



PARTICIPANT INFORMATION SHEET

NAME OF THE RESEARCH STUDY

'The psychosocial impact on parents of having a child diagnosed with Childhood Cerebral Adrenoleukodystrophy (CCALD)'

AN INVITATION

We are Dr Hilary Piercy and Charlotte Nutting. We are researchers at Sheffield Hallam University, and we would like to invite you to take part in an interview for a research study we are conducting in collaboration with Alex TLC.

ABOUT THE RESEARCH STUDY

The aim of the study is to provide detailed insights into the experiences of parents whose child has been diagnosed with Childhood Cerebral Adrenoleukodystrophy (CCALD). We aim to explore and understand:

- the route to initial diagnosis and impact of the diagnosis on parents
- the day to day realities of caring for a child with CCALD and the impact this has on parent's daily lives
- the formal and informal care and support available to parents and their experiences of this
- the wider impact of having a child with CCALD on parents and their families

The study also aims to generate evidenced-based recommendations regarding healthcare provision and care for families. It is anticipated the study will support ongoing efforts towards earlier diagnosis and access to treatments.

Before deciding whether to get involved, it is important you understand how and why the interviews are taking place. Please read the information in this document and contact us (Hilary and/or Charlotte) if you have any questions. Thank you.

WHY HAVE YOU ASKED ME TO TAKE PART?

You are being invited to take part in an interview as the parent of a child who has been diagnosed with CCALD.

DO I HAVE TO TAKE PART?

No. You can decide whether you would like to be involved in the study. If you would like to be interviewed, you will formally consent to an interview at a later date. If you don't want to be interviewed, you don't need to tell us why.

HOW WILL YOU USE THE INTERVIEW INFORMATION?

We aim to interview between 20 to 30 parents. The findings from the study will be presented as a final report which will be made available on the ALEX TLC website and via Sheffield Hallam University.

Additionally, we will publish the findings of the study in an international academic healthcare journal, increasing awareness of the condition and supporting wider efforts to improve early diagnosis and treatment.

Your name will not be used in the report or article, and we will use pseudonyms throughout. A selection of non-identifying quotes from parents will be used to illustrate and illuminate parental experiences. You can choose the pseudonym we use for you in the report and article.

WHAT WILL HAPPEN IF I TAKE PART?

You will be interviewed by Hilary or Charlotte, at a time and date that is convenient to you. The interview will be conducted virtually (online) using 'Zoom', 'Microsoft Teams' or over the telephone. Zoom and Microsoft Teams are online video conferencing applications which can be accessed free using a computer, a laptop or a smartphone. You can choose whether to be interviewed using Zoom, Microsoft Teams or over the telephone. We suggest you are in a quite private place for the interview. Likewise, we will be in a private office when we conduct interviews. If you've not used Zoom or Microsoft Teams before, we can talk you through how to use it before we meet. We are happy to interview you or you and your partner at the same time and you can let us know your preference.

Before we start the interview, we will go through the consent form with you and formally seek your consent which will be recorded. We will then interview you which will involve asking you questions related to having a child who has CCALD. There are no right or wrong answers to the questions. Our aim is to understand your expert experiences of having a child who has CCALD and the wider impact this has on you and your family. The interview will last about 1 hour.

WILL THE THINGS I SAY BE RECORDED?

Yes, we need to record the interview so we can capture all the details. We will use a hand-held digital recorder for this. We won't turn the voice recorder on without you knowing and without your consent. If the interview takes place using Zoom or Microsoft Teams, we will not use the recording option on that platform.

WHAT WILL HAPPEN AFTER THE INTERVIEW?

The audio recording of your interview will be transcribed. All names and any identifying information will be removed from the transcript to anonymise the data which will then be analysed.

The audio recording, the transcript and other information relating to your interview will be saved in a 'site file' on a secure university password protected computer network. We will be the only people who will listen to the audio recording and read the transcribed interview. The 'site file' may be inspected as part of the university standard quality monitoring process.

ARE THERE ANY RISKS IN BEING INTERVIEWED?

We do not anticipate any risks. However, if you find the interview upsetting, Suzanne Gosney and Karen Harrison, from the team at ALEX TLC, will be readily available and happy to provide you with any support you need. Their email details are:

karen@alexvlc.org and suzanne@alexvlc.org

WHAT WILL I GET OUT OF IT?

You may find it therapeutic to talk about your experiences. Your contribution will also enable us to disseminate essential insights into parent experiences of CCALD to medical and healthcare professionals. Your contribution will also enable us to outline evidence-based

recommendations directed towards improving healthcare provision and care for families, which supports ongoing efforts towards earlier diagnosis and access to treatment.

HOW LONG WILL THE PROJECT LAST?

The project will take us one year to complete but your involvement will be for the duration of the interview which we anticipate to be about 1 hour.

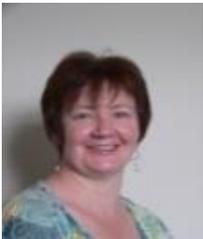
WHAT WILL HAPPEN TO THE INTERVIEW INFORMATION WHEN THE PROJECT HAS FINISHED?

We will securely destroy the audio recordings and your contact details. The 'site file'; containing anonymous transcripts and audio recordings of consent, will be placed in a long-term, secure archive facility at Sheffield Hallam University. All research study documents will be destroyed ten years after the end of the study.

WHO CAN I SPEAK TO IF I HAVE ANY QUESTIONS?

If you have any questions about the interview or the research study, you can contact us. Please also contact us should you wish to take part in the research study:

Dr Hilary Piercy: h.piercy@shu.ac.uk, 0114 225 5603



Charlotte Nutting: c.nutting@shu.ac.uk, 0114 225 5989



WHICH ORGANISATION IS RESPONSIBLE FOR LOOKING AFTER YOUR INFORMATION AND KEEPING IT SAFE?

During the study, we adhere to Sheffield Hallam University's policies and procedures regarding data security and management. The project received a favourable outcome by the Sheffield Hallam University Ethics Review Committee on 05/11/2021.

WHICH ORGANISATION HAS APPROVED THIS PROJECT?

To protect your safety, rights, wellbeing and dignity, this study has been reviewed and approved by Sheffield Hallam University's Research Ethics Committee.

WHO CAN I SPEAK TO IF I HAVE A CONCERN OR AM WORRIED ABOUT THE PROJECT?

You can speak to either of us or a member of staff at ALEX TLC. You can also contact the people below if you have any concerns about the project:

<p>Email the Data Protection Officer (DPO@shu.ac.uk) if:</p> <ul style="list-style-type: none"> • you have a question about how your data is used by the University • you would like to report a data security breach (e.g. if you think your personal data has been lost or disclosed inappropriately) • you would like to complain about how the University has used your personal data 	<p>Email the Head of Research Ethics, Dr Mayur Ranchordas (m.ranchordas@shu.ac.uk) if:</p> <ul style="list-style-type: none"> • you have concerns with how the research was undertaken or how you were treated
<p>Or you can telephone 0114 225 5555 or write: Sheffield Hallam University, Howard Street, Sheffield, S1 1WBT</p>	

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION SHEET AND CONSIDERING WHETHER YOU WOULD LIKE TO TAKE PART IN THE STUDY.

***HOW WE WILL BE USING YOUR PERSONAL DATA**

ALEX TLC is the sponsor for this study based in the United Kingdom. Sheffield Hallam University will be using information from you in order to undertake this study and will act as data controller for this study. This means we are responsible for looking after your information and looking after it properly.

Sheffield Hallam University will keep identifiable information about you for ten years after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information at: <https://www.shu.ac.uk/about-this-website/privacy-policy/privacy-notice/privacy-notice-for-research>.