



**Report of the Trustees and Financial Statements**  
**For the Year Ended 31<sup>st</sup> March 2025**

**2024** | **2025**

Myaware is a Registered Charity No. England & Wales 1046443. Scotland SC044744.  
Company Limited by Guarantee No. 3038358 (England & Wales)

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## **Chair's Report**

As I write my final report as Chair of myaware, I am filled with immense pride and gratitude for all that we have achieved together. Myaware's mission, to support everyone affected by Myasthenia, empower our community, and drive progress through research and advocacy, remains as vital as ever. It has been a privilege to witness the strength, resilience, and generosity of our members, supporters, and partners over the years.



This year, we have continued to build on our national support model, ensuring that every person living with a Myasthenia condition, wherever they are in the UK, can access the information, advice, and community they need. Our online support sessions, telephone helpline, and dedicated social media groups have remained lifelines for many, providing connection and reassurance in challenging times.

We have further strengthened our welfare benefits and advice service, helping members navigate complex systems and secure the support they deserve. Our commitment to funding and championing high-quality research has continued, with new partnerships and projects launched to deepen understanding of Myasthenia and accelerate progress towards better treatments and, ultimately, a cure.

Throughout the year, we have worked closely with healthcare professionals, academic partners, and industry stakeholders to ensure that the voices and experiences of people living with Myasthenia are heard and valued. Together, we have advocated for improved access to care, greater awareness, and meaningful policy change.

None of this would be possible without the unwavering support of our donors, fundraisers, corporate partners, trusts, and foundations. Your belief in our mission, and your willingness to stand with us, has enabled myaware to remain a beacon of hope and support for so many. Thank you for your generosity, your expertise, and your trust.

These past years have not been without their challenges. The ongoing pressures on health and social care, the cost-of-living crisis, and the lasting impact of the pandemic have tested us all. Yet, time and again, our community has shown remarkable adaptability, compassion, and determination. I am confident that myaware will continue to thrive and evolve, guided by these values.

As I step down as Chair, I want to express my deepest thanks to the Board of Trustees, our dedicated staff team, and every member of the myaware community. It has been an honour to serve alongside you. I look forward to seeing myaware continue to grow, innovate, and make a lasting difference in the lives of people with Myasthenia.

With heartfelt thanks and best wishes for the future,

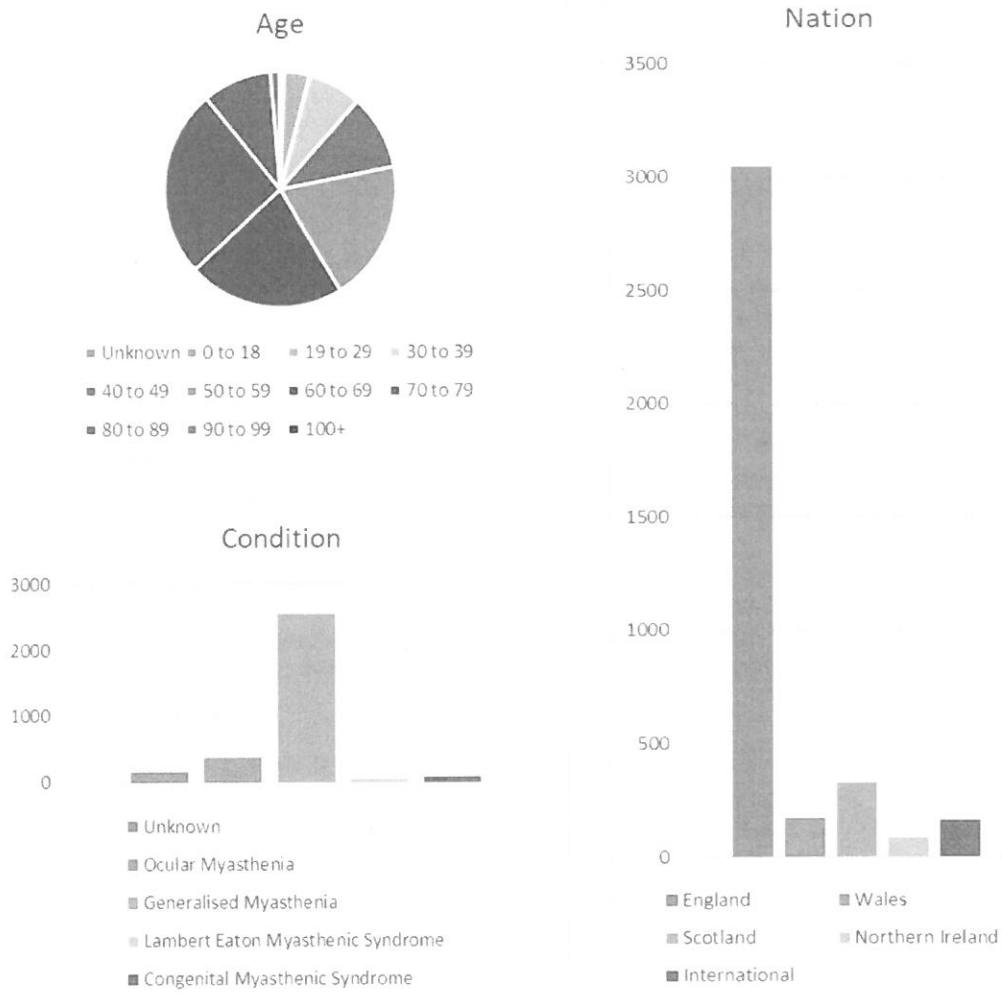
Trevor Ranson  
Chair, myaware

**CEO's Report**

**Membership**

Historic research publications have stated that there were approx. 12,000 people living with myasthenia in the UK. In December 2021 a research paper entitled *Prevalence and incidence of neuromuscular conditions in the UK between 2000 and 2019*, written by Iain Carey was published outlining that this data is now estimated at 20,000 people in the UK.

In April 2025, myaware recorded a 37.95% increase in active membership, rising from 2,746 to 3,788 over the financial year spanning April 2024 to March 2025. Myaware began implementing lifetime memberships effective from January 2024, to ensure that members can continue to access information and support throughout their myasthenia journey, without interruption. Our large increase in membership reflects this.



## CEO's Report - continued

### **Myaware national support services**

Myaware members have access to a comprehensive range of online and telephone support services, offering guidance to individuals and their families from diagnosis onward. In 2024–25, myaware continued to expand and improve its digital offerings, ensuring members could easily access reliable information, expert advice, and peer support. We maintained our commitment to a nationally coordinated delivery model, further streamlining services across the UK to enhance consistency and accessibility.

### **Connecting our members online**

#### **Zoom sessions and webinars**

Over the past year, we delivered 38 online Zoom sessions, creating opportunities for members to connect, share experiences, and discuss common challenges. These sessions were led by our expert National Support Coordinators and our Benefits and Welfare Officer, who provided compassionate updates on support services, awareness initiatives, and research developments, along with essential guidance on living well with myasthenia.

We also hosted three webinars, building on the success of the previous year. To launch My Awareness Month 2024, Dr. Channa Hewamadduma presented a session on the importance of lifestyle and exercise for individuals with Generalised Myasthenia Gravis. As part of the same awareness initiative, three of the UK's Myasthenia Specialist Nurses led a 'Frequently Asked Questions' webinar, addressing the most common queries raised by their patients.

In another webinar, our Research and Partnerships Manager, Charlotte Campbell, shared the latest findings on lung and bone health in relation to myasthenia. All webinars were facilitated by our dedicated support team.

Myaware continues to offer a diverse range of monthly Zoom sessions tailored to members who are newly diagnosed, as well as peer support sessions for the wider community. We also provide age-specific and condition-specific sessions, alongside new offerings for carers and welfare-related topics. Our goal is to reduce feelings of isolation by supporting members through the early stages of diagnosis and helping them stay connected with others facing similar experiences.

We're proud to report that over 1,209 members attended our online sessions this year—a nearly 15% increase from the previous year—highlighting the growing impact of our digital support services.

*"Very pleased with session, learnt a lot and when I do these sessions, feel much better knowing that there are other people out there with the same diagnosis but some of a lot worse than I am. Which makes me grateful that I have more good days than bad days."*

*"These events are very helpful. Discussing MG and its impacts with people who have direct experience of the condition (sufferers AND their partners who also live with this) gives some really helpful insights and knowledge. Thank you all for doing this."*

*"I find them very instrumental in my recovery. I was diagnosed on 29th May 2003. Severe recurrence about 7 months ago. The Myasthenia group now is so different from the 2003 era. I enjoy the Zoom meetings where there are a variety of questions. With the members at heart."*

## **CEO's Report - continued**

### **Peer support network via social media**

Myaware currently facilitates and manages six national closed Facebook groups, connecting 1,282 individuals living with myasthenia and their family members. This year, we expanded our online peer support network by launching dedicated groups for those affected by Congenital Myasthenic Syndromes (CMS) and Lambert-Eaton Myasthenic Syndromes (LEMS), offering these rarer patient communities a safe space to share experiences and access support.

These groups serve as a vital 24/7 lifeline, providing peer-to-peer connection, updates from myaware, and answers to frequently asked questions. Our national peer support group is open to all members, regardless of age, location, or type of myasthenia. We also offer tailored groups including:

- Myaware Kids – for parents of children diagnosed with any form of myasthenia
- Young Generation – for members aged 18–39, with discussions focused on education, employment, pregnancy, and other relevant topics
- Carers Group – newly introduced this year, offering support and resources for those caring for someone with myasthenia

These online communities play a crucial role in reducing isolation and fostering connection among those affected by myasthenia across the UK.

*"I have finally been officially diagnosed with CMS and I am in a bit of shock, it is bittersweet for sure... I am so grateful for the myaware Facebook group, it has been such an encouragement"*

### **Support offered by the team**

#### **Telephone and Email, Support and Information**

Our team are available Monday to Friday 9am to 5pm by telephone and email. Whether members have a question they want answering or want to know more about myaware objectives or services, our dedicated Head Office and the Support Team members are here to help inform and guide our members.

#### **Emotional support service**

People can have many reactions to myasthenia, and for this reason our National Support Coordinators are here to listen and when needed can help point you to specialist support.

*"Your response, as always, was extremely helpful, empathetic and kind. I cannot thank you enough. You are a brilliant organisation run by brilliant individuals."*

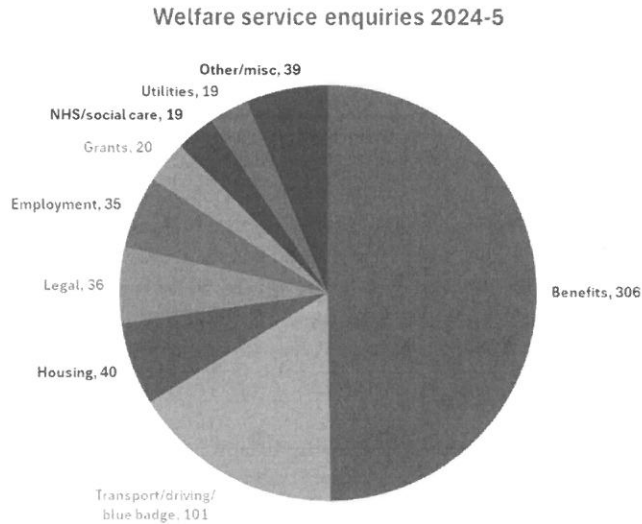
#### **Benefits and welfare advice service**

The benefits system is complex, the rules can change, and when living with an unpredictable and sometimes debilitating condition like myasthenia, it can be difficult to find the energy and time to fully research every opportunity to improve your quality of life. Myaware's dedicated Welfare officer is here to help our members navigate the benefits system and check if they are entitled to any financial assistance, or support relating to transport, employment, or education.

## CEO's Report - continued

### Benefits and welfare advice service - continued

This year myaware has responded to 615 benefits and welfare enquiries.



These enquiries were divided among topics like employment, housing, and transport. Almost half of these enquiries were focused on benefits.

Like all our support services this advice is available to all members in England, Scotland, Wales, and Northern Ireland. The service is provided by telephone, on the myaware website and via our Zoom sessions, and is available Monday to Friday, 9am to 5pm.

*"Thank you so much for this... I really appreciate all the info you provided, especially for the [Council Tax] benefit, which I had been led to believe I couldn't get any help with."*

*"Thank you again for helping me win this decision, I thought this would drag out to years of stress arguing with the DWP."*

### Website information

In an increasingly digital world, the myaware website (found at [www.myaware.org](http://www.myaware.org)), is one of the most useful digital and communication tools the charity has. Our website exists to establish and maintain a relationship with the Myasthenia community and a broad range of stakeholders.

From April 2024 to March 2025, over 118,000 people visited the myaware website, with 95,000 of them being first-time visitors. On average, each visitor spent over a minute exploring the site. In total, users interacted with the website more than 1.1 million times, including reading articles, clicking links, and using support resources. The most popular website pages included: 'Drugs to Avoid', 'What is Myasthenia?', 'Support' and 'Ocular Myasthenia' – all providing essential information and guidance.

Most visitors found the site through Google searches, followed by direct visits and referrals from trusted sources like NHS and Facebook. The highest levels of engagement came from users in London, New York, Birmingham, and Edinburgh, showing that myaware continues to reach and support people both in the UK and internationally.

## **CEO's Report – continued**

### **Website information - continued**

Together, the myaware website and the charity's social media acts as a digital hub enabling us to share the fantastic stories of our members and how they have been empowered to understand their conditions, have greater say on the treatments and therapies available, and connect with other members who have Myasthenia related conditions via peer-to-peer support. Our website includes lots of helpful information including current research on Myasthenia, drugs to avoid, and places to find additional support. We also use our website to promote good news stories, fundraising events, and future online community sessions.

The main objectives of the website are to provide advice and support for members and carers, to increase awareness in primary and acute medical audiences, as well as the general public, and fund much needed research, enhancing medicines, surgical treatments and therapeutic interventions. In addition, users can access the charity's annual accounts, online shop, register for support events, and attain membership information. We urge anyone visiting our website to become a myaware member, whether they have a Myasthenia diagnosis, are a relative, carer or a healthcare professional with an interest in the Myasthenia.

### **Website Accessibility**

Our website utilises the ReachDesk accessibility toolbar, which ensures visitors can access our content in a way that suits them best. Including text-to-speech, reading and translation support. Over the course of the year, the ReachDeck tool was estimated to be used around 6,444 times on the myaware website. The most actively used features were speech playback, with approximately 756 uses, and translation tools, used around 252 times, helping visitors listen to content aloud or access it in their preferred language. These figures reflect myaware's ongoing commitment to making its online information accessible, inclusive, and user-friendly for all.

### **Booklets, leaflets and flyers**

For those who prefer printed materials, myaware offers a comprehensive library of information booklets and leaflets tailored to different audiences. These include resources for individuals living with Myasthenia Gravis, LEMs, Ocular Myasthenia, and Congenital Myasthenia. We also provide specialised guides on Myasthenia and CMS during pregnancy, as well as healthcare guides for medical professionals, including a dedicated booklet on Ocular Myasthenia. In addition, we produce a range of flyers that promote myaware's services and support offerings.

As I conclude this annual report as Interim CEO, I want to express my heartfelt thanks to everyone who makes myaware such a supportive and forward-thinking community. The dedication of our members, volunteers, and staff is evident in every story, statistic, and service described in these pages. I am inspired by the progress we have made together, whether that's welcoming new members, expanding our digital reach, or making our resources more accessible than ever before.

Looking ahead, I am excited to work with you all to shape a new strategy that builds on these achievements and ensures myaware continues to be a lifeline for everyone affected by myasthenia. Thank you for your trust, your engagement, and your commitment to our shared mission.

Marc Smith  
Interim CEO, myaware

## **REPORT OF THE TRUSTEES**

The trustees, who are also directors of the charity for the purposes of the Companies Act 2006, present their report together with the financial statements for the year ending 31st March 2025. These statements are also prepared to meet the requirements of the directors' report and accounts under the Companies Act.

The financial statements comply with the Charities Act 2011, the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the charity's Articles of Association, and 'Accounting and Reporting by Charities: Statement of Recommended Practice' (SORP) 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).

## **OBJECTIVES AND ACTIVITIES OF THE CHARITY**

Myaware exists to support people affected by myasthenia and related conditions, to raise awareness, and to fund research aimed at reducing the impact of these conditions and ultimately finding a cure.

### **Our core support services include:**

- Support and information sessions delivered via Zoom, covering research updates, general support, and benefits and welfare advice.
- Monthly new member support sessions via Zoom.
- Condition-specific and age-specific Zoom sessions, including support for children (up to age 18) and young people (ages 18–39).
- Information and support available through the myaware website.
- Social media services, including closed, secure groups for peer support and public pages for information and signposting.
- Telephone and online welfare and benefits advice service.

### **We raise vital awareness of myasthenia by:**

- Representing our members through membership of umbrella organisations such as the UK Neurological Alliances, Rare Disease UK, and National Voices.
- Providing targeted information for members and the general public via our website.
- Supplying information packs for clinicians throughout the UK.

### **Our commitment to research:**

- Funding research projects focused on the cause, cure, prevention, treatment, and quality of life for people with myasthenia and related conditions.
- Supporting the training of clinicians in the field of myasthenia.
- Communicating research outcomes and future opportunities transparently to members and stakeholders.

To achieve these aims, we undertake a range of fundraising activities. We are deeply grateful to everyone who supports us financially and to our dedicated volunteers who contribute to both support and fundraising. Raising unrestricted funds to cover the charity's core costs, such as postage, telephone, printing, online services, and other essential expenses, remains a key challenge, and we are especially thankful to those who make donations that can be used flexibly in this way.

## **REPORT OF THE TRUSTEES**

### **Grant Making Policy**

The charity may award grants to scientific research, specialist myasthenia nurses, and training fellowships in support of its objectives and activities.

Grants are awarded by the Board of Trustees when funds are available and only when the charity's reserves position allows for the commitment of funds to multi-year projects.

Research grants are subject to a rigorous peer review process, overseen by the myaware Medical Committee.

### **Public Benefit**

The trustees have referred to the Charity Commission's general guidance on public benefit when reviewing myaware's aims and objectives and in planning future activities. In particular, the trustees always consider how planned activities will contribute to the charity's objectives and benefit the public.

## **ACHIEVEMENT AND PERFORMANCE**

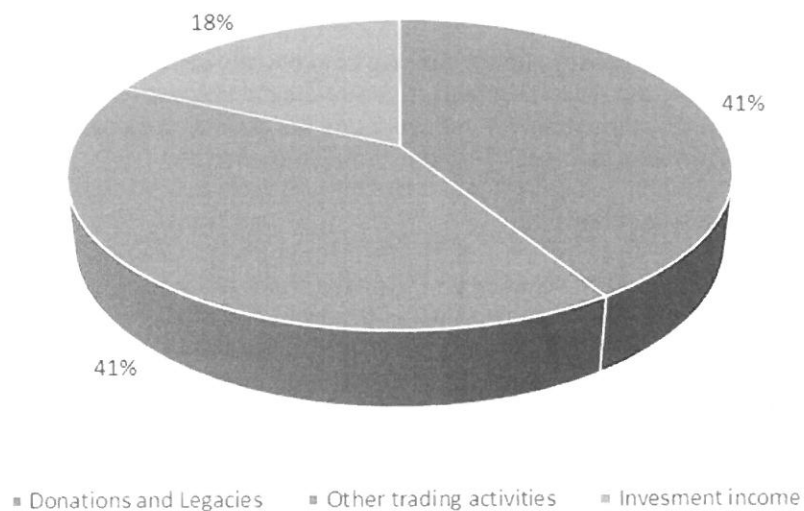
### **How we receive our money:**

Donations and legacies - £184,623

Other trading activities - £183,483

Investment income - £81,029

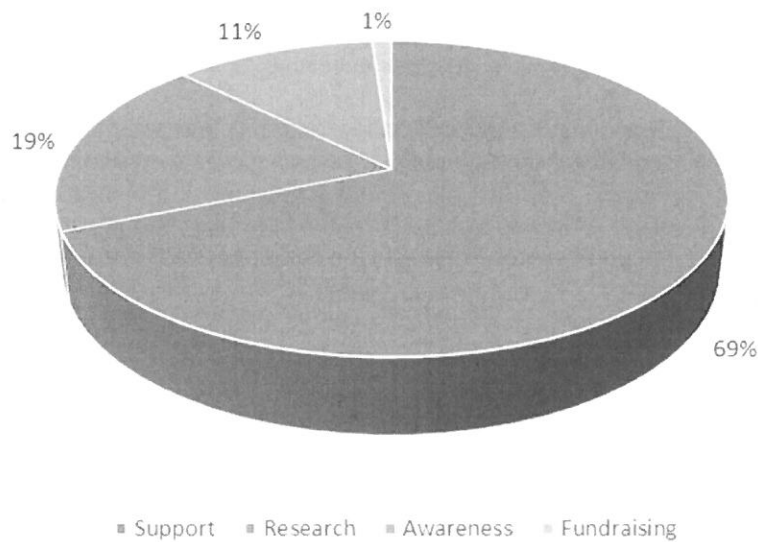
**TOTAL - £449,135**



## **REPORT OF THE TRUSTEES**

### **How we spend our money:**

Support – £725,425  
Research – £195,878  
Awareness – £121,094  
Fundraising – £11,691  
**TOTAL – £1,054,088**



The above data indicates a deficit of just over £0.6 million. While this is a significant shortfall, we have been fortunate to receive several substantial legacies in recent years, which have helped sustain the charity during this period. The Trustees acknowledge that this level of deficit is not sustainable in the long term, and a strategic plan is being developed to reduce the gap between income and expenditure.

### **Support of Members**

Our membership grew significantly during the financial year, increasing by 37.95% to 3,788 members. We welcomed 746 new members, each of whom received a *newly diagnosed support pack*. In January 2024, we transitioned to a lifetime membership model, which contributed to this substantial growth and enabled us to reach and support more individuals affected by myasthenia.

We continue to keep our members informed and connected through quarterly newsletters, which provide news, support, encouragement, and recognition for those who contribute through donations and fundraising. This year, we also brought together specialist myasthenia nurses from across the UK, fostering collaboration and sharing expertise across the sector.

## **REPORT OF THE TRUSTEES**

### **Support of Members - continued**

Throughout the year, we delivered 38 Zoom sessions led by our national support coordinators and Benefits & Welfare Officer. As part of My Awareness Month in June 2024, we hosted two webinars, one led by Dr. Channa Hewamadduma and another by the Myasthenia Specialist Nurses. A third webinar, focusing on the latest findings on lung and bone health, was delivered by our Research & Partnerships Manager.

In total, 1,209 members attended these national Zoom and webinar sessions (an increase of nearly 15% compared to the previous year) accessing peer support, information and friendship.

Our closed, members-only Facebook groups remain a safe and supportive space, with 1,282 members engaging to share experiences, ask questions, and receive guidance.

We provide telephone and email support Monday to Friday, 9am to 5pm, offering advice, information, and a listening ear through our dedicated support team and head office staff.

Our Benefits and Welfare Officer supported 615 members this year, an increase of over 70% from last year. This remarkable growth reflects the compassionate and effective support being provided.

### **Research**

The Research and Partnerships Manager (R&PM) oversaw the continued support of a variety of projects funded by myaware. The R&PM also prepared and pursued the execution of contracts related to funding new projects within the research budget for the financial year 2024-2025. This department also oversaw the advertisement, assessment, and delivery of funding agreements with five myasthenia specialist nurses in the United Kingdom. The details of these projects and contracts are as follows:

#### **Professor Isabel Leite (Oxford): *The Establishment and Use of a UK Database for Myasthenic Disorders:***

At present, the database coordinator is being funded by myaware until September 2025. Dr Ashraghi is working with the coordinator to continue populating the database for this period and then reassess the need for further funding. During this time, myaware will receive a yearly summary.

There are at present 801 patients entered:

- 494 Tier 1
- 35 are Tier 2
- 272 are Tier 3

Diagnosis:

- 781 MG
  - 90% AChR
  - 4.4% MuSK
  - 5.6% Seronegative
- LEMS: 18
- CMS: 2

## **REPORT OF THE TRUSTEES**

### **Research - continued**

- Sex distribution: 51.6% male, 48.4% female.
- Mean age at diagnosis 50 years.
- Mean duration of disease 9.9 years (0-71.65)
- Mean current age 60 years.
- Selected ethnicities: 71.5% White British, 2.4% Indian, 1.8% Black African, 1.8% Black Caribbean, 22.5% Not documented in patient records.

Reassuringly, the demographics of the patients in the registry reflect what we would expect to see in an MG population based on previous studies. This supports the integrity and quality of the data being entered into the database.

Oxford University Hospitals	414
UCLH/NHNN	Actively consenting with plan to enter in bulk.
University Hospitals Birmingham	141
University Hospitals Southampton	15
University Hospitals Sussex	27
Greater Glasgow	67
Imperial College Healthcare NHS Foundation Trust	41
Nottingham University Hospitals	43
Sheffield Teaching Hospitals	28
St George's Hospital NHS Foundation Trust	25
Barts Health NHS Trust	Actively consenting with plan to enter in bulk.
Northern Care Alliance	Actively consenting with plan to enter in bulk.
Swansea Bay University Health Board	Actively consenting with plan to enter in bulk.
Hywel Dda	Actively consenting with plan to enter in bulk.

### **Sites in process of being set up:**

Hull University Teaching Hospital  
 Northampton General Hospital  
 Gloucester Hospitals NHS  
 Royal Cornwall Hospitals  
 Moorefield's Eye Hospital  
 Chelsea and Westminster Hospitals  
 Dartford and Gravesham  
 Alder Hay Children's Hospital

## **REPORT OF THE TRUSTEES**

### **Research - continued**

#### **Dr Katy Dodd (Manchester): *Optimising the Immunosuppressive Management of Myasthenia Gravis:***

With funding from myaware, Dr Dodd, alongside Dr Sussman and immunology experts at the University of Manchester, examined T cells in the blood of patients with acetylcholine receptor antibody-positive myasthenia gravis (AChR-MG). She has found that those who have ongoing symptoms despite immunosuppression treatment have low “regulatory” T cells. Regulatory T cells help to regulate overactive immune responses. This may open further avenues for therapy, as there are several methods used in other autoimmune diseases to “boost” regulatory T cells, which would be worth studying in myasthenia gravis.

AChR antibodies are known to activate the complement system, another component of the immune system. Complement activation is known to cause further disruption at the nerve-muscle junction, but wider effects on the rest of the immune system are less well studied. The team looked at the expression of complement receptors on T cells and showed that these are increased in those who have more active and difficult to treat disease. Further work is needed to better understand how this might further impact upon the immune response. Additionally, following rituximab therapy, those who had the worst response demonstrated persistent elevation of complement receptors on T cells, suggesting that treatments targeting the complement system may have been better suited to those individuals.

There was no difference seen in the expression of “immune checkpoints” on the T cells in the different patient groups. These checkpoints are of interest in myasthenia, as when blocked by certain cancer treatments, a severe form of myasthenia can be triggered. Going forwards Dr Dodd, with collaborators from the Manchester Centre for Cancer Research are collecting blood samples from patients with this new form of myasthenia, to try to better understand it.

This work has been part of a wider project in which Dr Dodd has also studied other immune cell types and markers in AChR-MG, with funding from the NorthCare Charity and the Neuromuscular Study Group. Those with refractory disease have been found to have specific immune changes, including higher proportions of “memory” B cells and certain complement proteins, and lower proportions of dendritic cells. Additionally, there are wider inflammatory immune changes including higher frequencies of monocytes, and high production of inflammatory cytokines from B cells when stimulated.

The work is due to be submitted for publication in the near future but has been presented at national and international medical conferences.

#### **Hayley Ramjattan (Oxford) – *CMS Monitoring:***

This project set out to address the absence of key clinical outcome measures in Congenital Myasthenic Syndromes (CMS). Hayley Ramjattan, a specialist neuromuscular physiotherapist based in Oxford, sought to gain a better understanding of the natural progression of CMS and the different clinical phenotypes. This 2-year study recruited 50 patients and is currently being prepared for publication.

## **REPORT OF THE TRUSTEES**

### **Research - continued**

#### **Professor Isabel Leite (Oxford) - *COVID-19 Vaccine Response in Myasthenia Gravis Patients:***

The funding agreement for this project has now been signed by Oxford University and countersigned by the myaware CEO. Recruitment for an appropriate researcher to undertake this work is underway.

#### **Professor Isabel Leite (Oxford) - *Maternal acetylcholine receptor antibody-associated neonatal disorders: frequency and mechanisms:***

This clinical fellowship is being undertaken by Dr Ezgi Bakircioglu Duman and began in October 2024. Dr Duman has been developing her lab skills and familiarizing herself with the methodologies that will be used for the duration of the DPhil project. These methods include live cell-based assay, radioimmunoassay, and flow cytometry. This is in preparation for the arrival of serum samples from pregnant women with clinical information for their offspring of up to two years of age. It is also planned that Dr Duman will collect serum samples from pregnant mothers with myasthenia gravis at John Radcliffe Hospital to begin characterisation.

#### **Dr Adam Handel (Oxford) – *MyArchive: an irreplaceable resource for myasthenia gravis research:***

Emeritus Professor Nick Willcox built up a store of approximately 6,000 blood and tissue samples from over 2,000 people with myasthenia gravis dating back to 1980. These samples held at the University of Oxford are an irreplaceable and unique resource, which could help provide insight into why people develop myasthenia gravis and how those people respond to treatments.

MyArchive is a proposed method to safeguard the legacy of the donors and make sure that these samples are used in the best possible way to advance research into myasthenia. MyArchive provides access to these samples to research groups who can help to answer key research questions about disease mechanisms and their trends over time.

A panel of researchers based in Oxford coordinates the supply of MyArchive samples to a wide collaborative network to ensure that individual donor's samples are used for those experiments most likely to lead to breakthroughs in our understanding or treatment of myasthenia. MyArchive also promotes and enables excellence in research to best inform people with myasthenia about their condition and identify possible new treatments for the future.

Supporting MyArchive has enabled researchers around the world to benefit from access to an irreplaceable archive of tissues from people with myasthenia.

This has clear benefits to people with myasthenia gravis, since the diverse research projects that would be possible with MyArchive have both basic immunological and translational impact on the care of people with myasthenia gravis. It is likely that these research avenues will cast light on the causes and potentially identify new targets for treatment avenues in myasthenia.

Myaware also honours the legacy of those people with myasthenia gravis, who so kindly donated samples to Emeritus Professor Nick Willcox's team since 1980, and so supporting this archive ensures that their samples are best used to help research in myasthenia gravis.

## **REPORT OF THE TRUSTEES**

### **Research - continued**

MyArchive is now live at the University of Oxford website:

<https://www.ndcn.ox.ac.uk/research/myarchive>

#### **Dr Nicholas Jones (Swansea) – *Interrogating the contribution of adaptive immunometabolism in myasthenia gravis:***

This collaborative project between the University of Swansea and The George Washington University in Washington DC, USA, looks to examine the roll of immune-cell metabolism in myasthenia gravis. Dr Jones' group in Swansea is looking to confirm their hypothesis surrounding targets for potential new treatments for myasthenia gravis that focus on immune-cell metabolism. At present, thirteen samples from myasthenia gravis patients have been received in Swansea after being sent over from Washington. These samples have been run through a substantially optimised flow cytometry panel and the data is in the process of being analysed. It is hoped that this data will identify further therapeutic targets for myasthenia gravis.

#### **Dr Sithara Ramdas (Oxford) – *Future Management of Congenital Myasthenia Syndromes:***

This project looks to tackle delay in diagnosis for patients with congenital myasthenia syndromes (CMS) who present symptoms at birth. This delay can potentially result in death in severe cases and in others the inability to perform day to day activities, affecting their education, careers, and overall physical and mental wellbeing.

Dr Ramdas is looking to develop a pathway to help predict the likely type of CMS in a baby identified through newborn screening. This will help the medical teams manage these patients and apply the appropriate treatment strategy. Dr Ramdas has so far completed analysis of 252 patients from the Oxford CMS database focusing on age of onset and symptoms of onset, delineating those with onset under 2 years of age against over 10 years and over 18 years.

In addition to this, a pilot study will be undertaken to assess if a wearable device will help measure fatigable weakness in CMS patients, which could prove to be a crucial and premier outcome measure for CMS. This is currently in the early stages of design and planning.

Lastly, Dr Ramdas will look at the impact of CMS and disease burden, including economic impact, for CMS patients and their families. This will be crucial information to have for regulatory authorities as they review the cost effectiveness of new treatments and will be part of decision making on including CMS as part of routine national newborn screening programmes in the future. Five questionnaires focusing on quality of life and economic costs will be released to collect this data and approval has been granted by the hospital governance team.

### **Support - Nurses**

#### ***Imperial College Healthcare NHS Trust - Development of an MG thymic subspecialist AHP/nurse:***

This project aims to introduce an Allied Health Professional (AHP) that focuses on post-operative care of thymoma and thymic hyperplasia patients, assisting with the development of a dedicated thymic Multidisciplinary Team in collaboration with Oxford. This dedicated role aims to improve patient care, minimise complications and reduce length of stay, as well as assist with long term follow up procedures.

## **REPORT OF THE TRUSTEES**

### **Support – Nurses - continued**

#### ***University Hospitals Birmingham - Additional specialist nursing support:***

Myaware are helping to fund a new part time specialist nurse at University Hospitals Birmingham. It is hoped that by increasing the specialist nurses resource that this Trust will be able to support with monitoring Rituximab patients and assist with the implementation of a telephone service for patients.

#### ***Salford Royal Hospital, Manchester - Expanding myasthenia care and specialist nurse service:***

This grant will enable the establishment of a helpline for myasthenia patients to access nursing support, create a new immunosuppression initiation clinic, providing dedicated support for patients with questions or who are new to this type of treatment and require blood monitoring. The team at Salford will also use this funding to provide support for patients who are admitted to hospital due to fluctuations or crisis in their myasthenia and provide increased emotional and social support.

#### ***St George's NHS Foundation Trust / Southwest London ICB / Surrey Heartlands ICB – Myasthenia Specialist Nurse:***

This funding ensures the continuation of the current specialist nurse, who supports patients in Southwest London and Surrey and the administration of novel therapeutics at St George's. The myasthenia gravis nurse will act as a point of contact for patients including for relapsing patients which will enable a responsive MG service and rapid assessment and treatment of deteriorating patients.

Working across Southwest London and Surrey, including multiple Trusts and a large geography, the specialist nurse will ensure equity of access to specialist myasthenia care, irrespective of who is seeing the patient in a general neurology service. The specialist nurse will ensure a safe introduction of disease modifying drugs and close blood monitoring in the initial treatment stage and therefore improve patient safety.

With this support, they will be able to counsel patients on side effects of treatments including steroids or steroid sparing agents. Finally, they will accelerate the workup and therefore access of patients to novel disease modifying therapies.

#### ***King's College Hospital NHS Foundation Trust - Training for in-post specialist nurse***

Myaware have provided funding to further the training of an in-post specialist nurse at King's College hospital. The specialist nurse will attend two courses that will cover essential topics such as systemic and structured history-taking assessment and physical examination skills. They will also pursue a course in non-medical prescribing which will also further benefit not only the specialist nurse but their patients.

### **Partnerships**

The research and partnerships manager has continued to engage with external stakeholders, providing insight into educational projects with the Neurology Academy, sitting on the national myasthenia gravis steering group with the Health Innovation Network, and collaborating where appropriate with pharmaceutical companies to elevate the patient voice and unmet needs of the community.

## **REPORT OF THE TRUSTEES**

### **Partnerships - continued**

The research and partnerships manager has delivered an engaging workshop at MG: Connects in Birmingham, partnering with clinical staff around the country to identify better ways the charity can work alongside healthcare professionals. This meeting identified the need to share our patient packs with clinical staff so that myaware resources can be better integrated into the treatment pathway for myasthenia patients around the country.

There has been a successful application for funding from external partner UCB (£41,620.12) which cover the costs of attendance at both Pulse: Live events this coming year, in Newcastle and Glasgow. This funding will also go towards supporting our welfare and support services, ordering merchandise for myasthenia awareness month, and providing an update to our website. Additionally, these activities are also supported by funding from Merck (£17,824) received in the 2025/26 financial year.

### **Awareness**

Raising awareness of myasthenia and related conditions remains a central pillar of myaware's mission. Throughout the year, we have continued to champion greater understanding of myasthenia among healthcare professionals, patients, carers, and the wider public.

Our team has actively participated in a range of national and international events, including the London UCB Patient Day, the EuMGA Summit in Amsterdam, the Association of British Neurologists (ABN) Conference, the NEC, the RCGP Event in Liverpool, and the BJGP Conference. These opportunities have enabled us to share the experiences of those living with myasthenia, promote the latest research, and strengthen relationships with clinicians, researchers, and industry partners.

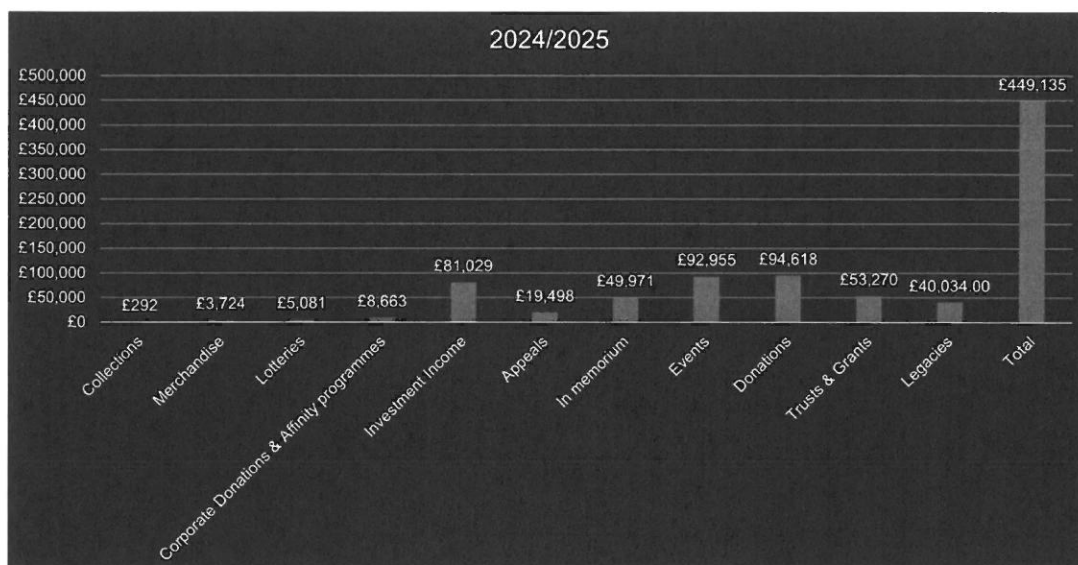
We have also maintained a strong digital presence, with our website and social media channels providing accessible, up-to-date information to a growing audience. Over 118,000 people visited the myaware website this year, with our online resources and support groups continuing to play a vital role in connecting individuals and families affected by myasthenia. Our printed materials, including booklets and leaflets, remain in high demand among both patients and healthcare professionals.

In addition, myaware has continued to represent the myasthenia community through membership of umbrella organisations such as the UK Neurological Alliances, Rare Disease UK, and National Voices. We have supplied information packs for clinicians across the UK and provided targeted resources for both members and the general public.

Our awareness initiatives are supported by the dedication of our staff, volunteers, and partners, whose efforts ensure that myasthenia remains visible and understood within the healthcare sector and beyond. We are grateful for the continued support that enables us to advocate for improved care, earlier diagnosis, and better outcomes for everyone affected by myasthenia.

## REPORT OF THE TRUSTEES

### Review of Income Activities



The Fundraising department recruited a full time Events Fundraiser (in post from October 2024) and a part time Community Fundraiser (in post from September 2024) the positive results of which have begun to show in the 2024~2025 income. Despite the ongoing external challenges of the cost-of-living crisis, we are incredibly grateful to all those who were able to continue to support myaware.

- During the year we were grateful to 9 people who remembered myaware in their wills. Restricted bequests totalled £1,000, and unrestricted bequests totalled £39,034.18.
- Donations have increased by 8.8% since last year to £94,618
- Corporate donations and affinity programmes have raised £8,663 during the period.
- We received £53,270 from trusts and grant giving organisations this year. An increase of 43% since last year. One of the donations for £41,620 was received from the UCB UK biopharmaceutical company as a restricted grant. Other donations ranged from £50 to £2,000.
- Income received via events increased by 124% on the previous year and totalled £92,955. This can be seen as a direct result of a dedicated part time Community Fundraiser and a full time Events Fundraiser being in post from September and October 2024 respectively.
- During this financial year myaware received £49,971 in In Memoriam donations and we are extremely grateful to those who have chosen to remember their loved ones by donating to myaware.
- Our quarterly fundraising appeals have been well received and have increased in income by 65.5% on the previous year to £19,498.

## **REPORT OF THE TRUSTEES**

### **Impact and Value**

Myasthenia means muscle weakness. It affects the muscles that allow voluntary movement, but not the automatic ones like the heart. In myasthenia, the brain's signals to the muscles are disrupted, making everyday activities such as walking, smiling, and talking extremely challenging. When swallowing and breathing are affected, it can become a medical emergency.

Myaware is dedicated to providing accessible support services and reliable information to everyone diagnosed with myasthenia. Recent research now estimates that around 20,000 people in the UK are living with myasthenia, a significant increase from previous figures. As of April 2025, myaware supports nearly 19% of those diagnosed, with active membership rising by 37.95% this year to 3,788 members. Our aim is to continue raising awareness so that everyone diagnosed can access the support they need to live well with myasthenia.

A myasthenia diagnosis can be life-changing. Myaware strives to make life easier for people with myasthenia and their families by:

#### **Accessible information and support online, by telephone, or via email:**

- 38 online Zoom support sessions delivered this year, providing information, advice, and peer connection.
- Three national webinars, including sessions led by specialist nurses and researchers.
- Six secure, closed Facebook groups, including groups for Congenital Myasthenic Syndromes (CMS), Lambert-Eaton Myasthenic Syndromes (LEMS), carers, and young people, providing 24/7 peer support.
- National Facebook, Twitter, and Instagram pages offering information and signposting.
- Telephone and email support available Monday to Friday, 9am–5pm, via our dedicated support and head office teams.
- Benefits and Welfare advice service, with 615 enquiries supported this year, a 70% increase from last year.
- Comprehensive online information for people living with myasthenia, their families, and healthcare professionals via our website, which saw over 118,000 visitors and 1.1 million interactions this year.

#### **Increased awareness among the public and healthcare professionals:**

- A comprehensive website offering accessible information on all aspects of living with myasthenia.
- A range of detailed booklets and leaflets, including resources for rarer myasthenia conditions and for healthcare professionals.
- Newly diagnosed information packs sent to all new members.
- Clinic awareness packs for GP surgeries, neurology clinics, dentists, opticians, and pharmacies.
- Representation of our members' needs at the Neurological Alliance, Rare Disease UK, National Voices, and the annual MG Connects meeting for neurologists.

#### **Commitment to research and clinical training:**

- Responsible funding of research projects in the areas of cause, cure, prevention, treatment, and quality of life.
- Support for the training of clinicians in the field of myasthenia.
- Transparent communication of research outcomes and opportunities to members and stakeholders.

## **REPORT OF THE TRUSTEES**

### **FUTURE DEVELOPMENTS, AMBITIONS AND LONG-TERM STRATEGIES**

As demand for our support continues to grow, myaware is committed to making every penny count and finding fresh, imaginative ways to connect with and support our community. We're focused on building a future where no one affected by myasthenia feels alone or unheard.

Since the pandemic, we've embraced a digitally connected support model, allowing us to reach people wherever they are. Through Zoom, social media, phone, and email, our national support team has been able to offer help, guidance, and community to more individuals than ever before.

Listening to our members is at the heart of everything we do. Our annual member survey, along with quick polls and feedback forms on social media, help shape the services we offer. We're also introducing new ways for people to share their experiences, including short "How did we do?" questionnaires, so we can keep improving and responding to real needs.

We're investing in our website to make it more intuitive, accessible, and informative, ensuring that vital resources are easy to find and available to everyone, including those with additional accessibility needs. This includes ongoing improvements to digital tools that make our content more inclusive.

Looking ahead, we're excited to deepen our relationships with healthcare professionals to help improve diagnosis and treatment pathways. We'll continue to represent our members at national forums such as the Neurological Alliance and Rare Disease UK, ensuring that the voices of people with myasthenia are heard where it matters most.

We remain deeply committed to using our restricted research funding responsibly, supporting projects that explore the causes, treatments, and potential cures for myasthenia, and ultimately, improving the quality of life for everyone affected.

Finally, we continue to uphold the highest standards in data protection, ensuring full compliance with the UK General Data Protection Regulation (2018). You can read our privacy policy here: <https://www.myaware.org/privacy-policy>



## **REPORT OF THE TRUSTEES**

### **REFERENCE AND ADMINISTRATIVE DETAILS**

Myaware is Company Limited by Guarantee.

Registered Company Number in England and Wales: 3038358

Registered Charity Number in England and Wales: 1046443

Registered Charity Number in Scotland: SC044744

#### **Registered Office**

Myaware  
The College Business Centre  
Uttoxeter New Road  
Derby  
DE22 3WZ

#### **Auditors**

Johnson Tidsall Limited  
Chartered Accountants  
81 Burton Road  
Derby  
DE1 1TJ

#### **Solicitors**

Ellis-Fermor & Negus  
2 Devonshire Avenue  
Beeston  
Nottingham  
NG9 1BS

#### **Bankers**

Virgin Money  
11 Smithy Row  
Nottingham  
NG1 3EJ

#### **Interim Chief Executive Officer**

Marc Smith (appointed 30.06.2025)

#### **Trustees**

Trevor Ranson – Chair  
Andrew Robinson – Treasurer  
Professor Bethan Peach  
Jon Rio  
Professor Saiju Jacob  
Rashmi Rungta  
Claire Wen  
Sara Jones (appointed 08.05.2024)  
Tony Ferrari (resigned 08.07.2024)  
Dr Channa Hewamadduma (appointed 24.07.2024)  
Penny Henrion (resigned 15.02.2025)  
Dr Fiona Norwood (resigned 05.06.2025)  
Dr Katy Dodd (appointed 25.07.2025)

More information regarding the Trustees can be found at:

<https://www.myaware.org/pages/faqs/category/meet-the-board>

## **REPORT OF THE TRUSTEES**

### **STRUCTURE, GOVERNANCE & MANAGEMENT**

Myaware is a company limited by guarantee, incorporated on 27<sup>th</sup> March 1995 (number 3038358), a registered charity in England and Wales (number 1046443) and a charity registered in Scotland (number SC044744). It is governed by its Memorandum and Articles of Association adopted on 27<sup>th</sup> March 1995 and amended on 29<sup>th</sup> March 2018.

Subject to the provisions of the Companies Act 2006, the articles and to any directions given by special resolution, the business of the Company is managed by the trustees who may exercise all the powers of the Company. No alteration of the articles and no such direction shall invalidate any prior act of the trustees which would have been valid if that alteration had not been made or that direction had not been given. The powers given by this article and a meeting of trustees at which a quorum is present may exercise all the powers exercisable by the trustees.

The pay and remuneration of the senior managers of myaware is considered annually by the trustees. The board of Trustees meets during the budget setting process to review salary levels, increment payments and inflation rises. The Trustees consider benchmark information relating to similar posts in similar organisations within the charity sector to assist with their decision. We continue to work in partnership with other organisations with shared interest, including Neurological Alliance and Rare Disease UK.

#### **Fundraising and data protection**

Myaware operates within a strict fundraising policy and never uses telephone cold-calling; purchase address lists to write unsolicited letters, share the membership list to third parties or use any other methods or approaches that may be deemed as harassing or pressurising the recipient. We always respect the privacy of those who share their personal information with us.

#### **Recruitment, appointment, induction and training of new Trustees**

Only members of the charity may become Trustees.

The Articles of Association allow the Trustees to appoint candidates to become a Trustee (and Director), either to fill a vacancy, or to strengthen the Board. Candidates become known to the Board through personal knowledge or research of existing Trustees, by interested members of the organisation volunteering their services or, occasionally, as a result of advertising by the Board. Before appointing a new Trustee, the Board will consider any perceived weaknesses in the current Board in terms of special abilities or experience which they believe to be lacking. A potential candidate will then be approached by the Chair. Where possible the candidate will be invited to attend one or more meetings of the Board as a nonvoting observer. The candidate may then be appointed as a Trustee by a formal motion of the Board.

The Chair takes care to ensure that new Trustees receive personal guidance on their responsibilities under the Charity's Articles, and Charity and Company law. They may also seek advice and assistance from the Treasurer and the other members of the Board.

A formal Trustee induction programme is currently being developed by the Interim Chief Executive Officer and the Senior Management Team.

## **REPORT OF THE TRUSTEES**

### **Myaware Sub-committees**

#### **Medical Committee:**

Professor Bethan Peach

Professor Saiju Jacob

Charlotte Campbell – Research & Partnerships Manager

Dr Channa Hewamadduma (appointed July 2024)

Sarah Cuthell (resigned July 2024)

Dr Heidi Harrison (appointed July 2024 and resigned January 2025)

Penny Henrion (resigned February 2025)

Dr Fiona Norwood (resigned June 2025)

Dr Katy Dodd (appointed July 2025)

Marc Smith – Interim Chief Executive Officer (appointed July 2025)

#### **Finance Committee:**

Andrew Robinson – Treasurer

Jon Rio

Rashmi Rungta

Jamie Caple – Accounts & Compliance Manager

Sarah Cuthell (resigned July 2024)

Dr Heidi Harrison (appointed July 2024 and resigned January 2025)

Marc Smith – Interim Chief Executive Officer (appointed July 2025)

The Chief Executive Officer (CEO) is appointed by the Trustees to manage the day-to-day operations of the charity. The CEO reports to the Chair as their line manager.

### **Risk Management**

The organisation conducts an annual risk review to assess and manage potential threats to its operations and objectives. The 2024-25 review was carried out in June 2024 by a committee of Trustees. A further review took place in September 2025, led by the Interim CEO and the Senior Management Team, focusing on major risks across the charity. As a result of these assessments, systems and procedures have been implemented to effectively manage identified risks.

An annual budget proposal, outlining projected income and expenditure, is prepared by the CEO in collaboration with the Finance Committee and submitted to the Trustees for approval. Once agreed, this budget forms the basis for the charity's financial reserves, ensuring that ongoing commitments can be met.

Performance against the approved budget is monitored monthly by the Finance Committee and reviewed quarterly by the full Board. Any significant variances are considered by the Board, and where necessary, adjustments are made to mitigate financial or operational risks.

## **REPORT OF THE TRUSTEES**

### **Financial Review**

#### **Financial Position**

The organisation reported a total net deficit of £615,093 compared with a total net surplus of £130,370 in the previous year.

Unrestricted funds decreased by £374,522 to £1,426,942

Restricted funds decreased by £240,571 to £98,915

#### **Incoming Resources**

Total incoming resources for the year were £449,135 down by £729,265 from the previous year.

This year we received £184,623 in donations, of which £40,034 relates to legacy gifts. We received £1,980 in restricted funds.

Income from other trading activities increased by £63,747 to £183,483.

Investment income has decreased by £5,393 to £81,029.

#### **Resources Expended**

Total resources expended decreased by £14,047 to £1,054,088.

Research costs were decreased by £206,530 on previous year to £195,878 of which £117,229 was restricted.

Support costs were increased by £179,951 on previous year to £725,425 of which £171,652 was restricted.

Awareness costs increased by £13,496 to £121,094 of which £9,731 was restricted.

Fundraising costs were decreased by £964 to £11,691.

Total funds stand as £1,525,857 compared with £2,140,950 last year.

Funds at the year-end were made up of unrestricted funds of £1,426,942 (2024: £1,801,464) and restricted funds of £98,915 (2024: £339,486).

The reported deficit reflects a year of reduced legacy income compared to last year, which had significantly boosted the overall financial result in that year. While overall income declined, core donation levels have shown a modest increase when legacy gifts are excluded, and other trading activity continues to grow.

Restricted expenditure remained high, demonstrating the charity's commitment to delivering on donor intent and ensuring that designated funds are used appropriately. The scale of the deficit highlights the need for continued focus on income generation and cost control going forward.

## **REPORT OF THE TRUSTEES**

### **Contingent Asset**

During the year, the charity remained in contact with the solicitor managing a significant legacy, for which myaware is the sole beneficiary of the residual estate. As in the previous year, the Trustees have been unable to obtain a reliable estimate of the amount due. Accordingly, the legacy continues to be treated as a contingent asset. Further details are provided in note 23 on page 46 of these financial statements.

### **Reserves Policy**

Reserves are held to ensure that planned and committed expenditure over the next five years can be met. Unrestricted funds not invested in tangible and intangible fixed assets (the free reserves) are held to meet a minimum of twelve months budgeted expenditure and to enable the charity to fulfil its planned and committed expenditure over the next five years which are not covered by restricted funds.

As of 31<sup>st</sup> March 2025, the 12 month's budgeted unrestricted expenditure equates to £896,760 and the free reserves, which amount to £1,377,748 leaving a surplus of £480,988 available for future expenditure. The surplus reflects legacies bequeathed. The charity cannot predict its legacy income year on year, and this can vary significantly. The surplus on funds generated is helping to fund our current year.

### **Going Concern**

The Trustees have set a realistic budget for 2025/26, forecasting a net deficit of £474,433 on unrestricted funds. This reflects inflationary cost increases across core activities and a cautious assumption of no legacy income during the year.

Despite the projected deficit, going concern is not considered an issue. The charity continues to operate within its reserves policy, and the Trustees monitor liquidity on a monthly basis. The surplus of unrestricted funds provides a buffer to support operations, and on this basis, the Trustees consider the going concern basis for the preparation of these financial statements to be appropriate.

### **Principal Funding Sources**

The charity benefitted during the year from a number of generous legacies amounting in total to £40,034.

Donations amounted to £94,618. Events fundraising generated £92,955 and In Memoriam donations raised £49,971.

### **Investment Policy and Objectives**

Trustees agree on investments in compliance with the Articles of Association. The return on investment for the year was 4.3% (2024: 4.1%). If the change in value of investments is included, the return is 3.8% (2024: 5.1%). Note that these figures do not include interest earned on bank current accounts – such interest is identified in a line item in the notes to the accounts. The Trustees consider these results to be satisfactory in the current investment climate but aim to keep this under regular review.

## **REPORT OF THE TRUSTEES**

### **Statement of Trustee Responsibilities**

The Trustees (who are also the directors of myaware Company Limited by Guarantee for the purposes of company law) are responsible for preparing the Report of the Trustees and the financial statements in accordance with the applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) including Financial Reporting Standard 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland.

Company law 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 charitable company and of the incoming resources and application resources, including the income and expenditure of the charitable company for that period. In preparing those financial statements, the trustees are required to:

- Select suitable accounting policies and they apply them consistently.
- Observe the methods and principles in the Charity SORP.
- Make judgements and estimates that are reasonable and prudent.
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006, The Charities and Trustees Investment Act (Scotland) 2005 and The Charities Accounts (Scotland) Regulations 2006 (as amended). They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the Trustees are aware:

- There is no relevant audit information of which the charitable company's auditors are unaware; and
- The Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

The report has been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

ON BEHALF OF THE BOARD:

Mr Trevor Ranson, Chair of the Board of Trustees



DATE: 22 October 2025

## REPORT OF THE INDEPENDENT AUDITORS TO THE TRUSTEES AND MEMBERS OF MYAWARE

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### Opinion

We have audited the financial statements of Myaware Company Limited by Guarantee (the 'charitable company') for the year ended 31 March 2025 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2025 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and Regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

### Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

### Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

### Other information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

### Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Report of the Trustees for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Report of the Trustees has been prepared in accordance with applicable legal requirements.

## REPORT OF THE INDEPENDENT AUDITORS TO THE TRUSTEES AND MEMBERS OF MYAWARE

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### **Matters on which we are required to report by exception**

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Report of the Trustees.

We have nothing to report in respect of the following matters where the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 (as amended) requires us to report to you if, in our opinion:

- adequate and proper accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to take advantage of the small companies exemption from the requirement to prepare a Strategic Report or in preparing the Report of the Trustees.

### **Responsibilities of trustees**

As explained more fully in the Statement of Trustees' Responsibilities, the trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

## REPORT OF THE INDEPENDENT AUDITORS TO THE TRUSTEES AND MEMBERS OF MYAWARE

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### **Our responsibilities for the audit of the financial statements**

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

In identifying and assessing the risks of material misstatement in respect of irregularities, including fraud and non-compliance with laws and regulations, we considered the following:

- The nature and control environment of the charitable company
- Our discussions with management and governance including whether they had knowledge of any actual, suspected or alleged fraud
- The internal controls to mitigate the risks of fraud

Following our review, we have identified the following areas which are deemed to have the highest potential for fraud or material misstatement within the financial statements:

- The timing of revenue recognition
- The evaluation of estimates in respect of legacies
- The correct identification of restricted funds
- The timing and recognition of committed expenditure
- The risk of management override

We also considered any laws and regulations that were central to the operation of the charitable company including company law, charity law, employment law and health and safety.

The following procedures were undertaken in respect of the risks where we identified the potential for material misstatement:

Income from donations and legacies was considered a risk due to the volume and nature of these transactions. Income may be pledged but there may be a timing difference between commitment and receipt. The overall income of the charitable company could be materially understated.

Income transaction testing was performed to ensure completeness of income. Post year end donations and legacies were reviewed to ensure that income was recognised in the correct accounting period in accordance with the charitable company's accounting policy.

In respect of legacies, we also tested the accuracy of estimates by reviewing correspondence obtained from solicitors and executors which included the wills and statements of assets and liabilities of the deceased person's estate and where possible agreed to receipts after date.

Restricted funds in respect of income were tested to donor correspondence to ensure that the restrictions imposed were adhered to by the charitable company in expending those funds. This included vouching a sample of expenditure. In addition, we tested unrestricted income mindful of any non-recognition of restricted funds.

## REPORT OF THE INDEPENDENT AUDITORS TO THE TRUSTEES AND MEMBERS OF MYAWARE

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The testing of committed expenditure in relation to grants awarded by the charitable company in respect of research was tested by obtaining copies of the formal grant offer and agreeing the terms to the creditor provision in the financial statements. Trustees' board meeting minutes were reviewed, and all commitments noted in the year were agreed to the financial statements to ensure completeness.

A sample of journal entries were tested for appropriateness and enquiries made of management as to the procedures in place for posting journal entries. During our audit we considered any large, unusual journals or transactions outside the normal course of business which were highlighted as a result of our testing.

We reviewed the minutes of trustees' board meetings and controls put in place by the board of trustees including a review of their risk assessment.

At the planning stage we discussed with management any laws and regulations which were central to the operation of the charitable company.

The financial statements were reviewed alongside our disclosure checklists to identify any unusual or unexpected relationships or any areas of non-compliance. Discussions were held with management where it was considered additional disclosures were required.

We remained alert to any indications of fraud, material misstatement or non-compliance with laws and regulations throughout the audit including those relating to the financial statements.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at [www.frc.org.uk/auditorsresponsibilities](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our Report of the Independent Auditors.

### Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006, and to the charitable company's trustees, as a body, in accordance with Regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members and the trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



David Mello FCA (Senior Statutory Auditor)  
for and on behalf of Johnson Tidsall Limited  
Chartered Accountants  
& Statutory Auditor  
Eligible to act as an auditor in terms of Section 1212 of the Companies Act 2006  
81 Burton Road  
Derby  
Derbyshire  
DE1 1TJ

Date: 22/10/2025

## MYAWARE

### STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT) FOR THE YEAR ENDED 31 MARCH 2025

	Notes	Unrestricted fund £	Restricted funds £	2025 Total funds £	2024 Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>					
Donations and legacies	3	182,643	1,980	184,623	972,242
Other trading activities	4	126,352	57,131	183,483	119,736
Investment income	5	81,029	-	81,029	86,422
<b>Total</b>		<b>390,024</b>	<b>59,111</b>	<b>449,135</b>	<b>1,178,400</b>
<b>EXPENDITURE ON</b>					
Raising funds	6	10,621	1,070	11,691	12,655
<b>Charitable activities</b>					
Research	7	78,649	117,229	195,878	402,408
Support		553,773	171,652	725,425	545,474
Awareness		111,363	9,731	121,094	107,598
<b>Total</b>		<b>754,406</b>	<b>299,682</b>	<b>1,054,088</b>	<b>1,068,135</b>
Net gains on investments		(10,140)	-	(10,140)	20,105
<b>NET INCOME/(EXPENDITURE)</b>		<b>(374,522)</b>	<b>(240,571)</b>	<b>(615,093)</b>	<b>130,370</b>
<b>RECONCILIATION OF FUNDS</b>					
Total funds brought forward		1,801,464	339,486	2,140,950	2,010,580
<b>TOTAL FUNDS CARRIED FORWARD</b>		<b><u>1,426,942</u></b>	<b><u>98,915</u></b>	<b><u>1,525,857</u></b>	<b><u>2,140,950</u></b>

The notes form part of these financial statements

**MYAWARE**  
**COMPANY NUMBER 3038358**  
**BALANCE SHEET**  
**31 MARCH 2025**

	Notes	Unrestricted fund £	Restricted funds £	2025 Total funds £	2024 Total funds £
<b>FIXED ASSETS</b>					
Intangible assets	14	-	-	-	-
Tangible assets	15	6,216	-	6,216	1,501
Investments	16	231,239	-	231,239	241,379
		<u>237,455</u>	<u>-</u>	<u>237,455</u>	<u>242,880</u>
<b>CURRENT ASSETS</b>					
Stocks	17	2,604	-	2,604	4,162
Debtors	18	618,661	-	618,661	838,534
Cash at bank and in hand		580,746	638,048	1,218,794	1,596,255
		<u>1,202,011</u>	<u>638,048</u>	<u>1,840,059</u>	<u>2,438,951</u>
<b>CREDITORS</b>					
Amounts falling due within one year	19	(12,524)	(302,321)	(314,845)	(237,449)
		<u>(12,524)</u>	<u>(302,321)</u>	<u>(314,845)</u>	<u>(237,449)</u>
<b>NET CURRENT ASSETS</b>		<u>1,189,487</u>	<u>335,727</u>	<u>1,525,214</u>	<u>2,201,502</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		<u>1,426,942</u>	<u>335,727</u>	<u>1,762,669</u>	<u>2,444,382</u>
<b>CREDITORS</b>					
Amounts falling due after more than one year	20	-	(236,812)	(236,812)	(303,432)
		<u>-</u>	<u>(236,812)</u>	<u>(236,812)</u>	<u>(303,432)</u>
<b>NET ASSETS</b>		<u>1,426,942</u>	<u>98,915</u>	<u>1,525,857</u>	<u>2,140,950</u>
<b>FUNDS</b>					
Unrestricted funds	21			1,426,942	1,801,464
Restricted funds				98,915	339,486
<b>TOTAL FUNDS</b>				<u>1,525,857</u>	<u>2,140,950</u>

These financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies' regime.

The financial statements were approved by the Board of Trustees and authorised for issue on 22 October 2025 and were signed on its behalf by:



Mr T Ranson - Chair

The notes form part of these financial statements

**MYAWARE****CASH FLOW STATEMENT  
FOR THE YEAR ENDED 31 MARCH 2025**

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	Notes	2025 £	2024 £
<b>Cash flows from operating activities</b>			
Cash generated from operations	1	<u>(451,548)</u>	<u>(522,431)</u>
Net cash used in operating activities		<u>(451,548)</u>	<u>(522,431)</u>
<b>Cash flows from investing activities</b>			
Purchase of tangible fixed assets		(6,942)	(2,000)
Interest received		<u>81,029</u>	<u>86,422</u>
Net cash provided by investing activities		<u>74,087</u>	<u>84,422</u>
<b>Change in cash and cash equivalents in the reporting period</b>		<b>(377,461)</b>	<b>(438,009)</b>
<b>Cash and cash equivalents at the beginning of the reporting period</b>		<u><b>1,596,255</b></u>	<u><b>2,034,264</b></u>
<b>Cash and cash equivalents at the end of the reporting period</b>		<u><b>1,218,794</b></u>	<u><b>1,596,255</b></u>

The notes form part of these financial statements

## MYAWARE

### NOTES TO THE CASH FLOW STATEMENT FOR THE YEAR ENDED 31 MARCH 2025

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#### 1. RECONCILIATION OF NET EXPENDITURE TO NET CASH FLOW FROM OPERATING ACTIVITIES

	2025 £	2024 £
<b>Net income/(expenditure) for the reporting period (as per the Statement of Financial Activities)</b>	<b>(615,093)</b>	130,370
<b>Adjustments for:</b>		
Depreciation charges	2,227	5,264
(Gain)/losses on investments	10,140	(20,105)
Interest received	(81,029)	(86,422)
(Increase)/decrease in stocks	1,558	(676)
(Increase)/decrease in debtors	219,873	(721,827)
Increase/(decrease) in creditors	<u>10,776</u>	<u>170,965</u>
<b>Net cash used in operations</b>	<b><u>(451,548)</u></b>	<b><u>(522,431)</u></b>

#### 2. ANALYSIS OF CHANGES IN NET FUNDS

	At 1/4/24 £	Cash flow £	At 31/3/25 £
<b>Net cash</b>			
Cash at bank and in hand	<u>1,596,255</u>	<u>(377,461)</u>	<u>1,218,794</u>
	<u>1,596,255</u>	<u>(377,461)</u>	<u>1,218,794</u>
<b>Total</b>	<b><u>1,596,255</u></b>	<b><u>(377,461)</u></b>	<b><u>1,218,794</u></b>

The notes form part of these financial statements

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## MYAWARE

### NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2025

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#### 1. STATUTORY INFORMATION

Myaware is a charitable company, registered in England and Wales and Scotland. The charitable company's registered company number, registered charity numbers, registered office address and business address can be found in the reference and administrative details of the Report of the Trustees.

#### 2. ACCOUNTING POLICIES

##### **Basis of preparing the financial statements**

The financial statements of the charitable company, 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 Companies Act 2006. The financial statements have been prepared under the historical cost convention, with the exception of investments which are included at market value, as modified by the revaluation of certain assets.

The currency basis for the preparation of these financial statements is pound sterling (£).

##### **Going concern**

The trustees regularly monitor the charity's reserves policy and risk assessment. A realistic budget for 2025/26 has been prepared. Liquid funds and cash flow are monitored on a monthly basis. To date, no material uncertainties exist that would affect the preparation of the financial statements on a going concern basis.

##### **Significant judgements and estimates**

The following judgements (apart from those involving estimates) have been made in the process of applying the charitable company's accounting policies that have had the most significant effect on amounts recognised in the financial statements:

Legacies - when calculating amounts due on legacies, management considers the wills of the deceased, executors accounts and notifications received from executors. As at 31 March 2025 there is a legacy debtor, included in other debtors, of £569,280.

Grants - when calculating grant commitments, management considers the nature of the grants as being within the charity's objectives and the possible future benefits for people affected by myasthenia.

##### **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.

Donated services and goods are recognised as income when the charity has control over them, the economic benefit is probable and can be measured reliably. In accordance with the Charities SORP (FRS102), the volunteer time of Support Groups is not recognised. Information about their contribution is provided in the Trustees' Annual Report.

For donations to be recognised the charity will have been notified of the amounts and the settlement date. If there are conditions attached to the donation and this requires a level of performance before entitlement can be obtained, then income is deferred until those conditions are fully met or the fulfilment of those conditions is within the control of the charity, and it is probable that they will be fulfilled.

For legacies, entitlement is the earlier of the charity being notified of an impending distribution or the legacy being received. The income is recognised when the value of the legacy can be measured reliably.

Income from trading activities includes income earned from fundraising events and trading activities to raise funds for the charity. Income is received in exchange for supplying goods and services in order to raise funds and is recognised when entitlement has occurred.

Investment income is earned through holding assets for investment purposes such as shares and bank deposit accounts. It includes dividends and interest. It is included when the amount can be measured reliably.

## MYAWARE

### NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2025

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#### 2. ACCOUNTING POLICIES - continued

##### Grants

Government grants are recognised at the fair value of the asset received or receivable when there is reasonable assurance that the charity will comply with conditions attaching to them and the grants will be received using the accrual model.

##### Debtors

Other debtors are recognised at the settlement amount due. Prepayments are valued at the amount prepaid.

##### 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.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

##### Allocation and apportionment of support costs and governance

Resources expended are allocated to the particular activity where the cost relates directly to that activity. However, the cost of overall direction and administration on each activity, including the salary and overhead costs of the general office and regional staff, is apportioned on the following bases which are an estimate, based on staff time, of the amount attributable to each activity:

	Percentage allocation
Research	11%
Support	74%
Awareness	15%

##### Intangible fixed assets

Amortisation is calculated so as to write off the cost of an asset, less its estimated residual value, over the useful economic life of that asset as follows:

Computer software - over 3 years straight line

##### Tangible fixed assets

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

Fixtures and fittings	- 20% on cost
Computer equipment	- 33% on cost

Tangible fixed assets are stated at cost or deemed costs less accumulated depreciation. Cost includes costs directly attributable to making the asset capable of operating as intended.

Individual fixed assets costing £500 or more are capitalised at cost.

##### Investments

Investments are valued at market value which is deemed to be fair value. Movements in market value are reflected in the statement of financial activities as a net gain/(loss).

##### Stocks

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

Stock is valued on a first in first out basis.

##### Taxation

The charity is exempt from corporation tax on its charitable activities.

## MYAWARE

### NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2025

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#### 2. ACCOUNTING POLICIES - continued

##### Fund accounting

The charitable company has both restricted and unrestricted funds. All funds are used to benefit and promote its charitable objects.

Restricted funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose and the restriction means that the funds can only be used for specific projects or activities.

When donors specify that donations and grants are for particular purposes which do not amount to pre-conditions regarding entitlement, this income is included in incoming resources of restricted funds when receivable. The relevant expenditure is then matched as restricted expenditure.

Unrestricted funds are general funds that are available for use at the trustees' discretion in furtherance of any objectives of the charity.

Designated funds are unrestricted funds set aside at the discretion of the trustees for specific purposes.

##### Pension costs and other post-retirement benefits

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

##### Operating lease agreements

Rentals applicable to operating leases where substantially all of the benefits and risks of ownership remain with the lessor are charged to the SOFA on a straight line basis over the period of the lease.

##### Reserves

The charitable company maintains a level of reserves required to fulfil its objectives. The trustees monitor reserves at regular meetings.

##### Financial instruments

Financial instruments are classified and accounted for, according to the substance of the contractual arrangement, as either financial assets, financial liabilities or equity instruments. An equity instrument is any contract that evidences a residual interest in the assets of the company after deducting all of its liabilities.

#### 3. DONATIONS AND LEGACIES

	2025	2024
	£	£
Donations	94,618	86,887
Legacies	40,034	856,054
In Memoriam	49,971	29,301
	<u>184,623</u>	<u>972,242</u>

The charity benefits greatly from the involvement of many helpers and volunteers, details of which are given in our annual report. In accordance with FRS102 and the Charities SORP (FRS102), the economic contribution of volunteers is not recognised in these financial statements.

**MYAWARE**

**NOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 31 MARCH 2025**

<b>4. OTHER TRADING ACTIVITIES</b>		<b>2025</b>	<b>2024</b>
		£	£
Affinity programmes		1,119	2,069
Appeals		19,498	11,782
Collections		292	2,825
Corporate		7,544	4,946
Grants		41,620	31,629
Lotteries		5,081	3,147
National events		23,308	15,063
Regional events		69,647	26,400
Sales of merchandise		3,724	4,375
Trusts		11,650	17,500
		<u>183,483</u>	<u>119,736</u>
<b>5. INVESTMENT INCOME</b>		<b>2025</b>	<b>2024</b>
		£	£
Deposit account interest		69,685	76,693
Current account interest		4,578	3,234
Dividends on shares and other investments		6,766	6,495
		<u>81,029</u>	<u>86,422</u>
<b>6. RAISING FUNDS</b>			
<b>Raising donations and legacies</b>		<b>2025</b>	<b>2024</b>
		£	£
Merchandise		5,129	3,308
Events		4,057	6,454
Appeal mailings		774	1,331
Lottery		1,731	1,562
		<u>11,691</u>	<u>12,655</u>
<b>7. CHARITABLE ACTIVITIES COSTS</b>			
	Direct	Support	Totals
	Costs (see	costs (see	
	note 8)	note 9)	
	£	£	£
Research	176,422	19,456	195,878
Support	594,543	130,882	725,425
Awareness	94,564	26,530	121,094
	<u>865,529</u>	<u>176,868</u>	<u>1,042,397</u>

## MYAWARE

### NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2025

#### 8. DIRECT COSTS OF CHARITABLE ACTIVITIES

	2025 £	2024 £
Staff costs	563,161	520,898
Medical research	114,475	317,424
Medical care	157,331	7,682
Travel and miscellaneous	22,136	28,626
MyNews & member communications	5,884	3,669
Meetings and conferences	2,542	1,094
	<u>865,529</u>	<u>879,393</u>

Grants payable during the year were as follows:

	2025 £	2024 £
Commitments as at 1 April 2024	505,511	356,612
Commitments made in the year	259,123	316,970
Commitments released in the year	-	-
Grants paid during the year	(225,501)	(168,071)
	<u>539,133</u>	<u>505,511</u>

Commitments as at 31 March 2025

#### 9. SUPPORT COSTS

	Management £	Governance costs £	Totals £
Research	17,384	2,072	19,456
Support	116,942	13,940	130,882
Awareness	23,704	2,826	26,530
	<u>158,030</u>	<u>18,838</u>	<u>176,868</u>

Support costs, included in the above, are as follows:

##### Management

	Research £	Support £	Awareness £	2025 Total activities £	2024 Total activities £
Rental of premises	1,653	11,123	2,255	15,031	14,948
Utilities and insurance	1,142	7,678	1,556	10,376	18,391
Office equipment	576	3,877	786	5,239	2,793
Printing, postage and stationery	973	6,543	1,326	8,842	9,603
Photocopier costs	81	546	111	738	825
Support website	2,974	20,008	4,056	27,038	24,964
IT support & software	5,697	38,325	7,769	51,791	53,657
H R costs	2,922	19,656	3,984	26,562	19,281
General expenses	995	6,692	1,356	9,043	5,771
Bank charges	126	846	171	1,143	1,235
Amortisation of intangible fixed assets	-	-	-	-	3,023
Depreciation of tangible fixed assets	245	1,648	334	2,227	2,241
	<u>17,384</u>	<u>116,942</u>	<u>23,704</u>	<u>158,030</u>	<u>156,732</u>

## MYAWARE

### NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2025

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#### 9. SUPPORT COSTS - continued

##### Governance costs

	Research	Support	Awareness	2025 Total activities	2024 Total activities
	£	£	£	£	£
Trustees' expenses	273	1,833	372	2,478	4,537
Auditors' remuneration	1,331	8,954	1,815	12,100	8,810
Legal and professional fees	<u>468</u>	<u>3,153</u>	<u>639</u>	<u>4,260</u>	<u>6,008</u>
	<u>2,072</u>	<u>13,940</u>	<u>2,826</u>	<u>18,838</u>	<u>19,355</u>

#### 10. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	2025	2024
	£	£
Auditors' remuneration	12,100	8,810
Depreciation - owned assets	2,227	2,241
Computer software amortisation	<u>-</u>	<u>3,023</u>

#### 11. TRUSTEES' REMUNERATION AND BENEFITS

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

##### Trustees' expenses

	2025	2024
	£	£
Trustees' expenses	<u>2,478</u>	<u>4,537</u>

During the year 4 trustees (2024: 4) received reimbursement of their expenses for attending meetings totalling £911.

The charge for 2025 includes accommodation, meeting room hire and meals / refreshments for trustee meetings of £1,567 (2024: £1,277).

**MYAWARE**

**NOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 31 MARCH 2025**

**12. STAFF COSTS**

	2025 £	2024 £
Wages and salaries	495,164	456,502
Social security costs	41,408	37,158
Other pension costs	<u>26,589</u>	<u>27,238</u>
	<b><u>563,161</u></b>	<b><u>520,898</u></b>

The average number of full time equivalent employees during the year was 11 (2024:13).

The average monthly number of employees during the year was as follows:

	2025	2024
Fundraising, support and awareness	13	13
Management and operations of the charity	<u>5</u>	<u>4</u>
	<b><u>18</u></b>	<b><u>17</u></b>

Employees receiving emoluments in excess of £60,000.	1	1
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The key management personnel of the charity comprises the Chief Executive Officer. The total employee benefits of the key management personnel of the charity amounted to £77,511 including pension contributions (2024: £74,658).

**13. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES**

	Unrestricted fund £	Restricted funds £	Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>			
Donations and legacies	960,754	11,488	972,242
Other trading activities	93,679	26,057	119,736
Investment income	<u>86,422</u>	<u>-</u>	<u>86,422</u>
<b>Total</b>	1,140,855	37,545	1,178,400
<b>EXPENDITURE ON</b>			
Raising funds	12,655	-	12,655
<b>Charitable activities</b>			
Research	72,893	329,515	402,408
Support	518,476	26,998	545,474
Awareness	106,886	712	107,598
<b>Total</b>	710,910	357,225	1,068,135
Net gains on investments	<u>20,105</u>	<u>-</u>	<u>20,105</u>
<b>NET INCOME/(EXPENDITURE)</b>	450,050	(319,680)	130,370
<b>RECONCILIATION OF FUNDS</b>			
<b>Total funds brought forward</b>	1,351,414	659,166	2,010,580
<b>TOTAL FUNDS CARRIED FORWARD</b>	<b><u>1,801,464</u></b>	<b><u>339,486</u></b>	<b><u>2,140,950</u></b>

**MYAWARE**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 31 MARCH 2025**

**14. INTANGIBLE FIXED ASSETS**

	Computer software £
<b>COST</b>	
At 1 April 2024	95,007
	<u>          </u>
At 31 March 2025	<u>95,007</u>
<b>AMORTISATION</b>	
At 1 April 2024	95,007
Charge for year	-
Eliminated on disposal	<u>-</u>
At 31 March 2025	<u>95,007</u>
<b>NET BOOK VALUE</b>	
At 31 March 2025	<u>          </u>
At 31 March 2024	<u>          </u>

**15. TANGIBLE FIXED ASSETS**

	Fixtures and fittings £	Computer equipment £	Totals £
<b>COST</b>			
At 1 April 2024	5,476	15,507	20,983
Additions	-	6,942	6,942
Disposals	<u>-</u>	<u>(9,433)</u>	<u>(9,433)</u>
At 31 March 2025	<u>5,476</u>	<u>13,016</u>	<u>18,492</u>
<b>DEPRECIATION</b>			
At 1 April 2024	5,476	14,006	19,482
Charge for year	-	2,227	2,227
Eliminated on disposal	<u>-</u>	<u>(9,433)</u>	<u>(9,433)</u>
At 31 March 2025	<u>5,476</u>	<u>6,800</u>	<u>12,276</u>
<b>NET BOOK VALUE</b>			
At 31 March 2025	<u>          </u>	<u>6,216</u>	<u>6,216</u>
At 31 March 2024	<u>          </u>	<u>1,501</u>	<u>1,501</u>

**MYAWARE****NOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 31 MARCH 2025****16. FIXED ASSET INVESTMENTS**

	Listed investments £
<b>MARKET VALUE</b>	
At 1 April 2024	241,379
Revaluations	<u>(10,140)</u>
At 31 March 2025	<u>231,239</u>
<b>NET BOOK VALUE</b>	
At 31 March 2025	<u>231,239</u>
At 31 March 2024	<u>241,379</u>

There were no investment assets outside the UK.

The historical cost of fixed asset investments as at 31 March 2025 was £89,858 (2024: £89,858).

**17. STOCKS**

	2025 £	2024 £
Finished goods	<u>2,604</u>	<u>4,162</u>

**18. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

	2025 £	2024 £
Other debtors	579,917	807,265
Prepayments and accrued income	<u>38,744</u>	<u>31,270</u>
	<u>618,661</u>	<u>838,534</u>

**MYAWARE**

**NOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 31 MARCH 2025**

<b>19. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR</b>	<b>2025</b>	<b>2024</b>
	£	£
Other creditors	1,063	26,007
Committed grants	302,321	202,079
Accruals and deferred income	<u>11,461</u>	<u>9,363</u>
	<u>314,845</u>	<u>237,449</u>

<b>20. CREDITORS: AMOUNTS FALLING DUE AFTER MORE THAN ONE YEAR</b>	<b>2025</b>	<b>2024</b>
	£	£
Committed grants	<u>236,812</u>	<u>303,432</u>

<b>21. MOVEMENT IN FUNDS</b>		Net movement in funds	Transfers between funds	At 31/3/25
	At 1/4/24	in funds	£	£
	£	£		
<b>Unrestricted funds</b>				
General fund	1,801,464	(374,522)	-	1,426,942
<b>Restricted funds</b>				
Research	251,269	(208,454)	-	42,815
Support	67,141	(22,754)	-	44,387
Awareness	<u>21,076</u>	<u>(9,363)</u>	-	<u>11,713</u>
	<u>339,486</u>	<u>(240,571)</u>	-	<u>98,915</u>
<b>TOTAL FUNDS</b>	<u>2,140,950</u>	<u>(615,093)</u>	-	<u>1,525,857</u>

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

	Incoming resources	Resources expended	Gains and losses	Movement in funds
	£	£	£	£
<b>Unrestricted funds</b>				
General fund	390,024	(754,406)	(10,140)	(374,522)
<b>Restricted funds</b>				
Research	10,168	(218,622)	-	(208,454)
Support	46,039	(68,793)	-	(22,754)
Awareness	<u>2,904</u>	<u>(12,267)</u>	-	<u>(9,363)</u>
	<u>59,111</u>	<u>(299,682)</u>	-	<u>(240,571)</u>
<b>TOTAL FUNDS</b>	<u>449,135</u>	<u>(1,054,088)</u>	<u>(10,140)</u>	<u>(615,093)</u>

**MYAWARE**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 31 MARCH 2025**

**21. MOVEMENT IN FUNDS - continued**

**Comparatives for movement in funds**

	At 1/4/23 £	Net movement in funds £	Transfers between funds £	At 31/3/24 £
<b>Unrestricted funds</b>				
General fund	1,351,414	450,050	-	1,801,464
<b>Restricted funds</b>				
Research	563,262	(311,993)	-	251,269
Support	93,758	(26,617)	-	67,141
Awareness	<u>2,146</u>	<u>18,930</u>	<u>-</u>	<u>21,076</u>
	<u>659,166</u>	<u>(319,680)</u>	<u>-</u>	<u>339,486</u>
<b>TOTAL FUNDS</b>	<u><u>2,010,580</u></u>	<u><u>130,370</u></u>	<u><u>-</u></u>	<u><u>2,140,950</u></u>

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

	Incoming resources £	Resources expended £	Gains and losses £	Movement in funds £
<b>Unrestricted funds</b>				
General fund	1,140,855	(710,910)	20,105	450,050
<b>Restricted funds</b>				
Research	17,522	(329,515)	-	(311,993)
Support	381	(26,998)	-	(26,617)
Awareness	<u>19,642</u>	<u>(712)</u>	<u>-</u>	<u>18,930</u>
	<u>37,545</u>	<u>(357,225)</u>	<u>-</u>	<u>(319,680)</u>
<b>TOTAL FUNDS</b>	<u><u>1,178,400</u></u>	<u><u>(1,068,135)</u></u>	<u><u>20,105</u></u>	<u><u>130,370</u></u>

## MYAWARE

### NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2025

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#### 21. MOVEMENT IN FUNDS - continued

##### **Restricted funds**

Restricted funds comprise:

##### **Research**

Restricted funds in this class will be applied to:

- a. Scientific and clinical research into the causes, disease mechanisms, diagnosis and epidemiology of Myasthenia Gravis, Lambert-Eaton Myasthenic Syndrome, Congenital Myasthenic Syndrome and other similar disorders of the Neuro-Muscular Junction.
- b. The provision of equipment and facilities to support (a).
- c. Provision of specialist medical facilities (including staff) where the Trustees consider that such provision has a significant impact on the effectiveness of (a).

##### **Support**

Restricted funds in this class will be applied to:

- d. Development of new support groups of the charity, to foster the health and welfare of myasthenics and their families and carers.
- e. Organisation of Regional Conferences to encourage mutual support between members, myasthenics, and support groups.
- f. In exceptional circumstances - provision of specialist medical facilities (including staff) where the Trustees consider that such provision would have a major impact on the health and welfare of myasthenics, and alternative funding cannot be obtained.

##### **Awareness**

Restricted funds in this class will be applied to:

- g. Preparation, publication and distribution of information about Myasthenia Gravis, Lambert-Eaton Myasthenic Syndrome, Congenital Myasthenic Syndrome and other similar disorders of the Neuro-Muscular Junction. (Including information on their causes, diagnosis and treatment, and issues concerning the lifestyle and quality-of-life of patients with these disorders). Publication and distribution includes development and maintenance of the association's internet websites.
- h. Publicity and promotion of events to foster awareness, in the general public, national and local government, and other bodies, of these disorders, and the problems experienced by patients and their families and carers.
- i. Activities to foster awareness in the medical profession of these disorders, and the problems experienced by patients and their families and carers.
- j. Activities to foster awareness in the medical profession of the current state of best medical practice in the diagnosis and treatment of these disorders.
- k. Regional and national events to disseminate information about these disorders to myasthenics, their families and carers (including information about current and planned future medical and scientific research).

For presentation purposes all restricted income receivable is allocated to one of the above three categories that best describes its restriction.

A detailed breakdown of the income and expenditure allocated to these categories is available on request.

## MYAWARE

### NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2025

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#### 22. EMPLOYEE BENEFIT OBLIGATIONS

The total contribution paid to Personal Pension Plans in the year for certain employees amounted to £24,661 (2024: £25,167).

#### 23. CONTINGENT ASSET

In the previous financial year, the charity was notified of a significant unrestricted legacy of which myaware is the sole beneficiary of the residual estate. Probate was granted on 21 November 2023.

Initial reports indicated that the net estate at date of death amount to £6,953,855, with a residual value to the charity of around £3.5m. The residual value due to myaware is after specific bequests to beneficiaries including property and chattels which are granted free on inheritance tax.

The trustees recognise the charity's entitlement to the legacy but there is uncertainty as to the amount of payment due to myaware in respect of its residual interest in the estate. This uncertainty arises due to:

- No information has been received from the executors' solicitors regarding the expected value of the distribution which would provide us with a reasonable estimate of the residuary amount due to the charity.
- No distributions on account have been received to date.
- The estate at date of death includes a listed shares portfolio of around £5.3m. The timing of the realisation of this portfolio could have significant effect on the value to be distributed.

After due consideration, the trustees are of the opinion that the interest of the charity in this significant residual legacy cannot be measured reliably and therefore should be disclosed as a contingent asset until the criteria for income recognition are met.

#### 24. OTHER FINANCIAL COMMITMENTS

At the year end the charity had financial commitments in respect of rent amounting to £15,764 (2024: £14,049) and other leases amounting to £5,280 (2024: £2,904).

#### 25. RELATED PARTY DISCLOSURES

During the year, the charity did not pay any salary, benefits, or expense reimbursements to an employee who is the spouse of a trustee, of which there were none during the year (2024: £21,585).

#### 26. ULTIMATE CONTROLLING PARTY

The charity is controlled by its Board of Trustees.