Alkaptonuria Discussion Guide

Complete this yourself to share with your healthcare provider

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If you think you have AKU, or if you've already been diagnosed and would like to be prescribed an FDA-approved treatment, complete this form and share it with your healthcare provider to start an informed conversation.

Symptoms

Tick any of the following symptoms you have experienced:

- ☐ Black urine after it has been exposed to air
- ☐ Kidney and bladder stones
- ☐ Heart complications
- ☐ Brown stains in your clothes from sweat

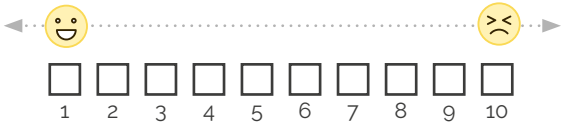
Joint pain in your:

- ☐ Back
- ☐ Knees
- ☐ Hips
- ☐ Shoulders

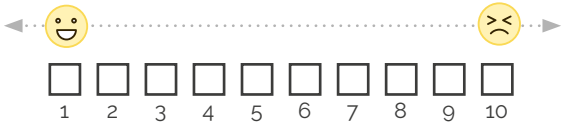
Blue/black discoloration in your:

- ☐ Skin
- ☐ Eyes
- ☐ Ears
- ☐ Nose

On a scale of 1-10, how are these symptoms impacting your quality of life on a daily basis?



On a scale of 1-10, how severe is your pain?



Other:

This is not an exhaustive list, and symptoms vary from patient to patient. You do not need to have experienced all these symptoms to have AKU.

Treatment

Answer the following questions to help your healthcare provider understand more about your symptoms, experiences, and treatment background. Give as much detail as you can:

How old are you?

How long have you been experiencing AKU symptoms?

Have you noticed a change in your symptoms?

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Have you ever been tested for AKU?

Do you have any family members with AKU?

Are you currently taking medication for AKU?

Would patient support be helpful to you alongside treatment?

Do you need financial support for a treatment?

Is there anything else you would like to discuss with your healthcare provider?

Once you have completed this form, take it to your healthcare provider, along with your information pack, which can be found at harliku.com/alkaptonuria-resources/ or scan the QR code.

If you have any questions, the Cycle Vita team is here for you, at every step.

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