

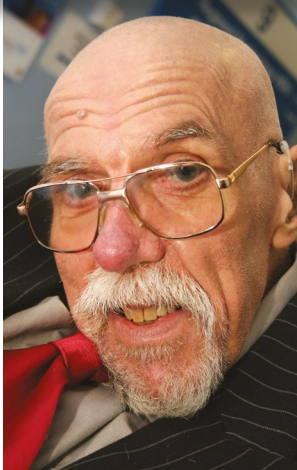
# AKU

+ Alkaptonuria Society →

## The Alkaptonuria Society



# Founders



Robert Gregory



Professor Ranganath

The AKU Society is a patient group supporting patients with alkaptonuria. It was founded in 2003 by a patient Robert Gregory and his doctor Professor Ranganath.

# Patient Support

Living with AKU can be challenging, with loss of mobility and pain affecting patients' physical and mental health. This is why it is so important for us to provide support to our patients and their families, helping them come to terms with the diagnosis and best manage their condition.

## Aims:

- Provide reliable, up-to-date information about AKU
- Run annual patient workshops
- Offer individual home support visits
- Provide ongoing support at the National AKU Centre (NAC) and for DevelopAKUre patients

# Mission

*'Transforming the lives of AKU patients; through patient support, community building and medical research.'*

Our history is one of perseverance, dedication and innovation. It demonstrates how rare disease patients and their relatives can be empowered to take control of their condition and actively drive forwards their own healthcare and treatment prospects, in partnership with medical experts.



*'The peer to peer support has really made a difference for me, helping me feel less isolated'*

# Community Building

Living with a rare disease can be isolating, as patients are sparsely located all over the world. Here at the AKU Society, we work hard to unite AKU patients and build a strong community.

## Aims:

- Encourage connections through our online communities
- Help raise awareness of AKU among the general public and healthcare professionals
- Establish and support AKU sister societies in other countries
- Unite AKU patients around the world through international patient workshops

Our online communication project, supported by the Big Lottery Fund, aims to bring AKU patients together in a supportive web-based community. We do this through our Facebook page and Twitter account, as well as the two online patient communities Rare Connect and PatientsLikeMe. Our regular blog posts on the website update patients about what the AKU Society is doing.

*'It is wonderful to know that you're not alone and there are others that you can learn from and there are people that care about you'*





# Medical Research

Our ultimate goal is to find a cure for this debilitating disease. We are currently running an international clinical trial, DevelopAKUre, measuring the effectiveness of nitisinone, the first potential treatment for AKU.



## Aims:

- Form scientific partnerships
- Understand and treat the disease

*'These trials have given us great hope. This treatment could completely change our lives. We're one step closer to a cure.'*



# Ongoing work and plans for the future:

We are entering the final stretch of our major clinical study into the use of nitisinone for the treatment of AKU. After the study ends, our partners will be assessing the data and considering whether to apply for marketing authorisation. If this is successful, the AKU Society will focus on how to ensure AKU patients around the world can access nitisinone.



## At the AKU Society we work to

- Support patients, their families and their caregivers
- Organise and run patient workshops
- Encourage patient communication through online communities
- Raise awareness of AKU
- Contribute to campaigns and research on rare disease policy
- Research into the causes, effects and treatments of AKU

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## How can I help?

We are always looking for volunteers to help with fundraising, our online communities, contacting patients and campaigning.

- 📍 **AKU Society**, C/O Advicehub,  
66 Devonshire Road, Cambridge, CB1 2BL
- ☎ Call us: **01223 322 897**
- ✉ Email: **info@akusociety.org**
- 🌐 Visit us: **www.akusociety.org**
- 📘 **@AKUSOCIETY**
- 🐦 **@AKUSociety**
- 📺 **AKU Society**

Please help us to cure AKU, a rare genetic disease,  
by donating online at:

[www.justgiving.com/alkaptonuria](http://www.justgiving.com/alkaptonuria)

Registered Charity: 1101052

The Robert Gregory   
National AKU Centre



*Understanding genetics together*

[www.breaking-down-barriers.org.uk](http://www.breaking-down-barriers.org.uk)