

Head of Patient Support and Welfare – AKU Society

Status: Part time
Reports to: CEO
Based: Home based, with monthly visits to Liverpool
Hours: 30/week
(four days/week)
Salary: £28,000
(for four days/week)

To apply: send a CV and covering letter to Dr Nick Sireau, Chair and CEO, AKU Society, at info@akusociety.org

Deadline for applications: Sunday 8 September (strong applicants will be interviewed as and when they apply before the deadline)

About the AKU Society

The AKU Society is a charity that supports patients with alkaptonuria (AKU for short), a rare genetic disease. Set up in 2003 by a patient and a doctor, it works in close partnership with the Royal Liverpool University Hospital and the University of Liverpool. The AKU Society's board of trustees is made up of patients, carers and doctors.

AKU is a rare genetic disorder caused by a missing enzyme, leading to the accumulation of homogentisic acid at 2,000 times the normal rate. This generates damage to cartilage and bone, leading to severe disability as life progresses. It is known as 'black bone disease' because of the way it discolours bone. It was the first genetic disease ever discovered, in 1901, but there is still no cure.

AKU patients are often severely isolated, marginalised and depressed because the rarity of their condition means that they are poorly cared for by the medical profession and statutory services, who do not understand their condition. AKU patients suffer from lack of information about their illness and how to care for it and find it difficult to access treatments.

We work with the Royal Liverpool University Hospital to run the National AKU Centre. This is a service for AKU patients from England and Scotland where they receive a wide range of assessments and access to treatment. The AKU Society provides the patient support for this service.

About this position

This is a patient facing position. The post holder provides essential support to the AKU Society by being the main point of contact with the Royal Liverpool University Hospital, patients/relatives/carers and their doctors/specialists; drawing patients into the AKU community; drawing up and providing them with advice, training and assistance on disability benefits, lifestyle, diet and access to treatments (physiotherapy and a drug called Nitisinone that stops the accumulation of homogentisic acid); communicating with the rest of the AKU community. The postholder will have strong communication, organisation and administration skills in order to support the activities, as well as a good understanding of disability.

Job Purpose: The Head of Patient Support and Welfare is responsible for leading the development and delivery of patient support and welfare services for the AKU Society. The role involves working closely with patients, their families, and healthcare professionals to ensure that patients receive the best possible care and support.

Key Activities

Key Responsibilities:

- Develop and implement a patient support and welfare programme that aligns with the AKU Society's mission and objectives.
- Build and maintain relationships with healthcare professionals, patient groups, and other stakeholders to promote awareness of the AKU Society and its services.
- Develop and deliver programs for healthcare professionals to improve their understanding of AKU and the support services available.
- Provide guidance and support to patients and their families, including advice on healthcare, welfare, and other matters.
- Ensure that patient data is collected and managed in accordance with data protection regulations and ethical standards.
- Monitor and evaluate the effectiveness of patient support and welfare services, making recommendations for improvements where necessary.

Key point of support for AKU patients

- Organising phone calls and visits to AKU patients
- With assistance from the medical team in Liverpool, responding to the AKU helpline for patients and relatives/carers who need advice
- Ensuring patients are properly linked to the AKU centre in Liverpool and to their GPs and specialists
- Attending the NHS National AKU Centre in Liverpool for 2-3 days at the beginning of each month to support patients.
- Visiting patients most in need to help and support them
- Putting patients in touch with each other
- Acting as a point of contact for and communicating to patients and doctors.
- Emotional support and care (including home visits)
- Information sharing (logistics such as what they can expect, where to go, what to do, and other such issues)
- Plan, organise and run regular patient workshops

AKU global registry

- Working with the registry provider to build and implement the registry
- Working with local patient groups and clinicians around the world to populate the registry
- Working with the registry provider to provider reports

Monitoring and evaluation

- Interviewing patients and doctors to assess their needs and level of knowledge
- Running offline monitoring and evaluation such as surveys and interviews and reporting back
- Providing regular reports and updates to the AKU Society
- Representing the AKU Society at patient network events and forums

Qualifications and Experience:

- Strong communication and interpersonal skills, with the ability to build relationships with a wide range of stakeholders.
- Sound knowledge of patient support and welfare issues, including healthcare, welfare, and other matters.
- Experience in developing and delivering training programs for healthcare professionals.
- Knowledge of data protection regulations and ethical standards.
- Nursing background preferably and an interest in rare diseases.

Competencies:

- Excellent communication and interpersonal skills
- Ability to build and maintain relationships with a wide range of stakeholders
- Sound knowledge of patient support and welfare issues

- Strong organizational and planning skills
- Ability to develop and deliver training programs for healthcare professionals
- Knowledge of data protection regulations and ethical standards

AKU Society website: www.akusociety.org