma associated with sickle cell disease (SCD) while empowering the community to share their stories for change.

Duration: The position is a full-time position, hybrid role. This position requires, at minimum, two days of in-person work at the DC office. The DC office is located at 1012 14th Street NW, STE 500.

Travel: This role requires work travel. Travel includes conferences, offsite meetings, and meetings with remote staff. There is about 30% travel.

Benefits:

- \$95k-\$110k
- 403(b) with matching
- Dental and vision insurance
- Health insurance
- 4-day work week (32-40 hrs/week)

- Continuing education stipend
- Paid leave
- Parental leave
- Office Closed Week of July 4 and Week of Christmas Eve to New Years

Job Role: The Director of Access Policy and Innovation will lead community advocacy and education as it relates to payer policy, Medicaid, and the CMMI Cell and Gene Therapy (CGT) Access Model initiative. The primary focus of this role will be managing a learning systems project related to SCD and CGT. This role requires strong project management skills, including managing timelines, deliverables, and deadlines.

This individual will build relationships with a broad range of stakeholders, including healthcare providers, patients, community organizations, and payers, to enhance equitable access to these cutting-edge therapies.

This position will oversee the planning, coordination, and implementation of program activities, ensuring alignment with the overarching goals of raising awareness, expanding knowledge, and promoting effective treatment for sickle cell disease.

Key Responsibilities:

Program Oversight

- Develop and implement a comprehensive program plan for the contract focused on the learning and diffusion of the SCD cell and gene therapy model.
- Ensure timely delivery of project milestones and oversee the quality of educational content dissemination.
- Ensure alignment of program goals with the overarching objectives of the SCD Cell and Gene Therapy Learning and Diffusion objectives.

Sick Cells 501 (C)(3) Nonprofit | sickcells.org Mailing Address | 1042 Maple Ave STE 103 | Lisle, IL. 60532 DC Office | 1012 14th Street STE 500 | Washington, DC. 20005



Stakeholder Management

- Cultivate and manage relationships with key stakeholders, including healthcare professionals, educational institutions, community organizations, and patient advocacy groups.
- Serve as the primary point of contact between subcontract partners and internal teams, facilitating collaboration and communication.
- Engage subject matter experts and coordinate their involvement in content development and dissemination strategies.

Educational Content Development & Dissemination

- Oversee the development of high-quality educational materials and resources, ensuring they are accurate and accessible to various audiences, including healthcare professionals, community members, and the public.
- Coordinate the design and execution of dissemination strategies to ensure widespread adoption of the SCD cell and gene therapy model.
- Promote the diffusion of research findings, therapy models, and new treatment approaches through publications, workshops, conferences, and digital platforms.

Business Development

- Participate in business development for the organization, i.e., grant writing and reviewing and partnership building.
- Participate in fundraising activities for organization, i.e., attend fundraising events.

Education and Work Experience:

- Bachelor's Degree plus 5-7 years of related work experience and cumulative 10 years of work experience
- Experience working on Medicaid, Medicare, and payer policy required
- Familiarity with patient advocacy, healthcare policy, and regulatory considerations related to gene therapy
- Experience in public speaking to large and small audiences, research, and analytical skills
- Experience writing in multiple formats including presentations, lay summaries, and reports
- Excellent communication skills with the ability to provide analysis and explanations of technical policies in written and oral format
- Project management experience required (2-4 years)
- Exemplary relationship management, interpersonal and communication abilities
- Strong computer/technology skills; proficient in Microsoft Office, Gsuite, and the ability to learn new software

To apply, send CV, cover letter, and written example of work to Pamela Edwards pedwards@armconsultingonline.com