

Trustees' Annual Report for the period

Period start date				Period end date			
From	1	April	2024	To	31	March	2025

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>

Summary of the main achievements of the charity during the year

We have had another quite busy and productive year.

Sue attended BES2025 in Harrogate in March (along with Kaz) where we had a presentation table and displayed our literature and spoke to numerous doctors/nurses/other support group reps and pharmaceutical company reps, exchanging information and developing relationships. As always this proved very useful and helped promote the support group in a positive light.

Sue remains involved with the CaHASE2 (Insights into the health status of adults with CAH in the UK and Ireland) steering group and has attended meetings throughout the year. Initial findings from this study were presented at various endocrine conferences throughout the year, including BES2025 AND ENDO2025 in San Francisco.

The group agreed last year to fund a Quality-of-Life study, to run alongside CaHASE2 which showed very interesting results and was presented at a meeting we held in London in June 2025. These results were also presented at other endocrine meetings including BSE2025 and ECE2025 (European Congress of Endocrinology) and as a result, a pharmaceutical company recognised the importance of the information that came out of this research and plan to do a further more in depth study on this subject, with more participants involved, which will give even more significance to the findings. Hopefully these studies will help with understanding and availability of psychological counselling (which has always been hard to access).

Our London meeting was very well intended, with excellent speakers and a variety of subjects. The notes from this meeting have been written up by Chris and put into a booklet which is currently with the printers but will be available soon for distributing to our members (possibly also going on our website)

We are currently working with all the other Patient Support Groups who are associated with the Society for Endocrinology to produce a rippable pad with QR codes, featuring all our Groups, which we plan to supply to all major hospitals/endocrine departments, in order that they can provide their patients with the relevant websites for support of their condition. A grant was applied for from the Society for Endocrinology for the printing of these but unfortunately, we were unsuccessful on this occasion, but as all Groups were keen to go ahead with this, we have agreed to fund this between us.

We were also asked to help with a Paediatric Adrenal Insufficiency Education survey. Sallyann sent out invites to all our relevant members and Jess also put it on our website requesting participants. The aim of this was to ensure parents and young people are confident about what they need to do if they/their child are unwell and the importance of acting immediately to prevent serious illness/a crisis or even death. A young persons focus group was also recruited following this. Information from this showed it was clear that there are gaps and inconsistencies in information on adrenal insufficiency and adrenal crisis available and the creation of a resource that is designed specifically for young people to help them understand and manage their condition and used nationwide would be very valuable. Funding for this resource was applied for through BSPED but unfortunately was not successful either. However, the Addisons Disease Self Help Group, the Pituitary Foundation and ourselves (CAH Group) recognising the value of this resource and agreed to split the

cost between the 3 of us, making all the hard work put into producing this resource (mainly by members of the endocrine team in Glasgow) worthwhile.

The campaign for an autoinjector for hydrocortisone for adrenal insufficiency continues. We are working together with the Addison's Disease Self Help Group, the Pituitary Foundation and with SOLUTION Medical (the company invested in designing this). It is still several years away from becoming available but progress is being made. For more information, check out the link below:

[Meet the Researcher - SOLUtion Medical | Addison's Disease Self-Help Group](#)

The CAH International Group – Kaz and Sallyann attend these online meetings which was set up to include CAH support groups throughout the World. It is interesting to learn how other Countries are treating CAH (including the medications available and the thoughts and regulations regarding genital surgery, which is controversial). We can also find out what other groups are doing to help patients/families and see how we might be able to help each other. It seems the UK is one of the few Countries that does not include CAH in newborn screening, which always surprises people!

Committee meetings have generally remained online, due to convenience and are held at regular intervals. We have decided that we should hold at least one meeting a year in person though, with the AGM being the first one here in Oxford. This also gives members the opportunity to come along too and hopefully see how we operate and should they wish to, to join the committee.

Although we continue to be invited to attend various official meetings run by the Society for Endocrinology (SfE), European Society for Endocrinology (ESPE), and the British Society for Paediatric Endocrinology and Diabetes (BSPED) due to work commitments and cost, it is unfortunately not viable for us to attend them all. We tend to prioritise BES and BSPED, as we feel these are the most relevant. Sue will therefore be attending BSPED2025 in Sheffield this November.

Sallyann was able to attend the Society for Endocrinology women's health summit meeting in June this year, held in Birmingham (so costs were minimal!). This was obviously of interest and Sallyann did a great job promoting the support group there, with a tabletop stand. She also continues to do an excellent job as our Treasurer and looks after our database, both of which are no mean feats!

Jess continues to provide us with great support as our secretary and IT specialist. As well as our computers, she also updates our website and as a youngster (compared to me) is always on the ball with new ideas and thoughts on how to develop the Group, for which I am very grateful.

Although Chris is based in Sweden, he also remains committed to the Group, producing our newsletter and helping with the updating of our information booklets, which is so important.

Kaz continues to support our adult population and arranges meetings specifically for them, which I know are much appreciated.

Liz continues to support parents of newborn children with CAH who contact us. I know she is able to help them by providing empathy and

understanding and the reassurance they crave at this difficult time. I know she also continues to provide that help as the years go on, by sharing experience and advice.

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 (2 of which are mentioned above) and funding meetings and conferences.

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 deficit of £12k for 2024/25.

Our overall balance is held as £1k in the current account and £79k in the cash interest account.

The charities principle source of funding is from our membership. Income through the year has been £2.8k in membership fees, this is up on the previous year. Donations from member fundraising has been £6k, less than the previous financial year.

Other income has come from conference payments or income from Gift Aid but we did have a small amount of interest payments.

Expenditure was £22k over the financial year, higher than the previous year, which was not surprising as we have contributed to a couple of research projects.

On a more detailed level, expenditure on administration was £0.2k, lower than the previous year due to less 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 £4.2k for the 2024 conference, newsletter and information packs £2.8k 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 continue the support of medical research

Section F Other optional information



The aims for the upcoming year include:

- Run a full conference
- 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 our resources

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	02/11/25	

CAH Support Group Accounts

INCOME	£ 2023/24	£ 2024/25
Subscriptions	£1,810.50	£2,814.50
Donations	£20,100.92	£5,915.35
Conference	£0.00	£849.06
Local Meetings	£93.00	£0.00
Resources	£0.00	£0.00
Savings Account	£687.80	£948.52
Grants	£0.00	£0.00
TOTALS	£22,692.22	£10,527.43

Accounts checked & sighed off
30/09/2024
Simone Thomson
ACMA, CGMA

1/4/24-31/3/25

EXPENDITURE	£ 2023/24	£ 2024/25
Admin	£758.04	£180.04
Meetings	£871.50	£623.13
Conference	£970.00	£3,643.89
Newsletter	£2,725.85	£2,116.69
Information Packs	£732.00	£704.18
Research	£40.78	£14,445.96
AGM	£0.00	£0.00
Insurance	£96.00	£96.00
Audit	£270.00	£270.00
Savings Account	£0.00	£0.00
	£6,464.17	£22,079.89
Income over Expenses		-£11,552.46