



The I-CAH Registry

(Information for Adults)

What is I-CAH?

I-CAH is an international registry for a wide range of conditions that affect the adrenal glands and may lead to congenital adrenal hyperplasia (CAH). The project was originally launched in 2008 and is helping patients, health care professionals and researchers to improve their knowledge of these rare conditions. To find out more about I-CAH, please visit the website at www.i-cah.org.

What is a Registry?

A registry is similar to a medical database containing a range of medical records. Registries are used very often these days by doctors and scientists to perform research into rare conditions. By pooling knowledge and experiences, registries can improve our understanding of these conditions and improve the care of all those affected.

What is the purpose of the Registry?

The information that will be collected by the Registry is routinely collected by your doctor as part of clinical care, and this includes details of your medical history, clinical examination and treatment. The purpose of the Registry is to share this information with approved users who want to perform research using these data. These approved users may be doctors and scientists, public health or government organisations, other registries of rare conditions, the pharmaceutical industry as well as patient organisations. You can ask your hospital doctor to show you more details of the information that is stored and you can also find out more at www.i-cah.org.

Why have I been approached?

The hospital doctor looking after you or your child and who is highlighted at the end of this leaflet is an approved user of the Registry and has provided this information to you. The Registry is open to all children or adults who have a condition that may be included within the broad umbrella of a CAH. There is another information leaflet which may suit a younger person and you can ask your doctor if you would like to read that one too. When the young person turns 16 years, we will approach them again to check whether they are keen to stay on the Registry.

My affected child is still very young – how do I know this is what my child will want?

Sometimes it can be difficult to decide on your child's behalf. Please remember that all the information can be removed from the Registry at any time by you or by your child. Your child does not need to wait until they turn 16 years old and you can discuss the Registry at an earlier age.

Do I have to take part?

No. If you do not return the attached sheet then your hospital doctor will assume that you do not want the information to be stored and shared on the Registry. The management of your condition/your child's condition will not be affected by your decision.

If I take part, what will happen when the data are included on the Registry?

The Registry users will not be able to make contact with you because the name, address and hospital number will not be recorded. Only your hospital doctor will be able to link the data in the Registry to the hospital records. Nobody else will be able to identify people in the Registry, not even the people who have set up the Registry. Your hospital doctor will enter very brief data and details of these data are present on the I-CAH website. Remember, you can ask your hospital doctor to show you the kind of information that is stored. If you choose to be included in the Registry, you can view your own details as they are entered in the Registry. In addition, the Registry will also provide you with the option to enter your own experiences of health care and choose whether you would like to take part in research. For this, you will need to provide an email address. You can also find out from your hospital doctor or the Registry about the studies in which your details have been used. As the Registry is designed to look at long-term outcome, the data shall be stored indefinitely even after the registered person has passed away.

What will happen to the information collected on the Registry?

- The data collected in the Registry might be used to perform research or develop new research studies
- The results of the studies will be published in medical journals so that other professionals and patients around the world can also benefit.
- The data will allow specialists around the world to contact other specialists looking after people with similar conditions
- The data will help the development of new treatments.
- We will also advise you and your doctor on studies and registries that may exist for you or your child's specific condition



Will the information be kept confidential?

You and/or your child's participation will be kept strictly confidential and all information will be handled through very secure electronic systems. As the Registry involves collecting information from many centres, the system will be password protected and only those who are directly involved with the Registry will have access. Please remember, the Registry does not collect any information about names, addresses and local hospital numbers.

What are the possible disadvantages and risks of the Registry?

There are no disadvantages to being included on the Registry that we can see. You do not have to pay to use the Registry. You will not be contacted by the Registry unless you have selected to do so.

What are the possible benefits of the Registry?

The Registry is designed to help scientists and doctors to improve their understanding of rare conditions and provide best care to affected children and adults. The Registry will also collect information directly from yourself and this will improve your doctors understanding of how the condition affects you. It is possible that, based on the information you provide, your doctor may want to discuss your condition in more detail with you.

Can I access my own record?

Yes. You can arrange access for yourself through the local doctor who has entered the data and you can directly view the information in the Registry. If you would like to change any of this information or would like to find out more, please ask your local doctor. Please remember, if you would like to view the information directly in the Registry, you will need to provide us with your email.

If I change my mind, have a complaint or want to provide feedback, who do I turn to?

If you wish to remove your details from the Registry, you can contact your local doctor or the I-CAH Registry team, directly, through the address at the end of this information sheet. If you are unhappy about any aspect of the way you have been approached or treated, you can also complain through your local health service complaints procedure. Your hospital doctor or your family doctor shall be able to advise you about this. In addition, you can also contact the I-CAH Registry team directly through the address at the end of this information sheet. The team is very keen to hear from you so please feel free to contact them with any comments.

Who has reviewed the activity of the I-CAH Registry?

The Registry has been active for over 10 years now. At its inception, the Registry was reviewed by a number of professional societies and patient groups in the UK as well as Europe. The Registry is used in several countries on all continents across the world and its projects are published after peer review in a number of journals. Every 5 years, the Registry is also reviewed by the UK National Research Ethics Service and the Information Governance Office at the Greater Glasgow & Clyde National Health Service Board. It was last reviewed in August 2019.

Who is funding the I-CAH Registry?

In the past the Registry has received funding from a variety of sources including the European Society for Paediatric Endocrinology, the European Union, the Medical Research Council of the UK, National Institutes of Health Research UK and Diurnal (a UK based pharmaceutical company dedicated to developing high-quality hormone therapeutics). Currently, it is primarily funded by fees that are paid by the doctors and researchers who use the platform.

What do I have to do?

Simply talk to your doctor to decide if it suits your circumstances to put the information on the Registry, and complete the attached form. You can always change your mind later and ask your hospital doctor to remove the information from the Registry.

For further information you can contact:-

- Contact your local specialist at your hospital
- Visit the I-CAH website (www.i-cah.org) and subscribe to receiving further news.
- Contact the I-CAH team – registry@i-dsd.org
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