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**About us**

Alström Syndrome UK (ASUK) is an award-winning charity which provides information, support and advice for individuals, their families, carers and professionals.

Alström Syndrome (AS) is a very rare genetic condition which can cause progressive blindness and hearing loss. It can also lead to heart and kidney failure, type 2 diabetes, liver dysfunction and associated problems. The symptoms arise at different stages making diagnosis and treatment difficult.

We raise awareness, manage a range of projects, support pioneering research and enable better treatments and monitoring through the AS multi-disciplinary NHS clinics.

**Our people**

We are a small and highly committed team made up of 6 staff and 6 Trustees. Many of the staff and Trustees are either directly affected by Alström Syndrome or care for a child or young person who has the condition. We are passionate about the work we do.

**About the Breaking Down Barriers project**

At Breaking Down Barriers, we believe that patient organisations and support groups have an important role to play in addressing the challenge of developing appropriate genetic services for the UK’s multi-ethnic population. The purpose of this project is to strengthen the ability of patient organisations and support groups to develop supportive and inclusive services for individuals and families from ethnic minority communities who are affected by genetic disorders.

**About the Sylvia Adams Charitable Trust**

The Sylvia Adams Charitable Trust provides the funding for Breaking Down Barriers and takes an active role in the development of the project. It provides grants to member organisations to improve information, education and the support they provide. The long term aim is to help reduce the number of children being born with recessive conditions, working with those communities who are at increased risk.

**The role of the Project Outreach Officer**

Breaking Down Barriers is a well-established project and we are now seeking additional support from a Project Outreach Officer. As the Project Outreach Officer, you will provide support to the Project Lead and work closely with member organisations to maximise their activities, working directly with people from ethnic minority communities to improve their access to services. You will help design, translate and user test information and resources in a variety of different formats and help establish new support groups for individuals and families, linking with relevant health care providers, community and faith leaders.

It would be advantageous to have some experience of genetic counselling and an understanding of patient organisations, charities and/or support groups. You will have excellent people skills and be a competent IT user. You will be a good listener, well organised and motivated. Critically important to this role is respect and sensitivity for the religious and cultural beliefs of individuals and families.

It will be a distinct advantage if you have personal experience of genetic conditions.

**How we work**

We work as a geographically dispersed team and this role will be home based. The Project Lead is based in Rotherham, South Yorkshire and member organisations are located throughout England and so extensive travel is required.

Our values are to work together with honesty and integrity, place individuals and families at the centre of the service, be respectful of those we work with and of each other and to be resourceful. We recognise that our behaviour demonstrates our values.

The team meets regularly to think about how to improve what we do and to talk about the achievements and challenges for member organisations, individuals and families and how we can make a difference.

**Salary, hours of work and benefits**

This is a 0.6 role, 3 days per week and there can be some flexibility around the working days.

The salary range is £10,800 - £14,522 dependent upon experience, knowledge and skills. (The full-time equivalent scale for this role is £18,000 - £24,203).

Relevant and agreed expenses will be reimbursed.

The holiday entitlement is 28 days (pro rata) during each complete holiday year, including a pro rata allowance for the 8 bank holidays

The Charity currently operates a Stakeholder Pension Scheme that you are eligible to join.

An enhanced DBS check is a requirement of this post.

**Closing date**

The closing date for applications is Monday 5th March at 5pm. Interviews will be held during the week commencing 12th March 2018 and as this is a national role, interviews will take place in different parts of the UK depending on the location of applicants. Details of how to apply are in the applicant pack. Thank you for your interest in ASUK and the Breaking Down Barriers project.