



Director of Access Policy and Innovation

Sick Cells is hiring a Director of Access Policy and Innovation. This is a leadership role and will work closely with leadership and Community Programs teams.

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:

- \$119k-123k
- 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

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 Access Model initiative. The primary focus of this role will be managing a learning systems project related to sickle cell disease and CGT.

The Director is responsible for understanding current and emerging policy around SCD across federal, state, and commercial payers. The Director should have a strong understanding of the payer landscape, with a focus on the Centers for Medicare & Medicaid Services (CMS), state Medicaid programs, and payer policy.

The role also focuses on managing the learning and diffusion of innovative access models for cell and gene therapies, ensuring the widespread adoption of successful practices. 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 sickle cell gene and 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.
 - Provide strategic direction and operational leadership, guiding the team in implementing key project milestones and deliverables.
 - Continuously evaluate the program's effectiveness and adjust strategies as necessary to ensure optimal results.
- **Stakeholder Management:**
 - Cultivate and manage relationships with key stakeholders, including healthcare professionals, educational institutions, community organizations, and patient advocacy groups.
 - Act 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 scientifically accurate and accessible to various audiences, including healthcare professionals and the public.
 - Coordinate the design and execution of dissemination strategies to ensure widespread adoption of the sickle cell gene and therapy model.
 - Promote the diffusion of research findings, therapy models, and new treatment approaches through publications, workshops, conferences, and digital platforms.
- **Monitoring & Evaluation:**
 - Develop and implement monitoring and evaluation frameworks to assess the program's impact and effectiveness.
 - Collect and analyze data on learning outcomes, audience engagement, and the adoption of new therapies.
 - Report on program progress, successes, challenges, and lessons learned to internal and external stakeholders.
- **Risk Management:**
 - Identify and manage potential risks related to the subcontract, ensuring proactive mitigation strategies are in place.
 - Ensure compliance with all relevant policies, regulations, and ethical standards related to healthcare education and research dissemination.



Other Responsibilities:

- Plan and execute advocacy and community outreach strategies including grassroots and community activation
- Lead education efforts for community members around relevant program or function activities, i.e., preparation for DURB meetings, townhalls, roundtables, etc
- Contribute to monthly newsletters, fundraising campaigns, and general organizational activities
- Identify and participate in research opportunities
- Author White Papers on relevant topics

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

Management

- Manage staff members
- Oversee project-specific contractors
- Track staff project work, deliverables, and professional development

Education and Work Experience:

- Bachelor's Degree plus 5-7 years of related work experience and cumulative 10 years of work experience
- Experience in working with Medicaid, Medicare, and payer policy
- Knowledge of dissemination and diffusion theories in healthcare or educational programs.
- Familiarity with patient advocacy, healthcare policy, and regulatory considerations related to gene therapy
- Experience in public speaking to large 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
- Excellent project management, leadership, and communication skills.
- Strong organizational and time management skills
- Exemplary relationship management, interpersonal and communication abilities
- Ability to work in a fast-paced environment, strong willingness to initiate deadlines and time frames for assignments and to follow up on all delegated activities
- Strong computer/technology skills; proficient in Microsoft Office, Gsuite, and the ability to learn new software
- Self-motivated and possess the ability to work well both independently and within a team

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