

# THE PSYCHOSOCIAL IMPACT OF ADRENAL INSUFFICIENCY AND CONGENITAL ADRENAL HYPERPLASIA ON CHILDREN AND THEIR PARENTS

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## Background

Those affected by adrenal insufficiency (AI), including congenital adrenal hyperplasia (CAH), are at risk of serious illness and growth problems, and as a result they require life-long daily hormone replacement therapy. Little is known about the psychosocial impact that living with and treating AI on a daily basis can have on both children and their parents.

## Aim

The aim of the study was to explore the psychosocial impact of AI from the perspective of parents of young children, across three European countries. The study was conducted by Genetic Alliance UK as part of the European Commission funded TAIN (Treatment of Adrenal Insufficiency in Neonates) Project.<sup>2</sup>

## Method

The study used mixed methods. In 2014, 17 semi-structured interviews with parents in the UK were conducted and analysed thematically, supported by NVivo 8 software. In 2015, an online survey was developed, piloted and disseminated (predominantly through support groups) to parents of children under the age of six in the UK, the Netherlands and Germany. Fifty-four responses were received and the data has been analysed with the support of SPSS.

In **conclusion**, the study has provided a rare insight into the wider impact of living with and managing AI and CAH, particularly from the perspective of parents. It demonstrates a number of challenges associated with both the rarity of the condition, and the intensive medication regime. The study has important implications for future research, and how families are cared for and supported in the future.

## Findings

The interviews and survey gathered parents' views in relation to a number of key themes including diagnosis, treatment and the future:

— 63.2% of survey respondents reported that their child was diagnosed between 2 days and 2 weeks old. However, the interviews provided an insight into the difficulties that UK families face prior to or during the diagnosis period including having to fight for a diagnosis and/or go through a traumatic adrenal crisis event before a diagnosis was confirmed.

*...the only thing that upset me about the whole experience was when that doctor said 20 minutes later and he probably would have died... And that brought it home. [Interviewee, 009]*

— Interview findings describe in-depth parents' experiences in relation to the burden, disruption and latent anxiety associated with having to get the *right dose* of medication to their child at the *right time*. Although, our findings suggest that the condition is generally well managed and that parents develop confidence and knowledge in relation to management over time.

— 86.4% of survey respondents felt that they had been equipped with the appropriate skills and knowledge and **over 95%** knew how to adapt their child's medication in times of illness.

*he's grown up with the medicine and it's one of those things where we just sort of got used to it as part of a new routine. [Interviewee, 001]*

— The perceived psychosocial impact on the patients themselves was low, although almost 98% of survey respondents reported worrying about their child's future either sometimes or often. Parents worried about their children taking on responsibility for their own medication; having relationships and their ability to have children; being tied to medication for the rest of their lives; coping with questions or decisions about surgery; and feeling different to peers and knowing what to tell others.



<sup>1</sup>Genetic Alliance UK is an alliance of over 180 patient organisations and the national charity working to improve the lives of patients and families affected by genetic conditions [www.geneticalliance.org.uk](http://www.geneticalliance.org.uk)

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