

AKU Society Patient Registry – Patient Informed Consent Form

The AKU Global Patient Registry is an international database for patients diagnosed with AKU which tracks the progression and prevalence of AKU globally. The AKU Global Patient Registry will provide us, and our approved third-party partners, with a unique resource to accelerate: (A) research into understanding, treating and curing AKU; and (B) universal access to new treatments by encouraging further international AKU societies to form. Giving your informed consent is voluntary and more information is available if you are unsure. If you have any questions, please contact registry@akusociety.org.

Details about how we collect, share and use your personal information which forms the AKU Global Patient Registry can be found in our Privacy Notice [https://aku.e-dendrite.com/Privacy_Notice.docx]. As further outlined in that Privacy Notice please note that we do not rely on the consent we capture in this informed consent form as our legal basis for using your personal information.

I consent: I hereby give my informed consent to participate in the AKU global patient registry. I understand:

- The purpose of the registry and agree to my personal details being stored in the registry.
- That the information collected about me will be used to support AKU research in the future and may be shared by the AKU Society with approved third parties (such as educational / research institutions and pharmaceutical companies) to support AKU research and AKU's charitable aims.
- That I give permission for the AKU Society to contact me regarding the AKU patient registry and any other relevant activities or work related to the AKU Society.

Please note: You may receive a copy of this consent form for your records upon request.

Thank you for your participation. Your contribution to the AKU global AKU patient registry is greatly appreciated.