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July Newsletter

Welcome to your July Newsletter

Hi everyone, welcome back to the AKU Society newsletter! This month marks a historic moment for the AKU community with the FDA approval of HARLIKU™ (nitisinone) - a huge breakthrough for patients who, for so long, had no approved treatment options.

But that's not all, AKU research is making headlines, featuring on the *Journal of Anatomy* front cover. Plus, with our new #SelfCare4Rare campaign kicking off, there's never been a better time to get involved!

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HARLIKU™ (nitisinone) is now FDA Approved!

We're thrilled to share a historic moment for the AKU community on 19th June 2025. [Cycle Pharmaceuticals](#) announced that the [FDA](#), has officially approved [HARLIKU™ \(nitisinone\)](#) as a treatment for AKU in the US!

HARLIKU™ 2mg tablets will be available for adults 18+ from July 2025, a major breakthrough for patients who previously had no approved options.

This approval is based on data from a [ground-breaking NIH clinical study](#) led by Dr. Wendy Intone MD where improvements in pain, energy and physical function were shown in patients with nitisinone.

[Click here for the official press release](#)

US patients and carers can contact Cycle Vita using this email to speak to their patient support: help@cyclevita.life

For patients and carers outside of the US, Cycle Pharma offer a free goods program for which patients can access Nitisinone you can reach out to them with this email: info@fda.cyclepharma.com

Reach out to us at AKU Society North America or AKU Society UK, we're here to support you. info@akusociety.org

AKU Research Makes the Cover of Journal of Anatomy

We're thrilled to share that Juliette Hughes, a lecturer and AKU researcher at the University of Liverpool, has made the cover of the June 2025 issue of the [Journal of Anatomy](#), with the striking "Ochronosis: 6 Ways" histology image.

Ochronosis is the build-up of pigment in connective tissues and is the main driver of damage in AKU, triggered by excess homogentisic acid (HGA) in the body.

The featured article: "[An anatomical investigation of alkaptonuria: Novel insights into ochronosis of cartilage and bone](#)", anatomically examines a 60-year-old AKU female body donor, allowing the investigation of previously understudied tissue. It's a fascinating read that deepens our understanding of how this ultra-rare disease affects the body.



[Read the full article here](#)



Introducing #SelfCare4Rare - A New Campaign This July

This July, to mark both [Chronic Disease Day](#) (10th July) and the [International Day of Self-Care](#) (26th July), we're excited to launch our new campaign: #SelfCare4Rare. This initiative is all about highlighting the importance of practicing and prioritising self-care while living with AKU.

As part of the campaign, we're creating a special resource for patients and we'd love your input. Whether it's a daily habit that makes life a little easier, a mindset shift that helps you cope, or practical tips for managing symptoms, your insights can make a real difference.

We also want to hear about your personal experience with AKU - the daily impact, challenges, and the small or big things you do to take care of yourself. Your experiences can help others feel supported and understood.

[Contact us here to get involved](#)

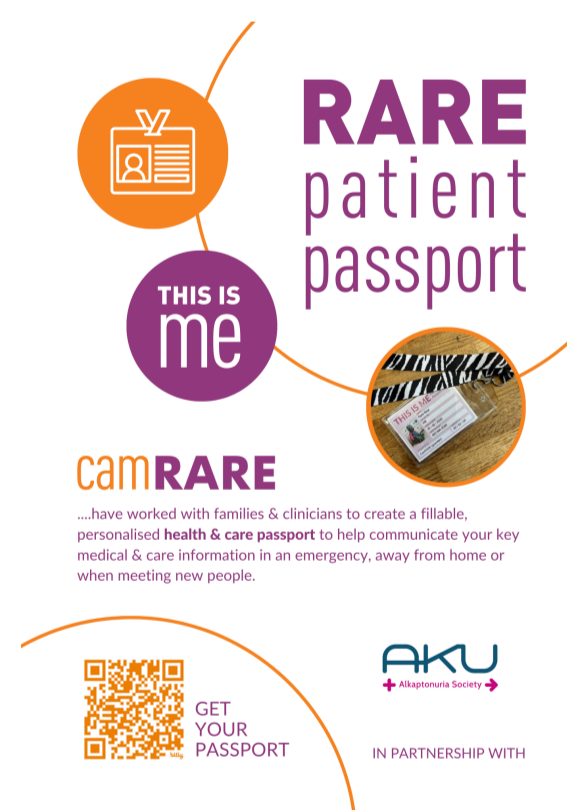
If you'd like to get involved or share a quote, tip or perspective, please email us at info@akusociety.org

The Passport That Speaks for You

Living with AKU can mean facing healthcare professionals unfamiliar with your condition, needing to explain complex information repeatedly, and feeling uncertain about whether your needs will be understood.

The ["This is Me" Rare Patient Passport](#) is helping people with AKU share key information more easily in healthcare and emergency settings.

The passport includes your diagnosis, treatment needs, emergency info, and personal preferences. By summarising key details about your health and preferences, the passport can support better understanding, fairer treatment, and more confidence in your care.



[Get your passport here](#)

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