

# AKU Society Fundraising Pack



Patient Support  
Community Building  
Medical Research

**AKU**  
+ Alkaptonuria Society →



## What is AKU?

Alkaptonuria (AKU), also known as 'black bone disease', was the first identified genetic disease. It causes a build-up of toxic acid in the body that eats away at patient's bones, cartilage and tissue, turning them black and brittle – a process called ochronosis. This leads to a variety of life-changing disabilities. Patients develop early-onset osteoarthritis, which leads to joint replacements and extreme pain. The funds that you raise will help our AKU patients immensely.

## Welcome to the AKU team

Thank you for fundraising for the AKU Society. We rely on our amazing supporters, like you, to fund our life-changing work with patients and families affected by AKU. This booklet contains essential information on how to start your fundraising journey, useful tips for meeting your fundraising target and for organising your fundraising event.

We would love to support your fundraising however we can, so if we can do anything to help you train, fundraise or build up to the event, please contact our Fundraising Officer Juliet Rowe, [juliet@akusociety.org](mailto:juliet@akusociety.org), and most importantly, have fun!

# About the AKU Society

The AKU Society was founded in 2003 by patient Robert Gregory and his doctor, Professor Ranganath. When Bob found out that AKU was the first genetic disease discovered over 100 years ago, he was appalled that nothing was being done to understand the condition and find a treatment. Nick Sireau, the father of two sons with AKU, joined the AKU Society to campaign for research to find a treatment for AKU. He helped to set up a patient support group to provide accurate information and life-changing support to help patients and their families cope with AKU. Sadly, Bob passed away in 2014, but the AKU Society continues to pursue his vision to transform the lives of AKU patients through community building, patient support and medical research.

## Who is affected?

AKU affects 1 in 250,000 people. We are currently in contact with just under 100 patients in the UK who have AKU. However, we believe there are more patients with AKU who are yet to be diagnosed.

Worldwide there is a higher prevalence of AKU in some regions, for example, in parts of Eastern Europe, the Middle East and Asia. We know 1188 patients in more than 30 countries around the world and we have helped establish sister societies in 12 of these locations.

AKU is present from birth and is often detected by patients' dark urine. It is normally in the third or fourth decade of life that the most severe, debilitating symptoms of AKU develop.



### Our Mission -

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

# Aims and Key Achievements

**To raise awareness and improve early diagnosis of AKU**—By educating GPs about spotting signs of AKU. We also regularly attend rare disease conferences and forums to raise the profile of AKU.

An AKU patient receiving eye tests at the NAC



**To find and license a treatment for AKU**—In 2013 we founded a consortium of 13 partners, called 'DevelopAKUre', to launch a major European clinical trial which measures the effectiveness and safety of a drug called nitisinone for treating AKU. This year we find out the results of this and if successful we will obtain a license for nitisinone.

**To provide accurate and reliable information about AKU**—To educate patients and their carers about AKU and how to cope with the symptoms. We also send out regular leaflets, newsletters, and social media updates to all our patients. This includes weekly blogs and e-news sent to our patients to keep them up-to-date.

**To improve the health of AKU patients**—In 2012 we secured funding from the Department of Health to open the world's first, and only, National Alkaptonuria Centre (NAC) at the Royal Liverpool University Hospital. Here, AKU clinics provide expert monitoring, care and advice to patients in the UK. We also want to make sure patients can access nitisinone freely.

**To reduce the isolation felt by rare disease patients**— We support networks between AKU patients at our patient workshops and through our online communities, such as RareConnect. We also have worked with representatives around the world to help them set up sister societies, to connect AKU patients worldwide.

# Hear from our patients

## Tony, Wales

Meet Tony, who was diagnosed with AKU at the age of 53. Prior to this, he was treated for severe osteoarthritis which had forced him to retire as a mental health nurse aged 40. Looking back, he feels he could have been diagnosed with AKU earlier if his GP had been aware of it; his mother noticed his nappies had a dark tinge and as a teenager, he had knee problems.

Tony is now a trustee for the AKU Society, helping bring the patient voice into regular trustee meetings. We value his comments and it is great to have someone from Wales as our trustee.

Living with AKU has presented many challenges for Tony, losing his job and contending with increasing mobility, pain, breathing and lifting issues. He is hopeful that future generations will get treated for AKU.

## Anna, Slovakia

Meet Anna, who was diagnosed with AKU at 19 years old. A routine gynaecological test revealed excess levels of HGA. Her symptoms worsened in her 30s, after having two children, including severe pain in her back and hips. As she gets older, the pains and strains in her daily life are growing.

'It is difficult', she says, 'because nobody understands how I am feeling everyday. Most people do not believe me when I talk about the future developments in my body, so I prefer not to talk about my feelings.'





Pam Ford hosting our second 'Stand Up to AKU' Comedy Night

## Planning your event

If you need some inspiration here is what other fundraisers have done for us.

### Ready, set, go!

We've had lots of brave supporters take on sponsored challenges for us - from 10k's to half marathons, cycle rides and Tough Mudders. Jamie ran the Edinburgh Half Marathon and raised £363.85 for the AKU Society! Hannah climbed Mount Everest basecamp, 5,364 metres above sea level, and raised £900 for us in 2017. We have runners regularly run the Cambridge Half Marathon for us. In 2017 our runners raised £1,609. This went towards our children's workshop we ran later that year. This year we had Katja and Ana run for us, raising £651.82 in total.

### Coffee Morning

Coffee mornings or bake sales are an excellent way to get your family, friends and colleagues together for a slice of cake to raise money for AKU. On the 25th of November, we celebrate the birthday of Sir Archibald Garrod, who discovered AKU in 1901, by asking our supporters to host their coffee mornings. Patients and supporters from all over the globe have held their own coffee mornings. Here in the AKU office, we asked our team to bake their favourite recipes and sold cakes to other companies in our building. We raised £67.20 selling cakes, our AKU Christmas cards and raffle tickets.

## Raffle

A raffle is a great way of raising money, either on its own or as part of a bigger event. The key is to get tempting prizes that people will want to get their hands on. We recently held a big raffle and asked local businesses for prize donations which included paintballing for 10, a box of fudge, punting tickets and an Italian food hamper. Remember, because raffles fall under the laws relating to small lotteries, there are some cases where a license from your local council may be required.

## Head shave

Weird and wonderful is often the best approach when it comes to getting people to sponsor you. Doing something novel will make you stand out from the crowd. Here at the AKU Society, we had a sponsored head shave and hair dye to raise money towards our DevelopAKUre clinical trial.

## ‘Stand Up to AKU’

### Comedy Night

We hold fabulous stand up comedy night fundraisers at a local venue in Cambridge, which is a great opportunity to raise money and awareness of AKU. Professional comedian Pam Ford has hosted our nights with performances from four comedy acts. The evenings were a huge success.

## Other ideas

Why not host a charity dinner? Put your cooking skills to the test by cooking a feast for your family and friends, then after the yummy meal, you ask them to donate to AKU. It's a great way to catch up with family and friends, have some great food and raise money for your event!

If you are tight on a fundraising deadline or the event is approaching, consider baking cakes and other baked goods the night before and bring them into work to sell to get last minute donations. People love cake!



Malteser Tiffin from our Garrod Day Coffee Morning

# Meeting your sponsorship target

## Set your goal

Set yourself a target or something to aim for– and aim high! If potential donors see that you have a lot to raise they may give more generously.

## Asking for donations

- Ask everyone you know–friends, family, colleagues, schools, neighbours–and get them to ask their connections too.
- Be strategic, get a generous sponsor to give first to encourage others to be as generous.
- Create a fundraising page–make sure it is compelling and explains your motivations for taking part in a sponsored event.
- Encourage the person sponsoring you to tick the Gift Aid box–if they are a UK taxpayer it means for everyone £1 they donate, an extra 25p will go to the AKU Society at no extra cost to them.

Use our official sponsorship forms for anyone not online yet.



Two AKU fundraisers prepared to run the Cambridge Half Marathon



## Keep your sponsors updated

Make sure you involve your supporters in your journey towards event day. You could create a blog or Facebook page where you can update your supporters on your training.

- You can sync most training apps to automatically update on your Facebook and Twitter, showing your training activity. Everyone will be able to see how hard you've trained, and you could attach a link to your fundraising page.
- Swap advice and connect with other AKU fundraisers by tweeting #AKUChallenge
- Starting a blog can be a great way to create a buzz about your event, and it will help to keep you motivated. There are lots of free blogging sites out there, like WordPress.
- Please also send us updates on your training and pictures of you so we can promote your fundraising on our website and social media.

## Share the “Why”

- Make sure you tell your potential donors why you are supporting the AKU Society and what difference their money will make. People want to know where their money will go.

- Take time to read a bit about the work of the AKU Society and feel free to ask any other questions you might have so that you feel prepared to share with others. You can direct any questions you have to [juliet@akusociety.org](mailto:juliet@akusociety.org).
- Take every opportunity to tell people about what you are doing and why you're doing it.
- Use social media to spread the word—Twitter, blog, Facebook.
- We now have Facebook donation set up for you to get donations through Facebook.
- We also have materials such as leaflets, newsletters, balloons and posters which help with sharing about the AKU Society. Contact us when you need these resources for your fundraising.



AKU staff celebrating Garrod Day with cake

## Get donations matched

Consider whether match funding is a possibility for you. Some employers are willing to support any fundraising activities undertaken by their staff to support charities e.g. for every £1 you raise they will match it with £1. It's a brilliant way to boost your fundraising total quickly.

## Be creative

Think of things you could do to entice your family and friends to sponsor you, for example:

- You could ask people to sponsor you based on you finishing in a certain amount of time or get them to double their sponsorship if you finish under a specific time.
- You could organise a 'finish time sweepstake' - get people in the office to pay a pound to guess what time you'll finish in, half of the money collected will go to the AKU Society and half will go to the person who guesses the closest.
- You could even spread the word about your fundraising by updating your email signature, business cards or anything else that regularly profiles you, with a quick line about your fundraising and how they can sponsor you.
- To keep the money coming in after the event, why not post photos from the event day and tag people who have already sponsored you. It will then show up on the newsfeeds of other friends and remind them to sponsor you too!



AKU fundraisers about to run the Cambridge Half Marathon



AKU fundraiser completing in the Reebok Spartan Race

## Set up a JustGiving fundraising page

Setting up a JustGiving page should be one of the first things you do to get your fundraising going. Your friends and family will be able to visit the page and donate online. That money will go straight to the AKU Society and get added to your fundraising total, making the process nice and easy for you, your supporters and the AKU Society.

- Create your page—if you don't already have a JustGiving account go to [www.justgiving.com](http://www.justgiving.com) and make an account.
- Personalise your page—Add a photo of yourself and write a blurb about why you're taking on a challenge for the AKU Society.
- Add a fundraising target—pages with a target raise almost 10% more than those without one. Hopefully, your target will be exceeded.
- Promote your page—Use word of mouth, Twitter, Facebook, email etc. to get the word out there.
- Regularly update your page— it is good to let your supporters know how you are getting on and reminding them to donate.
- Thank people—make sure to thank friends and family that sponsor you. If you do it through social media, it will act as a reminder to anyone that hasn't sponsored you!

## After the day

Don't forget that you can still collect sponsorship after the event ends and drum up more support by posting photos of you doing the event!

- A lot of your sponsorship money will probably come through JustGiving, but you're bound to collect some cash in person too. There are several ways you can get money to us: whichever one you choose, please make sure you send us your sponsorship forms because, without them, we won't be able to claim GiftAid.
- You can pay offline sponsorship through your online fundraising page, bank the money you've collected and then donate it to your own page.
- You can also send cheques to us, made payable to The Alkaptonuria Society: AKU Society, 66 Devonshire Road, Cambridge, CB1 2BL.
- Bank transfer is available: contact one of our team for more information.



AKU fundraisers running the Cambridge Half Marathon

# Good Luck

If you have any questions or ideas that you want running through or support, in general, do not hesitate to get in touch with our team. Contact our fundraising officer, [juliet@akusociety.org](mailto:juliet@akusociety.org), for fundraising advice, support and to get fundraising supplies. Alternatively call our office telephone number to talk to anyone on our team: 01223 322 897.

Make sure to use your JustGiving page effectively and use Facebook donation to get friends and family donating to AKU.

Don't forget to take photos of your fundraising journey and share them with us! We post fundraising images to our social media and have regular blogs.

Here at the AKU Society, we all wish you the best of luck on your fundraising journey.



Our Fundraising Officer, Juliet



Our CEO, Nick



Our Communications Manager, Ciarán



Our Patient Support Manager, Lesley

# Your funds raised could...

£15

## Provide vital information to a patient diagnosed with AKU

When diagnosed with a rare condition like AKU many patients find it hard to access specialised and accurate information, leaving them uncertain of their future. You could change this by providing a patient with our expert information pack, giving them the knowledge of AKU consultants in their own home.

£30

## Get a home-based exercise kit to a patient who needs it

AKU destroys patients' joints and limits their mobility. Your gift could cover the cost of a chair-based exercise kit proven to improve mobility, strength and wellbeing.

£100

## Give a patient a one-to-one home support visit

The expert advice and encouragement of Lesley, our specialist Patient Support Manager, makes such a big difference to patients and their families. You could enable more patients to receive a personalised visit and transform their ability to cope with AKU.

£500

## Give a course of essential hydrotherapy sessions

You could help a patient manage their symptoms by receiving hydrotherapy which reduces pain, promotes relaxation, mobilises joints and strengthens muscles.

£700

## Cover a place at our International Patient Workshop

Help an international patient to meet AKU world experts, learn about their condition and share their experiences with other AKU patients for the first time.

£800

## Provide a course of counselling to an AKU patient

Living with a chronic condition is a mental and physical challenge. It is vital that patients have the necessary support to look after their mental health.

£1,180

## Run a local AKU patient support and social group

Having a chance to meet other patients and share experiences in a social setting helps to reduce patients' sense of isolation and shows them they are not facing AKU alone.

# Keep in touch

We are always looking to build our community of supporters and raise awareness of AKU amongst the wider public. We have numerous fundraising events coming up, as well as regular newsletters and e-news updates. We also encourage our supporters to consider becoming committed givers, to provide regular backing for the work that we do.

Our annual AKU fundraising events are the 'Stand Up to AKU' Comedy Night and Garrod Day Coffee Morning. These are our biggest events and we need as many fundraising supporters as possible for these events. Please do get involved; all the funds raised are vital to helping AKU patients.

Please invite your supporters to get involved and stay in touch with the AKU Society. To receive further information about our future fundraising activities, conferences and events email our fundraising officer Juliet, [juliet@akusociety.org](mailto:juliet@akusociety.org). Don't forget to contact us if you have any questions and need any help on your fundraising journey.



AKU patients at our 2nd International Patient Workshop

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AKU

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