



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

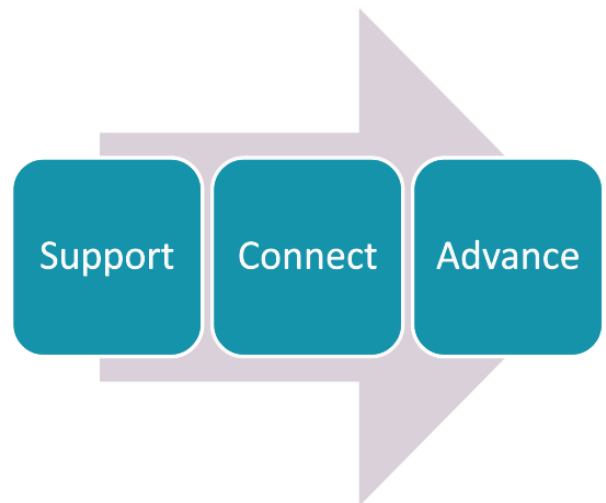
Our annual meetings are important because they bring our membership into contact with professionals who are interested in Addison's disease and adrenal insufficiency. Uniting people with AD/AI and healthcare professionals brings mutual benefits; those affected understand more about their rare disease 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.

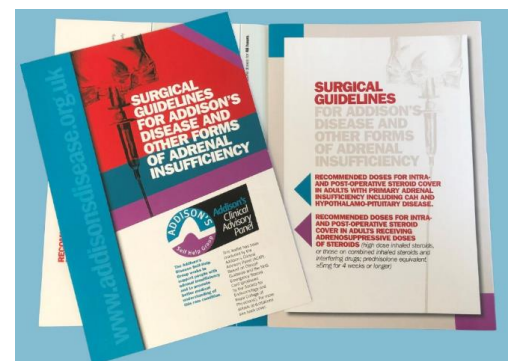


Volunteers

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.

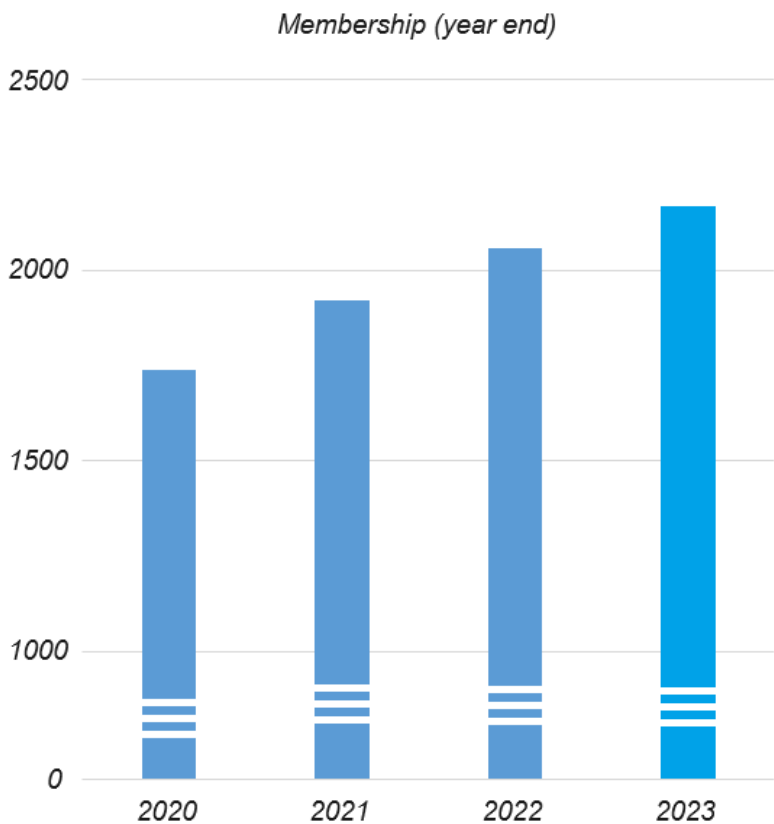
Members support us with their membership fees, and ensure that we are truly representing people affected by Addison’s disease and adrenal insufficiency. We are credible when we are talking to decision makers and healthcare professionals as a result of the number of patients that we represent.

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.



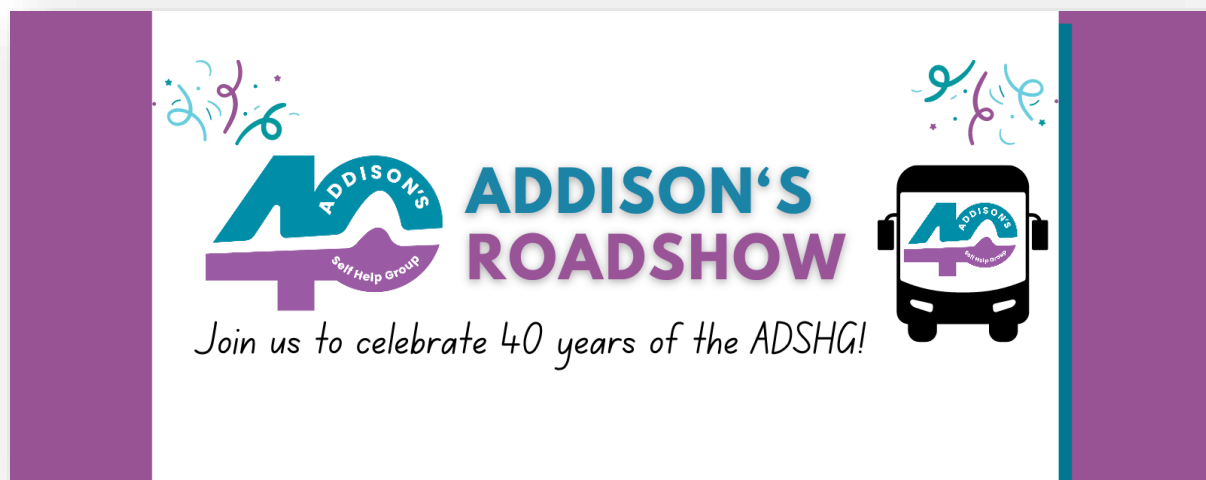
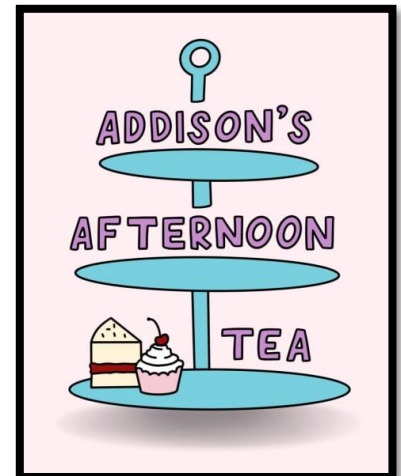
2024: Looking forward to a special year

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 0HP

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		209,915	-	-	209,915	281,973
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		228,542	-	-	228,542	256,464
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		144,285	19,330	13,739	177,354	195,981

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)
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><u>144,285</u></u>	<u><u>19,330</u></u>	<u><u>13,739</u></u>	<u><u>177,354</u></u>	<u><u>195,981</u></u>
FUNDS	10					
Unrestricted funds					144,285	162,912
Restricted funds					19,330	19,330
Endowment funds					13,739	13,739
TOTAL FUNDS					<u><u>177,354</u></u>	<u><u>195,981</u></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	<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>
TOTAL FUNDS	<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
	13,156	6,174	19,330
Endowment funds			
Medical Research Fund	13,739	-	13,739
TOTAL FUNDS	<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)	-
	35,370	(29,196)	6,174
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
	13,156	6,174	19,330
Endowment funds			
Medical Research Fund	13,739	-	13,739
TOTAL FUNDS	<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)	-
	35,370	(29,196)	6,174
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>37,609</u>	<u>30,672</u>
Total incoming resources	<u>209,915</u>	<u>281,973</u>
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