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Charity no: 1071196
Company no: 3557191

**Data Protection Act: Consent Form**

For Alström Syndrome UK (ASUK) to fully support you, your family and co-ordinate the NHS multi-disciplinary clinics effectively, we need to hold personal information about you.

To comply with the Data Protection Act (1998) and General Data Protection Regulation (GDPR) 2018, we must tell you how we use this data and ask for your permission. By signing this consent form, you are providing your permission for us to process your data for the purposes given below.

This information will be stored safely and securely and will only be seen by ASUK staff and professionals from NHS organisations who are contracted to run the multi-disciplinary AS clinics. Your information will not be disclosed to external third parties without your consent, unless we are required to do so by law.

If ASUK believe that sharing your information with another organisation would provide a better service, we will discuss this with you and ask for your permission.

Alström Syndrome UK is a data controller and is registered with the Information Commissioner’s Office as required under the Data Protection Act 1998.

**It must be noted that Child Protection and Safeguarding procedures take precedence over Data Protection when dealing with personal information. If we feel there is a risk to a child, young person or vulnerable adult we will disclose the information to ensure the safety of the individual concerned.**

The information which we currently hold could include:

* Family contact details
* Medical information relating to your health and wellbeing
* Data regarding when you were first diagnosed and when symptoms first presented
* Details of participation in research/clinical trials
* Ethnicity
* Data relating to fundraising activities

By signing this form you are agreeing that ASUK can hold this information about you.
This form must be signed by parents or carers of young people under the age of 18.

**I consent to have my/our details stored on the ASUK Database. These details will remain confidential and access to this information is** **strictly limited to people employed by ASUK and the NHS professionals that we work with.**

Signed: ………………………………… Print Name: …………………………………………………….
For those under the age of 18, your relationship to the patient: ……………………………………….
Date: ……………………………

If you have any questions or concerns relating to this document please contact ASUK Office Manager, Catherine Lewis on 07970071675 or email Catherine.lewis@alstrom.org.uk