**ASUK INFANT & CHILD HEALTH HISTORY**

**QUESTIONNAIRE
Please complete by the 26th July 2019**

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| 1. Name of individual with Alström Syndrome (AS)
 | Enter the full name here |
| 1. Date of Birth
 | Enter their Date of Birth here |
| 1. Gender at birth
 | Male |[ ]
|  | Female |[ ]
| 1. Was your baby born on his or her due date?
 | Yes |[ ]
|  | No |[ ]
| 4a. Or if born early by how many days?Enter your answer here. |
| 4b. Or if born late by how many days?Enter your answer here. |
| 1. How old were you/ the baby’s Mother when your baby was born?

Enter your answer here. |
| 1. What was your baby’s weight at birth?

Enter your answer here. |
| 6a) Did you, the Midwife, Health Visitor, GP or other health professional have any concerns about your baby’s weight in their first 12 months? If yes, please explain why.Enter your answer here. |
| 6b) Did you, the Midwife, Health Visitor, GP or other health professional have any concerns about your child’s weight when they were between 12 months and 3 years old? If yes, please explain why.Enter your answer here. |
| 1. Did your son/daughter have Nystagmus (wobbly eyes) as a baby?
 | Yes |[ ]
|  | No |[ ]
| 7a) How old was your child when you first noticed their wobbly eyes? | 3 months or under |[ ]
|  | Between 3 – 6 months |[ ]
|  | Between 6 – 9 months |[ ]
|  | Between 9 months – 1 year |[ ]
|  | Between 1 – 2 years |[ ]
|  | Between 2 – 3 years |[ ]
|  | Over 3 years |[ ]
| 7b) When did you talk about this with your child’s GP? (or any other health professional?) Enter your answer here. |
| 1. Did your child have Photophobia (light sensitivity) as a baby?
 | Yes |[ ]
|  | No |[ ]
| 8a) At what age did you notice your child’s eyes were sensitive to light? Enter your answer here. |
| 8b) When did you talk about this with your child’s GP (or any other health professional?) Enter your answer here. |
| 1. When did you first notice that your child had some problems with their sight?
 | Age 1 or under |[ ]
|  | Age 2  |[ ]
|  | Age 3 |[ ]
|  | Over 3 years |[ ]
| 9a) When did you talk about this with your child’s GP? (or any other health professional?) Enter your answer here.  |
| 9b) If your child is registered sight impaired are they registered ‘severely sight impaired’ or ‘sight impaired’?Enter your answer here.  |
| 1. If your child has hearing problems when did you first notice it?
 | Age 1 or under |[ ]
|  | Age 2  |[ ]
|  | Age 3 |[ ]
|  | Over 3 years (please specify exact age) |[ ]
| 10a) When did you talk about this with your child’s GP? (or any other health professional?) Enter your answer here. |
| 1. When did your child take their first steps?

Enter your answer here. |
| 11a) When did your child begin to walk with confidence? Enter your answer here. |
| 1. Did heart failure occur in your child under the age of 1?
 | Yes |[ ]
|  | No |[ ]
| 12a ) If you answered yes to Questions 12 please tell us the age of your child when heart failure occurred | At birth |[ ]
|  | Between 1 week – 3 months |[ ]
|  | Between 3 months – 6 months |[ ]
|  | Between 6 months – 1 year |[ ]
| 1. How did you feed your baby?
 | Breast fed |[ ]
|  | Bottle fed |[ ]
|  | Mixed Feeding |[ ]
| 1. At what age did you start weaning your child onto solid food?
 | 3 months |[ ]
|  | 4 months |[ ]
|  | 5 months |[ ]
|  | 6 months |[ ]
|  | 7 months |[ ]
|  | 8 months |[ ]
|  | 9 months |[ ]
|  | 10 months |[ ]
|  | 11 months |[ ]
|  | 12 months or over |[ ]
| If you have any other details or information about your child’s health within their first year please tell us about it here Enter your answer here. |

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| 1. **Ethnicity**

Ethnic monitoring is important to ASUK as it helps us to better meet the cultural, religious and language needs of our families. The following list is designed to allow you to identify your child. However, if you feel the categories do not describe your child’s ethnic origin or would prefer not to disclose it then please either select ‘any other group’ together with details of how you would describe your child’s ethnicity or simply leave the boxes blank.  |
| White British  |[ ]
| White Irish  |[ ]
| Any other White background  |[ ]
| Mixed race – White & Black Caribbean  |[ ]
| Mixed race – White & Black African  |[ ]
| Mixed race – White & Asian  |[ ]
| Mixed race – any other mixed background  |[ ]
| Asian or British Asian – Indian  |[ ]
| Asian or British Asian – Pakistani  |[ ]
| Asian or British Asian – Bangladeshi  |[ ]
| Asian or British Asian – any other mixed background |[ ]
| Black – Caribbean  |[ ]
| Black – African  |[ ]
| Black – any other Black Background  |[ ]
| Other ethnic group |[ ]

**Data Protection**

All personal information received will supplement the information held on the ASUK patient database but will be kept strictly confidential. All data from this survey that is used for statistical purposes will be anonymised.

**What happens next?**

When we have gathered together the information, we will analyse it and see if there are any patterns, we will then write a short summary of the findings (all anonymised) and share this with you.

If you are happy for us to use quotes from your response (again these will be anonymous) please click on the box to mark an x [ ]

Please contact Liz if you need any assistance in completing this form on 07517 278946

Please email completed forms by the **26th July 2019** to liz.loughery@alstrom.org.uk
or post to Alström Syndrome UK, 4 St Kitts Close, Torquay TQ2 7GD

Thank you for taking the time to complete this survey,
you really are making a difference to families now and in the future.