



**Myaware Report of the Trustees and Financial  
Statements For The Year 31st March 2022**

## Contents

|                                                   |              |
|---------------------------------------------------|--------------|
| • <b>Chairman's Report</b>                        | <b>1</b>     |
| • <b>CEO's Report</b>                             | <b>2 - 5</b> |
| • <b>Report of the Trustees</b>                   |              |
| • <b>Objectives and Activities of the Charity</b> | <b>6</b>     |
| • <b>Achievement and Performance</b>              | <b>7</b>     |
| • <b>Future Developments</b>                      | <b>14</b>    |
| • <b>Reference and Administrative Details</b>     | <b>15</b>    |
| • <b>Structure Governance and Management</b>      | <b>15</b>    |
| • <b>Financial Review</b>                         | <b>17</b>    |
| • <b>Statement of Trustees Responsibilities</b>   | <b>19</b>    |
| • <b>Report of the Independent Auditors</b>       | <b>20</b>    |
| • <b>Statement of Financial Activities</b>        | <b>24</b>    |
| • <b>Balance Sheet</b>                            | <b>25</b>    |
| • <b>Cash Flow Statement</b>                      | <b>26</b>    |
| • <b>Notes to the Cash Flow Statement</b>         | <b>27</b>    |
| • <b>Notes to the Financial Statement</b>         | <b>28</b>    |
| • <b>Detailed Statement of Financial Accounts</b> | <b>42</b>    |

### Chairman's Report – Trevor Ranson



At the start of this financial year, we had experienced twelve months of living with the effects of the Coronavirus pandemic and the continued inability to provide our previous face to face support services and awareness raising activities. This resulted in a drastic reduction in workload within the organisation, which subsequently resulted in placing 35% of our staff on furlough leave whilst utilising the Government's Coronavirus job retention scheme (CJRS). After five months of continued reduction in workload, the time had come to consider the long-term adjustments that would be necessary to ensure sustainability for the future of myaware and security of support services for our members.

After much deliberation, in July 2021 myaware implemented a new structure of operation. It was at this point that four members of the myaware team took voluntary redundancy. I would like to extend my heartfelt thanks to those members of staff and our remaining team for their long-standing dedication and support of our members and fundraising supporters.

The new operational structure has resulted in a step away from our previous 'regional' approach to support service delivery and now focuses on a national approach. Since July 2021 myaware's three National Support Co-ordinators and head office team have extended a listening ear, delivered information and signposted all of our members via telephone, online Zoom sessions and social media. Our benefits and welfare advice and emotional support services were unaffected and continue to be provided via telephone and Skype.

Our previous fundraising structure relied on fundraising events and activities out in the community which also proved to be non-existent or difficult throughout the first year of the pandemic and well into the second year. Following necessary changes to ensure effective and safe fundraising, our regional fundraisers became focused on specific types of fundraising, such as individual giving, events and applications to trusts and grant giving organisations on a national level. Despite the unknown and difficult times which we have all been through, myaware is exceptionally grateful to those donors and supporters who have continued to give what they can and continued to find new and creative ways in which to raise vital funds. Your help and support have kept myaware afloat during the most exceptional times in recent history.

I am delighted to report that despite necessary changes to our remote delivery of support services, they have thrived this year. Myaware has delivered 27 Zoom sessions which have benefited 620 myaware members. These sessions have included updates on myaware funded research projects, drop-in sessions for general chat. Discussion sessions on frequently asked questions and myasthenia subjects, monthly new member sessions. Myaware has also delivered Zoom sessions dedicated specifically to the different types of myasthenia and age categories, which demand information on more specific subjects such as education, employment and pregnancy but to name a few.

As many people turn to social media and web to find the information and networks required to live well with myasthenia, our social media closed groups and information pages continue to thrive and provide essential peer support and vital lifeline.

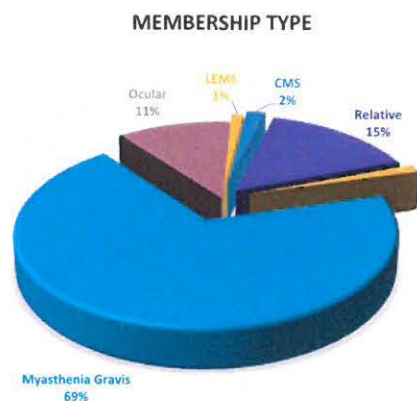
## CEO's Report – Sarah Cuthell



It is estimated that there are approximately 12,000 people living with myasthenia in the UK, at the end of March 2022 myaware had 2775 active members, a reduction of 3% for the same period last year. During this financial year 644 new members have signed up to myaware membership. This clearly identifies that myaware continues to struggle to retain members who have thankfully traversed through the difficult first year of diagnosis and stabilised to such a degree that urgent support is no longer required and so myaware will be concentrating on improving our services for every day living with myasthenia.

Myaware provides support to individuals across the UK, the following data is for members in each of the devolved nations:

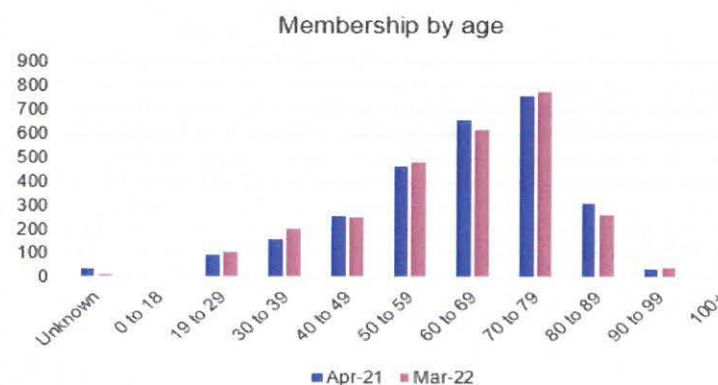
- England – 83%
- Northern Ireland – 3%
- Scotland – 9%
- Wales – 5%



Furthermore, our year end data clearly shows that the majority of our members (69%) have been diagnosed with general myasthenia and 15% of our membership are relatives of those who have been diagnosed with any type of myasthenia.

There have been no radical changes to the age demographic of our members during this financial year:

- 11% of members are aged between 18 and 39
- 49% of members are aged between 40 and 69
- 39% of members are aged over 70
- 1% of members have not shared their age



However, our member survey conducted in December 21 and January 22 shows that the average diagnosis age regardless of type is 53 years old.

## CEO's Report

### Myaware national support services

Myaware members benefit from our range of online and telephone support and information services which guide individuals and their family members through diagnosis and beyond. Since March 2020, myaware has been unable to provide our previous face to face support such as local support groups and annual region conferences due to the risks associated with Covid-19 for our members who are immunocompromised.

### Connecting our members online

#### • Zoom sessions

This year we have delivered 27 online Zoom sessions bringing our members together to discuss common issues and share valuable experience. Our highly experienced National Support Co-ordinators and our Benefits and Welfare Officer have delivered positive and empathetic updates regarding support, awareness and research and imparted vital information on how to live well with myasthenia. We are delighted that over 620 members have attended these Zoom sessions throughout the year and benefited from information and peer support. Myaware provides a monthly Zoom session for members who are new to the condition and to our organisation. Our aim is to remove any sense of isolation by guiding newly diagnosed members through the first few months and connecting them with others who find themselves in a similar set of circumstances.

*"I am writing to thank you for running the Zoom session for new members. I found it a very useful and interesting experience. The follow-up email has a lot of helpful detail and I thank you for that, too. I have been very impressed by the range of information and help which myaware offers. Thank you."*

Our other Zoom sessions include updates and presentations regarding myaware funded research projects. Discussions regarding first aid, medications and treatments, and collaboration with other support organisations like Age UK. Our regular drop-in sessions are for those who simply wish to have a chat and connect with fellow members.

*"I joined the Zoom research session last night - fascinating and so exciting and a really worthwhile research project."*

#### • Peer support network via social media

Myaware facilitates and manages three national Facebook closed groups and this year we have connected 771 people living with myasthenia and their family members. These groups provide a vital 24/7 lifeline of peer support and a platform for myaware to share updates and answer common questions. Our national peer support closed group caters for all members regardless of type of myasthenia, age, or location. Our myaware kids closed group is especially for parents of children who have been diagnosed with any form of myasthenia and our Young Generation closed group provided a platform for those aged between 18 and 39 where discussion can focus around education, employment or pregnancy and myasthenia.

*"I know how overwhelming and daunting it can be, so anyone on this thread please message me if you want to. I got so much strength from the wonderful support network on here so want to pay it forward xx."*

## CEO's Report

### Telephone support and information

Accessing services online can be difficult for some and so our team are available Monday to Friday 9am to 5pm by telephone. Whether members have a burning question or simply need to chat or want to know more about myaware objectives or services, our dedicated Head Office and Support Team members are here to help inform and guide our members.

“Thank you so much for listening and understanding my situation, frustration etc. I am generally a very private person and surprised myself that I have chatted about ‘things’ like I have. Your total understanding is exactly what I need at this time.”

### Website information and signposting

The myaware website; [www.myaware.org](http://www.myaware.org) exists to provide an online library of information about the organisation and our objectives, the different types of myasthenia and vital information about how to live well with myasthenia. During the course of the year, we have had over 151,000 visitors to the website. The pages most visited include information on ‘drugs to avoid,’ ‘extraocular muscles’ and Pyridostigmine information’.

Myaware utilises our website to showcase our members blogs so that others can feel reassured that they are not alone. Our ‘Coronavirus’ page has informed our members of key support available during the pandemic both from myaware and external support organisations and the government. Our ‘benefits and welfare’ page has informed our members of what they are eligible for and ways in which to make life with myasthenia easier, via hidden disability lanyards, RADAR keys for disabled toilets and assistance on public transport.

Our website hosts ReachDesk toolbar which ensures that our visitors can access our content in a way that suits them best. Including text-to-speech, reading and translation support.

### Emotional support service

People have many reactions to myasthenia. Our members may have strong reactions to changes to their body or be anxious about treatment. Some people find it difficult to cope with the feeling of loss of control. It can help to talk through any of these issues and feelings with someone outside of their friends and family. Members of myaware can access our confidential one-to-one counselling service, delivered via our accredited counsellor who have many years of experience with people with long-term conditions.

Our emotional support service provides a confidential counselling service by telephone or Skype to members of myaware and their immediate family and carers.

This service allows our members to discuss anything that is worrying them emotionally in complete confidence and without judgement. One of the key triggers of myasthenia is stress and often talking things through is a great way to alleviate stress.

This year the demand for emotional support has increased by 43% compared to last year and myaware has provided 191 counselling sessions to meet this demand.

## CEO's Report

### Benefits and welfare advice service

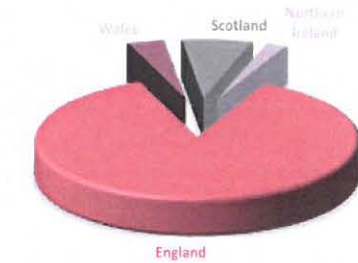
The benefits system is complex, and the rules often change and when living with an unpredictable and sometimes debilitating condition like myasthenia, it can be difficult to find the energy and time to fully research every opportunity to improve your quality of life. Myaware’s dedicated benefits and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

#### BENEFITS & WELFARE ENQUIRIES

This year myaware has responded to 295 benefits and welfare enquiries. Amongst these were:

- 41 driving & myasthenia enquiries
- 59 employment and myasthenia enquiries
- 75 Personal Independence Payment enquiries
- 22 Attendance Allowance enquiries
- 21 Blue Badge enquiries

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



“I would just like to take this opportunity to thank myaware for your invaluable advice throughout my PIP claim. My advice to others is don’t forget to get all the advice you can from myaware.”

### Myasthenia Literature Library

For those who prefer to learn about myasthenia in hard copy print, myaware provides a vast library of information booklets, leaflets, and fliers for those living with myasthenia and healthcare professionals, including the following:

| Information booklets                                |                                                           |
|-----------------------------------------------------|-----------------------------------------------------------|
| A medical Guide for Patients with Myasthenia Gravis | Ocular Myasthenia – a guide for the medical professionals |
| A medical Guide for Patients with LEMS              | Myasthenia and pregnancy factsheet                        |
| Myasthenia for Complete Beginners                   | Who am I? Booklet (myasthenia simplified)                 |
| Congenital Myasthenia – a guide                     | Variety of flyers promoting myaware services              |
| Ocular Myasthenia – a guide for patients            |                                                           |

Myaware regularly provide large print version for members with visual impairments.

Myasthenia is a rare condition, and it is therefore very important that we raise vital awareness amongst healthcare professionals. Due to grants from trusts and grant giving organisations, we have been able to provide clinical awareness packs to GP surgeries, pharmacists, dentists, ophthalmologists and neurology clinics.

**REPORT OF THE TRUSTEES**

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 March 2022 which are also prepared to meet requirements of the directors' reports and accounts for the Companies Act purposes.

The financial statements comply with the Charities Act 2011, The Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Articles of Association and Accounting and reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

**OBJECTIVES AND ACTIVITIES OF THE CHARITY**

We support people affected by myasthenia and related conditions, raise awareness about the conditions and fund research to find new therapies to reduce their impact and ultimately find a cure.

**We provide the following core support services:**

- Support and information sessions delivered via Zoom covering research information, general support discussion and benefits and welfare advice
- Monthly new members support sessions via Zoom
- Zoom sessions for condition type and age specific to support to children up to the age of 18 and young people between the ages of 18 and 39.
- Information and support via the myaware website
- Our social media services include closed, secure groups for peer support and pages for information and signposting
- Skype/Telephone counselling service
- Telephone and online welfare and benefits advice service

**We raise vital awareness of myasthenia in the following ways:**

- We represent our members via membership of umbrella organisations such as UK Neurological Alliances, Rare Disease UK and National Voices
- Myaware provides specific information for our members and the general public via our website
- Myaware provides information packs for clinicians throughout the UK

**Myaware is committed to effectively and responsibly funding research projects in the following areas:**

Cause, Cure, Prevention, Treatment and Quality of life, in relation to myasthenia and related conditions.

- Myaware is committed to training clinicians of the future in the field of myasthenia.
- Myaware is committed to effectively communicating research project outcomes and future research opportunities with transparency to our members and general stake holders.

To support these aims we undertake fundraising activities and as always are hugely grateful to the many people who have supported us financially and of course our team of volunteers who support us with support and fundraising activities. As always, the challenge is to raise more unrestricted funds that can be used to finance the day to day running of the charity – postage, telephone, printing, on-line services and other core costs and we are particularly grateful to those who donate money that can be used 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 objective and activities.

Grants are awarded by the Board of Trustees when funds become available, and only when the reserves position of the charity mitigates the risk committing funds to projects running across several years.

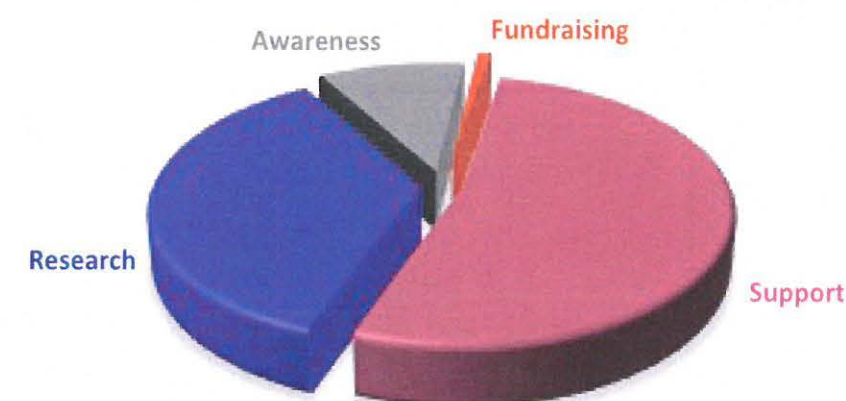
Research grants are awarded following a rigorous peer review process under the control and supervision of the myaware Medical Committee.

**Public Benefit**

The charitable company has referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing its aims and objectives and in planning its future activities. In particular, the trustees always consider how planned activities will contribute to the aims and objectives they have set.

**ACHIEVEMENT AND PERFORMANCE****How we spend our money**

|             |          |
|-------------|----------|
| Support     | £540,833 |
| Research    | £366,588 |
| Awareness   | £105,233 |
| Fundraising | £9,499   |

**HOW WE DID 21/22**

## REPORT OF THE TRUSTEES

## Support of Members

- Our membership reduced by 3% to 2,775 during the financial year. Our data shows that we have welcomed 644 new members during the year, all of whom have received a 'newly diagnosed support pack'. The reduction in general membership numbers shows that we have a great opportunity to improve our services for members who find themselves in a positive and stable situation by providing more appealing and relevant support for ongoing life with myasthenia.
- Last financial year our support costs reduced by 11% due to inability to deliver face to face support services. This year our support costs have reduced again by 15% as a result of reorganising the organisation to deliver national telephone and online services.
- Newsletters continue to be sent to our members quarterly, providing news, support, encouragement and acknowledgement to those who have supported myaware via donations and fundraising initiatives.
- Our Young Generation members who are aged 18-39, benefited from support Zoom sessions in September 2021.
- Myaware provided two Zoom sessions focused on Congenital Myasthenic Syndrome. These sessions covered subjects relating to physiotherapy, research and treatments and benefited 32 of 52 members who have a CMS diagnosis.
- 456 members attended national Zoom sessions to access peer support, information and friendship
- 164 members attended monthly new member Zoom sessions for an introduction to myaware and an opportunity to meet other newly diagnosed members.
- Over 771 people used the carefully moderated myaware member only closed Facebook groups, which provide a safe platform on which to share thoughts, concerns and experiences and receive information and support
- Telephone and email support are provided Monday to Friday, 9am to 5pm for members who need advice, information or someone to talk to. This service is delivered by our dedicated support team and head office staff
- Benefits and Welfare advice was effectively and empathetically delivered to 295 members
- The myaware Counsellor is available by Skype or 'phone to help members with the emotional impact of living with a long-term condition – this service has delivered 191 counselling sessions, helping our members to prioritise their mental health.

## REPORT OF THE TRUSTEES

## Research

During this financial year myaware has funded five main research projects relating to myasthenia and the board are currently in the process of reviewing a further three future projects:

The Covid - 19 pandemic has seriously impacted on all research in the United Kingdom with many of our researchers having their immediate focus on helping the NHS to fight the pandemic. However, the situation is slowly returning to normal and research projects are beginning to start up again.

Deep Phenotyping Study

Professor Paul Maddison, Prof Sarosh Irani, Dr Phil Ambrose (Nottingham and Oxford University Hospitals NHS Trust).

Dr Ambrose took 15 months away from his research to return to Nottingham NHS during the pandemic; he returned to his fellowship in the summer of 2021. Dr Ambrose writes:

*We have been continuing to follow the journey of patients with myasthenia gravis from first diagnosis since 2014 and now have follow-up data on over 200 patients at 3 years into their diagnosis and around 50 patients over 5 years into their diagnosis. The pandemic has made it hard to get some of the blood samples that we were collecting so a few safely planned home visits have had to be made to continue the banking of blood samples throughout the patients' journeys. We have been looking at immune system pathways that might tell us if the immune system is regulated differently in myasthenia gravis compared to people without the illness. There is also new work which aims to find new ways to isolate the specific immune cells (B cells) that might be causing production of antibodies in myasthenia gravis. This work will help us understand more about the disease-causing B cells and what the development process is leading to the formation of the antibodies.*

**Dr Sui Wong (Moorfields Eye Hospital NHS Foundation Trust).**

Dr Sui Wong has been involved in two myaware-funded projects

Prognostic outcomes of Ocular Myasthenia Gravis: Dr Wong is preparing the data for analysis on the long term (i.e., greater than 2 years) outcome of people with Ocular Myasthenia Gravis (OMG), looking to see how many go on to develop Generalised Myasthenia Gravis. She has initiated a Systematic Review on the characteristics of OMG, in line with the recent TRIPOD (transparent reporting of a multivariable prediction model for individual prognosis or diagnosis) reporting guidelines. This will help identify risk factors which can be assessed by testing in a prediction model designed to determine the risk of developing Generalised Myasthenia Gravis in people who first develop ocular (only) symptoms.

Understanding the pathophysiology of Ocular Myasthenia Gravis through Video Oculography:

Visual Oculography is a non-invasive, video-based method of quantifying movements of the eyes (eye tracking) using a head-mounted mask equipped with small camera. Classifying the subtypes of OMG according to eye movement deficit and antibody levels can begin to shed light on differences which will be relevant to both clinical outcome of the disease and the possibility of more targeted treatments. Dr Wong reports that pleasingly the recruitment targets were reached despite the challenges of COVID - 19. The very complex data collected is now being prepared for analysis, which will take a few months.

National Myasthenia Database (Dr Mohammed Ashraghi (University of Oxford):

This project is a myaware-funded research fellow and is working on the national database for patients with myasthenia, in conjunction with Dr Isabel Leite. Over the summer you may have "met", Dr Ashraghi as he spoke at several virtual myaware meetings describing the project and answering member's questions, which was found to be very helpful and informative. The database is now fully functional and security protocols are now in place to ensure the data security. Currently this is being reviewed by an independent assessor. Once completed and any queries satisfied, the paperwork will be submitted to the health research authority and research ethics committee for final approval. We hope this will not take too long and data collection should start very soon.

## REPORT OF THE TRUSTEES

**Developing antigen specific Immunotherapy in Myasthenia Gravis (Dr Pyae Phyo San - University of Birmingham)**

Dr Pyae Phyo San commenced a myaware-funded Clinical Research Fellowship in August 2021 under the supervision of Professors David Wraith and Saju Jacob, and so is just starting the research journey. The project "Developing Antigen Specific Immunotherapy in Myasthenia Gravis" is funded for three years.

Dr San is currently learning all the laboratory techniques and protocols required. This project will be one of the first studies in Myasthenia to explore the use of disease-specific immunotherapy, which will minimise the potential side effects of currently used non-specific immunosuppressive medications and should yield very exciting results in the future. As well as carrying out the research, Dr San has started seeing myasthenia gravis outpatients twice a week at Queen Elizabeth Hospital Birmingham.

In addition to these five ongoing projects, myaware has also agreed to fund two other smaller projects.

Myaware have agreed to fund a study (subject to contract) which will investigate the effectiveness of the Covid - 19 vaccinations in patients with myasthenia in Oxford. This project will look in detail at the magnitude and duration of the immune response to the vaccine including antibody and T cell responses and should provide invaluable information on the effectiveness of the vaccine protocol in patients with immunosuppressed myasthenia patients. We will share more details on this project in due course.

Finally, a small grant has been made available to Dr Katy Dodds (University of Manchester), working with Dr J Sussman, to enable her to carry out a side project in her main PhD project looking at how the effects of immune checkpoint and complement regulators on T cells differ in patients with myasthenia gravis. Immune checkpoint regulators are control points in the regulation of the immune system and are crucial for self-tolerance and help prevent the immune system from attacking cells indiscriminately. Information on these molecules should help physicians to predict a way to optimise treatment protocols for individual patients.

As always, myaware is only able to fund all these exciting and extremely important projects through the generosity of our members and their families. All the clinicians, scientists and fellows involved in the myaware research programme have asked us to pass on their heartfelt thanks to everyone who has helped fund this invaluable research.

## REPORT OF THE TRUSTEES

**Awareness**

Myaware continues to work with umbrella organisations such as Neurological Alliance and Rare Disease UK to ensure that our member's views and needs are presented. This year our Rare Disease Day appeal in February 2021 raised £4,545. This appeal raised the awareness of the challenges faced by carers of those living with myasthenia and shared the story of Georgina who cares for her husband Peter.

Myaware continues to raise awareness of the myasthenia's amongst healthcare professionals by providing information packs to GP and neurology clinics across the UK as well as ophthalmologists, dentists and pharmacists with the aim of reducing diagnosis time.

This year we reviewed the structure of our website, simplifying menu options and page contents to improve the web user journey. We continue to review all medical content and improve the user journey further. We have implemented a brand-new fundraising subsite, giving valuable instant support to our donors and fundraisers.

**Website performance**

|                                            | 2020/2021                                                                                                                                   | 2021/2022                                                                                                                               |
|--------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------|
| Visitors to the website:                   | 157,717                                                                                                                                     | 151,229                                                                                                                                 |
| Pages most visited:                        | <ul style="list-style-type: none"> <li>• Drugs to avoid</li> <li>• Pyridostigmine information</li> <li>• Coronavirus information</li> </ul> | <ul style="list-style-type: none"> <li>• Drugs to avoid</li> <li>• Extraocular muscles</li> <li>• Pyridostigmine information</li> </ul> |
| Averages session length                    | 1.41 seconds                                                                                                                                | 1.46 seconds                                                                                                                            |
| Bounce back rate:                          | 74.09%                                                                                                                                      | 72.65%                                                                                                                                  |
| Number of pages viewed during each session | 2.02                                                                                                                                        | 2.12                                                                                                                                    |

Myaware offers an all-in-one digital inclusion solution called Reachdeck across our whole website. It helps us to ensure that our online content is accessible and usable to everyone by:

- Improving the accessibility, readability and reach of our online content
- Protecting our communications, content and reputation
- Empowering our whole team to communicate with confidence

Reachdeck allows all of our web visitors to translate all content in over 100 languages, with the option to request read aloud content, increase or reduce text size and change font and background and text colours to increase readability for those who are visually impaired.

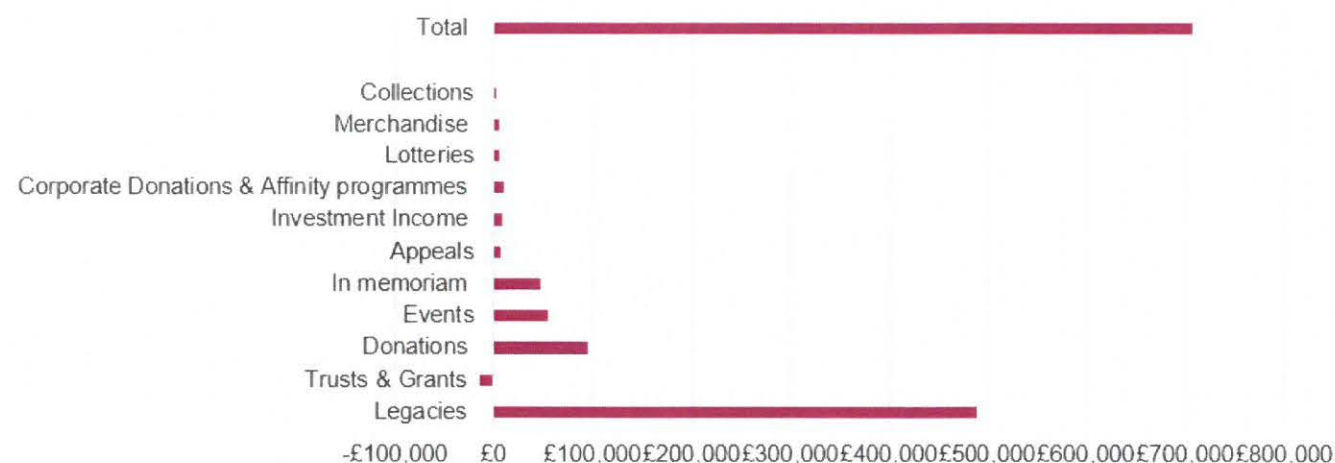
In December 2021 myaware engaged our members in a survey regarding living with myasthenia. We received over 900 responses via post and Survey Monkey. This survey data was then used to update and educate neurologists and clinicians from all over the UK at MG Connects, a national myasthenia conference for healthcare professionals.

Unfortunately, we were unable to hold 'My Awareness Month' in May 2021 due to the impacts of the pandemic on our service delivery and staff. We look forward to reinstating this in May 2023. However, our appeal in the month of May 21 raised £1,105. This raised awareness of the impacts of the pandemic on those living with myasthenia including feelings of vulnerability, isolation and the risk of job loss impacts on household finances.

## REPORT OF THE TRUSTEES

## Review of Fundraising Activities

## How we raised the money



## Total £706,904

The second year of the pandemic continued to pose challenges to our supporters, most of who are living with myasthenia or are relatives or friends of. Extra consideration has been required to protect those who are vulnerable against the Covid-19 virus, making face to face fundraising an ongoing challenge.

- Despite these challenges we are very grateful to all those who were able to continue to support myaware.
- During the year we were grateful to 22 people who remembered myaware in their wills. These bequests total £490,115
- Donations have increased by 14% since last year to £95,583.
- Corporate donations and affinity programmes have raised £9229 during the period.
- We received £40,123 from trusts and grant giving organisation this year. However, post pandemic we were forced to return a total of £53,847 to trusts who had restricted their grants to face to face activity in the year previous (20/21). This was due to myaware's ongoing inability to deliver face to face support services post pandemic.
- Income received via events increased by 20% in the previous year and totalled £54,719. This income is a direct result of myaware's dedicated supporters who took part in virtual runs and other events despite the challenges of the pandemic.
- During this financial year myaware received £46,050 in In Memoriam donations and we are extremely grateful to those who have chosen to remember their loved ones by donating to myaware.

## REPORT OF THE TRUSTEES

## Impact and Value

Myasthenia means muscle weakness. It affects the muscles that let you move but not the automatic ones like your heart that you don't have to think about. Your brain tells your muscles to work, but the message doesn't get through. Symptoms of myasthenia include muscle weakness which makes day to day activities like walking, smiling and talking very difficult. When swallowing and breathing are affected, this can lead to a medical emergency.

Myaware works tirelessly to provide accessible support services and information to everyone who receives a myasthenia diagnosis. We think there are approximately 12,000 people in the UK with myasthenia but there are currently no accurate published figures. Myaware supports approximately 25% of those who have received a myasthenia diagnosis and our aim is to raise more awareness to ensure that everyone who receives a diagnosis can access the support that they need to live well with myasthenia.

A myasthenia diagnosis can be life changing and we aim to make life easier for these people and their families in the following ways:

- Accessible information and support online, on the telephone or via skype
  - 27 online support get-togethers this year providing support, information and advice
  - Three secure Facebook closed groups providing 24/7 online peer support and advice
  - National Facebook, Twitter and Instagram pages offering information and signposting
  - Telephone support via our support and head office teams
  - Skype/telephone counselling service
  - Benefits and Welfare advice service
  - Online information for people living with myasthenia their family members and healthcare professionals via our website
- Increased awareness amongst the public and healthcare professionals
  - Vast website offering accessible information on all aspects of living with myasthenia
  - A range of detailed information booklets on myasthenia, it's symptoms and treatments
  - Newly diagnosed information packs
  - Clinic awareness packs for GP surgeries, neurology clinics, dentists, optician and pharmacies
  - Representation of our members needs at Neurological Alliance and Rare Disease UK
- Myaware is committed to effectively and responsibly funding research projects in the following areas:
  - Cause
  - Cure
  - Prevention
  - Treatment

Myaware is also committed to training clinicians of the future in the field of myasthenia and effectively communicating outcomes regarding current and future research opportunities with transparency.

## REPORT OF THE TRUSTEES

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

Meeting increasing demands of support from people affected by myasthenia requires the charity to maintain its tight focus on cost control.

During the financial year myaware has been continuing to work hard to comply with the General Data Protection Regulations (GDPR).

In light of pandemic impacts on face-to-face support delivery, myaware has reorganised the structure of our support delivery. We now provide a nationally focused support team who deliver support via online platforms such as Zoom, social media and Telephone.

Myaware is committed to seeking member feedback regarding if and when to resume face-to-face support and shared a myaware member survey in December 2021 to assist with future services strategy.

Myaware will continue to develop the support and information provided via our website and social media pages and groups.

Myaware aims to improve the awareness of our personal wellbeing services such as counselling and benefits & welfare advice to ensure our members are able to access with ease.

Myaware will continue to be committed to effective communication and engagement with our members.

Myaware will increase its work relating to raising awareness with healthcare professionals to improve accurate and timely diagnosis.

Myaware continues to be committed to representing our members at national forums such as Neurological Alliance and Rare Disease and to feedback updates and outcomes to our members.

Myaware is committed to effectively and responsibly utilising restricted research funding to support projects in the areas of cause, cure, prevention, treatment and general improvement of quality of life, in relation to myasthenia and related conditions.

## REPORT OF THE TRUSTEES

**REFERENCE AND ADMINISTRATIVE DETAILS**

Myaware is a 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**

The College Business Centre  
Uttoxeter New Road  
Derby DE22 3WZ

**Chief Executive Officer**

Ms Sarah Cuthell

**Bankers**

Yorkshire Bank  
28 St Peter's Square, Derby, DE1 1SL

**Trustees**

|                             |                                  |
|-----------------------------|----------------------------------|
| Trevor Ranson – Chairman    | Maria Isabel Leite               |
| Andrew Robinson – Treasurer | Penny Henrion                    |
| Bruce McColl                | Rashmi Rungta                    |
| Jon Rio                     | Huw Simmonds                     |
| Saiju Jacob                 | Liz McSheehy (resigned 30.08.21) |
| Prof Bethan Peach           | Stuart Mann (resigned 09.10.21)  |

**Auditors**

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

**Company Secretary**

Andrew Lutley  
A J Lutley also acts as solicitors to the  
charity: A J Lutley Solicitors, Springfield  
Rookery Hill, Ashted Park,  
Ashted KT21 1HY

More information regarding Trustees can be found at:

[www.myaware.org/Pages/FAQs/Category/meet-the-board](http://www.myaware.org/Pages/FAQs/Category/meet-the-board)

**STRUCTURE GOVERNANCE AND MANAGEMENT**

Myaware is 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 shall not be limited by any special power given to the trustees by the articles and a meeting of trustees at which a quorum is present may exercise all the powers exercisable by the trustees.

**REPORT OF 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 with 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 the 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 Chairman. 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.

At present the Board does not operate a formal scheme for the training of Trustees. The Chairman takes care to ensure that they 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 Company Secretary. The Board will keep under review the need for a formal training process, which must be consistent with the Charity's financial and personal resources.

**Medical Committee:**

Prof Bethan Peach

Saiju Jacob

Maria Isabel Leite

Liz McSheehy (resigned 30.08.21)

Sarah Cuthell (CEO)

**Finance Committee:**

Andrew Robinson (Treasurer)

Bruce McColl

Jon Rio

Stuart Mann (resigned 09.10.21)

Sarah Cuthell (CEO)

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 her line manager.

**REPORT OF THE TRUSTEES****Risk Management**

A risk review of the overall organisation takes place annually. The review took place in October 2020 and then July 2022 when the trustees assessed the major risks. Subsequently, systems and procedures have been established to manage those risks.

An annual budget proposal covering anticipated income and expenditure is created by the CEO and Finance Committee and reviewed by the Trustees. Once agreed, this forms the basis of the financial reserve held by the charity to ensure that commitments can be met. The Finance Committee review performance against the agreed budget on a monthly basis and the full Board considers this quarterly.

The board consider any variation to budget and if necessary, implement changes to mitigate any risks identified.

**FINANCIAL REVIEW****Financial Position**

The organisation reported a total net deficit of £296,756 compared with a total net deficit of £23,835 in the previous year due to reduced fundraising income and legacy gifts.

Unrestricted funds were increased by £87,237 to £1,727,997

Restricted funds decreased by £383,993 to £678,296

**Incoming Resources**

- Total incoming resources for the year were £706,904, down by £285,895 from the previous year.
- This year we received £635,330 in unrestricted donations, of which £490,115 relates to legacy gifts. We received £5636 in restricted funds.
- Income from other trading activities dropped by £248,812 to £58,106. The decrease reflects the inability to fundraise in the community and the changing donor trends in light of uncertainty, even 12 to 24 months after the first outbreak of the pandemic.
- Investment income has decreased by £2228 to £7832

**Resources Expended**

- Total resources expended reduced by £30,264 to £1,022,153.
- Research costs were reduced by £40,545 on previous year to £366,588 of which £291,025 was restricted.
- Support costs were reduced by £94,709 on previous year to £540,833 of which £20,295 was restricted.
- Awareness costs increased by £24,730 to £105,233. £792 of which was restricted.
- Fundraising costs were reduced by £830 to £9499
- Total funds stand at £2,406,293 compared with £2,703,049 last year.
- Funds at the year-end were made up of unrestricted funds of £1,727,997 (2021: £1,640,760) and restricted funds of £678,296 (2021: £1,062,289).

## REPORT OF THE TRUSTEES

## 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 2022, the 12 month's budgeted unrestricted expenditure equates to £580,046 and the free reserves, which amount to £1,716,258 leave a surplus of £1,136,212 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

## COVID-19

The pandemic has had a negative effect on the charitable sector, and myaware is no exception to this. The Trustees have set a realistic budget for 2022/23 with a net deficit on unrestricted funds of £596,730. This has been calculated on a reduction in giving and no legacies receivable in the year.

Going concern is not considered an issue as the charity can utilise the surplus on unrestricted funds referred to in the above reserves policy. The liquidity position is monitored by the trustees on a monthly basis and the charity is continuing to operate within its reserves policy. 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 £490,115

Donations amounted to £95,583. Events fundraising generated £54,719 and In Memoriam donations raised £46,050

## Investment Policy and Objectives

Trustees agree on investments in compliance with the Articles of Association. The return on investment for the year was 0.4% (2021 0.5%). If the change in value of investments is included, the return is 1.3% (2021 2.4%). 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 Trustees 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 Chairman – Chairman of the Board of Trustees

DATE: 13/12/22

## 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 (the 'charitable company') for the year ended 31 March 2022 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 2022 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 (as amended).

### 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

### 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.

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

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 charity

-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 charity including 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 charity 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 charity'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 charity 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.

The testing of committed expenditure in relation to grants awarded by the charity 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.

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

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

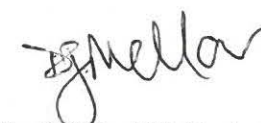
The financial statements were reviewed alongside our disclosure checklists to identify any unusual or unexpected relationships or any areas of non-compliance. Discussions were held with management where it was considered additional disclosures were required.

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 section 44 (1) (c) of the Charities and Trustee Investment Scotland Act 2005 and Regulation 10 of the Charities Accounts (Scotland) Regulations 2006 (as amended). 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 Mellor FCA (Senior Statutory Auditor)  
for and on behalf of Johnson Tidsall Limited  
Chartered Accountants  
& Statutory Auditor  
81 Burton Road  
Derby  
Derbyshire  
DE1 1TJ

Date: 13/12/2022

MYAWARE

STATEMENT OF FINANCIAL ACTIVITIES  
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)  
FOR THE YEAR ENDED 31 MARCH 2022

|                                    | Notes | Unrestricted fund<br>£ | Restricted funds<br>£ | 2022 Total funds<br>£ | 2021 Total funds<br>£ |
|------------------------------------|-------|------------------------|-----------------------|-----------------------|-----------------------|
| <b>INCOME AND ENDOWMENTS FROM</b>  |       |                        |                       |                       |                       |
| Donations and legacies             | 3     | 635,330                | 5,636                 | 640,966               | 675,821               |
| Other trading activities           | 4     | 118,908                | (60,802)              | 58,106                | 306,918               |
| Investment income                  | 5     | 7,832                  | -                     | 7,832                 | 10,060                |
| <b>Total</b>                       |       | <b>762,070</b>         | <b>(55,166)</b>       | <b>706,904</b>        | <b>992,799</b>        |
| <b>EXPENDITURE ON</b>              |       |                        |                       |                       |                       |
| Raising funds                      | 6     | 9,499                  | -                     | 9,499                 | 10,329                |
| Charitable activities              | 7     |                        |                       |                       |                       |
| Research                           |       | 75,563                 | 291,025               | 366,588               | 326,043               |
| Support                            |       | 520,538                | 20,295                | 540,833               | 635,542               |
| Awareness                          |       | 104,441                | 792                   | 105,233               | 80,503                |
| <b>Total</b>                       |       | <b>710,041</b>         | <b>312,112</b>        | <b>1,022,153</b>      | <b>1,052,417</b>      |
| Net gains on investments           |       | 18,493                 | -                     | 18,493                | 35,783                |
| <b>NET INCOME/(EXPENDITURE)</b>    |       | <b>70,522</b>          | <b>(367,278)</b>      | <b>(296,756)</b>      | <b>(23,835)</b>       |
| Transfers between funds            | 21    | 16,715                 | (16,715)              | -                     | -                     |
| Net movement in funds              |       | 87,237                 | (383,993)             | (296,756)             | (23,835)              |
| <b>RECONCILIATION OF FUNDS</b>     |       |                        |                       |                       |                       |
| Total funds brought forward        |       | 1,640,760              | 1,062,289             | 2,703,049             | 2,726,884             |
| <b>TOTAL FUNDS CARRIED FORWARD</b> |       | <b>1,727,997</b>       | <b>678,296</b>        | <b>2,406,293</b>      | <b>2,703,049</b>      |

MYAWARE  
COMPANY NUMBER 1046443  
BALANCE SHEET  
31 MARCH 2022

|                                              | Notes | Unrestricted fund<br>£ | Restricted funds<br>£ | 2022 Total funds<br>£ | 2021 Total funds<br>£ |
|----------------------------------------------|-------|------------------------|-----------------------|-----------------------|-----------------------|
| <b>FIXED ASSETS</b>                          |       |                        |                       |                       |                       |
| Intangible assets                            | 14    | 7,709                  | -                     | 7,709                 | 23,477                |
| Tangible assets                              | 15    | 4,030                  | -                     | 4,030                 | 3,661                 |
| Investments                                  | 16    | 229,797                | -                     | 229,797               | 211,304               |
|                                              |       | <b>241,536</b>         | <b>-</b>              | <b>241,536</b>        | <b>238,442</b>        |
| <b>CURRENT ASSETS</b>                        |       |                        |                       |                       |                       |
| Stocks                                       | 17    | 4,364                  | -                     | 4,364                 | 2,138                 |
| Debtors                                      | 18    | 577,599                | -                     | 577,599               | 859,595               |
| Cash at bank and in hand                     |       | 914,288                | 1,178,742             | 2,093,030             | 2,040,174             |
|                                              |       | <b>1,496,251</b>       | <b>1,178,742</b>      | <b>2,674,993</b>      | <b>2,901,907</b>      |
| <b>CREDITORS</b>                             |       |                        |                       |                       |                       |
| Amounts falling due within one year          | 19    | (9,790)                | (200,690)             | (210,480)             | (273,400)             |
| <b>NET CURRENT ASSETS</b>                    |       | <b>1,486,461</b>       | <b>978,052</b>        | <b>2,464,513</b>      | <b>2,628,507</b>      |
| <b>TOTAL ASSETS LESS CURRENT LIABILITIES</b> |       | <b>1,727,997</b>       | <b>978,052</b>        | <b>2,706,049</b>      | <b>2,866,949</b>      |
| <b>CREDITORS</b>                             |       |                        |                       |                       |                       |
| Amounts falling due after more than one year | 20    | -                      | (299,756)             | (299,756)             | (163,900)             |
| <b>NET ASSETS</b>                            |       | <b>1,727,997</b>       | <b>678,296</b>        | <b>2,406,293</b>      | <b>2,703,049</b>      |
| <b>FUNDS</b>                                 | 21    |                        |                       |                       |                       |
| Unrestricted funds                           |       |                        |                       | 1,727,997             | 1,640,760             |
| Restricted funds                             |       |                        |                       | 678,296               | 1,062,289             |
| <b>TOTAL FUNDS</b>                           |       |                        |                       | <b>2,406,293</b>      | <b>2,703,049</b>      |

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 ..... and were signed on its behalf by:

  
Mr T Ranson - Trustee

## MYAWARE

CASH FLOW STATEMENT  
FOR THE YEAR ENDED 31 MARCH 2022

|                                                                    | Notes | 2022<br>£        | 2021<br>£        |
|--------------------------------------------------------------------|-------|------------------|------------------|
| Cash flows from operating activities                               |       |                  |                  |
| Cash generated from operations                                     | 1     | <u>48,226</u>    | <u>195,137</u>   |
| Net cash provided by operating activities                          |       | <u>48,226</u>    | <u>195,137</u>   |
| Cash flows from investing activities                               |       |                  |                  |
| Purchase of intangible fixed assets                                |       | -                | (14,759)         |
| Purchase of tangible fixed assets                                  |       | (3,445)          | (2,768)          |
| Sale of intangible fixed assets                                    |       | 243              | -                |
| Interest received                                                  |       | <u>7,832</u>     | <u>10,060</u>    |
| Net cash provided by/(used in) investing activities                |       | <u>4,630</u>     | <u>(7,467)</u>   |
| Change in cash and cash equivalents in the reporting period        |       | <u>52,856</u>    | <u>187,670</u>   |
| Cash and cash equivalents at the beginning of the reporting period |       | <u>2,040,174</u> | <u>1,852,504</u> |
| Cash and cash equivalents at the end of the reporting period       |       | <u>2,093,030</u> | <u>2,040,174</u> |

## MYAWARE

NOTES TO THE CASH FLOW STATEMENT  
FOR THE YEAR ENDED 31 MARCH 2022

|    |                                                                                         |                  |                |                  |
|----|-----------------------------------------------------------------------------------------|------------------|----------------|------------------|
| 1. | RECONCILIATION OF NET EXPENDITURE TO NET CASH FLOW FROM OPERATING ACTIVITIES            |                  |                |                  |
|    |                                                                                         | 2022<br>£        | 2021<br>£      |                  |
|    | Net expenditure for the reporting period (as per the Statement of Financial Activities) | (296,756)        | (23,835)       |                  |
|    | Adjustments for:                                                                        |                  |                |                  |
|    | Depreciation charges                                                                    | 18,601           | 31,643         |                  |
|    | Gain on investments                                                                     | (18,493)         | (35,783)       |                  |
|    | Interest received                                                                       | (7,832)          | (10,060)       |                  |
|    | (Increase)/decrease in stocks                                                           | (2,226)          | 1,491          |                  |
|    | Decrease in debtors                                                                     | 281,996          | 3,802          |                  |
|    | Increase in creditors                                                                   | <u>72,936</u>    | <u>227,879</u> |                  |
|    | Net cash provided by operations                                                         | <u>48,226</u>    | <u>195,137</u> |                  |
| 2. | ANALYSIS OF CHANGES IN NET FUNDS                                                        |                  |                |                  |
|    |                                                                                         | At 1/4/21<br>£   | Cash flow<br>£ | At 31/3/22<br>£  |
|    | Net cash                                                                                |                  |                |                  |
|    | Cash at bank and in hand                                                                | <u>2,040,174</u> | <u>52,856</u>  | <u>2,093,030</u> |
|    |                                                                                         | <u>2,040,174</u> | <u>52,856</u>  | <u>2,093,030</u> |
|    | Total                                                                                   | <u>2,040,174</u> | <u>52,856</u>  | <u>2,093,030</u> |

## MYAWARE

### NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

#### 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 2022/23 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.

**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. At this point income is recognised.

**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 2022

#### 2. ACCOUNTING POLICIES - continued

##### Income – 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 2022

#### 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

|             | 2022           | 2021           |
|-------------|----------------|----------------|
|             | £              | £              |
| Donations   | 95,583         | 83,601         |
| Legacies    | 490,115        | 519,560        |
| Grants      | 9,218          | 29,355         |
| In Memoriam | 46,050         | 43,305         |
|             | <u>640,966</u> | <u>675,821</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.

Grants received, included in the above, are as follows:

|                                  | 2022         | 2021          |
|----------------------------------|--------------|---------------|
|                                  | £            | £             |
| Coronavirus Job Retention Scheme | <u>9,218</u> | <u>29,355</u> |

## MYAWARE

### NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2022

#### 4. OTHER TRADING ACTIVITIES

|                      | 2022          | 2021           |
|----------------------|---------------|----------------|
|                      | £             | £              |
| Affinity programmes  | 1,890         | 623            |
| Appeals              | 7,370         | 15,978         |
| Collections          | 468           | 921            |
| Corporate            | 7,339         | 7,065          |
| Grants               | (53,847)      | 140,428        |
| Lotteries            | 4,334         | 5,382          |
| National events      | 17,906        | 9,225          |
| Regional events      | 36,813        | 36,263         |
| Sales of merchandise | 4,928         | 4,686          |
| Trusts               | <u>30,905</u> | <u>86,347</u>  |
|                      | <u>58,106</u> | <u>306,918</u> |

During the year management implemented changes to the charity's fundraising structure. This restructure was an outcome of Covid and myaware's inability to continue to provide face to face support services. The regional fundraising structure was deemed unfit for current and future purpose and a new national fundraising team structure was implemented.

As a result of this, certain restricted grants totalling £71,683 applied for on a regional basis in previous years were repaid as the criteria for the grants could no longer be met.

#### 5. INVESTMENT INCOME

|                                           | 2022         | 2021          |
|-------------------------------------------|--------------|---------------|
|                                           | £            | £             |
| Deposit account interest                  | 908          | 3,815         |
| Current account interest                  | 538          | 150           |
| Dividends on shares and other investments | <u>6,386</u> | <u>6,095</u>  |
|                                           | <u>7,832</u> | <u>10,060</u> |

#### 6. RAISING FUNDS

##### Raising donations and legacies

|                 | 2022         | 2021          |
|-----------------|--------------|---------------|
|                 | £            | £             |
| Merchandise     | 2,173        | 2,976         |
| Events          | 3,098        | 3,357         |
| Appeal mailings | 996          | 349           |
| Lottery         | <u>3,232</u> | <u>3,647</u>  |
|                 | <u>9,499</u> | <u>10,329</u> |

## MYAWARE

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

## 7. CHARITABLE ACTIVITIES COSTS

|           | Direct<br>Costs (see<br>note 8)<br>£ | Support<br>costs (see<br>note 9)<br>£ | Totals<br>£      |
|-----------|--------------------------------------|---------------------------------------|------------------|
| Research  | 347,451                              | 19,137                                | 366,588          |
| Support   | 407,124                              | 133,709                               | 540,833          |
| Awareness | 78,472                               | 26,761                                | 105,233          |
|           | <u>833,047</u>                       | <u>179,607</u>                        | <u>1,012,654</u> |

## 8. DIRECT COSTS OF CHARITABLE ACTIVITIES

|                                | 2022<br>£      | 2021<br>£      |
|--------------------------------|----------------|----------------|
| Staff costs                    | 528,511        | 580,867        |
| Medical research               | 291,025        | 267,677        |
| Medical care                   | 1,529          | -              |
| Travel and miscellaneous       | 6,829          | 5,600          |
| MyNews & member communications | 4,098          | 7,158          |
| Meetings and conferences       | 1,055          | 1,427          |
|                                | <u>833,047</u> | <u>862,729</u> |

Grants payable during the year were as follows:

|                                  | 2022<br>£      | 2021<br>£      |
|----------------------------------|----------------|----------------|
| Commitments as at 1 April 2021   | 421,705        | 184,343        |
| Commitments made in the year     | 323,919        | 275,772        |
| Commitments released in the year | (32,894)       | (8,095)        |
| Grants paid during the year      | (212,284)      | (30,315)       |
|                                  | <u>500,446</u> | <u>421,705</u> |

## 9. SUPPORT COSTS

|           | Management<br>£ | Governance<br>costs<br>£ | Totals<br>£    |
|-----------|-----------------|--------------------------|----------------|
| Research  | 17,568          | 1,569                    | 19,137         |
| Support   | 123,158         | 10,551                   | 133,709        |
| Awareness | 24,623          | 2,138                    | 26,761         |
|           | <u>165,349</u>  | <u>14,258</u>            | <u>179,607</u> |

## MYAWARE

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

## 9. SUPPORT COSTS - continued

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

## Management

|                                         | Research<br>£ | Support<br>£   | Awareness<br>£ | 2022<br>Total<br>activities<br>£ | 2021<br>Total<br>activities<br>£ |
|-----------------------------------------|---------------|----------------|----------------|----------------------------------|----------------------------------|
| Rental of premises                      | 2,613         | 17,579         | 3,563          | 23,755                           | 23,760                           |
| Utilities and insurance                 | 1,999         | 13,451         | 2,727          | 18,177                           | 17,255                           |
| Office equipment                        | -             | 3,845          | -              | 3,845                            | 2,315                            |
| Printing, postage and stationery        | 1,097         | 7,383          | 1,497          | 9,977                            | 11,680                           |
| Photocopier costs                       | 143           | 961            | 195            | 1,299                            | 1,009                            |
| Support website                         | 2,633         | 17,710         | 3,590          | 23,933                           | 30,461                           |
| IT support & software                   | 4,982         | 34,642         | 7,460          | 47,084                           | 38,773                           |
| H R costs                               | 1,140         | 7,663          | 1,553          | 10,356                           | 5,044                            |
| General expenses                        | 751           | 5,050          | 1,024          | 6,825                            | 1,131                            |
| Bank charges                            | 165           | 1,108          | 224            | 1,497                            | 1,573                            |
| Amortisation of intangible fixed assets | 1,707         | 11,489         | 2,329          | 15,525                           | 25,363                           |
| Depreciation of tangible fixed assets   | 338           | 2,277          | 461            | 3,076                            | 6,280                            |
|                                         | <u>17,568</u> | <u>123,158</u> | <u>24,623</u>  | <u>165,349</u>                   | <u>164,644</u>                   |

## Governance costs

|                             | Research<br>£ | Support<br>£  | Awareness<br>£ | 2022<br>Total<br>activities<br>£ | 2021<br>Total<br>activities<br>£ |
|-----------------------------|---------------|---------------|----------------|----------------------------------|----------------------------------|
| Trustees' expenses          | 26            | 172           | 35             | 233                              | -                                |
| Auditors' remuneration      | 800           | 5,379         | 1,089          | 7,268                            | 7,941                            |
| Legal and professional fees | 743           | 5,000         | 1,014          | 6,757                            | 6,774                            |
|                             | <u>1,569</u>  | <u>10,551</u> | <u>2,138</u>   | <u>14,258</u>                    | <u>14,715</u>                    |

## 10. NET INCOME/(EXPENDITURE)

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

|                                | 2022<br>£ | 2021<br>£ |
|--------------------------------|-----------|-----------|
| Auditors' remuneration         | 7,268     | 7,941     |
| Depreciation - owned assets    | 3,076     | 6,280     |
| Computer software amortisation | 15,525    | 25,363    |

## MYAWARE

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

## 11. TRUSTEES' REMUNERATION AND BENEFITS

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

| Trustees' expenses | 2022       | 2021     |
|--------------------|------------|----------|
|                    | £          | £        |
| Trustees' expenses | <u>233</u> | <u>-</u> |

During the year 2 trustees (2021: 0) received reimbursement of their expenses for attending meetings.

## 12. STAFF COSTS

|                       | 2022           | 2021           |
|-----------------------|----------------|----------------|
|                       | £              | £              |
| Wages and salaries    | 463,558        | 509,640        |
| Social security costs | 34,490         | 36,906         |
| Other pension costs   | <u>30,463</u>  | <u>34,321</u>  |
|                       | <u>528,511</u> | <u>580,867</u> |

The average number of full time equivalent employees during the year was 15 (2021: 19).

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

|                                          | 2022      | 2021      |
|------------------------------------------|-----------|-----------|
|                                          | 15        | 20        |
| Fundraising, support and awareness       | 4         | 4         |
| Management and operations of the charity | <u>19</u> | <u>24</u> |

The number of employees whose employee benefits (excluding employer pension costs) exceeded £60,000 was:

|                   | 2022     | 2021     |
|-------------------|----------|----------|
|                   | 1        | -        |
| £60,001 - £70,000 | <u>1</u> | <u>-</u> |

Wages and salaries include redundancy costs of £16,327.

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 £67,090, including pension contributions (2021: £61,158).

## MYAWARE

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

## 13. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

|                                    | Unrestricted fund<br>£ | Restricted funds<br>£ | Total funds<br>£ |
|------------------------------------|------------------------|-----------------------|------------------|
| <b>INCOME AND ENDOWMENTS FROM</b>  |                        |                       |                  |
| Donations and legacies             | 673,194                | 2,627                 | 675,821          |
| Other trading activities           | 125,725                | 181,193               | 306,918          |
| Investment income                  | <u>10,060</u>          | <u>-</u>              | <u>10,060</u>    |
| <b>Total</b>                       | <u>808,979</u>         | <u>183,820</u>        | <u>992,799</u>   |
| <b>EXPENDITURE ON</b>              |                        |                       |                  |
| Raising funds                      | 10,329                 | -                     | 10,329           |
| <b>Charitable activities</b>       |                        |                       |                  |
| Research                           | 54,506                 | 271,537               | 326,043          |
| Support                            | 432,395                | 203,147               | 635,542          |
| Awareness                          | <u>80,503</u>          | <u>-</u>              | <u>80,503</u>    |
| <b>Total</b>                       | <u>577,733</u>         | <u>474,684</u>        | <u>1,052,417</u> |
| Net gains on investments           | <u>35,783</u>          | <u>-</u>              | <u>35,783</u>    |
| <b>NET INCOME/(EXPENDITURE)</b>    | 267,029                | (290,864)             | (23,835)         |
| Transfers between funds            | <u>73,908</u>          | <u>(73,908)</u>       | <u>-</u>         |
| Net movement in funds              | 340,937                | (364,772)             | (23,835)         |
| <b>RECONCILIATION OF FUNDS</b>     |                        |                       |                  |
| Total funds brought forward        | <u>1,299,823</u>       | <u>1,427,061</u>      | <u>2,726,884</u> |
| <b>TOTAL FUNDS CARRIED FORWARD</b> | <u>1,640,760</u>       | <u>1,062,289</u>      | <u>2,703,049</u> |

## MYAWARE

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

## 14. INTANGIBLE FIXED ASSETS

|                        | Computer<br>software<br>£ |
|------------------------|---------------------------|
| <b>COST</b>            |                           |
| At 1 April 2021        | 95,736                    |
| Disposals              | (729)                     |
| At 31 March 2022       | 95,007                    |
| <b>AMORTISATION</b>    |                           |
| At 1 April 2021        | 72,259                    |
| Charge for year        | 15,525                    |
| Eliminated on disposal | (486)                     |
| At 31 March 2022       | 87,298                    |
| <b>NET BOOK VALUE</b>  |                           |
| At 31 March 2022       | 7,709                     |
| At 31 March 2021       | 23,477                    |

## 15. TANGIBLE FIXED ASSETS

|                       | Fixtures<br>and<br>fittings<br>£ | Computer<br>equipment<br>£ | Totals<br>£ |
|-----------------------|----------------------------------|----------------------------|-------------|
| <b>COST</b>           |                                  |                            |             |
| At 1 April 2021       | 13,247                           | 41,763                     | 55,010      |
| Additions             | -                                | 3,445                      | 3,445       |
| At 31 March 2022      | 13,247                           | 45,208                     | 58,455      |
| <b>DEPRECIATION</b>   |                                  |                            |             |
| At 1 April 2021       | 13,247                           | 38,102                     | 51,349      |
| Charge for year       | -                                | 3,076                      | 3,076       |
| At 31 March 2022      | 13,247                           | 41,178                     | 54,425      |
| <b>NET BOOK VALUE</b> |                                  |                            |             |
| At 31 March 2022      | -                                | 4,030                      | 4,030       |
| At 31 March 2021      | -                                | 3,661                      | 3,661       |

## 16. FIXED ASSET INVESTMENTS

|                       | Listed<br>investments<br>£ |
|-----------------------|----------------------------|
| <b>MARKET VALUE</b>   |                            |
| At 1 April 2021       | 211,304                    |
| Revaluations          | 18,493                     |
| At 31 March 2022      | 229,797                    |
| <b>NET BOOK VALUE</b> |                            |
| At 31 March 2022      | 229,797                    |
| At 31 March 2021      | 211,304                    |

## MYAWARE

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

## 16. FIXED ASSET INVESTMENTS - continued

There were no investment assets outside the UK.

The historical cost of fixed asset investments as at 31 March 2022 was £89,858 (2021: £89,858).

## 17. STOCKS

|                | 2022<br>£ | 2021<br>£ |
|----------------|-----------|-----------|
| Finished goods | 4,364     | 2,138     |

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

|                                | 2022<br>£ | 2021<br>£ |
|--------------------------------|-----------|-----------|
| Other debtors                  | 568,640   | 848,353   |
| Prepayments and accrued income | 8,959     | 11,242    |
|                                | 577,599   | 859,595   |

## 19. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

|                              | 2022<br>£ | 2021<br>£ |
|------------------------------|-----------|-----------|
| Other creditors              | 1,039     | 6,864     |
| Committed grants             | 200,690   | 257,805   |
| Accruals and deferred income | 8,751     | 8,731     |
|                              | 210,480   | 273,400   |

## 20. CREDITORS: AMOUNTS FALLING DUE AFTER MORE THAN ONE YEAR

|                  | 2022<br>£ | 2021<br>£ |
|------------------|-----------|-----------|
| Committed grants | 299,756   | 163,900   |

## MYAWARE

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

## 21. MOVEMENT IN FUNDS

|                    | At 1/4/21<br>£          | Net<br>movement<br>in funds<br>£ | Transfers<br>between<br>funds<br>£ | At<br>31/3/22<br>£      |
|--------------------|-------------------------|----------------------------------|------------------------------------|-------------------------|
| Unrestricted funds |                         |                                  |                                    |                         |
| General fund       | 1,640,760               | 70,522                           | 16,715                             | 1,727,997               |
| Restricted funds   |                         |                                  |                                    |                         |
| Research           | 860,312                 | (287,494)                        | -                                  | 572,818                 |
| Support            | 198,440                 | (79,992)                         | (16,715)                           | 101,733                 |
| Awareness          | 3,537                   | 208                              | -                                  | 3,745                   |
|                    | <u>1,062,289</u>        | <u>(367,278)</u>                 | <u>(16,715)</u>                    | <u>678,296</u>          |
| <b>TOTAL FUNDS</b> | <b><u>2,703,049</u></b> | <b><u>(296,756)</u></b>          | <b><u>-</u></b>                    | <b><u>2,406,293</u></b> |

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

|                    | Incoming<br>resources<br>£ | Resources<br>expended<br>£ | Gains and<br>losses<br>£ | Movement<br>in funds<br>£ |
|--------------------|----------------------------|----------------------------|--------------------------|---------------------------|
| Unrestricted funds |                            |                            |                          |                           |
| General fund       | 762,070                    | (710,041)                  | 18,493                   | 70,522                    |
| Restricted funds   |                            |                            |                          |                           |
| Research           | 3,531                      | (291,025)                  | -                        | (287,494)                 |
| Support            | (59,697)                   | (20,295)                   | -                        | (79,992)                  |
| Awareness          | 1,000                      | (792)                      | -                        | 208                       |
|                    | <u>(55,166)</u>            | <u>(312,112)</u>           | <u>-</u>                 | <u>(367,278)</u>          |
| <b>TOTAL FUNDS</b> | <b><u>706,904</u></b>      | <b><u>(1,022,153)</u></b>  | <b><u>18,493</u></b>     | <b><u>(296,756)</u></b>   |

Comparatives for movement in funds

|                    | At 1/4/20<br>£          | Net<br>movement<br>in funds<br>£ | Transfers<br>between<br>funds<br>£ | At<br>31/3/21<br>£      |
|--------------------|-------------------------|----------------------------------|------------------------------------|-------------------------|
| Unrestricted funds |                         |                                  |                                    |                         |
| General fund       | 1,299,823               | 267,029                          | 73,908                             | 1,640,760               |
| Restricted funds   |                         |                                  |                                    |                         |
| Research           | 1,204,757               | (270,537)                        | (73,908)                           | 860,312                 |
| Support            | 220,117                 | (21,677)                         | -                                  | 198,440                 |
| Awareness          | 2,187                   | 1,350                            | -                                  | 3,537                   |
|                    | <u>1,427,061</u>        | <u>(290,864)</u>                 | <u>(73,908)</u>                    | <u>1,062,289</u>        |
| <b>TOTAL FUNDS</b> | <b><u>2,726,884</u></b> | <b><u>(23,835)</u></b>           | <b><u>-</u></b>                    | <b><u>2,703,049</u></b> |

## MYAWARE

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

## 21. MOVEMENT IN FUNDS - continued

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

|                    | Incoming<br>resources<br>£ | Resources<br>expended<br>£ | Gains and<br>losses<br>£ | Movement<br>in funds<br>£ |
|--------------------|----------------------------|----------------------------|--------------------------|---------------------------|
| Unrestricted funds |                            |                            |                          |                           |
| General fund       | 808,979                    | (577,733)                  | 35,783                   | 267,029                   |
| Restricted funds   |                            |                            |                          |                           |
| Research           | 1,000                      | (271,537)                  | -                        | (270,537)                 |
| Support            | 181,470                    | (203,147)                  | -                        | (21,677)                  |
| Awareness          | 1,350                      | -                          | -                        | 1,350                     |
|                    | <u>183,820</u>             | <u>(474,684)</u>           | <u>-</u>                 | <u>(290,864)</u>          |
| <b>TOTAL FUNDS</b> | <b><u>992,799</u></b>      | <b><u>(1,052,417)</u></b>  | <b><u>35,783</u></b>     | <b><u>(23,835)</u></b>    |

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

|                    | At 1/4/20<br>£          | Net<br>movement<br>in funds<br>£ | Transfers<br>between<br>funds<br>£ | At<br>31/3/22<br>£      |
|--------------------|-------------------------|----------------------------------|------------------------------------|-------------------------|
| Unrestricted funds |                         |                                  |                                    |                         |
| General fund       | 1,299,823               | 337,551                          | 90,623                             | 1,727,997               |
| Restricted funds   |                         |                                  |                                    |                         |
| Research           | 1,204,757               | (558,031)                        | (73,908)                           | 572,818                 |
| Support            | 220,117                 | (101,669)                        | (16,715)                           | 101,733                 |
| Awareness          | 2,187                   | 1,558                            | -                                  | 3,745                   |
|                    | <u>1,427,061</u>        | <u>(658,142)</u>                 | <u>(90,623)</u>                    | <u>678,296</u>          |
| <b>TOTAL FUNDS</b> | <b><u>2,726,884</u></b> | <b><u>(320,591)</u></b>          | <b><u>-</u></b>                    | <b><u>2,406,293</u></b> |

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

|                    | Incoming<br>resources<br>£ | Resources<br>expended<br>£ | Gains and<br>losses<br>£ | Movement<br>in funds<br>£ |
|--------------------|----------------------------|----------------------------|--------------------------|---------------------------|
| Unrestricted funds |                            |                            |                          |                           |
| General fund       | 1,571,049                  | (1,287,774)                | 54,276                   | 337,551                   |
| Restricted funds   |                            |                            |                          |                           |
| Research           | 4,531                      | (562,562)                  | -                        | (558,031)                 |
| Support            | 121,773                    | (223,442)                  | -                        | (101,669)                 |
| Awareness          | 2,350                      | (792)                      | -                        | 1,558                     |
|                    | <u>128,654</u>             | <u>(786,796)</u>           | <u>-</u>                 | <u>(658,142)</u>          |
| <b>TOTAL FUNDS</b> | <b><u>1,699,703</u></b>    | <b><u>(2,074,570)</u></b>  | <b><u>54,276</u></b>     | <b><u>(320,591)</u></b>   |

## MYAWARE

### NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2022

#### 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 2022

#### 21. MOVEMENT IN FUNDS - continued

##### Transfers between funds

During the year £16,715 was transferred from restricted funds to unrestricted funds as a result of the change in the charity's fundraising structure from a regional to a national basis.

As at 1 April 2021 the charity held restricted funds which had been donated for use on a regional basis. Since this was no longer applicable, the donors were contacted and offered repayment or asked if the funds could be transferred to general unrestricted funds. The above balance represents donations confirmed as transferrable to general unrestricted funds by the donor.

#### 22. EMPLOYEE BENEFIT OBLIGATIONS

The total contribution paid to Personal Pension Plans in the year for certain employees amounted to £30,463 (2021: £34,321).

#### 23. OTHER FINANCIAL COMMITMENTS

At the year end the charity had financial commitments in respect of rent amounting to £23,760. (2021: £23,760) and other leases amounting to £3,960. (2021: £5,016).

#### 24. RELATED PARTY DISCLOSURES

During the year the charity paid a salary, benefits and expenses reimbursement totalling £19,750 (2021: £19,547) to an employee who is the spouse of a trustee.

The charity also paid £403 (2021: £2,425) for legal services performed by Andrew Lutley, Company Secretary.

#### 25. ULTIMATE CONTROLLING PARTY

The charity is controlled by its Board of Trustees.

# MYAWARE

## DETAILED STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 MARCH 2022

|                                           | 2022<br>£      | 2021<br>£      |
|-------------------------------------------|----------------|----------------|
| <b>INCOME AND ENDOWMENTS</b>              |                |                |
| Donations and legacies                    |                |                |
| Donations                                 | 95,583         | 83,601         |
| Legacies                                  | 490,115        | 519,560        |
| Grants                                    | 9,218          | 29,355         |
| In Memoriam                               | 46,050         | 43,305         |
|                                           | <u>640,966</u> | <u>675,821</u> |
| Other trading activities                  |                |                |
| Affinity programmes                       | 1,890          | 623            |
| Appeals                                   | 7,370          | 15,978         |
| Collections                               | 468            | 921            |
| Corporate                                 | 7,339          | 7,065          |
| Grants                                    | (53,847)       | 140,428        |
| Lotteries                                 | 4,334          | 5,382          |
| National events                           | 17,906         | 9,225          |
| Regional events                           | 36,813         | 36,263         |
| Sales of merchandise                      | 4,928          | 4,686          |
| Trusts                                    | 30,905         | 86,347         |
|                                           | <u>58,106</u>  | <u>306,918</u> |
| Investment income                         |                |                |
| Deposit account interest                  | 908            | 3,815          |
| Current account interest                  | 538            | 150            |
| Dividends on shares and other investments | 6,386          | 6,095          |
|                                           | <u>7,832</u>   | <u>10,060</u>  |
| <b>Total incoming resources</b>           | <b>706,904</b> | <b>992,799</b> |
| <b>EXPENDITURE</b>                        |                |                |
| Raising donations and legacies            |                |                |
| Merchandise                               | 2,173          | 2,976          |
| Events                                    | 3,098          | 3,357          |
| Appeal mailings                           | 996            | 349            |
| Lottery                                   | 3,232          | 3,647          |
|                                           | <u>9,499</u>   | <u>10,329</u>  |
| Charitable activities                     |                |                |
| Wages                                     | 463,558        | 509,640        |
| Social security                           | 34,490         | 36,906         |
| Pensions                                  | 30,463         | 34,321         |
| Medical research                          | 291,025        | 267,677        |
| Medical care                              | 1,529          | -              |
| Travel and miscellaneous                  | 6,829          | 5,600          |
| Carried forward                           | 827,894        | 854,144        |

# MYAWARE

## DETAILED STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 MARCH 2022

|                                                    | 2022<br>£        | 2021<br>£        |
|----------------------------------------------------|------------------|------------------|
| <b>Charitable activities</b>                       |                  |                  |
| Brought forward                                    | 827,894          | 854,144          |
| MyNews & member communications                     | 4,098            | 7,158            |
| Meetings and conferences                           | 1,055            | 1,427            |
|                                                    | <u>833,047</u>   | <u>862,729</u>   |
| <b>Support costs</b>                               |                  |                  |
| Management                                         |                  |                  |
| Rental of premises                                 | 23,755           | 23,760           |
| Utilities and insurance                            | 18,177           | 17,255           |
| Office equipment                                   | 3,845            | 2,315            |
| Printing, postage and stationery                   | 9,977            | 11,680           |
| Photocopier costs                                  | 1,299            | 1,009            |
| Support website                                    | 23,933           | 30,461           |
| IT support & software                              | 47,084           | 38,773           |
| H R costs                                          | 10,356           | 5,044            |
| General expenses                                   | 6,825            | 1,131            |
| Bank charges                                       | 1,497            | 1,573            |
| Amortisation of intangible fixed assets            | 15,525           | 25,363           |
| Depreciation of tangible fixed assets              | 3,076            | 6,280            |
|                                                    | <u>165,349</u>   | <u>164,644</u>   |
| <b>Governance costs</b>                            |                  |                  |
| Trustees' expenses                                 | 233              | -                |
| Auditors' remuneration                             | 7,268            | 7,941            |
| Legal and professional fees                        | 6,757            | 6,774            |
|                                                    | <u>14,258</u>    | <u>14,715</u>    |
| <b>Total resources expended</b>                    | <b>1,022,153</b> | <b>1,052,417</b> |
| <b>Net expenditure before gains and losses</b>     | <b>(315,249)</b> | <b>(59,618)</b>  |
| <b>Realised recognised gains and losses</b>        |                  |                  |
| Realised gains/(losses) on fixed asset investments | 18,493           | 35,783           |
| <b>Net expenditure</b>                             | <b>(296,756)</b> | <b>(23,835)</b>  |



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

**Tel: 01332 290219**

**Email:** [info@myaware.org](mailto:info@myaware.org)

**Web:** [www.myaware.org](http://www.myaware.org)

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