

**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



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



RARE
DISEASE UK

NADF
National Adrenal Diseases Foundation



Living with
cah
CAH Support Group, Registered Charity



beacon
for rare diseases
no rare journey alone

jrcalc



the**bmj**

National
Voices



GENETIC
ALLIANCE UK

rare**m**inds
Mental Health for the Rare Disease Community



ACHIEVEMENTS & PERFORMANCE

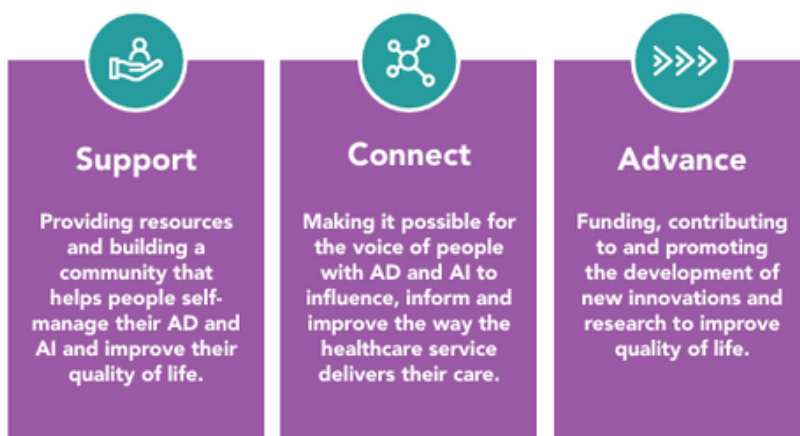


What we do



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.

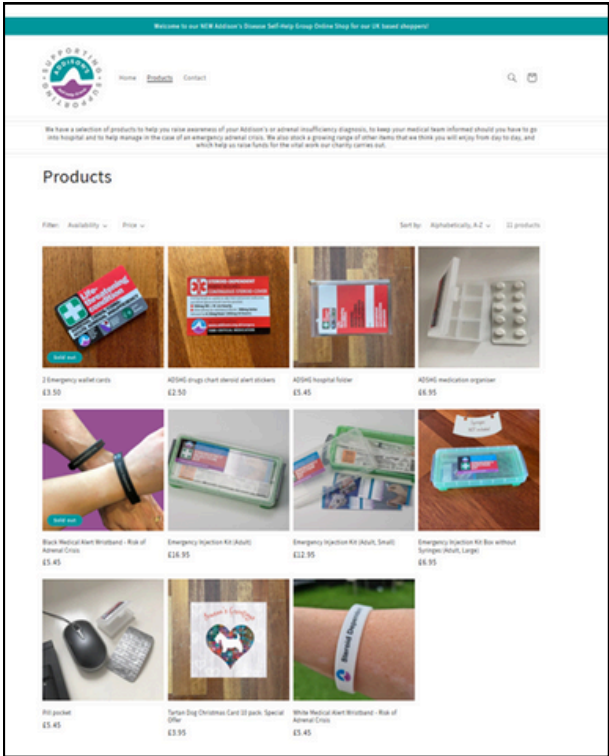
They remain full of useful information for members on managing day-to-day life with steroid-dependency, personal experiences, research updates and charity news.

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.

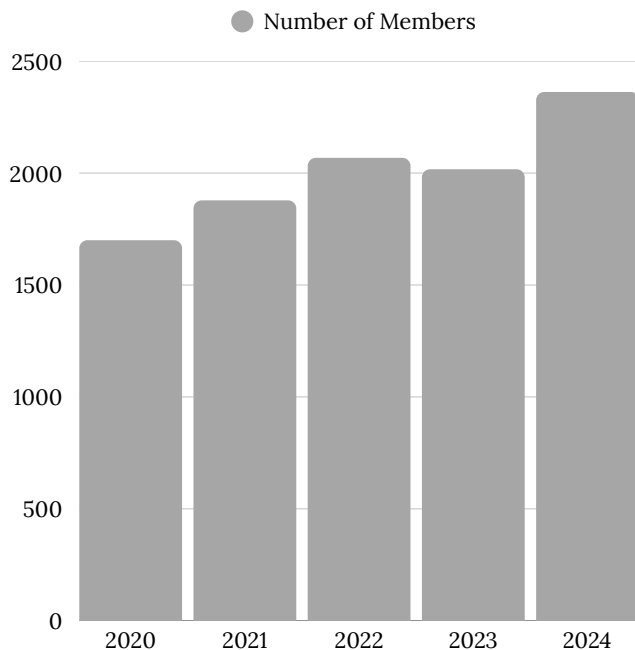
Attracting Researchers into Adrenal Medicine

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



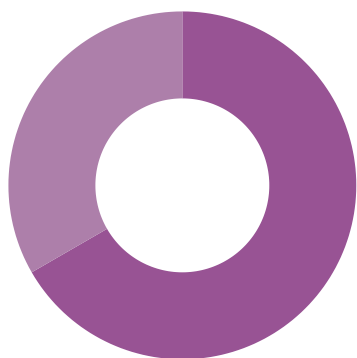
A growth in membership is a win-win in so many ways. It tells us that people are finding our services and support useful and finding value in their membership.

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!

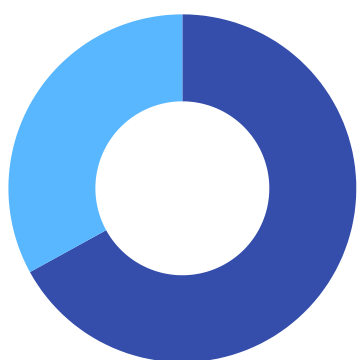
Member benefits

- 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.

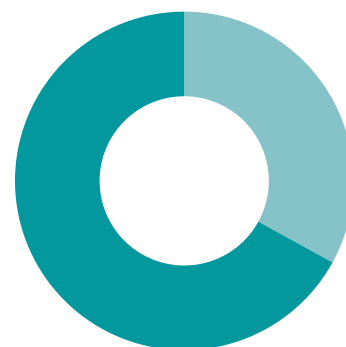


Age

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

Gender

The majority of our members are female



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!

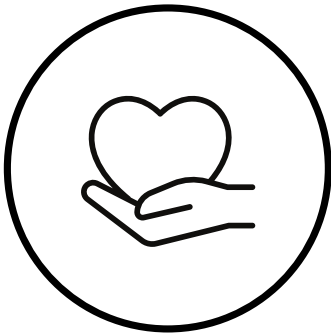


Thank You

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/Al, and those who care for them. The shop is online only and focuses on sales of items that can be used by people with Al 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	(213) <u>(5,000)</u>	- <u>5,000</u>	(7,500) <u>-</u>	(7,713) <u>-</u>	9,673 <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	<u>(17,551)</u>	<u>-</u>	<u>-</u>	<u>(17,551)</u>	<u>(24,971)</u>
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>-</u>	<u>-</u>	<u>-</u>	<u>3,739</u>
Total	<u>238,215</u>	<u>-</u>	<u>-</u>	<u>-</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>-</u>	<u>-</u>	<u>-</u>	<u>39,068</u>
Total	<u>228,542</u>	<u>-</u>	<u>-</u>	<u>-</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

Notes continued

Yr ending 31.12.24

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
	<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
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	<hr/> -	<hr/> -	<hr/> -
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	<hr/> -	<hr/> -	<hr/> -
NET BOOK VALUE			
At 31 December 2024	<hr/> -	<hr/> -	<hr/> -
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%)