FAIR PROCESSING NOTICE

The Society for Endocrinology is the Data Controller for the CaHASE study. If you are a patient taking part you will have consented to the information held by the NHS and records maintained by us (the central study office) being used to keep in touch with you and follow up your health status.

The overall aim of the study and the reason we wish to collect and process you data is to learn more about how different treatments and co-morbidities might influence mortality and morbidity of those with Congenital Adrenal Hyperplasia. We plan to use this knowledge to better inform day to day management of patients.

In addition to data collected originally at locally at your hospital, we request further information from NHS Digital - the national information and technology partner to the health and social care system. NHS Digital are the guardians of patient data, making sure it is protected and handled securely, and only ever used for the good of health and care. The information we request includes cancer registrations and date/cause of death. We believe collecting this extra data is the best way to achieve our aim of investigating mortality in patients with Congenital Adrenal Hyperplasia. Though we are no longer recruiting new patients we are continuing to collect death and cancer registration data from NHS digital until December 2020. To do this we continue to hold personal details of all patients who have enrolled on to the study.

Our lawful basis for processing your date is:

* Article 6 (f) processing is necessary for the purposes of the legitimate interests pursued by the controller or by a third party, except where such interests are overridden by the interests or fundamental rights and freedoms of the data subject which require protection of personal data, in particular where the data subject is a child.

Our legitimate interest assessment can be found at Endocrinology.org

* Article 9 (a): the data subject has given explicit consent to the processing of those personal data for one or more specified purposes, except where Union or Member State law provide that the prohibition referred to in paragraph 1 may not be lifted by the data subject;

Identifiable data (data that could potentially identify a specific individual or distinguish one person from another) is held locally at your hospital and at the Society for Endocrinology. Most of the time, a participant is referred to by a unique study identifier rather than by name and this is known as pseudo-anonymisation (the identifier does not reveal your true identity but we can link the data back to you when needed).

The study statistician is based at Sheffield University. He does not receive any data he doesn’t need – for example instead of your name and address he receives a unique number only. Date of Birth, Date of Death, Cause of death and cancer registrations are provided as these are necessary for him to analyse the data. Any published study results will always be anonymised, this means that no-one will be able to identify you.

We only intend to share your data within the study team, however, on certain occasions we may be obliged to allow statutory bodies/organisations to inspect or monitor what we are keeping and how we are keeping it. All participants are free to withdraw from this study at any time and without giving a reason. If anyone wishes to speak with someone about their participation please do not hesitate to contact either Natasha.Archer@endocrinology.org or Zoe.Plummer@endocrinology.org.

As per NIHR/NHS guidance, study data will be kept until the end of the recommended study archive period (usually 5 years). Research data will be anonymised, wherever possible at the earliest opportunity, and in all cases in accordance with the information provided to you at the time of your consent being documented.

You are entitled to a copy of all the information the Society holds about you, although you may not be able to receive information which identifies or relates to anybody else. If you would like a copy of the data we hold, please contact Dr Zoe Plummer, Research and Professional Practice Manager, Zoe.Plummer@emdocrinology.org or Mr Richard Cropley, Operations Director (and Data Protection Officer), Richard.cropley@endocrinology.org. In order to help us provide you with the information as quickly as possible, it would be very helpful if you could provide us with as much information as you can, particularly if you can specify the study name and your participant ID. You will be required to provide proof of identity.

If you feel that the Society has not dealt correctly you have the right to make a complaint at any time to the [Information Commissioner’s Office (ICO)](https://ico.org.uk/) , the UK supervisory authority for data protection issues.

Your legal rights

Under certain circumstances, you have rights under data protection laws in relation to your personal data.

Request access to your personal data (commonly known as a subject access request). This enables you to receive a copy of the personal data we hold about you and to check that we are lawfully processing it.

Request correction of the personal data that we hold about you. This enables you to have any incomplete or inaccurate data we hold about you corrected, though we may need to verify the accuracy of the new data you provide to us.

Request erasure of your personal data. This enables you to ask us to delete or remove personal data where there is no good reason for us continuing to process it. You also have the right to ask us to delete or remove your personal data where you have successfully exercised your right to object to processing (see below), where we may have processed your information unlawfully or where we are required to erase your personal data to comply with local law. Note, however, that we may not always be able to comply with your request of erasure for specific legal reasons which will be notified to you, if applicable, at the time of your request.

Object to processing of your personal data where we are relying on a legitimate interest (or those of a third party) and there is something about your particular situation which makes you want to object to processing on this ground as you feel it impacts on your fundamental rights and freedoms. In some cases, we may demonstrate that we have compelling legitimate grounds to process your information which override your rights and freedoms.

Request restriction of processing of your personal data. This enables you to ask us to suspend the processing of your personal data in the following scenarios: (a) if you want us to establish the data’s accuracy; (b) where our use of the data is unlawful but you do not want us to erase it; (c) where you need us to hold the data even if we no longer require it as you need it to establish, exercise or defend legal claims; or (d) you have objected to our use of your data but we need to verify whether we have overriding legitimate grounds to use it.

Withdraw consent at any time where we are relying on consent to process your personal data.

However, this will not affect the lawfulness of any processing carried out before you withdraw your consent

If you wish to exercise any of the rights set out above, please contact us.

Please note that we do not make use of automated decision making in relation to personal data. If this changes, we will let you know.