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August Newsletter

Welcome to your August Newsletter

Hi everyone, and welcome to the August edition of the AKU Society newsletter. As summer continues, we're excited to bring you the latest developments and opportunities from across the AKU community.

A brand new AKU-focused PhD, *Tendons Under Attack*, has just launched and we're looking ahead to Pain Awareness Month this September. And in case you missed it, the first and only FDA-approved treatment for AKU, was officially launched in the U.S this July!

So grab a drink, get comfy, and catch up on all the latest in this month's newsletter!

Contents: [New PhD Opportunity](#) | [Launch of HARLIKU](#) | [Campaign Calendar & Pain Awareness](#) | [New Self-Care Webpage](#)

New AKU-Focused PhD Opportunity

[Tendons Under Attack: The Role of Homogentisic Acid in Connective Tissue Degradation](#)

A unique PhD opportunity is now open at the University of Liverpool, focusing on how **AKU** affects tendons and connective tissue health.

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Alkaptonuria - damages tendons, offering unique insights into oxidative stress and tissue degeneration. Using various tendon models, it aims to uncover mechanisms behind pigmentation, rupture, and repair, with implications for both rare and common tendon disorders.”



[Click here for more information on the PhD](#)

 *Interested, or know someone who might be? Pass it on and help us spread the word within the AKU and research communities.*



[Read more from Cycle Pharma](#)

A Historic Milestone: FDA-Approved HARLIKU™ Now Available in the U.S.!



July has been a big month because [HARLIKU™ \(nitisinone\) Tablets](#), the first and only FDA-approved treatment for Alkaptonuria (AKU), are now commercially available in the United States!

For the first time ever, adults living with AKU in the U.S. can access an approved treatment specifically designed to reduce levels of homogentisic acid (HGA), the substance that causes the long-term damage in AKU.

 [Learn more about HARLIKU](#)

Campaigns by the Calendar: Shaping What's Next

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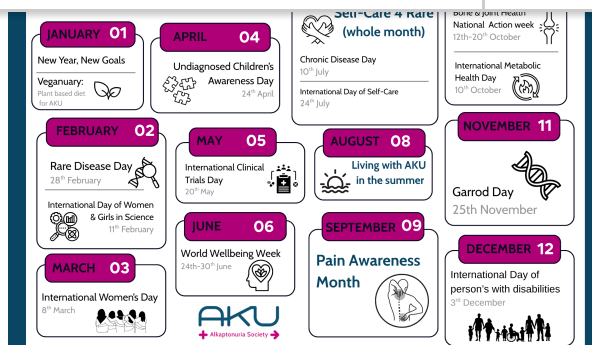
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we're excited to share that our [new campaign calendar](#) is now live! It's still a work in progress, but we've got plenty of ideas lined up and can't wait to get started.

[Looking Ahead: September is Pain Awareness Month](#)

Next month, we'll be focusing on [pain awareness](#), and we want to make sure the voices of people living with AKU are front and centre. The best way to support the community is by hearing directly from you how pain affects your daily life, and what you've found helpful in managing it.

If you have a couple minutes, we'd really appreciate it if you could [share your experience](#). You don't have to include your name or personal details - just your insights. We'll use your input to help shape helpful resources for others living with AKU.



[View our calendar here](#)

AKU Pain Awareness: Share Your Experience

B I U

We're putting together resources for Pain Awareness Month and would love to include real insights from people living with AKU. This form is completely anonymous, and we won't be able to follow up with you afterwards. All questions are optional- feel free to write as little or as much as you'd like or skip questions entirely.

When did your AKU-related pain first begin?

- In childhood
- In early adulthood
- In mid-life
- Recently
- Not sure

[Fill in the form here](#)

[Our new self-care 4 rare webpage is now live!](#)

Our [Self-Care 4 Rare webpage](#) is now live and it brings everything from the campaign into one easy place.

Yes, the virtual sessions were recorded! You can now rewatch **Campbell Gillespie's** powerful story of surviving a lightning strike and **Jim Fish's** uplifting session on aquatic therapy and building confidence in movement.

The page also features two brand new blogs:

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mental self-care.

- [Why Movement Matters](#) offers practical insights into exercise, pain management, and staying active.

[Explore the page here](#)

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