

## Trustees' Annual Report for the period

Period start date				Period end date			
From	1	April	2023	To	31	March	2024

### Section A Reference and administration details

**Charity name** CONGENITAL ADRENAL HYPERPLASIA SUPPORT GROUP

**Other names charity is known by** CAH SUPPORT GROUP & LIVING WITH CAH GROUP

**Registered charity number (if any)** 1178951 & SCO48814

**Charity's principal address**

27 FIRCROFT,  
KINGSBURY,

TAMWORTH

STAFFS

**Postcode**

B78 2JU

#### Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Sue Elford	Chair		
2	Sallyann Blackett	Treasurer		
3	Jess Loveless	Secretary		
4	Kaz Williams	Adult Coordinator		

#### Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

#### Names and addresses of advisers

Type of adviser	Name	Address
Medical (children)	Prof Faisal Ahmed	C/O Glasgow Children's Hospital
Medical (Adults)	Dr Helena Gleeson	C/O QE Hospital, Birmingham
Medical (Genetics)	Dr Trevor Cole	C/O Women's Hospital, Birmingham
Medical (Surgery)	Mr Liam McCarthy	C/O Birmingham Children's Hospital

## Section B Structure, governance and management

### Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	The Congenital Adrenal Hyperplasia support group is covered by a constitution
How the charity is constituted (eg. trust, association, company)	We are a Charitable Incorporated Organisation
Trustee selection methods (eg. appointed by, elected by)	Trustees are elected by the membership usually during an Annual General Meeting but there is also provision for a direct election by post or online. The constitution allows for current trustees to appoint directly for a period of under a year

### Additional governance issues

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

The support group has developed policies to support the efficient operation of the group.

From an administration basis we have an expenses policy for trustee claims, a reserves policy to safeguard our funds and funding assessment criteria for interactions with research grant proposals. To safeguard those we interact with there is a safeguarding policy and a trustee code of conduct.

The current structure is based on a core team with the ability to request support from members where needed, such as logistics for local meetings.

To keep operations effective and least cost we are using a cloud based online platform for file storage and communication.

The charity interacts with other charities in a similar rare condition space on a goodwill basis without any formal interaction or legal commitment.

Risk assessment has been targeted towards financial requirements and public events such as the conference. We have ensured that our insurance covers these areas.

## Section C Objectives and activities

### Summary of the objects of the charity set out in its governing document

The objects of the CIO are:

For public benefit,

to preserve and protect the health of patients with Congenital Adrenal Hyperplasia (CAH)

by providing support and information to individuals with CAH, their families and carers,

raising awareness among the public and the medical profession and advancing care/treatment of CAH by funding research into CAH,

the useful results of which will be disseminated for the public benefit.

**Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)**

The support group main activities are publication of information and support for those with CAH and their families.

So that members of the public who may be suffering from Congenital Adrenal Hyperplasia or may have children/relatives/friends who may suffer from the condition, be made aware of Congenital Adrenal Hyperplasia Support Group and how it can help them we have a website that is publicly available.

We also work closely with all endocrine centres who have information leaflets for the support group available. We regularly refresh these by mailshot.

We also have stands at endocrine conferences so that we can raise awareness of the group and our services.

One/more trustees attend events and conferences which are run by other organisations set-up with the purpose of bringing families where there is a child with CAH and adults with CAH together as well as those with other conditions which come under the DSD (differences of sexual development) definition, together. We extend our networks and highlight the work we do at these events as well as giving talks/ attending specialist medical events to raise awareness further of our organisation to pass the information to families/ adults they may be working with.

The support group currently holds a bi-ennial formal conference. This is advertised widely through hospitals, medical professionals, our membership and the website. This is open access and we have medical professionals who kindly give up their time to support through talks and questions.

We hold informal meetings in local areas once or twice a year that are also freely available, supported by one or two medical professionals and those with CAH or families managing the condition who can talk about their experiences.

We also provide adult only meetings for those with CAH to speak more freely about how they manage their condition. This is facilitated by our adult support advisor.

In all cases we advertise to our membership, through the medical centres and on our website.

We also provide individual support through phone calls, emails and social media if needed and as appropriate.

**Additional details of objectives and activities**

You **may choose** to include further statements, where relevant, about:

- policy on grant making;
- policy programme related investment;
- contribution made by volunteers.

<p>The support group has an assessment policy that Trustees can use to assess any grant requests. This is aimed at ensuring the use of funds is targeted at areas that support the in-year business plan and deliver maximum benefit to our members and those with CAH in general.</p> <p>We do not have a current policy for investment, however policies are reviewed annually at the Trustee meeting following the AGM.</p> <p>Volunteers are very much at the heart of our operation, and the support group would not function without their help. Contributions for local meeting administration, newsletter articles and editing are all essential support. In essence the Trustees are also volunteers as there are no paid roles.</p>
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**Summary of the main achievements of the charity during the year**

We had a conference in June this year at Drayton Manor. This was well attended and printed notes from this conference have been sent to all members and medical contacts. As part of our ambition to increase our virtual presence and make use of digital technology to be more efficient, the 2024 conference was the first of our events to be bookable using the online ticketing system [ticketsource.co.uk](https://ticketsource.co.uk). This made it much simpler for attendees to book tickets, as well as made it easier for the Group to manage bookings and payments. We will look to use this system for future events.

Committee meetings have remained online, due to convenience and are held at regular intervals. We all continue to be involved on various steering committees and advisory boards for both CAH and DSD and we are regularly consulted to comment on new research projects/papers/guidelines being written relating to the condition and also attend meetings regarding these too.

We continue to be invited to attend official meetings run by the European Society for Endocrinology (ESPE), the Society for Endocrinology (SfE) and the British Society for Paediatric Endocrinology and Diabetes (BSPED) which we attend (either in person or online) when able. We also attend hospital patient days where possible including one in June this year at Kings Hospital, London.

We continue to be very grateful for the support of our members, who through their membership fees, sponsored events and donations have kept our funds topped up, in order that we can help new families/those affected by CAH by providing an information pack at diagnosis (which is when support is vital) to help them understand the condition and realise they are not alone. These funds also mean we are able to continue with providing newsletters, developing our resources and funding meetings/conferences. We have agreed to fund a Quality of Life study which is being run alongside an adult study (CaHASE 2) on treatment/monitoring throughout the UK.

We held a successful adult support group meeting on-line in the Spring with the best attendance to date. We had a presentation from a Doctor involved with new research looking at a potential new treatment for CAH which could potentially reduce the amount of steroids patients would need to take.

The adult support coordinator continued to contribute as a Lay Member to the NICE Guidelines Committee and the Guidelines of Management of Adrenal Insufficiency were published in August this year.

**Brief statement of the charity's policy on reserves**

The support group aims to hold a reserve of two years operational requirements. These funds are held in a cash interest account.

**Details of any funds materially in deficit**

There are no funds in deficit.

**Further financial review details (Optional information)**

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- Investment policy and objectives including any ethical investment policy adopted.

The support group finishes the year with an operating surplus of £16k for 2023/24.

Our overall balance is held as £10k in the current account and £80k in the cash interest account.

The charities principle source of funding is from our membership. Income through the year has been £1.8k in membership fees, this is less than the previous year. Donations from member fundraising has been £20k, more than the previous financial year.

No other income has come from local meeting payments or income from Gift Aid but we did have a small amount of interest payments.

Expenditure was £6.5k over the financial year, higher than the previous year, which was not surprising as we ran a full in person conference.

On a more detailed level, expenditure on administration was £1.5k, higher than the previous year due to more in person meetings.

Our key objectives are to provide resources and support for members and the public. This is evident in the larger expense items during the year.

Conference and local meetings £1.7k for the 2024 conference, newsletter and information packs £3.4k continuing the refresh of literature.

As has been the case for other years our expenses are concentrated on provision of information in person at meetings, online through our website or in print through the newsletters and information booklets.

During this year we have concentrated on maintaining income, minimising expenditure where sensible and ensuring the group has sufficient operating reserves. We are working on how we invest reserves while we are waiting to support medical research

## Section F Other optional information



The aims for the upcoming year include:

- Run another online meeting
- Support the medical research project into quality of life with CAH
- Improve our virtual presence
- Support BSPED funded AI education research (ref Jarod Wong)
- Update the Ambulance guidelines

## Section G Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Sue Elford	Jess Loveless
Position (eg Secretary, Chair, etc)	Chair	Secretary
Date	07/12/24	

		CAH Support Group Accounts :			1/4/23-31/3/24						
INCOME		£	£			EXPENDITURE		£	£		
		2022/23	2023/24					2022/23	2023/24		
Subscriptions		£2,640.50	£1,810.50			Admin		£769.71	£758.04		
Donations		£12,198.77	£20,100.92			Meetings		£349.74	£871.50		
Conference		£0.00	£0.00			Conference		£1,724.00	£970.00		
Local Meetings		£0.00	£93.00			Newsletter		£715.66	£2,725.85		
Resources		£0.00	£0.00			Information Packs		£812.08	£732.00		
Savings Account		£5.50	£687.80			Website		£364.76	£40.78		
Grants		£0.00	£0.00			AGM		£0.00	£0.00		
						Insurance		£96.00	£96.00		
						Audit		£250.00	£270.00		
						Savings Account		£0.00	£0.00		
<b>TOTALS</b>		<b>£14,844.77</b>	<b>£22,692.22</b>					<b>£5,081.95</b>	<b>£6,464.17</b>		
						<b>Income over Expenses</b>			<b>£16,228.05</b>		
Accounts checked & signed off with a note see below											
30/09/2024											
Simone Thomson											
ACMA, CGMA		There is a difference of £9.97 between the opening and closing cash figures. Sallyann has confirmed that £9.97 got paid into the bank									