

AKU Patient Registry FAQ

What is the AKU patient registry?

The patient registry is a global online database created to monitor the progression of AKU, evaluate current treatment and management of the condition, and track the prevalence of patients across the world. The registry will also help to contribute to our understanding of AKU and help us to accelerate our research into developing new treatments and potential cures for the condition.

Why should you join the AKU patient registry?

The AKU patient registry will allow us to collect a wealth of information on the disease. We will be able to track the prevalence of the condition around the world, evaluate the effectiveness of current treatments, and increase our understanding of how the condition develops. Currently, little is known about the way the disease develops in various countries around the world. As an ultra-rare condition, the registry is a particularly important tool to advance our scientific research into developing new treatments and potential cures for the condition as the registry will provide us with a wealth of information on AKU to facilitate collaboration with researchers and pharmaceutical companies.

What information is being collected?

Information will be collected on the progression of the symptoms of AKU, any treatments you use, and your family history.

The aims of the AKU patient registry are:

- Track the prevalence of AKU.
- Monitor the progression of AKU.
- Understand evolution of AKU around the world
- Evaluate the effectiveness of current treatments
- Identify new hotspots of AKU.
- Accelerate our scientific research.

How does the AKU Patient Registry work?

When joining the registry you will be asked to complete a baseline questionnaire which will provide an overview to your family history, the current impact of AKU on your health, and any treatments you are currently taking. You will then be asked to submit follow up questionnaire once per year. We will collect all of your answers and plot the data over time, allowing us to see how your AKU is progressing over time.

What do we do with data?

The data will be used by the AKU Society to track the progression and prevalence of AKU. With this information, we will be able to improve the treatment and management of AKU while it will also allow us to accelerate our research into developing further treatments and potential cures.

Who has access to the information?

The data is managed by the AKU Society and the processes of handling and storing information are all fully GDPR compliant. The AKU Society may share information in collaboration with their research partners (e.g. universities and pharmaceutical companies). If this occurs, we will remove all contact information from exported data.

Do I have to participate?

No. The AKU patient registry is an informed-consent registry, meaning patients are only included if they choose to participate.

Can I change my mind?

Yes. If at any point you would like to halt your participation this can be done by contacting registry@akusociety.org

Who is in charge of the information?

The AKU Patient Registry is managed by the AKU Society.

How long will my data be kept?

The data in the registry will be stored indefinitely.

Is my data stored securely?

Yes. The AKU Society ensures that all data is stored securely, and that the registry is fully GDPR compliant.

Where can I find more information if I still have questions?

More information on the AKU patient registry can be found on the AKU Society website here. If you have any questions or require any assistance, please contact registry@akusociety.org