



# Alström Syndrome UK

Strength for today, hope for the future

## Patient & Public Involvement & Engagement (PPIE) Coordinator

### Job Description

**Employer:** Alström Syndrome UK

**Location:** Home based

**Line Manager:** Chief Executive

**Salary:** £26,242 - £29,749 (pro rata) depending on experience (actual salary for a 3 day per week post is £15,746 - £17,850)

**Term:** 3 days per week with some flexibility around working days. The post is for an initial 2 years with the possibility of extension dependent on project funding. There is a 3-month probationary period.

### Introduction to Alström Syndrome UK & Breaking Down Barriers

Alström Syndrome UK (ASUK) was established in 1998 and is a registered charity providing information and support to individuals and families affected by Alström Syndrome (AS) and to the service providers working with them. ASUK works in partnership with Birmingham Women's and Children's Hospital and the Queen Elizabeth Hospital, Birmingham to deliver a highly specialised service, funded by NHS England. As a patient led organisation, the needs and wishes of people affected by AS remain at the heart of everything we do. We aim to; provide personalised support, raise awareness, conduct pioneering research, and enable better treatments and monitoring through the AS multi-disciplinary clinics.

ASUK co-founded Breaking Down Barriers in partnership with The Sylvia Adams Charitable Trust.

Breaking Down Barriers is a network of over 70 organisations providing support to people living with rare and genetic conditions. We work together to learn, develop, and share good practice. Promoting equity, diversity and inclusion is at the centre of what we do. Our Experts by Experience Advisory Group help us to understand the lived experiences of people from diverse, marginalised and underserved communities who are affected by rare and genetic conditions. We create safe spaces for learning and collaboration, deliver training and run a community outreach project. We unite and strive for equitable access to services and support for all.

We have a skilled and experienced team and the charity is led by the Chief Executive with strategic direction, support and guidance from a Board of Trustees and advisors.

## **Purpose of the role**

This role is a pivotal part of our work in research and service development, both within ASUK and the wider BDB Network. The role will include:

1. Involving people with lived experience to further develop the work of ASUK and BDB
2. Supporting the BDB Experts by Experience Advisory Group
3. Supporting the BDB Network with PPIE initiatives
4. Coordinating PPIE activities for various research projects within the rare and genetic community

If you have a passion for supporting organisations who want to make a positive difference to the lives of families living with genetic conditions, then we would like to hear from you.

We would expect you to have excellent communication skills and the ability to work with individuals and collaboratively with organisations and other stakeholders.

Two references and an enhanced Disclosure and Barring Service check will be required.

## **Specific Areas of Responsibility**

- Develop and facilitate PPIE meetings with people with lived experience.
- Work with research teams to embed PPIE.
- Undertake and manage specific involvement and engagement activities, including but not limited to focus groups, engagement events and consultation activities.
- In collaboration with senior colleagues, support involvement of patients and the public in the governance of our work.
- Review materials and provide advice and guidance, incorporating PPIE.
- Develop methods to expand our reach and increase the involvement of people from diverse, marginalised and underserved communities in our work.
- Build and manage relationships with colleagues, communities, service providers and the BDB network, working collaboratively to support and manage involvement and engagement across all areas of work.
- Work closely with the Operations Manager to create engaging content (e.g. news stories on outputs and impact, videos, infographics, case studies) to share involvement and engagement activities.
- Raise awareness of ASUK and BDB by attending meetings, linking with communities, presenting at events and conferences, and identifying suitable opportunities to share our work and promote collaboration.

- Support the development of BDB members as requested by individual organisations and agreed by the Chief Executive.
- Support the planning and delivery of meetings and events to increase engagement with families from diverse, marginalised and underserved communities and supporting people to access appropriate services.
- Promote PPIE and support individuals and groups to take part in research and service development.
- Support the development of plain language documents and translated information.
- Organise interpreting services for individuals and families who do not speak English as their first language.
- Support organisations to develop good practice resources to enable them to increase their reach within communities.
- Manage internal and external communications effectively using a range of channels including social media.
- Contribute to research and funding bids.

## **General Areas of Responsibility**

The post-holder will be expected to:

- Further the aims and objectives of Alström Syndrome UK
- Cooperate fully with all Alström Syndrome UK's policies and procedures.
- Assist with any reasonable duty at the request of the Chief Executive.
- Work from home and be able to work flexibly dependent upon the needs of PPIE members and the charity.

The responsibilities above form the core of the role; however, the employee may be asked to undertake additional activities from time to time.

## **Confidentiality**

1. The confidential nature of the work means that employees working for Alström Syndrome UK must maintain the strictest security in relation to documentation and maintain confidentiality, in accordance with relevant Data Protection and associated legislation.

## **Health & Safety**

The post holder is expected to make themselves aware of and comply with Alström Syndrome UK's Health & Safety Policy

This role profile is designed to identify principal responsibilities. The post holder is required to be flexible in developing the role in accordance with changes within Alström Syndrome UK's management agenda and priorities.