

AKU research travel bursary

AKU Overview

Alkaptonuria (AKU), also known as 'black bone disease', is an ultra-rare genetic condition that affects one in every 250,000 people. The condition is caused by a build-up of a toxic acid which turns the bones and connective tissue black and brittle, destroying every joint in the body. AKU causes severe early onset osteoarthritis, chronic pain, a crippling disability, and a life-time of joint replacement surgery.

The AKU Society

The AKU Society is a patient-group which works to support all people affected by AKU. Our mission statement is: Transforming the lives of AKU patients; through patient support, community building and medical research.

AKU scientific network and our research

The AKU Society has an extensive record of successful scientific research which has had a life-changing impact on AKU patients. We have acted as a catalyst to unite world-leading AKU researchers across the world, resulting in considerable progress towards our goal of curing AKU.

The AKU Society works closely with the University of Liverpool (UoL) where we have established a research group dedicated to AKU. Two researchers at UoL are trustees of the Society, while a number of others are funded by us. The UoL has become a world-leading hub for research into AKU. In 2012, we established the National Alkaptonuria Centre (NAC) at the Royal Liverpool University Hospital where patients receive annual highly specialised care and treatment. One of the key obstacles to researching a rare disease is the limited patient pool available, so the NAC being located at the UoL has significantly advanced our understanding and research into AKU.

In 2012, we formed a trans-national consortium which launched a seven-year study called DevelopAKUre. This study set out to prove the effectiveness of the drug nitisinone to treat AKU. Our results showed nitisinone reduced the acid which causes AKU by 97% and we successfully acquired a license for nitisinone to treat AKU from the European Medicines Agency, making the drug available to patients across Europe and the UK.

Building on the success of our collaborative DevelopAKUre study, we have worked to establish an international AKU scientific network. We have achieved this via hosting regular international scientific conferences on AKU where we invite academics and researchers from around the world to share their research and network with others in the field. This has led to us forming strong relationships with a number of laboratories specialising in AKU around the world including in Belgium (Brussels), Slovakia (Bratislava), Czechia (Brno), and Alabama (USA).

AKU research bursary

The AKU research bursary will stimulate research into AKU by facilitating the opportunity for early-stage researchers to visit other laboratories specialising in AKU around the world. These researchers would have the opportunity to experience first-hand the research currently being conducted into AKU around the world. We have already established a strong network of researchers across a number of specialist centres which will allow us to easily implement our bursary scheme.

Aims

The aim of this bursary is to stimulate cooperation between AKU researchers and facilitate early-stage researchers to develop their knowledge and understanding of AKU. Across our scientific network, a number of different projects are being conducted including a tyrosine-reduction study, a gene therapy study, developing a zebrafish AKU model, and collating an AKU mutation database. This bursary will allow researchers from differing projects to observe the wide-range of research which is occurring and facilitate the sharing of knowledge and collaboration across projects.

Outcome

The outcome of this bursary scheme would be the advancement of our understanding of AKU by involving early-stage researchers in a number of AKU projects around the world. This scheme will also allow us to continue to foster an international and collaborative approach to AKU research. The rarity of AKU means that it is essential that we coordinate our research with as many patient groups, academics, and researchers around the world to maximise our impact and drive our research forward to achieve our goal of curing AKU.

Criteria

- This bursary is intended to fund travel, accommodation and lab costs.
- This scheme will provide £6,000 in funding per year allocated between a minimum of two students.
- Applicants must be no more than five years post PhD.
- Individuals must provide a breakdown of costs in the application and provide receipts of spending.
- Upon return, a report must be submitted on how the bursary has furthered the aims of the AKU Society which may be shared on the website and/or social media.