

FUNDRAISING AND COMMUNICATIONS OFFICER

Job Title:	Fundraising and Communications Officer
Location:	Either fully remote (but has to be living in the UK) or at the AKU Society office in Cambridge or hybrid
Responsible to:	CEO
Salary:	£23,000
Hours:	Full-time (37.5 hours per week)
Benefits:	25 days holiday + 8 bank holidays, office closure Christmas-New Year, gym discounts, shopping discounts through Pirkx

Please send a CV and covering letter to: Dr Nicolas Sireau, Chairman and CEO, at nick@akusociety.org

BACKGROUND

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. We have a small office in **Cambridge's AdviceHub**, where this position will be based alongside the rest of the AKU Society team.

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 know of 81 AKU patients in the UK and 1,000 worldwide.

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.

In November 2012, we launched international clinical trials of a potential new medication to treat AKU. This drug, called nitisinone, will be studied over 6 years to assess its effects on slowing the progression of disease. The trials recruit patients from across Europe into three clinical centres in Liverpool (UK), Paris (France) and Piestany (Slovakia). The AKU Society is a key part of the studies, leading on patient recruitment, patient support and dissemination.

Please see the AKU Society's website at www.akusociety.org and the DevelopAKUre website at www.developAKUre.eu for more information.

OVERVIEW OF THE ROLE

As the Fundraising and Communications Officer, you will focus on maximising revenue from all income streams to achieve the fundraising targets through providing effective administration and research.

We're looking for someone who has experience in a fundraising environment and has an understanding of communications. The successful candidate will be an excellent administrator, researcher, organiser and communicator who will relish this varied role, while being able to deal with competing priorities and working collaboratively with the other members of the team.

MAIN DUTIES AND RESPONSIBILITIES

Fundraising

- Work closely with the rest of the team to identify fundraising goals, to write funding proposals and maintain relationships to grant making bodies and charitable trusts of all sizes.
- Maintain an up-to-date calendar for upcoming trust deadlines.
- Develop existing and pitch for new corporate relationships to maximise staff fundraising, CSR, gifts in kind and other forms of corporate giving.
- Manage our crowdfunding campaigns in partnership, offering support during planning and preparation, as well as contributing to the running of the campaign and follow up with donors.
- Organise and manage fundraising events. Liaise with event partners and sponsors to maximise fundraising opportunities. Research new ideas/venues for future events.
- Maintain and develop the database of supporters, contacts, and donors.
- Research and identify potential donors to feed into the prospective pipeline.
- Manage and steward any ad hoc requests from individuals wanting to fundraise on our behalf or for individual one-off donations.
- Survey our users, both online and offline, with an aim to develop an annual evaluation report. These reports should highlight areas for new fundraising projects.
- Manage the delivery of an integrated plan for donor communications materials.

Communications

- Manage the website, social media, e-news and other online communications.
- Manage the global AKU patient registry working with our registry provider Dendrite and our Head of Patient Support & Welfare.
- Manage print communications such as newsletters, leaflets and annual reports.
- Help with organisation of patient and scientific workshops and events.
- Help keep the charity's CRM database updated.
- Assist with general administration of the charity.

PERSON SPECIFICATION

This is an entry-level role suitable for an individual with some experience in fundraising, or an understanding of marketing.

Essential

- Experience of fundraising, communication, administration and research.
- Exceptional organisational skills with experience of managing multiple tasks and prioritizing effectively.
- A good communicator with the ability to build relationships with a variety of people.
- Excellent interpersonal and team working skills, with an ability to work independently and seize opportunities.
- Ability to work independently with little supervision; strong sense of initiative
- High level of analytical and written skill – fluent in written and spoken English with strong presentation and persuasion skills.
- Computer literate and confident using all MS Office software and databases.
- Understanding of, and commitment to, the objectives of the AKU Society.

Desirable

- Experience of organising and co-ordinating events

Please submit an up to date CV and covering letter outlining your relevant skills and experience, relating to the listed responsibilities and person specification. Shortlisted candidates will be contacted for interviews.

We regret that we can only respond to applicants who make it to the interview stage. No agencies please.