**I-CAH Registry Consent Form**

 **We would like to enter some information about the person named below on the I-CAH Registry**

**This information will allow us to**:-

a. Share information about the person with other registered users of the I-CAH Registry

b. To plan services

c. To help our understanding of these rare conditions

You can ask your Hospital Doctor (details below) to find out more about the information that is in the Registry

**If any of the following apply to you please place initials in box and let your hospital doctor know**

 [ ]  I have read the information sheet about the I-CAH Registry

 [ ]  I have discussed the information sheet about the I-CAH Registry with the hospital doctor who is looking after the care of the person below.

 [ ]  I approve of the information to be stored on the Registry and shared with other health professionals in the EU

 [ ]  I approve of the information to be stored on the Registry and shared with other health professionals beyond the EU

[ ]  I approve of the information to be stored on the Registry and shared with approved researchers

[ ]  I require on-line access to the Registry to view the record of the person named below

 e-mail address:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name of the person to be registered:

Name of parent if person to be registered is less than 16 years old:

Address of person to be registered:

Signature of person to be registered:

Signature of parent of person to be registered (if less than 16 yrs old):

Date

The person’s information shall be provided to the register by the following Hospital Doctor:-

{Local clinician}

{Local Hospital Address}

Please keep one copy of this sheet in case records and hand one copy to the person who has signed this form

The I-CAH Registry is maintained by:

**Dr Jillian Bryce (Registry Manager)** Prof. S. Faisal Ahmed

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