

ADDISON'S DISEASE SELF HELP GROUP

England & Wales · Charity number 1179825

Details

Other names THE ADDISON'S DISEASE SELF-HELP GROUP

Status Registered

Legal form CIO

Registered 2018-09-05

Register [View on the Charity Commission register](#)

Contact

Address 117 Kingsley Avenue
Rugby
Warwickshire
CV21 4JZ

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Email enquiries@addisons.org.uk

Website www.addisonsdisease.org.uk

Activities

Objects: TO PROMOTE THE RELIEF OF PERSONS WITH ADDISON'S DISEASE, IN PARTICULAR BY THE PROVISION OF SUPPORT, INFORMATION AND COMMUNICATION FOR SUCH PERSONS, THEIR FAMILIES AND CARERS AND BY SUCH CHARITABLE MEANS AS THE TRUSTEES DETERMINE.

Activities: Addison's Disease Self Help Group covers the UK and Ireland. It promotes the relief of persons with Addison's Disease and other forms of adrenal insufficiency, in particular by the provision of support, information and communication for such persons, their families and carers and by such charitable means as the trustees determine.

Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Children/young People, Elderly/old People, People With Disabilities, The General Public/mankind

Geography

- Ireland
- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-12-31	£389,162	£333,115	-	-
2024-12-31	£316,000	£324,000	-	-
2023-12-31	£209,915	£228,542	-	-
2022-12-31	£281,973	£256,464	-	-
2021-12-31	£212,568	£204,296	-	-
2020-12-31	£128,323	£141,460	-	-

Trustees

Name	Role	Appointed
Dominic Stuart Hargreaves	Chair	2019-07-01
Benjamin Ducaseau		2025-09-13
Christine Jane Walters		2022-09-10
Dr Alessandro Prete		2022-07-16
Katie Harris		2024-07-20
Lisa Shepherd		2019-07-01
Martin James Hendry		2024-07-20
Robert Sherrard McClements		2020-06-20
Ryan Andrew Richardson		2025-10-24
Stuart Andrew Pinkerton		2018-09-05
Tom James Barnes		2025-04-01

ADDISON'S DISEASE SELF HELP GROUP

England & Wales - Charity number 1179825

Accounts

**Addison's Disease
Self-Help Group**

ANNUAL REPORT 2025

**Trustees Annual Report & Accounts for
the Year ended 31 December 2025**



www.addisonsdisease.org.uk
Charity no. 1179825

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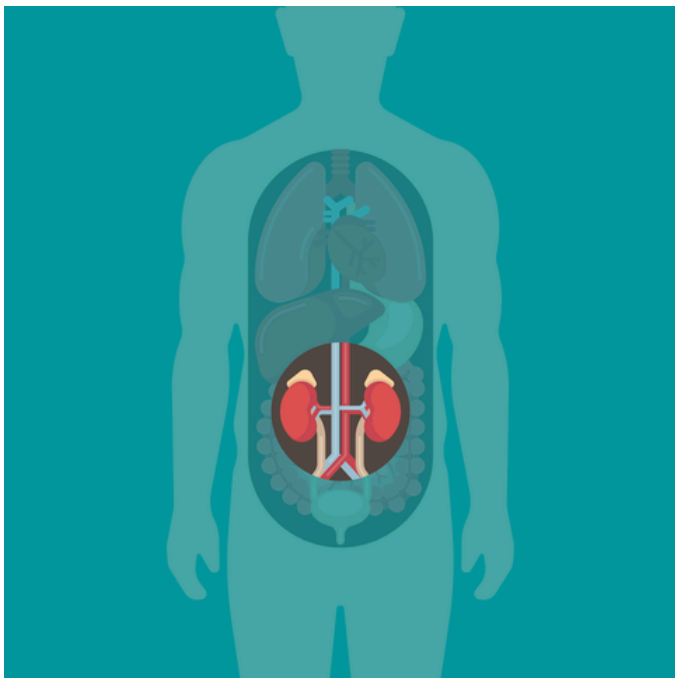
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Who are we?



The Addison's Self Help Group (ADSHG) is the leading UK charity specialising in supporting people with all forms of adrenal insufficiency, including Addison's disease, their families and the healthcare professionals working with them.

Addison's disease (Primary adrenal insufficiency) is a rare endocrine condition where the adrenal glands (acorn sized glands that sit on top of the kidneys) stop functioning, no longer producing life-essential steroid hormones, most notably cortisol. It affects around 1:10,000 in the UK, of different ages and genders.



There are also two other types of adrenal insufficiency:

- Secondary adrenal insufficiency, caused by a problem with the pituitary gland in the brain, and
- Tertiary adrenal insufficiency which can occur in people who have taken long-term steroid medication for conditions such as asthma, and who stop their medication suddenly.

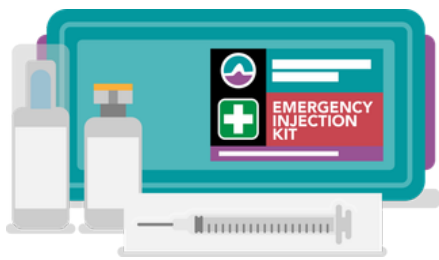
All forms of adrenal insufficiency affect production of steroid hormones by the adrenal gland, notably cortisol.

TREATMENT & MANAGEMENT

Adrenal insufficiency is treated by the time-critical, daily replacement of steroid hormones in medication form (glucocorticoids). Patients are steroid-dependent.

ADRENAL CRISIS

An inherent complication of all types of adrenal insufficiency is the risk of experiencing a life-threatening adrenal crisis, triggered by low cortisol levels. This occurs when the body is under physiological or extreme psychological stress and its need for cortisol outstrips replacement medication doses. It requires an increase in daily medication doses (Sick Day Rules) to provide additional cortisol.



Without sufficient steroid-hormone-replacement medication, all patients with adrenal insufficiency are at risk of a life-threatening adrenal crisis, requiring urgent administration of an emergency hydrocortisone injection, followed by medical monitoring and IV fluids.

Symptoms of adrenal crisis include extreme weakness, a significant drop in blood pressure, drowsiness or mental confusion. Treatment is time-critical but there are many obstacles to successfully drawing up and self-administering an emergency injection whilst acutely unwell. Deterioration in an adrenal crisis can be very fast and can affect even experienced patients.

Each year, typically 8% of people with Addison's disease will have an adrenal crisis.

1 in 200 adrenal crises are fatal.





ACHIEVEMENTS & PERFORMANCE



Our impact in 2025

ADDISON'S DISEASE SELF-HELP GROUP



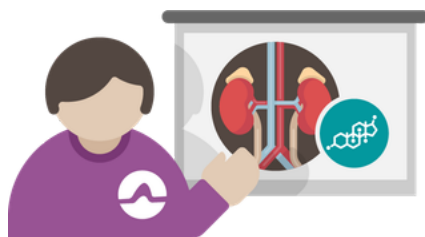
“

Striving for a world where Addison's disease and adrenal insufficiency are recognised early and managed effectively so that anyone affected can live confidently and thrive.



13

AWARENESS STANDS



937 PARAMEDICS, EMTS & STUDENTS TRAINED IN ADRENAL CRISIS MANAGEMENT

1253



EMERGENCY INJECTION KITS SOLD



3

CONFERENCES ATTENDED

930

REGISTRATIONS FOR ADSHG MEMBER EVENTS & WEBINARS



190



GIVEN EMERGENCY INJECTION TRAINING



SOCIAL MEETINGS & ADDISON'S AFTERNOON TEAS

13

2489

MEMBERS SUPPORTED



15

RESEARCH PROJECTS SUPPORTED



We had 3 main strands to our work in 2025: Support, Connect & Advance

SUPPORT



Providing resources and building a community that helps people self manage their condition and improve their quality of life.

Publications



Building on work in 2024, we have continued to prioritise updating our range of printed information booklets, aimed at both patient and healthcare professional audiences, to provide clinically up to date and reviewed information on topics such as:

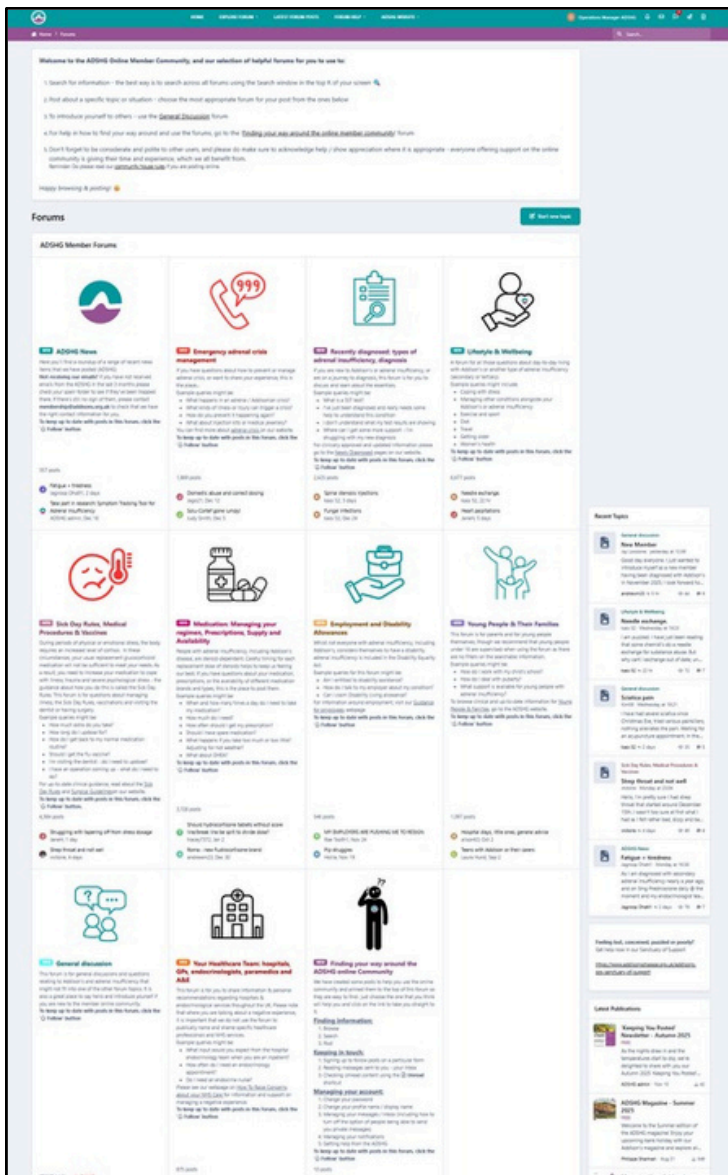
- What are Addison's disease and adrenal insufficiency?
- Notes for Primary Care and A&E nurses
- Notes for Ward Nurses
- Managing Your Addison's disease or adrenal insufficiency
- When an employee has Addison's disease or adrenal insufficiency
- Diagnosis & Care of a patient with adrenal insufficiency (for GPs)

Shop (<https://d42c94e0.myshopify.com>)

Our online shop has continued to go from strength to strength in 2025. Over 1096 orders were placed with our top products over the course of the year being:

- NHS Steroid Emergency cards
- Emergency Injection Instruction Leaflets
- Medic alert keyrings
- ADSHG Steroid Emergency Cards
- Small Emergency Injection Kits





Member community

All members are given an account to join our online, member-only community. The wealth of information shared in our forums is testament to the generosity of our community, to use their experiences to help others. 2025 has seen a focus on how to simplify using the online community for first-time users.

“A person facing this life-changing diagnosis needs someone who's got your back, and up to date reliable information which is clinically verified. That's the ADSHG.”

Thank you to our volunteer 'Forum Buddies' for their support in keeping the online community informed, safe and accessible.

Member emails, newsletters & magazines

We are never short of information to share with our members; from news and updates on our products and services and policy changes, to inspirational personal stories and opportunities to get involved in research. Our monthly member emails and bi-annual newsletters and magazines keep our members aware and prepared.



Website & Social Media

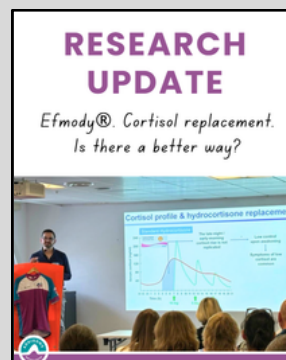


It is important to us that clinically accurate information is freely available to anyone affected by adrenal insufficiency. Our website is kept up to date with information to help support people from 'newly diagnosed' to 'expert patient'.

218,000 users benefitted from our webpages during 2025, with the US, UK and Canada being our most popular browsers. Our Sick Day Rules page continues to draw the most views (over 46,000 in 2025) leading us to develop a Sick Day Rules leaflet to launch in 2026 to help address the questions and uncertainty in the community.

“ I'm so grateful for all the info and support from ADSHG because my GP knows very little about Addison's and was not convinced until my cortisol results came back. Am still waiting for my first endocrinologist appointment so ADSHG has been literally a life saver!

Social media helps us send information beyond our membership, to an engaged audience of over 37,000 followers across all platforms, all keen to learn and support each other. We keep our posts varied; to educate, to engage, to support and to inspire.



CONNECT



Making it possible for the voice of people with adrenal insufficiency, including Addison's disease, to influence, inform & improve the way the healthcare service delivers their care

Working with, and supporting, healthcare professionals



This year has seen the launch of our quarterly e-newsletter for healthcare professionals (HCPs): **ADSHG Connection**.

By engaging with HCPs at endocrinology medical conferences (British Endocrinology Society: Mar 25, Clinical Update: Nov 25 and British Society for Paediatric Endocrinology & Diabetes: Nov 25), we have attracted over 500 sign ups, allowing us to directly communicate the needs of our adrenal insufficiency community.

As hoped, our **Addison's Disease Day** campaign in 2025 saw us top 2024's engagement with 13 awareness stands in hospitals across the UK. We are so grateful to the endocrine teams that helped share their expertise with colleagues and the public alike.

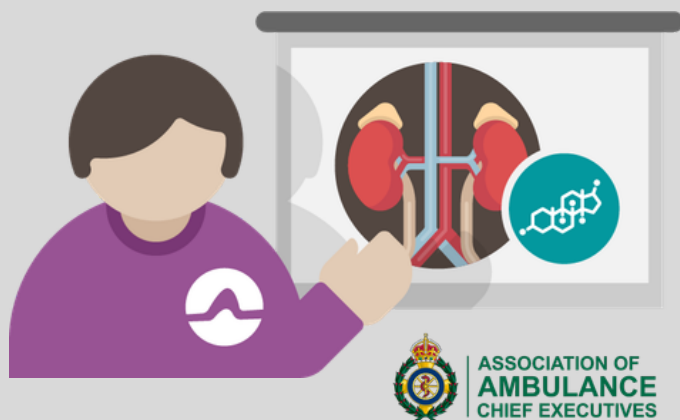


Shrewsbury & Telford NHS Trust



Royal United Hospitals Bath NHS Foundation Trust

Awareness Training: 937 Paramedics, EMTs & students trained



We are so grateful to the support of the Association of Ambulance Chief Executives (AACE) for helping signpost Ambulance trusts across the UK to our free, online Adrenal Crisis Management Awareness Training sessions.

Our clinically reviewed content, presented by people with lived experience, supports and brings to life, the Joint Royal Colleges Ambulance Liaison Committee (JRCALC) guidelines for adrenal insufficiency.

Feedback from attendees at our sessions, which are led by ADSHG staff Philippa and Chloe, as well as volunteers Alison and Jackie, have been beyond excellent, with an average rating of 9.6/10 from 323 respondents.

“

“Very good course. Very informative slides. Really good having people who have the condition taking the course, this offers invaluable insight. ”

“

I loved the course content and found it extremely helpful as you all covered lots of information, from symptoms, treatments, linking it to JRCALC guidelines, and how to spot someone in an adrenal crisis. I now feel much more confident that I will be able to identify it on the road and know how to treat a patient.

“

“Very informative with personal stories. Its easy to read about signs and symptoms but having someone describe their own reactions and how they were diagnosed was really helpful”

ADVANCE

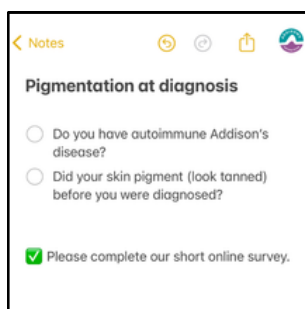
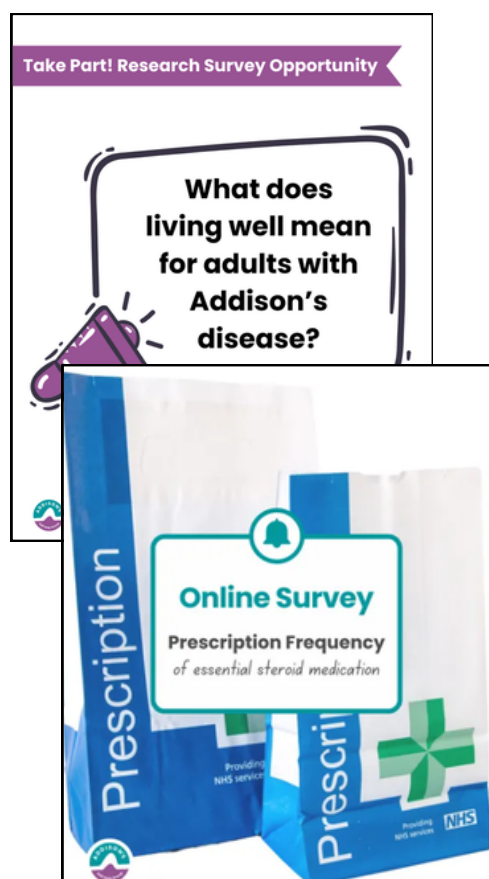


Funding, contributing to, and promoting the development of new innovations and research to improve quality of life for all those with adrenal insufficiency.

We continue to be actively involved in looking to advance the understanding and treatment of Addison's disease (AD) and adrenal insufficiency through:

- Funding and facilitating research (seed-funding)
- Disseminating information and best practice
- Raising awareness of AD/adrenal insufficiency across the healthcare community
- Providing training to GPs, paramedics and others critical to patient care and survival
- Informing and lobbying healthcare decision makers

Below are just a sample of the projects we have supported through member engagement, data collection and direct funding.



The Real Story – Improving Adrenal Crisis Management

As we planned last year, in 2025 we focused on adrenal crisis management and where it is today, over 5 years on from Patient Safety initiatives such as the National Steroid Emergency Card, and over a year on from the launch of the NICE Guidelines for the Identification and Management of Adrenal Insufficiency. We named the project 'The Real Story'.

Our initial goal has been to bring together (virtually) experts and stakeholders from across the UK: researchers and clinicians, Patient Support Groups, and people with lived experience.

By the end of 2025, we united a group of 30 people with an expertise or interest in adrenal crisis management in the UK, across clinical, patient, PSG and pharmaceutical industries as well as having MP interest. The group is picking up momentum in their achievements and in early 2026 the ADSHG, in collaboration with City St Georges, University of London, plan to launch a patient survey to collect detailed information on the patient experience of adrenal crisis.

We look forward to giving a progress report in 2026.

CALL FOR EMERGENCY CARE PRACTITIONERS
Help improve care for life-threatening emergencies.

ADRENAL CRISIS is a rare but life-threatening emergency
By sharing your experience, you can help us improve how adrenal crisis is recognised and managed to save lives.

ABOUT THE STUDY
This research explores adrenal crisis management in pre-hospital and emergency care settings in the UK. Please take part if you are registered with NMC, GMC or HCPC, and working in:
A&E Emergency departments (medical doctors, nurses, advanced clinical practitioners, nurse practitioners)

WHAT IS INVOLVED?
 Complete a short anonymous online survey (~ 10 minutes)
 Optional post-survey 1:1 online interview (~ 30 minutes)
 Participants taking part in interviews will receive a £20 voucher as a thank you.

Take part! Help shape emergency care practice

Click this link or scan the QR code below:
https://cityunilondon.eu.qualtrics.com/jfe/form/SV_6W0j2CLPVTtCO86

For more details contact:
Heather Reid
 Advanced Clinical Practitioner Trainer (Emergency Nurses)
Heather.Reid@citystgeorges.ac.uk

CITY ST GEORGES

ADDISON'S DISEASE SELF HELP GROUP (ADSHG) www.addisonsdisease.org.uk

Take part & share!

We are collaborating in a study aiming to better understand how adrenal crises are recognised and managed in real-world emergency care settings (ambulance and A&E) across the UK.

We are inviting you to contribute to the study or share it within your professional networks to help reach emergency care clinicians, including paramedics, nurses, and medical doctors.

The study, led by Dr Sofia Llahana, has received ethics approval from City St George's, University of London.

Thank you for your support in helping us reach emergency care professionals across the UK.

Survey link: https://cityunilondon.eu.qualtrics.com/jfe/form/SV_6W0j2CLPVTtCO86

Or scan the QR code:



ADDISON'S

Share your experience of Adrenal Crisis to drive improvement

Support our study to understand what it is like to go through an adrenal crisis, how you recognise the symptoms, manage the crisis and seek emergency care.

Please take part if you:

- Are aged **18** or over and receive **medical care in the UK**
- Have been **diagnosed with adrenal insufficiency** (any type)
- Have **experienced an adrenal crisis** in the UK, requiring emergency hydrocortisone administration.

What is involved?

Stage 1:
An **anonymous online survey** (~ 20-25 minutes)

<https://tinyurl.com/survey-adrenal-crisis>

Stage 2:
1:1 online interview with consent (~45 minutes). *Interview participants will receive a £20 voucher, may close earlier

Scan the survey or interview QR code for more information or type in the links below

<https://tinyurl.com/interview-adrenal-crisis>

For more details contact:
Dr Sofia Llahana
adrenal.research@city.ac.uk

www.addisonsdisease.org.uk
 Charity no: 1179825

Our Membership



Membership numbers have continued their slow but steady rise during 2025, with both digital and postal memberships paid memberships available (£33 and £35 respectively). We continue to offer up to 250 sponsored places to those who are unable to afford their subscription.

“Belonging is strength.

Sponsor a Member Donor, 2025

Total of £2584 raised in campaign



Type of Membership

The majority of our members like to receive our news and updates through their front door (postal members)



Gender

The majority of our members are female



Age

The largest age group of our members is 55 - 70 with only one third being outside of this range.

Member Benefits


- Access to our online member forum
- A member pack with a copy of all of our key leaflets
- An invitation to our annual member events with access to expert speaker
- Access to member only 'Social Meetings' when they are held regionally by volunteers
- News updates and information via our monthly member emails and bi-annual magazine & newsletters
- Shop discount codes
- A member vote at our annual AGM


Support to suit everyone




We strive to provide resources and support that everyone affected by Addison's disease and adrenal insufficiency might need and look for.

Here we share just some of the comments left on our social media to show how the charity can impact lives in different ways.


 **Jane**
This charity is a godsend to those of us with Adrenal Insufficiency, our friends and family. So much help and advice, all backed by medical professionals. The website is so very important as it contains advice for sufferers, our friends and family plus our GPs, dentists, and other health care professionals.

 **Jane**
Thank you - this will no doubt be lifesaving work.


Thank you so much for the incredible work you all do to help support and educate those of us with Addison's disease and those who take care of us!! have had this disease for 38 years and I'm still learning from this site! You are all so appreciated! ❤️

 **Lashell**
I don't know how I would make it through all my ups and downs with this disease without an encouraging group like this. Thank you all for sharing because you do understand and know what one goes through ❤️❤️❤️

hey, im not sure if u guys check ure messages but i just wanted to say thank u, ure page has helped my dad & me understand his condition more and how to help it, and the official website taught my mama how to administer a hydrocortisone injection, which very well saved my dads life, even though hes currently in the hospital on life support, that injection gave him a second chance, i cannot thank ure charity enough for helping families, friends & individuals with addisons & adrenal insufficiency, thank you endlessly
❤️

 **Daisy**
The Self Help Group was absolutely invaluable when my partner was diagnosed 2 years ago. Can't recommend the website more!

where_the_wildflowers_grow79 Fantastic webinar this evening. Thank you so much to [@raremindsuk](#) and [@addisonsdiseaseuk](#) for hosting. It is wonderful to feel seen and supported, and to come away with lots of useful and practical suggestions to support our wellbeing 💕

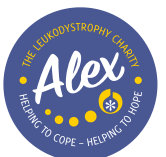
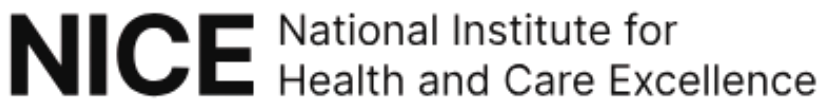
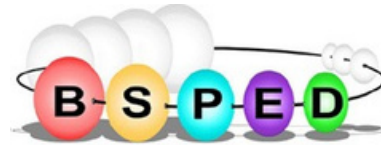
 **frauhaus1** Superb! Not something we ever want to need but the fact you are offering this shoes that time and again it is exactly what we are often faced with! Thank you for your wonderful work supporting us all x

Progress against key Strategic Goals



Key Goals	Progress / Status
Invest in and Improve website navigation & usability	Website re-design project started Nov 2025. Projected completion June 26
Improve navigation & accessibility of Community Online Forum	Forum updates completed and 'How To' guides in development. Projected completion Q3 2026
Expand staffing resource to support Social Media	Social Media Assistant recruited (7hrs/week)
Review & update all printed leaflets	In progress. All existing leaflets have been reviewed post NICE Guidelines and re-designed with a focus on readability and accessibility. New leaflets ongoing
Promote direct interaction of members with Healthcare professionals	Rolling and expanding programme of member events, webinars and injection training events with balance of online and in-person events, and geographically varied venues (allowing as many people to engage as possible).
Grow Awareness of key audiences through direct training and provision of training resources	Paramedic Awareness Training ongoing, expanding (900+ trained in 2025) and well received. Projects in progress with Call Handlers and Carers/Care Homes. Sign ups to the HCP newsletter promoted via conferences.
Ongoing support of Healthcare Professionals, and Education of Primary Care and A&E staff	Rolling programmes. Publication of updated GP leaflet and collaboration with Pituitary Foundation to produce Adrenal Insufficiency Action Plan, both particularly targeting GPs. Plan to attend RCGP conference in 2026.
High level Influence as: Developing advocacy role as appropriate	Real Story project (adrenal crisis management) launched in 2025 - ongoing. Planned advocacy campaign around discontinuation of Hydrocortisone Sodium Phosphate in 2026

Our Collaborations & Associations



Volunteers



We are thrilled to welcome some new volunteers to our team in 2025: helping with proof reading, awareness stands and literature reviews. We have some obvious stand out volunteers whom, it is not exaggerating to say, are part of the very core of the charity, and we owe them a huge debt of gratitude.

There are however, also so many people involved, in so many ways, that offer their time and their expertise to work with us to achieve the most we can for the Addison's and adrenal insufficiency community.

So, to the...

- **Trustees:** for your loyalty, experience and strategic guidance
- **Conference Stand Dynamos:** Alison, Noel and Jennifer, for your enthusiasm, engagement, patience and diligence
- **Proof readers:** for your eye for detail and your kind feedback
- **Article and blog writers:** for your interest, eloquency, and honesty
- **Enquiries aka 'Ask Alison':** for your knowledge, empathy and dedication
- **Clinical Advisory Panel:** for your expertise, patience, and guidance
- **Awareness Stand Organisers:** for your energy, passion and motivation
- **Project volunteers / Consultants:** for your advice and expertise
- **Gratitude Team:** for your thoughtfulness and kindness
- **Events Support team:** for your support, energy and drive
- **Social Meeting hosts:** for your kindness and support of others



Thank You!



2025 has been an incredible year for fundraising, with our community coming together in inspiring ways to raise both vital funds and awareness. Chloe, our Community Fundraising Manager, has proudly supported our fundraisers throughout the year and introduced several new and recurring fundraising campaigns, helping bring people together and make an even greater impact.



Steps for Addison's Awareness Campaign Launch

In February, we launched the 'Steps for Addison's Awareness' fundraising challenge. Participants took on a personalised step or distance goal throughout the month, symbolising the challenging journey faced by many people living with these rare conditions. Our team of 20 fundraisers raised over £7,000 for our charity across the month, culminating on Rare Disease Day (28 February).

The London Landmarks Half Marathon (LLHM)

In April, we had the privilege of supporting our nine fundraisers who ran in the LLHM. These incredible runners raced past iconic landmarks such as Big Ben, St Paul's Cathedral and the Tower of London, raising over an impressive £8,400. Chloe attended the race alongside an ADSHG team of staff and volunteers, creating a truly supportive atmosphere at our charity cheer station.



Addison's Afternoon Tea Campaign

2025 was the second year of our 'Addison's Afternoon Tea' campaign. Throughout May, eight tea parties were hosted by community members to raise awareness, funds and bring people with adrenal insufficiency together. Thanks to the dedication of our volunteers and hosts, these events were a huge success, raising an astounding £12,700.



Small Charity Week Campaign Launch

From 23-30 June, we participated in our first matched-funding campaign with the Big Give. Our target was to raise £2,500 from our community, matched by another £2,500 from the champion sponsor, Global's Make Some Noise.

However, thanks to the generosity of our community, we raised over £9,500 in total! The success of this campaign has truly inspired us and we hope to take part in another matched-funding campaign in 2026.

Sponsor a Member This September Campaign

In September, our 'Sponsor a Member This September' campaign invited donors to give £33 to fund a year's membership for someone who is unable to afford the membership fee. The campaign was another great success, raising funds to sponsor 73 charity memberships.

Each sponsored member will have full access to our digital membership, including forum access, a member pack and other exclusive member benefits.

“
As an existing member I fully appreciate the value of this organisation. Happy to be able to help someone else benefit from this amazing support & resources.
(Campaign Donor)

Festive Fundraiser: Buy a Bauble Campaign

To wrap up an exciting year, we had our 'Buy a Bauble' campaign in December, where donors could add a virtual bauble to our Christmas tree to raise funds. The campaign raised an impressive £2,070, with 111 supporters participating.



This year, our incredible supporters organised everything from sponsored challenges and fundraising nights to bake sales and parties - each making a meaningful difference.

We are deeply grateful to all our fundraisers and donors, including our corporate donors, legacy donors and those who have given in memory of someone special.

Quite simply, none of our work would be possible without you all. Your generosity enables us to continue our vital work. Thank you for standing with us and we look forward to building on this success in 2026 and beyond.

Corporate supporters



In 2025, our charity has been fortunate to receive support from a wide range of corporate organisations. The generosity of these businesses has enabled us to continue our vital work for our community.

Below, we are delighted to share a selection of the companies that have supported us this year:



As a small charity, corporate support makes a significant difference. We rely on the generosity of both individuals and organisations to sustain and grow our work. Whether through donations, pro bono support, volunteering, matched giving or payroll giving, every contribution strengthens our impact.

We would like to extend our sincere thanks to all our corporate supporters in 2025. Your input has been invaluable and we look forward to continuing our collaboration (and welcoming new supporters) in 2026. Together, we can make a difference.



GOVERNANCE & STRUCTURE



Statutory information



The Addison's Disease Self-Help Group (ADSHG) is a Charitable Incorporated Organization (CIO) registered with the Charity Commission for England and Wales as charity number 1179825 and CIO number CE015063. The charity was founded by Deana Kenward MBE in 1984. She remains a Patron of the charity.

Registered Office: ADSHG, 117 Kingsley Avenue, Rugby, CV21 4JZ

Email: enquiries@addisons.org.uk

Website: www.addisonsdisease.org.uk

Constitution

The charity is controlled by its governing document (constitution) which is available on our website. As stated, we exist to "promote the relief of persons with Addison's disease, in particular by the provision of support, information and communication for such persons, their families and carers and by such charitable means as the trustees determine."

Principal Bankers:

CAF Bank Ltd

Independent Examiner:

Andrew Churchill-Stone FCA DChA

Mercer Lewin Ltd Chartered Accountants

Botley Road, Oxford, OX2 OHP

Trustee Board:

The charity is governed by an elected body of trustees consisting of not more than twelve and not less than three members. Each trustee is elected for a three-year term at an Annual General Meeting (AGM), or may be co-opted by existing trustees between AGMs. Meeting in person or virtually, with additional subgroup or single-item agenda meetings convened where needed, the trustees provide direction to the charity's executive team.

www.addisonsdisease.org.uk

Charity no. 1179825

Trustee Report



As Chair of Trustees, I am happy to report we have a well balanced Trustee body, bringing not only a wide range of Trustees with lived experience of Addison's Disease, but also large and small scale business experience blended with the expertise of specialist medics who are world leading in their knowledge of adrenal insufficiency. During 2025 we were sorry to say goodbye to Phil Kaye who retired from his position for reasons of ill health. We welcomed new trustees, Tom Barnes, Benjamin Ducaseau and Ryan Richardson. New trustees are warmly welcomed, onboarded both in terms of the responsibilities of a trustee role, and a comprehensive introduction to the charity.

I think the Trustee board and the Charity are in the best shape that I have seen the Charity in my seven years as a Trustee.

dom hargreaves



CHAIRMAN



Dom Hargreaves



Stuart Pinkerton



Robert McClements



Christine Walters



Alessandro Prete



Martin Hendry



Katie Harris



Lisa Shepherd



Tom Barnes



Benjamin Ducaseau



Ryan Richardson

Statement of Trustee Responsibilities



The charity trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England and Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, of the charity for that period.

In preparing the financial statements, the trustees are required to:

- select suitable accounting policies and apply them consistently;
- observe the methods and principles in the applicable Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures that must be disclosed and explained in the financial statements; and
- prepare the financial statements on a going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports) Regulations 2008 and the provisions of the charity's constitution.

They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.



We continue to routinely monitor operational risks, financial risks, reputational risks, and legal risks such as data protection, regulatory, safeguarding and others.

Major risks which the charity faces on a regular basis are reviewed regularly by trustees. We have internal controls, policies and procedures to provide reasonable assurances against material misstatement or loss.

Other risks that are considered include, for example, cybersecurity and human resource risks.

Financial risk and controls

Financial risks we need to monitor, manage or mitigate against include funding shortfalls, inadequate reserves, investment losses, and fraud. The Treasurer approves all spending or refers to other trustees where decisions need full board approval. Payments require dual authorisation. Reserve funds are retained in fixed term deposit based (no-risk) accounts. The charity's receipts and payments processes, book-keeping and annual statutory accounts are managed by contracted agencies. The charity maintains liability and indemnity insurances.

Clinical and scientific information quality

The ADSHG is supported by an independent clinical panel of endocrinologists with an interest in adrenal medicine, known as the Clinical Advisory Panel (CAP).

We are indebted to our medical advisers for their pro bono support and advice.

The current CAP members (in no particular order) are Professor John Wass, Dr Alessandro Prete, Professor Wiebke Arlt, Professor Will Drake, Dr Steve Kell, Professor Simon Pearce, Stuart Pinkerton, Dr Georgina Russell, Lisa Shepherd RN, Dr Francesca Swords, Sam Westall, Dr Prethivan Gopalakrishnan, Dr Sofia Llahana and Matthew Heppel.

Our Team



In 2025 the day-to-day running of the charity was carried out by a hard working and passionate team. Led by Cathy Thompson, Director, who joined the charity in May 2024, the staffing team has grown to be able to achieve more of their goals, and grow their engagement with members, the wider adrenal insufficiency community, and the clinicians that support them.

Each team member has a specialist skill set and experience in relation to their individual role, however there is inevitable cross over within a team of this size, and it is very much testament to the team pulling together, that they manage to achieve so much on limited resource.

“

2025 has been an exciting and packed year for the operational team: we have defined our roles a little, and as a result, become more confident in them. We have pushed forwards together to expand our aspirations, and clarify our goals for the year, and are thrilled that we have been able to use our limited resources with such impact.

Although all of our team works remotely and nearly all of our team work part-time, we have a strong connection and a shared passion for working as hard as we can for the adrenal insufficiency community.



Chloe Mezzetti
Fundraising
Manager



Charlotte Owst
Social Media Assistant



Cathy Thompson
Director



Thea Blunt
Ops & Member Support



Alison Mainwaring
Enquiries



Sophie Dziwinski
Trusts & Grants



Philippa Sharman
Comms & Health
Liaison Mgr

Our 2026 Wish List



- To further develop our Adrenal Crisis Management training to Paramedics and Paramedic Students.
- To develop a website resource that is easy to navigate, clinically accurate and which helps people feel aware and prepared
- To offer members access to online webinars on a variety of subjects from Sick Day Rules to emotional and psychological well-being
- To continue to bring people together to drive improvements in effective Adrenal Crisis Management, improving patient safety.
- To increase the number of face-to-face member events and access to expert advice from healthcare professionals presenting
- To have more video and animated assets to engage people on social media
- To support improvements in therapeutic treatment programs for people with adrenal insufficiency, including Addison's disease.



FINANCIAL REVIEW



Treasurer's Finance Report



I'm pleased to present our annual accounts. Over the past year we have continued to refine our financial processes, resulting in clearer, more accurate reporting. The ADSHG has benefitted significantly from the restructuring of several key areas of the Charity. These changes have improved efficiency, reduced costs, and strengthened our long-term position. We have also been fortunate to have Cathy leading the organisation for the last 18 months; her leadership has brought positive progress across all areas of our work.

Income

Our income was £389,162; an increase of £72,819 from 2024. The increase was due to multiple factors:

- We received a Gift Aid payment relating to donations from previous years, that had been due but not yet claimed.
- An increase in donations and fundraising was very welcoming. Although this is an important part of our income, it is probably the most vulnerable to cost of living and other issues. I must thank all our members and non-members who tirelessly raise money for the Charity and Chloe, our Community Fundraising Manager for her hard work to support them.
- Membership numbers have increased. We always endeavour to make the Charity an invaluable part of a member's life. It is always positive to see our membership renewals at a good level and membership retention is so important for any Charity. Your membership allows us to plan and build for the year and the future. Never think that it doesn't matter.
- Our shop has increased its sales. The shop has moved to a new system which has reduced costs and makes a more efficient, user friendly experience for members. We have also expanded our range of products.

Expenditure and fund balances

Our expenditure was £333,115; an increase of £9,059.

Our expenditure increased mostly due to our wage bill increasing. This was due to the increase in our employed staffing (our hard working Communications & Health Liaison Manager, Philippa, now has some part-time support. Chloe moved her focus to her fundraising position and we employed a part-time Trust & Foundations manager.

Funding our member get-togethers is another important function of the Charity. Having attended most of the events, it's satisfying to talk to members about their experiences. I'm always moved by the number of members who have never met anyone else that has adrenal insufficiency. For them, these meetings are a potential lifesaver and for many, these gatherings are deeply meaningful and often life changing.

Primary purpose training

Our trading activity helps us deliver against our charitable objects by providing resources to fund the support of people living with adrenal insufficiency, including Addison's Disease, and those who care for them. The shop is online only and focuses on sales of items that can be used by people with adrenal insufficiency, to manage their medications, deal with emergency situations, educate their family and friends, and handle interactions with their healthcare professionals.

Reserves Strategy

During the period the charity will retain minimum unrestricted liquid reserves sufficient to meet normal operating costs including payroll for a minimum of six months, plus any projected winding up costs.

Financial position

The Charity remains in a strong financial position, with reserves that provide against short term fluctuations in membership, donations, or fundraising income.

The Charity is there for the benefit of our members. All employees, volunteers, medical experts and trustees work tirelessly to make the Charity a success. Our volunteers, medical experts, and trustees attend the various meetings, with only minimal expenses – typically travel and accommodation reimbursed.

I am pleased with our financial performance this year. At the same time, it is essential that we continue to plan to safeguard the Charity's long-term health. Every member of our community plays a vital role in sustaining and strengthening ADSHG.

A handwritten signature in blue ink, appearing to read "Stuart Pinkerton".

Stuart Pinkerton

ADSHG TRUSTEE AND TREASURER

Independent Examiners Report



I report to the charity trustees on my examination of the accounts of Addison's Disease Self Help Group (the Charity) for the year ended 31 December 2025.

Responsibilities and basis of report: As the charity trustees of the Charity you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act'). I report in respect of my examination of the Charity's accounts carried out under Section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under Section 145(5)(b) of the Act.

Independent examiner's statement Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales, which is one of the listed bodies. I have completed my examination.

I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Charity as required by Section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Andrew Churchill Stone 

MERCER LEWIN CHARTERED ACCOUNTANTS, 6-7 CITIBASE NEW BARCLAY HOUSE,
234 BOTLEY RD, OXFORD, OX2 OHP

Statement of Financial Activities



ADDISON'S DISEASE SELF HELP GROUP

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2025

	Notes	Unrestricted funds £	Designated Fund £	Restricted funds £	2025 Total funds £	2024 Total funds £
INCOME AND ENDOWMENTS FROM						
Donations and legacies		232,814	-	13,355	246,169	198,179
Charitable activities						
Shop sales income		64,186	-	-	64,186	39,741
Membership fee income		72,894	-	-	72,894	61,039
Other income		1,764	-	-	1,764	12,142
Investment income	2	<u>4,149</u>	<u>-</u>	<u>-</u>	<u>4,149</u>	<u>5,242</u>
Total		<u>375,807</u>	<u>-</u>	<u>13,355</u>	<u>389,162</u>	<u>316,343</u>
EXPENDITURE ON Charitable activities						
Supporting patients and families		62,416	-	-	62,416	72,508
Connecting healthcare professionals and patients		46,606	-	-	46,606	41,884
Advancing knowledge and understanding		59,197	-	-	59,197	43,320
Other project work		1,765	18,811	17,640	38,216	43,963
Shop costs		<u>57,391</u>	<u>-</u>	<u>-</u>	<u>57,391</u>	<u>43,375</u>
Total expenditure on Charitable activities		<u>227,375</u>	<u>18,811</u>	<u>17,640</u>	<u>263,826</u>	<u>245,050</u>
Cost of raising funds		51,970	-	-	51,970	60,285
Governance cost		<u>17,319</u>	<u>-</u>	<u>-</u>	<u>17,319</u>	<u>18,721</u>
Total		<u>296,664</u>	<u>18,811</u>	<u>17,640</u>	<u>333,115</u>	<u>324,056</u>
NET INCOME/(EXPENDITURE)						
Transfers between funds	8	79,143	(18,811)	(4,285)	56,047	(7,713)
		<u>(155,000)</u>	<u>155,000</u>	<u>-</u>	<u>-</u>	<u>-</u>
Net movement in funds		(75,857)	136,189	(4,285)	56,047	(7,713)
RECONCILIATION OF FUNDS						
Total funds brought forward		167,372	5,000	25,569	197,941	205,654
		<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS CARRIED FORWARD		<u>91,515</u>	<u>141,189</u>	<u>21,284</u>	<u>253,988</u>	<u>197,941</u>

Balance Sheet



ADDISON'S DISEASE SELF HELP GROUP

BALANCE SHEET 31 DECEMBER 2025

	Notes	Unrestricted funds £	Designated Fund £	Restricted funds £	2025 Total funds £	2024 Total funds £
CURRENT ASSETS						
Stocks	5	8,275	-	-	8,275	8,491
Debtors	6	6,259	-	-	6,259	15,086
Cash at bank and in hand		<u>83,192</u>	<u>141,189</u>	<u>21,284</u>	<u>245,665</u>	<u>191,915</u>
		97,726	141,189	21,284	260,199	215,492
CREDITORS						
Amounts falling due within one year	7	(6,211)	-	-	(6,211)	(17,551)
NET CURRENT ASSETS		<u>91,515</u>	<u>141,189</u>	<u>21,284</u>	<u>253,988</u>	<u>197,941</u>
TOTAL ASSETS LESS CURRENT LIABILITIES						
		<u>91,515</u>	<u>141,189</u>	<u>21,284</u>	<u>253,988</u>	<u>197,941</u>
NET ASSETS		<u>91,515</u>	<u>141,189</u>	<u>21,284</u>	<u>253,988</u>	<u>197,941</u>
FUNDS						
Unrestricted funds	8				232,704	172,372
Restricted funds					<u>21,284</u>	<u>25,569</u>
TOTAL FUNDS					<u>253,988</u>	<u>197,941</u>

These financial statements were approved by the board of trustees and authorised for issue on 9th May 2026, and were signed on it's behalf by:

Stuart Pinkerton, Trustee/Treasurer
9th May 2026



1. ACCOUNTING POLICIES

BASIS OF PREPARING THE FINANCIAL STATEMENTS

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention, as modified by the revaluation of certain assets.

INCOME

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

EXPENDITURE

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

TANGIBLE FIXED ASSETS

No assets were purchased, depreciated or disposed of in this reporting period.

STOCKS

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

TAXATION

The charity is exempt from tax on its charitable activities.

FUND ACCOUNTING

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

PENSION COSTS AND OTHER POST-RETIREMENT BENEFITS

The charity operates a defined contribution pension scheme. Contributions payable to the charity's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

2. INVESTMENT INCOME

	2025	2024
	£	£
Deposit account interest	<u>4,149</u>	<u>5,242</u>

3. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2025 nor for the year ended 31 December 2024.

TRUSTEES' EXPENSES

Reimbursements totalling £830 were paid to trustees' to cover expenses paid by trustees' for the year ended 31 December 2025.

4. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Designated Fund £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM				
Donations and legacies	198,179	-	-	198,179
Charitable activities				
Shop sales income	39,741	-	-	39,741
Membership fee income	61,039	-	-	61,039
Other income	12,142	-	-	12,142
Investment income	<u>5,242</u>	-	-	<u>5,242</u>
Total	<u>316,343</u>	-	-	<u>316,343</u>
EXPENDITURE ON				
Charitable activities				
Supporting patients and families	72,508	-	-	72,508
Connecting healthcare professionals and patients	41,884	-	-	41,884
Advancing knowledge and understanding	35,820	-	7,500	43,320
Other project work	43,963	-	-	43,963
Shop costs	<u>43,375</u>	-	-	<u>43,375</u>
Total expenditure on Charitable activities	<u>237,550</u>	-	<u>7,500</u>	<u>245,050</u>
Cost of raising funds	60,285	-	-	60,285
Governance cost	<u>18,721</u>	-	-	<u>18,721</u>
Total	<u>316,556</u>	-	<u>7,500</u>	<u>324,056</u>
NET INCOME/(EXPENDITURE)	(213)	-	(7,500)	(7,713)
Transfers between funds	<u>(5,000)</u>	<u>5,000</u>	-	-
Net movement in funds	(5,213)	5,000	(7,500)	(7,713)
RECONCILIATION OF FUNDS				
Total funds brought forward	172,585	-	33,069	205,654

4. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued				
	Unrestricted funds £	Designated Fund £	Restricted funds £	Total funds £
TOTAL FUNDS CARRIED FORWARD	<u>167,372</u>	<u>5,000</u>	<u>25,569</u>	<u>197,941</u>
5. STOCKS				
			2025 £	2024 £
Stocks			<u>8,275</u>	<u>8,491</u>
6. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR				
			2025 £	2024 £
Trade debtors			13	-
Prepayments and accrued income			<u>6,246</u>	<u>15,086</u>
			<u>6,259</u>	<u>15,086</u>
7. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR				
			2025 £	2024 £
Trade creditors			3,631	14,969
Other creditors			<u>2,580</u>	<u>2,582</u>
			<u>6,211</u>	<u>17,551</u>
8. MOVEMENT IN FUNDS				
	At 1/1/25 £	Net movement in funds £	Transfers between funds £	At 31/12/25 £
Unrestricted funds				
General fund	167,372	79,143	(155,000)	91,515
Addison's and Pituitary Ireland	5,000	-	-	5,000
Emergency Reserve Fund	-	-	110,000	110,000
Website Development Fund	-	(18,811)	35,000	16,189
Living With Addison's Fund	-	-	<u>10,000</u>	<u>10,000</u>
	<u>172,372</u>	<u>60,332</u>	-	<u>232,704</u>
Restricted funds				
Medical Research Fund	25,569	(17,640)	-	7,929
Hospital Saturday Fund Grant	-	2,000	-	2,000
The BIG Give	-	8,368	-	8,368
Neroscine Biosciences Fund	-	<u>2,987</u>	-	<u>2,987</u>
	<u>25,569</u>	<u>(4,285)</u>	-	<u>21,284</u>
TOTAL FUNDS	<u>197,941</u>	<u>56,047</u>	-	<u>253,988</u>

8. MOVEMENT IN FUNDS - continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	316,343	(316,556)	(213)
Restricted funds			
Medical Research Fund	-	(7,500)	(7,500)
TOTAL FUNDS	<u>316,343</u>	<u>(324,056)</u>	<u>(7,713)</u>

A current year 12 months and prior year 12 months combined position is as follows:

	At 1/1/24 £	Net movement in funds £	Transfers between funds £	At 31/12/25 £
Unrestricted funds				
General fund	172,585	78,930	(160,000)	91,515
Addison's and Pituitary Ireland	-	-	5,000	5,000
Emergency Reserve Fund	-	-	110,000	110,000
Website Development Fund	-	(18,811)	35,000	16,189
Living With Addison's Fund	-	-	10,000	10,000
	<u>172,585</u>	<u>60,119</u>	<u>-</u>	<u>232,704</u>
Restricted funds				
ADSHG Medical Research Fund	11,190	-	(11,190)	-
Addison's Ireland Fund	333	-	(333)	-
Endocrinology Travel Fund	64	-	(64)	-
Ronald Rogers - Gwent	633	-	(633)	-
RCGP module	5,000	-	(5,000)	-
Publications Review Reserve	1,900	-	(1,900)	-
Young and Newly Diagnosed Medical Research Reserve	210	-	(210)	-
Medical Research Fund	13,739	(25,140)	19,330	7,929
Hospital Saturday Fund Grant	-	2,000	-	2,000
The BIG Give	-	8,368	-	8,368
Neroscine Biosciences Fund	-	2,987	-	2,987
	<u>33,069</u>	<u>(11,785)</u>	<u>-</u>	<u>21,284</u>
TOTAL FUNDS	<u>205,654</u>	<u>48,334</u>	<u>-</u>	<u>253,988</u>

8. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	692,150	(613,220)	78,930
Website Development Fund	-	(18,811)	(18,811)
	692,150	(632,031)	60,119
Restricted funds			
Medical Research Fund	-	(25,140)	(25,140)
Hospital Saturday Fund Grant	2,000	-	2,000
The BIG Give	8,368	-	8,368
Neroscine Biosciences Fund	2,987	-	2,987
	13,355	(25,140)	(11,785)
TOTAL FUNDS	705,505	(657,171)	48,334

-The Medical Research Fund consists on monies donated to fund medical research and support medical professionals.

-The Hospital Saturday Fund Grant is designated (set aside by the trustees) to provide 5 x Paramedic Training Sessions in 2026.

-The BIG Give Fund is designated (set aside by the trustees) to provide 2 Member Get Togethers in 2026.

-The Neurocrine Biosciences fund is designated (set aside by the trustees) for the creation of updated emergency injection videos and the design and print of an information booklet for young people with adrenal insufficiency at Secondary School.

9. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 December 2025.

10. ADDITIONAL NOTES

i) The charity's core costs have been allocated based on staff activity as follows: Charitable activities 78% (Support 22%, Connect 22%, Advance 22%, Projects 10%, Shop 2%), Fundraising 20%, and Governance 2%.

ADDISON'S DISEASE SELF HELP GROUP

England & Wales - Charity number 1179825

Accounts

**Addison's Disease
Self-Help Group**

ANNUAL REPORT 2024

**Trustees Annual Report & Accounts for
the Year ended 31 December 2024**



www.addisonsdisease.org.uk
Charity no. 1179825

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Statutory information



The Addison's Disease Self-Help Group (ADSHG) is a Charitable Incorporated Organization (CIO) registered with the Charity Commission for England and Wales as charity number 1179825 and CIO number CE015063. The charity was founded by Deana Kenward MBE in 1984. She remains a dedicated volunteer and Patron of the charity.

Registered Office: ADSHG, Starling House, 1600 Bristol Parkway North, Bristol, BS34 8YU
Email: enquiries@addisons.org.uk
Website: www.addisonsdisease.org.uk

Constitution

The charity is controlled by its governing document (constitution) which is available on our website. As stated, we exist to "promote the relief of persons with Addison's disease, in particular by the provision of support, information and communication for such persons, their families and carers and by such charitable means as the trustees determine."

Trustees serving throughout 2024:

Dominic Hargreaves (Chair)	Stuart Pinkerton (Treasurer)
Philip Kaye	Lisa Shepherd
Robert McClements	Christine Walters
Dr Alessandro Prete	Katie Harris
Martin Hendry	

Principal Bankers:

CAF Bank Ltd

Independent Examiner:

Andrew Churchill-Stone FCA DChA
Mercer Lewin Ltd Chartered Accountants
Botley Road, Oxford, OX2 OHP

www.addisonsdisease.org.uk
Charity no. 1179825



INTRODUCTION

From the Chair



This 2024 report marks the fortieth anniversary of the charity, which has evolved considerably in its 40-year term, from a lone individual, Deana Kenward, sat at her dining room table sending individual hand written letters, to an organisation that now employs 3 staff and enjoys a dedicated volunteer team, which has a website with 21,500 hits a month and 33,000 followers on social media.

Last year's report finished explaining that 2023 had been a challenging year for our small organisation and that we had concluded the reporting period by appointing Cathy Thompson as the new Operations Manager for the charity. I am pleased to report that Cathy has made her mark on the charity with her small dynamic team, in 7 months in role. The charity has continued to develop in presence and standing across the UK over the past year and our membership numbers continue to increase.

At the end of 2023 we identified that, due to a change in law in Ireland, the ADSHG, like a number of other British charities, needed to change its formal legal set up in the Republic of Ireland. After consultation with lawyers in Dublin, we were left with three options:

- Register a new entity in Ireland, with the Irish Register of Charitable Organisations
- Change the charities constitution and register in Ireland
- Withdraw from all activities in Ireland.

After considerable debate, including at the AGM, the decision was taken to formally withdraw our operations from the Republic of Ireland, but to assist Irish members with setting up a new charity in the Republic of Ireland by means of a grant and administrative support from ADSHG staff. I am pleased to report that Rachel Bracken and a number of the Irish members from the Pituitary Foundation have set up a new charity in Ireland called the Addison's and Pituitary Support Group Ireland. Irish members of the ADSHG can of course remain as international members.

Support

To mark the 40th anniversary of the charity we hosted a roadshow, with events in Glasgow, London, Cardiff and Newry reaching just under 300 members and their supporters and far surpassing the number of members who usually attend our AGM (in 2023, coming out of Covid restrictions, 30 people attended the AGM in London). Particularly remarkable was the sharing of common experiences of having a rare disease and the dedication of the endocrine healthcare professionals offering their time and expertise to our members.

Connect

The connect strand of the charity's work continued with the charity attending British Endocrine Shows in Belfast and Birmingham, presenting at the Simba Adrenal conference and also as The Patient's Voice at the European Society of Endocrinology Conference.

Advance

The charity's work continues on the Advance strand of which there is more in the later sections of the report, but our main area of focus continues to be the development of a more effective self-administered emergency treatment for adrenal crisis, than the very complex self-injection system that we have at this time.

Governance

David Head started the year as the acting Operations Manager and once Cathy stepped in, he stepped back into his "normal" Governance role. The Trustees are very dependent on David for quality governance advice and guiding us along the way – thank you.

We recruited two new Trustees over the period; Martin Hendry and Katie Harris, who both bring a younger outlook to the board and a diverse range of experience. Steve Kell stood back from his role as a Trustee due to work pressures, but is retained as a member of the Clinical Advisory Panel. I would like to take this opportunity to thank Steve for his invaluable support to the Trustees and the charity.

Summary

I would like to take this opportunity to thank everyone who made the 40th Anniversary celebration for the charity so special, including our founder Deana Kenward, David Head for taking the lead on the roadshows with able support from Cathy Thompson, Philippa Sharman and Chloe Mezzetti. A debt of gratitude too, to all the volunteers and Trustees who attended the events, enabling us to sell merchandise, field questions and run a brilliant celebratory roadshow for this small patient support group.

As the charity moves into 2025, I can report that the ADSHG is in a strong position financially, although heavily dependent on donations, and that we are well positioned, with plans to continue to flourish in the next few years.

dom hargreaves

CHAIRMAN



Our 2024 Calendar



- JAN Winter 24 Magazine
- FEB #Rare Workshop
- MAR Paramedic Awareness Training
- APR Fundraisers run in the LLHM
- MAY Cathy joins as Operations Manager
ECE Patient's Voice Talk
Addison's Disease Day - 11 Awareness stands & 7 Addison's Afternoon Teas
- JUL Glasgow Roadshow
London AGM
Summer 24 Magazine
- AUG Publication of the NICE Guidelines for Adrenal Insufficiency
Cardiff Roadshow
Newry Roadshow
- SEPT UHW Adrenal Insufficiency Study Day
Awareness Training Working Group
Paramedic Awareness Training
BSPED Working Group
'Sponsor a Member' campaign
- OCT BSPED Conference
SfE Conference Belfast
- NOV Paramedic Awareness Training
- DEC ESE Adrenal Patient Forum
'Buy a Bauble' Campaign

Our Year in Words



Our Year in Numbers

3 members of staff

30,000 Social Media Followers

40 YEARS OLD

ROADSHOWS

500 Christmas Cards sold

5439 Forum posts

387 Paramedics & EMTs given Adrenal Crisis Awareness Training

201 FB Posts

14,641 FB Likes

45 Just Giving Fundraising Pages

48 Hours for Shop Orders

2 conferences attended

9 Volunteer Trustees

11 ADDISON'S DISEASE DAY AWARENESS STANDS

298 Roadshow Attendees

230,000 website clicks

5304 Twitter Followers

220 Medic Alert Keyrings sold

3 Social Meetings

Our Collaborations & Associations



ASSOCIATION OF
AMBULANCE
CHIEF EXECUTIVES



**MEDICS
FOR RARE
DISEASE**

NICE National Institute for
Health and Care Excellence

ESPE European Society for
Paediatric Endocrinology



Irish Endocrine Society



NADF
National Adrenal Diseases Foundation



Living with
cah
CASH Support Group, Registered Charity

beacon
for rare diseases
no rare journey alone



jrcalc

thebmj

**National
Voices**



rareminds
Mental Health for the Rare Disease Community



ACHIEVEMENTS & PERFORMANCE

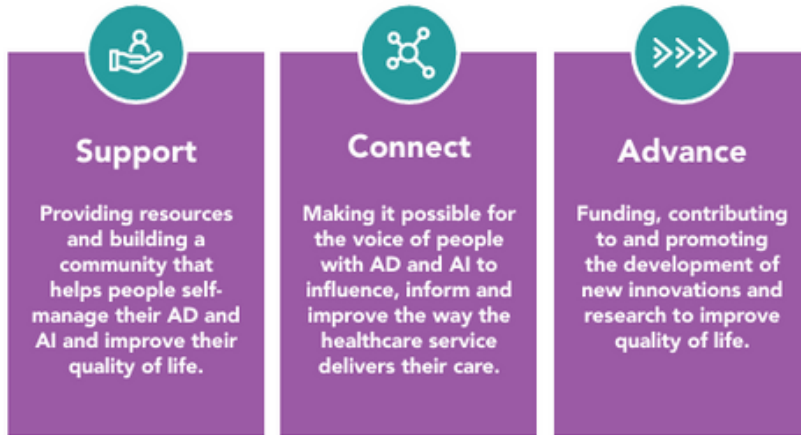


What we do



Whilst 2024 has been a year of change for the charity, in that we successfully recruited a new Operations Manager, Cathy Thompson, to lead our team of staff and volunteers, it has also been a year of consolidation: focusing on the charity's priorities, and celebration, of our 40th anniversary. Taking a look back to the charity's humble beginnings around Deana's kitchen table in 1984, has helped us to recognise the progress that has been made since, and to re-focus us on what we have yet to achieve.

We have continued to view our work across 3 strands: Support, Connect and Advance



Support

Supporting our members in a myriad of ways has remained a strong focus for the team this year, and, thanks to a decision to focus on face-to-face member events, we were able to complete a roadshow between June and September, with events in Glasgow, London, Cardiff and Newry (N.Ireland). It is the first time we have offered this many regional events in a year, and they were very warmly received, showing us just how important meeting up in person is for all of us.

Member Events

Just under 300 members and guests attended our conferences, enjoying expert presentations on Addison's and adrenal insufficiency, presenting questions to our expert panel and brushing up on emergency injection techniques.



“

“I learned so much and felt privileged, after many years of not knowing anyone else with Addison’s, to not only meet so many who share the same condition as myself, but to also be able to ask experts in this field questions.” *Event attendee & Member, 2024*

Member Forum



Our online ‘member only’ forum continues to offer a valued benefit to membership, with access to an online community of others willing to share their experience and knowledge.

Supported by a small group of volunteers, fondly referred to as the **Forum Buddies**, users of the forum can expect a listening ear, warmth and understanding, as well as signposting to useful resources.

Publications and Leaflets

With a tidy up of our logo in Summer 2024, and the launch of the NICE guidelines for Adrenal Insufficiency in Aug 2024, we wanted to re-do our full library of leaflets and publications. We are so grateful to input from our Clinical Advisory Panel, who are involved in the review of our literature to ensure it is accurate and up-to-date. We have just started this ongoing project, but are pleased with our new look and more accessible content.



Social Media

The number of people we reach with our social media platforms has continued to grow, in no small part due to the dedication and diligence of our Communications and Research Manager, Philippa. She offers our followers a wide variety of educational, informative and interesting posts, with everything from reminders to check your kit and advice on Sick Day Rules, to shout out’s when Addison’s or adrenal insufficiency hits the media. With representation on Facebook, LinkedIn, Insta, X and Bluesky, she really has it covered, and we love the engagement we get from our community as they support each other.

Member Comms & Website

Helping our members along their journey from 'newly diagnosed' to 'expert patient' has been facilitated by updates and additions to our website (18 articles and blog posts this year!), distribution of leaflets and publications, and signposting on the online member forum. Our website is a resource that receives frequent praise and mention from members, and attracts visitors from Europe, the US and Canada, as well as the UK. It received over 230,000 clicks during 2024, with our page on **Sick Day Rules** being the most visited.

“

I was diagnosed in Sept 2024: it's awful and very confusing. My friend accessed some information for me which has been very helpful. The ADSHG Group has a fantastic website- it's got everything I need to know about Addison's." (Member social media post, 2024)

Our usual twice yearly magazines and newsletters saw some design updates in the second half of the year to improve accessibility and maximise space for content.

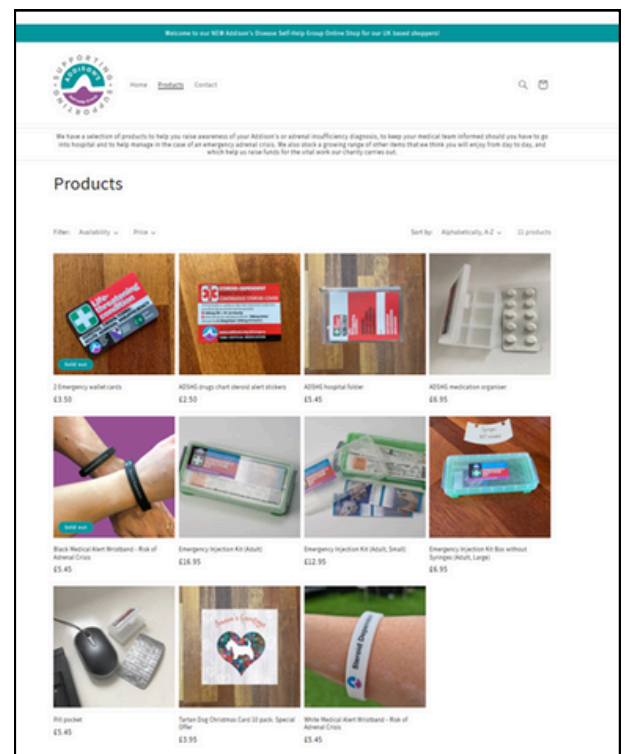
They remain full of useful information for members on managing day-to-day life with steroid-dependency, personal experiences, research updates and charity news.

Shop

Our online shop received a much needed overhaul in the summer and now enjoys a brand new 'Shopify' shop front and offers our shoppers a 48hr tracked delivery on all UK orders. This has been particularly well received and resulted in an increase in its use.

The last few months of 2024 saw bumper sales with over 450 packs of Christmas cards sold, and over 220 of our new 'Medic Alert' keyring!

With a fully functioning 'shop' and a responsive fulfilment service, we would like to continue to grow our range of products next year, in line with suggestions from our community.



Connect

The positive support that the charity receives from healthcare professionals all over the UK was clearly demonstrated this year when we had healthcare professional volunteers (primarily endocrine nurses) running 11 Awareness Stands in hospitals around the UK, for Addison's Disease Day.

The largest response we have had to date, it was a fantastic opportunity for us to help our volunteers to spread awareness of Addison's and adrenal insufficiency to other healthcare staff and the general public. We'd love to top it for Addison's Disease Day in 2025!



Addison's Disease Day Awareness Stand

Promoting Best Practice

We were invited to attend an Adrenal Insufficiency Study Day for staff at University Hospital Wales (UHW), as a part of their campaign to raise awareness of the risks of adrenal crisis in inpatients. The day was an opportunity to bring together a group of junior doctors and nurses to learn about adrenal insufficiency and how to manage it in specific scenarios such as surgery or inpatient situations.

We were able to share the personal experience of one of our Trustees', whose son went into adrenal crisis requiring emergency admission, and the challenges that can entail.

Feedback from the session was overwhelmingly positive.



UHW Study Day

Launch of the NICE Guidelines for the Identification and Management of Adrenal Insufficiency

August 2024 saw the long awaited publication of the NICE Guidelines for adrenal insufficiency. ADSHG were stakeholders in the development of the guidelines, forming a Working Group from our Clinical Advisory Panel. Our Community Fundraising Manager, Chloe, was also a lay member on the NICE committee. We were extremely excited at the launch of these best practice guidelines and are so grateful to all involved in bringing this watershed project to fruition.

They now serve as an important point of reference for all healthcare professionals, raising standards of care for the adrenal insufficiency community.

Paramedic Adrenal Crisis Awareness Training

We're proud to report that this year we have delivered Adrenal Crisis Awareness Training to **387 Paramedics and EMTs** across all the Ambulance Teams in the UK. Our online presentation is delivered by Philippa, Chloe and Alison, our longstanding 'enquiries email' volunteer. Whilst we cover the key medical information required and the charity's ongoing work with JRCALC and AACE, the difference is we use lived experience to bring the presentation to life, making it so much more meaningful for the attendees.

“

“Listening to people sharing their own experiences has taught me more than any textbook or teaching has, or could.” *(Paramedic attendee, 2024)*



Developing an improved resource for Secondary Schools

We have brought together a selection of volunteers with expertise in adrenal insufficiency medicine, and others with experience parenting a child with Addison's, to join us in a Working Group. It will look at developing a resource to serve UK schools, parents and students themselves, to use when navigating secondary school education with a diagnosis of adrenal insufficiency. This project will continue into 2025.

Advance

We continue to be actively involved in looking to advance the understanding and treatment of Addison's disease (AD) and adrenal insufficiency (AI), however we can:

- Funding and facilitating research (seed-funding)
- Disseminating information and best practice
- Raising awareness of AD/AI across the healthcare community
- Providing training to GPs, paramedics and others critical to patient care and survival
- Informing and lobbying healthcare decision makers

Obstacles to Adrenal Crisis Management

In particular this year has seen some interesting research into the obstacles to self-administration, and administration by a carer, of an emergency hydrocortisone injection during adrenal crisis. This supports the anecdotal evidence we are already aware of around the difficulty our members face in managing adrenal crisis, even as expert patients. It is an area we feel is a priority for a renewed focus in 2025.

In 2020 we made a \$13,000 grant to SOLUtion Medical who are progressing towards the manufacture of a pre-filled syringe, which initially would be launched in the US market, followed by applications to bring it to the UK market. We've continued to support their development through focus group feedback at our Dublin 2022 event, and also online. We continue to eagerly follow and report back on their progress.

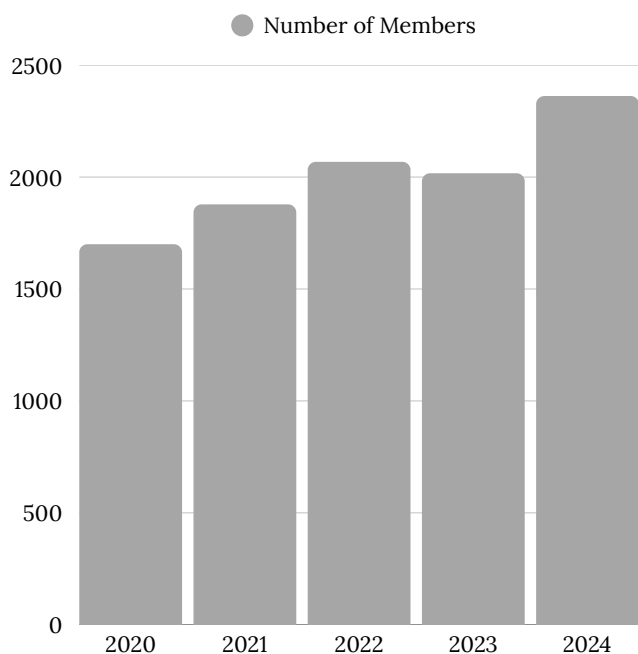
Attracting Researchers into Adrenal Medicine

We continue to actively engage with endocrine healthcare professionals, looking to attract them into adrenal medicine, and to show them that we

are there to offer what support we can, if they are able to undertake research in this area of medicine. Our presence at the Society for Endocrinology (SfE) Joint Irish and UK conference in Belfast in October, was another opportunity to get in front of, and chat to, existing and potential future researchers.



Our Membership



A growth in membership is a win-win in so many ways. It tells us that people are finding our services and support useful and finding value in their membership.

It tells us that more and more people are becoming aware of Addison's and adrenal insufficiency, one of our core goals, and, of course, it helps to generate an increased income for the charity, which we can put to excellent use in growing our impact.

2024 saw us begin to focus on the full experience that our members have, to make sure we can offer them as much as possible and ensure that we are representing their priorities with the impact we make. We've begun to look at making improvements to how our members join our charity, and renew their membership... work that will come to fruition in 2025!

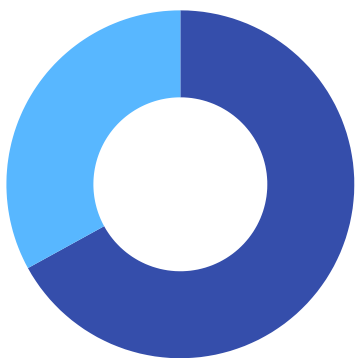
Member benefits

- Access to our online member forum, a wealth of clinically accurate information and support
- A member pack with a copy of all of our key leaflets, and steroid card, posted out
- An invitation to our annual member events with access to expert speakers, emergency injection training and time with others who have lived experience of Addison's and adrenal insufficiency
- Access to member only 'Social Meetings' when they are held regionally by volunteers
- News updates and information via our twice a year magazine and twice a year 'Keeping You Posted' newsletter (received digitally or in the post)
- 10% discount code off Christmas cards in our online shop plus other discount options on new stock ranges
- A member vote at our annual AGM



Type of Membership

The majority of our members like to receive our news and updates through their front door.



Gender

The majority of our members are female



Age

The largest age group of our members is 55 - 70 with only one third being outside of this range.

Sponsored members

Our website resources are purposefully available to members and non-members so that finances are not an obstacle to accessing information and support. Our trustees have taken this one step further in making a number of sponsored memberships available to those who are not able to afford the annual membership fee.

In September 2024 we ran a 'Sponsor a Member This September' campaign via our website and social media. We raised £973.00 from 33 willing sponsors, allowing us to fund a further 30 sponsored members. The testimonials said it all....

“ —

The single most useful thing after diagnosis of adrenal insufficiency was becoming a member of ADSHG. Thank you so much. I want to sponsor someone to join so they can get all the benefit too!" (Sponsor A Member Donor, 2024)

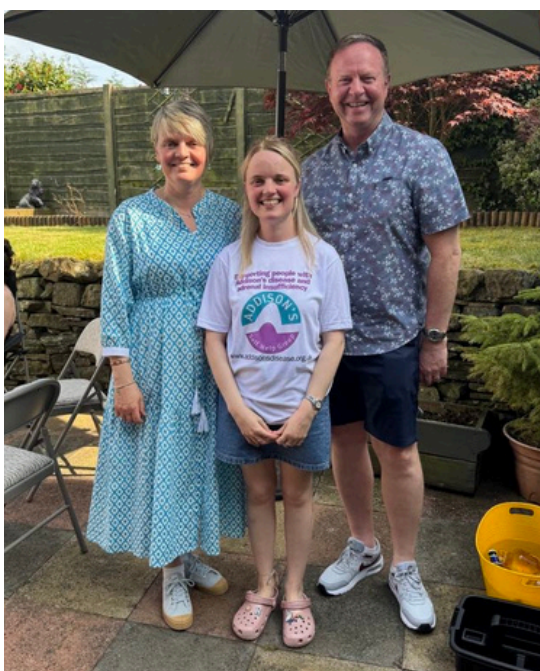
We continue to remove financial obstacles to receiving support by our ongoing commitment to support **250 sponsored member places**.



2024 has been a year of incredible fundraising efforts for the ADSHG, with a range of events and initiatives that have helped raise both vital funds and awareness. Our community has come together in remarkable ways, initiated and supported by our Community Fundraising Manager, Chloe, and we are immensely grateful for their motivation and support.

The London Landmarks Half Marathon

In April, we had the privilege of supporting our 'Super 7' fundraisers who ran in the London Landmarks Half Marathon. These seven incredible runners raced past iconic landmarks such as Big Ben, St Paul's Cathedral, and the Tower of London, raising over an astounding £6,800. Chloe was there to cheer them on alongside longstanding volunteers Alison, Noel and Anna, creating a truly supportive atmosphere at our ADSHG cheer station.



Addison's Afternoon Tea Parties

To mark the 40th anniversary of the ADSHG, Chloe introduced our Addison's Afternoon Tea events. Throughout May, seven individuals across the UK hosted tea parties to raise awareness and bring our community together. Held in the lead-up to **Addison's Disease Day on 29 May**, they provided a platform for fundraising and getting people talking about Addison's and adrenal insufficiency. We supported hosts with our Addison's Afternoon Tea pack, filled with useful resources and advice. Thanks to the dedication of our volunteers and hosts, these events were a huge success.

'Sponsor a Member This September' Campaign

In September, we launched the 'Sponsor a Member This September' campaign, which asked donors to donate £32 to sponsor a year's membership for another person. This initiative highlighted the vital role our members play in supporting each other. The campaign was a great success, raising funds to sponsor 30 charity memberships.

“

“Our membership has been a lifeline, hoping this can be a lifeline to someone else.” (Campaign Donor)

Festive Fundraiser: 'Buy a Bauble' Campaign

To wrap up an exciting year, we introduced our first 'Buy a Bauble' campaign in November; a festive initiative where donors could add a virtual bauble to our Christmas tree to raise funds. The campaign raised an impressive £2,465, with 130 supporters participating and placing a bauble on what ended up being a highly decorated virtual tree!

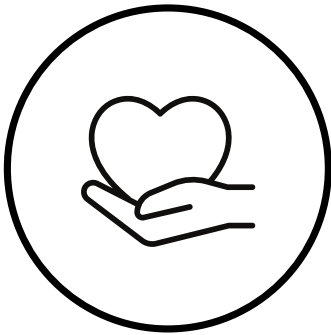


Thank You

Throughout the year, our incredible fundraisers hosted a variety of events, from bake sales and parties to fundraising nights and sponsored challenges such as swims, walks, runs and cycles. We saw supporters travel across the globe for our charity; Trustee Robert and his friend Mark, who cycled from Verona to Venice, Megan, who skated the Berlin Marathon, Izzy who ran the New York Marathon, and Hannah who hosted bake sales in Gibraltar. A truly international effort!

None of this would have been possible without the dedication and passion of our fundraisers. From local gatherings to global challenges, your unwavering support allows us to continue our vital work for the Addison's disease and adrenal insufficiency community.

Thank you all for your remarkable commitment - we can't wait to build on this success in 2025 and beyond!



What is a volunteer?

IT is not always obvious what constitutes a volunteer. We have some obvious stand out volunteers whom, it is not exaggerating to say, are part of the very core of the charity, and we owe them a huge debt of gratitude.

There are however, also so many people involved, in so many ways, that offer their time and their expertise to work with us to achieve the most we can for the Addison's and adrenal insufficiency community.

So, to the...

- **Trustees:** for your loyalty, experience and strategic guidance
- **Conference Stand Dynamos:** Alison, Noel and Jennifer, for your enthusiasm, engagement, patience and diligence
- **Article and blog writers:** for your interest, eloquency, and honesty
- **Enquiries aka 'Ask Alison':** for your knowledge, empathy and dedication
- **Clinical Advisory Panel:** for your expertise, patience, and guidance
- **Awareness Stand Organisers:** for your energy, passion and motivation
- **Project volunteers / Consultants:** for your advice and expertise
- **Gratitude Team:** for your thoughtfulness and kindness
- **Events Support team:** for your support, energy and drive



Thank You!

Support to suit everyone



We strive to provide resources and support that everyone affected by Addison's disease and adrenal insufficiency might need and look for.

Here we share an example of how the charity can impact lives in different ways - through the experiences of a sibling, parents, and the individual diagnosed. Thank you to the Bartlett family for sharing how the ADSHG has supported them.



From Eddie

“

When I was diagnosed, it felt like everything had changed in my life, and no one could understand what I was going through. I felt alone in what I was going through. Like I had to find out everything for myself and learn from what goes wrong. But then I was told about ADSHG, and after reading through the stories and the messages, I started to feel like I wasn't going through this on my own.

There was helpful advice telling me what other people realised and what worked for them; helping me know what to do and what signs to look for, as well as helpful information on how to inform others of what I have and how they can help.

Without the ADSHG I don't think I would be where I am today, with work, friends, or my health in general.”

From Kathryn, Eddie's mum

“

When Eddie was diagnosed with Addisons, it was when the country was in full lockdown. Ian and I were at home alone, while Eddie at 18, was in the hospital alone. We weren't allowed to be with him.

When a Dr calls you and asks you to talk about your family history of autoimmune diseases and you ask 'How is he?' and the reply is 'I'm trying to save his life', you are suddenly shot into a whole new world you weren't expecting. You feel completely in shock. You are confused, frightened, anxious, stressed, overwhelmed, lost & many other things besides. We had no idea at that point if he would survive. You start to look back and think, is this my fault he's at death's door? What did I miss? Why didn't I push him to go to the Drs more quickly? We had literally no idea what Addison's Disease was, we hadn't even heard of it! How on earth could I have been such a bad parent and missed all of the signs? We felt useless to Eddie.

But, then we discovered the ADSHG website and all of their online information. It was literally a lifeline to us. It had all of the information we needed to help us understand what Addison's was, what had happened to Eddie's body, what to expect next and in the future, what support Eddie would need and helped us work out what questions to ask and what to do next.

It also made us realise, we weren't bad parents because we had missed things, it was just difficult to recognise, especially if you've never even heard of it!! I'm not going to pretend everything was instantly ok and that all of those difficult feelings went away, but it seriously helped us cope.

It meant we had all of the information we needed to help our son. It meant we could study and become more knowledgeable about Addison's. It meant we didn't feel as alone. It meant there was hope.

It has been a long and tricky journey, with many bumps in the road along the way. But, 4 years on and I cannot believe how differently everything is now. We cannot thank the ADSHG enough for being our lifeline in our hour of need.

We are not the only ones who have benefited from the ADSHG & their amazing support. Family members can use the website, Eddie's close friends can use the website, Eddie's girlfriend and her family can use the website, so that Eddie has a whole team of people around him who truly understand. This helps him feel loved and supported in difficult times.

The support from ADSHG still goes on, we are still reading, learning and keeping up with research and developments through their newsletter, website and events. They also give Eddie useful reminders about vaccinations, medication, support to go on holiday, the list goes on. They are as important to us now as they always have been.

If you are reading this and are at the beginning of your Addison's journey and in a similar situation, hang in there, it will get easier, it will get better. You are not alone. Thank you ADSHG!"

From Grace, Eddie's sister

“

When Ed was first diagnosed I was stuck in a lockdown away from the family. I felt pretty helpless and often didn't know exactly what was going on. It felt like there was nothing I could do, despite being a medical professional myself. However, the information and support on the ADSHG website was incredible.

I was able to read the professional guidelines and use them to help Eddie advocate for good care for himself. I was also able to point my parents to a place where they could be supported.

Even better, the blogs and patient stories gave me an insight into what Eddie might be feeling or thinking and therefore helped me understand how I could support him. I even started using the resources at work to help look after my patients better!

I can't thank the charity enough for everything they've done for our family, and I know their support will continue to help Eddie thrive!"

Grace is a resident doctor and also volunteers with rare education charity Medics for Rare Disease.





GOVERNANCE & STRUCTURE



Trustee Board



The charity is governed by an elected body of trustees consisting of not more than twelve and not less than three members. Each trustee is elected for a three-year term at an Annual General Meeting (AGM), or may be co-opted by existing trustees between AGMs. Meeting in person or virtually, with additional subgroup or single-item agenda meetings convened where needed, the trustees provide direction to the charity's executive team.

Training for new trustees includes a welcome pack which includes a copy of the constitution, background information on the charity and a copy of the relevant commission publication *The Essential Trustee*, all alongside a comprehensive introduction to our work and processes. Diversity, equity and inclusion

During 2024 we were sorry to say goodbye to Dr Steve Kell, who has however retained links with the charity through his position on our Clinical Advisory Panel. We welcomed new trustees, Martin Hendry and Katie Harris onto the board who bring lived experience and professional skills with them.

We are committed to being a fully inclusive charity and board and are always ready to welcome interest from those wishing to join us.



Dom
Hargreaves



Stuart
Pinkerton



Robert
McClements



Christine
Walters



Alessandro
Prete



Martin Hendry



Katie Harris



Lisa Shepherd



Phil Kaye

Statement of Trustee Responsibilities



The charity trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England and Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, of the charity for that period.

In preparing the financial statements, the trustees are required to:

- select suitable accounting policies and apply them consistently;
- observe the methods and principles in the applicable Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures that must be disclosed and explained in the financial statements; and
- prepare the financial statements on a going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports) Regulations 2008 and the provisions of the charity's constitution.

They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Risk Management



We continue to routinely monitor operational risks, financial risks, reputational risks, and legal risks such as data protection, regulatory, safeguarding and others.

Major risks which the charity faces on a regular basis are reviewed regularly by trustees. We have internal controls, policies and procedures to provide reasonable assurances against material misstatement or loss.

Other risks that are considered include, for example, cybersecurity and human resource risks.

Financial risk and controls

Financial risks we need to monitor, manage or mitigate against include funding shortfalls, inadequate reserves, investment losses, and fraud. The Treasurer approves all spending or refers to other trustees where decisions need full board approval. Payments require dual authorisation. Reserve funds are retained in fixed term deposit based (no-risk) accounts. The charity's receipts and payments processes, book-keeping and annual statutory accounts are managed by contracted agencies. The charity maintains liability and indemnity insurances.

Clinical and scientific information quality

The ADSHG is supported by an independent clinical panel of endocrinologists with an interest in adrenal medicine, known as the Clinical Advisory Panel (CAP).

We are indebted to our medical advisers for their pro bono support and advice. The current CAP members (in no particular order) are Professor John Wass, Dr Alessandro Prete, Professor Wiebke Arlt, Professor Will Drake, Dr Steve Kell, Professor Simon Pearce, Stuart Pinkerton, Dr Georgina Russell, Lisa Shepherd RN, Dr Francesca Swords, Sam Westall, and Matthew Heppel.

Our Team



In 2024 the day-to-day running of the charity is carried out by a hard working and passionate team of three. Each team member has a specialist skill set and experience in relation to their individual role, however there is inevitable cross over within a team of this size, and it is very much testament to the team pulling together, that they manage to achieve so much on limited resource.

On reflecting on the year just passed they commented:

“

What an exciting, whirlwind of a year this has been. I'm thrilled to have joined the ADSHG, and been so warmly welcomed by Philippa, Chloe and the wider team of Trustees and volunteers. The charity has come so far in 40 years, and it is clear so much can be achieved with the support of our members, our Trustees, volunteers, Clinical Advisory Panel and the wider Addison's and adrenal insufficiency community. **Cathy**

“

Another year has flown by, and together we've continued to support our community in awareness, diagnosis and treatment. While we celebrate the wins of reaching a wider audience, working with engaged, passionate medics and researchers and improving education, we remain focused and fully aware of the many challenges faced by those living with our rare conditions. Now with a growing team of staff, I'm excited for all that we can achieve moving forward. **Philippa**

“

This year has been incredibly busy and inspiring for the ADSHG, with more fundraisers and support than ever before. I launched new campaigns, met our wonderful community at the 40th Roadshow events in Glasgow and London, and cheered on our incredible runners at the LLHM. We are so grateful for everyone's dedication and can't wait to build on this momentum in the years ahead. **Chloe**



Cathy Thompson
Operations Manager



Philippa Sharman
Communications & Research
Manager



Chloe Mezzetti
Community Fundraising
Manager

Our 2025 Wish List



- To further develop our Adrenal Crisis Management training to Paramedic Students.
- To offer members access to online webinars on a variety of subjects from Sick Day Rules to emotional and psychological well-being
- To produce a set of tools to help people move from 'newly diagnosed' to 'expert patient'
- To increase the number of face-to-face member events and access to expert advice from healthcare professionals presenting
- To encourage more healthcare professionals into adrenal research
- To have more video and animated assets to engage people on social media



FINANCIAL REVIEW



Treasurer's Finance Report



It is the time of the year that our accounts are released, and we assess our overall performance in financial terms.

The ADSHG continues to perform well, in a time when there is cost of living crisis. We are fortunate to have an amazing team of staff, volunteers and trustees, that steer the charity in these turbulent times.

Income

Our income was £316,343; an increase of £78,128 from 2023. Our expenditure was £316,556; a decrease of £7500. This is a very good performance, showing a reasonable increase of income, whilst reducing our expenses. All income streams remained steady, whilst membership income reduced due to a change of accounting practices; in reality, membership income is about the same as last year.

Expenditure and fund balances

Our large increase in expenditure in 2024 was due to the ADSHG roadshow, which toured the country, and was hugely successful, based on member attendance and feedback. Our total funds showed a small decrease of £7,713.

Primary purpose training

Our trading activity helps us deliver against our charitable objects by providing resources to fund the support of people living with AD/AI, and those who care for them. The shop is online only and focuses on sales of items that can be used by people with AI to manage their medications, deal with emergency situations, educate their family and friends, and handle interactions with their healthcare professionals.

Reserves Strategy

During the period the charity will retain minimum unrestricted liquid reserves sufficient to meet normal operating costs including payroll for a minimum of six months, plus any projected winding up costs.

Financial position

The charity is currently showing a positive balance. We have reasonable funds to protect against any short-term financial issues that could occur due to a change in membership numbers, donations or fund-raising revenue.

It is easy to be complacent, but it is a difficult world for charity fundraising, and we must always look to maximise our income to ensure we are resilient to potential risks and most importantly, to enable us to do more for our member community. Particularly where awareness is concerned, to achieve a higher rate of awareness, we need to run more projects, attend more conferences and run more campaigns.

A 'Preventing Future Death' coroners report was made this year, about a 24-year-old man who tragically died from adrenal crisis, reinforcing that there is always more that needs to be done to save lives, as well as to improve the quality of life for people with AD and adrenal insufficiency.

We have necessarily increased our staffing levels, due to the high workload that Cathy, Philippa and Chloe hold, where they continue to grow our impact, meet the needs and hopes of our members, and work towards our vision. The charity is proactive in making sure that we will always be able to meet our aspirations.

Therefore, I am very happy with our financial situation, but we must keep looking to the future, and make sure that we can always financially support the charity. It is so important that staff, volunteers, members and trustees look after the charity, in all aspects.



Stuart Pinkerton

ADSHG TRUSTEE AND TREASURER

Independent Examiners Report



I report to the charity trustees on my examination of the accounts of Addison's Disease Self Help Group (the Trust) for the year ended 31 December 2024.

Responsibilities and basis of report: As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act'). I report in respect of my examination of the Trust's accounts carried out under Section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under Section 145(5)(b) of the Act.

Independent examiner's statement Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales, which is one of the listed bodies. I have completed my examination.

I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by Section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Andrew Churchill Stone 

MERCER LEWIN CHARTERED ACCOUNTANTS, 6-7 CITIBASE NEW BARCLAY HOUSE,
234 BOTLEY RD, OXFORD, OX2 OHP

Statement of Financial Activities



STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2024

	Notes	Unrestricted funds £	Designated Fund £	Restricted funds £	2024 Total funds £	2023 Total funds £
INCOME AND ENDOWMENTS FROM						
Donations and legacies		198,179	-	-	198,179	107,944
Charitable activities						
Shop sales income		39,741	-	-	39,741	37,105
Membership fee income		61,039	-	-	61,039	87,604
Other income		12,142	-	-	12,142	1,823
Investment income	2	<u>5,242</u>	<u>-</u>	<u>-</u>	<u>5,242</u>	<u>3,739</u>
Total		<u>316,343</u>	<u>-</u>	<u>-</u>	<u>316,343</u>	<u>238,215</u>
EXPENDITURE ON						
Supporting patients and families		72,508	-	-	72,508	60,627
Connecting healthcare professionals and patients		41,884	-	-	41,884	11,588
Advancing knowledge and understanding		35,820	-	7,500	43,320	49,965
Other project work		43,963	-	-	43,963	15,438
Shop costs		<u>43,375</u>	<u>-</u>	<u>-</u>	<u>43,375</u>	<u>39,068</u>
Total expenditure on Charitable activities		<u>237,550</u>	<u>-</u>	<u>7,500</u>	<u>245,050</u>	<u>176,686</u>
Cost of raising funds		60,285	-	-	60,285	44,099
Governance cost		<u>18,721</u>	<u>-</u>	<u>-</u>	<u>18,721</u>	<u>7,757</u>
Total		<u>316,556</u>	<u>-</u>	<u>7,500</u>	<u>324,056</u>	<u>228,542</u>
NET INCOME/(EXPENDITURE)						
Transfers between funds	9	<u>(5,000)</u>	<u>5,000</u>	<u>-</u>	<u>-</u>	<u>-</u>
Net movement in funds		(5,213)	5,000	(7,500)	(7,713)	9,673
RECONCILIATION OF FUNDS						
Total funds brought forward		<u>172,585</u>	<u>-</u>	<u>33,069</u>	<u>205,654</u>	<u>195,981</u>
TOTAL FUNDS CARRIED FORWARD		<u>167,372</u>	<u>5,000</u>	<u>25,569</u>	<u>197,941</u>	<u>205,654</u>

Balance Sheet



BALANCE SHEET 31 DECEMBER 2024

	Notes	Unrestricted funds £	Designated Fund £	Restricted funds £	2024 Total funds £	2023 Total funds £
FIXED ASSETS						
Tangible assets	5	-	-	-	-	2,794
CURRENT ASSETS						
Stocks	6	8,491	-	-	8,491	10,100
Debtors	7	15,086	-	-	15,086	10,556
Cash at bank and in hand		<u>161,346</u>	<u>5,000</u>	<u>25,569</u>	<u>191,915</u>	<u>207,175</u>
		184,923	5,000	25,569	215,492	227,831
CREDITORS						
Amounts falling due within one year	8	(17,551)	-	-	(17,551)	(24,971)
NET CURRENT ASSETS		<u>167,372</u>	<u>5,000</u>	<u>25,569</u>	<u>197,941</u>	<u>202,860</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>167,372</u>	<u>5,000</u>	<u>25,569</u>	<u>197,941</u>	<u>205,654</u>
NET ASSETS		<u>167,372</u>	<u>5,000</u>	<u>25,569</u>	<u>197,941</u>	<u>205,654</u>
FUNDS	9					
Unrestricted funds					172,372	172,585
Restricted funds					<u>25,569</u>	<u>33,069</u>
TOTAL FUNDS					<u>197,941</u>	<u>205,654</u>

These financial statements were approved by the board of trustees and authorised for issue on 8th May 2025, and were signed on it's behalf by:

Stuart Pinkerton, Trustee/Treasurer
8th May 2025



1. ACCOUNTING POLICIES

BASIS OF PREPARING THE FINANCIAL STATEMENTS

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

INCOME

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

EXPENDITURE

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

TANGIBLE FIXED ASSETS

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

STOCKS

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

TAXATION

The charity is exempt from tax on its charitable activities.

FUND ACCOUNTING

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

PENSION COSTS AND OTHER POST-RETIREMENT BENEFITS

The charity operates a defined contribution pension scheme. Contributions payable to the charity's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

2. INVESTMENT INCOME

	2024	2023
	£	£
Deposit account interest	<u>5,242</u>	<u>3,739</u>

3. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2024 nor for the year ended 31 December 2023.

TRUSTEES' EXPENSES

Reimbursements totalling £250 were paid to trustees' to cover expenses paid by trustees' for the year ended 31 December 2024.

4. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Designated Fund £	Restricted funds £	Endowment fund £	Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	107,944	-	-	-	107,944
Charitable activities					
Shop sales income	37,105	-	-	-	37,105
Membership fee income	87,604	-	-	-	87,604
Other income	1,823	-	-	-	1,823
Investment income	<u>3,739</u>	-	-	-	<u>3,739</u>
Total	<u>238,215</u>	-	-	-	<u>238,215</u>
EXPENDITURE ON					
Charitable activities					
Cost of raising funds	44,099	-	-	-	44,099
Operation costs	-	-	-	-	-
Other project work	15,438	-	-	-	15,438
Supporting patients and families	60,627	-	-	-	60,627
Connecting healthcare professionals and patients	11,588	-	-	-	11,588
Advancing knowledge and understanding	49,965	-	-	-	49,965
Governance cost	7,757	-	-	-	7,757
Shop costs	<u>39,068</u>	-	-	-	<u>39,068</u>
Total	<u>228,542</u>	-	-	-	<u>228,542</u>
NET INCOME	9,673	-	-	-	9,673
Transfers between funds	<u>-</u>	<u>-</u>	<u>13,739</u>	<u>(13,739)</u>	<u>-</u>
Net movement in funds	9,673	-	13,739	(13,739)	9,673

4. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

	Unrestricted funds £	Designated Fund £	Restricted funds £	Endowment fund £	Total funds £
RECONCILIATION OF FUNDS					
Total funds brought forward	162,912	-	19,330	13,739	195,981
	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS CARRIED FORWARD	<u>172,585</u>	<u>-</u>	<u>33,069</u>	<u>-</u>	<u>205,654</u>

5. TANGIBLE FIXED ASSETS

	Fixtures and fittings £	Computer equipment £	Totals £
COST			
At 1 January 2024	859	3,507	4,366
Disposals	<u>(859)</u>	<u>(3,507)</u>	<u>(4,366)</u>
At 31 December 2024	<u>-</u>	<u>-</u>	<u>-</u>
DEPRECIATION			
At 1 January 2024	315	1,257	1,572
Eliminated on disposal	<u>(315)</u>	<u>(1,257)</u>	<u>(1,572)</u>
At 31 December 2024	<u>-</u>	<u>-</u>	<u>-</u>
NET BOOK VALUE			
At 31 December 2024	<u>-</u>	<u>-</u>	<u>-</u>
At 31 December 2023	<u>544</u>	<u>2,250</u>	<u>2,794</u>

6. STOCKS

	2024 £	2023 £
Stocks	<u>8,491</u>	<u>10,100</u>

7. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024	2023
	£	£
Trade debtors	-	1,113
Other debtors	-	2,587
Prepayments and accrued income	15,086	2,775
Prepayments	-	4,081
	<u>15,086</u>	<u>10,556</u>

8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024	2023
	£	£
Trade creditors	14,969	21,898
Taxation and social security	-	1,573
Other creditors	2,582	1,500
	<u>17,551</u>	<u>24,971</u>

9. MOVEMENT IN FUNDS

	At 1/1/24	Net movement in funds	Transfers between funds	At 31/12/24
	£	£	£	£
Unrestricted funds				
General fund	172,585	(213)	(5,000)	167,372
Addison's and Pituitary Ireland	-	-	5,000	5,000
	172,585	(213)	-	172,372
Restricted funds				
ADSHG Medical Research Fund	11,190	-	(11,190)	-
Addison's Ireland Fund	333	-	(333)	-
Endocrinology Travel Fund	64	-	(64)	-
Ronald Rogers - Gwent	633	-	(633)	-
RCGP module	5,000	-	(5,000)	-
Publications Review Reserve	1,900	-	(1,900)	-
Young and Newly Diagnosed Medical Research Reserve	210	-	(210)	-
Medical Research Fund	13,739	(7,500)	19,330	25,569
	33,069	(7,500)	-	25,569
TOTAL FUNDS	<u>205,654</u>	<u>(7,713)</u>	<u>-</u>	<u>197,941</u>

9. MOVEMENT IN FUNDS - continued

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	316,343	(316,556)	(213)
Restricted funds			
Medical Research Fund	-	(7,500)	(7,500)
TOTAL FUNDS	<u>316,343</u>	<u>(324,056)</u>	<u>(7,713)</u>

Comparatives for movement in funds

	At 1/1/23 £	Net movement in funds £	Transfers between funds £	At 31/12/23 £
Unrestricted funds				
General fund	162,912	9,673	-	172,585
Restricted funds				
ADSHG Medical Research Fund	11,190	-	-	11,190
Addison's Ireland Fund	333	-	-	333
Endocrinology Travel Fund	64	-	-	64
Ronald Rogers - Gwent	633	-	-	633
RCGP module	5,000	-	-	5,000
Publications Review Reserve	1,900	-	-	1,900
Young and Newly Diagnosed Medical Research Reserve	210	-	-	210
Medical Research Fund	-	-	13,739	13,739
	19,330	-	13,739	33,069
Endowment funds				
Medical Research Fund	13,739	-	(13,739)	-
TOTAL FUNDS	<u>195,981</u>	<u>9,673</u>	<u>-</u>	<u>205,654</u>

9. MOVEMENT IN FUNDS - continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	238,215	(228,542)	9,673
TOTAL FUNDS	<u>238,215</u>	<u>(228,542)</u>	<u>9,673</u>

A current year 12 months and prior year 12 months combined position is as follows:

	At 1/1/23 £	Net movement in funds £	Transfers between funds £	At 31/12/24 £
Unrestricted funds				
General fund	162,912	9,460	(5,000)	167,372
Addison's and Pituitary Ireland	-	-	5,000	5,000
	162,912	9,460	-	172,372
Restricted funds				
ADSHG Medical Research Fund	11,190	-	(11,190)	-
Addison's Ireland Fund	333	-	(333)	-
Endocrinology Travel Fund	64	-	(64)	-
Ronald Rogers - Gwent	633	-	(633)	-
RCGP module	5,000	-	(5,000)	-
Publications Review Reserve	1,900	-	(1,900)	-
Young and Newly Diagnosed Medical Research Reserve	210	-	(210)	-
Medical Research Fund	-	(7,500)	33,069	25,569
	<u>19,330</u>	<u>(7,500)</u>	<u>13,739</u>	<u>25,569</u>
TOTAL FUNDS	<u>195,981</u>	<u>1,960</u>	<u>-</u>	<u>197,941</u>

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	554,558	(545,098)	9,460
Restricted funds			
Medical Research Fund	-	(7,500)	(7,500)
TOTAL FUNDS	<u>554,558</u>	<u>(552,598)</u>	<u>1,960</u>



10. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 December 2024.

11. ADDITIONAL NOTES

- i) Accounts for 2023 are restated to include membership income that had been treated as prepayments in previous years; membership income is now recognised in full as and when it is received
- ii) From 01/01/2024 costs previously recorded as for "Advocacy" and "Membership costs" in the SOFA are now incorporated under the costs of our work supporting patients and families
- iii) From 01/01/2024 costs previously reported as "Operation costs" in the SOFA have been allocated based on staff activity across our charitable activities (70%), fundraising (25%) and governance costs (5%)

ADDISON'S DISEASE SELF HELP GROUP

England & Wales - Charity number 1179825

Accounts



Addison's Disease Self-Help Group (ADSHG)

Trustees' Annual Report & Accounts
for the year ended 31 December 2023



Registered charity 1179825
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Statutory information

The Addison's Disease Self-Help Group (ADSHG) is a Charitable Incorporated Organization (CIO) registered with the Charity Commission for England and Wales as charity number 1179825 and CIO number CE015063. Deana Kenward MBE founded the charity in 1984 and is still a dedicated volunteer and Patron of the charity.

Registered Office

ADSHG, Starling House, 1600 Bristol Parkway North, Bristol, BS34 8YU

Email: enquiries@addisons.org.uk

Website: www.addisonsdisease.org.uk



Constitution

The charity is controlled by its governing document (constitution) which is available on our website. As stated in our constitution, we exist to “promote the relief of persons with Addison’s disease, in particular by the provision of support, information and communication for such persons, their families and carers, and by such charitable means as the trustees determine.”

Trustees serving throughout 2023

Dominic Hargreaves (Chair)
Philip Kaye
Dr Stephen Kell

Robert McClements
Dr Alessandro Prete
Stuart Pinkerton (Treasurer)

Thanooshan Selvarajah
Lisa Shepherd
Christine Walters

Principle bankers

CAF Bank Ltd

Independent Examiner

Andrew Churchill-Stone FCA DChA,
Mercer Lewin Ltd Chartered Accountants
Botley Road
Oxford
OX2 OHP



Visit us online



Overview of 2023 from our chairman

Dominic Hargreaves

This is my second report as Chairman of the Addison's Disease Self-Help Group. We have continued to make progress in a number of core areas in line with our strategy, despite 2023 being a challenging year due to staff issues. Our success despite this is testament to the resilience and passion for improved quality of life for everyone affected by Addison's and adrenal insufficiency, no matter the hurdles we face.



The ADSHG is an organisation of just three staff, though they work with a very dedicated set of volunteers. Our previous Operations Manager stood back from work for health reasons in the summer and then left us at the end of the year; as we went into 2024 and the preparation of this report we were working hard on recruiting a replacement. Our team went from three to two, although thanks to everyone pulling together, no one would have been aware.

I must take this opportunity to thank our staff Philippa Sharman and Chloe Mezzetti, and trustee Stuart Pinkerton, for their sterling efforts to keep the charity running throughout the latter half of the year. Philippa and Chloe took up the reins of the day to day management and delivery of the charity's operations. With great composure and fortitude they took on a wide range of new responsibilities, some of which were outside their experience. They persevered through some challenging and stressful times, and as a result ADSHG delivered everything that was expected of it in 2023. I am pleased to report that David Head was also able to step back into the charity on a part time basis and provide support to Philippa and Chloe, for which we are all very grateful; this also reduced some of the workload on myself and Stuart.

By the time this report is published our new Operations Manager Cathy Thompson will have started in early May 2024. Cathy has a lot of experience working in small organisations in operational roles, and no doubt we will all benefit from her experience. Our 2024 report will, I am sure, reflect her impact.

Despite challenges, the charity delivered its usual annual events for members, presented our stand at the Society for Endocrinology conferences in Glasgow and Birmingham, and presented at the European Society of Endocrinology conference in Istanbul. Local meet-ups also continued thanks to our volunteer social hosts. I cannot thank the team of volunteers enough - Noel Hawkes, Alison Mainwaring, Christine Walters, Rachel Bracken and Robert McClements to name a few - who put so much effort into pulling together these events, at low cost to the charity, making a big impact with our members and the endocrine doctors and nurses.

This year we discussed a contract for a grant with Cardiff and Manchester universities for the provision of research to help us justify an auto-injector for adrenal crisis when one of the pharma companies gets the technology through the approval route. Alongside funding projects, we continued to let you know about opportunities to volunteer as research participants; thank you to everyone who has taken part over the past year. We also continued our Behind the Research updates, such as those on pulsatile infusion pumps, delivering to you the latest Endocrine news. By supporting research, we can explore key questions and invest in people to help nurture the endocrine researchers of the future.

Our role as a stakeholder influencing the new NICE Guidelines *Adrenal insufficiency; identification and management*, continued, with the support of the Addison's Clinical Advisory Panel. We also sit on the working group for the BSPED paediatric adrenal insufficiency education standards, and the European Society Endocrinology Position Statement on self-management for patients and adrenal insufficiency.

After the success of our RCGP training module, we have been exploring different GP education platforms, as well as attending national GP education conferences for the first time with the support of the Society for Endocrinology. Our training programme with the Royal College of General Practitioners, originally released in 2022, was kept on the free side of the RCGP paywall for the initial year. The programme remains available for all RCGP members but, with other GP education platform opportunities available to us and even with firm negotiation by our trustees, we were unable to meet RCGP's dramatically increased prices. The module remains on the platform for all RCGP members to access, and we have turned our attention to the range of other GP education providers that we can collaborate with, in some cases for free. Being across a range of providers gives us greater reach, and we are grateful to trustee Dr Steve Kell who, as a GP himself, has done an excellent job raising the charity's profile in the GP community.

Other initiatives such as our GP posters have had great feedback, encouraging audits on steroid-dependent patients at surgeries as a consequence. This helps to ensure our community is receiving the correct support from GPs including steroid cards, injection kit medication on repeat prescription, and 3 months' reserve supplies of essential steroid medication. In secondary care, we collaborated with the SfE on the Consultation Reference Guide, to directly tackle the inequalities in care in routine Endocrinology checks and appointments.

Our influence on emergency care continues with edits to the JRCALC (paramedic guidelines) and involvement in longer term projects such as Emergency Call Handler training. This will be a long journey requiring patience due to the number of different stakeholders involved and the extra hurdles that come with very rare conditions, but it's one we continue to persist with. Philippa Sharman and Chloe Mezzetti continued to deliver CPD training courses to paramedics on adrenal insufficiency and adrenal crisis – a critical intervention in our view which is no doubt saving lives.

None of our work would be possible without the dedicated support of our volunteers, so I must extend my personal thanks to you all. Our thanks also go out to everyone who raised funds or donated to the charity; in 2023 the Allgood Family and Christine Walters deserve special mention, though that doesn't take anything away from any of our supporters. We cannot operate without you!

I am delighted that the charity remains strong financially despite some tough times, with robust income and respectable reserves. Our Treasurer, Stuart Pinkerton, reports on this later in this document (see page 17).

As we write this report we are planning several activities for the 40th anniversary of the charity in 2024 with great excitement. It also transpires that Brexit has altered how we must comply with charity law in the Republic of Ireland, so we are working hard to understand the consequences of that change and its impact on operations.

In summary 2023 was a very challenging year, which our small team of staff and ever-supportive band of volunteers and fundraisers have navigated very successfully. I look forward to a productive 2024 with Cathy in place, and to celebrating 40 years of the very resilient ADSHG in the company of our staff, volunteers, members, and founder Deana Kenward MBE, across a programme of Addison's Afternoon Teas, roadshows and conferences.

I cannot thank you enough for your support.

My best wishes

Dom Hargreaves

Chairman



What we do

Over the past 12 months we have reached and supported more people than we've done before, we've shone a spotlight on Addison's and adrenal insufficiency and the need for correct treatment and care, educated the public and professionals, and supported and funded research. This success story has its roots in people - our trustees, volunteers, Clinical Advisory Panel and members. Together we continue to rise to the challenge of supporting our community through our three-strand strategy of Support, Connect, Advance.

Support

Our key area of work as a charity is supporting our members, wider community and healthcare providers. We see and hear, every day, how hard some people find day-to-day living with Addison's disease and adrenal insufficiency. The fundamental *raison d'être* of the charity is to provide information and support so that our membership and the wider adrenal insufficiency (AI) community can lead their best lives.

Key to this are our membership scheme, forum, magazine and other publications, meetings and conferences, shop, wide range of social media, website, and the enquiries email line (which is so well looked after by knowledgeable volunteers).

We all know that a very effective way to learn how to manage Addison's disease or other adrenal insufficiency is to learn from the experiences of people with the illness. We also engage with healthcare professionals, including some of the most eminent in the field, who help us to promote broader medical understanding and effective management of this rare condition.






Connect

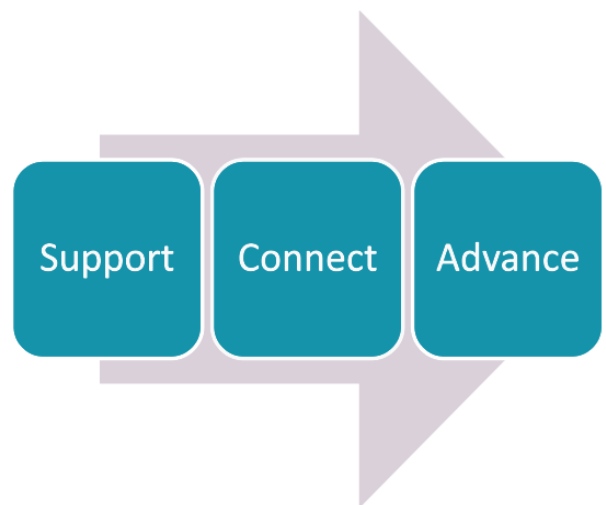
Our annual meetings are important because they bring our membership into contact with professionals who are interested in Addison's disease and adrenal insufficiency. Uniting people with AD/AI and healthcare professionals brings mutual benefits; those affected understand more about their rare disease and how to manage it, and the professionals take away insights from the patient's perspective. Those healthcare professionals then better represent the patient voice when they work with the NHS, NICE or other influential bodies, to inform the healthcare policies or guidelines that impact on our lives.

We actively seek a presence at Society for Endocrinology events and similar events throughout the year, in an effort to inform and influence healthcare decision makers.

Advance

We seek to advance understanding and treatment of AD/AI in several ways:

-  Funding and facilitating research (seed-funding)
-  Disseminating information and best practice
-  Raising awareness of AD/AI across the healthcare community
-  Providing training to GPs, paramedics and others critical to patient care and survival
-  Informing and lobbying healthcare decision makers



Support: Working for people with Addison's/AI in 2023

We have continued our work supporting people affected by Addison's disease and adrenal insufficiency and those who support them, which will always be the bedrock of what we do.

We maintained our online forum for members. This is an important source of information, support and re-assurance, especially for those newly diagnosed and still learning about their condition and how to manage it. There are no financial barriers to joining us and receiving support; for those who perhaps cannot afford the annual membership fee, we offer free sponsored memberships, especially important in the current cost of living crisis.

We continued to supply posters and other materials to hospitals and GP waiting rooms, and other healthcare centres at every opportunity. This enables us to reach the people affected, and raises awareness of AD and AI amongst both the public and healthcare professionals. If you know of a space where we could display our posters, please let us know.



The charity had a presence at a variety of endocrine events. These included the Society for Endocrinology conferences in Glasgow and Birmingham, as well as speaking at the European Society of Endocrinology conference in Istanbul. We use these events to enhance understanding of the patient perspective amongst healthcare professionals, thus improving support for people affected.

Much of our work supporting people affected is online. As well as maintaining the forum, we deliver the Addison's blog, producing 18 articles this year informing, supporting and reassuring our readers. Social media initiatives such as #ShareYourKit, for hydrocortisone emergency injection kits, allow people to share experiences and advice with each other, which is hugely beneficial to our community. Our support is worldwide, and we take part in International Adrenal Disease Consortium meetings with AD/AI support groups around the world.



We continued to make equipment and advisory publications available in our online shop, ensuring those facing possible adrenal crises are equipped to deal with them, and our email enquiries line – run by dedicated volunteers with lived experience of Addison's and adrenal insufficiency - responded to dozens of questions.

Connect: Linking people and organisations in 2023

Connecting people is important to us. Healthcare professionals need to better understand patients' needs, people with Addison's disease and adrenal insufficiency benefit from talking to others 'in the same boat', and we all have experiences, knowledge and advice that can be passed on. Our efforts to facilitate connections throughout 2023 included:

- 🌐 Taking part in #RareDiseaseDay, a national initiative raising the profile and understanding of rare diseases - including Addison's and adrenal insufficiency. Whilst AD and AI may be rare, by working together our impact is impossible to ignore
- 🌐 Our annual awareness day, #AddisonsDiseaseDay, on May 29th, with awareness stands in hospitals, activities to improve education and medical understanding, and increased social media activity
- 🌐 Facilitating social meetings up and down the country
- 🌐 Social media enables the charity to punch well above its weight in connecting people, with
 - 14,000 followers on Facebook
 - 5,000 followers on X (Twitter)
 - 5,000 followers on Instagram
 - A growing audience on LinkedIn and the relatively new Threads
- 🌐 Our main Annual Conference in July (incorporating our formal AGM) and other meetings bringing together people with AD/AI, those who support them, healthcare professionals, scientists and our team.
- 🌐 Our website connected over 90,000 people with the charity during 2023 (recorded unique visitors)
- 🌐 Continued association with related groups and organization around the world



Advance: Knowledge and innovation in 2023

The third strand of our work is about advancing medical knowledge, understanding and management of Addison's disease and adrenal insufficiency. This strand of work takes the form of engaging with endocrine and other healthcare professionals at all levels, and highlighting the needs of those affected.

Research and innovation

In our engagements with members, most people are seeking a better system for an emergency injection in the event of adrenal crisis. By engaging with some of the excellent packages of research driven by Dr Sofia Llahana and Lisa Shepherd, as a charity we now have a better overview of the incidence of adrenal crisis in the UK, the challenges of managing an emergency injection whilst in an emergent adrenal crisis, and the importance of patient self-management. We continue to develop our knowledge, so that when a pharma company get an adrenal crisis auto injector "over the line" we are ready to fight the case for NHS funding.

We have agreed to fund a package of work by Manchester and Cardiff universities on *Adverse Outcomes for Adrenal Crisis*. The initial part of the study has been completed, identifying that 1.4% of the UK population over 55 take corticosteroids for at least three months. As this research progresses we are looking for data about the incidence and outcomes of adrenal crisis in the UK. In parallel, we are tracking the development of an auto injector with SOLUtion Medical in the US, a project that we have supported for a number of years.

Representatives from the charity attended Society of Endocrinology events in Glasgow and Birmingham, spreading awareness of Addison's disease and adrenal insufficiency across the full spectrum of endocrine medical professionals, from nurses to junior doctors to senior professors. We were one of just two patient groups to attend the SIMBA Adrenal 3 conference in Birmingham, which brought a wide range of specialist from across the world together to talk about treatment of adrenal issues and the management of adrenal crisis.

ADSHG continues to sponsor the Annette Louise Seal award, presented by the Society of Endocrinology for the best nurse led presentation on adrenal insufficiency. This year the winner was Louise Breen RN for her work on *Implementation and Impact of Perioperative Guidelines for the Steroid Card and Prevention of Adrenal Crisis*.

Primary and secondary healthcare

Work this year to advance understanding in primary and secondary healthcare included:

- Collaboration with SfE on the *Consultation Reference Guide* tackling inequalities in routine endocrinology
- Our RCGP training module for GPs, *Adrenal insufficiency with a focus on Addison's disease*
- Progress with developing further GP training with "Fourteen Fish" and other potential providers
- Stakeholder for the new NICE guidelines *Adrenal insufficiency; identification and management*
- Waiting room and staff room posters
- Part of the working group for the British Society for Paediatric Endocrinology and Diabetes (BSPED) adrenal insufficiency education standards
- Part of the working group for the European Society Endocrinology (ESE) Position Statement on self-management for patients and adrenal insufficiency



Emergency healthcare

Work to improve emergency healthcare included:

- 🌀 Delivery of CPD paramedic training on adrenal crisis management
- 🌀 Revisions to the JRCALC steroid dependent patients guidelines
- 🌀 Development of a project to train emergency call handlers



“A very well presented session, efficient yet human, about a subject I knew too little about. Lots of useful, practical information.”

“Philippa was incredible engaging, information was pitched at the right level and showed a good understanding of the ambulance service and what we need to know. Personal experiences made it even more tangible and realistic to us. The feedback from staff who attended the sessions has been overwhelmingly positive.”

“Absolutely brilliant. I learnt so much. Having a professional and personal experience was great and really aided my understanding. It was truly awesome! If you're up for it, we would love to arrange another date in the future. I have never seen a group so engaged in a session before! The feedback has been enormously positive from everyone.”

Developing the 'expert patient'

We continue to support and develop the concept of the expert patient, providing good quality information to enable people to engage constructively with their healthcare professionals and to manage their condition well.

In this regard, during 2023 the charity:

- 🌀 Secured nearly 76,000 views of our information videos online, including by over 440 new subscribers
- 🌀 Supplied 1,088 emergency injection kits and instructions through our online shop
- 🌀 Joined the Wren Project Partnership providing free, 1-1 listening support
- 🌀 Provided information and support on vaccinations for 'flu, COVID-19 and shingles
- 🌀 Promoted the 4 E's initiative: patients should be Engaged, Educated, Equipped and Empowered
- 🌀 Published *Behind The Research* articles to explain new developments in endocrinology

2023: A year of change

There is an old saying that tells us that “change is the only constant”.

Trustees at the Addison’s Disease Self-Help Group are certainly not unused to change, but 2023 brought a set of challenging circumstances which, though overcome, were at times stressful and have given us some important learning for the future.

We have been reminded that, as a small organization, the charity is vulnerable if a team member becomes unwell or decides to move on. These two combined in 2023 to leave us without an Operations Manager for the second half of the year.

Being without a key resource had a number of impacts. Most notably, our remaining two part time members of staff took on a lot more work and responsibility, something which has underlined their abilities and value to the organization. Philippa and Chloe have the thanks and utmost respect from the board of trustees for what they achieved.

In addition to coping with the departure of our Operations Manager at no notice, other changes in 2023 included:

- 🔄 The introduction of an interim resource to assist from September
- 🔄 Revision of the job descriptions and remuneration packages for the executive team
- 🔄 Review and revision of several of our systems
- 🔄 Re-appraisal of our planned short term objectives for 2023
- 🔄 Preparation for new events to celebrate our 40th Anniversary to be delivered in 2024
- 🔄 Starting the recruitment process to replace our Operations Manager

COVID-19 also merits (what we hope will be!) a final mention. In recent previous years the pandemic and its aftermath impacted on the way we were working, and on the nature of the support we were providing to people with Addison’s disease and adrenal insufficiency. This has now eased and the demand for support has returned to a more normal level; if there is such a thing. The crisis had also impacted heavily on our intended strategy for the period 2020-25, so it was our intention in 2023 to reassess our strategic plans, something that was then delayed by the Operations Manager’s departure. The appointment of a new Operations Manager and the creation of some breathing space in late 2024 should allow us to do this properly in the coming months.

Our success, despite change and challenge, is a testament to our resilience and passion for improved quality of life for everyone affected by Addison’s and adrenal insufficiency. We kept running as normal during this time, no one would have been aware of the issues; thanks to the team pulling together and working hard, we were able to continue our focus on achieving outcomes that will improve day-to-day living and the long-term future for our community, maximising our impact as a charity.



Fundraisers and volunteers in 2023

Fundraisers

Trustees extend their grateful thanks to the many people who have fundraised for us over the course of the year. Like all charities, we rely on donations for our very existence, and it would be impossible for ADSHG to have the impact it does without that backing. So if you ran, jumped, climbed, quizzed, partied, raffled, swam, hiked, or did anything else to raise money for ADSHG in 2023, huge thanks to you – you are one of many stars – too many to mention by name in a report like this, but please know that we value you hugely.

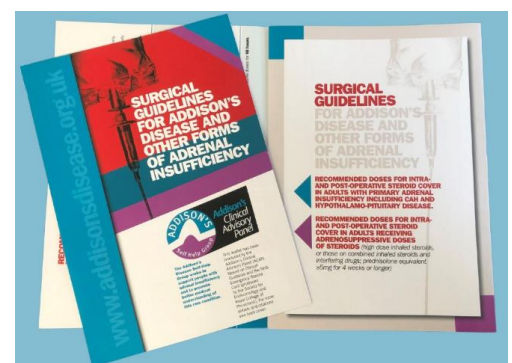


Volunteers

Once again volunteers played a crucial role throughout the year, providing support, time, energy, expertise and resources. Volunteers provided support to those affected by Addison's disease and adrenal insufficiency by offering emotional support, companionship, and practical assistance. Our enquiries email line is ably managed by volunteers who have supported us for many years, and our forum users benefit from the experience of a core group of 'forum buddies' who moderate, guide and inform; we cannot thank them enough for their input and support. Our clinical panelists review and verify our guidance and deliver valued talks on managing Addison's disease and adrenal insufficiency at our events.

Volunteers help raise awareness of the issues our community experiences and advocate for changes that will benefit those affected. Our medical conference volunteers travel the country to attend endocrine conferences, hospital stands and other events, to talk to healthcare professionals about life with Addison's disease and adrenal insufficiency. Volunteers also help us reach out to the community by providing information and resources, organising awareness days, running social events, and participating in educational programmes.

To all of our volunteers, thank you very much indeed!



Membership

Membership of the charity grew again in 2023, at the time of preparing this report there are approximately 2,100 people who are part of the charity.

Members support us with their membership fees, and ensure that we are truly representing people affected by Addison's disease and adrenal insufficiency. We are credible when we are talking to decision makers and healthcare professionals as a result of the number of patients that we represent.

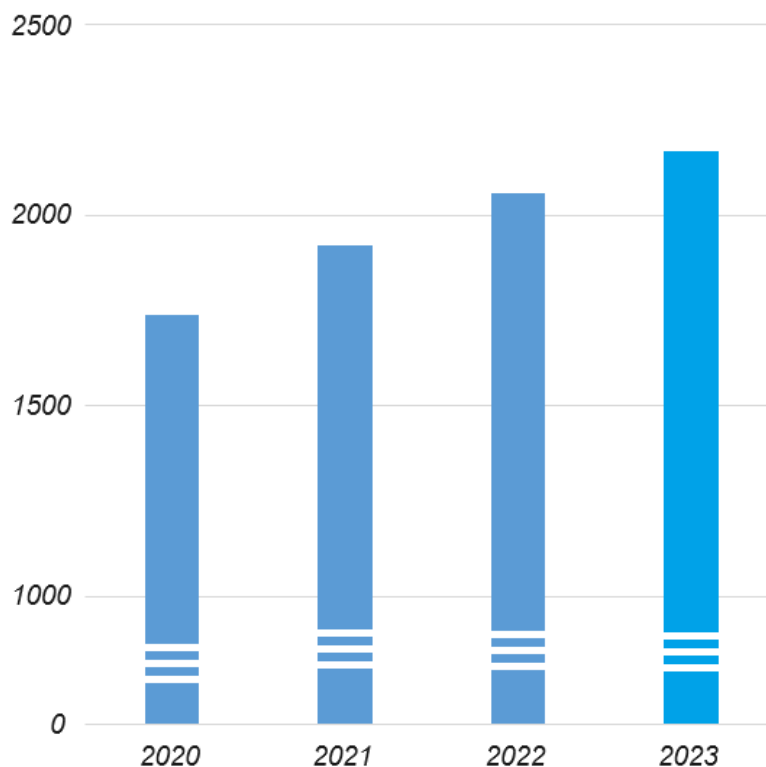
Members receive access to the Addison's forum, regular magazines and email newsletters, advance and discounted invitations to our events, and access to all of our resources about AD and AI. The network is a mutually supportive one which we value very highly indeed.

Many people join the charity at a time of great need, for example at the time of diagnosis, or when someone they support needs information, or when a medical professional is not answering the questions that inevitably arise. Most then remain members for many years, and many go on to become our greatest supporters – volunteers, fundraisers, donors, and trustees.

Trustees make membership available free of charge to people who may not be able to afford the membership subscription, for example through being out of work, by running a sponsored membership scheme. At year end there were approximately 100 members who have taken advantage of this.

Together, we are stronger.

Membership (year end)



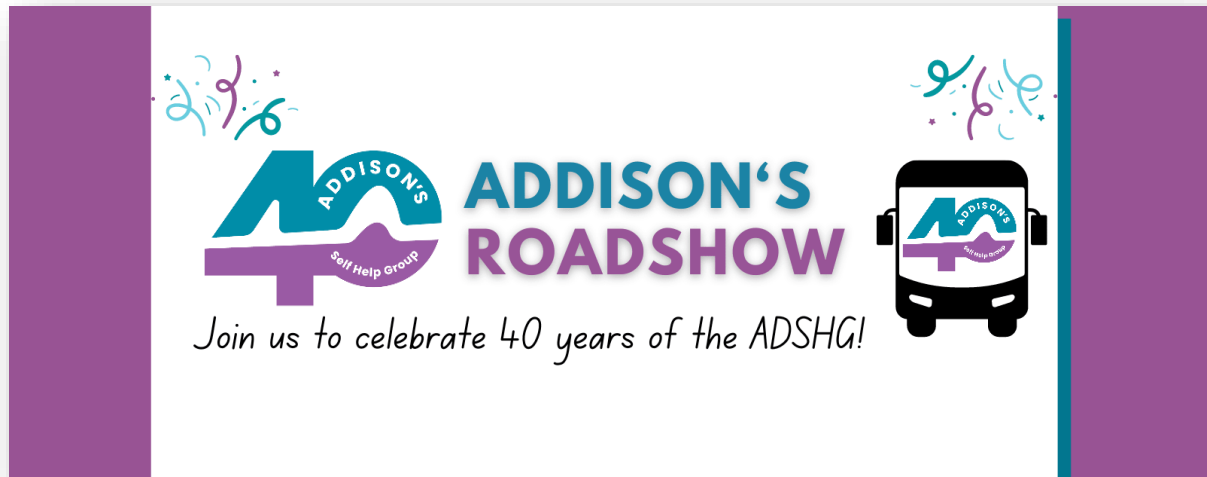
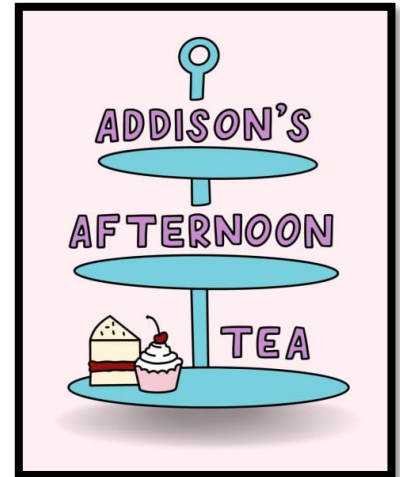
2024: Looking forward to a special year

2024 gives us two great reasons to celebrate; it's our 40th anniversary – the charity was founded back in 1984 – and we have appointed Cathy Thompson as our new Operations Manager, bringing a new stimulus and great skill set to our work.

Our anniversary year

This year sees ADSHG celebrate 40 years since being founded by Deana Kenward back in 1984. We are not only celebrating, but using the anniversary as a way of spreading more awareness about the charity, our work, and of course about Addison's disease and adrenal insufficiency.

At the time of writing we are already underway with a series of 'Addison's Afternoon Teas' run by members up and down the UK. We are also planning lots of activity around Addison's Disease Day, a series of roadshows – mini conferences for our members and non-members – one in each of Glasgow, London, Cardiff and Newry in Northern Ireland - and special support for our fundraisers.



Watch out for lots more about all of this over the course of the year, especially if you use social media! Let's tell the world about what we do.

Perhaps you can join us at one of the ADSHG roadshows; supporting us supporting you.

Oh ... and there will be birthday cake too!

Cathy Thompson

By the time this report is published, our new Operations Manager Cathy Thompson will be in post. Cathy is an experienced manager who we know will have a positive impact very quickly, we are excited by our prospects under her operational leadership. She writes:

“I’m delighted to introduce myself as the UK Operations Manager for the Addison’s Disease Self-Help Group. I have a lot to learn, but I have some excellent resources at my disposal and the experience of Philippa, Chloe and the board to support me.

“I have had such an incredibly warm welcome from everyone at the charity, from my first response to questions I asked before applying for the job (thank you David), and a cheerful and friendly interview panel that put me at ease, to the patience and the helpfulness of everyone who has made this charity the success that it is. I am honoured to be able to work with such a passionate, motivated and empowering group, and in an organization whose aims and values I respect and share. The core three strands of our work – Support :: Connect :: Advance – are all key priorities in their own right.

“I feel lucky to be joining in the charity’s 40th anniversary year. As there clearly has been right from the charity’s beginnings, at Deana’s kitchen table, there is so much potential and so much effort and goodwill from everyone involved. Match that with the dedication and commitment of the endocrine medical community, and it is a truly powerful combination.

“I’m excited to see what can be achieved!

“My 13 year old daughter’s testimonial, for what it is worth, is that ‘People who are very productive can be scary ... but you’re not’. That sums up my aspirations well - to get a lot done, working reliably, efficiently and happily alongside a great team to achieve our goals for you.

“I look forward to meeting as many of you as possible, as soon as possible.”

Amongst Cathy’s early objectives will be a review of many of our systems - including the shop, membership, finance and donor management systems - and working very closely with the board of trustees to prepare plans for our next strategic planning period.



Governance and Trustees' responsibilities

Trustee board

The charity is governed by an elected body of trustees consisting of not more than 11 and not less than five members. Each trustee is elected for a three-year term at an Annual General Meeting, or may be co-opted by existing trustees between AGMs. Meeting in person or virtually, with additional subgroup or single-item agenda meetings convened where needed, the trustees provide direction to the charity's executive team.

Training for new trustees includes a welcome pack which includes a copy of the constitution, background information on the charity and a copy of the relevant commission publication *The Essential Trustee*, all alongside a comprehensive introduction to our work and processes.

Diversity, equity and inclusion

Our trustee board has welcomed new voices and perspectives in recent years and has then remained stable during 2023. However we are conscious that one trustee is likely to step down in 2024, thus we are actively recruiting one or two more trustees with relevant skills to present to the members at our 2024 AGM. We are committed to being a fully inclusive charity and board.

Risk management

We continue to routinely monitor operational risks, financial risks, reputational risks, and legal risks such as data protection, regulatory, safeguarding and others. Major risks which the charity faces on a regular basis are reviewed regularly by trustees. We have internal controls, policies and procedures to provide reasonable assurances against material misstatement or loss. Other risks that are considered include, for example, cybersecurity and human resource risks.

Financial risk and controls

Financial risks we need to monitor, manage or mitigate against include funding shortfalls, inadequate reserves, investment losses, and fraud. The Treasurer approves all spending or refers to other trustees where decisions need full board approval. Payments require dual authorisation. Reserve funds are retained in fixed term deposit based (no-risk) accounts. The charity's receipts and payments processes, book-keeping and annual statutory accounts are managed by contracted agencies. The charity maintains liability and indemnity insurances.

Clinical and scientific information quality

The ADSHG is supported by an independent clinical panel of endocrinologists with an interest in adrenal medicine, known as the Clinical Advisory Panel (CAP). We are indebted to our medical advisers for their pro bono support and advice. The current CAP members (in no particular order) are Professor John Wass, Dr Alessandro Prete, Professor Wiebke Arlt, Professor Will Drake, Dr Steve Kell, Professor Simon Pearce, Stuart Pinkerton, Dr Georgina Russell, Lisa Shepherd RN, Dr Francesca Swords, Sam Westall, and Matthew Heppel.



The trustees present the ADSHG Annual Report and Accounts 2023

This document is the ADSHG trustees' formal report and financial statements of the charity for the year ended 31 December 2023. The trustees have adopted the provisions of 'Accounting and Reporting by Charities: Statement of Recommended Practice' and 'Charities (Protection and Social Investment) Act 2016 applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

Statement of trustees' responsibilities

The charity trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice). The law applicable to charities in England and Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, of the charity for that period.

In preparing the financial statements, the trustees are required to:

- select suitable accounting policies and apply them consistently;
- observe the methods and principles in the applicable Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures that must be disclosed and explained in the financial statements; and
- prepare the financial statements on a going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports) Regulations 2008 and the provisions of the charity's constitution. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Public Benefit

Our trustees have regard to the Charity Commission's guidance on public benefit. In this annual report we have recorded, under pages dedicated to each strategic strand, the public benefit we have delivered in 2023.



Finance Report

I can report another financially successful year for ADSHG, despite the various challenges. Against a backdrop of cost-of-living crisis, donor fatigue, and a competitive fundraising and donor management environment, we remain stable and optimistic. We have proved to be resilient through the dedication of our wonderful team of staff, volunteers, and trustees. However we increasingly recognise that human resources can be fragile and require care and investment.

Income

In round figures to summarise, total income this year was circa £210k. This is down some £70k on 2022, however last year's total included a £103k legacy – an unusual one-off. Thus our underlying income increased by some £33k. In difficult times this is very gratifying. The balance of income between donations, shop sales and membership subscriptions also remained stable.

Expenditure and fund balances

We did not make research grants in 2023, thus our overall expenditure was down from circa £256k to £228k. Excluding grants, expenditure rose by some £20k, which we regard as eminently manageable. The bottom line is that the charity made a small deficit of around £19k, reducing our funds overall to £177k, of which £144k is unrestricted.

Primary purpose trading

Our trading activity helps us deliver against our charitable objects by providing resources to fund the support of people living with AD/AI, and those who care for them. The shop is online only and focusses on sales of items that can be used by people with AI to manage their medication, deal with emergency situations, educate their family and friends, and handle interactions with their healthcare professionals.



Financial position

We carry forward total funds of £177,354 of which £144,285 is unrestricted. As treasurer I am thus satisfied that our finances remain strong. I anticipate that in celebrating our 40th anniversary and recruiting new staff in 2024 we will see a deficit again in 2024; this is expected, planned and manageable. Once again, as stated last year, we recognise the need to be more proactive in our fundraising, in particular in approaching charitable trusts and foundations for grants to support our project work. Membership fees, donations and traditional fundraising allow us to deliver our current work, but new project ideas depend on that proactivity. Our reserves are adequate, and we can do what we need to do without putting the charity at risk. We have scope to contribute to medical and scientific research, albeit in a small way in the context of the cost of medical research generally.

The full formal accounts for the year are presented below, but if you have any questions about our finances I will be very pleased to help; the trustees are keen to operate as transparently as possible.

Stuart Pinkerton

Trustee and Treasurer

Independent examiner's report

Independent examiner's report to the trustees of Addison's Disease Self-Help Group

I report to the charity trustees on my examination of the accounts of Addison's Disease Self-Help Group (the charity) for the year ended 31 December 2023.

Responsibilities and basis of report

As the charity trustees you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under Section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under Section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by Section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view, which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



20 June 2024

Mr Andrew Churchill Stone FCA DChA
Mercer Lewin Ltd Chartered Accountants
234 Botley Road
Oxford
OX2 OHP

Statement of Financial Activities

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2023

	Notes	Unrestricted fund £	Restricted funds £	Endowment fund £	2023 Total funds £	2022 Total funds £
INCOME AND ENDOWMENTS FROM						
Donations and legacies		108,617	-	-	108,617	196,821
Charitable activities						
Shop sales		37,105	-	-	37,105	30,672
Raising funds		504	-	-	504	-
Other trading activities	2	59,950	-	-	59,950	54,319
Investment income	3	3,739	-	-	3,739	161
Total		<u>209,915</u>	<u>-</u>	<u>-</u>	<u>209,915</u>	<u>281,973</u>
EXPENDITURE ON						
Charitable activities						
Advocacy advice		7,078	-	-	7,078	12,073
Raising funds		44,656	-	-	44,656	47,412
Shop stock purchases		-	-	-	-	36,057
Operation costs		154,046	-	-	154,046	109,616
Membership costs		22,762	-	-	22,762	-
Grants and projects		-	-	-	-	51,306
Total		<u>228,542</u>	<u>-</u>	<u>-</u>	<u>228,542</u>	<u>256,464</u>
NET INCOME/(EXPENDITURE)		(18,627)	-	-	(18,627)	25,509
RECONCILIATION OF FUNDS						
Total funds brought forward		162,912	19,330	13,739	195,981	170,472
TOTAL FUNDS CARRIED FORWARD		<u>144,285</u>	<u>19,330</u>	<u>13,739</u>	<u>177,354</u>	<u>195,981</u>

Balance Sheet

BALANCE SHEET 31 DECEMBER 2023

	Notes	Unrestricted fund £	Restricted funds £	Endowment fund £	2023 Total funds £	2022 Total funds £
FIXED ASSETS						
Tangible assets	6	2,794	-	-	2,794	3,886
CURRENT ASSETS						
Stocks	7	10,100	-	-	10,100	10,100
Debtors	8	10,556	-	-	10,556	8,373
Cash at bank and in hand		174,106	19,330	13,739	207,175	216,475
		<u>194,762</u>	<u>19,330</u>	<u>13,739</u>	<u>227,831</u>	<u>234,948</u>
CREDITORS						
Amounts falling due within one year	9	(53,271)	-	-	(53,271)	(42,853)
		<u>141,491</u>	<u>19,330</u>	<u>13,739</u>	<u>174,560</u>	<u>192,095</u>
NET CURRENT ASSETS						
		<u>141,491</u>	<u>19,330</u>	<u>13,739</u>	<u>174,560</u>	<u>192,095</u>
TOTAL ASSETS LESS CURRENT LIABILITIES						
		<u>144,285</u>	<u>19,330</u>	<u>13,739</u>	<u>177,354</u>	<u>195,981</u>
NET ASSETS						
		<u>144,285</u>	<u>19,330</u>	<u>13,739</u>	<u>177,354</u>	<u>195,981</u>
FUNDS						
Unrestricted funds	10				144,285	162,912
Restricted funds					19,330	19,330
Endowment funds					13,739	13,739
TOTAL FUNDS						
					<u>177,354</u>	<u>195,981</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 20 June 2024, and were signed on its behalf by:

Stuart Pinkerton
Trustee/Treasurer
20 June 2024

Notes to the accounts

1. ACCOUNTING POLICIES

BASIS OF PREPARING THE FINANCIAL STATEMENTS

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

INCOME

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

EXPENDITURE

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

TANGIBLE FIXED ASSETS

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

STOCKS

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

TAXATION

The charity is exempt from tax on its charitable activities.

FUND ACCOUNTING

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

PENSION COSTS AND OTHER POST-RETIREMENT BENEFITS

The charity operates a defined contribution pension scheme. Contributions payable to the charity's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

2. OTHER TRADING ACTIVITIES

	2023 £	2022 £
Membership fees	59,304	53,489
Royalties	646	830
	<u>59,950</u>	<u>54,319</u>

3. INVESTMENT INCOME

	2023 £	2022 £
Deposit account interest	3,739	161
	<u>3,739</u>	<u>161</u>

4. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2023 nor for the year ended 31 December 2022.

TRUSTEES' EXPENSES

Reimbursements totalling £1,114 were paid to trustees' to cover expenses paid by trustees' for the year ended 31 December 2022 no reimbursements took place for the year ended 31 December 2021.

5. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £	Restricted funds £	Endowment fund £	Total funds £
INCOME AND ENDOWMENTS FROM				
Donations and legacies	161,451	35,370	-	196,821
Charitable activities				
Shop sales	30,672	-	-	30,672
Other trading activities	54,319	-	-	54,319
Investment income	161	-	-	161
Total	<u>246,603</u>	<u>35,370</u>	<u>-</u>	<u>281,973</u>
EXPENDITURE ON				
Charitable activities				
Advocacy advice	12,073	-	-	12,073
Raising funds	18,216	29,196	-	47,412
Shop stock purchases	36,057	-	-	36,057
Operation costs	109,616	-	-	109,616
Grants and projects	51,306	-	-	51,306
Total	<u>227,268</u>	<u>29,196</u>	<u>-</u>	<u>256,464</u>
NET INCOME	19,335	6,174	-	25,509
RECONCILIATION OF FUNDS				
Total funds brought forward	143,577	13,156	13,739	170,472

5. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued				
	Unrestricted fund £	Restricted funds £	Endowment fund £	Total funds £
TOTAL FUNDS CARRIED FORWARD	<u>162,912</u>	<u>19,330</u>	<u>13,739</u>	<u>195,981</u>
6. TANGIBLE FIXED ASSETS				
		Fixtures and fittings £	Computer equipment £	Totals £
COST				
At 1 January 2023 and 31 December 2023		<u>859</u>	<u>3,507</u>	<u>4,366</u>
DEPRECIATION				
At 1 January 2023		100	380	480
Charge for year		<u>215</u>	<u>877</u>	<u>1,092</u>
At 31 December 2023		<u>315</u>	<u>1,257</u>	<u>1,572</u>
NET BOOK VALUE				
At 31 December 2023		<u>544</u>	<u>2,250</u>	<u>2,794</u>
At 31 December 2022		<u>759</u>	<u>3,127</u>	<u>3,886</u>
7. STOCKS				
			2023 £	2022 £
Stocks			<u>10,100</u>	<u>10,100</u>
8. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR				
			2023 £	2022 £
Trade debtors			1,113	162
Other debtors			2,587	1,476
Prepayments and accrued income			2,775	6,735
Prepayments			<u>4,081</u>	<u>-</u>
			<u>10,556</u>	<u>8,373</u>

9. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2023 £	2022 £
Trade creditors	21,898	10,697
Taxation and social security	1,573	2,354
Other creditors	29,800	29,802
	<u>53,271</u>	<u>42,853</u>

10. MOVEMENT IN FUNDS

	At 1/1/23 £	Net movement in funds £	At 31/12/23 £
Unrestricted funds			
General fund	162,912	(18,627)	144,285
Restricted funds			
ADSHG Medical Research Fund	11,190	-	11,190
Addison's Ireland Fund	333	-	333
Endocrinology Travel Fund	64	-	64
Ronald Rogers - Gwent	633	-	633
RCGP module	5,000	-	5,000
Publications Review Reserve	1,900	-	1,900
Young and Newly Diagnosed Medical Research Reserve	210	-	210
	<u>19,330</u>	<u>-</u>	<u>19,330</u>
Endowment funds			
Medical Research Fund	13,739	-	13,739
	<u>195,981</u>	<u>(18,627)</u>	<u>177,354</u>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	209,915	(228,542)	(18,627)
	<u>209,915</u>	<u>(228,542)</u>	<u>(18,627)</u>

10. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1/1/22 £	Net movement in funds £	At 31/12/22 £
Unrestricted funds			
General fund	143,577	19,335	162,912
Restricted funds			
ADSHG Medical Research Fund	11,690	(500)	11,190
Addison's Ireland Fund	333	-	333
Endocrinology Travel Fund	500	(436)	64
Ronald Rogers - Gwent	633	-	633
RCGP module	-	5,000	5,000
Publications Review Reserve	-	1,900	1,900
Young and Newly Diagnosed Medical Research Reserve	-	210	210
	<u>13,156</u>	<u>6,174</u>	<u>19,330</u>
Endowment funds			
Medical Research Fund	13,739	-	13,739
	<u>170,472</u>	<u>25,509</u>	<u>195,981</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	246,603	(227,268)	19,335
Restricted funds			
ADSHG Medical Research Fund	-	(500)	(500)
Endocrinology Travel Fund	500	(936)	(436)
RCGP module	5,000	-	5,000
Emergency Injection research reserve	13,460	(13,460)	-
Publications Review Reserve	4,000	(2,100)	1,900
Young and Newly Diagnosed Medical Research Reserve	210	-	210
GP Education	12,200	(12,200)	-
	<u>35,370</u>	<u>(29,196)</u>	<u>6,174</u>
TOTAL FUNDS	<u>281,973</u>	<u>(256,464)</u>	<u>25,509</u>

10. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined position is as follows:

	At 1/1/22 £	Net movement in funds £	At 31/12/23 £
Unrestricted funds			
General fund	143,577	708	144,285
Restricted funds			
ADSHG Medical Research Fund	11,690	(500)	11,190
Addison's Ireland Fund	333	-	333
Endocrinology Travel Fund	500	(436)	64
Ronald Rogers - Gwent	633	-	633
RCGP module	-	5,000	5,000
Publications Review Reserve	-	1,900	1,900
Young and Newly Diagnosed Medical Research Reserve	-	210	210
	<u>13,156</u>	<u>6,174</u>	<u>19,330</u>
Endowment funds			
Medical Research Fund	13,739	-	13,739
	<u>170,472</u>	<u>6,882</u>	<u>177,354</u>

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	456,518	(455,810)	708
Restricted funds			
ADSHG Medical Research Fund	-	(500)	(500)
Endocrinology Travel Fund	500	(936)	(436)
RCGP module	5,000	-	5,000
Emergency Injection research reserve	13,460	(13,460)	-
Publications Review Reserve	4,000	(2,100)	1,900
Young and Newly Diagnosed Medical Research Reserve	210	-	210
GP Education	12,200	(12,200)	-
	<u>35,370</u>	<u>(29,196)</u>	<u>6,174</u>
TOTAL FUNDS	<u>491,888</u>	<u>(485,006)</u>	<u>6,882</u>

11. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 December 2023.

**DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 DECEMBER 2023**

	2023 £	2022 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	108,617	94,035
Legacies	-	102,786
	<u>108,617</u>	<u>196,821</u>
Other trading activities		
Membership fees	59,304	53,489
Royalties	646	830
	<u>59,950</u>	<u>54,319</u>
Investment income		
Deposit account interest	3,739	161
Charitable activities		
Shop sales	37,609	30,672
	<u>209,915</u>	<u>281,973</u>
TOTAL INCOMING RESOURCES		
EXPENDITURE		
Charitable activities		
Wages	66,913	56,182
Social security	-	765
Pensions	2,120	1,912
Fundraising costs	5,051	2,544
Medical goods	39,605	36,057
Publications	30,236	35,399
Conferences	12,666	3,680
Membership service costs	22,173	22,277
Volunteer expenses	-	69
Grants and project costs	3,494	51,306
	<u>182,258</u>	<u>210,191</u>
Support costs		
Management		
Accountancy and bookkeeping	5,778	6,340
Insurance	1,233	1,234
	<u>7,011</u>	<u>7,574</u>
Finance		
Sundries	1,091	-
Bank charges	1,799	1,261
Fixtures and fittings	-	100
Computer equipment	-	380
	<u>2,890</u>	<u>1,741</u>

This page does not form part of the statutory financial statements

**DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 DECEMBER 2023**

	2023 £	2022 £
Finance		
Information technology		
Communication and IT costs	23,385	21,011
Human resources		
Travel and subsistence	332	-
Other		
Other costs	2,792	322
Governance costs		
Accountancy fees	1,300	1,300
Consultancy fees	2,976	5,654
AGM and trustees meeting costs	5,598	8,671
	<u>9,874</u>	<u>15,625</u>
Total resources expended	<u>228,542</u>	<u>256,464</u>
Net (expenditure)/income	<u>(18,627)</u>	<u>25,509</u>

This page does not form part of the statutory financial statements

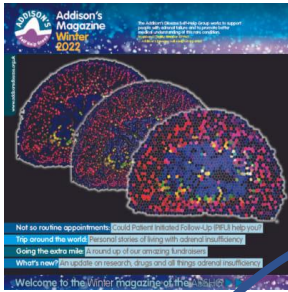
ADDISON'S DISEASE SELF HELP GROUP

England & Wales - Charity number 1179825

Accounts



Addison's Disease Self Help Group Annual Report and Accounts 2022



**ADDISON'S
DISEASE DAY**



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About the ADSHG

Registration and structure

The Addison's Disease Self Help Group is a Charitable Incorporated Organization (CIO) registered with the Charity Commission for England and Wales ("the commission") in September 2018 as charity number 1179825 and CIO number CE015063. It took over the activities of the previous charity of the same name (registration number 1106791) in January 2019. Deana Kenward MBE founded the Addison's Disease Self-Help Group in 1984 and is still a dedicated volunteer.

Registered Office (ADSHG runs on a virtual office operations basis)

ADSHG, Starling House 1600 Bristol Parkway North Bristol BS34 8YU



Contact Details

Telephone: 0117 214 0473

Email: enquiries@addisons.org.uk

Website: www.addisonsdisease.org.uk

The objects of the charity, as stated in our constitution are:

"To promote the relief of persons with Addison's Disease, in particular by the provision of support, information and communication for such persons, their families and carers and by such charitable means as the trustees determine."

Constitution

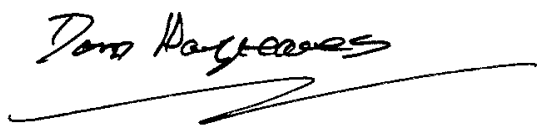
The charity is controlled by its governing document (our constitution) available on our website:

<https://www.addisonsdisease.org.uk/adshg-annual-reports>

The current constitution was adopted on 30 August 2018 and subsequently revised on 16 July 2022.



Report and accounts approved on behalf of the ADSHG board of trustees by:



Dom Hargreaves - Chair



Stuart Pinkerton - Treasurer

Introduction

The trustees present their ADSHG Annual Report and Accounts 2022

This document is the ADSHG trustees' report and financial statements of the charity for the year ended 31 December 2022.

The trustees have followed best practise and relevant regulations when compiling this report:

The trustees have adopted the provisions of 'Accounting and Reporting by Charities: Statement of Recommended Practice' and 'Charities (Protection and Social Investment) Act 2016 applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

Statement of trustees' responsibilities:

The charity trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice). The law applicable to charities in England and Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, of the charity for that period.

In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and apply them consistently;
- observe the methods and principles in the applicable Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures that must be disclosed and explained in the financial statements; and
- prepare the financial statements on a going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports) Regulations 2008 and the provisions of the charity's constitution. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Public Benefit

Our trustees have regard to the Charity Commission's guidance on public benefit. In this annual report we've recorded, under pages dedicated to each strategic strand, the public benefit we've delivered in 2022.

ADSHG CHARITY OBJECTS – The work we are here to do

To promote the relief of persons with Addison's disease, in particular by the provision of support, information and communication for such persons, their families and carers and by such charitable means as the trustees determine.



3 STRATEGIC STRANDS (Support, Connect, Advance) – How we divide up the work

To deliver our objects we provide an immediate-term service to people with Addison's Disease by providing **support**. We also improve the care they receive through representation and **connection** with the healthcare profession. We then look to the future to **advance** the medical and healthcare innovations that would relieve the difficulties of life with Addison's in the future.

SUPPORT

Aim: Provide resources and build a community to help people self-manage their Addison's and improve their quality of life

- **ADSHG Membership** – Online Forum, regular magazines and newsletters, member events and webinars
- **Publicly available resources** about self-management of Addison's including emergencies, sickness and more – educational website, printed leaflets, social media feeds and chats, signposting related support organisations.
- **Raising awareness publicly** to help improve diagnosis rates, empathy and attract funding.
- **News alerts** about medication, the healthcare system, pandemic guidelines and vaccines, new developments in research and more
- **Online Enquiries service** by email, answerphone, website form, social media direct message and by post
- **Online shop** to stock up on Addison's essentials like emergency kits
- **Addison's Disease Day** run by ADSHG to raise awareness

CONNECT

Aim: Make it possible for the voice of people with Addison's to influence, inform and improve the way the healthcare system delivers their care

- **Affiliation** with relevant learned medical societies
- **Medical conference attendance** with stands
- **Webinars** for healthcare professionals
- **Healthcare profession committee participation**
- **Research participant recruitment** support
- **Collaborating** on improvements to clinical and patient resources used and issued by the healthcare profession
- **Inviting healthcare professionals to attend** and speak at our events
- **Adding our signature and support** to open letters / other campaigns asking for change

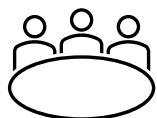
ADVANCE

Aim: Fund, contribute to and promote the development of new innovations that will improve the quality of life of people with Addison's.

- Funding research projects that:**
- **Advance good clinical practice** (Alfred Potter Memorial Award)
 - **Encourage early career researchers** (Sue Chambers Memorial Award)
 - **Stimulate innovations and best practice in emergency medicine** (Professor John Wass Emergency Medical Award)
 - **Advance steroid awareness and patient safety** (Annette Seal Memorial Award for nurse led projects).
 - **Speed up Addison's Disease diagnosis**
 - **Develop technologies that make life easier for people with Addison's**

Tactical approaches – how our small charity achieves big things:

- Membership of rare disease umbrella organisations helps us get behind national initiatives, often at government level that help all people with rare diseases.
- Collaboration with related health charities for economies of scale on shared projects and gives us a bigger voice than working alone.
- ADSHG Clinical Panel and medic trustees connect us to important contacts and help us better understand how the healthcare system works.
- Continuous work to make our operation more resilient in difficult times



Connect: Ensuring patient voices influence healthcare quality in 2022

Achievements - What we did

Over the last 12 months we enriched the below healthcare professional resources with lived experiences of life with AI:

We worked closely with healthcare professionals in the UK, ROI and abroad

- NICE 'Draft AI Guidelines Scope' for improving outcomes for people using the NHS and UK social care from 2024
- 5 NHS Website Addison's Disease pages
- JRCALC Guidelines for ambulance technicians
- BSPED draft paediatric guidelines for endocrinologists
- SIMBA simulation training for medical students
- Medics 4 Rare Disease platform for medics
- RCGP training module for GPs



Treasurer comments about the charity monies used to pay for our support services work

We've spent £900 on our medical conference attendances including travel, accommodation and our stand full of resources. A proportion of operational costs (including staff time and costs associated with producing and transporting resources) go towards our costs in this 'connect' strand of our work. Travel costs are up and are supported by a £500 Society of Endocrinology grant. We spent £3000 on sponsoring medical student attendances at medical conferences. See more from page 20 onwards.

Success measures - How we checked our progress and impact

We're continuing to find ways to represent our impact with figures we can compare year on year. The below make results will be a great initial benchmark for future years. We introduced a **new impact survey** of people with AI. Next year we will expand it to include healthcare professionals and set goals for improvement

- Increased NHS referrals to the ADSHG website by **35%** by updating 5 AI related pages on the NHS Website
- Educated **7** classes of paramedics in emergency AI care
- Funded a group of student medics to attend the European Society of Endocrinology annual conference
- Talked to hundreds of medics attending **3** UK and International medical conferences

79

The number of our 2022 impact survey respondents **whose healthcare professionals recommended the ADSHG or its services** by healthcare professionals

who had heard about us through the healthcare liaison work our donors fund support.



Public benefit of our 'connect' activities: Advancement of education and promotion of the efficiency of ambulance services and healthcare professionals

Direct recipients (People with AI and those who care for them) – Improved quality of life through better healthcare

Wider public – Reduction in demand on under-pressure health services between appointments and prevention of avoidable hospital admissions. Efficiencies in emergency care.

- Providing Vocational training for healthcare professionals
- Publishing guidance on self management of AI
- Collaboration with JRCALC to improve their guidance
- Provision of paramedic training

Advance: Funding and supporting the development of new innovations in Addison's care

Grant making policy

Our focus has been on emergency injection solutions and GP training in 2022. Our research working group review all applications and opportunities for grants in these areas. Our current strategy combines a yearly medical research grants programme and welcoming approaches from researchers working in our above focus areas. For significant grants, due diligence is completed and checkpoints put in place where segments of the grants will be issued on completion of agreed actions.

Achievements - What we did:

2022 Grant-making:

Medical Research: During the year we were pleased to approve and issue the following new grants for medical research:

- £20,000 to fund development of emergency injection technologies via Solution Medical
- £500 issued in our annual Research Awards



Other grants:

- £3000 funding of endocrine medical student attendance at conferences
- £23,000 issued to GP education projects with the RCGP

2022 ADSHG Project:

- We've continued to progress our Endocrine Nurse project to provide a helpline .



Public benefit of our 'Advance' activities: Advancement of science, health and saving lives

Direct recipients (People with AI and those who care for them) – Improved quality of life

Wider public – Efficiencies in healthcare systems. Reduction in demand on under-pressure health services between appointments and prevention of avoidable hospital admissions

- Medical research into diagnosis, better care and prevention of adrenal crisis
- Promoting and supporting development of proper standards of medical practice
- Funding and participation in medical research
- Collaboration with learned societies eg RCGP, Society for Endocrinology, BSPED, JRCALC

ADSHG progress in 2022: Our Reach in numbers

3,860

new followers on our
social media accounts

18,000

unique visitors to
our emergency
page

13

new blog pages
published

197,000

new users on our
website this year

**Reaching the
public**

440,000

unique ADSHG
website page views

34,000

unique visitors to our
Sick Day Rules page

3,600

ADSHG Christmas
cards sold to refer
medics and loved ones
to ADSHG resources

4

medical conferences
attended meeting
hundreds of
endocrinology
professionals

595

New members
welcomed this year
who all received an
online or digital
welcome pack of
ADSHG resources

200,000

visits to our
member forum

90

welcome messages
posted by forum buddies
to new members

**Reaching our
members**

80

Members joined our
online meetings for
families of young people,
Women's health and our
London AGM

84

pages of member
magazine and
newsletter content
published

90

members attended our
in-person events

22

Member News Alert emails issued

ADSHG progress in 2022: Thankyou - We couldn't do it without you

Our Donors and Fundraisers

Sports fundraisers
Fundraising event organisers
Individual fundraisers
Corporate donors
Grant issuing bodies
Lifestyle giving organisations
Gifts in wills and in memoriam

Our Partners

Related charities including: Pituitary Foundation, Alex TLC, Living with CAH, Wren Project.

Consultants and suppliers including: Mercer Lewin, VJH Accountancy, Bioscientifica, Bryc Solutions, 421 Typing, CITOC, Leave a Trail, Giftease, MSBouloux Ltd, Sitemorse, Zoho, The Workshop, Quorum Print, Microsoft, Typeform, Invision Community, 123Reg, Jurassic Embroidery, Handy Labels, GandN Medical, MUJI, Really Useful Boxes, Priory Direct, Amazon, Zazzle, Charity Learning Consortium, CCT Venues, CAF Bank, Canva

Umbrella organisations including: Beacon and Genetic Alliance, NCVO, Getting on Board, Directory of social change. Fundraising platforms e.g. Enthuse.

Our state

The Charity Commission

Regulators

The Fundraising Regulator

Our Volunteers

Healthcare professional awareness
Advising our whole team
Meeting hosts and helpers
Content contributors
Enquiries desk
Donor and fundraiser thankyou's
Christmas cards to friends of ADSHG
Trustees and Clinical Advisory Panel

Our community

Members
Shop customers
Families of people with AI
Followers on our social media accounts
Website visitors
Healthcare professionals
Employers, carers, friends

Our healthcare sector partners

The NHS, HSE, NICE
JRCALC, Society for Endocrinology, European Society for Endocrinology, BSPED, RCGP, Association of Ambulance, Medics4Rare
Solution Medical, Diurnal
Our research grantees

Our Employees

Digital Communications and Engagement Manager
Ops Support Assistant
Executive Director

Our Volunteers: We're dependent on and grateful for their support

Volunteers play a crucial role in our work to support people with Addison's. They provide support, time, and resources. Here are some examples of what volunteers do for the ADSHG:

<p>Support services:</p> <p>Volunteers provide support to individuals and families affected by Addison's by offering emotional support, companionship, and practical assistance. Our Enquiries email account is ably managed by a dedicated volunteer who has supported the ADSHG for many years and we are so fortunate to have their support. Our Clinical Panel review and verify our guidance and deliver valued talks on managing Addison's at our events.</p>	<p>Advocacy:</p> <p>Volunteers help raise awareness of the issues our community experiences and advocate for changes that will benefit those affected by the Addison's. Our medical conference volunteer team travel the country to attend endocrine conferences and talk to healthcare professionals about life with Addison's Disease</p>	<p>Fundraising:</p> <p>Volunteers help with organising and running fundraising activities such as charity walks, runs, and community events. We have valued volunteers who help us show our gratitude to fundraisers by organising a note of thanks in the post.</p>
<p>Governance:</p> <p>Our trustees are all volunteers giving their own time to meet the responsibilities outlined in the 'Statement of trustees' responsibilities in this report. In addition to these legal and fiduciary responsibilities, trustees also bring a wealth of experience, expertise, and connections to the ADSHG. We are grateful to our volunteer GDPR advisor who has a wealth of experience consulting on Data Protection professionally.</p>	<p>Community outreach:</p> <p>Volunteers help the ADSHG reach out to the community by providing information and resources, organising awareness days, and participating in educational programs.</p>	<p>Research:</p> <p>Volunteers assist with clinical trials and research studies. They share their own experiences and opinions so that new developments suit the needs of people with AI.</p>

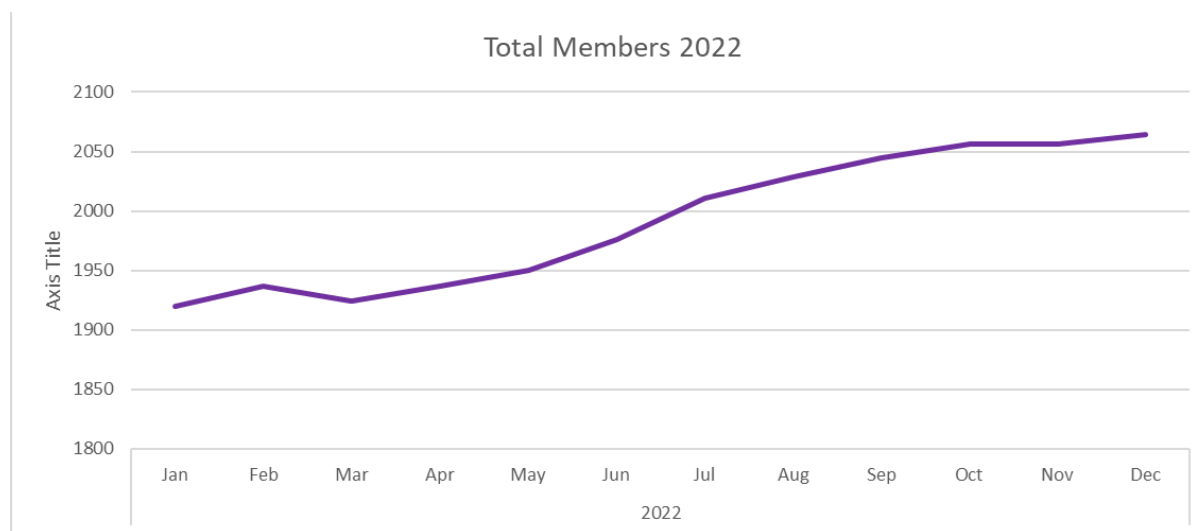
"I feel it is really important to continually raise awareness of Addison's and adrenal insufficiency which is why I volunteered. The added bonus is the lovely people I have met along the way" **Jackie R**



Our volunteers are critical to the success of the ADSHG as they provide support, raise awareness, and help to make a positive impact on the lives of those affected by Addison's.



ADSHG Memberships



Membership trends in 2022:

We welcomed nearly 600 new members this year. We also saw the impacts of the cost of living crisis as our hardship programme reached the limit of people we were able to accept as hardship members. We also heard from so many people keen to renew but weighing up if it would be affordable for them in the current climate. Membership rates have slowed towards the end of the year as people adjust to more challenging times financially. We are grateful to those able to renew their memberships. We offer many of our support resources free of charge on our website so hope that people without memberships can still benefit from our guidance and advice.

A note of thanks to our members:

The ADSHG has always benefitted from the enthusiasm, ideas, donations, and efforts of members to build a friendly community to support people with Addison's. We know for many of you it's been a challenging few years and we appreciate you staying connected with us in this way and contributing to the maintenance of our services to our whole membership.

Membership inclusion:

We help our members to engage with us in a range of ways depending on their preferences and needs - paper, digital, hybrid, large print, face-to-face, answerphone, SMS and more. We run a hardship scheme so that we can include a limited number of people facing economic difficulties in ADSHG membership.



ADSHG Aims for 2023

As a newly reformed team, with new trustees, volunteers and staff joining our existing colleagues, we've been able to gauge over the year what constitutes a realistic, manageable pace and workload. An ambitious strategy was developed in late 2021 to early 2022 and we've decided to select just three items from it and give them dedicated focus in the next twelve months. We have heard from our community at our events, via our enquiries helpdesk and our communications channels that improving care and providing ways people can get support between medical appointments are high priorities. This makes the implementation of an endocrine nurse helpline and investment in medical research important deliverables for us as a charity.

In addition to **putting in place measures to keep our Operation resilient and compliant**, we hope to:

Fund further medical research and projects with our medical research reserves that have been boosted significantly by the generous support of dedicated fundraisers and donors this year. We are fortunate to have organisations receiving ADSHG grants and delivering innovative projects in 2023 and welcome applications from others wishing to help us meet our charity objects through improved care for our community.



Establish an endocrine nurse helpline by creating or outsourcing the required expertise of a qualified endocrine nurse, telephony, operational processes and compliance. Funds from our unrestricted donations will fund the initial implementation of this project.



Plan how we'll mark the fortieth anniversary of the founding of the Addison's Disease Self-Help Group by Deana Kenward in 1984. We're very grateful to our founder and all involved in growing such an important source of support and information for people with Addison's. We will be inviting our members and wider community to celebrate and fundraise for the future support of people with this condition. Unrestricted funds will be dedicated to ensuring this celebration raises awareness to reach those who've yet to receive our support, and gathers support from donors towards our planned projects.



Longer term strategy

Our ADSHG trustees published a strategy document in 2022 that provides a view of longer-term goals. It can be accessed on our website: <https://www.addisonsdisease.org.uk/adshg-annual-reports>.

Fundraising

Thank You!



We are extremely grateful to everyone who donated or fundraised to help support our work:

- Members paying their annual fees
- The public responding to our social media campaigns
- Sports enthusiasts taking up event places we purchased as a charity
- Individuals organising fundraising activities and collections
- Individuals gaining support for us via their employer
- Individuals leaving a gift to us in their will
- Donors indicating their eligibility for Gift Aid in relation to donation

Streams of fundraising income in 2022 were made up of payments made to us via:

- Our websites, by card or Paypal
- Directly to our bank via cheque or online banking payments
- Fundraising platforms such as Just Giving, Enthuse, Paypal giving including GoFundMe.
- Lifestyle giving platforms such as Amazon Smile (closed in Feb 2023), Give As You Live, EasyFundraising

**Total 2022 donations and fundraising:
£196,821 exc. GiftAid**

Corporate Fundraising

In 2023 we will begin to use the services of Work for Good to enable compliant commercial agreements to allow sales fundraising by businesses and sole traders. We will also use the services of Giftease to process back-dated and future Gift Aid claims to increase our income from donations. We do not use any third-party professional fundraisers.

Compliance in Fundraising

We are registered with the Fundraising Regulator. We follow the Code of Fundraising Practice. We ask all fundraisers to make contact with us so we can advise them on responsible fundraising and how to make the most of their activities to raise monies. From 2023 fundraising agreement will be put in place for any fundraising activities where the fundraiser(s):

- Want to use the ADSHG or ADSHG logo or merchandise during their activity (excludes those purely raising online donations from individuals using a recognised fundraising platform).
- Are raising money through a business or selling something
- Will be running a raffle or auction
- Will be selling event tickets
- Are receiving a reward for fundraising for us
- Are deducting any amount from donations to cover costs, or
- Are splitting the money raised between the ADSHG and another charity/charities.

Our fundraising agreement sets out acceptable conduct for those fundraising for us so that we can discourage unreasonable intrusion on a person's privacy, unreasonably persistent approaches or placing undue pressures on a person to give money or other property.

The ADSHG Trustee Board

The ADSHGs governed by an elected body of trustees consisting of not more than 11 and not less than five members. Each trustee is elected for a three-year term at an Annual General Meeting, or may be co-opted by the trustees between AGMs. Meeting in person or virtually, with additional subgroup or single-item agenda meetings convened where needed, the Trustees provide governance and direction to the charity's Executive Director, staff team, engaged consultants and our volunteers.

Recruitment, appointment, induction and training of Trustees

The trustees can appoint any appropriate person to be a trustee. Training for new trustees includes a Welcome Pack which includes a copy of the Constitution, background information on the Charity and a copy of the relevant commission publication The Essential Trustee, all alongside a comprehensive introduction to our work and processes.

Diversity, equity and inclusion:

Our trustee board continues to grow in diversity welcoming new voices and perspectives in recent times.

<p>We need to improve our board representation of people:</p>	<p>We welcome people to help us represent more of our membership and wider community – whether you can provide a voice for an under-represented group or have skills and experiences that could help us govern the charity.</p>
<p>From a wider range of ethnic groups Of a non-binary gender Who have caring responsibilities (other than as parents) Who come from a wider range social-economic backgrounds Aged 65+</p>	<p>Our Future Trustees programme aims to demystify trusteeship and dispel myths that it's for C-suite, late-career individuals of a specific background.</p>

We are rolling out training and reporting on Diversity Equity and Inclusion across our teams. We've been improving the diversity and accessibility of the imagery and content we publish.

Trustees as at 31 December 2022

The following individuals acted as Trustees throughout the year except where otherwise stated

<p>Dominic S Hargreaves (Chair) Stuart A Pinkerton (Treasurer) Lisa Shepherd Robert S McClements Philip J Kaye Dr Stephen W Kell Dr Alessandro Prete (elected July 2022) Tilly Rose (co-opted June 2022)</p>	<p>Thanooshan Selvarajah (co-opted September 2022) Christine Walters (co-opted September 2022) Andrew Glass (resigned September 2022, Chair until May 2022) Chloe Mezzetti elected July 2022 (resigned August 2022) Rachel E Bracken (resigned July 2022) Mary (Tag) McEntegart (resigned April 2022) Dr Helen Simpson (resigned January 2022)</p>
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Delegations

Trustees delegate to or take advice from:

<p>Executive Director – Mrs Vick Smith - day-to-day management</p>
<p>Financial Steering Group – Three ADSHG trustees monitoring and preparing proposals around charity finances</p>
<p>Operations Steering Group - Three ADSHG trustees making decisions around charity operations</p>
<p>ADSHG Clinical Panel – A team of volunteer healthcare professionals who oversee our clinical guidance</p>
<p>Principle bankers - CAF Bank Ltd</p>
<p>Independent Examiner - Mr Andrew Churchill Stone FCA DChA, Mercer Lewin Ltd Chartered Accountants</p>

A view from our Chair



This is my first annual report as Chairman of the Trustees. 2022 has been a better year for the charity, we started the year signing off and approving our strategy, which takes us to 2025 and setting a number of key goals for the Charity.

Before I go into the detail I must thank everyone involved in the charity for their efforts in supporting this small patient support group. The Charity offers support, connection and advancement to the people of the UK and ROI's with Addison's Disease and members of the wider Adrenal Insufficiency community. Most people's initial contact with the charity is at the point of diagnosis, which for everyone with this rare disease is always a challenge. At diagnosis people reach into the charity, with a thirst for knowledge, which ADSHG provides. People are often immediately grateful, for the work of the charity. To enable us to continue this work I must thank our membership and all our fundraisers. The fundraisers allow the Charity to continue the work that we do, and have enabled the charity to expand our efforts on behalf of the AI community. I wish to thank our staff, volunteers and trustees for their time and efforts over the past year, and look forward to taking the charity into its 40th Anniversary year in 2024. In this update I'll follow the three key strands of the work that we do as a charity:

“Support, Connect and Advance the lives of people with Addison's Disease”

SUPPORT

The key area of work that we do as a charity is to support to our membership and wider Ai community. I read everyday on social media how hard some people find day-to-day living with Addison's Disease. The fundamental purpose of the charity is to provide information and support so that our membership and the wider Adrenal insufficiency (AI) community can lead their best lives.

The charity membership has continued to grow throughout the year. A challenge we have as a charity is to then retain that membership. We have found that the hardship fund has been well received by the membership and at times fully subscribed.

Key elements of support strand of our work is our meetings, not only our main medical lectures in London and Dublin, but also the gatherings out in the regions. This year's meetings in London and Dublin, were very well attended, not only by people with Addison's Disease, but the professionals who help us treat and manage this rare illness. The meetings were run as hybrid events. In-person presence accounted for over a third of the attendance at each event, with the remainder joining us virtually. Combined, the events were attended by over 150 people, equating to around 15% of our total membership. Certainly, I find the gatherings of the charities membership emotional – in my routine life – I never knowingly encounter anyone else with Addison's Disease. The opportunity to share experiences is key for newly diagnosed people, but also rewarding for those of us that have had Addison's disease for a few years.

My big takeaway from the meeting in Dublin, was the young people, many either at University or starting their professional careers, seated around a table, exchanging thoughts and ideas – and signing up to various social media forums.

Our magazine, newsletter and our multiple social media forms go from strength to strength thanks to the work of our dedicated editorial and operations teams. We're grateful for the messages of thanks, and the submissions we receive from our followers and readers. Sharing stories and improving our communications are very important in improving the quality of life of people with AI.

A view from our Chair (cont..)

Our member-only forum continues, despite competition from various groups on Facebook and other social media channels. I learned in Dublin that there is an active WhatsApp group for the younger crowd with 75 members (organised independently of the ADSHG). The plan for 2023 is to relaunch the social meetings after a break during the pandemic, as they are so important to our members. An effective way to learn how to manage your Addison's Disease is to learn from the experiences of people with the illness.



CONNECT

The meetings we hold in London and Dublin are important because they bring our membership into contact with professionals who are interested in Addison's Disease. Uniting people with AI and healthcare professionals brings mutual benefits. Our membership understand more about their rare disease and how to manage it, and the professionals' takeaway insights from the patient's perspective. Those healthcare professionals can then better represent the patient voice if they are invited to work with the NHS, NICE or other influential bodies to inform health policy that impacts all of our lives.

Charity volunteers managed a stand at the Society for Endocrinology BES Conference and offer online learning for paramedics. In 2021 we provided input to the NHS Steroid card and continue to support its implementation. This year we have had significant input into the NHS website pages on Addison's Disease.

ADVANCE

The Charity has funded two key projects, to advance the care needs of people with Addison's Disease.

The first was a package of learning at the Royal College of General Practitioners (RCGP). This was a new venture for the Charity – RCGP has 64,000 members across the UK. The idea was to fund an e-learning module, dedicated to Addison's Disease that GPs would undertake as part of their continuing professional development, or be able to access as required when dealing with a potential patient or patient with adrenal insufficiency. Our module is one of 138 modules hosted by the RCGP. The module was launched in October and so far just under 500 GPs have undertaken 15 minutes of training in Addison's Disease. We wait to see whether this represents good value for money, but every GP trained in Addison's Disease is a step in the right direction.

In the second project we have provided our last round of funding this year to Solution Medical, in their quest to develop an auto-injector for adrenal insufficiency. As a business, over two years they have been operating, they have developed a prototype auto-injector and have formulated the solution to inject from it. That said, Solution Medical have a lot to do, to get the auto-injector through accreditation and to the market – a business journey which is potentially another four years of effort and another \$10 million. As part of our due diligence process we interviewed the new CEO of Solution Medical, who is a specialist in bringing innovative medical solutions to market. His experience combined with the founder's passion convinced the trustees that granting funding would be prudent. A number of trustees and staff have handled the prototype and the attendees in Dublin completed feedback forms on the device. Our contributions as regards funding are now ending with quite a level of funding still required to help bring this device to market. We can however help support the building of a business case of an auto-injector to be available through the NHS and HSE. While Solution Medical have made great progress and could be the first to get their product to market, we are open to approaches by other companies to assist with their development of similar technologies.

A view from our Chair (cont..)



We been approached for funding by Manchester University, who are undertaking a data analysis of NHS records to establish amongst other things the number of people in the UK with adrenal insufficiency, both primary and secondary. As a condition of our funding we have asked them to establish the number of hospital admissions and fatalities for Primary and Secondary AI for adrenal crisis. At this point of time, our offer is in the acceptance phase and we await the release of the data set later in 2023.

A healthy uptake on the surveys we have advertised to our membership linked to patient education, adrenal crisis management and quality of life with adrenal insufficiency has been very encouraging.

GOVERNANCE

We have increased our number of operations staff and resilience by bringing Chloe Mezzetti into the team. Chloe brings another young face to the charity. She has attended events across the country for us and is part of the team working with NICE on new medical guidelines for Adrenal Insufficiency due out in 2024. Vick Smith and Philippa Sharman, both continue in their respective roles, with Vick becoming Executive Director and stepping into a wider governance role across the charity.

As far as the Trustee body goes, we have continued to diversify the board, bringing some younger people to the team. This includes Thanooshan Selvarajah who is currently working through qualifications to become a lawyer. Tilly Rose, who has a significant social media following, applied to become a trustee and has attended a meeting as a co-opted Trustee. Alessandro Prete has joined as the endocrine specialist trustee, delivering an excellent lecture at the Annual Meeting in London. Christine Walters has joined the team and is keen to build an events programme for the charity.

We continue to improve our compliance position and we routinely review our risk register as a charity to monitor data protection, safeguarding and other charity legal requirements.

FINANCES

Our finances are positive, and Stuart, our charity treasurer provides, in this report, a summary of our 2022 accounts to introduce our annual accounts pages compiled by our accountants Mercer Lewin.

A LOOK AHEAD

An objectives for 2023 is to set up a endocrine nurse helpline for our membership. Our aim is to work with other endocrine charities to make this possible for our membership and other people with AI across the UK and ROI. As an endocrine patient I had never met a endocrine nurse previously (I am told they are very rare), but as a member of the charity I now meet them regularly and recognise that they are very valuable in terms of patient education.

We are looking forward to the 40th Anniversary of the Charity in 2024 – now's the time to think about how you'll celebrate and join us in marking this important milestone.

You can read more about our future plans elsewhere in this report.

We are always looking for volunteers, either to fund raise or help out – all support is very much appreciated.

Our Executive/Operations Team of Permanent Staff

Permanent Staff Members as at 31 December 2022

The following individuals acted as Permanent Staff Members (part-time) throughout the year except where otherwise stated.

Executive Director – Vick Smith

Digital Communications and Engagement Manager – Philippa Sharman

Operations Support Assistant – Chloe Mezzetti



ADSHG
Operations

Growing our permanent staff made the ADSHG more resilient and able to support a growing community

In 2022 we hired Chloe to a new role as Operations Support Assistant. She's been able to help us support our growing crowd of fundraisers and shop customers. This has given Philippa space to handle an increasing amount of queries and contacts from our popular social media accounts. Vick is now has capacity to support the trustees in their governance work. Our amazing enquiries volunteer Alison can focus on providing supportive responses to increasing numbers people reaching out to us for information.

Diversity, equity and inclusion in our working practices:

We work with our employees to check for, improve and monitor working practises to ensure we provide safe and healthy working conditions. We continue to improve our personnel practices so that we can actively avoid discrimination. All our team are entitled to work flexibly and remotely so that they can share their work schedule around family, disability-related, faith-based or other commitments. All workers are treated equally regardless of role or level within the charity organisation - and are encouraged to voice any ideas, feedback or concerns to any member of the charity executive or trustee board without fear of reprisals. We do not utilise support or condone unethical personnel practices such as forced or compulsory, or child labour. We expect the same principles to be upheld by our suppliers and partners.

While do not officially recognise any individual trade and workers unions, we respect the right of our staff to join such organisations without fear of intimidation or reprisal in accordance with national law. We respect the role these organisations can usefully play in collective bargaining and problem solving.

To make working for and volunteering at the ADSHG economically inclusive we operate according to staff and volunteer expenses policies and encourage claiming of reasonable expenses.

Arrangements for setting pay and remuneration of key management personnel – benchmarks, parameters, or criteria used

The treasurer of the board of trustees determines salary and other benefit changes for the Executive Director and wider executive team. The treasurer makes these decisions in consultation with the Finance Steering Group and Board of Trustees. When we set our salaries, we consider:

- the prevailing wages and benefits for comparable positions in the non-profit sector
- the charity's financial health
- any legal requirements or guidelines governing staff remuneration
- the level of responsibility associated with each staff member's role

By taking these factors into consideration, we can ensure that we are providing staff with appropriate levels of compensation while protecting the funds the charity requires to achieve its objects.

Risk management and internal controls

Major risks which the charity faces on a regular basis are reviewed regularly by trustees. We have internal controls, policies and procedures to provide reasonable assurances against material misstatement or loss.

Financial risk and controls

Financial risks we need to monitor, manage or mitigate against include funding shortfalls, inadequate reserves, investment losses, and fraud. The Treasurer, Financial Steering Group or Executive Director approve all spending according to our Scheme of Delegation that also outlines which decisions need full trustee board approval. Payments via CAF Bank require dual authorisation. Reserve funds are retained in fixed term deposit based (no-risk) accounts. The charity's receipts and payments processes, book-keeping and annual statutory accounts are managed by contracted agencies.

Governance risk and controls to monitor, manage or mitigate against are

- **Reputation risks:** The risk of our actions are perceived as inappropriate or if our leadership is called into question.
- **Regulatory risks:** The risk of failing to comply with a range of charity regulations, including accounting and financial reporting requirements, fundraising regulations, and data protection laws.
- **Operational risks:** These can include risks related to governance, health and safety, and the delivery of services.
- **Cybersecurity risks:** We store data about our members and customers and must be conscious that these types of data attractive targets for cyber attacks.
- **Human resources risks:** We regularly review our processes to reduce the likelihood of risks related to employee safety, discrimination, harassment, and other employment-related issues.

Governance assessments, training and controls

A new compliance learning management system has been rolled out to Operations staff (and will soon be available to trustees and volunteers in 2023) to ensure training in core compliance for charity operations is completed and refreshed regularly. The programme includes GDPR, Safeguarding, Diversity and Inclusion, Workstation Assessments. In 2023 our trustees will complete The Governance App assessment for Board excellence and act on the findings. The Operations Team complete Quarterly controls to ensure regular compliance actions are completed. Partnerships are subject to due-diligence to deter corrupt practices. We aim to have an anti-corruption policy in place by the end of 2023.

Clinical Compliance and Quality

The ADSHG is supported by an independent clinical panel of endocrinologists with an interest in adrenal medicine, known as the Clinical Advisory Panel (CAP). We are indebted to our medical advisers for their pro bono support and advice.

Environmental sustainability:

We continue to adopt new practises to protect the environment. Recent examples include:

- More compact magazines (to use less paper and manage shipping costs) printed on carbon-captured paper verified by The Woodland Trust.
- Hybrid face-to-face annual events
- Venues within easy reach of public transport.
- Cashless donation displays instead of plastic buckets Newsletters page lengths reduced.
- Sending international membership communications digitally to save on the shipping carbon footprint.

Factors affecting the achievement of current and future objectives

We've benefitted from a refreshed more diverse board to bring new perspectives and voices to our charity. Investments in staff and the expertise of charity consultants have helped us to build the resilience and capacity of our Operation again this year. The NHS, HSE, NICE and the learned societies continue to approach us enthusiastically to collaborate meaning that in many cases we are able to directly influence systemic change in the quality of care for people with Addison's at a quicker pace than was previously possible.

Several external challenges impacting our work have been:

- **Cost of living crisis** – with potential to increase our community's need for support and ability to fund our work through donations.
- **Pandemic recovery** – slow return to face to face fundraising and departure of some existing social meeting hosts. Staff and volunteers who are still shielding due to vulnerabilities are less able to travel. Healthcare delays are driving higher demand for our small team. This trend has been recorded across the majority of the non-profit sector this year.
- **Brexit** – An existing supplier stopped services to us owing to customs complexity. We also experienced additional fees in sending items to European locations. Medical research projects run between the European Union and the UK healthcare researchers continue to be impacted by funding being withdrawn or not available for co-located projects.
- **Industrial action** – We've managed to maintain our shop services by setting expectations with customers and members about likely delays and the importance of ordering early.
- **Insurance limitations** – We introduced a policy not to sell our products to the US for insurance reasons.

As we grow, we drive more demand for our services. We're keen to ensure we strike the right balance between growth, resilience, compliance and ensuring we keep adequate reserves for the financial stability of the charity.

Finance update from our treasurer

“Once again, I am delighted to report on a financially successful year for The Addison’s Self-Help Group. Last year we were seeing the end of the effects of the pandemic, and as a charity, were looking positively to the future. Unfortunately, the cost-of-living crisis is now starting to have a big effect on public finances. As a Charity, we have proved to be resilient in respect of indirect and direct pressures. This is helped by our amazing team of staff, volunteers, and Trustees.



Income

Income from all sources does add up. No donation is too small. Any project approved by Trustees has been fully funded without adversely affecting the Charities' underlying financial support.

Total income in 2022 was £281,973, an increase of about £70,000 on 2021. This was due to a large legacy. Elsewhere, other channels of income have stayed constant. Our net income was £25,509 in 2022, this was an increase of about £17,000 from 2021. I am pleased to see an increase in our underlying profits.

Expenditure

Total expenditure in 2022 was £256,464, an increase of about £52,000. We were able to dispense more grants, and these were offset by our reduction in Advocacy costs. Our operation costs have increased, reflected in our investment in our staff team, external resources to support them, and increased spending on the Endocrine Nurse viability.

Our costs versus income in relation to the shop showed a deficit in the past year. The shop is an important part of our services that we offer to our members. With this in mind, we have increased our fees minimally to cover this.

Financial position

We carry forward total charitable funds of £195,981 of which £162,912 is unrestricted. This does allow the Charity to be flexible in its funding. As we mentioned last year, we reviewed our budgeting, bookkeeping and financial reporting systems, and we are now able to access up to date information and project this forward. I believe we are in a strong financial position however we need to be proactive in raising money. Membership fees, donations, fundraising, and legacies allow the Charity to fulfill our investment in current and new projects while keeping the Operation running

Our membership has increased in 2022 compared to 2021. Since the start of 2023, we have noticed a small drop off in membership. We accept that this is due to the current cost of living crisis. However, the membership is still in an extremely healthy position. Our Hardship fund has been paused due to reaching capacity. We will review that monthly and consider resuming the fund as soon as we can.

Fundraising in relation to virtual sporting events has been disappointing. However, as we get back to non-virtual events, I feel that this will once again be profitable. Low-cost fundraising continues to be profitable for the Charity..

Our reserves are adequate, and we can do all our activities without putting the Charity at risk. Our projects are fully funded, and we can contribute to medical advancements, which help all people who suffer Adrenal Insufficiency. As the Treasurer, it is my responsibility to financially sustain the Charity for the long term. We are in an exceptionally outstanding position to fulfill that aim. ”

Finance (cont.)

Reserves policy

Total Restricted funds held: £246,603	Amount of funds held	Restricted funds held owing to donor wishes: £35,370	Designated funds: £143,094	Total remaining reserves excluding restricted and designated funds: £68,139
	Purpose and schedule for use	Medical research (2023/24) Emergency Injection Research (2023/24) Gwent only (2023/24) Newly diagnosed and Young people (2023/24) Publications content review (July 2023) Addison's Ireland Fund (2023/2024)	- 8 Months of contingency Operations costs and salaries - Endocrine Nurse project 2023/24	

Difference in the reserves figure shown above with the reserves policy: **None**

Amount of total fund that can only be realised by disposing of tangible assets or programme-related investments: **None**

Primary purpose trading

Our trading activities help us deliver against our objects as a charity by providing resources to promote the support of persons with Addison's Disease and those who care for them.

- Our online shop focusses on sales of items that can be used by people with AI to manage their medication, emergency situations, educating their loved ones and handling interactions with the medical profession.
- Our book, 'Living with Addison's' provides vital advice for people with Addison's to help them improve their quality of life.

What our community told us about the items we supplied



"Emergency injection kit and hospital info folder. The folder was very useful when at casualty with a near crisis and needed to make receptionist aware. I was able to wave it at him."

Christopher E

"I use the big and small injection kit, small one goes in my bag that goes everywhere with me when I'm out the house. I use the big injection kit at home and put it with all my medications in a big box. I use the wrist band alert when out the house so I know if something happens when I'm alone with strangers and unable to communicate that someone might call an ambulance if I take ill and that paramedics should be able to see that I have adrenal insufficiency. **Laura B**"



**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
ADDISON'S DISEASE SELF HELP GROUP**

Independent examiner's report to the trustees of Addison'S Disease Self Help Group

I report to the charity trustees on my examination of the accounts of Addison'S Disease Self Help Group (the Trust) for the year ended 31 December 2022.

Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under Section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under Section 145(5)(b) of the Act.

Independent examiner's statement

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a registered member of ICAEW which is one of the listed bodies.

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by Section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



Mr Andrew Churchill Stone FCA DChA
ICAEW
Mercer Lewin Ltd
Chartered Accountants
6-7 Citibase
New Barclay House
234 Botley Road
Oxford
OX2 0HP

Date: 27 April 2022

ADDISON'S DISEASE SELF HELP GROUP
REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022

Mercer Lewin Ltd
Chartered Accountants
6-7 Citibase
New Barclay House
234 Botley Road
Oxford
OX2 0HP

ADDISON'S DISEASE SELF HELP GROUP

**STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 DECEMBER 2022**

	Notes	Unrestricted fund £	Restricted funds £	Endowment fund £	2022 Total funds £	2021 Total funds £
INCOME AND ENDOWMENTS FROM						
Donations and legacies		161,451	35,370	-	196,821	114,077
Charitable activities						
Shop sales		30,672	-	-	30,672	37,944
Other trading activities	2	54,319	-	-	54,319	59,916
Investment income	3	<u>161</u>	<u>-</u>	<u>-</u>	<u>161</u>	<u>631</u>
Total		<u>246,603</u>	<u>35,370</u>	<u>-</u>	<u>281,973</u>	<u>212,568</u>
EXPENDITURE ON						
Charitable activities						
Advocacy advice		12,073	-	-	12,073	42,816
Raising funds		18,216	29,196	-	47,412	48,831
Shop stock purchases		36,057	-	-	36,057	27,049
Operation costs		109,616	-	-	109,616	70,844
Grants and projects		<u>51,306</u>	<u>-</u>	<u>-</u>	<u>51,306</u>	<u>14,756</u>
Total		<u>227,268</u>	<u>29,196</u>	<u>-</u>	<u>256,464</u>	<u>204,296</u>
NET INCOME		19,335	6,174	-	25,509	8,272
RECONCILIATION OF FUNDS						
Total funds brought forward		<u>143,577</u>	<u>13,156</u>	<u>13,739</u>	<u>170,472</u>	<u>162,200</u>
TOTAL FUNDS CARRIED FORWARD		<u>162,912</u>	<u>19,330</u>	<u>13,739</u>	<u>195,981</u>	<u>170,472</u>

The notes form part of these financial statements

ADDISON'S DISEASE SELF HELP GROUP

**BALANCE SHEET
31 DECEMBER 2022**

	Notes	Unrestricted fund £	Restricted funds £	Endowment fund £	2022 Total funds £	2021 Total funds £
FIXED ASSETS						
Tangible assets	6	3,886	-	-	3,886	-
CURRENT ASSETS						
Stocks	7	10,100	-	-	10,100	12,334
Debtors	8	8,373	-	-	8,373	2,338
Cash at bank and in hand		<u>183,406</u>	<u>19,330</u>	<u>13,739</u>	<u>216,475</u>	<u>195,038</u>
		201,879	19,330	13,739	234,948	209,710
CREDITORS						
Amounts falling due within one year	9	(42,853)	-	-	(42,853)	(39,238)
NET CURRENT ASSETS						
		<u>159,026</u>	<u>19,330</u>	<u>13,739</u>	<u>192,095</u>	<u>170,472</u>
TOTAL ASSETS LESS CURRENT LIABILITIES						
		<u>162,912</u>	<u>19,330</u>	<u>13,739</u>	<u>195,981</u>	<u>170,472</u>
NET ASSETS						
		<u><u>162,912</u></u>	<u><u>19,330</u></u>	<u><u>13,739</u></u>	<u><u>195,981</u></u>	<u><u>170,472</u></u>
FUNDS						
	10					
Unrestricted funds					162,912	143,577
Restricted funds					19,330	13,156
Endowment funds					<u>13,739</u>	<u>13,739</u>
TOTAL FUNDS						
					<u>195,981</u>	<u>170,472</u>

The financial statements were approved by the Board of Trustees and authorised for issue on and were signed on its behalf by:

.....
Trustee

The notes form part of these financial statements

ADDISON'S DISEASE SELF HELP GROUP**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022****1. ACCOUNTING POLICIES****BASIS OF PREPARING THE FINANCIAL STATEMENTS**

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

INCOME

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

EXPENDITURE

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

TANGIBLE FIXED ASSETS

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

STOCKS

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

TAXATION

The charity is exempt from tax on its charitable activities.

FUND ACCOUNTING

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

PENSION COSTS AND OTHER POST-RETIREMENT BENEFITS

The charity operates a defined contribution pension scheme. Contributions payable to the charity's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

ADDISON'S DISEASE SELF HELP GROUP

**NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 DECEMBER 2022**

2. OTHER TRADING ACTIVITIES

	2022 £	2021 £
Membership fees	53,489	57,248
Royalties	<u>830</u>	<u>2,668</u>
	<u>54,319</u>	<u>59,916</u>

3. INVESTMENT INCOME

	2022 £	2021 £
Deposit account interest	<u>161</u>	<u>631</u>

4. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2022 nor for the year ended 31 December 2021.

TRUSTEES' EXPENSES

Reimbursements totalling £1,114 were paid to trustees' to cover expenses paid by trustees' for the year ended 31 December 2022 no reimbursements took place for the year ended 31 December 2021.

5. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £	Restricted funds £	Endowment fund £	Total funds £
INCOME AND ENDOWMENTS FROM				
Donations and legacies	112,944	1,133	-	114,077
Charitable activities				
Shop sales	37,944	-	-	37,944
Other trading activities	59,916	-	-	59,916
Investment income	<u>631</u>	<u>-</u>	<u>-</u>	<u>631</u>
Total	<u>211,435</u>	<u>1,133</u>	<u>-</u>	<u>212,568</u>
EXPENDITURE ON				
Charitable activities				
Advocacy advice	42,816	-	-	42,816
Raising funds	48,831	-	-	48,831
Shop stock purchases	27,049	-	-	27,049
Operation costs	70,844	-	-	70,844
Grants and projects	<u>14,756</u>	<u>-</u>	<u>-</u>	<u>14,756</u>
Total	<u>204,296</u>	<u>-</u>	<u>-</u>	<u>204,296</u>
NET INCOME	7,139	1,133	-	8,272
RECONCILIATION OF FUNDS				
Total funds brought forward	136,438	12,023	13,739	162,200

ADDISON'S DISEASE SELF HELP GROUP

**NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 DECEMBER 2022**

5. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

	Unrestricted fund £	Restricted funds £	Endowment fund £	Total funds £
TOTAL FUNDS CARRIED FORWARD	<u>143,577</u>	<u>13,156</u>	<u>13,739</u>	<u>170,472</u>

6. TANGIBLE FIXED ASSETS

	Fixtures and fittings £	Computer equipment £	Totals £
COST			
Additions	<u>859</u>	<u>3,507</u>	<u>4,366</u>
DEPRECIATION			
Charge for year	<u>100</u>	<u>380</u>	<u>480</u>
NET BOOK VALUE			
At 31 December 2022	<u>759</u>	<u>3,127</u>	<u>3,886</u>
At 31 December 2021	<u>-</u>	<u>-</u>	<u>-</u>

7. STOCKS

	2022 £	2021 £
Stocks	<u>10,100</u>	<u>12,334</u>

8. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022 £	2021 £
Trade debtors	162	-
Other debtors	1,476	-
Prepayments and accrued income	<u>6,735</u>	<u>2,338</u>
	<u>8,373</u>	<u>2,338</u>

ADDISON'S DISEASE SELF HELP GROUP

**NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 DECEMBER 2022**

9. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022 £	2021 £
Trade creditors	10,697	5,149
Taxation and social security	2,354	66
Other creditors	<u>29,802</u>	<u>34,023</u>
	<u>42,853</u>	<u>39,238</u>

10. MOVEMENT IN FUNDS

	At 1/1/22 £	Net movement in funds £	At 31/12/22 £
Unrestricted funds			
General fund	143,577	19,335	162,912
Restricted funds			
ADSHG Medical Research Fund	11,690	(500)	11,190
Addison's Ireland Fund	333	-	333
Endocrinology Travel Fund	500	(436)	64
Ronald Rogers - Gwent	633	-	633
RCGP module	-	5,000	5,000
Publications Review Reserve	-	1,900	1,900
Young and Newly Diagnosed Medical Research Reserve	-	210	210
	13,156	6,174	19,330
Endowment funds			
Medical Research Fund	13,739	-	13,739
	<u>170,472</u>	<u>25,509</u>	<u>195,981</u>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	246,603	(227,268)	19,335
Restricted funds			
ADSHG Medical Research Fund	-	(500)	(500)
Endocrinology Travel Fund	500	(936)	(436)
RCGP module	5,000	-	5,000
Emergency Injection research reserve	13,460	(13,460)	-
Publications Review Reserve	4,000	(2,100)	1,900
Young and Newly Diagnosed Medical Research Reserve	210	-	210
GP Education	12,200	(12,200)	-
	35,370	(29,196)	6,174
TOTAL FUNDS	<u>281,973</u>	<u>(256,464)</u>	<u>25,509</u>

ADDISON'S DISEASE SELF HELP GROUP

**NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 DECEMBER 2022**

10. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1/1/21 £	Net movement in funds £	At 31/12/21 £
Unrestricted funds			
General fund	136,438	7,139	143,577
Restricted funds			
ADSHG Medical Research Fund	11,690	-	11,690
Addison's Ireland Fund	333	-	333
Endocrinology Travel Fund	-	500	500
Ronald Rogers - Gwent	-	633	633
	12,023	1,133	13,156
Endowment funds			
Medical Research Fund	13,739	-	13,739
TOTAL FUNDS	<u>162,200</u>	<u>8,272</u>	<u>170,472</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	211,435	(204,296)	7,139
Restricted funds			
Endocrinology Travel Fund	500	-	500
Ronald Rogers - Gwent	633	-	633
	1,133	-	1,133
TOTAL FUNDS	<u>212,568</u>	<u>(204,296)</u>	<u>8,272</u>

ADDISON'S DISEASE SELF HELP GROUP

**NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 DECEMBER 2022**

10. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined position is as follows:

	At 1/1/21 £	Net movement in funds £	At 31/12/22 £
Unrestricted funds			
General fund	136,438	26,474	162,912
Restricted funds			
ADSHG Medical Research Fund	11,690	(500)	11,190
Addison's Ireland Fund	333	-	333
Endocrinology Travel Fund	-	64	64
Ronald Rogers - Gwent	-	633	633
RCGP module	-	5,000	5,000
Publications Review Reserve	-	1,900	1,900
Young and Newly Diagnosed Medical Research Reserve	-	210	210
	<u>12,023</u>	<u>7,307</u>	<u>19,330</u>
Endowment funds			
Medical Research Fund	13,739	-	13,739
	<u>162,200</u>	<u>33,781</u>	<u>195,981</u>

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	458,038	(431,564)	26,474
Restricted funds			
ADSHG Medical Research Fund	-	(500)	(500)
Endocrinology Travel Fund	1,000	(936)	64
Ronald Rogers - Gwent	633	-	633
RCGP module	5,000	-	5,000
Emergency Injection research reserve	13,460	(13,460)	-
Publications Review Reserve	4,000	(2,100)	1,900
Young and Newly Diagnosed Medical Research Reserve	210	-	210
GP Education	12,200	(12,200)	-
	<u>36,503</u>	<u>(29,196)</u>	<u>7,307</u>
TOTAL FUNDS	<u>494,541</u>	<u>(460,760)</u>	<u>33,781</u>

ADDISON'S DISEASE SELF HELP GROUP

**NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 DECEMBER 2022**

11. RELATED PARTY DISCLOSURES

The total amount of money donated by the trustees to the charity during the year was £1,050.

ADSHG Contacts

By post: ADSHG, Starling House 1600 Bristol Parkway North Bristol BS34 8YU



ADSHG General Contact Details

Telephone: 0117 214 0473

Email: enquiries@addisons.org.uk

Website: www.addisonsdisease.org.uk



Contact our Trustee Board

<https://www.addisonsdisease.org.uk/our-team>



ADSHG Clinical Panel

<https://www.addisonsdisease.org.uk/our-clinical-advisors>

Professor John Wass, Dr Alessandro Prete, Professor Wiebke Arlt, Professor Will Drake, Dr Steve Kell, Professor Simon Pearce, Stuart Pinkerton, Dr Georgina Russell, Lisa Shepherd RN, Dr Francesca Swords, Sam Westall, Matthew Heppel

Principle bankers

CAF Bank Ltd, West Malling, Kent ME19 4JQ

Independent Examiner

Mr Andrew Churchill Stone FCA DChA

Mercer Lewin Ltd Chartered Accountants, 41 Cornmarket Street, Oxford OX1 3HA

ADDISON'S DISEASE SELF HELP GROUP

England & Wales - Charity number 1179825

Accounts

Addison's Disease Self Help Group

Annual Report and Accounts 2021



Addison's Disease Self Help Group (ADSHG) is registered charity number 1179825.
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A) Legal and Administrative Information

The trustees present their report and financial statements of the charity for the year ended 31 December 2021. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

Governing document

The charity is controlled by its governing document and constitutes a Charitable Incorporated Organisation (CIO) registered with The Charity Commission for England and Wales ("the commission").

Registration

Registered charity number 1179825 Registered CIO number CE015063

Registered Office

ADSHG, Starling House 1600 Bristol Parkway North Bristol BS34 8YU

Contact Details

Telephone: 0117 214 0473

Email: enquiries@addisons.org.uk

Website: www.addisonsdisease.org.uk

Trustees as at 31 December 2021

Mr Andrew R Glass (Chair)

Mr Dominic S Hargreaves (Vice-Chair)

Mr Stuart A Pinkerton (Treasurer)

Ms Lisa Shepherd

Mr Robert S McClements

Dr Helen Simpson (resigned January 2022)

Ms Rachel E Bracken (resigned effective from 2022 AGM)

Ms Mary (Tag) McEntegart (resigned April 2022)

Mr Philip J Kaye

Dr Stephen W Kell

Principle bankers

CAF Bank Ltd, West Malling, Kent ME19 4JQ

Independent Examiner

Mr Andrew Churchill Stone FCA DChA

Mercer Lewin Ltd Chartered Accountants, 41 Cornmarket Street, Oxford OX1 3HA

B) A view from the chair

From previous Chair of Trustees, Andrew Glass

2021 was another very active and successful year for the Addison's charity, as you will read in our report. I decided in February 2022 to stand down as Chairman after three and a half years as I felt it right to hand over to new leadership one we had agreed the three-year strategy, and in Dom we have the right person to take us forward.

On a personal level the challenges of a new job, new country and culture, particularly in a part of the world bordering Ukraine, meant I would not be able to give the attention the role needs. It has been a privilege to work with the trustees, present and past, since 2018, as well as everyone associated with the charity.

A significant amount of trustee and staff effort in 2021 was committed to developing and writing our strategic plans. The Charity remains committed to three core strands of effort, under the headings SUPPORT – CONNECT – ADVANCE.

Fundamentally the charity is a patient support group, it's what we do. We support and connect our members, carers, medics and the wider adrenal insufficiency community from pre-diagnosis to expert patient.

We use our advance strand to advance knowledge in Addison's Disease and adrenal insufficiency within the wider medical and pharmaceutical community and create a wider support network for our community. Our advance strand, led so strongly by Dom, is taking our impact to a whole new level.

The detailed strategy has been agreed internally and a simplified document will be prepared shortly for release on the website.

40th Anniversary

In 1984 Deana Kenwood MBE founded the Addison's Disease Self Help Group, and as I write this the trustees are very aware that we are rapidly approaching our 40th anniversary. We would welcome thoughts from our membership on how

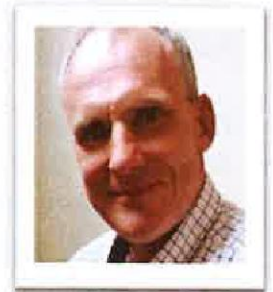
we can best celebrate this amazing milestone. We recognise that the Charity has changed significantly from the self-help group that started around Deana's kitchen table. We have staff, a web site, multiple social media channels, processes and procedures and an international membership. We feel that as a Charitable Incorporated Organisation, the 40th anniversary presents an opportunity not only to celebrate our past but to embrace the future, by updating aspects of our brand identity.

Operations

Vick and Pippa, as the operations team, have been very busy over the past year. The Charity is very well served by the two of them working hard in all our interests.

From the new Chair of Trustees, Dom Hargreaves

I have been a trustee with the Charity since 2019, and have enjoyed my time with the organisation.



I look forward to taking on the mantle from Andrew, who has run a tight ship in some very challenging times – navigating us through staff changes and the pandemic.

Andrew has agreed to stay on as a trustee until 2023, which provides me with the benefit of his advice and wisdom.

I would like to welcome two new Trustees to the team Alessandro Prete and Chloe Mezzetti. Alessandro in his role as Endocrine Consultant will bring that medical insider knowledge that we need on the board and Chloe brings youth and a fresh outlook to the Trustee body, and also influence as a volunteer on the NICE Guidelines Consultation on Adrenal Insufficiency.

Cont. overleaf...

B) A view from the chair (cont.)

From the new Chair of Trustees, Dom Hargreaves (cont.)

It is with sadness that I must report the untimely death of Katherine White. Katherine held the role of Chair of ADSHG for a number of years, standing down from the Charity in 2018. The Charity posted a tribute to her on our website, and have had a very appreciative response back from her husband and children. We will pay tribute to her during the Annual meeting.

I look forward to meeting more of our members face-to-face in London, Dublin or at events around and about, as well as in the virtual setting which has typified a lot of our meetings in the past two years.



Dom Hargreaves
Chair of Trustees

C) Trustee's Report

Our aims and achievements in 2021

The charity's primary objective is to provide support to people with Addison's Disease, their families, and other connected people. Addison's disease is a rare endocrine condition where the adrenal glands cease to function, so that the body no longer produces enough of certain essential hormones, known as steroid hormones. This leads to a wide range of distressing symptoms, and indeed Addison's Disease can be fatal. However, in the vast majority of cases patients will live normal lives by carefully managing their condition themselves.

We work to provide for people affected through a programme of activities under three broad headings that reflect our ambitions to SUPPORT – CONNECT – ADVANCE.

Support

Over 2021 we have continued to offer a number of benefits to its members including magazines containing medical updates and first person experiences of living with Addison's Disease, information about day-to-day management of the condition, and an online members' discussion forum supervised by experienced volunteer moderators. These are all particularly valued by newly diagnosed patients who are finding their feet in day-to-day self-management of their essential steroid therapy.

Despite the disruption wrought by COVID-19, we have also continued to:

- organise public 'question and answer' events using social media
- deliver a mini-conference and AGM online attended by some 70 members
- produce our usual two newsletters and two magazines of the year
- send timely member emails and website articles to keep members up to date with important news such as drug shortages, vaccines or other guidance related to the pandemic
- issue welcome packs that contain an ADSHG emergency wallet card, hospital steroid awareness stickers and a selection of our publications

- offer emergency injection kits and other essentials for purchase from our online shop
- provide educational videos explaining steroid injection methods free-to-view for members and the public
- develop a programme of review and update of our publications
- support a number of local social meetings throughout the UK and Ireland as well as online, albeit limited during the pandemic
- operate a mutually supportive subscription membership programme, including providing funds to enable people to join who might otherwise struggle to pay the fees

Unfortunately, due to some technical considerations, we were unable to start the planned Endocrine nurse project alluded to in last year's report. However, at the end of 2021 these problems, around liability insurance, appear to have been resolved and the project will be revitalised in 2022.

Connect

During 2021 we are also very pleased to have been able to maintain and build on our links with other support groups and medical professionals, including with other endocrine support groups across the UK and Ireland. We especially like to work with organisations representing associated autoimmune, congenital or genetic adrenal conditions. The ADSHG is a member of National Voices, an umbrella group representing health and social care charities, and of the National Council for Voluntary Organisations, which offers guidance on charitable best practice.

We are also members of or affiliated with Rare Diseases UK, Rare Diseases Ireland, Eurodis, The European Society for Endocrinology and the UK based Society for Endocrinology.

We take part in the Society for Endocrinology Patient Support Groups Collective and the European Adrenal Network. We also collaborate with the British Society for Paediatric Endocrinology and Diabetes.

We run the Adrenal Causes Together (ACT) initiative with global patient support groups for related adrenal conditions.

C) Trustee's Report (cont.)

As we go forward into 2022 we are strengthening our connections with GPs through the development of a training project alongside the Royal College of General Practitioners.

This, we believe, will enhance GPs knowledge and understanding of Addison's Disease which in turn will lead to earlier diagnoses and better informed management of the condition.

Advance

Medical Research During the year we were pleased to approve and issue two new grants for medical research:

- Sherwin Criseno - The 4Es (Engage, Educate, Equip and Empower): A framework for supporting the approach in the prevention, early recognition and effective management of adrenal crisis in adults. *Endocrine Abstracts* (2021) 77 P17 | DOI: 10.1530/endoabs.77.P17
- Lisa Shepherd - Development of interventions to prevent adrenal crisis – How can application of behaviour change theory and intervention frameworks inform practice? *Endocrine Abstracts* (2021) 77 P133 | DOI: 10.1530/endoabs.77.P133

The Ireland Healthcare Pathway

Our Ireland Co-Ordinator and Trustee Rachel Bracken, joined by ADSHG volunteer participants, lead our involvement with this important HSE healthcare pathways that patients should, in future be lead through by healthcare professionals to improve their quality of life.

Addison's Disease during Ramadan

We were delighted to work with Dr Shazia Hussain alongside fellow patient support charities The Pituitary Foundation and CAH Support Group, to create a Society of Endocrinology endorsed patient leaflet on this subject based on her recent research into the effects of fasting on Addison's Disease patients.

<https://onlinelibrary.wiley.com/doi/full/10.1111/cen.14250>

Other projects to advance healthcare quality

We collaborated with the NHS's website content team to amend their published guidance and content on Addison's Disease. These changes have now been implemented

We are registered stakeholders in the consultation being run by NICE (The National Institute for Health and Care Excellence) on new guidelines for adrenal insufficiency that are expected to be published in 2024.

We collaborated with the Joint Royal Colleges Ambulance Liaison Committee (JRCALC) on improvements to their guidance for paramedics on managing adrenal crisis. These changes have now been published.

We contributed to the Medics for Rare Disease RD101 training module explaining more about how patient advocacy groups can support medical professionals.

Operations

Once again, COVID-19 has impacted significantly. The pandemic led to additional needs for support and information whilst at the same time changed the way our supporters fundraised and donated; like many charities we have had to make changes to the way we operate to align with these new trends.

Our income from membership subscriptions increased from £54,311 to £57,248 in 2021. We also saw a marked increase in people applying to our hardship membership scheme, reflecting new financial pressures brought about by the pandemic and the global political climate.

We value the support of all our members and will continue to ensure they receive a membership service that meets their needs while providing value for money.

Online sales of medical supplies, leaflets and accessories have been a fantastic help to all our members especially with the ongoing pandemic and our bulk buying allows everyone to access emergency kit supplies and essentials at an affordable price.

C) Trustee's Report (cont.)

Operations (cont.)

The income we receive during the year allows us to function to the benefit of all people who have adrenal insufficiency, improving quality of life.

Behind the scenes, the operations team and the trustees have continued to enhance the ways we keep members and customer safe while using our services. From data protection to safeguarding and cyber security, we're committed to operating in a compliant, accountable, transparent and respectful way. Making our processes better, quicker and easier for our members is something we always aspire to and we welcome feedback to help us make the changes that matter.

Fundraising

Despite these challenging times, continued fundraising and donations from our determined and generous supporters and donors (taking part in everything from 24-hour game streaming to spinning classes) has allowed us to award grants to researchers to bring new innovations to healthcare including simpler ways to administer emergency injections.

We're so grateful to everyone who has made a donation or fundraised for us, whatever the amount, they continue to played a vital role in our ongoing work to improve the quality of life of people with Addison's Disease.

Digital Communications

As Vick mentioned earlier in this report, growing our presence on social media has allowed our Digital Communications and Engagement Manager to share our resources with a worldwide audience and to build important relationships with medics who work in endocrinology.

We also find that our followers on social media are often generous with their time and donations. Thank you to all our followers for their contributions this year. Over 2021 we have again grown our digital presence and social media following; for example nearly 40,000 people engaged with us via our

website, Twitter, Facebook, Instagram and YouTube in December alone.

Other notable 2021 statistics include that our YouTube videos were viewed over 92,000 times during the year (with the most popular being our emergency injection videos) and that our website received over 500,000 page views from some 240,000 users.

Volunteers

With a small employed team, our volunteers are essential to keep many important elements of our work going.

Trustees are unpaid guardians of the charity giving much of their spare time to governance work, strategic planning and overseeing the work of the team.

Our Clinical Advisory Panel are unpaid volunteer medics who despite already challenging workloads give time to ensure our medical advice is accurate, connect us with the NHS and deliver the seminars and articles our community values so much.

We have dedicated group of operational volunteers who respond to and support those who make enquiries, work as ambassadors at conferences and member events, train paramedics, provide their expertise, send out thank yous and Christmas cards, moderate our forum, write content for our magazines, newsletters and digital channels, and so much more.

To all of you, thank you very much indeed.

D) Operations Report

A view from Vick Smith, Operations Manager

An important focus for 2021 has been supporting our members and the wider Addison's community through the evolving challenges of Covid-19 and the lifting of restrictions in the UK.

For our enquiries, digital and membership teams, helping people with Addison's everyday has remained our most important and most rewarding work. Whether it's Alison answering a question for someone who has just been diagnosed, Thea talking through membership options or Pippa sharing tips on managing medication while travelling, enabling our community to live well is where our founder and patron Deana Kenward MBE started back in 1984; we continue that legacy proudly.

Increased sales of emergency kits through our shop team at AlexTLC and increased member numbers recorded by our partners at Bioscientifica, reflect how valued the ADSHG's offerings are, especially to those aspiring to a better quality of life with Addison's disease, and in the context of the pandemic.

Behind the scenes, operations and our trustees continue to further enhance the ways we keep you and your data safe while using our services. We're committed to operating in a compliant, accountable, transparent and respectful way. Making processes better, quicker and easier for our members is something we make time for in our plans for the year and we always welcome your feedback.

I hope you have found our magazines and newsletters informative and enjoyable to read. We're grateful to the large team of charity staff, contributors, clinical panel members, volunteers, design and print specialists, medics and trustees who make it happen.

Growing our presence on social media platforms such as Instagram, Facebook and Twitter has allowed our Digital Communications and Engagement Manager Pippa Sharman to share our

resources with a worldwide audience and to build important relationships with medics who work in endocrinology. It's through these connections that we find opportunities to work with rising stars in the profession who are full of enthusiasm and keen to collaborate with us. We're also finding that our followers on social media are generous with their time and donations. Thank you to all our followers for their contributions this year.

Key to improving the care available to our community is partnering with the NHS. Our Clinical Advisory Panel have worked with us to do just that. Building on strong foundations created at the height of the pandemic, 2021 saw our amazing paramedic training team train over 100 emergency workers, our digital team take part in Rare Disease Day and manage Addison's Disease Day, our operations team influence the NHS to update their website content on Addison's, Pippa to work with the Joint Royal Colleges Ambulance Liaison Committee – known to us as JRCALC – to update their guidance for paramedics, and us all to encourage the medics we've met at major medical conferences this year to connect with us to improve the care they offer to their patients.

Continued fundraising and donations from our determined and generous donors (taking part in everything from 24-hour game streaming to spinning classes) has allowed us to award grants to researchers to bring new innovations to healthcare including simpler ways to administer emergency injections.

While 2021 saw us largely operate online, we look forward in 2022 to more face-to-face events, new support options, fundraising fun and further NHS collaboration. Here's to another progressive and supportive year for all who run and rely on our charity.

Vick Smith

Vick Smith
Operations Manager



E) Public benefit statement

In shaping our objectives for the year and planning our activities, the trustees have considered the commission's guidance on public benefit, including the publication Public benefit: running a charity (PD2). As trustees we are confident that the activities described above clearly demonstrate public benefit. Furthermore, the charity makes all of its medical information freely available online as a public benefit and hosts a video hub which is free to view online.

All of our website content, including videos, is accessible on mobile devices, so that (for example) the injection videos showing how to prepare and give a life-saving hydrocortisone injection can be viewed immediately, without prior registration or payment, anywhere that has mobile reception - including in the street if necessary.

All publications authored by the charity's Clinical Advisory Panel are open access and are published in PDF form for download and print, all leaflets are clearly marked that they can be copied for personal use or by medical practitioners for the education of their patients.

Future planning

In late 2021 the board of trustees consulted with others, took advice, and met together specifically to discuss and agree a strategic plan for the coming four years 2022-2025 inclusive.

As with previous strategic plans, the focus has been the three broad headings of SUPPORT – CONNECT – ADVANCE, and our vision of a better quality of life for people with Addison's Disease.

We have been fortunate coming into 2022 to have been in receipt of a substantial legacy which will allow us to:

- confidently press ahead with the GPs education project and the appointment of an Endocrine nurse adviser
- maintain and enhance our support services to members
- invest in our own development, infrastructure and resources
- grow our investment in medical and scientific research
- plan our own patient research enabling us to gather the evidence we need to press for change within the health service
- implement the strategic plan 2022-2025

Obviously, all of our planning is subject still to the prevalence of COVID-19 and any restrictions that may be re-introduced or continue.

F) Governance

Constitution

The Addison's Disease Self Help Group is a Charitable Incorporated Organization (CIO) registered with the Charity Commission in September 2018 as charity number 1179825. It took over the activities of the previous charity of the same name (registration number 1106791) in January 2019.

Recruitment, appointment, induction and training of Trustees

The trustees can appoint any appropriate person to be a trustee. Training for new trustees includes a "Welcome Pack" which includes a copy of the Constitution and background information on the Charity and a copy of the relevant commission publication *The Essential Trustee*, all alongside a comprehensive introduction to our work and processes.

Organisational structure

The charity is governed by an elected body of trustees consisting of not more than 11 and not less than five members. Each trustee is elected for a three-year term at an Annual General Meeting, or may be co-opted by the trustees between AGMs. The group normally meets either in person or virtually, with additional subgroup or single-item agenda meetings convened where needed. The Trustees provide governance and direction for the charity's Operations Manager, other staff, engaged consultants and our volunteers. ADSHG is run by and for people with Addison's Disease, but is also supported by an independent clinical panel of endocrinologists with an interest in adrenal medicine, known as the Clinical Advisory Panel (CAP). We are indebted to our medical advisers for their pro bono support and advice.

Risk management and internal controls

The trustees actively review the major risks which the charity faces on a regular basis and have internal control policies and procedures in place to provide reasonable assurances against material misstatement or loss.

All spending decisions require prior approval from the trustees, and the savings with CAF Bank require dual authorisation. Reserve funds are retained in fixed term deposit based (no-risk) accounts. The charity's receipts and payments processes, book-keeping and annual statutory accounts are managed by contracted agencies.

Statement of trustees' responsibilities

The charity trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice). The law applicable to charities in England and Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, of the charity for that period.

In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and apply them consistently;
- observe the methods and principles in the applicable Charities SORP;
- make judgements and estimates that are reasonable and prudent; state whether applicable accounting standards have been followed, subject to any material departures that must be disclosed and explained in the financial statements; and
- prepare the financial statements on a going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports) Regulations 2008 and the provisions of the charity's constitution. **(Cont. overleaf)**

F) Governance (cont.)

Statement of Trustees' responsibilities (cont.)

They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approval

This trustees' report was approved by the board on 30th May 2022 and signed on their behalf. (insert signature) Mr D Hargreaves Trustee and Chair.



Mr D Hargreaves
Trustee and Chair

G) Accounts: Treasurer's Report A view from Treasurer Stuart Pinkerton

Once again I am delighted to report a financially successful year for The Addison's Disease Self Help Group.

This is especially gratifying after two years of strife for the charity sector as a whole, with fundraising activities hugely curtailed due to the COVID-19 pandemic, and many donors directing funds and fundraising activity, where it has been possible, to supporting our NHS, NHS Charities Together, and many hospital charities. This has been wholly understandable of course.

This charity has proved to be quite robust, partly as a result of dedication and innovation from our members and other supporters, and partly as a result of some substantial legacy income. These factors have meant that we have not had to curtail any of our project work or reign in any of our aspirations.

Total income in 2021 was £212,000, an increase of £84,000 on 2020. General donations and membership income continued, as expected, to form the core of our support.

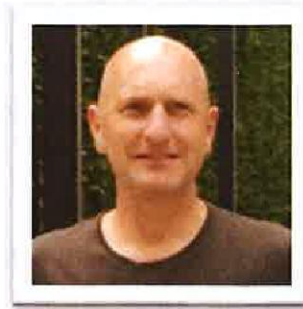
Total expenditure also rose to £209,000 (from £141,000), reflecting investment in our staff team, external resources to support them, and increased spending on the services we provide.

The small surplus generated over the year means of course that we carry forward significant funds into 2022.

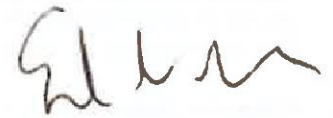
Towards the end of the year our bookkeeper and accountant until now, Mr Frank McKee, chose to retire. We have taken this opportunity to review and improve our budgeting, bookkeeping and financial reporting systems, a necessary step given our growth and strategic plans.

Financial position

We carry forward total charitable funds of some



Stuart Pinkerton
Treasurer and Trustee



£165,000 of which £138,000 is unrestricted, which gives the trustees plenty of discretion as regards future expenditure and investment. As I write this report, in early new year, I have also been advised of another substantial legacy which will, of course, be reflected in our accounts for 2022.

Our membership and donor income is anticipated to continue at similar levels to those in 2021 in the coming year.

All of this means that as treasurer I am confident that the charity is in a strong position financially going forward. I am satisfied that the trustees strategic plans, which include investment in new projects and in further medical research, are affordable. Indeed, as a board, the trustees are conscious that the charity's planned activities could and perhaps should be accelerated in order that our donors' money is put to work doing what they want it to do, as soon as is practical.

Reserves policy

As of 31st December 2020 accounts showed unrestricted reserves of £138,000. These unrestricted funds are not designated or invested in tangible fixed assets. This amounts to approximately 8 months of our average recent spending. The trustees aim to maintain unrestricted reserves of at least 6 months' expenditure on minimum essential operations to ensure that the charity is able to maintain its activities in the event of an unexpected drop in income or, in a worst case scenario, can be wound up in a controlled manner. (Cont. overleaf)

G) Accounts: Independent Examiner's Report to the Trustees of Addison's Disease Self Help Group

Independent examiner's report to the trustees of Addison'S Disease Self Help Group

I report to the charity trustees on my examination of the accounts of Addison'S Disease Self Help Group (the Trust) for the year ended 31 December 2021.

Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



Mr Andrew Churchill Stone
FCA DChA
Mercer Lewin Ltd
Chartered Accountants
41 Cornmarket Street
Oxford
OX1 3HA

Date: 6 June 2022

H) Accounts: Statement of Financial Activities For the Year Ended 31 December 2021

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 DECEMBER 2021

	Notes	Unrestricted fund £	Restricted funds £	Endowment fund £	2021 Total funds £	2020 Total funds £
INCOME AND ENDOWMENTS FROM						
Donations and legacies		112,944	1,133	-	114,077	48,327
Charitable activities						
Shop sales		37,944	-	-	37,944	20,514
Other trading activities	2	59,916	-	-	59,916	59,336
Investment income	3	631	-	-	631	146
Total		211,435	1,133	-	212,568	128,323
EXPENDITURE ON						
Charitable activities						
Advocacy advice		135,694	-	-	135,694	95,162
Raising funds		41,552	-	-	41,552	34,696
Shop stock purchases		27,050	-	-	27,050	11,602
Total		204,296	-	-	204,296	141,460
NET INCOME/(EXPENDITURE)		7,139	1,133	-	8,272	(13,137)
RECONCILIATION OF FUNDS						
Total funds brought forward		136,438	12,023	13,739	162,200	175,337
TOTAL FUNDS CARRIED FORWARD		143,577	13,156	13,739	170,472	162,200

H) Accounts: Balance Sheet - 31 December 2021

Unrestricted	Notes	fund £	Restricted funds £	Endowment fund £	Total funds £	Total funds £
CURRENT ASSETS						
Stocks	6	12,334	-	-	12,334	6,986
Debtors	7	2,338	-	-	2,338	880
Cash at bank and in hand		<u>168,143</u>	<u>13,156</u>	<u>13,739</u>	<u>195,038</u>	<u>184,067</u>
		182,815	13,156	13,739	209,710	191,933
CREDITORS						
Amounts falling due within one year	8	(39,238)	-	-	(39,238)	(29,733)
NET CURRENT ASSETS		<u>143,577</u>	<u>13,156</u>	<u>13,739</u>	<u>170,472</u>	<u>162,200</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>143,577</u>	<u>13,156</u>	<u>13,739</u>	<u>170,472</u>	<u>162,200</u>
NET ASSETS		<u>143,577</u>	<u>13,156</u>	<u>13,739</u>	<u>170,472</u>	<u>162,200</u>
FUNDS						
Unrestricted funds	9				143,577	136,438
Restricted funds					13,156	12,023
Endowment funds					<u>13,739</u>	<u>13,739</u>
TOTAL FUNDS					<u>170,472</u>	<u>162,200</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 30th May 2022 and were signed on its behalf by:



Trustee Dom Hargreaves
(Chair)

H) Accounts: Notes to the Financial Statements for the Year Ended December 2021

1. ACCOUNTING POLICIES

BASIS OF PREPARING THE FINANCIAL STATEMENTS

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

INCOME

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

EXPENDITURE

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

STOCKS

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

TAXATION

The charity is exempt from tax on its charitable activities.

FUND ACCOUNTING

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

PENSION COSTS AND OTHER POST-RETIREMENT BENEFITS

The charity operates a defined contribution pension scheme. Contributions payable to the charity's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

2. OTHER TRADING ACTIVITIES

	2021	2020
	£	£
Sponsorships	-	2,465
Membership fees	57,248	54,311
Royalties	<u>2,668</u>	<u>2,560</u>
	<u>59,916</u>	<u>59,336</u>

Continued...

H) Accounts: Notes to the Financial Statements for the Year Ended December 2021

3. INVESTMENT INCOME

	2021 £	2020 £
Deposit account interest	<u>631</u>	<u>146</u>

4. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2021 nor for the year ended 31 December 2020.

TRUSTEES' EXPENSES

There were no trustees' expenses paid for the year ended 31 December 2021 nor for the year ended 31 December 2020.

5. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £	Restricted funds £	Endowment fund £	Total funds £
INCOME AND ENDOWMENTS FROM				
Donations and legacies	48,327	-	-	48,327
Charitable activities				
Shop sales	20,514	-	-	20,514
Other trading activities	59,336	-	-	59,336
Investment income	<u>146</u>	<u>-</u>	<u>-</u>	<u>146</u>
Total	128,323	-	-	128,323
EXPENDITURE ON				
Charitable activities				
Advocacy advice	95,162	-	-	95,162
Raising funds	34,696	-	-	34,696
Shop stock purchases	11,602	-	-	11,602
Total	141,460	-	-	141,460
NET INCOME/(EXPENDITURE)	(13,137)	-	-	(13,137)
RECONCILIATION OF FUNDS				
Total funds brought forward	149,575	12,023	13,739	175,337
TOTAL FUNDS CARRIED FORWARD	<u>136,438</u>	<u>12,023</u>	<u>13,739</u>	<u>162,200</u>

H) Accounts: Notes to the Financial Statements for the Year Ended December 2021

6. STOCKS		2021	2020
		£	£
Stocks		<u>12,334</u>	<u>6,986</u>
7. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR		2021	2020
		£	£
Prepayments and accrued income		<u>2,338</u>	<u>880</u>
8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR		2021	2020
		£	£
Trade creditors		5,149	5,490
Taxation and social security		66	265
Other creditors		<u>34,023</u>	<u>23,978</u>
		<u>39,238</u>	<u>29,733</u>
9. MOVEMENT IN FUNDS			
		Net	At
	At 1/1/21	movement	31/12/21
	£	in funds	£
		£	
Unrestricted funds			
General fund	136,438	7,139	143,577
Restricted funds			
ADSHG Medical Research Fund	11,690	-	11,690
Addison's Ireland Fund	333	-	333
Endocrinology Travel Fund	-	500	500
Ronald Rogers - Gwent	-	633	633
	<u>12,023</u>	<u>1,133</u>	<u>13,156</u>
Endowment funds			
Medical Research Fund	13,739	-	13,739
	<u>162,200</u>	<u>8,272</u>	<u>170,472</u>

Net movement in funds, included in the above are as follows:

	Incoming	Resources	Movement
	resources	expended	in funds
	£	£	£
Unrestricted funds			
General fund	211,435	(204,296)	7,139
Restricted funds			
Endocrinology Travel Fund	500	-	500
Ronald Rogers - Gwent	633	-	633
	<u>1,133</u>	<u>-</u>	<u>1,133</u>
TOTAL FUNDS	<u>212,568</u>	<u>(204,296)</u>	<u>8,272</u>

Continued...

H) Accounts: Notes to the Financial Statements for the Year Ended December 2021

9. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1/1/20 £	Net movement in funds £	At 31/12/20 £
Unrestricted funds			
General fund	149,575	(13,137)	136,438
Restricted funds			
ADSHG Medical Research Fund	11,690	-	11,690
Addison's Ireland Fund	<u>333</u>	<u>-</u>	<u>333</u>
	12,023	-	12,023
Endowment funds			
Medical Research Fund	<u>13,739</u>	<u>-</u>	<u>13,739</u>
TOTAL FUNDS	<u>175,337</u>	<u>(13,137)</u>	<u>162,200</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	128,323	(141,460)	(13,137)
TOTAL FUNDS	<u>128,323</u>	<u>(141,460)</u>	<u>(13,137)</u>

A current year 12 months and prior year 12 months combined position is as follows:

	At 1/1/20 £	Net movement in funds £	At 31/12/21 £
Unrestricted funds			
General fund	149,575	(5,998)	143,577
Restricted funds			
ADSHG Medical Research Fund	11,690	-	11,690
Addison's Ireland Fund	<u>333</u>	<u>-</u>	<u>333</u>
Endocrinology Travel Fund	-	500	500
Ronald Rogers - Gwent	<u>-</u>	<u>633</u>	<u>633</u>
	12,023	1,133	13,156
Endowment funds			
Medical Research Fund	<u>13,739</u>	<u>-</u>	<u>13,739</u>
TOTAL FUNDS	<u>175,337</u>	<u>(4,865)</u>	<u>170,472</u>

Continued...

H) Accounts: Notes to the Financial Statements for the Year Ended December 2021

9. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	339,758	(345,756)	(5,998)
Restricted funds			
Endocrinology Travel Fund	500	-	500
Ronald Rogers - Gwent	<u>633</u>	<u>-</u>	<u>633</u>
	<u>1,133</u>	<u>-</u>	<u>1,133</u>
TOTAL FUNDS	<u>340,891</u>	<u>(345,756)</u>	<u>(4,865)</u>

10. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 December 2021.

H) Accounts: Detailed Statement of Financial Activities for the Year Ended December 2021

DETAILED STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2021

	2021 £	2020 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Corporate donations	-	1,806
Donations	68,568	36,075
Legacies	<u>45,509</u>	<u>10,446</u>
	114,077	48,327
Other trading activities		
Sponsorships	-	2,465
Membership fees	57,248	54,311
Royalties	<u>2,668</u>	<u>2,560</u>
	59,916	59,336
Investment income		
Deposit account interest	631	146
Charitable activities		
No description	<u>37,944</u>	<u>20,514</u>
Total incoming resources	212,568	128,323
EXPENDITURE		
Charitable activities		
Wages	48,835	35,674
Pensions	1,187	703
Fundraising costs	1,358	774
Medical goods	26,953	8,363
Publications	25,298	12,618
Conferences	1,731	2,000
Website costs	3,286	2,289
Membership service costs	22,041	24,237
Volunteer expenses	134	279
Solution Medical donation	4,756	5,034
Mendelian Limited donation	-	10,000
UCL Donation	<u>10,000</u>	<u>-</u>
	145,579	101,971
Support costs		
Management		
Accountancy and bookkeeping	3,631	3,369
Legal and professional fees	24,233	17,002
Insurance	<u>1,771</u>	<u>354</u>
	29,635	20,725
Information technology		
Communication and IT costs	4,211	6,579

H) Accounts: Detailed Statement of Financial Activities for the Year Ended December 2021

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 DECEMBER 2021

	2021 £	2020 £
Information technology		
Human resources		
Travel and subsistence	666	757
Other		
Other costs	10,987	2,592
Governance costs		
Accountancy fees	1,200	1,200
Consultancy fees	11,000	6,911
AGM and trustees meeting costs	<u>1,018</u>	<u>725</u>
	<u>13,218</u>	<u>8,836</u>
Total resources expended	<u>204,296</u>	<u>141,460</u>
Net income/(expenditure)	<u>8,272</u>	<u>(13,137)</u>

ADDISON'S DISEASE SELF HELP GROUP

England & Wales - Charity number 1179825

Accounts



**ADDISON'S DISEASE SELF HELP GROUP
(A Charitable Incorporated Organisation)**

TRUSTEES' REPORT AND ACCOUNTS

FOR THE PERIOD ENDED 31ST DECEMBER 2020

**Charity No: 1179825
Company No: CE015063**

ADDISON'S DISEASE SELF HELP GROUP

REPORT AND ACCOUNTS

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FOR THE PERIOD ENDED 31ST DECEMBER 2020

The trustees present their annual report and financial statements of the charity for the period ended 31st December 2020.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the accounts and comply with the charity's constitution, the Charities Act 2011 and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland.

OUR PURPOSE AND ACTIVITIES

The Addison's Disease Self Help Group is a Charitable Incorporated Organization registered with the Charity Commission on 5th September 2018 under charity number 1179825. It took over the activities of the previous charity of the same name (registration number 1106791) and commenced activity on 1st January 2019.

Addison's Disease Self Help Group covers the UK and Ireland. It promotes the relief of persons with Addison's disease, in particular, by the provision of support, information and communication to such persons, their families and carers and by such charitable means as the trustees determine. As part of this, ADSHG facilitates donations to give grants for medical or other relevant research.

AIMS AND OBJECTIVES

Support to members

The Charity offers a number of benefits to its members including a newsletter (available online or in print) containing medical updates, first person experiences of living with Addison's and information about day-to-day management of the condition and an online discussion forum. It is supervised by experienced volunteer moderators, where members can post questions and comments throughout the day. This facility is particularly valued by newly-diagnosed members who are finding their feet in day-to-day self-management of their essential steroid therapy. ADSHG has also continued to organise public 'question and answer' events on Twitter.

There are two newsletters and two magazines produced yearly.

The Charity produces a regular email News Alert service to keep members up to date with breaking news such as drug shortages or guidance related to the pandemic for example.

A laminated emergency card and printed hospital awareness stickers about their steroid-dependent condition are issued free of charge to all members on joining the group. The Charity's education videos explaining injection method are free-to-view for both members and the public on the charity's website.

The Charity hosts an annual general meeting with talks relevant to adrenal insufficiency and with the opportunity for hands on training injection method. A number of local social meetings are also held throughout the UK and Ireland as well as online.

Group members hosted many local social meetings around the UK in the years before 2020. Since then, it has not been possible to have these very beneficial meetings face-to-face. As we progress out of the Pandemic, we hope that these in-person meetings will restart.

The 2020 AGM and Medical Q&A was carried out remotely by zoom. This was a huge success and, many members indicated their preference for this type of meeting. It was thought a mixture of both might be a possibility in the future.

The number of subscribing members remained stable at 1741. The Hardship fund helped 26 people to become members of the Charity. The Trustees are fully supportive of the continuation of this offering in the years ahead.



Links with other support groups and medical professionals

The ADSHG continued to maintain links with other endocrine support groups across the UK, especially those representing steroid-dependence and those working to support associated autoimmune, congenital or genetic adrenal conditions.

The ADSHG is a member of National Voices, an umbrella group representing health and social care charities, and of the National Council for Voluntary Organisations, which offers guidance on charitable best practice. It also belongs to Rare Diseases UK and Rare Diseases Ireland.

Also ADSHG are involved in and participate with the SoFE Pat Portal Panel, ACT Panel and the European Adrenal Network. We also collaborate in EJE research.

ACTIVITIES

Special Projects

It has been a busy year for everybody at ADSHG. One of our aims over the last year was to offer an Endocrine Helpline Nurse. We've given it a lot of focus and investigated it thoroughly. At the time of writing this report, we are having great problems sourcing insurance for this service. Obviously, the Charity has to be protected from any liability and we are still exploring options.

Dealing with Covid has taken up a huge amount of time. We were able to advise our members on an ever-changing situation. Having a strong support from our Medical Trustees and Clinical Advisory Panel allowed us to act quickly and effectively.

Research

The Charity has run an adrenal medical research programme this year, awarding grants to two commercial bodies and two academic research bodies.

In terms of the commercial bodies, one is developing an adrenal autoinjector for use in an adrenal crisis, and another company developing software to aid diagnosis of patients with adrenal insufficiency [and other rare diseases]. Both commercial parties have demonstrated effective use of their funds in a timely manner, to the satisfaction of the Trustees.

Both academic parties have stalled in the delivery of the programmes citing conflicts with the management of the covid pandemic.

The Charity has offered support to research teams applying to other [bigger] third party research fund holders.

We supported a final year university student, who was doing a research project on children with Addison's and how we could improve their management.



ACHIEVEMENTS AND PERFORMANCE

In 2020 we:

- Collaborated with the NHS and SfE to support the new NHS Emergency Steroid Card development and clearer guidance on Covid and Covid vaccines.
- Hired our Digital Comms and engagement Officer and Governance Consultant.
- Focussed on governance products to renew our GDPR compliance and core policies and procedures.
- Raised Awareness - Rare Disease day including the Guardian article, Comix Videos and Ramadan leaflets.
- Improved resources- Young people, Ramadan, Content review project.
- Built stronger relationships with Genetic Alliance and Rare Disease UK.
- Collaborated internationally- ACT panel, support for Brazil, working with European groups via AdrenalNET and EndoERN.
- Supported the development of the HSE Ireland rare disease pathway.
- Maintained a good level of support from fundraisers with donations remaining stable during a challenging year.

Our reach via social media

In today's world social media plays a huge part of any organisation's marketing and communications approach. For the ADSHG it's been, along with our website and forums, an important channel for reaching people with adrenal insufficiency. This year we've grown our social media following by 5k:

- Twitter followers are up by 390.
- Facebook followers by 1651.
- YouTube: Our videos were viewed 106,836 times in total. Our top videos being Professor Simon Pearce's Covid care video and our emergency injection videos. Our subscribers increased by 615.
- Instagram following grew to 423 [started in June 2020].

Website reach

Users increased from 5,468 in Dec 2019 to 18,403 in Dec 2020 – an increase of 12,935.

Sessions (Site visits by users) increased from 88,014 in 2019 to 328,222 in 2020 – an increase of 240,208.

Member Communications

As well as our magazines and newsletters, we had 3 postal mailings at the height of the Covid Pandemic in May 2020. We also issued 27 email alerts.

OUR VOLUNTEERS

No Charity can flourish without the support of its volunteers. ADSHG have the support of a dedicated group of volunteers who have worked selflessly during 2020. We couldn't accomplish as much as we have without that help.



FOR THE PERIOD ENDED 31ST DECEMBER 2020

Public Benefit Statement

In shaping our objectives for the year and planning our activities, the trustees have considered the Charity Commission's guidance on public benefit, including the guidance 'public benefit: running a charity (PD2)'. The achievements and activities above demonstrate the public benefit arising through the Charity's activities.

The Charity makes all its medical information freely available online as a public benefit and hosts a video hub which is free to view online. All web content, including videos, is accessible on mobile devices, so that the injection videos showing how to prepare and give a life-saving hydrocortisone injection can be viewed immediately, without prior registration or payment, anywhere that has mobile reception - including in the street if necessary. All publications authored by the charity's advisory clinical panel are open access online and are published in PDF form suitable for home download and print the copyright statement on the group's medical literature states:

This leaflet may be copied for personal use or by medical practitioners for the education of their patients. Otherwise, it should not be reproduced without written permission from the ADSHG.

FINANCIAL REVIEW

The statement of financial activities showed a net deficit of £13,137 (2019 – Net surplus of £175,337). Total reserves stand at £162,200 (2019 - £175,337) of which £150,177 (2019 - £163,314) are unrestricted funds and £12,023 (2019 - £12,023) are restricted funds.

The pandemic has resulted in a difficult time for many Charities and the ADSHG is no different in that respect.

We rely on various sources of income - from donations, yearly subscriptions, legacies and sales of medical supplies.

Member Subscriptions

Our yearly income from subscriptions has increased from £32,437 to £54,311 in 2020. Without the support of our members, it would be very difficult to run a Charity successfully. It is very satisfying to see that our membership has stayed stable and gives us a solid foundation during the year. This has provided ADSHG with stability and allows us to create an environment in which people with Adrenal Insufficiency are given continuous support and advice which enhances the quality of their lives.

Donations

Donations have dropped overall, in part due to a large legacy in 2019, but we are very pleased to say that individual donations have been quite resilient despite the difficulties faced in 2020.

As we start to move out of the pandemic, we would expect to see an increase in fundraising and donations.

We benefitted from a large legacy in 2019 but that was not the case in 2020. We are unable to rely on legacies as a source of income alone. Therefore, donations and fundraising are essential for our survival.

Online shop sales

Our online sales of medical supplies have been a fantastic help to all our members. Our bulk buying allows everyone to access emergency kit supplies and essentials at an affordable price.

The income we receive during the year allows us to function to the benefit of all people who have Adrenal Insufficiency. This involves us going in various directions with the same end result - improving our quality of life.

Awarding of research and personal grants

We have exciting grant applications as mentioned earlier, but we must support people who are unable to afford the membership fee, for whatever reason. 26 people received membership through the hardship fund in 2020. This makes me very proud to be associated with this amazing charity.



FOR THE PERIOD ENDED 31ST DECEMBER 2020

EXPENDITURE

Our expenditure increased from £136,025 in 2019 to £141,460 in 2020. This is very encouraging as we are still fulfilling our aims without putting the Charity under any financial pressure.

Membership costs

Our membership costs have increased substantially from 2019 from £10,603 to £24,237 in 2020. When we employed Bioscientifica, they quoted for the anticipated work load. However, as it became obvious that costs were far higher, they requested for the next contract. The cost was deemed reasonable by Trustees.

Legal costs

Legal costs were related to the liability in relation the employment of an endocrine Nurse. We are very lucky to have, as one of our Trustees, Philip Kaye, who is an experienced Solicitor. He helps us on all legal matters which reduces greatly our legal expenditure.

Governance

Good Governance is fundamental to a charity's success. It enables and supports a charity's compliance with the law and relevant regulations. It also promotes a culture in which everything works towards fulfilling the charity's vision. It is because of this that we have retained David Head, an experienced charity consultant, to help us achieve best standards.

Income

Our income was £128,323 in 2020 and in 2019 our income was £311,362. The difference was due to a large legacy and transfer of funds from the old Charity.

Therefore, we are doing well, but even more so than in the past, we have to keep working to raise money for ADSHG, and making sure that we keep aspiring to make life easier for all our members and all people with Adrenal insufficiency.

I have been involved with the. ADSHG for 3 years and I feel that we are in a very positive position. With Vick, Pippa, our amazing volunteers, our subcontractors and our Trustees, I feel we can look forward to the future with confidence.

Investment policy

The investment policy of the charity is determined by the board of trustees and carried out by the treasurer and book-keeper. Currently all funds are held in bank deposit accounts with the CAF Bank, which offers the security of dual authorisation and the flexibility to retain on-call access to funds as required by the trustees. Reserve funds are allocated to long-term deposit accounts within CAF Bank. There are no investments in equities, gilts or bonds.

Reserves Policy

As of 31st December 2020 accounts showed reserves of £162,200 (2019 - £175,337) of which £136,438 (2019 - £149,575) was general funds, £13,739 (2019 - £13,739) was designated funds and £12,023 (2019 - £12,023) was restricted funds. The unrestricted funds not designated or invested in tangible fixed assets held by the charity are £136,438 (2019 - £149,575).

The unrestricted free reserves are equivalent to approximately 12 months average spending. The Charity aims to maintain an amount equivalent to around 6 to 12 months regular expenditure on essential operational spend (member support/benefit activities and supporting contractor services) to ensure it is able to maintain its activities in the event of an unexpected drop in income.



FOR THE PERIOD ENDED 31ST DECEMBER 2020

Plans for future periods

Our three-point strategy will see us driving more achievements towards our goals to 'Support, Connect and Advance' in pursuit of a better quality of life for people with adrenal insufficiency.

Support:

We'll continue to grow and enrich our friendly, supportive community of members and followers while continuing to supply reliable, user friendly support materials and publications. It is hoped our fundraising opportunities will grow during 2021 as it becomes possible for sporting events to take place where it's safe to do so. Continued focus on process improvements behind the operational scenes will help us ensure we get the best value from the investments we make into our core services and systems.

Connect:

Our Paramedic Training Programme, outreach to professionals via social media and our attendances at medical conferences will be key to our approach to ensuring medical professionals hear the Patient's Voice. We hope to encourage local efforts by groups of members to raise awareness amongst those working at their local healthcare institutions and the wider community.

Advance:

We've announced our 2021 Research Awards Programme and look forward to reporting on the recipients and their projects in our next annual report. Opportunities are on the rise for our patients to take part in research and consultations on patient care so we'll continue to connect our members and audiences with those looking to involve them in their projects.

As always we are keen to hear from members about their aspirations for the future of their care and quality of life so we can look at ways we can contribute to making those ideals a reality.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The organisation is a Charitable Incorporated Organisation (CIO), established in 2018 and registered as a charity with the Charity Commission on 5th September 2018 under registration number 1179825. The organisation is governed by a constitution based upon the Charity Commission model documentation, which sets out the objects and powers of the charity and governs the actions of the trustees.

Recruitment, Appointment, Induction and Training of Trustees

In accordance with the Constitution, the trustees shall have power at any time, from time to time, to appoint any person to be a trustee.

Training for new trustees includes a "Welcome Pack" which includes a copy of the Constitution and background information on the Charity and a copy of the relevant Charity Commission guidance: "*CC3 - The Essential Trustee*". The inaugural trustee meeting, following election of new trustees at the Annual General Meeting, is substantially focused on a review of the Charity Commission guidance on the responsibilities and duties of trustees.

Governance and organisation structure

The ADSHG is governed by an elected body of trustees consisting of not more than 11 and not less than five members of the association. Each trustee is elected for a three-year term at the Annual General Meeting, or may be co-opted by the trustees between annual general meetings. This group normally meets either in person or via web and phone conference, with additional sub-committee meetings convened where needed. The Trustees provide governance and direction for the charity's Chief Executive and our wider group of volunteers. The ADSHG is run by and for people with Addison's and welcomes involvement from partners and families of people with Addison's to pursue of the group's charitable aims.

ADSHG is supported by an independent panel of endocrinologists with an interest in adrenal medicine, known as the Addison's Clinical Advisory Panel. The Addison's Clinical Advisory Panel has authored a series of valuable medical guidelines on the management of Addison's disease, which the charity makes available to the public on its website, free of charge. The ADSHG is indebted to its medical advisers for their pro bono support and advice.

**FOR THE PERIOD ENDED 31ST DECEMBER 2020**

The ADSHG works closely with the Society for Endocrinology, the organisation representing clinical endocrinologists, and is grateful to the Society for its support to patient groups in the endocrine sector. The charity also a member of National Voices, the National Council for Voluntary Organisations, Rare Diseases UK and Rare Diseases Ireland.

Risk management and internal controls

The trustees actively review the major risks which the charity faces on a regular basis and have internal control policies and procedures in place to provide reasonable assurances against material misstatement or loss. The charity maintains no delegated spending authority, so that all new spending decisions require prior approval from the trustees or finance committee.

To reduce any risk of fraud, the group's savings are held with the CAF Bank, which operates dual authorisation accounts. Reserve funds are retained in fixed term accounts. Payments are managed from the current account, with additional use of the charity's HSBC current account for its international payment facility.

The ADSHG's receipts and payments processes, book-keeping and annual accounts are managed by contract agencies.

REFERENCE AND ADMINISTRATIVE DETAILS

Charity Number: 1179825

Company Number: CE015063

Trustees: Andrew Richard Glass – Chair
Dominic Stuart Hargreaves
Lisa Shepherd
Stuart Andrew Pinkerton
Rachel Elizabeth Bracken
Phillip Jeffrey Kaye – Appointed 20/06/2020
Dr Helen Louise Simpson – Appointed 20/06/2020
Mary McEntegart – Appointed 20/06/2020
Robert Sherrard McClements – Appointed 20/06/2020
Dr Stephen Wallace Kell – Appointed 20/06/2020

Registered Office: Starling House, 1600 Bristol Parkway North, Bristol, BS34 8YU.

Independent Examiner: Mr. David Terry
Ramon Lee Ltd, 93 Tabernacle Street, London EC2A 4BA

Bankers: CAF Bank, 25 Kings Hill Ave, Kings Hill, West Malling ME19 4JQ, United Kingdom.



STATEMENT OF TRUSTEES' RESPONSIBILITIES

The charity trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England and Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, of the charity for that period. In preparing these financial statements, the trustees are required to:

- (a) select suitable accounting policies and apply them consistently;
- (b) observe the methods and principles in the applicable Charities SORP;
- (c) make judgements and estimates that are reasonable and prudent;
- (d) state whether applicable accounting standards have been followed, subject to any material departures that must be disclosed and explained in the financial statements; and
- (e) prepare the financial statements on a going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports) Regulations 2008 and the provisions of the charity's constitution. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

APPROVAL

This report was approved by the trustees on 3rd June 2021 and signed on their behalf.

A handwritten signature in blue ink, appearing to read 'A.R. Glass'.

Andrew Glass (Chair)

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
ADDISON'S DISEASE SELF HELP GROUP**

I report on the accounts of the charitable incorporated organisation for the period ended 31st December 2020.

This report is made solely to the charity's trustees, as a body, in accordance with the Charities Act 2011. My work has been undertaken so that I might state to the charity's trustees those matters I am required to state to them in an independent examiner's report and for no other purpose. To the fullest extent permitted by law, I do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for my Independent Examination, for this report, or for the opinions I have formed.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination

I have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



**DAVID TERRY – CHARTERED ACCOUNTANT
RAMON LEE LTD
93 TABERNACLE STREET
LONDON EC2A 4BA**

3rd June 2021

ADDISON'S DISEASE SELF HELP GROUP
STATEMENT OF FINANCIAL ACTIVITIES
FOR THE PERIOD ENDED 31ST DECEMBER 2020

	Notes	Unrestricted Funds	Restricted Funds	2020	2019
		£	£	£	£
Income					
Donations	2	48,327	-	48,327	242,460
Income from charitable activities	3	20,514	-	20,514	31,788
Income from trading activities	4	59,336	-	59,336	36,894
Investment income	5	146	-	146	220
Total income		128,323	-	128,323	311,362
Expenditure					
Cost of raising funds	6	34,696	-	34,696	18,031
Expenditure on charitable activities	6	106,764	-	106,764	117,994
Total expenditure		141,460	-	141,460	136,025
Net income/(expenditure) and net movement in funds for the year		(13,137)	-	(13,137)	175,337
Reconciliation of funds					
Total funds, brought forward		163,314	12,023	175,337	-
Total funds, carried forward		150,177	12,023	162,200	175,337

CONTINUING OPERATIONS

None of the charity's activities were acquired or discontinued during the financial periods.

TOTAL RECOGNISED GAINS AND LOSSES

The Charity has no recognised gains or losses other than the above movement in funds for the above financial period.

The notes on pages 13 to 21 form part of these financial statements.

ADDISON'S DISEASE SELF HELP GROUP
BALANCE SHEET AS AT 31ST DECEMBER 2020

	Notes	2020		2019	
		£	£	£	£
Current assets					
Debtors	10	880		1,443	
Stock	11	6,986		-	
Cash at bank and in hand		184,064		198,652	
		191,930		200,095	
Liabilities					
Creditors falling due with in one year	12	29,730		24,758	
Net current assets			162,200		175,337
Net assets			162,200		175,337
 The funds of the charity					
Unrestricted funds	13				
General			136,438		149,575
Designated			13,739		13,739
Restricted funds	13		12,023		12,023
Total charity funds			162,200		175,337

These accounts were approved by the trustees on 3rd June 2021 and were signed on their behalf by:



Andrew Glass (Chair)

The notes on pages 13 to 21 form part of these financial statements.

ADDISON'S DISEASE SELF HELP GROUP

NOTES TO THE ACCOUNTS

FOR THE PERIOD ENDED 31ST DECEMBER 2020

1. ACCOUNTING POLICIES

1.1 Basis of preparation of accounts

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) – (Charity SORP (FRS 102), The Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Charities Act 2011 and applicable regulations.

Addison's disease self help group meets the definition of a public benefit entity under FRS 102.

The financial statements are prepared in sterling, which is the functional currency of the Charity. Monetary amounts in these financial statements are rounded to the nearest pound.

The accounts have been prepared under the historical cost convention with items recognised at cost or transaction value otherwise stated in the relevant note(s) to these accounts.

1.2 Preparation of accounts on a going concern basis

The Charity's Financial Statements show net deficit of £13,137 (2019 – Net surplus £175,337) for the year and free reserves of £136,438 (2019 - £149,575). Having regard to the level of reserves and the ongoing level of expenditure against unrestricted funds in conjunction with the development of the fundraising activities in the coming year the trustees are of the view that these results have secured the immediate future of the Charity for the next 12 to 18 months and on this basis the Charity is a going concern.

1.3 Income recognition

Income is recognised when the Charity has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and amount can be measured reliably.

- (a) Income received by way of donations and legacies are included in full in the Statement of Financial Activities when received, unless they relate to a specified future period, in which case they are deferred.
- (b) Legacies entitlement is taken as the earlier of the date on which either: the charity is aware that the probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the Charity that the distribution is made, or when a distribution is received from the estate.
- (c) Revenue grants are credited to income on the earlier date of when they are received or when they are receivable, unless they relate to a specified future period, in which case they are deferred.
- (d) Grants and donations of general nature which are not conditional on delivering certain levels of service are included as part of Donations and Legacies as shown under note 2. Performance related grants and donations which have conditions for a specific outcome are include as Income from Charitable Activities as shown in Note 3.
- (e) Sale of medical supplies are recognised as earned (that is, as the related goods or are provided).
- (f) Investment income is included when receivable.

1.4 Volunteers and donated services, facilities and goods

Donated professional services and donated facilities are recognised as income when the charity has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use by the charity of the item is probable and that economic benefit can be measured reliably. In accordance with the Charities SORP (FRS 102), the general volunteer time of the charity is not recognised in the main body of the financial accounts but detail is contained in the Trustees report.

On receipt, donated professional services, donated facilities and goods are recognised on the basis of the value of the gift to the charity which is the amount the charity would have been willing to pay to obtain services or facilities of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt. There were no donations in kind during the year.

ADDISON'S DISEASE SELF HELP GROUP

NOTES TO THE ACCOUNTS (Cont/d)

FOR THE PERIOD ENDED 31ST DECEMBER 2020

1.5 Expenditure recognition and irrecoverable VAT

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably. All expenditure is accounted for on an accrual's basis.

Expenditure is classified under the following activity headings:

- (a) Cost of raising funds comprises the cost of raising donations and their associated support costs.
- (b) Expenditure on charitable activities includes expenditure associated with the main objectives of the charity and includes both direct costs and their associated support costs.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

1.6 Allocation of support costs

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Support costs include back office costs, finance and governance costs which support the Trust's programmes and activities. These costs have been allocated between cost of raising funds and expenditure on charitable activities. The basis on which support costs have been allocated are set out in note 7.

1.7 Fund accounting

Unrestricted funds are available to spend on activities that further any of the purposes of Charity.

Designated funds are unrestricted funds of the Charity which the Trustees have decided at their discretion to set aside to use for a specific purpose.

Restricted funds are grants and donations, which the donor has specified are to be solely used for particular areas of the Charity's work or for specific projects being undertaken by the Charity.

1.8 Debtors

Debtors are recognised at the settlement amount due after any trade discount offered.

1.9 Cash at bank and in hand

Cash at bank and in hand includes cash deposits and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

1.10 Creditors and provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

1.11 Financial instruments

The Charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

1.12 Taxation

The charity is a registered charity and therefore, is not liable to income tax or corporation tax on income derived from its charitable activities, as it falls within the various exemptions available to registered charities.

ADDISON'S DISEASE SELF HELP GROUP

NOTES TO THE ACCOUNTS (Cont/d)

FOR THE PERIOD ENDED 31ST DECEMBER 2020

1.13 Judgement and key sources of estimation uncertainty

In the application of the Charity's accounting policies, the charity is required to make judgments, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

1.14 Cash flow statement

The charitable incorporated organisation qualifies as a small charity and advantage has been taken of the exemption provided by SORP (FRS 102) as amended by Bulletin 2, not to prepare a cash flow statement.

2. DONATIONS AND LEGACIES

	Unrestricted Funds	Restricted Funds	2020	2019
	£	£	£	£
Donation from Addison's Disease Self-Help Group	-	-	-	121,114
Corporate donations	1,806	-	1,806	15,358
Individual donations	26,333	-	26,333	34,167
Other donations	9,722	-	9,722	4,955
Legacies	10,466	-	10,466	66,731
Gift Aid claimed	-	-	-	135
	<u>48,327</u>	<u>-</u>	<u>48,327</u>	<u>242,460</u>

Donation from Addison's Disease Self-Help Group in 2019 represents the transfer to the charity following the closure of Addison's Disease Self-Help Group (charity number 1106791). Donations and legacies income in 2019 totalling £242,460 was attributed to unrestricted funds £222,417 and restricted funds £20,043.

3. INCOME FROM CHARITABLE ACTIVITIES

	Unrestricted Funds	Restricted Funds	2020	2019
	£	£	£	£
Sale of medical supplies	20,514	-	20,514	31,788
	<u>20,514</u>	<u>-</u>	<u>20,514</u>	<u>31,788</u>

Income from charitable activities in 2019 totalling £31,788 was attributed to unrestricted funds.

ADDISON'S DISEASE SELF HELP GROUP

NOTES TO THE ACCOUNTS (Cont/d)

FOR THE PERIOD ENDED 31ST DECEMBER 2020

4. OTHER TRADING ACTIVITIES

	Unrestricted Funds	Restricted Funds	2020	2019
	£	£	£	£
Membership fees	54,311	-	54,311	32,437
Royalties	2,560	-	2,560	3,957
Sponsorship	2,465	-	2,465	500
	-	-	-	-
	<u>59,336</u>	<u>-</u>	<u>59,336</u>	<u>36,894</u>

Income from other trading activities in 2019 totalling £36,894 was attributable to unrestricted funds.

5. INVESTMENT INCOME

	Unrestricted Funds	Restricted Funds	2020	2019
	£	£	£	£
Investment income	146	-	146	220
	<u>146</u>	<u>-</u>	<u>146</u>	<u>220</u>

Investment income in 2019 totalling £220 was attributable to unrestricted funds.

6. EXPENDITURE ON CHARITABLE ACTIVITIES

	Raising Funds	Advocacy advice	Medical Supplies	2020	2019
	£	£	£	£	£
Staff costs	-	36,377	-	36,377	28,403
Staff recruitment and training	-	-	-	-	225
Volunteer expenses	-	279	-	279	626
Publications	-	12,618	-	12,618	7,348
Shane McNichols donation	-	-	-	-	8,000
Solution Medical donation	-	5,034	-	5,034	-
Mendelian Limited donation	-	10,000	-	10,000	-
Website Costs	-	2,289	-	2,289	11,238
Conferences	-	2,000	-	2,000	2,125
Costs of sale of medical supplies	-	-	8,363	8,363	21,923
Membership service costs	24,237	-	-	24,237	10,603
Fundraising costs	774	-	-	774	1,604
Governance costs (Note 7)	2,167	5,944	725	8,836	24,217
Support costs (Note 7)	7,518	20,621	2,514	30,653	19,713
	<u>34,696</u>	<u>95,162</u>	<u>11,602</u>	<u>141,460</u>	<u>136,025</u>

Of the £141,460 expenditure in 2020 (2019 - £136,025), £141,460 was charged to unrestricted funds (2019 - £128,005) and £Nil to restricted funds (2019 - £8,020).

ADDISON'S DISEASE SELF HELP GROUP

NOTES TO THE ACCOUNTS (Cont/d)

FOR THE PERIOD ENDED 31ST DECEMBER 2020

7. ANALYSIS OF SUPPORT AND GOVERNANCE COSTS

The Charity initially identifies the costs of its support functions. It then identifies those costs which relate to the governance function. Governance costs and other support costs are apportioned separately between charity's key activities undertaken (see note 6) in the period. All the general support and governance costs have been apportioned to the various charitable activities on the basis of a proportion of direct costs, allocated to each activity.

	General Support Costs	Governance Costs	2020	2019
	£	£	£	£
Communication and IT costs	6,579	-	6,579	5,595
Travelling and subsistence	757	-	757	3,910
Insurance	354	-	354	513
Accountancy and book-keeping fees	3,369	-	3,369	10,828
Legal and professional fees	17,002	5,990	22,992	14,435
Other expenses	2,592	-	2,592	3,371
AGM and trustees meeting costs	-	1,646	1,646	4,078
Independent Examiners fees	-	1,200	1,200	1,200
	<u>30,653</u>	<u>8,836</u>	<u>39,489</u>	<u>43,930</u>

8. NET INCOME / EXPENDITURE FOR THE YEAR

	2020	2019
	£	£
Net movement in funds is shown after charging:		
Independent examiners' fee	1,200	1,200
	<u>1,200</u>	<u>1,200</u>

9. ANALYSIS OF STAFF COSTS, TRUSTEES REMUNERATION AND EXPENSES

	2020	2019
	£	£
STAFF COSTS		
Salaries	35,674	26,617
National Insurance	-	1,785
Pension	703	-
	<u>36,377</u>	<u>28,402</u>

No employee received remuneration in excess of £60,000 during the period.

None of the Trustees received any remuneration or reimbursement of expenses during the year (2019 - £Nil)

The key management personnel of the charity comprise the Chief Executive. The total employee benefits of the key management personnel of the charity, consisting of wages were £30,647 (2019 - £28,402)

ADDISON'S DISEASE SELF HELP GROUP

NOTES TO THE ACCOUNTS (Cont/d)

FOR THE PERIOD ENDED 31ST DECEMBER 2020

10. STAFF NUMBERS

The average monthly number of full time staff employed by the charity during the year was as follows:

The average number of full- time equivalent employees was as follows:

	2020	2019
Direct project work		
Administration work	1.50	1.00

11. DEBTORS FALLING DUE WITHIN ONE YEAR

	2020 £	2019 £
Debtors	-	65
Prepayments	880	1,378
	<u>880</u>	<u>1,443</u>

12. Stock

	2020 £	2019 £
Stock	6,986	-
	<u>6,986</u>	<u>-</u>

13. CREDITORS FALLING DUE WITHIN ONE YEAR

	2020 £	2019 £
Creditors	5,488	1,184
Other Creditors	217	-
Accruals	1,381	4,090
PAYE and National Insurance	265	-
Deffered Income (Note 16)	22,380	19,484
	<u>29,730</u>	<u>24,758</u>

ADDISON'S DISEASE SELF HELP GROUP

NOTES TO THE ACCOUNTS (Cont/d)

FOR THE PERIOD ENDED 31ST DECEMBER 2020

14. ANALYSIS OF CHARITABLE FUNDS

	Balance at 01.01.20 £	Income £	Expenditure £	Transfer £	Balance at 31.12.20 £
Restricted funds:					
ADSHG Medical Research Fund	11,690	-	-	-	11,690
Addison's Ireland Fund	333	-	-	-	333
	12,023	-	-	-	12,023
Designated funds:					
Medical Research Fund	13,739	-	-	-	13,739
	13,739	-	-	-	13,739
General funds:	149,575	128,323	141,460	-	136,438
Total unrestricted funds	163,314	128,323	141,460	-	150,177
Total funds	175,337	128,323	141,460	-	162,200

Previous Year

	Balance at 01.01.19 £	Income £	Expenditure £	Transfer £	Balance at 31.12.19 £
Restricted funds:					
Addison's Video Fund	-	20	20	-	-
ADSHG Medical Research Fund	-	11,690	-	-	11,690
Paramedic Conference Fund	-	3,000	-	(3,000)	-
Addison's Ireland Fund	-	5,333	8,000	3,000	333
	-	20,043	8,020	-	12,023
Designated funds:					
Medical Research Fund	-	13,739	-	-	13,739
	-	13,739	-	-	13,739
General funds:	-	277,581	128,006	-	149,575
Total unrestricted funds	-	291,320	128,006	-	163,314
Total funds	-	311,363	136,026	-	175,337

ADDISON'S DISEASE SELF HELP GROUP

NOTES TO THE ACCOUNTS (Cont/d)

FOR THE PERIOD ENDED 31ST DECEMBER 2020

Description, nature and purpose of restricted funds:

Addison's Video Fund: The Addison's Video Fund is towards the costs produce further educational video modules, both about injection method and broader aspects of self-management for adrenal steroid-dependence.

ADSHG Medical Research Fund: the ADSHG medical research fund was set up to allow the Charity to expand its support for applied medical research and the advancement of good clinical and nursing practice. The group offers two medical research awards from this fund: the Annette Seal nursing prize and the Alfred Potter medical research grant. The Charity may award more than 1 medical research grant per year, where there are suitable applications. Where there is a strong second candidate for the Annette Seal nursing prize, a runner-up award of £250 may be offered.

Paramedic Conference Fund: The Society for Endocrinology gave a grant for the purpose of contributing to the cost of providing an ADSHG presence at eight or more student paramedic conferences/events nationwide over the period to July 2019.

Addison's Ireland Fund: The Addison's Ireland Fund was a series of donations gathered in Warrenpoint as a result of the sad passing of Shane Nicholl, a young boy who suffered from Addison's.

General funds:

General fund represents funds available to spend at the discretion of the Trustees after allowing for all the designated funds.

Designated funds:

Medical Research Fund: The Medical Research Fund has been designed by the Trustees to include the donation from the legacy of Elsie Gaitens and will be used to support grants for medical research.

15. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	General Funds £	Designated Funds £	Restricted Funds £	Total 2020 £
Net Current assets	136,438	13,739	12,023	162,200
	<u>136,438</u>	<u>13,739</u>	<u>12,023</u>	<u>162,200</u>

Previous Year

	Funds £	Funds £	Funds £	2019 £
Net Current assets	149,575	13,739	12,023	175,337
	<u>149,575</u>	<u>13,739</u>	<u>12,023</u>	<u>175,337</u>

ADDISON'S DISEASE SELF HELP GROUP

NOTES TO THE ACCOUNTS (Cont/d)

FOR THE PERIOD ENDED 31ST DECEMBER 2020

16. DEFERRED INCOME

	2020	2019
	£	£
Opening Balance as on 1st January	19,484	-
Amount deferred in year	22,380	19,484
Amount released in year	(19,484)	-
Closing balance as on 31st December	<u>22,380</u>	<u>19,484</u>

Deferred income represents membership income received in advance.

17. RELATED PARTY TRANSACTIONS

Details of transactions with trustees and senior management are in note 9. There are no other related party transactions.