



Genomics and Sickle Cell Partnership Manager

Job Description and Person Specification

The Sickle Cell Society is looking for a Genomics and Sickle Cell Partnership Manager to deliver the Society's partnership programme with Genomics England, in particular a Priority Setting Partnership and Exercise.

Post: Genomics and Sickle Cell Partnership Manager

Base: Flexible, at home, at Sickle Cell Society Office, 54-56 Station Road, London NW10 4UA and at Genomics England office 1 Canada Square, Canary Wharf London.

Reports to: Chief Executive with close relationship to Community Manager for Diverse Data at Genomics England

Responsible for: No direct reports

Working Hours: Part-time (21 hours per week) Monday-Friday, flexible

Salary: £27,000 – £30,000 pro rata

Contract: 18 months

Job Purpose

To coordinate and ensure the successful delivery of a partnership programme between Sickle Cell Society and Genomics England. This includes working with the James Lind Alliance to deliver a Priority Setting Exercise for future genomics research on Sickle Cell.

About the Sickle Cell Society:

The Sickle Cell Society (SCS) is the only national charity in the UK that supports and represents people affected by a sickle cell disorder. We provide information, advice and support to enable and empower individuals and families to improve their overall quality of life. Approximately 15,000 people in the UK have a sickle cell disorder. These inherited conditions predominantly affect people of Black African and Black Caribbean heritage; and to a lesser extent people of Mediterranean, Middle Eastern, South Asian and Central/South American heritage. We assist and enable people living with SCD to realise their full potential whilst successfully managing the challenges they face in living with this potentially life-limiting condition.

We are a small, friendly and close-knit team of 14 skilled and highly committed staff (9 part-time / 5 full-time) and approximately 30 active volunteers.

Key responsibilities and duties

Support the delivery of a Priority Setting Partnership project with Sickle Cell Society and Genomics England:

- Organising teleconferences, Steering Group meetings and workshops for PSE and wider partnership activities
- Recruitment of individuals attending workshops: members of public, patients, experts, etc.
- Writing and following up on action notes
- Managing communications with stakeholders and the wider community e.g., liaise with Comms Leads at GEL and SCS to create relevant content
- Prepare any further supporting materials needed for meetings
- Communication activity such as preparing a website, communicating via e.g., Twitter
- Support producing and publicising the survey and downloading the survey results ready for the Information Specialist for PSP

Skills and Experience

- Engagement, project management or similar proven experience of at least 3 years in a similar role
- Experience of delivering on successful communications and health engagement projects
- Strong and enthusiastic communicator who is comfortable liaising with people at all levels
- Experience of co-ordinating and writing reports
- Eye for detail and understanding of developing powerful and engaging communications
- Excellent IT skills across a wide range of channels including website content management platforms, Microsoft, survey platforms, social media tools, graphic design, video editing and experience of Content Management Systems
- A strong team player who is also self-motivated with the initiative to identify opportunities for campaigning and engagement
- Ability to multi-task, meet deadlines and add value, develop in the role
- An interest in health research, rare conditions and genomics

To Apply

Please complete our **Application Form** and send it along with your **CV** to <u>info@sicklecellsociety.org</u> before the closing date.

Please note that applicants must reside in the UK.

Closing date for applications: 23rd May 2023

Interview date: Thursday 1st June 2023

Secondments from other organisations will be welcomed.