

# MEDICS 4 RARE DISEASES

England & Wales · Charity number 1183996

## Details

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Other names	MEDICS 4 RARE DISEASES LTD, M4RD, Medics for Rare Disease
Status	Registered
Legal form	CIO
Registered	2019-06-20
Register	<a href="#">View on the Charity Commission register</a>

## Contact

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**Website** [www.m4rd.org](http://www.m4rd.org)

## Activities

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**Objects:** THE RELIEF OF SICKNESS AND PRESERVATION OF HEALTH OF THOSE SUFFERING FROM RARE DISEASES, THROUGHOUT THE WORLD, BY:(A) ADVANCING THE EDUCATION OF MEDICS, ASSOCIATED PROFESSIONALS AND THE PUBLIC IN RARE DISEASES, GENETIC AND GENOMIC MEDICINE(B) PROMOTING RESEARCH IN ALL AREAS RELATING TO RARE DISEASES, GENETIC AND GENOMIC MEDICINE AND PUBLISHING THE USEFUL RESULTS(C) PROMOTING IMPROVED CARE AND TREATMENT OF THOSE SUFFERING FROM RARE DISEASES.

**Activities:** Medics4RareDiseases is raising awareness of the relevance of rare disease to medical practice in order to relieve sickness of those living with rare diseases. This is achieved through events, learning resources, linking medical professionals with patients and advocates, competitions and creating/promoting other opportunities for medics in the field of rare diseases.

## Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Other Defined Groups, The General Public/mankind

## Geography

- Australia
- Canada
- Ghana
- Ireland
- Northern Ireland
- Scotland
- United States
- Throughout England And Wales

## Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£288,229	£268,013	-	-
2023-12-31	£259,637	£228,852	-	-
2022-12-31	£135,183	£132,627	-	-
2021-12-31	£101,327	£74,702	-	-
2020-12-31	£58,593	£39,543	-	-

## Trustees

Name	Role	Appointed
CHRIS FRANCE		2018-07-25
Emma Macleod		2025-02-04
Harriet Gordon-Brown		2025-02-23
Professor Russell Hearn		2025-02-14
Sheela Updhyaya		2025-02-11

**MEDICS 4 RARE DISEASES**

England & Wales - Charity number 1183996

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# Accounts

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Charity registration number 1183996

**MEDICS 4 RARE DISEASES**  
**ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 DECEMBER 2024**

# MEDICS 4 RARE DISEASES

## LEGAL AND ADMINISTRATIVE INFORMATION

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<b>Trustees</b>	Christopher James France Daniel Conrad Jeffries Emma Macleod Sheela Updhyaya Professor Russel Hearn Harriet Gordon Brown Lindsay Jane Birrell Dr Debra Rachel Fine Dr Olivia Hannah Grant	(Appointed on 04/02/2025) (Appointed on 11/02/2025) (Appointed on 14/02/2025) (Appointed on 23/02/2025) (Resigned on 04/12/2025 ) (Resigned on 08/12/2025 ) (Resigned on 05/12/2025 )
<b>Secretary</b>	Dr L M R McKay	
<b>Charity number</b>	1183996	
<b>Company number</b>	CE029671	11119884 Converted to CIO
<b>Principal address</b>	Unit 12 Treadaway Technical Centre Treadaway Hill Loudwater High Wycombe HP10 9RS	
<b>Bookkeeping and payroll</b>	Adder Bookkeeping	
<b>Independent Examiner</b>	Caroline Brazier ACA DChA Cansdales Business Advisers Limited Chartered Accountants St Mary's Court The Broadway Old Amersham Bucks HP70UT	

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# MEDICS 4 RARE DISEASES

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# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT

### FOR THE YEAR ENDED 31 DECEMBER 2024

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The Trustees present their annual report and financial statements for the year ended 31 December 2024.

The financial statements have been prepared in accordance with the accounting policies set out in note to the financial statements and comply with the Charity's CIO foundation, the Charities Act 2011, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and the Charities SORP "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)".

#### **Structure, governance and management**

Trustees have been appointed to the M4RD board based on their experience, skills and enthusiasm for the work of M4RD. M4RD relies on the voluntary time that its Trustees generously provide to advance the purposes of the charity. The minimum number of Trustees is three and there is no maximum number. The requirements to be considered for the position of Trustee are outlined in the Charity's CIO Constitution. Trustee induction is provided by the CEO with input from the Chair of Trustees. This is carried out remotely. The new Trustee is provided with a New Trustee Induction Pack and access to the Charity's documents. M4RD makes use of readily available online training created by other organisations and provides a PDF copy of The Charity Commission's document 'The Essential Trustee'.

The Trustee Board meets quarterly via video conferencing and annually at a face-to-face Strategy Meeting. The CEO, Dr Lucy McKay, is a founding member of the Charity and has been in the role of CEO since September 2018. Lucy is a key opinion leader in the rare disease field having had personal experience of rare disease and training in the NHS as a doctor. She reports to the Trustee Board and is responsible for: implementing the strategy of the charity, as agreed by the Trustees; managing the staff team; oversight of finances and fundraising; and identifying and assessing strategic risks and opportunities.

The current M4RD staff team comprises: Jo McPherson (Partnerships & Community Manager) responsible for daily operations, managing the finances, fundraising and patient advocacy group liaison; Dr Emma Huskinson (Medical Communications Lead) responsible for public relations, liaising with press and writing medical content; Eleanor Churchill (Digital Communications Lead) responsible for the development and delivery of digital projects and digital marketing; and Dr Helen Maginnis (Training Programme Manager) responsible for M4RD's healthcare professional training projects and activities, delivering the NHS England contract for The Genomics Education Programme and rolling out Rare Disease 101 training for healthcare professionals all over the UK.

Lucy, Jo and Emma work part-time. Both Eleanor and Helen work full-time. The charity has an allocated desk and space for storage at the registered address of the charity. Staff work from home or co-working space. All staff report to the CEO who in turn reports to the Chair. Lucy holds regular 1:1 meetings with the staff team; Jo and Lucy meet weekly with the Chair.

The M4RD Board of Trustees continue to contribute generously to the success of the charity. Following an extraordinary board meeting on 04 December 2024 we welcomed 4 new Trustees, and said goodbye to three Trustees who gave so much in time, thought and support to M4RD:

Dr Debra Fine resigned from the board  
Dr Olivia Hannah Grant resigned from the board  
Mrs Lindsay Birrell resigned from the board  
Mr Chris France was appointed as Chair of the board  
Prof Russell Hearn appointed as trustee  
Mrs Sheela Upadhyaya appointed as trustee  
Mrs Harriet Gordon-Brown appointed as trustee  
Mrs Emma Macleod appointed as trustee

It was with sadness that the charity said goodbye to Dr Hannah Grant and Dr Debra Fine at the end of the year. Both were founding trustees and part of the original group of medical students from Barts and The London School of Medicine and Dentistry who saw the gap in their training. During their time as Trustees, they qualified as GPs and started families but still managed to dedicate their time and expertise to Medics for Rare Disease. The charity would not have got off the ground or had its successes without them and we will continue to build their legacy.

# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2024

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Lindsay Birrell also stepped down at the end of the year. While her time at the charity was shorter, she made a huge impact. In her 18 months tenure as Chair of Trustees she supported the whole team through a strategy review that resulted in a brand change and a clarity of vision, mission and direction. Thank you to Lindsay who will now be able to watch the fruits of her labour unfold while she cheers on Medics 4 Rare Diseases as an integral member of the rare disease community.

Chris France continues as Trustee and has taken the place of interim Chair while the new Trustees settle in. Chris has a background in sales; he founded a successful e-commerce company and continues to work with start-ups. He played a pivotal role in getting M4RD's structure established, mentoring Lucy and steering the charity in the direction of successful strategies.

Dan Jeffries is M4RD's patient representative but has many skills within IT. His day job of creating online interactive educational software means he is able to provide bespoke and greatly discounted services in the creation and development of M4RD's learning management system (M4RD: Learn).

The Board of Trustees and the CEO are responsible for reviewing and updating the Charity's strategic plan. This was most recently carried out at M4RD's Strategy Meeting in July 2023. The priority for 2024 was to have a new brand in terms of look and feel and the tools to clearly communicate the charity's purpose and activities. Decision-making in 2024 was driven by an agreed annual plan.

The CEO uses quarterly Board Meetings to update the Trustees on the progress being made by the charity and to ask questions and receive advice. The CEO is largely responsible for making decisions about activities that achieve the aims and objectives. Large financial decisions (outside of pre-authorised projects) are taken to the board by the CEO to be discussed.

#### **Objectives and activities**

Medics 4 Rare Diseases was registered at Companies House as a private company registered by guarantee without share capital (Company Number 11119884) on 20th December 2017. It was registered as a charity in England & Wales (Registered Charity Number 1183996) on 20th June 2019. It became a Charitable Incorporated Organisation (CIO) on 11 July 2022.

Below are the charity's purposes as set out in the objects contained in the Charity's CIO Constitution:

The company is established for the objects of the relief of sickness and preservation of health of those suffering from rare diseases, throughout the world, by:

- (a) advancing the education of medics, associated professionals and the public in rare diseases, genetic and genomic medicine
- (b) promoting research in all areas relating to rare diseases, genetic and genomic medicine and publishing the useful results
- (c) promoting improved care and treatment of those suffering from rare diseases.

#### **Aims and public benefit:**

The Charity aims to improve the lives of a certain portion of the public: those living with rare diseases and their communities. It does this through raising awareness of the relevance of rare diseases in medical practice. The Charity provides education about rare disease and opportunities to develop a clinician's understanding of this large population group in the UK in order to better serve it.

#### **Review:**

During 2019 the Board of Trustees worked with the Charity Commission to make sure its structure, objects and governing documents were ready for the organisation to be registered as a charity. This required a review of our purposes to make sure they were wholly charitable and benefited the public. In the case of M4RD 'the public' refers to the estimated 3.5 million people in the UK who suffer from a rare disease - and their communities.

# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2024

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Following guidance from the Charity Commission the Board of Trustees adapted the company's original Memorandum & Articles to make sure the wording was suitable for the charity. Subsequently the Charity's CIO Constitution was written to reflect the recommendations from the Charity Commission. The organisation's objects are wholly charitable. Any personal benefit arising is legitimately incidental.

The Board of Trustees review M4RD's objectives, goals and strategies on an annual basis at the Strategy Meeting. This is done with reference to guidance contained in the Charity Commission's general guidance on public benefit

#### **Activities:**

A rare disease is defined in the UK as a condition that affects fewer than 1 in 2,000 people. Almost 7,000 rare diseases have been identified, which means that understanding and teaching about rare diseases in medical education is extremely challenging. However this is a challenge that we cannot afford to avoid because approximately 3.5 million people in the UK have a rare disease. So while each disease is individually rare, they are collectively common.

Of these diseases, 80% are known to be genetic in origin and 70% present exclusively in childhood. However, despite this large prevalence (equivalent to all adults in the UK who suffer with asthma), each individual condition affects so few people that they tend to be overlooked and misunderstood by health professionals, researchers, education and social care providers and the general public. This lack of awareness amongst medical professionals is particularly devastating and can lead to extreme diagnostic delay. A person with a rare disease will wait on average 4-6 years for an accurate diagnosis. They will see numerous doctors, receive misdiagnoses and potentially even inappropriate treatment. This long and arduous journey to a diagnosis has been named "the Diagnostic Odyssey".

The challenges of having a rare disease do not stop after getting a diagnosis. People living with completely different diseases often report the same difficulties in terms of healthcare, social care, family life, education, work and mental health. There are many wonderful charities in the UK that support rare disease patients depending on their disease or specific need. Umbrella charities run successful public awareness campaigns. However M4RD specifically targets an audience that nobody else has been specifically concentrating on but could make the greatest impact on the diagnostic odyssey and the challenges that follow: medical students and doctors.

In 2024 Medics 4 Rare Diseases decided to become known as Medics for Rare Disease - a small but important change that aligns with our own training. The charity advocates for a Rare Aware approach to medical training and practice. Doctors do not need to name or know about 1000s of rare diseases however they do need to understand the prevalence of rare disease (6%), when to suspect a patient may have an undiagnosed rare disease and know how to effectively care for their rare disease patients. After 18 months of reflection and discussion the Trustees and Staff decided that...

**Our vision** is equitable healthcare for everybody.

**Our mission** is to shape a medical profession that can provide a timely diagnosis and excellent care for people living with rare disease.

All of our activities fall under three strategic pillars:

- Advocacy
- Training
- Network

Our main target audience is medical students, doctors and those that govern or train these two groups. However we also work with other healthcare professionals and can't do any of our work without the generous collaboration of Patient Advocacy Groups and individuals within the rare community. Please refer to the section on 2024 activities for more details.

# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2024

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#### **Wider network:**

M4RD collaborates with many umbrella and disease-specific rare disease advocacy groups in order to achieve its objectives. To name a few: CamRare, Genetic Alliance UK, Rare Revolution Magazine, Breaking Down Barriers, Rare Community Network, Rareminds, Metabolic Support UK and EDIRA.

M4RD also partners with Beacon to run the annual 'Student Voice Prize' essay competition and with The Royal Society of Medicine to host its annual symposium 'The Unusual Suspects'. Both are UK registered charities.

M4RD works with the UK Government's Department of Health and Social Care in relation to The UK Rare Diseases Framework.

M4RD has a global reach, working with Medscape and The Global Nursing Network and is a Commissioner for The Lancet's Global Commission on Rare Disease.

M4RD receives pro bono support from the health communications agency, [Emotive](#). The charity also depends on volunteers to contribute to projects and speak at events.

#### **Achievements and performance**

##### **Chair comments**

2024 marked a pivotal year for Medics 4 Rare Diseases, defined by the fresh energy of an increased number of staff and work towards a bold new identity. The work on our rebrand has not only modernised our look but also given us an opportunity to reaffirm our commitment to patient-centered medical education about rare disease. This year saw us deliver training to hundreds of medical students, doctors and other healthcare professionals, and continue providing our flagship Rare Disease 101 online learning, which is now reaching wider and more diverse audiences than ever before.

We were proud to contribute to the four nations' Rare Disease Action Plans, take part in Rare Disease Day Celebration at the Houses of Parliament, and strengthen our voice through collaborative work with NHS England and patient organisations. These efforts, combined with the dedication of our staff, trustees, and supporters, have helped move the needle so that rare is no longer synonymous with overlooked. As we look to the future, we remain focused on driving systemic change so that every medic is equipped to serve patients with rare conditions—confidently, compassionately, and competently.

Mr Chris France  
Trustee and Chair

##### **CEO comments**

The end of 2024 saw the end of an 18 month chapter in the life of the charity and the start of the next phase. In 2011 we started as Barts and London Rare Disease Society, by 2014 we had become Students 4 Rare Diseases. We graduated to Medics 4 Rare Diseases in 2018 and we end 2024 as Medics for Rare Disease. Each name change signifies an adaptation to the changing landscape of rare disease in the consciousness of medical professionals. Our new name better suits our ethos and our tag line of 'excellence in rare disease training' reflects that rare disease medical training is a necessity not a nicety. And any rare disease training needs to be of top quality standard in order to meet the needs of this large and marginalised patient population.

I am so grateful to the Trustee and Staff team for their perseverance during this time of re-evaluation and I look forward to seeing how the public respond to the charity's new look and direction when it's launched in 2025.

Dr Lucy McKay  
CEO

# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT (CONTINUED)

**FOR THE YEAR ENDED 31 DECEMBER 2024**

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### **ADVOCACY Achievements**

#### **Rare Disease Day**

Building on the success of last year's Error in formula ->#ShowYourStripes<- campaign, we targeted whole teams of HCPs, alongside key individual contacts. We increased our audience, reaching new teams and groups of HCPs, whilst also contacting those HCPs who took part last year and asking them to help spread the word by sharing the message with a colleague or 'Rare Ally'.

Dozens of branded, shiny red envelopes containing stripey socks, posters and personalised letters were posted. Letters and key messages were tailored to the different audiences. We strengthened our relationships with those who took part last year by sending them fun new, colourful stripey socks for themselves plus a black and white pair to give to a colleague and spread the message by word-of-mouth.

Buy-in was overwhelming, with involvement from healthcare professionals and advocates across the globe. We received over 200 photos, many of which were group shots! Medics of all sorts took part, from GPs, acute and general physicians and surgeons through to paediatricians, neurologists, obstetricians! There was also an incredible effort from nurses, geneticists, medical students and teams of loyal advocates. Furthermore, a whole school got involved and we managed to get some lovely local media coverage of the story!

#### **Policy**

M4RD has been granted permission by The Department of Health and Social Care to create an Independent Advisory Group for The UK Rare Diseases Framework Forum. The purpose of this group is to bring expertise from across the four Nations together to combine efforts for addressing Priority 2, 'Healthcare Professional Awareness'. The group is in its early stages and we will keep you updated on progress made in the next update.

#### **Defining clinical excellence**

M4RD is now a Registered Stakeholder with NICE, contributing to consultations. In 2024 M4RD gave guidance as part of the consultation on 'NICE integrated topic prioritisation and strategic principles' which we saw as a chance to ensure Rare Disease is integrated into all decision making and decision making takes into account the unique challenges in RD.

M4RD's Ambassadors contributed valuable clinical and lived experience insight for the consultation on NICE Clinical Guidelines for Adrenal Insufficiency in July 2024. Adrenal insufficiency is the core issue in Addison's Disease, and is also a component of many other rare conditions. This condition starts in early life and can be fatal if not diagnosed and treated competently - both diagnosis and treatment are well known and understood however the condition remains poorly managed due to a lack of HCP awareness. This leaves individuals and families at risk and anxious, having to always advocate despite the condition being well understood.

We also consulted with other advocacy groups with an interest in the timely diagnosis and management of adrenal insufficiency to ensure we reinforced their input as well. You can listen to an episode with Dr Grace Knight whose brother has Addison's Disease [here](#) to find out more about this process and what it means to families.

#### **The Lancet's Global Commission on Rare Diseases**

The [Lancet's Global Commission on Rare Diseases](#) is a new global initiative dedicated to generating evidence and equity-informed recommendations that are implementable and impactful across the world to dramatically improve the lives of People Living with a Rare Disease (PLWRD). The initiative brings together 27 commissioners representing countries around the world to make recommendations on implementing global recognition and action. Split between 5 working groups each focussed on a different challenge faced by PLWRD.

Lucy McKay is a Commissioner and Co-Chair of Working Group 2, researching the visibility of PLWRD in society and achievement of social justice. We will be working alongside collaborators to generate evidence based recommendations and actions towards societal justice for PLWRD. To ensure that all people living with a rare condition are supported by society and services to live well and that their voices are heard globally.

# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2024

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#### **The Rare Disease Podcast 4 Medics**

We published 26 new episodes of [The Rare Disease Podcast 4 Medics](#) in 2024. By the end of 2024 7 Seasons of the podcast had been completed encompassing 74 episodes and reaching 14,000 downloads. The podcast's title was changed to The Rare Disease Podcast in order to broaden its appeal and guests include advocates, clinicians, authors, researchers.

The Rare Disease Podcast for Medics is available on Apple Podcasts and Spotify, as well as other major podcast providers. It is rated five stars and is often the way that people first hear about the charity.

The best performing episode of Season 6 was an interview with Bonnie Jackson who is the mum of a young girl living with a rare connective tissue disorder. Vascular EDS can seem invisible however it can be fatal if not managed appropriately. Bonnie discussed the importance of timely diagnosis and HCPs knowing where to go for help diagnosing suspected undiagnosed genetic conditions. The episode is called 'Think Rare Think Genetics'.

The episode podcast discussing *"Two for Joy - the uplifting true story of one courageous family's life of happiness with severely disabled twins"* by James Melville-Ross was the best performing episode of Season 7, with 136 downloads so far and proves book reviews are popular with our audience.

#### **TRAINING Achievements**

##### **NHS England: Genomics Education Programme**

So much has been achieved from the collaboration between NHS England's [Genomics Education Programme](#) and M4RD. M4RD co-hosted an online webinar in January 'Building NHS healthcare professional awareness resources' to hear from the rare disease community, and over 30 people attended, which enabled a fantastic conversation about mental health and transition of care in rare disease. Four knowledge summaries were published to GeNotes on RDD.

M4RD hosted an in-person workshop in Birmingham with the GEP team to explore and advise on GEP's strategic priorities and to determine how we could continue to support the development of this trusted resource for healthcare professionals.

##### **Red Flags of Rare Disease Survey results published in OJRD**

M4RD is proud to announce our most recent study, published in the Orphanet Journal of Rare Diseases. The study has identified seven key clinical clues, or 'red flags', that point to a possible underlying rare condition. The findings will aid the development of clinical decision-making tools for healthcare professionals, such as general practitioners. The aim of such tools will be to help the user detect when a patient may have an underlying undiagnosed rare condition, thereby shortening the diagnostic odyssey. The study was authored by Dr Lucy McKay, alongside Dr Mariam Al-Attar (M4RD Ambassador) and Dr Sondra Butterworth (RareQOL/EDIRA). With thanks to Costello Medical's pro bono support to get the final manuscript completed and published. You can read the full [report here](#).

We are so proud of this study, which really launched M4RD into the rare advocacy world in 2018 and now is finally part of medical literature. We know - from our network of patients, families and advocates - that clinical recognition of 'rare disease' can greatly improve patient outcomes. Whilst 'rare disease' isn't a final diagnosis, it is often the turning point in clinical management that directs patients towards the investigation, care and support they need.

Since its publication the results of this research have already been used for training healthcare professionals. The example above demonstrates the difference between expert opinions from clinicians vs PAGs. The message is that HCPs must use a mix of expert resources in order to develop a gut feeling for when someone may have an undiagnosed rare condition.

##### **The Unusual Suspects: Rare disease in everyday medicine 2024**

2024 marked 10 years since the event was first hosted at the RSM and M4RD's Annual Meeting has become a key date for everyone's diaries where healthcare professionals, students, educators, patients and carers gather to raise awareness and emphasise the importance of a holistic approach to rare disease, providing tips to improve the diagnostic journey and management.

# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2024

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The in-person tickets for the 21st February at the Royal Society of Medicine were SOLD OUT and over 200 participants registered for the online streaming/watch on demand option. This year, the focus of the event was on communication with those impacted by rare disease. Focusing on how communication can be a doctor's greatest tool or greatest weapon, speakers provided training on how to provide psychologically informed care.

A full report from the event [available here](#).

*"I found the event to be really helpful and eye-opening. As a medical student we are taught to identify high yield topics and ignore the rare/less important ones. We are trained to give care to the wide public, and not trained to cater to specific needs of people with serious diseases. Attending this webinar changed my point of view, and showed me how I can implement small changes and improve care for all patients."*

Many thanks to the RSM Medical Genetics Section for supporting us with our event and allowing us to use their prestigious platform.

### **First Do No Harm: Expert reflections on a rare bone condition**

In February M4RD organised an event at the Royal College of Surgeons of England in association with FOP Friends and the Hunterian Museum. This event for HCPs highlighted the challenges faced by rare disease patients through the rare bone condition Fibrodysplasia Ossificans Progressiva (FOP). The variety of speakers took us on a journey of understanding the history of FOP and the realities of living with the condition. After the talks, delegates visited the skeleton of Mr Jeffs, a gentleman who lived with FOP in the 18th Century. The Hunterian Museum is keen to continue working with M4RD to use their collection for greater understanding about rare conditions.

*"The speakers were exceptional. Their honesty of the people with rare diseases was disarming and very moving. Hearing their stories will stay with me forever and positively influence my interactions with patients in the future."*

### **Postgraduate Rare Disease 101 Training**

M4RD was delighted to work with Sheffield Teaching Hospitals NHS Foundation Trust to deliver mandatory Rare Disease 101 training to Foundation Year 1 doctors for a second year. 80 doctors joined us over two dates in September and October for the first of three sessions exploring the impact of rare conditions on impacted people. 93% of attendees who returned feedback rated the training session as either good or very good.

### **GP VTS Training**

Upon graduation, all UK doctors complete the two-year Foundation Programme, after which time many doctors choose to enter further formal training. General Practice Specialty Training (GPST) accommodates the largest number of doctors taking this route, with 3935 available ST1 training places in England in 2023.

Whilst it would be unrealistic for GPs to be experts in thousands of rare conditions, it is crucial that they appreciate when a person could be presenting with symptoms attributable to a rare condition and where to access further diagnostic support. As the "gatekeepers" of NHS healthcare, they must also be able to effectively coordinate the complex care of those impacted by rare conditions.

In November, M4RD delivered updated training to sixty three GP trainees. Following training, attendees felt more confident in their understanding of the common challenges faced by those impacted by rare conditions and had an improved understanding of resources that could assist them in supporting these patients. The percentage of GP trainees who felt that learning about rare conditions was either important or very important in relation to their clinical practice increased from 59% to 96%.

### **Online Training**

'Rare disease 101: an online resource teaching on over 7000 rare diseases in one short course' is being used to inform resources for other healthcare educators. At the end of 2024 [M4RD: Learn](#) has 2068 users, across 79 countries. The median length of medical training amongst users was 6.5 years (based on those who provided this info).

The study evaluates Rare Diseases 101, an online training designed and created by M4RD with the assistance - as always - of the rare community. Dr Thomas Dunne and M4RD trustee Dan Jeffries performed the evaluation and authored the study, alongside M4RD's CEO, Dr Lucy McKay. Read the [report here](#).

# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2024

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### NETWORK Achievements

#### M4RD Ambassadors Programme

On the lead up to Rare Disease Day, M4RD's Ambassadors delivered Rare Disease 101 training sessions in various settings including to: neonatal colleagues at The Royal London Hospital, Respiratory colleagues in Poole, the Paediatrics Department at Colchester Hospital, the University of Manchester Students Union, GP trainee doctors from around Dorset and a group of nurses in Wales during their development day.

We encourage ambassadors to not only engage with each other on our private forums, but have also introduced regular online brews. These sessions have been so popular and have really helped the ambassadors to unite and feel part of a team.

*"I genuinely think the ambassador programme is amazing! The addition of the online brews and the end of year in-person meetings have been very positive and it has been amazing to meet so many different people so passionate about rare diseases!"*

In July, our second annual 'Ambassador Lunch & Learn' took place in Clerkenwell Green, London, and was attended by ambassadors from all over the UK - many who were meeting each other for the first time! You can read the report [here](#).

*"M4RD has become a sacred space where I am heard, where I am seen, where I am believed. It has allowed me to rebuild trust in medical professionals and to seek to understand why things are the way they are, and what we can do to change them."*

In September, M4RD welcomed its new cohort with an evening induction session attended by 26 new ambassadors and 3 alumni. 35 new ambassadors joined M4RD this year bringing our total of ambassadors 'on programme' to 57 PLUS 18 ambassadors who graduated to our alumni!

To accommodate the growing numbers of interested applicants and to maximise benefit to both the charity and those who offer their time to us, successful applicants to M4RD's ambassador programme will now be eligible for a maximum two-year tenure, after which time they will graduate to Ambassador Alumni. This will ensure that M4RD retains capacity to onboard new ambassadors at the beginning of each academic year, increasing the reach of the programme whilst acknowledging the valued input of our alumni and maintaining the charity's connection with them. Over the next few months M4RD will consult and consider how to best serve our cohort of Ambassador Alumni to maintain their engagement with the charity.

*"When I make my debut onto the wards for the first time as a doctor, I will take forward the lessons that I have learnt from the Lunch and Learn, and from the wonderful people that I have met through M4RD. I know that there are tough and stressful times ahead, but being involved in this group of student, clinical and patient ambassadors will make me a better doctor going forwards, for both people who live with a rare disease and those who don't."*

The M4RD team would like to thank all the [Ambassadors](#) for playing such a pivotal role in enabling M4RD to work with the wider rare disease community and making sure that the patient voice is heard through our work.

#### The Student Voice Prize 2024

The [Student Voice Prize](#) (SVP) is our international essay competition that shines a light on rare conditions amongst budding healthcare professionals and students of the life sciences. Delivered in partnership with Beacon for Rare Diseases thanks to generous sponsorship from Emotive, the 2024 competition saw 123 essays submitted by students from 52 universities across 18 countries - an increase in entries of nearly a quarter from 2023!

What makes the SVP unique is our patient group pairing scheme, offering students the chance to be paired with a rare disease patient or advocate to learn first-hand about their condition and patient experience. This enhances not only their essay submission, but more importantly ensures their future practice will be informed by the lived reality of those impacted by rare conditions.

*"Exploring rare conditions through the lens of the SVP has been a profound journey of discovery, empathy, and a deepened appreciation for the complexities of human health. Each case is a testament to the resilience of individuals facing unique challenges, inspiring me to advocate for greater awareness and understanding in the realm of rare diseases."*

# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2024

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#### Financial Review

##### Financial Position

The budget for this financial year was decided based on the goals we set out to achieve in 2024 towards the M4RD strategy. We set out to raise £372k in order to fund activities for 2024. In total £274K of funding was secured through sponsorship, donations and contracts.

Total funds carried forward at the end of 2024 is £113,210

The final cash position is £72,327\*

\*£40,000 kept in a 60 Day Savings Account with CAF Bank

##### Principal Funding Sources

The principal funding sources for this period were as follows.

*Sponsorship* by commercial companies via the charity's Partnership Programme. Partner companies included: Alexion Therapeutics, Alnylam, Amicus Therapeutics, BioCryst, Kyowa Kirin, Novartis, Orchard Therapeutics, PTC Therapeutics, SOBI, Takeda UK, and UCB.

*Donations* from Takeda UK, Ultragenyx and individuals.

*Charitable grants* from the Hamamelis Trust and Souter Charitable Trust.

*Contracted services* by Alexion Pharmaceuticals, Amicus, Costello Medical, LifeArc, Intent Health, Medscape, NHS England, NIHR Rare Care Project, Simbec Orion and The Royal College of General Practitioners.

*Pro Bono* work was provided by Emotive to the value of £66,000.

##### Reserves Policy and Review

The Reserves Policy was put in place by The Board of Trustees in 2019. Reserves are to be maintained at a level that ensures that the charity's core activity could continue during a 3 month period of unforeseen financial difficulty during which funding is to be secured. If funding is not secured then this is followed by a 3 month period in which the organisation could be dissolved with all outstanding debt settled.

##### Financial Risk

The staff team and Trustees can all work from home or remotely in an appropriate location so the charity doesn't own property or have a long term rental contract. M4RD's biggest financial commitment is staff. The majority of the charity's work is done 'in house' or provided to M4RD on a pro bono basis therefore external contracts for services are kept to a minimum.

M4RD continues to bank with CAF Bank, which allows a good level of financial oversight by the Treasurer and other Trustees. All the Trustees have access to the online banking system and all payments require two-person authorisation.

The main financial risk, as always, is if funding is not secured. In previous years M4RD has relied predominantly on commercial donations and sponsorship. However, since 2022 the charity has started diversifying funding avenues in order to reduce risk from losing sponsors by identifying grantmakers that M4RD could apply to for charitable funding.

The Trustees also have procedures to alert them early on to a financial short-fall and to act appropriately depending on the situation. This includes a Reserves Policy and close monitoring of actual income vs requested income, and expenditure against the budget set for the year. In 2024, M4RD did not meet its fundraising target however due to its internal policies and procedures the charity was not put at financial risk and was able to meet its key objectives for the year. This demonstrates that these safety nets are helpful for managing risk.

# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2024

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#### Plans for future periods

In 2025 Medics 4 Rare Diseases aims to define its next 5 years of strategy. It will need to scale in order to keep up with demand for delivery of Rare Disease 101 and provision of expert advice.

- Our vision is equitable healthcare for everybody.
- Our mission is to shape a medical profession that can provide a timely diagnosis and excellent care for people living with rare disease.

We achieve our mission through our three strategic pillars of work and all our activities contribute to the overarching goal under that pillar:

**ADVOCACY:** Medics for Rare Disease advocates for a Rare Aware approach to education for all medical professionals

**TRAINING:** Medics for Rare Disease creates and provides Rare Aware medical training

**NETWORK:** Medics for Rare Disease is building a Rare Aware network of global healthcare professionals and advocates

Our main aims in 2025 will be:

1. Launch the new branding including a working name change to Medics for Rare Disease
2. Rare Disease Day 2025 Error in formula ->#ShowYourStripes<- campaign
3. Launch the new Medics for Rare Disease Website
4. Providing Rare Disease 101 training to our target audience
5. Run The Ambassador Programme
6. Launch Season 8 of The Rare Disease Podcast
7. Carry out research as a Commissioner of The Lancet's Global Commission on Rare Diseases

#### Organisational plans:

The new working name, Medics for Rare Disease, and brand will be publicly launched in January 2025. In early 2025 the new Trustees will settle in and have an induction. Chris France will remain interim Chair until the annual Strategy Meeting. The charity also plans to further diversify its income through applying for more charitable grants.

#### Future funding:

Medics 4 Rare Diseases' budget for 2025 is £344k, it carries forward £113k from 2024, and will raise the balance of funds through a diversified funding raising strategy that will target established funding sources, newly identified grant gives and exploring philanthropic opportunities.

#### Events after the end of the reporting period

Particulars of events after the reporting date are detailed in note 20 to the financial statements.

#### Small company provisions

This report has been prepared in accordance with the provisions applicable to companies entitled to the small companies exemption.

# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT (CONTINUED)

**FOR THE YEAR ENDED 31 DECEMBER 2024**

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### **Statement of Trustees' annual responsibilities**

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

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

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

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

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

The trustees' annual report was approved on ..... and signed on behalf of the board of trustees by:

Mr Chris France  
**Trustee and Chair**

7 September 2025

# MEDICS 4 RARE DISEASES

## INDEPENDENT EXAMINER'S REPORT

### TO THE TRUSTEES OF MEDICS 4 RARE DISEASES

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I report to the Trustees on my examination of the financial statements of Medics 4 Rare Diseases (the Charity) for the year ended 31 December 2024.

#### **Responsibilities and basis of report**

As the Trustees of the Charity you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011.

I report in respect of my examination of the Charity's financial statements carried out under section 145 of the Charities Act 2011. In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the Charities Act 2011.

#### **Independent examiner's statement**

Your attention is drawn to the fact that the charity has prepared the financial statements in accordance with the relevant version of the Statement of Recommended Practice applicable to charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) in preference to the Accounting and Reporting by Charities: Statement of Recommended Practice issued on 1 April 2005 which is referred to in the extant regulations but has now been withdrawn. I understand that this has been done in order for the financial statements to provide a true and fair view in accordance with UK Generally Accepted Accounting Practice.

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

- 1 accounting records were not kept in respect of the Charity as required by section 130 of the Charities Act 2011.
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the applicable requirements concerning the form and content of financial statements set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the financial statements give a true and fair view, which is not a matter considered as part of an independent examination.

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

Caroline Brazier ACA DChA  
Cansdales Business Advisers Limited  
Chartered Accountants  
St Mary's Court  
The Broadway  
Old Amersham  
Bucks  
HP70UT

Dated: 22 September 2025

## MEDICS 4 RARE DISEASES

### STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 DECEMBER 2024

	Notes	Unrestricted funds 2024 £	Restricted funds 2024 £	Total Unrestricted funds 2024 £	Restricted funds 2023 £	Total 2023 £
<b>Income from:</b>						
Donations and legacies	3	28,173	-	28,173	52,962	52,962
Sponsorships	4	167,000	15,000	182,000	164,000	179,000
Investments	5	1,623	-	1,623	770	770
Other income	6	76,433	-	76,433	26,905	26,905
<b>Total income</b>		<b>273,229</b>	<b>15,000</b>	<b>288,229</b>	<b>244,637</b>	<b>259,637</b>
<b>Expenditure on:</b>						
Charitable activities	7	258,314	9,699	268,013	223,107	228,852
<b>Net income for the year/ Net movement in funds</b>		<b>14,915</b>	<b>5,301</b>	<b>20,216</b>	<b>21,530</b>	<b>30,785</b>
Fund balances at 1 January 2024		76,664	16,330	92,994	55,134	62,209
<b>Fund balances at 31 December 2024</b>		<b>91,579</b>	<b>21,631</b>	<b>113,210</b>	<b>76,664</b>	<b>92,994</b>

The statement of financial activities includes all gains and losses recognised in the year.

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Charities Act 2011.

# MEDICS 4 RARE DISEASES

## BALANCE SHEET

AS AT 31 DECEMBER 2024

	Notes	2024 £	£	2023 £	£
<b>Fixed assets</b>					
Intangible assets	14		2,290		2,290
Tangible assets	15		2,314		2,294
			<u>4,604</u>		<u>4,584</u>
<b>Current assets</b>					
Debtors	16	58,587		18,925	
Cash at bank and in hand		72,327		79,269	
		<u>130,914</u>		<u>98,194</u>	
<b>Creditors: amounts falling due within one year</b>	17	(22,308)		(9,784)	
Net current assets			108,606		88,410
<b>Total assets less current liabilities</b>			<u>113,210</u>		<u>92,994</u>
<b>Income funds</b>					
Restricted funds	20		21,631		16,330
Unrestricted funds			91,579		76,664
			<u>113,210</u>		<u>92,994</u>

The company is entitled to the exemption from the audit requirement contained in section 142(2) of Charities Act 2011, for the year ended 31 December 2024. The accounts have been examined by an independent examiner and their report have been included in these financial statements.

The directors acknowledge their responsibilities for complying with the requirements of the Charities Act 2011 with respect to accounting records and the preparation of financial statements.

The financial statements were approved by the Trustees on 7 September 2025

Mr Chris France  
Trustee and Chair

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2024

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### 1 Accounting policies

#### Charity information

Medics 4 Rare Diseases is a public benefit entity and a private company limited by guarantee, registered in England and Wales and a registered charity in England and Wales. The address of the registered office is Unit 12 Treadaway Technical Centre, Treadaway Hill, Loudwater, High Wycombe, HP10 9RS.

#### 1.1 Accounting convention

The financial statements have been prepared on the historical cost basis, as modified by the revaluation of certain financial assets and liabilities and investment properties measured at fair value through income or expenditure.

The financial statements are prepared in sterling, which is the functional currency of the entity.

#### Statement of compliance

These financial statements have been prepared in compliance with FRS 102, 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland', the 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) (Charities SORP (FRS 102)) and the Companies Act 2006.

#### 1.2 Going concern

There are no material uncertainties about the charity's ability to continue.

#### 1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the Trustees in furtherance of their charitable objectives.

Designated funds are unrestricted funds earmarked by the trustees for particular future project or commitment.

Restricted funds are subjected to restrictions on their expenditure declared by the donor or through the terms of an appeal, and fall into one of two sub-classes: restricted income funds or endowment funds.

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2024

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### 1 Accounting policies

(Continued)

#### 1.4 Income

All incoming resources are included in the statement of financial activities when entitlement has passed to the charity; it is probable that the economic benefits associated with the transaction will flow to the charity and the amount can be reliably measured. The following specific policies are applied to particular categories of income:

- income from donations or grants is recognised when there is evidence of entitlement to the gift, receipt is probable and its amount can be measured reliably.
- legacy income is recognised when receipt is probable and entitlement is established.
- income from donated goods is measured at the fair value of the goods unless this is impractical to measure reliably, in which case the value is derived from the cost to the donor or the estimated resale value. Donated facilities and services are recognised in the accounts when received if the value can be reliably measured. No amounts are included for the contribution of general volunteers.
- income from contracts for the supply of services is recognised with the delivery of the contracted service. This is classified as unrestricted funds unless there is a contractual requirement for it to be spent on a particular purpose and returned if unspent, in which case it may be regarded as restricted.

#### 1.5 Expenditure

Expenditure is recognised on an accruals basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is classified under headings of the statement of financial activities to which it relates:

- expenditure on raising funds includes the costs of all fundraising activities, events, non-charitable trading activities, and the sale of donated goods.
- expenditure on charitable activities includes all costs incurred by a charity in undertaking activities that further its charitable aims for the benefit of its beneficiaries, including those support costs and costs relating to the governance of the charity apportioned to charitable activities.
- other expenditure includes all expenditure that is neither related to raising funds for the charity nor part of its expenditure on charitable activities.

All costs are allocated to expenditure categories reflecting the use of the resource. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs are apportioned between the activities they contribute to on a reasonable, justifiable and consistent basis.

#### 1.6 Intangible fixed assets other than goodwill

Intangible asset acquired on account of registration of trademark & logo is recognised at cost incurred on filling the patent with the competent authority.

There is no Amortisation charged for intangible acquired on account of registration of trademark & Logo. The carrying value, however will be reviewed at each Balance sheet date. If an entity determines that one of its trademarks is worth less than it was a year ago, the value of the intangible asset must be impaired. When an impairment occurs, the value of the asset must be decreased to its current market value. The difference between the current value of the trademark and its former value must be recorded as a financial loss.

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2024

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### 1 Accounting policies

(Continued)

#### 1.7 Tangible fixed assets

Tangible assets are initially recorded at cost, and subsequently stated at cost less any accumulated depreciation and impairment losses. Any tangible assets carried at revalued amounts are recorded at the fair value at the date of revaluation less any subsequent accumulated depreciation and subsequent accumulated impairment losses.

An increase in the carrying amount of an asset as a result of a revaluation, is recognised in other recognised gains and losses, unless it reverses a charge for impairment that has previously been recognised as expenditure within the statement of financial activities. A decrease in the carrying amount of an asset as a result of revaluation, is recognised in other recognised gains and losses, except to which it offsets any previous revaluation gain, in which case the loss is shown within other recognised gains and losses on the statement of financial activities.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Computers	25% Reducing Balance method
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The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in the statement of financial activities.

#### 1.8 Impairment of fixed assets

A review for indicators of impairment is carried out at each reporting date, with the recoverable amount being estimated where such indicators exist. Where the carrying value exceeds the recoverable amount, the asset is impaired accordingly. Prior impairments are also reviewed for possible reversal at each reporting date.

For the purposes of impairment testing, when it is not possible to estimate the recoverable amount of an individual asset, an estimate is made of the recoverable amount of the cash-generating unit to which the asset belongs. The cash-generating unit is the smallest identifiable group of assets that includes the asset and generates cash inflows that largely independent of the cash inflows from other assets or groups of assets.

#### 1.9 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

#### 1.10 Financial instruments

A financial asset or a financial liability is recognised only when the charity becomes a party to the contractual provisions of the instrument.

Basic financial instruments are initially recognised at the amount receivable or payable including any related transaction costs.

Current assets and current liabilities are subsequently measured at the cash or other consideration expected to be paid or received and not discounted.

Debt instruments are subsequently measured at amortised cost.

Where investments in shares are publicly traded or their fair value can otherwise be measured reliably, the investment is subsequently measured at fair value with changes in fair value recognised in income and expenditure. All other such investments are subsequently measured at cost less impairment.

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2024

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#### 1 Accounting policies

(Continued)

Other financial instruments, including derivatives, are initially recognised at fair value, unless payment for an asset is deferred beyond normal business terms or financed at a rate of interest that is not a market rate, in which case the asset is measured at the present value of the future payments discounted at a market rate of interest for a similar debt instrument.

Other financial instruments are subsequently measured at fair value, with any changes recognised in the statement of financial activities, with the exception of hedging instruments in a designated hedging relationship.

Financial assets that are measured at cost or amortised cost are reviewed for objective evidence of impairment at the end of each reporting date. If there is objective evidence of impairment, an impairment loss is recognised under the appropriate heading in the statement of financial activities in which the initial gain was recognised.

For all equity instruments regardless of significance, and other financial assets that are individually significant, these are assessed individually for impairment. Other financial assets are either assessed individually or grouped on the basis of similar credit risk characteristics.

Any reversals of impairment are recognised immediately, to the extent that the reversal does not result in a carrying amount of the financial asset that exceeds

#### **Basic financial assets**

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

#### **Basic financial liabilities**

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

#### **Derecognition of financial liabilities**

Financial liabilities are derecognised when the Charity's contractual obligations expire or are discharged or cancelled.

#### 1.11 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the Charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

#### 1.12 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2024

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#### 1 Accounting policies

(Continued)

##### 1.13 Fund accounting

Unrestricted funds are available for use at the discretion of the trustees to further any of the charity's purposes.

Designated funds are unrestricted funds earmarked by the trustees for particular future project or commitment.

Restricted funds are subjected to restrictions on their expenditure declared by the donor or through the terms of an appeal, and fall into one of two sub-classes: restricted income funds or endowment funds.

##### 1.14 Defined contribution plans

Contributions to defined contribution plans are recognised as an expense in the period in which the related service is provided. Prepaid contributions are recognised as an asset to the extent that the prepayment will lead to a reduction in future payments or a cash refund.

When contributions are not expected to be settled wholly within 12 months of the end of the reporting date in which the employees render the related service, the liability is measured on a discounted present value basis. The unwinding of the discount is recognised as an expense in the period in which it arises.

##### 1.15 Limited by guarantee

Medics 4 Rare Disease Ltd is a company limited by guarantee and accordingly does not have a share capital.

Every member of the company undertakes to contribute such amount as may be required not exceeding £1 to the assets of the charitable company in the event of its being wound up while he or she is a member, or within one year after he or she ceases to be a member.

#### 2 Critical accounting estimates and judgements

In the application of the Charity's accounting policies, the Trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

##### Critical judgements

The preparation of the financial statements requires management to make judgements, estimates and assumptions that affect the amounts reported. These estimates and judgements are continually reviewed and are based on experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances.

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2024

### 3 Donations and legacies

	Unrestricted funds	Total Unrestricted funds		Total
	2024 £	2024 £	2023 £	2023 £
Donations and gifts	22,673	22,673	46,287	46,287
Other	5,500	5,500	6,675	6,675
	<u>28,173</u>	<u>28,173</u>	<u>52,962</u>	<u>52,962</u>

### 4 Income from charitable activities

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
Sponsorships	<u>167,000</u>	<u>15,000</u>	<u>182,000</u>	<u>164,000</u>	<u>15,000</u>	<u>179,000</u>

### 5 Investments

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Interest receivable	<u>1,623</u>	<u>770</u>

### 6 Other income

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Other income	<u>76,433</u>	<u>26,905</u>

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2024

### 7 Charitable activities

	Activities undertaken directly	Support costs	Total	Activities undertaken directly	Support costs	Total
	2024	2024	2024	2023	2023	2023
	£	£	£	£	£	£
Staff costs	174,347	-	174,347	156,077	-	156,077
Depreciation	730	-	730	732	-	732
Rent	4,503	-	4,503	6,590	-	6,590
Insurance	1,822	-	1,822	438	-	438
Telephone	48	-	48	48	-	48
Computer expenses	7,195	-	7,195	7,615	-	7,615
Subscriptions	1,407	-	1,407	159	-	159
Bank charges	100	-	100	66	-	66
Administration support	1,583	-	1,583	275	-	275
Advertising and marketing	16,408	-	16,408	11,879	-	11,879
Event costs	18,264	-	18,264	8,435	-	8,435
Travelling and subsistence	12,355	-	12,355	11,502	-	11,502
Postage and Print	982	-	982	1,346	-	1,346
Consultancy	21,136	-	21,136	14,783	-	14,783
Staff welfare and training	1,642	-	1,642	1,744	-	1,744
Other Cost	12	5,479	5,491	113	7,050	7,163
	<u>262,534</u>	<u>5,479</u>	<u>268,013</u>	<u>221,802</u>	<u>7,050</u>	<u>228,852</u>
<b>Analysis by fund</b>						
Unrestricted funds	252,835	5,479	258,314	216,057	7,050	223,107
Restricted funds	9,699	-	9,699	5,745	-	5,745
	<u><u>262,534</u></u>	<u><u>5,479</u></u>	<u><u>268,013</u></u>	<u><u>221,802</u></u>	<u><u>7,050</u></u>	<u><u>228,852</u></u>

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2024

### 8 Support costs

	2024 £	2023 £
Independent examination	1,386	1,320
Other assurance services	4,092	5,730
	<u>5,478</u>	<u>7,050</u>

### 9 Net movement in funds

	2024 £	2023 £
Net movement in funds is stated after charging/(crediting)		
Depreciation of owned tangible fixed assets	<u>730</u>	<u>732</u>

### 10 Trustees

None of the Trustees (or any persons connected with them) received any remuneration or benefits from the Charity during the year. However, the trustees are reimbursed for legitimate costs that the trustees have had to meet personally to carry out their duties.

£Nil (2023: £900) was paid to Mr D Jeffries, one of the trustees, for his professional services in setting up e-learning facilities for the charity.

### 11 Employees

The average monthly number of employees during the year was:

	2024 Number	2023 Number
Charitable activities	<u>5</u>	<u>5</u>

#### Employment costs

	2024 £	2023 £
Wages and salaries	160,901	144,715
Social security costs	10,510	8,277
Other pension costs	2,936	3,085
	<u>174,347</u>	<u>156,077</u>

Out of the above employment cost, amounting to £Nil (2023:£4,845) forms part of restricted expenditure.

There were no employees whose annual remuneration was more than £60,000.

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2024

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### 12 Pensions and other post retirement benefits

#### Defined contribution plans

The amount recognised in income or expenditure as an expense in relation to defined contribution plans was £2,936 (2023: £3,085).

### 13 Taxation

The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.

### 14 Intangible fixed assets

	Intangibles Assets £
<b>Cost</b>	
At 1 January 2024 and 31 December 2024	2,290
	<hr/>
<b>Amortisation charge</b>	
At 1 January 2024 and 31 December 2024	-
	<hr/>
<b>Carrying amount</b>	
At 31 December 2024	2,290
	<hr/> <hr/>
At 31 December 2023	2,290
	<hr/> <hr/> <hr/>

### 15 Tangible fixed assets

	Computers £
<b>Cost</b>	
At 1 January 2024	4,332
Additions	750
	<hr/>
At 31 December 2024	5,082
	<hr/>
<b>Depreciation charge</b>	
At 1 January 2024	2,038
Depreciation charged in the year	730
	<hr/>
At 31 December 2024	2,768
	<hr/>
<b>Carrying amount</b>	
At 31 December 2024	2,314
	<hr/> <hr/>
At 31 December 2023	2,294
	<hr/> <hr/> <hr/>

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2024

<b>16 Debtors</b>		<b>2024</b>	<b>2023</b>
		£	£
<b>Amounts falling due within one year:</b>			
Trade debtors		25,000	13,643
Prepayments and accrued income		33,587	5,282
		<u>58,587</u>	<u>18,925</u>

<b>17 Creditors: amounts falling due within one year</b>		<b>2024</b>	<b>2023</b>
		£	£
	<b>Notes</b>		
Other taxation and social security		4,983	3,413
Deferred income	<b>18</b>	15,000	-
Trade creditors		1,934	3,429
Accruals		391	2,942
		<u>22,308</u>	<u>9,784</u>

<b>18 Deferred income</b>		<b>2024</b>	<b>2023</b>
		£	£
Other deferred income		15,000	-
		<u>15,000</u>	<u>-</u>

Deferred income is included in the financial statements as follows:

		<b>2024</b>	<b>2023</b>
		£	£
Deferred income is included within:			
Current liabilities		15,000	-
		<u>15,000</u>	<u>-</u>
Movements in the year:			
Deferred income at 1 January 2024		-	-
Resources deferred in the year		15,000	-
		<u>15,000</u>	<u>-</u>
Deferred income at 31 December 2024		<u>15,000</u>	<u>-</u>

<b>19 Retirement benefit schemes</b>		<b>2024</b>	<b>2023</b>
		£	£
<b>Defined contribution schemes</b>			
Charge to profit or loss in respect of defined contribution schemes		2,936	3,085
		<u>2,936</u>	<u>3,085</u>

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2024

#### 19 Retirement benefit schemes

(Continued)

The Charity operates a defined contribution pension scheme for all qualifying employees. The assets of the scheme are held separately from those of the Charity in an independently administered fund.

#### 20 Restricted funds

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

	At 1 January 2024	Incoming resources	Resources expended	At 31 December 2024
	£	£	£	£
M4RD Learn	16,330	15,000	(9,699)	21,631
	<u>16,330</u>	<u>15,000</u>	<u>(9,699)</u>	<u>21,631</u>
<b>Previous year:</b>	<b>At 1 January 2023</b>	<b>Incoming resources</b>	<b>Resources expended</b>	<b>At 31 December 2023</b>
	£	£	£	£
M4RD Learn	7,075	15,000	(5,745)	16,330
	<u>7,075</u>	<u>15,000</u>	<u>(5,745)</u>	<u>16,330</u>

#### 21 Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 January 2024	Incoming resources	Resources expended	At 31 December 2024
	£	£	£	£
General funds	76,664	273,229	(258,314)	91,579
	<u>76,664</u>	<u>273,229</u>	<u>(258,314)</u>	<u>91,579</u>
<b>Previous year:</b>	<b>At 1 January 2023</b>	<b>Incoming resources</b>	<b>Resources expended</b>	<b>At 31 December 2023</b>
	£	£	£	£
General funds	55,134	244,637	(223,107)	76,664
	<u>55,134</u>	<u>244,637</u>	<u>(223,107)</u>	<u>76,664</u>

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2024

### 22 Analysis of net assets between funds

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
Fund balances at 31 December 2024 are represented by:						
Intangible fixed assets	2,290	-	2,290	2,290	-	2,290
Tangible assets	2,314	-	2,314	2,294	-	2,294
Current assets/(liabilities)	86,975	21,631	108,606	72,080	16,330	88,410
	<u>91,579</u>	<u>21,631</u>	<u>113,210</u>	<u>76,664</u>	<u>16,330</u>	<u>92,994</u>

### 23 Related party transactions

During the year the Charity entered into the following transactions with related parties:

Consulting fees of £Nil (2023- £600) paid to Dan Jeffries who is trustees of charity.

Reimbursement of expenses amounting to £62 was paid to Dan Jeffries during the year (2023: £Nil).  
Additionally, travel expenses of £234 were reimbursed to Chris France (2023: £Nil).

**MEDICS 4 RARE DISEASES**

England & Wales - Charity number 1183996

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# Accounts

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Charity registration number 1183996

**MEDICS 4 RARE DISEASES**  
**ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 DECEMBER 2023**

# MEDICS 4 RARE DISEASES

## LEGAL AND ADMINISTRATIVE INFORMATION

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<b>Trustees</b>	Dr Debra Fine Mr Chris France Dr Olivia Grant Mr Daniel Jeffries Mrs Lindsay Birrell
<b>Secretary</b>	Dr L M R McKay
<b>Charity number</b>	1183996
<b>Company number</b>	11119884
<b>Principal address</b>	Unit 12 Treadaway Technical Centre Treadaway Hill Loudwater High Wycombe HP10 9RS
<b>Bookkeeping and payroll</b>	Adder Bookkeeping
<b>Independent Examiner</b>	Samir Shah ATII, FCA SKS Ramon Lee 93 Tabernacle Street London EC2A 4BA

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# **MEDICS 4 RARE DISEASES**

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# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT

### FOR THE YEAR ENDED 31 DECEMBER 2023

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The Trustees present their annual report and financial statements for the year ended 31 December 2023.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the Charity's governing document, the Charities Act 2011 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (effective 1 January 2019).

#### Structure, governance and management

Trustees have been appointed to the M4RD board based on their experience, skills and enthusiasm for the work of M4RD. M4RD relies on the voluntary time that its Trustees generously provide to advance the purposes of the charity. The minimum number of Trustees is 3 and there is no maximum number. The requirements to be considered for the position of Trustee are outlined in the Charity's CIO Constitution. Trustee Induction is provided by the CEO with input from the Chair of Trustees. This is carried out remotely. The new Trustee is provided with a New Trustee Induction Pack and access to the Charity's documents. M4RD makes use of readily available online training created by other organisations and provides a PDF copy of The Charity Commission's document 'The Essential Trustee'.

The Trustee Board meets quarterly via video conferencing and annually at a face-to-face Strategy Meeting. The CEO, Dr Lucy McKay, is a founding member of the Charity and has been in the role of CEO since September 2018. Lucy is a key opinion leader in the rare disease field having had personal experience of rare disease and training in the NHS as a doctor. She reports to the Trustee Board and is responsible for: implementing the strategy of the charity, as agreed by the Trustees; managing the staff team; oversight of finances and fundraising; and identifying and assessing strategic risks and opportunities.

The current M4RD staff team comprises: Jo McPherson (Operations and Finance Manager) responsible for daily operations, managing the finances, fundraising and patient advocacy group liaison; Dr Emma Huskinson (Communications Lead) responsible for public relations, liaising with press and writing medical content; Eleanor Churchill (Digital Projects Officer) responsible for the development and delivery of digital projects, e.g. M4RD: Learn; the Rare Disease Podcast 4 Medics series; and Nadine Jefferies (Project Coordinator) responsible for delivering the NHS England contract for The Genomics Education Programme, involving the development of the rare disease hub and GeNotes.

Lucy, Jo and Emma work part-time. Both Eleanor and Nadine work full-time. Lucy and Nadine work from a hot desk in an office at the business Analogue Wonderland, High Wycombe (the registered address of the Charity). All remaining staff work from home and report to Lucy who in turn reports to the Chair. Lucy holds weekly 1:1 meetings with the staff team; Jo and Lucy meet weekly with the Chair.

The M4RD Board of Trustees continue to contribute generously to the success of the charity. Two Trustees are GPs and have been involved in M4RD (in its previous forms) since 2011. Dr Olivia Hannah Grant is an international lacrosse player, but for M4RD she provides insight into day to day life and learning needs of being a GP in the NHS. The Treasurer, Dr Debra Fine, was an Accountant prior to training to become a doctor and this range of experience is invaluable to the role.

At the Strategy Meeting in July 2023 Lindsay Birrell was voted in as Chair of M4RD, replacing Chris France whose first term was complete. Lindsay's prior experience working for Metabolic Support UK as CEO has been invaluable to Lucy and the rest of the Trustee Board. After a vote by remaining Trustees, Chris France returned to the Board for his second term as Trustee. Chris' background is in sales and he founded a successful e-commerce company. He played a pivotal role in getting M4RD's structure established, mentoring Lucy and steering the charity in the direction of successful strategies. Now that M4RD has moved on from its start-up phase and his term had come to an end, Chris felt it was time for a new Chair to be appointed.

Dan Jeffries is M4RD's patient representative but has many skills within IT. His day job of creating online interactive educational software means he is able to provide bespoke and greatly discounted services in the creation and development of M4RD's learning management system (M4RD: Learn).

The aims and objectives of the 2023 plan drove the decision making during this period.

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# **MEDICS 4 RARE DISEASES**

## **TRUSTEES' ANNUAL REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2023**

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The Board of Trustees and the CEO are responsible for reviewing and updating the Charity's strategic plan. This was most recently done at M4RD's Strategy Meeting in July 2023, outlining plans to develop a new growth and scaling strategy for the charity.

The CEO uses quarterly Board Meetings to update the Trustees on the progress being made by the charity and to ask questions and receive advice. The CEO is largely responsible for making decisions about activities that achieve the aims and objectives. Large financial decisions (outside of pre-authorised projects) are taken to the board by the CEO to be discussed.

### **Objectives and activities**

M4RD was registered at Companies House as a private company registered by guarantee without share capital (Company Number 11119884) on 20th December 2017. It was registered as a charity in England & Wales (Registered Charity Number 1183996) on 20th June 2019. It became a Charitable Incorporated Organisation (CIO) on 11 July 2022.

Below are the charity's purposes as set out in the objects contained in the Charity's CIO Constitution:

The company is established for the objects of the relief of sickness and preservation of health of those suffering from rare diseases, throughout the world, by:

- (a) advancing the education of medics, associated professionals and the public in rare diseases, genetic and genomic medicine
- (b) promoting research in all areas relating to rare diseases, genetic and genomic medicine and publishing the useful results
- (c) promoting improved care and treatment of those suffering from rare diseases.

### **Aims and public benefit:**

The Charity aims to improve the lives of a certain portion of the public: those living with rare diseases and their communities. It does this through raising awareness of the relevance of rare diseases in medical practice. The Charity provides education about rare disease and opportunities to develop a clinician's understanding of this large population group in the UK in order to better serve it.

### **Review:**

During 2019 the Board of Trustees worked with the Charity Commission to make sure its structure, objects and governing documents were ready for the organisation to be registered as a charity. This required a review of our purposes to make sure they were wholly charitable and benefited the public. In the case of M4RD 'the public' refers to the estimated 3.5 million people in the UK who suffer from a rare disease - and their communities.

Following guidance from the Charity Commission the Board of Trustees adapted the company's original Memorandum & Articles to make sure the wording was suitable for the charity. Subsequently the Charity's CIO Constitution was written to reflect the recommendations from the Charity Commission. The organisation's objects are wholly charitable. Any personal benefit arising is legitimately incidental.

The Board of Trustees review M4RD's objectives, goals and strategies on an annual basis at the Strategy Meeting. This is done with reference to guidance contained in the Charity Commission's general guidance on public benefit.

# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2023

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#### Activities:

A rare disease is defined in the UK as a condition that affects fewer than 5 in 20,000 people. Over 7,000 rare diseases have been identified which means that understanding and teaching about rare diseases in medical education is extremely challenging. However this is a challenge that we cannot afford to avoid because approximately 3.5 million people in the UK have a rare disease. So, while each disease is individually rare, they are collectively common.

Of these diseases, 80% are known to be genetic in origin and 70% present exclusively in childhood. However, despite this large prevalence (equivalent to all adults in the UK who suffer with asthma), each individual condition affects so few people that they tend to be overlooked and misunderstood by health professionals, researchers, education and social care providers and the general public. This lack of awareness amongst medical professions is particularly devastating and can lead to extreme diagnostic delay. A person with a rare disease will wait on average 4-6 years for an accurate diagnosis. They will see numerous doctors, receive misdiagnoses and potentially even inappropriate treatment. This long and arduous journey to a diagnosis has been named "the Diagnostic Odyssey".

The challenges of having a rare disease do not stop after getting a diagnosis. People living with completely different diseases often report the same difficulties in terms of healthcare, social care, family life, education, work and mental health. There are many wonderful charities in the UK that support rare disease patients depending on their disease or specific need. Umbrella charities run successful public awareness campaigns. However, M4RD specifically targets an audience that nobody else has been specifically concentrating on but could make the greatest impact on the diagnostic odyssey and the challenges that follow: medical students and doctors.

By creating a medical profession equipped to suspect, diagnose and manage rare disease we can help people living with rare conditions have the best outcomes and reach their full potential. To do this M4RD is driving providing education and practical tools for medical students and doctors. Without appropriate training, the idea that rare diseases are irrelevant to clinical practice will continue to contribute to the diagnostic odyssey. We remedy this by presenting the statistics to our audience and asking people living with rare conditions to share their stories. M4RD have developed a new approach to satisfactorily cover the subject of rare disease within undergraduate and postgraduate medical training. Finally, we're creating our own resources and promoting others' resources in order to support medical professionals when they need help on the subject of rare disease.

M4RD provides education online events, e-learning, social media, via podcast and in person training events.

#### Wider network:

M4RD collaborates with many umbrella and disease-specific rare disease advocacy groups in order to achieve its objects. To name a few: Cambridge Rare Disease Network, Genetic Alliance UK, Rare Revolution Magazine, Breaking Down Barriers, Rare Community Network, Rareminds, Metabolic Support UK and EDIRA.

M4RD also partners with Beacon to run the annual 'Student Voice Prize' essay competition and with The Royal Society of Medicine to host its annual symposium 'The Unusual Suspects'. Both are UK registered charities.

M4RD receives pro bono support from the health communications agency, emotive. The charity also depends on volunteers to contribute to projects and speak at events.

M4RD was also a founding organisation of an informal group called Action for Rare Disease Empowerment (ARDEnt), alongside Cambridge Rare Diseases Network and Rare Revolution Magazine.

In 2023 M4RD expanded its connections within medical education to working with The Genomics Education Programme in early 2023 to update and expand the content on its Rare Disease Education Hub webpage. M4RD are now working to provide other content for the website and for GeNotes.

Alongside RDIG Wales, University of Cardiff and The University of Oxford, M4RD submitted a bid for funding by LifeArc for a Translational Research Centre for Rare Disease. M4RD contributed to designing a new service for assessing and supporting people with rare conditions in health, social care, education and employment via a hybrid digital and face-to-face enhanced package of care.

With support from one of its Partners, M4RD has been working with the company Medics Academy to create Rare Disease 101 training for Foundation Programme doctors.

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# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2023

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M4RD collaborated with Medscape to interpret and publish a study of the awareness and learning needs of nearly 1000 clinicians in the US and (what was) EU5.

#### Declaration of Payment to Trustee

In 2023 Dan Jeffries was paid £900.00 in total to further develop M4RD's learning management system, 'M4RD: Learn' and to create an additional Mental Health module. Payments to Trustees for services are allowed by the charity's governing document provided conditions in sub-clause 6.2 are satisfied. These conditions were satisfied and the Board of Trustees (excluding Dan Jeffries) decided that hiring Dan Jeffries for this specific service was in the best interest of the charity given his in depth knowledge of the charity, his personal experience of living with two rare diseases and his professional experience in this area.

#### Achievements and performance

##### Chair comments

2023 has been a year of reflection on the charity's progress so far, from its start up roots where a small team took an idea in 2018 and put it to the test, through to now being considered by stakeholders such as PAGs, education establishments, Department of Health and Social Care as being an important voice that can help shape and deliver education and support to Healthcare Professionals (HCPs), therefore improving outcomes for those living with rare conditions.

In a network of hundreds of patient advocacy groups and trailblazing rare disease specific charities, M4RD has created a space to uniquely advocate for an innovative way to deliver education to HCPs improving the rare disease experience for all patients regardless of their specific condition.

The notion that HCPs cannot possibly know how to identify and manage all 7000 specific rare diseases has driven the evolution of an idea that by creating and delivering education that places certain unchanging principles at the heart of HCP practice they can be better equipped to support those with rare diseases.

Through its key activities of online education, advocacy and a flourishing Ambassador Programme, M4RD has begun helping HCPs be more effective in a way that will allow individuals with a rare condition to be identified, diagnosed, access the right healthcare and support, engage with systems and have better outcomes.

The Trustees and staff team believe in the vision more than ever having seen this proof of concept produce evidence and data to give confidence that its work is having an impact where it was intended. We believe that with a new strategy in 2024, focussed resources, growth of income and the passion and expertise of the team, the charity can grow in the sector and be a key deliverer of education helping to create a new wave of HCPs who are better supported provide care for those living with rare conditions.

We have looked at the charity's progress and future direction in the context of the changes and challenges in policy and healthcare environments in which we operate in the UK and are committed to creating solutions based on multi stakeholder perspectives such as patients, HCPs, policy makers and education providers.

In addition the charity has extended its global reach giving us early indication that this approach to education could be taken worldwide.

The Board of Trustees would like to thank Lucy, Jo, Nadine, Eleanor and Emma for embracing this year of challenge and reflection. They have been critical in developing a new ambitious strategy which will be launched in 2024. Without their open mindedness and curiosity this new strategy with its tremendous potential could not have been possible. I am excited about the year ahead.

My personal highlights from 2023 include The Unusual Suspects at The Royal Society of Medicine which gave insight into how M4RD's online education has improved HCP care and patient experience in areas such as mental health. It also demonstrated how through the growth of its Ambassador Programme more professionals are working in a new way to improve outcomes for those living with rare diseases.

## MEDICS 4 RARE DISEASES

### TRUSTEES' ANNUAL REPORT (CONTINUED)

#### FOR THE YEAR ENDED 31 DECEMBER 2023

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The main aims of 2023 were:

- Host the 10th annual symposium with the The Royal Society of Medicine 'The Unusual Suspects: rare disease in everyday medicine' - achieved on 15th February.
- Run M4RD's first structured awareness campaign for Rare Disease Day on 28th February - completed.
- Expand the online learning platform, M4RD: Learn. Mental Health and Rare Disease was launched in 2023.
- Collaborate with the Rare Disease Nurse Network to author, design create and publish a nursing specific version of Rare Disease 101 to be hosted on M4RD: Learn platform - Due to events outside of M4RD's control we have unfortunately not been able to complete this project and funds were directed into a bigger mental health course instead. As we now have a specialist nurse on the Ambassador Programme, we will be taking this project into 2024 working alongside the Global Rare Disease Nurse Network.
- Undergraduate education: continue conversations with Medical Schools about Rare Disease 101 education - completed and ongoing.
- Postgraduate training: continue providing Rare Disease 101 training to doctors, especially within GP, Paediatrics and Emergency Medicine - completed and ongoing.
- Create 'Rare Disease in Primary Care' - a model guideline - Dr Hannah Grant researched and wrote a Rare Disease summary for Primary Care which has had interest from a famous Primary Care education provider for publication as a 'Red Whale Pearl'. These are free written resources that are shared each week covering key primary care topics.
- Collect data on medical student understanding about rare disease and their learning needs via the UK RISE project - this study was completed, has been written up and will soon be submitted for publication in a medical journal.
- Represent M4RD in public affairs engagement with The Department of Health and Social Care and its delivery partners - M4RD has been working with the public affairs company, Denton's Global Advisors, on upskilling the team and developing a PA strategy. This has contributed greatly to developing M4RD's new strategy and plans for 2024. Lucy continues to be a member of The UK Rare Diseases Framework Forum, including the Quality Standards Independent Advisory Group.

#### **The Unusual Suspects: Rare disease In everyday medicine 2023**

The event in 2023 focussed on mental wellbeing in rare diseases and was held in a hybrid format this year in association with the Medical Genetics Section of the Royal Society of Medicine.

278 participants registered for the event with 55 people attending in person and 103 joining us online. The recording has also been watched on-demand by those who couldn't make it on the day. A full report from the event is [available here](#). Before this meeting, only 43% of participants were aware that 3.5 million people in the UK (1 in 17) are affected by a rare disease in their lifetime!

*"It changed my perception on rare diseases and actually furthered my interest in it, hoping that I could specialise in a topic like that for medicine."*

*"As a medical student, I found the webinar very insightful. We have limited teaching on rare diseases, so I would recommend attending future webinars, to my peers."*

Many thanks to the RSM Medical Genetics Section for supporting us with our event and allowing us to use their prestigious platform.

# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2023

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#### Rare Disease Day

M4RD's '# ShowYourStripes for # RareDiseaseDay' campaign 2023 was M4RD's first ever Rare Disease Day campaign. Our message was lighthearted and straight forward, targeting healthcare professionals; asking them to show their support for people with rare conditions by wearing stripey socks for Rare Disease Day! We did a huge mail-out of eye-catching, shiny red, branded envelopes (that could not be overlooked!) and posted to key targets. We included zebra stripe socks together with a branded pin, and leaflets and posters with our key messages. We ran a full social media campaign alongside, to drive the messaging and maintain momentum in the weeks leading up to the big day. Our # ShowYourStripes gallery is a heartening demonstration of how far and wide the message reached.

In total 73 parcels were sent, and 342 people got involved with the campaign. 203 photos were shared which either tagged us @medics4rarediseases or used the hashtag # showyourstripes.

Some notable large accounts shared their participation e.g. Sarah Jarvis who has 36.K followers. Her # showyourstripes post gained 287 likes and 43 re-tweets. Baroness Nicola Blackwood shared a picture of her socks on show in The House of Lords, to her account of 17.2K followers. Genomics England, the BIU Southampton and Cambridge University Hospitals and Queen Mary University of London also joined in!

The campaign reached multiple countries around the world, including the US, Australia and even Kazakhstan.

#### M4RD: Learn

The new online course, 'Mental Health and Rare Disease' was launched in July in collaboration with Rareminds, consisting of 8 interactive lessons each focusing on a different topic related to the challenges that living with a rare disease poses to a person's mental health. This course forms part of M4RD: Learn platform and complements M4RD's existing 'Rare Disease 101' course. As with all of M4RD's learning content, this course has been developed with people with real-lived experience at the core. Lessons include novel scenarios and specific challenges such as the presence of an inheritable or genetic condition and the impact it has on patients and families. There are practical tips on how to better communicate about mental health, with patients and carers. It also includes steps that medics can take to maintain their own mental health whilst supporting the mental health of others. The course has 127 participants and has caught the attention of stakeholders as a first attempt to deliver this kind of training.

As of the end of 2023, M4RD: Learn has 1000 users and its material is being used to inform resources for other healthcare educators.

#### M4RD Ambassadors Programme

In July, 12 ambassadors attended our first ever F2F meeting in London! Patient advocates, medical students and clinicians from all over the UK, came together to celebrate the end of their first academic year on the programme and to share stories and experiences, engaging and inspiring each other.

*"The ambassador day really was better than I ever expected. I left feeling like I had a whole new sense of purpose and importance to carry the ethos of M4RD in my clinical work as a medical student and then as a doctor. I really enjoyed all the speeches and hearing the ambassadors discuss their work over the past year. It was great to hear from everyone!"*

In September we welcomed 25 new ambassadors to the programme and M4RD now has 39 ambassadors made up of 16 clinicians, 12 medical students and 11 patient advocates. This year we welcomed an Anaesthetist, Speech & Language Therapist, Geneticist and Clinical Nurse Specialist onto the clinical programme, and our increased number of medical students enables us to access medical schools in the UK.

During 2023, following completion of Train The Trainer, our medical student and clinical ambassadors delivered Rare 101 training in more than 6 settings across the UK.

Jo McPherson runs the ambassador programme, maintaining regular contact throughout the academic year with online 'brew' sessions, 'Train The Trainer' sessions, an online forum on M4RD Learn and a WhatsApp group.

The M4RD team would like to thank all the Ambassadors for playing such a pivotal role in enabling M4RD to work with the wider rare disease community and making sure that the patient voice is heard through our work.

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## **MEDICS 4 RARE DISEASES**

### **TRUSTEES' ANNUAL REPORT (CONTINUED)**

#### **FOR THE YEAR ENDED 31 DECEMBER 2023**

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##### **Medical Student placements**

M4RD took on Lottie Mercer, a 4th year medical student at The University of Southampton, in April for 2 weeks. During this time Lottie reviewed our Mental Health Module, and spoke with Sarah Wynn, CEO of Unique, and Angela Comwall, founder of Diamond Blackfan Anaemia. In Lottie's blog, one of the main things she learnt was the power of listening.

*Quote from Lottie: "A big thank you to M4RD, who have welcomed me onto their team for the past couple of weeks as part of my final year elective placement. It was great to have the opportunity to meet people from some of the patient advocacy groups they work with, and to hear about their experiences and interactions with healthcare professionals, as well as gaining some exposure to public affairs and rare disease policy making. During this placement, I also began to recognise and appreciate the complex interplay between mental and physical health, and reflect upon how I can support the mental health of people living with rare diseases once I start work as a junior doctor."*

##### **Undergraduate Rare Disease 101 Training**

Undergraduate training events for medical students were held at Cambridge, Barts & The London, Dundee, Glasgow Universities. Lucy also spoke at the Annual Students for Global Health Conference.

##### **Postgraduate Rare Disease 101 Training**

6 GP Training events held across England and Wales.

3 Foundation Year Training events in England.

7 Paediatric Training Events.

1 Pharmacy Training Event.

M4RD had an exhibition table at the East Genomics Medicine Showcase speaking to postgraduates working within the NHS.

##### **UK Rare Diseases Framework**

M4RD continues to be represented by Lucy on The UK Rare Diseases Framework Forum which provides expertise to the UK Implementation Group and The Department of Health and Social Care. Lucy has been working with an off-shoot of this group that is working with NICE to design Quality Standards for rare disease for the first time.

It is thanks to this Forum that M4RD has been collaborating with The Genomics Education Programme (part of NHS England) to create rare disease resources for the website and for GeNotes. GeNotes provides quick, concise information to help healthcare professionals make the right genomic decisions at each stage of a clinical pathway. Medics4RareDiseases was mentioned in the England Action Plan for Rare Diseases published on Rare Disease Day 2023.

##### **The Rare Disease Podcast 4 Medics**

By the end of 2023 the podcast had hit 8699 downloads and 48 episodes of the podcast have now been published. Season 5's episode, 'ALK Positive Lung Cancer and Me' with Debra Montague, has had 163 downloads and is so far our sixth most listened to podcast ever.

'From Melbourne to Manchester - a clinical trials story' received 135 downloads in the first 7 days making it into the top 25% of podcast episodes on Buzzsprout.

Total global download distribution: 5,755 downloads in Europe, 2238 downloads in North America, 318 downloads in Asia, 44 in Africa, 321 in Oceania and 21 downloads in South America.

# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2023

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#### The Student Voice Prize 2023

M4RD works in a 50:50 partnership with Beacon to produce the annual Student Voice Prize.

Following the success of the 2022 SVP, M4RD and Beacon co-hosted an online student event on Rare Disease Day 2023 'Beyond the Student Voice Prize'. The theme of the evening was to highlight the wide range of opportunities available through a career focused on rare disease and the exciting further opportunities available from individuals involved in various aspects of rare disease. The event was attended by 28 participants.

In October 2023 the SVP launched for its 10th year, sponsored by the global medical communications company Emotive. The questions focussed on communication and inclusivity in rare disease. We received 100 entries and paired 69 of these students with patients through the pairing scheme.

English was not the native language for 27 of the students who submitted essays. Essays submitted from 18 different countries. In comparison to 2022 there was a 49% increase in the number of essays entered and a 46% increase in essays submitted by students who took part in the patient pairing scheme.

#### RISE UK survey

We are in the process of writing up and submitting the results from The UK RISE Survey executed in collaboration with Dr Duncan Cole at University of Cardiff. We had 257 responses from 32 medical schools all over the UK (all 4 nations). Results clearly show there is room for improvement in rare disease education within medical undergraduate programs. Some of the unpublished findings show that the majority of respondents rated their understanding of rare diseases as 'low' and were dissatisfied with the extent of rare disease education they had received. This was reflected in their awareness of rare diseases and their understanding of the prevalence and impact of these conditions within the UK. We look forward to publishing the paper to a medical journal for peer review in 2024.

#### Financial Position

The budget for this financial year was decided based on the goals we set out to achieve in 2023 which reflect the M4RD strategy. We set out to fundraise £247k in order to fund activities for 2023. In total £214k of funding was secured through sponsorship and donations.

Total funds carried forward is £92,995. The final cash position is £79,270, £11,000 of which is kept in a savings account as per the charity's Reserves Policy.

#### Principal Funding Sources

The principal funding sources for this period were sponsorship and donations from commercial companies, including pharmaceutical companies. These were: Alexion Therapeutics, Alnylam, Amicus Therapeutics, BioCryst, Bionical Ermas, Chiesi, Gilead, Kyowa Kirin, Orchard Therapeutics, PTC Therapeutics, Sanofi, SOBI, Takeda UK and UCB. Charitable grants were also received from the Kenneth Hargreaves Trust, RKT Charitable Trust, the Forrester Family Trust and Souter Charitable Trust.

#### Reserves Policy and Review

The Reserves Policy was put in place by The Board of Trustees in 2019. Reserves are to be maintained at a level which ensures that the charity's core activity could continue during a 3 month period of unforeseen financial difficulty during which funding is to be secured. If funding is not secured then this is followed by a 3 month period in which the organisation could be dissolved with all outstanding debt settled. The Board of Trustees have set a minimum of £11,000 to be held in the charity's reserves.

#### Financial Risk

The staff team and Trustees can all work from home or remotely in an appropriate location so the charity doesn't own property or have a long term rental contract. M4RD's biggest financial commitment is staff. The majority of the charity's work is done 'in house' or provided to M4RD on a pro bono basis therefore external contracts for services are kept to a minimum.

M4RD continues to bank with CAF Bank which allows a good level of financial oversight by the Treasurer and other Trustees. All the Trustees have access to the online banking system and all payments require 2-person authorisation.

## MEDICS 4 RARE DISEASES

### TRUSTEES' ANNUAL REPORT (CONTINUED)

#### FOR THE YEAR ENDED 31 DECEMBER 2023

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The main financial risk, as always, is if funding is not secured. In previous years M4RD has relied predominantly on commercial donations and sponsorship. However during 2022 the charity started diversifying funding avenues in order to reduce risk from losing sponsors by identifying grantmakers that M4RD could apply to for charitable funding. £6k was secured in charitable donations during 2022 following successful applications and further opportunities are being explored.

The Trustees also have procedures to alert them early on to a financial short-fall and to act appropriately depending on the situation. This includes a Reserves Policy and alternative annual budgets to follow based on actual income vs requested income. In 2023 M4RD met its fundraising target.

#### Plans for future periods

In 2024 M4RD aims to define its next 5 years of strategy. It will need to scale in order to keep up with demand for delivery of Rare Disease 101 and provision of expert advice. By the end of 2024 M4RD will have launched its next phase of strategy.

#### Organisational plans:

- Recruit an Operations & Finance Manager (Jo McPherson will then focus on Partnerships and Fundraising of her current role)
- Recruit a Training Programmes Manager.
- Review the make up of the Trustees Board and recruit Trustees based on skill gaps

#### Future funding:

At the end of 2023 M4RD sent out funding applications to companies involved in the rare disease field, explaining the charity's 2024 work programme including the estimated costs involved. In total M4RD plans to raise £372K to achieve its aims and objectives for 2024. £50K has been carried over from 2023 and the remainder will be raised by reaching out to established funding sources, newly identified grant givers and exploring philanthropic opportunities..

#### Events after the end of the reporting period

Particulars of events after the reporting date are detailed in note 20 to the financial statements.

#### Small company provisions

This report has been prepared in accordance with the provisions applicable to companies entitled to the small companies exemption.

1517124

The trustees' annual report was approved on \_\_\_\_\_ and signed on behalf of the board of trustees by:

Mrs L Birrell  
Trustee and Chair

# MEDICS 4 RARE DISEASES

## STATEMENT OF TRUSTEES' ANNUAL RESPONSIBILITIES

FOR THE YEAR ENDED 31 DECEMBER 2023

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

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

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

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

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

The trustees' annual report was approved on ..... and signed on behalf of the board of trustees by:



Mrs L Birrell  
Trustee

Date: 15.07.24

# MEDICS 4 RARE DISEASES

## INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF MEDICS 4 RARE DISEASES

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I report to the Trustees on my examination of the financial statements of Medics 4 Rare Diseases (the Charity) for the year ended 31 December 2023.

### Responsibilities and basis of report

As the Trustees of the Charity you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011 (the 2011 Act).

I report in respect of my examination of the Charity's financial statements carried out under section 145 of the 2011 Act. In carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

### Independent examiner's statement

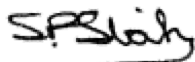
Your attention is drawn to the fact that the charity has prepared financial statements in accordance with Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) in preference to the Accounting and Reporting by Charities: Statement of Recommended Practice issued on 1 April 2005 which is referred to in the extant regulations but has now been withdrawn.

I understand that this has been done in order for financial statements to provide a true and fair view in accordance with Generally Accepted Accounting Practice effective for reporting periods beginning on or after 1 January 2015.

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

- 1 accounting records were not kept in respect of the Charity as required by section 130 of the 2011 Act; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an Independent examination.

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



Samir Shah ATII, FCA  
SKS Ramon Lee  
93 Tabernacle Street  
London  
EC2A 4BA

Dated: 15/07/2024

## MEDICS 4 RARE DISEASES

### STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31 DECEMBER 2023

	Notes	Unrestricted funds 2023 £	Restricted funds 2023 £	Total Unrestricted funds 2023 £	Restricted funds 2022 £	Total 2022 £
<b>Income from:</b>						
Donations and legacies	3	79,867	-	79,867	30,083	32,583
Sponsorships	4	164,000	15,000	179,000	10,000	115,000
Investments	5	770	-	770	100	100
<b>Total income</b>		<b>244,637</b>	<b>15,000</b>	<b>259,637</b>	<b>12,500</b>	<b>147,683</b>
<b>Expenditure on:</b>						
Charitable activities	6	223,107	5,745	228,852	5,425	138,052
<b>Net income for the year/ Net movement in funds</b>		<b>21,530</b>	<b>9,255</b>	<b>30,785</b>	<b>2,556</b>	<b>9,631</b>
<b>Fund balances at 1 January 2023</b>		<b>55,134</b>	<b>7,075</b>	<b>62,209</b>	<b>-</b>	<b>52,578</b>
<b>Fund balances at 31 December 2023</b>		<b>76,664</b>	<b>16,330</b>	<b>92,994</b>	<b>7,075</b>	<b>62,209</b>

The statement of financial activities includes all gains and losses recognised in the year.

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Charities Act 2011.

# MEDICS 4 RARE DISEASES

## BALANCE SHEET

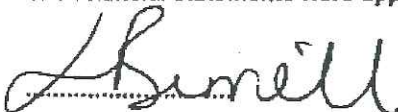
AS AT 31 DECEMBER 2023

	Notes	2023 £	£	2022 £	£
<b>Fixed assets</b>					
Intangible assets	13		2,290		2,290
Tangible assets	14		2,294		2,658
			<u>4,584</u>		<u>4,948</u>
<b>Current assets</b>					
Debtors	15	18,925		5,405	
Cash at bank and in hand		79,269		57,787	
		<u>98,194</u>		<u>63,192</u>	
<b>Creditors: amounts falling due within one year</b>	16	(9,784)		(5,931)	
<b>Net current assets</b>			<u>88,410</u>		<u>57,261</u>
<b>Total assets less current liabilities</b>			<u>82,994</u>		<u>62,209</u>
<b>Income funds</b>					
Restricted funds	17		16,330		7,075
Unrestricted funds			76,664		55,134
			<u>92,994</u>		<u>62,209</u>

The company is entitled to the exemption from the audit requirement contained in section 142(2) of Charities Act 2011, for the year ended 31 December 2023. The accounts have been examined by an independent examiner and their report have been included in these financial statements.

The directors acknowledge their responsibilities for complying with the requirements of the Charities Act 2011 with respect to accounting records and the preparation of financial statements.

The financial statements were approved by the Trustees on 15.07.24,



Mrs L Birrell  
Trustee and Chair

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2023

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### 1 Accounting policies

#### Charity information

Medics 4 Rare Diseases is a public benefit entity and a private company limited by guarantee, registered in England and Wales and a registered charity in England and Wales. The address of the registered office is Unit 12 Treadaway Technical Centre, Treadaway Hill, Loudwater, High Wycombe, HP10 9RS.

#### 1.1 Accounting convention

The financial statements have been prepared on the historical cost basis, as modified by the revaluation of certain financial assets and liabilities and investment properties measured at fair value through income or expenditure.

The financial statements are prepared in sterling, which is the functional currency of the entity.

#### Statement of compliance

These financial statements have been prepared in compliance with FRS 102, 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland', the 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) (Charities SORP (FRS 102)) and the Companies Act 2006.

#### 1.2 Going concern

There are no material uncertainties about the charity's ability to continue.

#### 1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the Trustees in furtherance of their charitable objectives.

Designated funds are unrestricted funds earmarked by the trustees for particular future project or commitment.

Restricted funds are subjected to restrictions on their expenditure declared by the donor or through the terms of an appeal, and fall into one of two sub-classes: restricted income funds or endowment funds.

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2023

---

### 1 Accounting policies

(Continued)

#### 1.4 Income

All incoming resources are included in the statement of financial activities when entitlement has passed to the charity; it is probable that the economic benefits associated with the transaction will flow to the charity and the amount can be reliably measured. The following specific policies are applied to particular categories of income:

- income from donations or grants is recognised when there is evidence of entitlement to the gift, receipt is probable and its amount can be measured reliably.
- legacy income is recognised when receipt is probable and entitlement is established.
- income from donated goods is measured at the fair value of the goods unless this is impractical to measure reliably, in which case the value is derived from the cost to the donor or the estimated resale value. Donated facilities and services are recognised in the accounts when received if the value can be reliably measured. No amounts are included for the contribution of general volunteers.
- income from contracts for the supply of services is recognised with the delivery of the contracted service. This is classified as unrestricted funds unless there is a contractual requirement for it to be spent on a particular purpose and returned if unspent, in which case it may be regarded as restricted.

#### 1.5 Expenditure

Expenditure is recognised on an accruals basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is classified under headings of the statement of financial activities to which it relates:

- expenditure on raising funds includes the costs of all fundraising activities, events, non-charitable trading activities, and the sale of donated goods.
- expenditure on charitable activities includes all costs incurred by a charity in undertaking activities that further its charitable aims for the benefit of its beneficiaries, including those support costs and costs relating to the governance of the charity apportioned to charitable activities.
- other expenditure includes all expenditure that is neither related to raising funds for the charity nor part of its expenditure on charitable activities.

All costs are allocated to expenditure categories reflecting the use of the resource. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs are apportioned between the activities they contribute to on a reasonable, justifiable and consistent basis.

#### 1.6 Intangible fixed assets other than goodwill

Intangible asset acquired on account of registration of trademark & logo is recognised at cost incurred on filing the patent with the competent authority.

There is no Amortisation charged for intangible acquired on account of registration of trademark & Logo. The carrying value, however will be reviewed at each Balance sheet date. If an entity determines that one of its trademarks is worth less than it was a year ago, the value of the intangible asset must be impaired. When an impairment occurs, the value of the asset must be decreased to its current market value. The difference between the current value of the trademark and its former value must be recorded as a financial loss.

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

---

### 1 Accounting policies

(Continued)

#### 1.7 Tangible fixed assets

Tangible assets are initially recorded at cost, and subsequently stated at cost less any accumulated depreciation and impairment losses. Any tangible assets carried at revalued amounts are recorded at the fair value at the date of revaluation less any subsequent accumulated depreciation and subsequent accumulated impairment losses.

An increase in the carrying amount of an asset as a result of a revaluation, is recognised in other recognised gains and losses, unless it reverses a charge for impairment that has previously been recognised as expenditure within the statement of financial activities. A decrease in the carrying amount of an asset as a result of revaluation, is recognised in other recognised gains and losses, except to which it offsets any previous revaluation gain, in which case the loss is shown within other recognised gains and losses on the statement of financial activities.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Computers	25% Reducing Balance method
-----------	-----------------------------

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in the statement of financial activities.

#### 1.8 Impairment of fixed assets

A review for indicators of impairment is carried out at each reporting date, with the recoverable amount being estimated where such indicators exist. Where the carrying value exceeds the recoverable amount, the asset is impaired accordingly. Prior impairments are also reviewed for possible reversal at each reporting date.

For the purposes of impairment testing, when it is not possible to estimate the recoverable amount of an individual asset, an estimate is made of the recoverable amount of the cash-generating unit to which the asset belongs. The cash-generating unit is the smallest identifiable group of assets that includes the asset and generates cash inflows that largely independent of the cash inflows from other assets or groups of assets.

#### 1.9 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

#### 1.10 Financial Instruments

A financial asset or a financial liability is recognised only when the charity becomes a party to the contractual provisions of the instrument.

Basic financial instruments are initially recognised at the amount receivable or payable including any related transaction costs.

Current assets and current liabilities are subsequently measured at the cash or other consideration expected to be paid or received and not discounted.

Debt instruments are subsequently measured at amortised cost.

Where investments in shares are publicly traded or their fair value can otherwise be measured reliably, the investment is subsequently measured at fair value with changes in fair value recognised in income and expenditure. All other such investments are subsequently measured at cost less impairment.

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2023

---

### 1 Accounting policies

(Continued)

Other financial instruments, including derivatives, are initially recognised at fair value, unless payment for an asset is deferred beyond normal business terms or financed at a rate of interest that is not a market rate, in which case the asset is measured at the present value of the future payments discounted at a market rate of interest for a similar debt instrument.

Other financial instruments are subsequently measured at fair value, with any changes recognised in the statement of financial activities, with the exception of hedging instruments in a designated hedging relationship.

Financial assets that are measured at cost or amortised cost are reviewed for objective evidence of impairment at the end of each reporting date. If there is objective evidence of impairment, an impairment loss is recognised under the appropriate heading in the statement of financial activities in which the initial gain was recognised.

For all equity instruments regardless of significance, and other financial assets that are individually significant, these are assessed individually for impairment. Other financial assets are either assessed individually or grouped on the basis of similar credit risk characteristics.

Any reversals of impairment are recognised immediately, to the extent that the reversal does not result in a carrying amount of the financial asset that exceeds

#### *Basic financial assets*

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

#### *Basic financial liabilities*

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

#### *Derecognition of financial liabilities*

Financial liabilities are derecognised when the Charity's contractual obligations expire or are discharged or cancelled.

### 1.11 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the Charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

### 1.12 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2023

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### 1 Accounting policies

(Continued)

#### 1.13 Fund accounting

Unrestricted funds are available for use at the discretion of the trustees to further any of the charity's purposes.

Designated funds are unrestricted funds earmarked by the trustees for particular future project or commitment.

Restricted funds are subjected to restrictions on their expenditure declared by the donor or through the terms of an appeal, and fall into one of two sub-classes: restricted income funds or endowment funds.

#### 1.14 Defined contribution plans

Contributions to defined contribution plans are recognised as an expense in the period in which the related service is provided. Prepaid contributions are recognised as an asset to the extent that the prepayment will lead to a reduction in future payments or a cash refund.

When contributions are not expected to be settled wholly within 12 months of the end of the reporting date in which the employees render the related service, the liability is measured on a discounted present value basis. The unwinding of the discount is recognised as an expense in the period in which it arises.

#### 1.15 Limited by guarantee

Medics 4 Rare Disease Ltd is a company limited by guarantee and accordingly does not have a share capital.

Every member of the company undertakes to contribute such amount as may be required not exceeding £1 to the assets of the charitable company in the event of its being wound up while he or she is a member, or within one year after he or she ceases to be a member.

### 2 Critical accounting estimates and judgements

In the application of the Charity's accounting policies, the Trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

#### Critical judgements

The preparation of the financial statements requires management to make judgements, estimates and assumptions that affect the amounts reported. These estimates and judgements are continually reviewed and are based on experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances.

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

### 3 Donations and legacies

	Unrestricted funds	Restricted funds	Total	Unrestricted funds	Restricted funds	Total
	2023	2023	2023	2022	2022	2022
	£	£	£	£	£	£
Donations and gifts	46,287	-	46,287	20,656	2,500	23,156
Other	33,580	-	33,580	9,427	-	9,427
	<u>79,867</u>	<u>-</u>	<u>79,867</u>	<u>30,083</u>	<u>2,500</u>	<u>32,583</u>

### 4 Income from charitable activities

	Unrestricted funds	Restricted funds	Total	Unrestricted funds	Restricted funds	Total
	2023	2023	2023	2022	2022	2022
	£	£	£	£	£	£
Sponsorships	164,000	15,000	179,000	105,000	10,000	115,000
	<u>164,000</u>	<u>15,000</u>	<u>179,000</u>	<u>105,000</u>	<u>10,000</u>	<u>115,000</u>

### 5 Investments

	Unrestricted funds	Unrestricted funds
	2023	2022
	£	£
Interest receivable	770	100
	<u>770</u>	<u>100</u>

## MEDICS 4 RARE DISEASES

### NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2023

#### 6 Charitable activities

	Activities undertaken directly	Support costs	Total 2023	Activities undertaken directly	Support costs	Total 2022
	2023	2023	2023	2022	2022	2022
	£	£	£	£	£	£
Staff costs	156,077	-	156,077	103,233	-	103,233
Depreciation	732	-	732	487	-	487
Rent	6,590	-	6,590	1,460	-	1,460
Insurance	438	-	438	247	-	247
Telephone	48	-	48	12	-	12
Computer expenses	7,615	-	7,615	3,426	-	3,426
Subscriptions	159	-	159	170	-	170
Interest paid	-	-	-	3	-	3
Bank charges	66	-	66	142	-	142
Administration support	275	-	275	322	-	322
Advertising and marketing	11,879	-	11,879	18,752	-	18,752
Event costs	8,435	-	8,435	66	-	66
Travelling and subsistence	11,502	-	11,502	2,436	-	2,436
Postage and Print	1,346	-	1,346	675	-	675
Consultancy	14,783	-	14,783	540	-	540
Administrative Support & Welfare	1,744	-	1,744	2,696	-	2,696
Other Cost	113	7,050	7,163	49	3,336	3,385
	<u>221,802</u>	<u>7,050</u>	<u>228,852</u>	<u>134,716</u>	<u>3,336</u>	<u>138,052</u>
<b>Analysis by fund</b>						
Unrestricted funds	216,057	7,050	223,107	129,291	3,336	132,627
Restricted funds	5,745	-	5,745	5,425	-	5,425
	<u>221,802</u>	<u>7,050</u>	<u>228,852</u>	<u>134,716</u>	<u>3,336</u>	<u>138,052</u>

#### 7 Support costs

	2023	2022
	£	£
Independent examination	1,320	1,200
Other assurance services	5,730	2,136
	<u>7,050</u>	<u>3,336</u>

## MEDICS 4 RARE DISEASES

### NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2023

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8	Net movement in funds	2023	2022
		£	£
	Net movement in funds is stated after charging/(crediting)		
	Depreciation of owned tangible fixed assets	732	487

#### 9 Trustees

None of the Trustees (or any persons connected with them) received any remuneration or benefits from the Charity during the year.

£900 (2022: £300) was paid to Mr D Jeffries, one of the trustees, for his professional services in setting up e-learning facilities for the charity.

#### 10 Employees

The average monthly number of employees during the year was:

	2023	2022
	Number	Number
Charitable activities	5	4

	2023	2022
	£	£
Employment costs		
Wages and salaries	144,715	98,105
Social security costs	8,277	3,085
Other pension costs	3,085	2,043
	156,077	103,233

Out of the above employment cost, cost amounting to £4,845 (2022: 4,468) forms part of restricted expenditure.

There were no employees whose annual remuneration was more than £60,000.

#### 11 Pensions and other post retirement benefits

##### Defined contribution plans

The amount recognised in income or expenditure as an expense in relation to defined contribution plans was £3,086 (2022: £2,043).

#### 12 Taxation

The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.

## MEDICS 4 RARE DISEASES

### NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2023

#### 13 Intangible fixed assets

Intangibles Assets  
£

**Cost**

At 1 January 2023 and 31 December 2023

2,290

**Amortisation charge**

At 1 January 2023 and 31 December 2023

-

**Carrying amount**

At 31 December 2023

2,290

At 31 December 2022

2,290

#### 14 Tangible fixed assets

Computers  
£

**Cost**

At 1 January 2023

3,964

Additions

368

At 31 December 2023

4,332

**Depreciation charge**

At 1 January 2023

1,306

Depreciation charged in the year

732

At 31 December 2023

2,038

**Carrying amount**

At 31 December 2023

2,294

At 31 December 2022

2,658

#### 15 Debtors

2023

2022

Amounts falling due within one year:

£

£

Trade debtors

13,643

300

Prepayments and accrued income

5,282

5,105

18,925

5,405

## MEDICS 4 RARE DISEASES

### NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2023

#### 16 Creditors: amounts falling due within one year

	2023 £	2022 £
Other taxation and social security	3,413	3,077
Trade creditors	3,429	234
Accruals and deferred income	2,942	2,620
	<u>9,784</u>	<u>5,931</u>

#### 17 Restricted funds

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

	At 1 January 2023 £	Incoming resources £	Resources expended £	At 31 December 2023 £
M4RD Leam	<u>7,075</u>	<u>15,000</u>	<u>(5,745)</u>	<u>16,330</u>
Previous year:	At 1 January 2022 £	Incoming resources £	Resources expended £	At 31 December 2022 £
M4RD Leam	<u>-</u>	<u>12,500</u>	<u>(5,425)</u>	<u>7,075</u>

#### 18 Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 January 2023 £	Incoming resources £	Resources expended £	At 31 December 2023 £
General funds	<u>55,134</u>	<u>244,637</u>	<u>(223,107)</u>	<u>76,664</u>
Previous year:	At 1 January 2022 £	Incoming resources £	Resources expended £	At 31 December 2022 £
General funds	<u>52,578</u>	<u>135,183</u>	<u>(132,627)</u>	<u>55,134</u>

## MEDICS 4 RARE DISEASES

### NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2023

#### 19 Analysis of net assets between funds

	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £
Fund balances at 31 December 2023 are represented by:						
Intangible fixed assets	2,290	-	2,290	2,290	-	2,290
Tangible assets	2,294	-	2,294	2,658	-	2,658
Current assets/(liabilities)	72,080	16,330	88,410	50,186	7,075	57,261
	<u>76,664</u>	<u>16,330</u>	<u>92,994</u>	<u>55,134</u>	<u>7,075</u>	<u>62,209</u>

#### 20 Related party transactions

During the year the Charity entered into the following transactions with related parties:

Donation of £Nil (2022- £485) received from Lucy Martha Rosemary McKay who is company secretary of charity.

Consulting fees of £600 (2022- £300) paid to Dan Jeffries who is trustees of charity.

**MEDICS 4 RARE DISEASES**

England & Wales - Charity number 1183996

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# Accounts

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Charity registration number 1183996

**MEDICS 4 RARE DISEASES**  
**ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 DECEMBER 2022**

# **MEDICS 4 RARE DISEASES**

## **LEGAL AND ADMINISTRATIVE INFORMATION**

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<b>Trustees</b>	Dr Debra Fine Mr Chris France Dr Olivia Grant Mr Daniel Jeffries Mrs Lindsay Birrell
<b>Secretary</b>	Dr L M R McKay
<b>Charity number</b>	1183996
<b>Company number</b>	11119884
<b>Principal address</b>	Unit 12 Treadaway Technical Centre Treadaway Hill Loudwater High Wycombe HP10 9RS
<b>Bookkeeping and payroll</b>	Adder Bookkeeping
<b>Independent Examiner</b>	Caroline Brazier Cansdales Business Advisers Limited St Mary's Court The Broadway Old Amersham Bucks England HP7 0UT

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# **MEDICS 4 RARE DISEASES**

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# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT

### FOR THE YEAR ENDED 31 DECEMBER 2022

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The Trustees present their annual report and financial statements for the year ended 31 December 2022.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the Charity's governing document, the Charities Act 2011 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (effective 1 January 2019).

#### Structure, governance and management

Trustees have been appointed to the M4RD board based on their experience, skills and enthusiasm for the work of M4RD. M4RD relies on the voluntary time that its Trustees generously provide to advance the purposes of the charity. The minimum number of Trustees is 3 and there is no maximum number. The requirements to be considered for the position of Trustee are outlined in the Charity's CIO Constitution. Trustee induction is provided by the CEO with input from the Chair of Trustees. This is carried out remotely. The new Trustee is provided with a New Trustee Induction Pack and access to the Charity's documents. M4RD makes use of readily available online training created by other organisations and provides a PDF copy of The Charity Commission's document 'The Essential Trustee'.

The Trustee Board meets quarterly via video conferencing and annually at a face-to-face Strategy Meeting. The CEO, Dr Lucy McKay, is a founding member of the Charity and has been in the role of CEO since September 2018. Lucy is a key opinion leader in the rare disease field having had personal experience of rare disease and training in the NHS as a doctor. She reports to the Trustee Board and is responsible for: implementing the strategy of the charity, as agreed by the Trustees; managing the staff team; oversight of finances and fundraising; and identifying and assessing strategic risks and opportunities.

The current M4RD staff team comprises: Jo McPherson (Operations and Finance Manager) responsible for daily operations, managing the finances, fundraising and patient advocacy group liaison; Dr Emma Huskinson (Communications Lead) responsible for public relations, liaising with press and writing medical content; Melissa Clasen (Training & Education Officer) responsible for the development and delivery of a variety of projects focussed on raising awareness of rare disease and providing education and practical tools targeted at medical professionals e.g. RISE UK, Mystery Monday and training o; and Eleanor Churchill (Digital Projects Officer) responsible for the development and delivery of digital projects, e.g. M4RD: Learn; the podcast series and YouTube.

Lucy, Jo and Emma work part-time. Both Melissa and Eleanor work full-time. Lucy works from a hot desk in an office at the business Analogue Wonderland, High Wycombe (the registered address of the Charity). All remaining staff work from home and report to Lucy who in turn reports to the Chair bi-monthly unless more frequent support is needed. Lucy and Jo also report quarterly to the Treasurer to ensure the smooth and financially prudent running of the charity. Both of these recurring meetings were initiated in 2019 and have been immensely valuable to the team as a whole.

The M4RD Board of Trustees continue to contribute generously to the success of the charity. Two Trustees are GPs and have been involved in M4RD (in its previous forms) since 2011. Dr Olivia Hannah Grant is an International lacrosse player, but for M4RD she provides insight into day to day life and learning needs of being a GP in the NHS. The Treasurer, Dr Debra Fine, was an Accountant prior to training to become a doctor and this range of experience is invaluable to the role. Lindsay Birrell is the Vice Chair of M4RD, her prior experience working for Metabolic Support UK as CEO has been invaluable to Lucy and the rest of the Trustee Board. Dan Jeffries is M4RD's patient representative but has many skills within IT. His day job of creating online interactive educational software means he is able to provide bespoke and greatly discounted services in the creation and development of M4RD's learning management system (M4RD: Learn). The Chair, Chris France, is the founder of a successful e-commerce company and has been pivotal in getting M4RD's structure established, mentoring Lucy and steering the charity in the direction of successful strategies.

# **MEDICS 4 RARE DISEASES**

## **TRUSTEES' ANNUAL REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022**

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The aims and objectives of the 2022 plan drove the decision making during this period.

The Board of Trustees and the CEO are responsible for reviewing and updating the Charity's strategic plan. This was most recently done at M4RD's Strategy Meeting in July 2022. The CEO uses quarterly Board Meetings to update the Trustees on the progress being made by the charity and to ask questions and receive advice. The CEO is largely responsible for making decisions about activities that achieve the aims and objectives. Large financial decisions (outside of pre-authorised projects) are taken to the board by the CEO to be discussed.

### **Objectives and activities**

M4RD was registered at Companies House as a private company registered by guarantee without share capital (Company Number 11119884) on 20th December 2017. It was registered as a charity in England & Wales (Registered Charity Number 1183996) on 20th June 2019. It became a Charitable Incorporated Organisation (CIO) on 11 July 2022.

Below are the charity's purposes as set out in the objects contained in the Charity's CIO Constitution:

The company is established for the objects of the relief of sickness and preservation of health of those suffering from rare diseases, throughout the world, by:

- (a) advancing the education of medics, associated professionals and the public in rare diseases, genetic and genomic medicine
- (b) promoting research in all areas relating to rare diseases, genetic and genomic medicine and publishing the useful results
- (c) promoting improved care and treatment of those suffering from rare diseases.

### **Aims and public benefit:**

The Charity aims to improve the lives of a certain portion of the public: those living with rare diseases and their communities. It does this through raising awareness of the relevance of rare diseases in medical practice. The Charity provides education about rare disease and opportunities to develop a clinician's understanding of this large population group in the UK in order to better serve it.

### **Review:**

During 2019 the Board of Trustees worked with the Charity Commission to make sure its structure, objects and governing documents were ready for the organisation to be registered as a charity. This required a review of our purposes to make sure they were wholly charitable and benefited the public. In the case of M4RD 'the public' refers to the estimated 3.5 million people in the UK who suffer from a rare disease - and their communities.

Following guidance from the Charity Commission the Board of Trustees adapted the company's original Memorandum & Articles to make sure the wording was suitable for the charity. Subsequently the Charity's CIO Constitution was written to reflect the recommendations from the Charity Commission. The organisation's objects are wholly charitable. Any personal benefit arising is legitimately incidental.

The Board of Trustees review M4RD's objectives, goals and strategies on an annual basis at the Strategy Meeting. This is done with reference to guidance contained in the Charity Commission's general guidance on public benefit.

# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2022

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### Activities:

A rare disease is defined in the UK as a condition that affects fewer than 5 in 20,000 people. Over 7,000 rare diseases have been identified which means that understanding and teaching about rare diseases in medical education is extremely challenging. However this is a challenge that we cannot afford to avoid because approximately 3.5 million people in the UK have a rare disease. So, while each disease is individually rare, they are collectively common.

Of these diseases, 80% are known to be genetic in origin and 70% present exclusively in childhood. However, despite this large prevalence (equivalent to all adults in the UK who suffer with asthma), each individual condition affects so few people that they tend to be overlooked and misunderstood by health professionals, researchers, education and social care providers and the general public. This lack of awareness amongst medical professions is particularly devastating and can lead to extreme diagnostic delay. A person with a rare disease will wait on average 4-6 years for an accurate diagnosis. They will see numerous doctors, receive misdiagnoses and potentially even inappropriate treatment. This long and arduous journey to a diagnosis has been named "the Diagnostic Odyssey".

The challenges of having a rare disease do not stop after getting a diagnosis. People living with completely different diseases often report the same difficulties in terms of healthcare, social care, family life, education, work and mental health. There are many wonderful charities in the UK that support rare disease patients depending on their disease or specific need. Umbrella charities run successful public awareness campaigns. However, M4RD specifically targets an audience that nobody else has been specifically concentrating on but could make the greatest impact on the diagnostic odyssey and the challenges that follow: medical students and doctors.

By creating a medical profession equipped to suspect, diagnose and manage rare disease we can help people living with rare conditions have the best outcomes and reach their full potential. To do this M4RD is driving providing education and practical tools for medical students and doctors. Without appropriate training, the idea that rare diseases are irrelevant to clinical practice will continue to contribute to the diagnostic odyssey. We remedy this by presenting the statistics to our audience and asking people living with rare conditions to share their stories. M4RD have developed a new approach to satisfactorily cover the subject of rare disease within undergraduate and postgraduate medical training. Finally, we're creating our own resources and promoting others' resources in order to support medical professionals when they need help on the subject of rare disease.

M4RD provides education online events, e-learning, social media, via podcast and in person training events.

### Wider network:

M4RD collaborates with many umbrella and disease-specific rare disease advocacy groups in order to achieve its objects. To name a few: Cambridge Rare Disease Network, Genetic Alliance UK, Rare Revolution Magazine, Breaking Down Barriers, Rare Community Network and EDIRA.

M4RD partners with Beacon to run the annual 'Student Voice Prize' essay competition and with The Royal Society of Medicine to host its annual symposium 'The Unusual Suspects'. Both are UK registered charities.

M4RD receives pro bono support from the health communications agency, emotive. The charity also depends on volunteers to contribute to projects and speak at events.

M4RD is also a founding organisation of an informal group called Action for Rare Disease Empowerment (ARDEnt), alongside Cambridge Rare Diseases Network and Rare Revolution Magazine.

In 2022 M4RD has expanded its connections within medical education to work with: Barts and The London School of Medicine and Dentistry, Medscape, Medics Academy, Health Education and Innovation Wales, and we are in preliminary discussions with Health Education England

### Declaration of Payment to Trustees

In 2022 Dan Jeffries was paid £300 in total to further develop M4RD's learning management system, 'M4RD: Learn' and to create additional modules. Payments to Trustees for services are allowed by the charity's governing document provided conditions in sub-clause 6.2 are satisfied. These conditions were satisfied, and the Board of Trustees (excluding Dan Jeffries) decided that hiring Dan Jeffries for this specific service was in the best interest of the charity given his in depth knowledge of the charity, his personal experience of living with two rare diseases and his professional experience in this area.

# MEDICS 4 RARE DISEASES

## TRUSTEES' ANNUAL REPORT (CONTINUED)

**FOR THE YEAR ENDED 31 DECEMBER 2022**

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### Achievements and performance

#### CEO comments

The charity has continued to deliver on the actions needed to address the unmet needs of both medical professionals and people living with rare conditions in 2022, becoming increasingly recognised as pivotal for delivering on the UK Rare Diseases Framework. I continue to advise at a Governmental level via the UK Rare Diseases Framework Forum and M4RD is listed as a delivery partner on the Welsh Action Plan. Conversations with England, Scotland and Northern Ireland continue to be positive, and we hope to facilitate a more coordinated, national response to Priority 2 going forward.

In February Melissa, M4RD's Training and Education Officer, joined the team which has been game-changing in terms of delivering Rare Disease 101 training sessions to medics. Currently these are organised 'on demand', demonstrating that medics want this education and that they recommend it to their colleagues. This is paving the way towards embedding this Rare Disease 101-style education into regular training and education for doctors and future doctors.

This year the team delivered thirteen training sessions to a number of clinical groups including paediatricians, GPs and medical students. M4RD: Learn, the Charity's e-learning platform, has nearly 900 users and The Rare Disease Podcast 4 Medics is on track to hit 4000 downloads by the end of the year! Digital learning is going to continue to grow as we have now welcomed another team member, Eleanor, M4RD's Digital Projects Officer.

We've spent two years building this wonder team and designing patient-centred, pragmatic education. We've been demonstrating that our approach benefits patients and clinicians alike. And now we just need to keep rolling it out: through M4RD's own channels; through medical schools; through post-graduate training; through putting pressure in the right places within policy and public bodies.

I am determined to keep using my dual experiences as advocate and medic to ask the much-needed questions; to keep examining why so many people living with rare conditions today still face similar challenges to the friends I grew up with; to keep the focus on tangible benefits to the rare disease community.

Dr Lucy McKay  
CEO

The main aims of 2022 were:

- Host the annual meeting with The Royal Society of Medicine 'The Unusual Suspects: rare disease in everyday medicine' - *achieved on 9th February.*
- Continue to engage with the Department of Health and Social Care and its delivery partners - *achieved.*
- Organise a series of webinars with the RSM's Medicine and Me section on 'lessons learned from the COVID-19 pandemic' in collaboration with the ARDEN group - *achieved throughout January and February.*
- Develop a rare disease toolkit using the findings from our Red Flags survey - *this is now planned for 2023 following the publication of the survey.*
- Launch a mini-module focussing on clinical trials and early access programmes as well as some 'deep-dive' modules on mental health and care coordination - *Clinical trials & early access programmes were launched with support from Blonical Emas in 2022. Rare Mental Health deep-dive module authored and created in collaboration with Raremines, ready for launch 2023.*
- Develop a Best Practice Guide for PAGS on how to engage with healthcare professionals - *this has been delayed until 2023 however M4RD has been providing this advice to PAGs on request.*
- Launch the second and third series of the Rare Disease Podcast 4 Medics - *achieved.*
- Launch The Student Voice Prize 2022 with Beacon - *achieved.*
- Induct a new cohort of Patient, Clinical and Medical Student Ambassadors - *achieved in September 2022.*
- Grow the team by recruiting two full-time positions: Training & Education Officer and Digital Communications Officer - *Melissa and Eleanor both appointed.*
- Finalise the charity's conversion to Charitable Incorporated Company - *achieved in July 2022.*

## MEDICS 4 RARE DISEASES

### TRUSTEES' ANNUAL REPORT (CONTINUED)

#### FOR THE YEAR ENDED 31 DECEMBER 2022

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##### **The Unusual Suspects: Rare disease in everyday medicine 2022**

A very popular event in the rare disease calendar, the M4RD Annual Symposium encourages healthcare professionals, medical trainees and students to come together and learn more about the importance of a holistic approach to understanding rare disease, with a focus on providing practical tools and pragmatic tips for improving diagnosis and management. In 2021, the online presence of the symposium meant that a higher proportion of international delegates could take part and this year was no different.

The event was held on 19th February in association with the Medical Genetics Section of the Royal Society of Medicine, with over 330 people registering for the online event and 94% of attendees saying that the event would impact their clinical practice.

The first speaker was Aisha Seedat, a patient and rare disease advocate who opened her talk by introducing herself and the UK Rare Diseases Framework, a policy paper established early in 2021 that aimed to improve the lives of those living with rare diseases. She shared her own experiences and insights into the rare disease community in parallel with the priorities set out in The Framework.

The subsequent talk was given by Dr Denise Williams, Consultant Clinical Geneticist at Birmingham Women's and Children's Hospital NHS Foundation Trust. Denise opened her talk by highlighting reports over the last 20 years warning about infant mortality of genetic origin in the West Midlands and publications recommending the enhancement of genetic services in England. Denise pointed out that patients need to be well informed about the possibility that genetic testing can fail to detect disease variants and/or pick up unintended genomic information.

Denise's talk was followed by a talk by Dr Sondra Butterworth, Community Psychology Specialist, founder of RareQoL. Sondra highlighted the fact that people living with rare conditions and their families tell their stories not just about their illness but also through their illness, sharing their personal perspective. She explored the concept of narrative-based medicine, which uses a holistic approach to study a patient's perspective through their diagnostic 'odyssey' and gain knowledge that can positively influence the patient's diagnostic journey and quality of life.

The next talk was given by Dr David Adlam, Associate Professor of Acute and Interventional Cardiology at the University of Leicester, who plays a key role in the advocacy of spontaneous coronary artery disease (SCAD). David talked about the challenges that remain for the SCAD community; a lack of research support from funding bodies means research relies solely on patient contribution and a lack of support from specialist commissioning means specialist SCAD clinics risk being overburdened and under-resourced.

Our final speaker was Zainab Alani, winner of the The Student Voice Prize 2021, who spoke about her essay "Putting the 'I' in Intersectionality: The Unspoken Pandemic". She explained that her diagnostic journey started with uncertainty from her GP, disbelief from her optician and a subsequent game of 'ping-pong' that involved jumping from one specialist to another and back to square one. Her diagnosis was eventually communicated to her over the phone when she was alone at the vulnerable age of 15!

*"I will try to keep a rare disease on my [differential diagnosis] list from now on which had been somewhat brushing off in the past unless it was more obvious than the more common diseases; will pay more attention to learning about the rare diseases collectively."*

[Click here](#) for a full report of the event.

Many thanks to the RSM Medical Genetics Section for supporting us with our event and allowing us to use their prestigious platform.

##### **M4RD: Learn**

In 2021 M4RD launched its online, interactive e-learning platform dedicated to teaching medics the fundamentals of rare disease and help them manage both their undiagnosed and diagnosed patients. Rare Disease 101 was the first module available on the platform.

## **MEDICS 4 RARE DISEASES**

### **TRUSTEES' ANNUAL REPORT (CONTINUED)**

#### **FOR THE YEAR ENDED 31 DECEMBER 2022**

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In 2022 M4RD launched the Clinical Trials and Early Access Programmes mini module with support from Bionical Emas. In collaboration with Rareminds, M4RD has authored and created a deep-dive module on Mental Health and Rare Disease, ready for launch in 2023. In 2022 Rare Disease 101 Australia was launched in collaboration with Western Australia's Rare Care Centre and The Australian Department of Health and the creation of a disease-specific education area for M4RD's industry partners to link to/upload their educational resources is in development.

As of the end of 2022, M4RD: Learn has 874 users and the current enrolment rate to the Rare Disease 101 module is 32 new users per month.

#### **M4RD Ambassadors Programme**

In September 2022 after a period of recruitment, we welcomed our 2022/23 cohort of ambassadors with a structured induction evening with presentations from patient advocate and M4RD trustee, Dan Jeffries; patient advocate, medical student and SVP2021 winner Zainab Alani; and long-standing clinical ambassador Dr Tom Dunne. The 2022/2023 cohort includes 10 clinicians, 5 medical students and 4 patient advocates. This was the first year that we welcomed medical students onto the programme, enabling us access to medical schools in the UK which helped enormously with the RISE UK project and promoting the Student Voice Prize.

Jo McPherson and Melissa Clasen run the ambassador programme and following a full review ahead of the new cohort induction, implemented activity logs, event calendars and an online forum within the M4RD: Learn platform. Regular contact has been maintained throughout the academic year and a 'Train the Trainer' event was introduced which has enabled ambassadors to deliver Rare Disease 101 training events for their peers! The cohort has been completely engaged with the work of M4RD and has been involved in writing content for the website and for peer-reviewed literature. They are also invited to speak at events and are really important for making sure that the patient voice is heard through our work.

The M4RD team would like to thank all the Ambassadors for playing such a pivotal role in enabling M4RD to work with the wider rare disease community and making sure that the patient voice is heard through our work. We look forward to our first face-to-face meeting with them in 2023.

#### **Medical Student placements**

Melissa has developed virtual/hybrid placements at M4RD for 7 medical students: 3 weeks virtual elective placement with Grace (medical student, Keele University); 1-day virtual placement with Amy (medical student, Manchester University); 1-day virtual placement with Kelly and Jason (medical students from Hong Kong); 3 month virtual placement for 3 medical students from Zimbabwe.

*"It was honestly excellent. I would highly recommend and really valued my time as part of the team. I had trained for 6 years, across 5 trusts and 2 universities and no one had even mentioned rare disease before I came across M4RD."*

Rare Disease 101 training was delivered to Paramedic Undergraduates at Oxford Brookes University alongside BeatSCAD and Addison's Disease Self Help Group.

#### **Postgraduate Rare Disease 101 training sessions**

Training day for Paediatric Trainees in South Wales. Two training sessions held with St George's Hospital Paediatrics Dept. Training session for Evelina Hospital's Community Paediatric team. Evelina Hospital's Paediatric Grand Round with the South East Thames GMST. London School of Paediatrics series of lectures on rare disease (2 taking place in 2022 and 3 more in 2023). Training session with the Royal College of GPs supported by Alexion Therapeutics. Training session for GPs supported by Health Education and Innovation Wales.

#### **UK Rare Diseases Framework**

M4RD continues to work with the UK's Department of Health and Social Care, Health Education England/NI & Wales/Scotland and other NHS Delivery Partners. Lucy is an active member of The UK Rare Disease Forum and is a member of the Quality Standards AIG.

## **MEDICS 4 RARE DISEASES**

### **TRUSTEES' ANNUAL REPORT (CONTINUED)**

**FOR THE YEAR ENDED 31 DECEMBER 2022**

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#### **The Rare Disease Podcast 4 Medics**

Launched in October 2021, M4RD's podcast series features interviews with people from across the rare disease and medical world, looking at different experiences and perspectives while providing pragmatic tips and advice for healthcare professionals. At the end of Season 1 it had reached 878 downloads. Season 2 reached 2122 downloads and Season 3 reached over 4000 downloads. Each Season consists of 9 episodes.

#### **Website and social media**

m4rd.org continues to be an important hub for rare disease news, information, videos and resources aimed at medical professionals and the team has continued to build up M4RD's online presence.

M4RD Mystery Monday created in collaboration with PAGs continues to be one of M4RD's most popular features with over 1950 followers on Instagram, reaching up to 10k accounts in any month. M4RD's weekly Instagram Story feature showcased 34 rare conditions in 2022 with over 650 votes and 3750 story views.

#### **The Student Voice Prize 2022**

M4RD works in a 50:50 partnership with Beacon to produce the annual Student Voice Prize. Following the success of the 2021 competition, M4RD and Beacon hosted its first joint online event 'Beyond the Student Voice Prize' in February 2022. 59 participants registered for the event with 27 participants attending on the night. 5 are now M4RD Ambassadors or working with other PAGs.

In October 2022 the SVP launched for its 9th year and the questions focussed on mental health in rare disease. 67 medical students entered the competition with 65 Patient Group pairings.

#### **RISE UK survey**

PI confirmed and protocol submitted for ethical approval. The survey will be rolled out in early 2023.

#### **Financial Position**

The budget for this financial year was decided based on the goals we set out to achieve in 2022 which reflect the M4RD strategy. We set out to fundraise £152,100 in order to fund activities for 2022. In total £147,583 of funding was secured through sponsorship and donations.

Total funds carried forward is £62,209. The final cash position is £57,787, £11,000 of which is kept in a savings account as per the charity's Reserves Policy.

#### **Principal Funding Sources**

The principal funding sources for this period were sponsorship and donations from commercial companies, including pharmaceutical companies. These were: Alexion Therapeutics, Amicus Therapeutics, Biomarin, Bionical Emas, Chiesi, Heabx, Kyowa Kirin, Novartis, Orchard Therapeutics, PTC Therapeutics, Sanofi, SOBI and Takeda UK. Charitable grants were also received from the Grace Trust, the James Tudor Trust, the Newby Trust and the Souter Charitable Trust.

#### **Reserves Policy and Review**

The Reserves Policy was put in place by The Board of Trustees in 2019. Reserves are to be maintained at a level which ensures that the charity's core activity could continue during a 3-month period of unforeseen financial difficulty during which funding is to be secured. If funding is not secured, then this is followed by a 3 month period in which the organisation could be dissolved with all outstanding debt settled. The Board of Trustees have set a minimum of £11,000 to be held in the charity's reserves.

#### **Financial Risk**

The staff team and Trustees all work and meet remotely so the charity doesn't own property or have a long-term rental contract. M4RD's biggest financial commitment is staff. The majority of the Charity's work is done 'in house' or provided to M4RD on a pro bono basis therefore external contracts are kept to a minimum.

M4RD continues to bank with CAF Bank which allows a good level of financial oversight by the Treasurer and other Trustees. All the Trustees have access to the online banking system and all payments require 2-person authorisation.

# **MEDICS 4 RARE DISEASES**

## **TRUSTEES' ANNUAL REPORT (CONTINUED)**

### **FOR THE YEAR ENDED 31 DECEMBER 2022**

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The main financial risk, as always, is if funding is not secured. In previous years M4RD has relied predominantly on commercial donations and sponsorship. However, during 2022 the charity started diversifying funding avenues in order to reduce risk from losing sponsors by identifying grantmakers that M4RD could apply to for charitable funding. £6k was secured in charitable donations during 2022 following successful applications and further opportunities are being explored.

The Trustees also have procedures to alert them early on to a financial short-fall and to act appropriately depending on the situation. This includes a Reserves Policy and alternative annual budgets to follow based on actual income vs requested income. In 2022 M4RD were able to meet its fundraising target.

#### **Plans for future periods**

M4RD exists to provide education and practical tools targeted at medical professionals, enabling them to reduce the diagnostic odyssey and improve the patient experience.

We've spent two years building a 'wonder team' and designing patient-centred, pragmatic education. We've clearly demonstrated that our approach benefits patients and clinicians alike. And now we just need to keep rolling it out through M4RD's own channels; through medical schools; through post-graduate training; through putting pressure in the right places within policy and public bodies.

#### **In 2023 M4RD aims to:**

- Host the 10th annual symposium with the The Royal Society of Medicine 'The Unusual Suspects: rare disease in everyday medicine' on 15th February.
- Run a structured awareness campaign and events around Rare Disease Day on 28th February.
- Expand M4RD; Learn, including: the launch of the Mental Health module created in 2022; plan Rare Disease in Primary Care and Coordinated Care modules.
- Collaborate with the Rare Disease Nurse Network to author, design create and publish a nursing specific version of Rare Disease 101 to be hosted on M4RD; Learn platform.
- Expand our online video content on our dedicated YouTube channel.
- Undergraduate education: continue conversations with Medical Schools about Rare Disease 101 education
- Postgraduate training: continue providing Rare Disease 101 training to doctors, especially within GP, Paediatrics and Emergency Medicine
- Create 'Rare Disease in Primary Care' - a model guideline.
- Collect data on medical student understanding about rare disease and their learning needs via the UK RISE project.
- Represent M4RD in public affairs engagement with The Department of Health and Social Care and its delivery partners.

#### **Organisational plans:**

- Engaging Cansdales as the charity's accountants and independent examiner.
- Recruit a new trustee who has lived experience of living with a rare condition.
- Recruit an additional clinical trustee e.g., medical student or specialty trainee.
- Identify a possible patron for the charity.

#### **Future funding:**

At the end of 2022 M4RD sent out funding applications to companies involved in the rare disease field, explaining the charity's 2023 work programme including the estimated costs involved. In total M4RD hopes to raise £247,430 to achieve its aims and objectives for 2023 by reaching out to established funding sources and newly identified grant givers.

# MEDICS 4 RARE DISEASES

## STATEMENT OF TRUSTEES' ANNUAL RESPONSIBILITIES FOR THE YEAR ENDED 31 DECEMBER 2022

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

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

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

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

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

The trustees' annual report was approved on ..... <sup>18<sup>th</sup> October 2023</sup> and signed on behalf of the board of trustees by:



Mr C J France  
Trustee

Date: ..... 18/10/23 .....

# MEDICS 4 RARE DISEASES

## INDEPENDENT EXAMINER'S REPORT

### TO THE TRUSTEES OF MEDICS 4 RARE DISEASES

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I report to the Trustees on my examination of the financial statements of Medics 4 Rare Diseases (the Charity) for the year ended 31 December 2022.

#### Responsibilities and basis of report

As the Trustees of the Charity you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011 (the 2011 Act).

I report in respect of my examination of the Charity's financial statements carried out under section 145 of the 2011 Act. In carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

#### Independent examiner's statement

Your attention is drawn to the fact that the charity has prepared financial statements in accordance with Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) in preference to the Accounting and Reporting by Charities: Statement of Recommended Practice issued on 1 April 2005 which is referred to in the extant regulations but has now been withdrawn.

I understand that this has been done in order for financial statements to provide a true and fair view in accordance with Generally Accepted Accounting Practice effective for reporting periods beginning on or after 1 January 2015.

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

- 1 accounting records were not kept in respect of the Charity as required by section 130 of the 2011 Act; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

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

Caroline Brazler ACA  
Cansdales Business Advisors Limited  
St Marys Court  
The Broadway  
Old Amersham  
HP7 0UT

Dated: 21 November 2023

## MEDICS 4 RARE DISEASES

### STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31 DECEMBER 2022

		Unrestricted funds 2022 £	Restricted funds 2022 £	Total Unrestricted funds 2022 £	Total Unrestricted funds 2021 £
<b>Income from:</b>					
Donations and legacies	3	30,083	2,500	32,583	15,597
Sponsorships	4	105,000	10,000	115,000	85,729
Investments	5	100	-	100	1
<b>Total income</b>		<b>135,183</b>	<b>12,500</b>	<b>147,683</b>	<b>101,327</b>
<b>Expenditure on:</b>					
Charitable activities	6	132,627	5,425	138,052	74,703
<b>Net income for the year/ Net movement in funds</b>		<b>2,556</b>	<b>7,075</b>	<b>9,631</b>	<b>26,624</b>
Fund balances at 1 January 2022		52,578	-	52,578	25,954
<b>Fund balances at 31 December 2022</b>		<b>55,134</b>	<b>7,075</b>	<b>62,209</b>	<b>52,578</b>

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Charities Act 2011.

# MEDICS 4 RARE DISEASES

## BALANCE SHEET

AS AT 31 DECEMBER 2022

	Notes	2022		2021	
		£	£	£	£
<b>Fixed assets</b>					
Intangible assets	12		2,290		-
Tangible assets	13		2,658		1,536
			<u>4,948</u>		<u>1,536</u>
<b>Current assets</b>					
Debtors	14	5,405		450	
Cash at bank and in hand		57,787		55,755	
		<u>63,192</u>		<u>56,205</u>	
<b>Creditors: amounts falling due within one year</b>	15	(5,931)		(5,163)	
<b>Net current assets</b>			<u>57,261</u>		<u>51,042</u>
<b>Total assets less current liabilities</b>			<u>62,209</u>		<u>52,578</u>
<b>Income funds</b>					
Restricted funds	16		7,075		-
Unrestricted funds			55,134		52,578
			<u>62,209</u>		<u>52,578</u>

The company is entitled to the exemption from the audit requirement contained in section 142(2) of Charities Act 2011, for the year ended 31 December 2022. The accounts have been examined by an independent examiner and their report have been included in these financial statements.

The directors acknowledge their responsibilities for complying with the requirements of the Charities Act 2011 with respect to accounting records and the preparation of financial statements.

The financial statements were approved by the Trustees on 4/1/23.....



Mr C J France  
Trustee

# **MEDICS 4 RARE DISEASES**

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

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### **1 Accounting policies**

#### **Charity information**

Medics 4 Rare Diseases is a public benefit entity and a private company limited by guarantee, registered in England and Wales and a registered charity in England and Wales. The address of the registered office is Unit 12 Treadaway Technical Centre, Treadaway Hill, Loudwater, High Wycombe, HP10 9RS.

#### **1.1 Accounting convention**

The financial statements have been prepared on the historical cost basis, as modified by the revaluation of certain financial assets and liabilities and investment properties measured at fair value through income or expenditure.

The financial statements are prepared in sterling, which is the functional currency of the entity.

#### **Statement of compliance**

These financial statements have been prepared in compliance with FRS 102, 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland', the 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) (Charities SORP (FRS 102)) and the Companies Act 2006.

#### **1.2 Going concern**

There are no material uncertainties about the charity's ability to continue.

#### **1.3 Charitable funds**

Unrestricted funds are available for use at the discretion of the Trustees in furtherance of their charitable objectives.

Designated funds are unrestricted funds earmarked by the trustees for particular future project or commitment.

Restricted funds are subjected to restrictions on their expenditure declared by the donor or through the terms of an appeal, and fall into one of two sub-classes: restricted income funds or endowment funds.

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2022

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### 1 Accounting policies

(Continued)

#### 1.4 Income

All incoming resources are included in the statement of financial activities when entitlement has passed to the charity; it is probable that the economic benefits associated with the transaction will flow to the charity and the amount can be reliably measured. The following specific policies are applied to particular categories of income:

- income from donations or grants is recognised when there is evidence of entitlement to the gift, receipt is probable and its amount can be measured reliably.
- legacy income is recognised when receipt is probable and entitlement is established.
- income from donated goods is measured at the fair value of the goods unless this is impractical to measure reliably, in which case the value is derived from the cost to the donor or the estimated resale value. Donated facilities and services are recognised in the accounts when received if the value can be reliably measured. No amounts are included for the contribution of general volunteers.
- income from contracts for the supply of services is recognised with the delivery of the contracted service. This is classified as unrestricted funds unless there is a contractual requirement for it to be spent on a particular purpose and returned if unspent, in which case it may be regarded as restricted.

#### 1.5 Expenditure

Expenditure is recognised on an accruals basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is classified under headings of the statement of financial activities to which it relates:

- expenditure on raising funds includes the costs of all fundraising activities, events, non-charitable trading activities, and the sale of donated goods.
- expenditure on charitable activities includes all costs incurred by a charity in undertaking activities that further its charitable aims for the benefit of its beneficiaries, including those support costs and costs relating to the governance of the charity apportioned to charitable activities.
- other expenditure includes all expenditure that is neither related to raising funds for the charity nor part of its expenditure on charitable activities.

All costs are allocated to expenditure categories reflecting the use of the resource. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs are apportioned between the activities they contribute to on a reasonable, justifiable and consistent basis.

#### 1.6 Intangible fixed assets other than goodwill

Intangible asset acquired on account of registration of trademark & logo is recognised at cost incurred on filing the patent with the competent authority.

There is no Amortisation charged for intangible acquired on account of registration of trademark & Logo. The carrying value, however will be reviewed at each Balance sheet date. If an entity determines that one of its trademarks is worth less than it was a year ago, the value of the intangible asset must be impaired. When an impairment occurs, the value of the asset must be decreased to its current market value. The difference between the current value of the trademark and its former value must be recorded as a financial loss.

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2022

### 1 Accounting policies

(Continued)

#### 1.7 Tangible fixed assets

Tangible assets are initially recorded at cost, and subsequently stated at cost less any accumulated depreciation and impairment losses. Any tangible assets carried at revalued amounts are recorded at the fair value at the date of revaluation less any subsequent accumulated depreciation and subsequent accumulated impairment losses.

An increase in the carrying amount of an asset as a result of a revaluation, is recognised in other recognised gains and losses, unless it reverses a charge for impairment that has previously been recognised as expenditure within the statement of financial activities. A decrease in the carrying amount of an asset as a result of revaluation, is recognised in other recognised gains and losses, except to which it offsets any previous revaluation gain, in which case the loss is shown within other recognised gains and losses on the statement of financial activities.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Computers	25% Reducing Balance method
-----------	-----------------------------

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in the statement of financial activities.

#### 1.8 Impairment of fixed assets

A review for indicators of impairment is carried out at each reporting date, with the recoverable amount being estimated where such indicators exist. Where the carrying value exceeds the recoverable amount, the asset is impaired accordingly. Prior impairments are also reviewed for possible reversal at each reporting date.

For the purposes of impairment testing, when it is not possible to estimate the recoverable amount of an individual asset, an estimate is made of the recoverable amount of the cash-generating unit to which the asset belongs. The cash-generating unit is the smallest identifiable group of assets that includes the asset and generates cash inflows that largely independent of the cash inflows from other assets or groups of assets.

#### 1.9 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

#### 1.10 Financial Instruments

A financial asset or a financial liability is recognised only when the charity becomes a party to the contractual provisions of the instrument.

Basic financial instruments are initially recognised at the amount receivable or payable including any related transaction costs.

Current assets and current liabilities are subsequently measured at the cash or other consideration expected to be paid or received and not discounted.

Debt instruments are subsequently measured at amortised cost.

Where investments in shares are publicly traded or their fair value can otherwise be measured reliably, the investment is subsequently measured at fair value with changes in fair value recognised in income and expenditure. All other such investments are subsequently measured at cost less impairment.

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2022

---

#### 1 Accounting policies

(Continued)

Other financial instruments, including derivatives, are initially recognised at fair value, unless payment for an asset is deferred beyond normal business terms or financed at a rate of interest that is not a market rate, in which case the asset is measured at the present value of the future payments discounted at a market rate of interest for a similar debt instrument.

Other financial instruments are subsequently measured at fair value, with any changes recognised in the statement of financial activities, with the exception of hedging instruments in a designated hedging relationship.

Financial assets that are measured at cost or amortised cost are reviewed for objective evidence of impairment at the end of each reporting date. If there is objective evidence of impairment, an impairment loss is recognised under the appropriate heading in the statement of financial activities in which the initial gain was recognised.

For all equity instruments regardless of significance, and other financial assets that are individually significant, these are assessed individually for impairment. Other financial assets are either assessed individually or grouped on the basis of similar credit risk characteristics.

Any reversals of impairment are recognised immediately, to the extent that the reversal does not result in a carrying amount of the financial asset that exceeds

#### **Basic financial assets**

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

#### **Basic financial liabilities**

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

#### **Derecognition of financial liabilities**

Financial liabilities are derecognised when the Charity's contractual obligations expire or are discharged or cancelled.

#### 1.11 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the Charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

#### 1.12 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

# MEDICS 4 RARE DISEASES

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2022

### 1 Accounting policies

(Continued)

#### 1.13 Fund accounting

Unrestricted funds are available for use at the discretion of the trustees to further any of the charity's purposes.

Designated funds are unrestricted funds earmarked by the trustees for particular future project or commitment.

Restricted funds are subjected to restrictions on their expenditure declared by the donor or through the terms of an appeal, and fall into one of two sub-classes: restricted income funds or endowment funds.

#### 1.14 Defined contribution plans

Contributions to defined contribution plans are recognised as an expense in the period in which the related service is provided. Prepaid contributions are recognised as an asset to the extent that the prepayment will lead to a reduction in future payments or a cash refund.

When contributions are not expected to be settled wholly within 12 months of the end of the reporting date in which the employees render the related service, the liability is measured on a discounted present value basis. The unwinding of the discount is recognised as an expense in the period in which it arises.

### 2 Critical accounting estimates and judgements

In the application of the Charity's accounting policies, the Trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

#### Critical Judgements

The preparation of the financial statements requires management to make judgements, estimates and assumptions that affect the amounts reported. These estimates and judgements are continually reviewed and are based on experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances.

### 3 Donations and legacies

	Unrestricted funds	Restricted funds	Total Unrestricted funds	
	2022	2022	2022	2021
	£	£	£	£
Donations and gifts	20,656	2,600	23,156	15,597
Other	9,427	-	9,427	-
	<u>          </u>	<u>          </u>	<u>          </u>	<u>          </u>

## MEDICS 4 RARE DISEASES

### NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2022

#### 4 Sponsorships

	2022 £	2021 £
Sponsorships	115,000	85,729
Analysis by fund		
Unrestricted funds	105,000	85,729
Restricted funds	10,000	-
	115,000	85,729

#### 6 Investments

	Unrestricted funds	Unrestricted funds
	2022 £	2021 £
Interest receivable	100	1



## MEDICS 4 RARE DISEASES

### NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 DECEMBER 2022

<b>8</b>	<b>Net movement in funds</b>	<b>2022</b>	<b>2021</b>
		<b>£</b>	<b>£</b>
	Net movement in funds is stated after charging/(crediting)		
	Depreciation of owned tangible fixed assets	<u>487</u>	<u>512</u>

#### **9 Trustees**

None of the Trustees (or any persons connected with them) received any remuneration or benefits from the Charity during the year.

£300 (2021: £800) was paid to Mr D Jeffries, one of the trustees, for his professional services in setting up e-learning facilities for the charity.

#### **10 Employees**

The average monthly number of employees during the year was:

	<b>2022</b>	<b>2021</b>
	<b>Number</b>	<b>Number</b>
Charitable activities	<u>4</u>	<u>3</u>
<b>Employment costs</b>	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
Wages and salaries	98,105	43,620
Social security costs	3,085	-
Other pension costs	2,043	1,033
	<u>103,233</u>	<u>44,653</u>

Out of the above employment cost, cost amounting to £4,468 (2021: Nil) forms part of restricted expenditure.

There were no employees whose annual remuneration was more than £60,000.

#### **11 Pensions and other post retirement benefits**

##### **Defined contribution plans**

The amount recognised in income or expenditure as an expense in relation to defined contribution plans was £2,043 (2021: £1,033).

## MEDICS 4 RARE DISEASES

### NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022

#### 12 Intangible fixed assets

	Intangibles Assets £
<b>Cost</b>	
At 1 January 2022	-
Additions -Trademark	2,290
	<u>          </u>
At 31 December 2022	2,290
	<u>          </u>
<b>Amortisation charge</b>	
At 1 January 2022 and 31 December 2022	-
	<u>          </u>
<b>Carrying amount</b>	
At 31 December 2022	2,290
	<u>          </u>
At 31 December 2021	-
	<u>          </u>

#### 13 Tangible fixed assets

	Computers £
<b>Cost</b>	
At 1 January 2022	2,355
Additions	1,609
	<u>          </u>
At 31 December 2022	3,964
	<u>          </u>
<b>Depreciation charge</b>	
At 1 January 2022	819
Depreciation charged in the year	487
	<u>          </u>
At 31 December 2022	1,306
	<u>          </u>
<b>Carrying amount</b>	
At 31 December 2022	2,658
	<u>          </u>
At 31 December 2021	1,536
	<u>          </u>

#### 14 Debtors

	2022 £	2021 £
<b>Amounts falling due within one year:</b>		
Trade debtors	300	-
Prepayments and accrued income	5,105	450
	<u>          </u>	<u>          </u>
	5,405	450
	<u>          </u>	<u>          </u>

## MEDICS 4 RARE DISEASES

### NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

#### FOR THE YEAR ENDED 31 DECEMBER 2022

#### 15 Creditors: amounts falling due within one year

	2022	2021
	£	£
Other taxation and social security	3,077	1,808
Trade creditors	234	1,095
Other creditors	-	394
Accruals and deferred income	2,620	1,866
	<u>5,931</u>	<u>5,163</u>

#### 16 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes:

	Movement In funds		Movement in funds		
	Incoming resources	Balance at 1 January 2022	Incoming resources	Resources expended	Balance at 31 December 2022
	£	£	£	£	£
M4RD Learn	-	-	12,500	(5,425)	7,075
	<u>-</u>	<u>-</u>	<u>12,500</u>	<u>(5,425)</u>	<u>7,075</u>

#### 17 Unrestricted funds

	Movement in funds			Movement in funds			Balance at 31 December 2022
	Balance at 1 January 2021	Incoming resources	Resources expended	Balance at 1 January 2022	Incoming resources	Resources expended	
	£	£	£	£	£	£	
	25,954	101,327	(74,702)	52,579	147,682	(138,052)	62,209
	<u>25,954</u>	<u>101,327</u>	<u>(74,702)</u>	<u>52,579</u>	<u>147,682</u>	<u>(138,052)</u>	<u>62,209</u>

#### 18 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total Unrestricted funds	
	2022	2022	2022	2021
	£	£	£	£
Fund balances at 31 December 2022 are represented by:				
Intangible fixed assets	2,290	-	2,290	-
Tangible assets	2,658	-	2,658	1,536
Current assets/(liabilities)	50,186	7,075	57,261	51,042
	<u>55,134</u>	<u>7,075</u>	<u>62,209</u>	<u>52,578</u>

## **MEDICS 4 RARE DISEASES**

### **NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**

***FOR THE YEAR ENDED 31 DECEMBER 2022***

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#### **19 Related party transactions**

During the year the Charity entered into the following transactions with related parties:

Donation of £485 (2021- Nil) received from Lucy Martha Rosemary McKay who is company secretary of charity.

**MEDICS 4 RARE DISEASES**

England & Wales - Charity number 1183996

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# Accounts

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**Medics 4 Rare Diseases Ltd**  
**Company Limited by Guarantee**  
**Unaudited Financial Statements**  
**31 December 2021**

**HOWARD MATTHEWS PARTNERSHIP**

Chartered accountants  
Queensgate House  
23 North Park Road  
Harrogate  
North Yorkshire  
HG1 5PD

# Medics 4 Rare Diseases Ltd

Company Limited by Guarantee

## Financial Statements

Year ended 31 December 2021

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Independent examiner's report to the trustees	<b>15</b>
Statement of financial activities (including income and expenditure account)	<b>16</b>
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<b>The following pages do not form part of the financial statements</b>	
Detailed statement of financial activities	<b>28</b>
Notes to the detailed statement of financial activities	<b>29</b>

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# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report)

Year ended 31 December 2021

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The trustees, who are also the directors for the purposes of company law, present their report and the unaudited financial statements of the charity for the year ended 31 December 2021.

#### Reference and administrative details

<b>Registered charity name</b>	Medics 4 Rare Diseases Ltd
<b>Charity registration number</b>	1183996
<b>Company registration number</b>	11119884
<b>Principal office and registered office</b>	Unit 12 Treadaway Technical Centre Treadaway Hill Loudwater High Wycombe HP10 9RS

#### The trustees

Dr D R Fine  
Mr C J France  
Dr O H Grant  
Mr D C Jeffries  
Mrs L J Birrell

<b>Bookkeeping and payroll</b>	Adder Bookkeeping
<b>Company secretary</b>	Dr L M R McKay
<b>Independent examiner</b>	Howard Matthews BA FCA Queensgate House 23 North Park Road Harrogate North Yorkshire HG1 5PD

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 December 2021

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#### Structure, governance and management

Trustees have been appointed to the M4RD board based on their experience, skills and enthusiasm for the work of M4RD. M4RD relies heavily on the voluntary time that its Trustees generously provide. The minimum number of Directors is 2 and there is no maximum number. The requirements to be considered for the position of Director is outlined in the company's Articles of Association. Trustee induction is provided by the CEO with input from the Chair. This is carried out remotely. The new Trustee is provided with a New Trustee Induction Pack and access to the Charity's documents. M4RD makes use of readily available online training created by other organisations such as The Small Charities Coalition and provides a PDF copy of The Charity Commission's document 'The Essential Trustee'.

The board meets quarterly via video conferencing. The CEO, Lucy McKay, is a founding member of the company and has been in the role of CEO since September 2018. Lucy is a key opinion leader in the rare disease field having had personal experience of rare disease and training in the NHS as a doctor. She reports to the Trustee Board and is responsible for: implementing the strategy of the charity, as agreed by the Trustees; managing the staff team; oversight of finances and fundraising; and identifying and assessing strategic risks and opportunities. Until recently Lucy has been the main external face of M4RD, however with the addition of new employees this responsibility is being shared more.

In April 2021 Jo McPherson joined the M4RD staff team as Operations and Finance Manager. Jo's main responsibilities are operations, managing the finances, fundraising and patient advocacy group liaison. In August Dr Emma Huskinson also joined the staff team as Medical Communications Officer, responsible for public relations, liaising with press and writing medical content.

Lucy, Jo and Emma work part-time from home. Jo and Emma report to Lucy. Lucy reports to the Chair bi-monthly unless more frequent support is needed. Lucy and Jo report to the Treasurer quarterly in order to ensure the smooth and financially prudent running of the charity. Both of these recurring meetings were initiated in 2019 and have been immensely valuable to the team as a whole.

The M4RD Board of Trustees contribute generously to the success of the charity. Two Trustees are GPs and have been involved in M4RD (in its previous forms) since 2011. Dr Olivia Hannah Grant is an international lacrosse player, but for M4RD she provides insight into day to day life and learning needs of being a GP in the NHS. The Treasurer, Dr Debra Fine, was an Accountant prior to training to become a doctor and this range of experience is invaluable to the role. Lindsay Birrell is the Vice Chair of M4RD, her prior experience working for Metabolic Support UK as CEO has been invaluable to Lucy and the rest of the Trustee Board. Dan Jeffries is M4RD's patient representative but has many skills within IT. His day job of creating online interactive educational software meant he was able to provide bespoke and greatly discounted services in the creation of M4RD's learning management system (LMS). The Chair, Chris France, is the founder of a successful e-commerce company and has been pivotal in getting M4RD's structure established, mentoring Lucy and steering the charity in the direction of successful strategies.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

#### Year ended 31 December 2021

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##### **Structure, governance and management** *(continued)*

The aims and objectives of the 2021 plan drove the decision making during this period.

The Board of Trustees and the CEO are responsible for reviewing and updating the charity's strategic plan. This was most recently done at M4RD's Strategy Meeting in July 2021. The CEO uses quarterly Board Meetings to update the Trustees on the progress being made by the charity and to ask questions and receive advice. The CEO is largely responsible for making decisions about activities that achieve the aims and objectives. Large financial decisions (outside of pre-authorised projects) are taken to the board by the CEO to be discussed.

##### **Objectives and activities**

The organisation is a charitable company limited by guarantee incorporated on 20th December 2017 and registered as a charity on 20th June 2019. The company was established under a Memorandum of Association which established the objects and powers of the company and is governed under its Articles of Association which were updated on 20th June 2019 in line with recommendations from the Charity Commission. In the event of the company being wound up, members are required to contribute an amount not exceeding £1.

Below are the charity's purposes as set out in the objects contained in the company's Memorandum of Association.

The company is established for the objects of the relief of sickness and preservation of health of those suffering from rare diseases, throughout the world, by:

- (a) advancing the education of medics, associated professionals and the public in rare diseases, genetic and genomic medicine
- (b) promoting research in all areas relating to rare diseases, genetic and genomic medicine and publishing the useful results
- (c) promoting improved care and treatment of those suffering from rare diseases.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

#### Year ended 31 December 2021

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#### **Objectives and activities** *(continued)*

##### Aims and public benefit:

The charity aims to improve the lives of a certain portion of the public: those living with rare diseases and their communities. It does this through raising awareness of the relevance of rare diseases in medical practice. The charity provides education about rare diseases and opportunities to develop a clinician's understanding of this large population group in the UK in order to better serve it.

The trustees received guidance on public benefit from the Charity Commission during the registration process. The company's Articles of Association were updated on 20th June 2019 in line with recommendations from the Charity Commission. The organisation's objects are wholly charitable. Any personal benefit arising is legitimately incidental.

##### Review:

During 2019 M4RD worked with the Charity Commission to make sure its structure, objects and governing document were ready for the organisation to be registered as a charity. This required a review of our purposes to make sure they were wholly charitable and benefited the public. In the case of M4RD 'the public' refers to the estimated 3.5 million people in the UK who suffer from a rare disease - and their communities.

Following guidance from the Charity Commission the Board of Trustees adapted the company's original Memorandum & Articles to make sure the wording was suitable for the charity. The full Articles of Association can be viewed in the Filing History of M4RD on the Companies House website.

The Board of Trustees review M4RD's objectives, goals and strategies on an annual basis at the Strategy Meeting. This is done with reference to guidance contained in the Charity Commission's general guidance on public benefit.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

#### Year ended 31 December 2021

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##### Objectives and activities *(continued)*

###### Activities:

A rare disease is defined in the UK as a condition that affects fewer than 5 in 20,000 people. Over 7,000 rare diseases have been identified which means that understanding and teaching about rare diseases in medical education is extremely challenging. However this is a challenge that we cannot afford to avoid because approximately 3.5 million people in the UK have a rare disease. So while each disease is individually rare, they are collectively common.

Of these diseases, 80% are known to be genetic in origin and 75% present in childhood. 30% of those living with a rare disease will sadly die before their fifth birthday. However, despite this large prevalence (equivalent to all adults in the UK who suffer with asthma), each individual condition affects so few people that they tend to be overlooked and misunderstood by health professionals, researchers, education and social care providers and the general public. This lack of awareness amongst medical professions is particularly devastating and can lead to extreme diagnostic delay. A person with a rare disease will wait on average 5.6 years for an accurate diagnosis. They will see numerous doctors, receive misdiagnoses and potentially even inappropriate treatment. This long and arduous journey to a diagnosis has been named "the diagnostic odyssey".

The challenges of having a rare disease do not stop after getting a diagnosis. People living with completely different diseases often report the same difficulties in terms of healthcare, social care, family life, education, work and mental health. There are many wonderful charities in the UK that support rare disease patients depending on their disease or specific need. Umbrella charities run successful public awareness campaigns. However M4RD specifically targets an audience that nobody else was concentrating on but could make the greatest impact on the diagnostic odyssey and the challenges that follow: medical students and doctors in training.

By creating a medical profession equipped to suspect, diagnose and manage rare diseases we can help people living with rare diseases have the best outcomes and reach their full potential. To do this M4RD is driving an attitude change towards rare diseases amongst medical students and doctors in training. Without appropriate training, the idea that rare diseases are irrelevant to clinical practice will continue to contribute to the diagnostic odyssey. We remedy this by presenting the statistics to our audience and asking people with rare diseases to share their stories. M4RD have developed a new approach to satisfactorily cover the subject of rare disease within undergraduate and postgraduate medical training. Finally, we're creating our own resources and promoting others' resources in order to support medical professionals when they need help on the subject of rare disease.

###### Wider network:

M4RD works with other charities in order to achieve its objects. These are usually patient groups within the rare disease field. Of particular note are Beacon who M4RD partners with in order to run an essay competition that raises awareness of rare diseases. The annual symposium is organised in association with The Royal Society of Medicine, also a UK registered charity.

M4RD also collaborates with other not-for-profit organisations such as Genetic Alliance UK, Rare Revolution Magazine, Rare QOL and the Rare Disease Nurse Network.

M4RD receives pro bono support from the health communications agency, emotive <https://thinkemotive.com>. The charity also depends on volunteers to contribute to projects and speak at events.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 December 2021

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#### Objectives and activities *(continued)*

M4RD is a founding organisation of an informal group called Action for Rare Disease Empowerment (ARDEnt), alongside Cambridge Rare Diseases Network and Rare Revolution Magazine. In May 2021 they published a report called 'Making the Unseen Seen: Rare disease and lessons learned from the COVID-19 pandemic' <https://www.camraredisease.org/ardent/>.

#### Declaration of Payment to Trustee

In 2021 Dan Jeffries was paid £800 in total to create a new on line learning module for M4RD Learn. Payments to Trustees for services are allowed by the charity's governing document provided conditions in sub-clause 6.2 are satisfied. These conditions were satisfied and the Board of Trustees (excluding Dan Jeffries) decided that hiring Dan Jeffries for the specific service of creating Rare Disease 101 was in the best interest of the charity given his in depth knowledge of the charity, his personal experience of living with two rare diseases and his professional experience in this exact service.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

#### Year ended 31 December 2021

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#### Achievements and performance

It's been a momentous year for M4RD as the charity continues to be widely recognised as a key player in the rare disease advocacy world.

The main aims of 2021 were:

- The Unusual Suspects 2021 online symposium with the Royal Society of Medicine - achieved Feb 2021
- Launch Rare Disease 101 on the M4RD learning management system "M4RD: Learn" - achieved Feb 2021
- Start work on additional M4RD: Learn modules to supplement the Rare Disease 101 module e.g. early access programmes, clinical trials, mental health
- Complete analysis of data from the Red Flags Survey and preparing for publication - Achieved
- Collaborate with National Student Association for Medical Research (NSAMR) on the UK Rare disease Student Evaluation project - a study surveying medical students about their attitudes towards rare disease and identifying their learning needs - Partially achieved (awaiting a Principal Investigator)
- Work with the Rare 2030 project to address the issue of medical education
- Continue working with Action for Rare Disease Empowerment (ARDEnt) - a series of webinars held in association with the Royal Society of Medicine's 'Medicine & Me' section - planned for early 2022
- Continue developing the M4RD website into an educational hub - ongoing
- Evaluate and relaunch the Ambassadors Programme - planned for early 2022
- Launch Student Voice Prize 2021 with Beacon - achieved

Organisational plans:

- Develop a more diverse fundraising strategy - achieved
- Grow the team by recruiting two part-time positions: Operations & Finance Manager and Medical Communications Officer - achieved
- Convert to a Charitable Incorporated Company - awaiting a response
- Appoint a bookkeeper - achieved

#### The Unusual Suspects 2021

The annual symposium has been a popular event in the rare disease calendar for many years - allowing medical professionals at all levels, trainees and students, to come together to learn more about the relevance of rare disease in everyday medicine.

In previous years the event has had a largely UK audience, but with the meeting being held virtually this year we were able to reach a much wider audience - with over 200 participants watching live which made for a really engaging and interactive meeting and lots of questions raised during the panel sessions.

Dr Lucy McKay played a video to showcase Rare Disease 101 - a free, online and interactive module created by M4RD, aimed at medical professionals in the early stages of their careers to educate them on the fundamentals of rare diseases. She explained how the series of lessons helps to address some of the issues highlighted in the Government's UK Rare Diseases Framework, specifically increasing awareness of rare diseases amongst healthcare professionals.

The first talk was given by Dr Gareth Baynam, a clinical geneticist from Australia who focused on "Y and How?", discussing why healthcare professionals should care about rare diseases and also touching on a wider outlook in terms of finding treatments for rare diseases and how they can have

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

#### Year ended 31 December 2021

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advantages for patients with other illnesses. He shared his thoughts on how to better approach the management of rare diseases and how to raise awareness within the healthcare system and encouraged us all to consider system-wide thinking alongside the idea that one size doesn't fit all: "we need to utilise different approaches and be more agile in order to improve the doctor-patient relationship and speed up the journey to diagnosis".

Georgina Morton from the ArchAngel MLD Trust discussed her experiences from a parent's perspective and shared valuable insights on the process of finding a clinical trial for her daughter. Listening to Georgina's story was particularly moving and highlighted the value that RD101 can bring to doctors, patients and families in the future.

Following on from Georgina's talk was a talk by Prof. Bobby Gaspar, Honorary Clinical Professor at Great Ormond Street Hospital and the UCL Institute of Child Health and CEO of Orchard Therapeutics. Prof. Gaspar spoke about his work with haematopoietic stem cell (HSC) gene therapies.

Abie Epstein and David Rose gave a talk on the "I am number 17" campaign. Abie from Takeda UK and David, a person living with an ultra-rare disease and an advocate at Rare Revolution Magazine, started off with a brief video outlining the objectives of the campaign which focuses on 17 'changemakers', whose aim it is to show that although people may have had very different experiences reaching their diagnosis, there are still so many shared challenges that people who live with rare diseases face. David touched on what his experience of getting a diagnosis was like and the impact this can have on a person's life. Hearing the experiences of people living with rare diseases really emphasises why it is so important to continue to raise awareness of rare diseases and the importance of patient groups working with healthcare professionals on this issue.

The final speaker was the winner of the 2020 Student Voice Prize, a medical student from Barts and The London School of Medicine and Dentistry, who spoke about her essay "Unmasked: An insight into three patients with rare disease in the COVID-19 pandemic". Catriona Chaplin discussed her experience of talking to three people who have been diagnosed with or care for someone with mastocytosis and reflected on the challenges faced as a result of the COVID-19 pandemic. 96% of clinical delegates said that this event will prompt them to consider rare diseases in their future practice. Comments included: "This has taught me the prevalence of rare disease collectively and has inspired me to ask more questions regarding the patients I see." and "Best event in Rare Disease Week so far - informative, varied and great pace!"

In response to the question "Were you aware that 3.5 million people in the UK (1 in 17) are affected by a rare disease in their lifetime?": 23% were aware; 37% knew that rare diseases are common as a whole but were not aware how common; 40% did not know that so many people in the UK are affected by rare diseases We were grateful once again to the RSM Medical Genetics Section for supporting us with our event and allowing us to use their prestigious platform.

#### Rare Disease 101

In February M4RD launched its online, interactive e-learning platform dedicated to teaching medics the fundamentals of rare disease and help them manage both their undiagnosed and diagnosed patients - M4RD Learn. Rare diseases pose challenges for medical education due to their low prevalence and the resulting lack of knowledge by society and healthcare providers. Rare Disease 101 is the first module available on the platform.

Rare Disease 101 is about the basics of rare disease. The kind of information that would not need to be explained at a rare disease conference but that some medical professionals may not be aware of. It has been in the making for years as we have listened to and learned from those with rare diseases

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

#### Year ended 31 December 2021

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and RD advocates, while at the same time understanding the medical education system and the huge pressures the medical profession is under on a daily basis. In order to balance our aims with the needs of the target audience, it was important to the M4RD team that Rare Disease 101 not only explains the impact of living with a rare disease but also provides pragmatic tips for medical professionals. We demonstrate tools that are already at their fingertips (but they might not know of yet). As well as coming up with new methods for approaching when to suspect someone has an underlying rare condition.

People with very different rare diseases often report facing remarkably similar challenges. Rare Disease 101 proves the concept that with a disease-agnostic approach to rare disease education medics can be prepared to manage any patient living with a diagnosed or undiagnosed condition.

#### ARDEnt

At the beginning of the COVID-19 pandemic of early 2020, a group of concerned advocates came together to take Action for Rare Disease Empowerment. The group became known as ARDEnt and their aim was to shed light on the unseen impact of the pandemic on people living with rare conditions in order to protect the existing services that they depend on and to harness any opportunities that arose. Information was gathered by a review of the published literature, grey literature review (including government documents, patient advocacy and public health documents) and interviews with key stakeholders, including patients, healthcare professionals, researchers, industry and advocacy groups. Although the focus of this review was the UK, the information search was not restricted to the UK.

In May they published their report, <https://www.camraredisease.org/ardent/> which revealed the impact of the pandemic on every stage of the patient journey, from diagnosis to eventual management. It catalogues the re-assignment of specialists away from rare disease, the fear of infection, the closure of clinics, the fracture of coordination of health and social care, and the delay or termination of clinical studies. At the same time, the pandemic has accelerated the evolution of remote monitoring, the adoption of video calling and virtual appointments.

This Action for Rare Disease Empowerment (ARDEnt) report is the product of a cross-sector collaboration of rare disease experts led by Lucy and includes the collation of published data on the impact of the pandemic on the rare disease community alongside insights from a range of interviewees in order to identify the post pandemic risks and opportunities in this field.

Lucy is working with Theme 1 participants to publish their findings. These demonstrate that diagnostic delay was exacerbated by the pandemic and provides solutions for mitigating this problem. It is in the peer review stage with the journal.

#### UK Rare Diseases Framework

In January 2021 the publication of the UK Rare Disease Framework by the Department of Health and Social Care highlighted 4 key priority areas in rare disease and Priority 2 is "increasing awareness amongst healthcare professionals". Lucy was invited to be an expert member of the UK Rare Disease Forum that advises the UK Rare Diseases Implementation Board and has also represented M4RD at roundtables for Public Policy Projects with Baroness Nicola Blackwood this year. On 27 May 2021 Sondra Butterworth, CEO of RareQoL and founder of the #WhoseVoice campaign, and Lucy McKay from M4RD hosted an engagement session on the UK Rare Diseases Framework and the England Action Plan on behalf of NHS England (NHSE) and NHS Improvement (NHSI). The report was published in October 2021.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

#### Year ended 31 December 2021

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##### Podcast

The Rare Disease Podcast 4 Medics was launched in October 2021 featuring interviews with people from across the rare disease and medical world, looking at different experiences and perspectives while providing pragmatic tips and advice for healthcare professionals. The first series included interviews with representatives from BeatSCAD for 'Not your usual heart attack'; previous SVP winner; a GP diagnosed with a rare genetic condition 'Doctors are patients too'; Dr Shanali talking about identity; and Dr Sondra Butterworth who spoke about inclusivity. The first season was downloaded 620 times.

##### Rare diseases in primary care: assessment and management

In December 2021 the Royal College of General Practitioners (RCGP) held an evening webinar about rare disease in primary care, initiated and funded by an M4RD sponsor, Alexion Therapeutics. Lucy provided Rare Disease 101 education, including M4RD's popular 'Top Tips for GPs'. She was joined by Dr Will Evans, a GP, and Karen Harrison, a parent of two sons with a rare genetic condition. The webinar was very well received, with an engaged audience who provided really inspiring feedback. Demonstrating that this is not only an unmet need for patients but also medical professionals.

"This was such a helpful and thought-provoking webinar. I took myself to a genetics clinic when I was a GP trainee following meeting a family during my A&E job who brought in their boys who both had muscular dystrophy. I also remember my father being saddened when a young anesthetist died suddenly whilst at work from a complication of Marfans syndrome. As a medical student I met a Mum in the obstetric unit who had PKU. "Tonight's webinar was a reminder of the importance of being alive to rare disease and ways to equip ourselves and the team around us to help these patients and their families."

"Great topic and sheds a light on a group of patients who remain to this day constantly challenged by the lack of support and knowledge in relation to their rare conditions."

During the meeting, a poll revealed that GPs underestimate prevalence with only 30% answering correctly (3.5 million) and overestimate the rarity of individual conditions: 22% answered correctly defined a rare disease (<1 in 2000). 63% guessed <1 in 20000. This demonstrates that some medical professionals cannot even define a rare disease and that M4RD's plan to reframe rare disease in medical education is vital.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

#### Year ended 31 December 2021

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##### **Achievements and performance** *(continued)*

###### Website and Social Media

m4rd.org continues to be an important hub for rare disease news, information, videos and resources aimed at medical professionals. Online learning has really come into the fore as students have been kept away from their normal learning environments. Therefore the team has continued to build up M4RD's online presence. M4RD also has a well established presence on Facebook, Twitter, Instagram and LinkedIn.

For a brief period of time M4RD was able to externally contract a Genetic Counsellor to create the educational content for MysteryDiseaseMonday. Her medical insight in this area enabled her to design eye-catching and detailed (but effective) Instagram Stories using information provided by patient advocacy groups. Unfortunately Melissa could not continue providing this service for M4RD when she took up a Genetic Counselling position. However the engagement we saw from followers demonstrated the benefit of keeping this kind of regular content going in the future, with over 23 rare conditions featured during 2021 on Mystery Monday and over 1280 views of the stories alone.

###### The Student Voice Prize 2021

Once again M4RD worked in a 50:50 partnership with Beacon (formerly Findacure) in order to produce The Student Voice Prize for its 8th year. This essay competition was started by Findacure and M4RD have been involved in it for several years. M4RD's trustees have been responsible for marking the essays for a number of years and Lucy has played an increasing role in organising the competition. The medical school experiences of Lucy and the M4RD trustees has helped Findacure target medical students. The aim of the competition is to provide an attractive opportunity (becoming a published author in a medical journal) to encourage medical students to research rare diseases, engage with the rare disease community and pass on what they learned to their peers. The questions are carefully designed to make this competition accessible across the globe. There were 50 entries, 29 of which were paired with patient groups. This year's questions revolved around health inequality and intersectionality within the rare disease patient experience, allowing students to share their thoughts on how healthcare can be improved for a large, but poorly represented community.

The winner, a 1st year medical student who lives with a rare condition herself, spoke at the M4RD annual symposium in 2022. Zainab Alani's essay 'Exploring intersectionality: an international yet individual issue' was published in The Orphanet Journal of Rare Diseases <https://ojrd.biomedcentral.com/articles/10.1186/s13023-022-02255-3>

###### The Ambassador Programme

The ambassador programme enables M4RD to work with the wider rare disease community so we can learn from their expertise and experience. We currently have two types of Ambassadors: Clinical and Patient. Clinical Ambassadors help inform our projects, identify teaching opportunities, spread the word about events and opportunities for medics. Our Patient Ambassadors are really important for making sure that the patient's voice is heard through our work because communicating the lived experience of having a rare disease is fundamental in our message to medical students and doctors in training.

The M4RD team would like to thank all the Ambassadors for playing such a pivotal role in getting the charity to where we are today and we're looking forward to the new cohort of ambassadors joining us in 2022, including medical students.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

#### Year ended 31 December 2021

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#### Financial review

##### Financial Position

The budget for this financial year was decided based on the goals we set out to achieve in 2021 which reflect the M4RD strategy. We set out to fundraise £80,000 in order to fund activities for 2021. In total £101,326 of funding was secured through sponsorship and donations.

Total funds carried forward is £52,579.

The final cash position is £55,755.

£11,000 of which is kept in a savings account as per the charity's Reserves Policy.

##### Principal Funding Sources

The principal funding sources for this period were sponsorship and donations from commercial companies, including pharmaceutical companies. These were: Alexion Therapeutics, Amicus Therapeutics, Biomarin, Bionical Emas, Freeline, Illumina Foundation, PTC Therapeutics, Sarepta, SOBI and Takeda UK.

##### Reserves Policy and Review

The Reserves Policy was put in place by The Board of Trustees in 2019. Reserves are to be maintained at a level which ensures that the charity's core activity could continue during a 3 month period of unforeseen financial difficulty during which funding is to be secured. If funding is not secured then this is followed by a 3 month period in which the organisation could be dissolved with all outstanding debt settled. The Board of Trustees have set a minimum of £11,000 to be held in the charity's reserves.

##### Financial Risk

The risks that M4RD are exposed to are fairly low as its committed spend and running costs were still relatively low throughout 2020. The CEO and Trustees all work and meet remotely so the charity doesn't own or rent property. The majority of work is done 'in house' or pro bono therefore external contracts are kept to a minimum. However as staff costs have increased, with the addition of new employees, the overheads are naturally greater at the end of 2021 than 2020.

M4RD continues to bank with CAF Bank which allows a good level of financial oversight by the Treasurer and other Trustees. All the Trustees have access to the online banking system and all payments require 2-person authorisation.

The main financial risk, as always, is that funding is not secured. In previous years M4RD has relied predominantly on commercial donations and sponsorship. However part of the 2021 plan was to diversify funding avenues in order to reduce risk from losing sponsors. As such the charity contracted an external consultant who identified grantmakers that M4RD could apply to for charitable funding.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 December 2021

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#### Plans for future periods

M4RD exists to provide education and practical tools targeted at medical professionals, enabling them to reduce the diagnostic odyssey and improve the patient experience.

In 2022 M4RD aims to:

- Host its annual meeting with the The Royal Society of Medicine 'The Unusual Suspects: rare disease in everyday medicine' on 9th February.
- Continue to engage with the Department of Health and Social Care and its delivery partners.
- Organise a series of webinars with the RSM's Medicine and Me section on 'lessons learned from the COVID-19 pandemic' in collaboration with the ARDEnt group.
- Develop a rare disease toolkit using the findings from our Red Flags survey.
- Launch a Rare Disease 101 mini-module focussing on clinical trials and early access programmes as well as some 'deep-dive' modules on mental health and care coordination.
- Develop a Best Practice Guide for PAGS on how to engage with healthcare professionals.
- Launch the second and third series of the Rare Disease Podcast 4 Medics.
- Launch The Student Voice Prize 2022 with Beacon.
- Induct a new cohort of Patient, Clinical and Medical Student Ambassadors

Organisational plans:

- Grow the team by recruiting two full-time positions: Training & Education Officer and Digital Communications Officer.
- Finalise the charity's conversion Charitable Incorporated Company.
- Transfer the charity's payroll to Adder Bookkeeping.
- Recruit a new trustee who has lived experience of having a rare condition.
- Recruit an additional clinical trustee e.g. medical student or specialty trainee.
- Identify possible patrons for the charity.

Future funding:

In 2021 M4RD sent out funding applications to companies involved in the rare disease field. The application explained the charity's 2022 work programme including the estimated costs involved. In total M4RD hopes to raise £152,000 to achieve its aims and objectives for 2022 by reaching out to established funding sources and newly identified grant givers.

# **Medics 4 Rare Diseases Ltd**

## **Company Limited by Guarantee**

### **Trustees' Annual Report (Incorporating the Director's Report) *(continued)***

**Year ended 31 December 2021**

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#### **Events after the end of the reporting period**

Particulars of events after the reporting date are detailed in note 20 to the financial statements.

#### **Small company provisions**

This report has been prepared in accordance with the provisions applicable to companies entitled to the small companies exemption.

The trustees' annual report was approved on 11 August 2022 and signed on behalf of the board of trustees by:

Mr C J France  
Trustee

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Independent Examiner's Report to the Trustees of Medics 4 Rare Diseases Ltd

Year ended 31 December 2021

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I report to the trustees on my examination of the financial statements of Medics 4 Rare Diseases Ltd ('the charity') for the year ended 31 December 2021.

#### Responsibilities and basis of report

As the trustees of the company (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of the charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

#### Independent examiner's statement

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

1. accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
2. the financial statements do not accord with those records; or
3. the financial statements do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination; or
4. the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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

Howard Matthews BA FCA  
Independent Examiner

Queensgate House  
23 North Park Road  
Harrogate  
North Yorkshire  
HG1 5PD

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Statement of Financial Activities (including income and expenditure account)

Year ended 31 December 2021

		2021		2020
	Note	Unrestricted funds £	Total funds £	Total funds £
<b>Income and endowments</b>				
Donations and legacies	5	101,326	101,326	58,592
Investment income	6	1	1	1
<b>Total income</b>		<u>101,327</u>	<u>101,327</u>	<u>58,593</u>
<b>Expenditure</b>				
Expenditure on charitable activities	7,8	74,702	74,702	39,543
<b>Total expenditure</b>		<u>74,702</u>	<u>74,702</u>	<u>39,543</u>
<b>Net income and net movement in funds</b>		<u>26,625</u>	<u>26,625</u>	<u>19,050</u>
<b>Reconciliation of funds</b>				
Total funds brought forward		25,954	25,954	6,904
<b>Total funds carried forward</b>		<u>52,579</u>	<u>52,579</u>	<u>25,954</u>

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

The notes on pages 18 to 26 form part of these financial statements.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Statement of Financial Position

31 December 2021

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	Note	2021 £	2020 £
<b>Fixed assets</b>			
Tangible fixed assets	13	1,536	921
<b>Current assets</b>			
Debtors	14	450	15,000
Cash at bank and in hand		55,755	27,141
		<u>56,205</u>	<u>42,141</u>
<b>Creditors: amounts falling due within one year</b>	15	<u>5,162</u>	<u>17,108</u>
<b>Net current assets</b>		<u>51,043</u>	<u>25,033</u>
<b>Total assets less current liabilities</b>		<u>52,579</u>	<u>25,954</u>
<b>Net assets</b>		<u>52,579</u>	<u>25,954</u>
<b>Funds of the charity</b>			
Unrestricted funds		<u>52,579</u>	<u>25,954</u>
<b>Total charity funds</b>	18	<u>52,579</u>	<u>25,954</u>

For the year ending 31 December 2021 the charity was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Directors' responsibilities:

- The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476;
- The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of financial statements.

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

These financial statements were approved by the board of trustees and authorised for issue on 11 August 2022, and are signed on behalf of the board by:

Mr C J France  
Trustee

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The notes on pages 18 to 26 form part of these financial statements.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Financial Statements

Year ended 31 December 2021

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#### 1. General information

The charity is a public benefit entity and a private company limited by guarantee, registered in England and Wales and a registered charity in England and Wales. The address of the registered office is Unit 12 Treadaway Technical Centre, Treadaway Hill, Loudwater, High Wycombe, HP10 9RS.

#### 2. Statement of compliance

These financial statements have been prepared in compliance with FRS 102, 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland', the 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) (Charities SORP (FRS 102)) and the Companies Act 2006.

#### 3. Accounting policies

##### Basis of preparation

The financial statements have been prepared on the historical cost basis, as modified by the revaluation of certain financial assets and liabilities and investment properties measured at fair value through income or expenditure.

The financial statements are prepared in sterling, which is the functional currency of the entity.

##### Going concern

There are no material uncertainties about the charity's ability to continue.

##### Changes in accounting policies

The company obtained charitable status on 20 June 2019 and for the year ended 31 December 2019 has, in agreement with the Charity Commission, prepared its financial statements in compliance with the Charities SORP. There has been no change in the business activity of the company since its incorporation and the comparatives have been restated in light of using the Charities SORP.

##### Judgements and key sources of estimation uncertainty

The preparation of the financial statements requires management to make judgements, estimates and assumptions that affect the amounts reported. These estimates and judgements are continually reviewed and are based on experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 December 2021

---

#### 3. Accounting policies *(continued)*

##### Fund accounting

Unrestricted funds are available for use at the discretion of the trustees to further any of the charity's purposes.

Designated funds are unrestricted funds earmarked by the trustees for particular future project or commitment.

Restricted funds are subjected to restrictions on their expenditure declared by the donor or through the terms of an appeal, and fall into one of two sub-classes: restricted income funds or endowment funds.

##### Incoming resources

All incoming resources are included in the statement of financial activities when entitlement has passed to the charity; it is probable that the economic benefits associated with the transaction will flow to the charity and the amount can be reliably measured. The following specific policies are applied to particular categories of income:

- income from donations or grants is recognised when there is evidence of entitlement to the gift, receipt is probable and its amount can be measured reliably.
- legacy income is recognised when receipt is probable and entitlement is established.
- income from donated goods is measured at the fair value of the goods unless this is impractical to measure reliably, in which case the value is derived from the cost to the donor or the estimated resale value. Donated facilities and services are recognised in the accounts when received if the value can be reliably measured. No amounts are included for the contribution of general volunteers.
- income from contracts for the supply of services is recognised with the delivery of the contracted service. This is classified as unrestricted funds unless there is a contractual requirement for it to be spent on a particular purpose and returned if unspent, in which case it may be regarded as restricted.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 December 2021

---

#### 3. Accounting policies *(continued)*

##### Resources expended

Expenditure is recognised on an accruals basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is classified under headings of the statement of financial activities to which it relates:

- expenditure on raising funds includes the costs of all fundraising activities, events, non-charitable trading activities, and the sale of donated goods.
- expenditure on charitable activities includes all costs incurred by a charity in undertaking activities that further its charitable aims for the benefit of its beneficiaries, including those support costs and costs relating to the governance of the charity apportioned to charitable activities.
- other expenditure includes all expenditure that is neither related to raising funds for the charity nor part of its expenditure on charitable activities.

All costs are allocated to expenditure categories reflecting the use of the resource. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs are apportioned between the activities they contribute to on a reasonable, justifiable and consistent basis.

##### Tangible assets

Tangible assets are initially recorded at cost, and subsequently stated at cost less any accumulated depreciation and impairment losses. Any tangible assets carried at revalued amounts are recorded at the fair value at the date of revaluation less any subsequent accumulated depreciation and subsequent accumulated impairment losses.

An increase in the carrying amount of an asset as a result of a revaluation, is recognised in other recognised gains and losses, unless it reverses a charge for impairment that has previously been recognised as expenditure within the statement of financial activities. A decrease in the carrying amount of an asset as a result of revaluation, is recognised in other recognised gains and losses, except to which it offsets any previous revaluation gain, in which case the loss is shown within other recognised gains and losses on the statement of financial activities.

##### Depreciation

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

Equipment	-	25% reducing balance
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##### Impairment of fixed assets

A review for indicators of impairment is carried out at each reporting date, with the recoverable amount being estimated where such indicators exist. Where the carrying value exceeds the recoverable amount, the asset is impaired accordingly. Prior impairments are also reviewed for possible reversal at each reporting date.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 December 2021

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#### 3. Accounting policies *(continued)*

##### Impairment of fixed assets *(continued)*

For the purposes of impairment testing, when it is not possible to estimate the recoverable amount of an individual asset, an estimate is made of the recoverable amount of the cash-generating unit to which the asset belongs. The cash-generating unit is the smallest identifiable group of assets that includes the asset and generates cash inflows that largely independent of the cash inflows from other assets or groups of assets.

For impairment testing of goodwill, the goodwill acquired in a business combination is, from the acquisition date, allocated to each of the cash-generating units that are expected to benefit from the synergies of the combination, irrespective of whether other assets or liabilities of the charity are assigned to those units.

##### Financial instruments

A financial asset or a financial liability is recognised only when the charity becomes a party to the contractual provisions of the instrument.

Basic financial instruments are initially recognised at the amount receivable or payable including any related transaction costs.

Current assets and current liabilities are subsequently measured at the cash or other consideration expected to be paid or received and not discounted.

Debt instruments are subsequently measured at amortised cost.

Where investments in shares are publicly traded or their fair value can otherwise be measured reliably, the investment is subsequently measured at fair value with changes in fair value recognised in income and expenditure. All other such investments are subsequently measured at cost less impairment.

Other financial instruments, including derivatives, are initially recognised at fair value, unless payment for an asset is deferred beyond normal business terms or financed at a rate of interest that is not a market rate, in which case the asset is measured at the present value of the future payments discounted at a market rate of interest for a similar debt instrument.

Other financial instruments are subsequently measured at fair value, with any changes recognised in the statement of financial activities, with the exception of hedging instruments in a designated hedging relationship.

Financial assets that are measured at cost or amortised cost are reviewed for objective evidence of impairment at the end of each reporting date. If there is objective evidence of impairment, an impairment loss is recognised under the appropriate heading in the statement of financial activities in which the initial gain was recognised.

For all equity instruments regardless of significance, and other financial assets that are individually significant, these are assessed individually for impairment. Other financial assets are either assessed individually or grouped on the basis of similar credit risk characteristics.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 December 2021

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#### 3. Accounting policies *(continued)*

##### Financial instruments *(continued)*

Any reversals of impairment are recognised immediately, to the extent that the reversal does not result in a carrying amount of the financial asset that exceeds what the carrying amount would have been had the impairment not previously been recognised.

##### Defined contribution plans

Contributions to defined contribution plans are recognised as an expense in the period in which the related service is provided. Prepaid contributions are recognised as an asset to the extent that the prepayment will lead to a reduction in future payments or a cash refund.

When contributions are not expected to be settled wholly within 12 months of the end of the reporting date in which the employees render the related service, the liability is measured on a discounted present value basis. The unwinding of the discount is recognised as an expense in the period in which it arises.

#### 4. Limited by guarantee

Medics 4 Rare Disease Ltd is a company limited by guarantee and accordingly does not have a share capital.

Every member of the company undertakes to contribute such amount as may be required not exceeding £1 to the assets of the charitable company in the event of its being wound up while he or she is a member, or within one year after he or she ceases to be a member.

#### 5. Donations and legacies

	Unrestricted Funds £	Total Funds 2021 £	Unrestricted Funds £	Total Funds 2020 £
<b>Donations</b>				
Donations	15,597	15,597	13,592	13,592
<b>Sponsorship</b>				
Sponsorship	85,729	85,729	45,000	45,000
	<u>101,326</u>	<u>101,326</u>	<u>58,592</u>	<u>58,592</u>

#### 6. Investment income

	Unrestricted Funds £	Total Funds 2021 £	Unrestricted Funds £	Total Funds 2020 £
Bank interest receivable	<u>1</u>	<u>1</u>	<u>1</u>	<u>1</u>

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# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

Year ended 31 December 2021

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#### 7. Expenditure on charitable activities by fund type

	Unrestricted Funds £	<b>Total Funds 2021 £</b>	Unrestricted Funds £	Total Funds 2020 £
Medical education	71,854	71,854	36,755	36,755
Support costs	2,848	2,848	2,788	2,788
	<u>74,702</u>	<u>74,702</u>	<u>39,543</u>	<u>39,543</u>

#### 8. Expenditure on charitable activities by activity type

	Activities undertaken directly £	Support costs £	<b>Total funds 2021 £</b>	Total fund 2020 £
Medical education	71,854	–	71,854	36,755
Governance costs	–	2,848	2,848	2,788
	<u>71,854</u>	<u>2,848</u>	<u>74,702</u>	<u>39,543</u>

#### 9. Net income

Net income is stated after charging/(crediting):

	<b>2021 £</b>	2020 £
Depreciation of tangible fixed assets	<u>512</u>	<u>307</u>

#### 10. Independent examination fees

	<b>2021 £</b>	2020 £
Fees payable to the independent examiner for:		
Independent examination of the financial statements	900	900
Other assurance services	1,948	1,888
	<u>2,848</u>	<u>2,788</u>

#### 11. Staff costs

The total staff costs and employee benefits for the reporting period are analysed as follows:

	<b>2021 £</b>	2020 £
Wages and salaries	43,620	20,155
Social security costs	–	392
Employer contributions to pension plans	1,033	654
	<u>44,653</u>	<u>21,201</u>

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# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 December 2021

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#### 11. Staff costs *(continued)*

The average head count of employees during the year was 3 (2020: 1). The average number of full-time equivalent employees during the year is analysed as follows:

	<b>2021</b>	2020
	<b>No.</b>	No.
Charitable activities	3	1

No employee received employee benefits of more than £60,000 during the year (2020: Nil).

#### 12. Trustee remuneration and expenses

No remuneration or other benefits from employment with the charity or a related entity were received by the trustees.

£800 was paid to Mr D Jeffries, one of the trustees, for his professional services in setting up e-learning facilities for the charity.

#### 13. Tangible fixed assets

	<b>Equipment</b>
	<b>£</b>
<b>Cost</b>	
At 1 January 2021	1,228
Additions	1,127
<b>At 31 December 2021</b>	<u>2,355</u>
<b>Depreciation</b>	
At 1 January 2021	307
Charge for the year	512
<b>At 31 December 2021</b>	<u>819</u>
<b>Carrying amount</b>	
<b>At 31 December 2021</b>	<u>1,536</u>
At 31 December 2020	<u>921</u>

#### 14. Debtors

	<b>2021</b>	2020
	<b>£</b>	£
Trade debtors	–	15,000
Prepayments and accrued income	450	–
	<u>450</u>	<u>15,000</u>

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# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 December 2021

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#### 15. Creditors: amounts falling due within one year

	<b>2021</b>	2020
	£	£
Trade creditors	1,094	–
Accruals and deferred income	2,260	16,992
Social security and other taxes	1,808	116
	<u>5,162</u>	<u>17,108</u>

#### 16. Deferred income

	<b>2021</b>	2020
	£	£
Amount deferred in year	–	15,000
	<u>–</u>	<u>15,000</u>

#### 17. Pensions and other post retirement benefits

##### Defined contribution plans

The amount recognised in income or expenditure as an expense in relation to defined contribution plans was £1,033 (2020: £654).

#### 18. Analysis of charitable funds

##### Unrestricted funds

	At 1 January 202	Income	Expenditure	At 31 December 2021
	£	£	£	£
General funds	25,954	101,327	(74,702)	52,579
	<u>25,954</u>	<u>101,327</u>	<u>(74,702)</u>	<u>52,579</u>

	At 1 January 202	Income	Expenditure	At 31 December 2020
	£	£	£	£
General funds	6,904	58,593	(39,543)	25,954
	<u>6,904</u>	<u>58,593</u>	<u>(39,543)</u>	<u>25,954</u>

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

Year ended 31 December 2021

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#### 19. Analysis of net assets between funds

	Unrestricted Funds £	Total Funds 2021 £
Tangible fixed assets	1,536	1,536
Current assets	56,205	56,205
Creditors less than 1 year	(5,162)	(5,162)
<b>Net assets</b>	<u>52,579</u>	<u>52,579</u>

	Unrestricted Funds £	Total Funds 2020 £
Tangible fixed assets	921	921
Current assets	42,141	42,141
Creditors less than 1 year	(17,108)	(17,108)
<b>Net assets</b>	<u>25,954</u>	<u>25,954</u>

#### 20. Post balance sheet events

A special resolution was agreed and passed on 14 January 2020 to convert the charitable company to a charitable incorporated organisation (CIO) without changes to the organisation's name, details or Memorandum and Articles of Association. The application was not successful and after reapplying in 2021 the charity is still awaiting a decision.

#### 21. Related parties

There have been no related party transactions during the period that require disclosure.

**Medics 4 Rare Diseases Ltd**

**Company Limited by Guarantee**

**Management Information**

**Year ended 31 December 2021**

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**The following pages do not form part of the financial statements.**

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Detailed Statement of Financial Activities

Year ended 31 December 2021

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	2021 £	2020 £
<b>Income and endowments</b>		
<b>Donations and legacies</b>		
Donations	15,597	13,592
Sponsorship	85,729	45,000
	<u>101,326</u>	<u>58,592</u>
<b>Investment income</b>		
Bank interest receivable	1	1
	<u>101,327</u>	<u>58,593</u>
<b>Total income</b>		
	<u>101,327</u>	<u>58,593</u>
<b>Expenditure</b>		
<b>Expenditure on charitable activities</b>		
Wages and salaries	43,620	20,155
Employer's NIC	–	392
Pension costs	1,033	654
Rent	320	–
Insurance	62	420
Legal and professional fees	2,848	2,788
Telephone	12	14
Depreciation	512	307
Other interest payable and similar charges	1	–
Computer costs	1,745	811
General expenses	97	31
Subscriptions	22	65
Event costs	1,284	2,416
Bank charges	108	81
Administration support	1,800	4,972
Advertising and marketing	10,319	917
Travelling and subsistence	1,534	–
Printing, postage and stationery	50	–
Consultancy	8,960	5,520
Staff training	375	–
	<u>74,702</u>	<u>39,543</u>
<b>Total expenditure</b>		
	<u>74,702</u>	<u>39,543</u>
<b>Net income</b>		
	<u>26,625</u>	<u>19,050</u>

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# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Detailed Statement of Financial Activities

Year ended 31 December 2021

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	2021	2020
	£	£
<b>Expenditure on charitable activities</b>		
<b>Medical education</b>		
<i>Activities undertaken directly</i>		
Wages and salaries	43,620	20,155
Employer's NIC	–	392
Pension costs	1,033	654
Rent	320	–
Insurance	62	420
Telephone	12	14
Depreciation	512	307
Interest paid	1	–
Computer expenses	1,745	811
Sundries	97	31
Subscriptions	22	65
Event costs	1,284	2,416
Bank charges	108	81
Administration support	1,800	4,972
Advertising and marketing	10,319	917
Travelling and subsistence	1,534	–
Printing, postage and stationery	50	–
Consultancy	8,960	5,520
Staff training	375	–
	<u>71,854</u>	<u>36,755</u>
<b>Governance costs</b>		
Accountancy fees	<u>2,848</u>	<u>2,788</u>
	<u>74,702</u>	<u>39,543</u>

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**MEDICS 4 RARE DISEASES**

England & Wales - Charity number 1183996

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# Accounts

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**Medics 4 Rare Diseases Ltd**  
**Company Limited by Guarantee**  
**Unaudited Financial Statements**  
**31 December 2020**

**HOWARD MATTHEWS PARTNERSHIP**

Chartered accountants  
Queensgate House  
23 North Park Road  
Harrogate  
North Yorkshire  
HG1 5PD

# Medics 4 Rare Diseases Ltd

Company Limited by Guarantee

## Financial Statements

Year ended 31 December 2020

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Statement of financial activities (including income and expenditure account)	<b>13</b>
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Detailed statement of financial activities	<b>25</b>
Notes to the detailed statement of financial activities	<b>26</b>

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# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report)

Year ended 31 December 2020

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The trustees, who are also the directors for the purposes of company law, present their report and the unaudited financial statements of the charity for the year ended 31 December 2020.

#### Reference and administrative details

<b>Registered charity name</b>	Medics 4 Rare Diseases Ltd
<b>Charity registration number</b>	1183996
<b>Company registration number</b>	11119884
<b>Principal office and registered office</b>	Unit 12 Treadaway Technical Centre Treadaway Hill Loudwater High Wycombe HP10 9RS

#### The trustees

Dr D R Fine	
Mr C J France	
Dr O H Grant	
Mr D C Jeffries	
Mrs T Collin-Histed	(Resigned 14 January 2020)
Mrs L J Birrell	(Appointed 1 August 2020)

**Company secretary** Dr L M R McKay

**Independent examiner** Howard Matthews BA FCA  
Queensgate House  
23 North Park Road  
Harrogate  
North Yorkshire  
HG1 5PD

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 December 2020

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#### Structure, governance and management

Trustees have been appointed to the M4RD board based on their experience, skills and enthusiasm for the work of M4RD. M4RD relies heavily on the voluntary time that its Trustees generously provide. The minimum number of Directors is 2 and there is no maximum number. The requirements to be considered for the position of Director is outlined in the company's Articles of Association. Trustee induction is provided by the CEO with input from the Chair. This is carried out remotely. The new Trustee is provided with a New Trustee Induction Pack and access to the Charity's documents. M4RD makes use of readily available online training created by other organisations such as The Small Charities Coalition and provides a PDF copy of The Charity Commission's document 'The Essential Trustee'.

The board meets quarterly via video conferencing. The CEO, Lucy McKay, is a founding member of the company and has been in the role of CEO since September 2018. Lucy has been employed by the Trustees to manage the day-to-day operations of the charity and to achieve the charity's aims and objectives. Lucy receives administrative support from Absolute Virtual Assistance on an ad-hoc basis. Lucy reports to the Chair monthly unless more frequent support is needed. Lucy reports to the Treasurer quarterly in order to ensure the smooth and financially prudent running of the charity. Both of these recurring meetings were initiated in 2019 and have been immensely valuable to the team as a whole.

The M4RD Board of Trustees contribute generously to the success of the charity. Two Trustees are GPs and have been involved in M4RD (in its previous forms) since 2011. Dr Olivia Hannah Grant is an international lacrosse player, but for M4RD she provides insight into day to day life and learning needs of being a GP in the NHS. The Treasurer, Dr Debra Fine, was an Accountant prior to training to become a doctor and this range of experience is invaluable to the role. Early in 2020 Founding Director of M4RD, Tanya Collin-Histed, stepped down as Trustee in order to concentrate on her other endeavours. The Board respected her decision and would like to thank Tanya publicly for her drive to put M4RD in a position to improve the lives of those living with rare disease. Without her foresight the charity may not have been able to create the change we all see happening today in this area. In order to represent Patient Advocacy Groups, who are crucial to the work of M4RD, Lindsay Birrell was appointed to the position of Vice Chair. Her experience working for Metabolic Support as CEO has been invaluable to Lucy and the rest of the Trustee Board. Dan Jeffries is M4RD's patient representative but has many skills within IT. His day job of creating online interactive educational software meant he was able to provide bespoke and greatly discounted services in the creation of M4RD's learning management system (LMS). The Chair, Chris France, is the founder of a successful e-commerce company and has been pivotal in getting M4RD's structure established, mentoring Lucy and steering the charity in the direction of successful strategies.

The aims and objectives of the 2020 plan drove the decision making during this period. M4RD were able to achieve its objectives despite the pandemic because 1. The organisation was already entirely remote with minimal in-person activities per year and 2. The charity is not responsible for a particular patient cohort unlike other patient advocacy groups working in the rare disease field.

The CEO is largely responsible for making decisions about activities that achieve the aims and objectives. The annual workplan is proposed by the CEO and the Trustee Board provide feedback at Board Meetings. The CEO is largely responsible for making decisions about activities that achieve the aims and objectives. Large financial decisions (outside of pre-authorised projects) are taken to the board by the CEO to be discussed. These usually constitute costs over £200.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 December 2020

---

#### Objectives and activities

The organisation is a charitable company limited by guarantee incorporated on 20th December 2017 and registered as a charity on 20th June 2019. The company was established under a Memorandum of Association which established the objects and powers of the company and is governed under its Articles of Association which were updated on 20th June 2019 in line with recommendations from the Charity Commission. In the event of the company being wound up, members are required to contribute an amount not exceeding £1.

Below are the charity's purposes as set out in the objects contained in the company's Memorandum of Association.

The company is established for the objects of the relief of sickness and preservation of health of those suffering from rare diseases, throughout the world, by:

- (a) advancing the education of medics, associated professionals and the public in rare diseases, genetic and genomic medicine
- (b) promoting research in all areas relating to rare diseases, genetic and genomic medicine and publishing the useful results
- (c) promoting improved care and treatment of those suffering from rare diseases.

#### Aims and public benefit:

The charity aims to improve the lives of a certain portion of the public: those living with rare diseases and their communities. It does this through raising awareness of the relevance of rare diseases in medical practice. The charity provides education about rare diseases and opportunities to develop a clinician's understanding of this large population group in the UK in order to better serve it.

The trustees received guidance on public benefit from the Charity Commission during the registration process. The company's Articles of Association were updated on 20th June 2019 in line with recommendations from the Charity Commission. The organisation's objects are wholly charitable. Any personal benefit arising is legitimately incidental.

#### Review:

During 2019 M4RD worked with the Charity Commission to make sure its structure, objects and governing document were ready for the organisation to be registered as a charity. This required a review of our purposes to make sure they were wholly charitable and benefited the public. In the case of M4RD 'the public' refers to the estimated 3.5 million people in the UK who suffer from a rare disease - and their communities.

Following guidance from the Charity Commission the Board of Trustees adapted the company's original Memorandum & Articles to make sure the wording was suitable for the charity. The full Articles of Association can be viewed in the Filing History of M4RD on the Companies House website: [beta.companieshouse.gov.uk/company/11119884/filing-history](https://beta.companieshouse.gov.uk/company/11119884/filing-history).

Going forward the Board of Trustees will review M4RD's aims, objectives and activities on an annual basis. This will be done with reference to guidance contained in the Charity Commission's general guidance on public benefit.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 December 2020

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#### Objectives and activities *(continued)*

##### Activities:

A rare disease is defined by the European Union as a condition that affects fewer than 5 in 20,000 people. Over 7,000 rare diseases have been identified which means that understanding and teaching about rare diseases in medical education is extremely challenging. However this is a challenge that we cannot afford to avoid because approximately 3.5 million people in the UK have a rare disease. So while each disease is individually rare, they are collectively common.

Of these diseases, 80% are known to be genetic in origin and 75% affect children. 30% of those living with a rare disease will sadly die before their fifth birthday. However, despite this large prevalence (equivalent to all adults in the UK who suffer with asthma), each individual condition affects so few people that they tend to be overlooked and misunderstood by health professionals, researchers, education and social care providers and the general public. This lack of awareness amongst medical professions is particularly devastating and can lead to extreme diagnostic delay. A person with a rare disease will wait on average 5.6 years for an accurate diagnosis. They will see numerous doctors, receive misdiagnoses and potentially even inappropriate treatment. This long and arduous journey to a diagnosis has been named "the diagnostic odyssey".

The challenges of having a rare disease do not stop after getting a diagnosis. People living with completely different diseases often report the same difficulties in terms of healthcare, social care, family life, education, work and mental health. There are many wonderful charities in the UK that support rare disease patients depending on their disease or specific need. Umbrella charities run successful public awareness campaigns. However M4RD specifically targets an audience that nobody else was concentrating on but could make the greatest impact on the diagnostic odyssey and the challenges that follow: medical students and doctors in training.

By creating a medical profession equipped to suspect, diagnose and manage rare diseases we can help people living with rare diseases have the best outcomes and reach their full potential. To do this M4RD is driving an attitude change towards rare diseases amongst medical students and doctors in training. Without appropriate training, the idea that rare diseases are irrelevant to clinical practice will continue to contribute to the diagnostic odyssey. We remedy this by presenting the statistics to our audience and asking people with rare diseases to share their stories. M4RD are also working on an approach to satisfactorily cover the subject of rare disease within undergraduate and postgraduate medical training. Finally, we're creating our own resources and promoting others' resources in order to support medical professionals when they need help on the subject of rare disease.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 December 2020

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#### Objectives and activities *(continued)*

Wider network:

M4RD works with other charities in order to achieve its objects. These are usually patient groups within the rare disease field. Of particular note are Findacure who M4RD partners with in order to run an essay competition that raises awareness of rare diseases and Cambridge Rare Disease Network and The British Paediatric Surveillance Unit. The annual symposium is organised in association with The Royal Society of Medicine, also a UK registered charity.

M4RD also collaborates with other not-for-profit organisations such as Rare Revolution Magazine - an online digital magazine for the rare disease community.

M4RD receives pro bono support from the health communications agency, emotive <https://thinkemotive.com>. The charity also depends on volunteers to contribute to projects and speak at events.

#### Declaration of Payment to Trustee

In 2020 Dan Jeffries was paid £1500 in total to set up M4RD's learning management system and create Rare Disease 101. Payments to Trustees for services are allowed by the charity's governing document provided conditions in sub-clause 6.2 are satisfied. These conditions were satisfied and the Board of Trustees (excluding Dan Jeffries) decided that hiring Dan Jeffries for the specific service of creating Rare Disease 101 was in the best interest of the charity given his in depth knowledge of the charity, his personal experience of living with two rare diseases and his professional experience in this exact service.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

Year ended 31 December 2020

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#### Achievements and performance

The main aims of 2020 were:

- Hold the annual symposium The Unusual Suspects - achieved Feb 2020
- Analyse Red Flags of Rare Disease data - achieved Dec 2020
- Create an M4RD learning management system for online education - achieved Dec 2020
- Create Rare Disease 101 e-learning module - achieved Dec 2020
- Partner with Findacure on the Student Voice Prize 2020
- Increasingly use social media to raise awareness - achieved
- Build up video wall and resource centre on website - achieved
- Continue MysteryDiseaseMonday collaborations with patient advocacy groups to raise awareness of individual conditions
- Continue the M4RD Ambassador Programme

#### The Unusual Suspects 2020

In February 2020, a month before lockdown in the UK, M4RD held its 6th annual symposium at the Royal Society of Medicine: 'The Unusual Suspects: Rare disease in everyday medicine'. It was attended by 66 participants.

The expert talks started with the return of Dr Will Evans who gave an update on his work with Mendelian, a company who are helping doctors identify rare disease patients through digital pattern matching. Sarah Lippett, artist and author of 'A Puff of Smoke', shared her story of growing up with an undiagnosed illness. Sarah also brought part of her Puff of Smoke exhibit for delegates to look at and reflect on in their own time. Dr Richard Scott from NHS Genomics talked to us about reducing the diagnostic odyssey in rare diseases and revealed lessons learned from the 100K Genomes Project. Winner of the The Student Voice Prize 2019 essay competition, Anna-Lucia Koeling, described an interaction between herself and a young man with neurofibromatosis type 1. Dr Rick Thompson, CEO of Findacure, talked about drug repurposing as an exciting, more cost-efficient and speedy way to develop treatments for rare diseases. Lastly, Dr Alexandra Downes and Karen Harrison from Alex the Leukodystrophy Charity told the story of how Karen's talk to paediatric trainees on leukodystrophy improved Alexandra's clinical practice. Alex was working as the Paediatric SHO on-call when she was called down to A&E to see a patient with deteriorating ALD. She recounted how listening to Karen's talk just a week before helped her provide what the family needed.

Feedback from the symposium was positive and proved the need for such an event. 100% of the clinical delegates who provided feedback said that it would moderately or extremely impact their clinical practice: "We need all GPs in the UK and across the globe to think how he (Will Evans) thinks, to be prepared to encounter rare diseases and what steps to take."

We were grateful once again to the RSM Medical Genetics Section for supporting us with our event and allowing us to use their prestigious platform.

#### Rare Disease 101

Rare Disease 101 is an online learning module for medical professionals. It is the first module to be hosted on M4RD's learning management system, built by the charity's trustee, Dan Jeffries. This is a first-of-its-kind, interactive module which aims to reduce the Diagnostic Odyssey and improve the rare patient experience. Rare Disease 101 addresses the basics of rare disease and the shared challenges that people with rare diseases face, especially when accessing healthcare. It includes information that the average medical professional may not be aware of, with many stories, examples, tools, websites, knowledge sources and images from the rare disease community.

The new module has been in development for years enabling significant input from those with rare

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# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

#### Year ended 31 December 2020

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diseases and rare disease advocates that M4RD have worked with over time. With practising GPs on the M4RD team they also understand the medical education system and the huge pressures the medical profession is under on a daily basis. As a result, Rare Disease 101 not only explains the impact of living with a rare disease but also provides pragmatic tips for medical professionals and highlights tools that are readily available (but medical professionals might not know of yet).

Users are those who come across Rare Disease 101 organically. The M4RD team realise that greater traffic will require future investment in online marketing. Part of next year's plan will be to demonstrate effectiveness of the module and to encourage medical training institutions to use it within their mandatory training. Previously it may have seemed infeasible to teach about rare diseases without cherry-picking a handful out of 7000 conditions - now M4RD can present the medical world with a solution to this problem and pressure the system to start recognising this educational need.

#### Red Flags of Rare Disease

In 2018 M4RD carried out The Red Flags of Rare Disease Survey. The team recruited patient groups to answer a survey about their particular condition of interest in order to see if we could find commonalities between different rare diseases.

Initial analysis of the data was performed by Lucy and one of the M4RD Clinical Ambassadors however the analysis stalled at the qualitative data because of a lack of in-house skills. In 2020 M4RD had the budget to contract a Qualitative Data Research Analyst called Dr Sondra Butterworth who is also a rare disease advocate. Sondra carried out the qualitative analysis and we are looking to publish the data in 2021.

#### Other Events

The last event that Lucy attended in person was the Findacure Drug Repurposing Conference. This is always a special event because delegates are able to hear the perspectives of a winning medical student from The Student Voice Prize. Lucy and Rick Thompson from Findacure presented the winners with their certificates.

After this point all events were held remotely, which has only helped increase the reach and diversify the audience. Although arguably, networking opportunities are lost, the more medics they can reach in a single event, the better. So on balance this change has been a welcome one. It also allows for more diverse voices from the rare disease community to take part because they are not expected to travel across the country to deliver a short talk.

Lucy was the first speaker, after the opening plenary, in the Diagnostic stream of the European Conference on Rare Diseases organised by EURORDIS, which was originally going to be held in Stockholm. She spoke about the importance of medical education in tackling the diagnostic odyssey. The talk was well received and this was excellent exposure for M4RD.

The M4RD team helped medical students across the UK to hold their own rare disease events, for example students from Barts and The London School of Medicine and Dentistry held an event about rare disease in Primary Care.

Lucy also co-produced an event with The Royal Society of Medicine about the risks and opportunities that the pandemic posed for rare disease as part of the Medical Genetics Section's COVID-19 series. This was a great opportunity to raise the profile of rare disease to a wider audience of medics via a prestigious training institution.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

#### Year ended 31 December 2020

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##### **Achievements and performance *(continued)***

###### Website and Social Media

m4rd.org is a hub for rare disease news, information, videos and resources aimed at medical professionals. Online learning has really come into the fore as students have been kept away from their normal learning environments. Therefore the team has continued to build up M4RD's online presence, with Dan Jeffries overseeing everything looking professional and working seamlessly. M4RD has an established presence on Facebook, Twitter, Instagram and LinkedIn.

For a brief period of time M4RD was able to externally contract a Genetic Counsellor to create the educational content for MysteryDiseaseMonday. Her medical insight in this area enabled her to design eye-catching and detailed (but effective) Instagram Stories using information provided by patient advocacy groups. Unfortunately Melissa could not continue providing this service for M4RD when she took up a Genetic Counselling position. However the engagement we saw from followers demonstrated the benefit of keeping this kind of regular content going in the future.

###### The Student Voice Prize 2020

Once again M4RD worked in a 50:50 partnership with Findacure in order to produce The Student Voice Prize. This essay competition was started by Findacure and M4RD have been involved in it for several years. Our trustees have been responsible for marking the essays for a number of years and Lucy has played an increasing role in organising the competition. The medical school experiences of Lucy and the M4RD trustees has helped Findacure target medical students. The aim of the competition is to provide an attractive opportunity (becoming a published author in a medical journal) to encourage medical students to research rare diseases, engage with the rare disease community and pass on what they learned to their peers. The questions are carefully designed to make this competition accessible across the globe. There were more entrants than ever before and our judges were blown away by the winning essays, which highlighted the impact of shielding during COVID-19 on rare disease patients, the diagnostic odyssey and the rare disease patient experience. This was the first year that every winning essay was written in collaboration with a patient group pair - 45 students were paired with patient advocacy groups - and the winning essays beautifully reflected this. The winning essay gave an insight into three patients' rare disease experiences during the pandemic. The winner spoke at the M4RD annual symposium in 2021.

###### The Ambassador Programme

Our ambassador programme enables M4RD to work with the wider rare disease community so we can learn from their expertise and experience. We currently have two types of Ambassadors: Clinical and Patient. Clinical Ambassadors help inform our projects, identify teaching opportunities, spread the word about events and opportunities for medics. Our Patient Ambassadors are really important for making sure that the patient's voice is heard through our work because communicating the lived experience of having a rare disease is fundamental in our message to medical students and doctors in training.

We would like to thank all the M4RD Ambassadors for playing such a pivotal role in getting us to where we are today!

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

#### Year ended 31 December 2020

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#### Financial review

##### Financial Position

The budget for this financial year was decided based on the goals we set out to achieve in 2020. In total £55,000 of funding was secured through sponsorship and donations from six commercial companies. An additional £3,592 was donated through one individual's fundraising effort.

At the end of 2020, sponsorship was received from two companies to the total amount of £15,000 which has been deferred because it is for activities taking place in 2021.

Total funds carried forward is £25,954.

The final cash position is £27,141.

£11,000 of which is kept in a savings account as per the charity's Reserves Policy.

##### Principal Funding Sources

The principal funding sources for this period were sponsorship and donations (ranging from £5,000-10,000) from commercial companies. These were: Alexion Therapeutics, Amicus Therapeutics, Biomarin, Sanofi Genzyme, SOBI and Takeda.

##### Reserves Policy and Review

The Reserves Policy put in place by The Board of Trustees in 2019 remains in place. Reserves are to be maintained at a level which ensures that the charity's core activity could continue during a 3 month period of unforeseen financial difficulty during which funding is to be secured. If funding is not secured then this is followed by a 3 month period in which the organisation could be dissolved with all outstanding debt settled. The Board of Trustees have set a minimum of £11,000 to be held in the charity's reserves. This is to ensure they are able to maintain running the charity and to meet its main objects for which it was created.

##### Financial Risk

The risks that M4RD are exposed to are fairly low as its committed spend and running costs were still relatively low throughout 2020. The CEO and Trustees all work and meet remotely so the charity doesn't own or rent property. There is only one member of staff and the majority of work is done 'in house' or pro bono. This year M4RD bought its first asset: a laptop for the CEO who had previously used her own computer for M4RD work.

M4RD changed from Lloyd's Bank to CAF Bank in May 2020 which was a rocky transition due to the pandemic meaning services provided by the bank were not their most efficient. However the change allows a greater level of financial oversight by the Treasurer and other Trustees. All the Trustees have access to the online banking system and all payments require 2-person authorisation.

The main financial risk is, as always, managing to secure future funding. In previous years M4RD has relied 100% on commercial donations and sponsorship. We had planned to diversify revenue streams however opportunities to do this were limited by the pandemic. Over £3000 was raised through one individual's fundraising feat. We hope to keep moving forward with this diversification plan next year in order to ensure the charity can continue its work well into the future, until the diagnostic odyssey is no longer a problem faced by those with rare diseases.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Trustees' Annual Report (Incorporating the Director's Report) *(continued)*

#### Year ended 31 December 2020

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##### Plans for future periods

Future plans for M4RD include:

- The Unusual Suspects 2021 online symposium with the Royal Society of Medicine.
- Launch Rare Disease 101 on the M4RD learning management system. Rare Disease 101 is an online and interactive learning module for use by medical professionals. This project is the first step in campaigning for Rare Disease 101 education to be mandatory during medical school studies and in postgraduate medical education.
- Start work on additional RD101 lessons e.g. early access programmes, clinical trials, mental health.
- Complete analysis of data from the Red Flags Survey and publish results to highlight the patient journey. Start designing a rare disease tool kit for medical professionals.
- Collaborate with NSAMR and the University of Birmingham on the UKRISE project in which we plan to survey medical students about their attitudes towards rare diseases.
- Work with the Rare 2030 project to address the issue of medical education.
- Continue working with Action for Rare Disease Empowerment (ARDEnt)
- Continue developing the M4RD website into an educational hub.
- Evaluate and relaunch the Ambassadors Programme.
- Launch Student Voice Prize 2020 with Findacure.

Organisational plans:

- Develop a more diverse fundraising strategy.
- Grow the team by recruiting two part-time positions:  
Operations & Finance Manager and Medical Communications Officer.
- Convert to a Charitable Incorporated Company
- Appoint a bookkeeper.

Future funding:

In 2020 M4RD sent out funding applications to over 40 companies involved in the rare disease field. The application explained the charity's 2021 work programme including the estimated costs involved. In total M4RD hopes to raise £80,000 to achieve its aims and objectives for 2021. Before the year end £27,000 had been promised by 5 companies.

##### Events after the end of the reporting period

Particulars of events after the reporting date are detailed in note 20 to the financial statements.

# **Medics 4 Rare Diseases Ltd**

**Company Limited by Guarantee**

**Trustees' Annual Report (Incorporating the Director's Report) *(continued)***

**Year ended 31 December 2020**

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## **Small company provisions**

This report has been prepared in accordance with the provisions applicable to companies entitled to the small companies exemption.

The trustees' annual report was approved on 19 August 2021 and signed on behalf of the board of trustees by:

Mr C J France  
Trustee

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Independent Examiner's Report to the Trustees of Medics 4 Rare Diseases Ltd

Year ended 31 December 2020

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I report to the trustees on my examination of the financial statements of Medics 4 Rare Diseases Ltd ('the charity') for the year ended 31 December 2020.

#### Responsibilities and basis of report

As the trustees of the company (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of the charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

#### Independent examiner's statement

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

1. accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
2. the financial statements do not accord with those records; or
3. the financial statements do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination; or
4. the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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

Howard Matthews BA FCA  
Independent Examiner

Queensgate House  
23 North Park Road  
Harrogate  
North Yorkshire  
HG1 5PD

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Statement of Financial Activities (including income and expenditure account)

Year ended 31 December 2020

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		2020		2019
	Note	Unrestricted funds £	Total funds £	Total funds £
<b>Income and endowments</b>				
Donations and legacies	5	58,592	58,592	9,190
Investment income	6	1	1	–
<b>Total income</b>		<u>58,593</u>	<u>58,593</u>	<u>9,190</u>
<b>Expenditure</b>				
Expenditure on charitable activities	7,8	39,543	39,543	29,070
<b>Total expenditure</b>		<u>39,543</u>	<u>39,543</u>	<u>29,070</u>
<b>Net income/(expenditure) and net movement in funds</b>		<u>19,050</u>	<u>19,050</u>	<u>(19,880)</u>
<b>Reconciliation of funds</b>				
Total funds brought forward		6,904	6,904	26,784
<b>Total funds carried forward</b>		<u>25,954</u>	<u>25,954</u>	<u>6,904</u>

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

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The notes on pages 15 to 23 form part of these financial statements.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Statement of Financial Position

31 December 2020

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	Note	2020 £	2019 £
<b>Fixed assets</b>			
Tangible fixed assets	13	921	–
<b>Current assets</b>			
Debtors	14	15,000	–
Cash at bank and in hand		27,141	30,560
		<u>42,141</u>	<u>30,560</u>
<b>Creditors: amounts falling due within one year</b>	15	<u>17,108</u>	<u>23,656</u>
<b>Net current assets</b>		<u>25,033</u>	<u>6,904</u>
<b>Total assets less current liabilities</b>		<u>25,954</u>	<u>6,904</u>
<b>Net assets</b>		<u>25,954</u>	<u>6,904</u>
<b>Funds of the charity</b>			
Unrestricted funds		<u>25,954</u>	<u>6,904</u>
<b>Total charity funds</b>	18	<u>25,954</u>	<u>6,904</u>

For the year ending 31 December 2020 the charity was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Directors' responsibilities:

- The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476;
- The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of financial statements.

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

These financial statements were approved by the board of trustees and authorised for issue on 19 August 2021, and are signed on behalf of the board by:

Mr C J France  
Trustee

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The notes on pages 15 to 23 form part of these financial statements.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Financial Statements

Year ended 31 December 2020

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#### 1. General information

The charity is a public benefit entity and a private company limited by guarantee, registered in England and Wales and a registered charity in England and Wales. The address of the registered office is Unit 12 Treadaway Technical Centre, Treadaway Hill, Loudwater, High Wycombe, HP10 9RS.

#### 2. Statement of compliance

These financial statements have been prepared in compliance with FRS 102, 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland', the 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) (Charities SORP (FRS 102)) and the Companies Act 2006.

#### 3. Accounting policies

##### Basis of preparation

The financial statements have been prepared on the historical cost basis, as modified by the revaluation of certain financial assets and liabilities and investment properties measured at fair value through income or expenditure.

The financial statements are prepared in sterling, which is the functional currency of the entity.

##### Going concern

There are no material uncertainties about the charity's ability to continue.

##### Changes in accounting policies

The company obtained charitable status on 20 June 2019 and for the year ended 31 December 2019 has, in agreement with the Charity Commission, prepared its financial statements in compliance with the Charities SORP. There has been no change in the business activity of the company since its incorporation and the comparatives have been restated in light of using the Charities SORP.

##### Judgements and key sources of estimation uncertainty

The preparation of the financial statements requires management to make judgements, estimates and assumptions that affect the amounts reported. These estimates and judgements are continually reviewed and are based on experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 December 2020

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#### 3. Accounting policies *(continued)*

##### **Fund accounting**

Unrestricted funds are available for use at the discretion of the trustees to further any of the charity's purposes.

Designated funds are unrestricted funds earmarked by the trustees for particular future project or commitment.

Restricted funds are subjected to restrictions on their expenditure declared by the donor or through the terms of an appeal, and fall into one of two sub-classes: restricted income funds or endowment funds.

##### **Incoming resources**

All incoming resources are included in the statement of financial activities when entitlement has passed to the charity; it is probable that the economic benefits associated with the transaction will flow to the charity and the amount can be reliably measured. The following specific policies are applied to particular categories of income:

- income from donations or grants is recognised when there is evidence of entitlement to the gift, receipt is probable and its amount can be measured reliably.
- legacy income is recognised when receipt is probable and entitlement is established.
- income from donated goods is measured at the fair value of the goods unless this is impractical to measure reliably, in which case the value is derived from the cost to the donor or the estimated resale value. Donated facilities and services are recognised in the accounts when received if the value can be reliably measured. No amounts are included for the contribution of general volunteers.
- income from contracts for the supply of services is recognised with the delivery of the contracted service. This is classified as unrestricted funds unless there is a contractual requirement for it to be spent on a particular purpose and returned if unspent, in which case it may be regarded as restricted.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 December 2020

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#### 3. Accounting policies *(continued)*

##### Resources expended

Expenditure is recognised on an accruals basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is classified under headings of the statement of financial activities to which it relates:

- expenditure on raising funds includes the costs of all fundraising activities, events, non-charitable trading activities, and the sale of donated goods.
- expenditure on charitable activities includes all costs incurred by a charity in undertaking activities that further its charitable aims for the benefit of its beneficiaries, including those support costs and costs relating to the governance of the charity apportioned to charitable activities.
- other expenditure includes all expenditure that is neither related to raising funds for the charity nor part of its expenditure on charitable activities.

All costs are allocated to expenditure categories reflecting the use of the resource. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs are apportioned between the activities they contribute to on a reasonable, justifiable and consistent basis.

##### Tangible assets

Tangible assets are initially recorded at cost, and subsequently stated at cost less any accumulated depreciation and impairment losses. Any tangible assets carried at revalued amounts are recorded at the fair value at the date of revaluation less any subsequent accumulated depreciation and subsequent accumulated impairment losses.

An increase in the carrying amount of an asset as a result of a revaluation, is recognised in other recognised gains and losses, unless it reverses a charge for impairment that has previously been recognised as expenditure within the statement of financial activities. A decrease in the carrying amount of an asset as a result of revaluation, is recognised in other recognised gains and losses, except to which it offsets any previous revaluation gain, in which case the loss is shown within other recognised gains and losses on the statement of financial activities.

##### Depreciation

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

Equipment	-	25% reducing balance
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##### Impairment of fixed assets

A review for indicators of impairment is carried out at each reporting date, with the recoverable amount being estimated where such indicators exist. Where the carrying value exceeds the recoverable amount, the asset is impaired accordingly. Prior impairments are also reviewed for possible reversal at each reporting date.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 December 2020

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#### 3. Accounting policies *(continued)*

##### Impairment of fixed assets *(continued)*

For the purposes of impairment testing, when it is not possible to estimate the recoverable amount of an individual asset, an estimate is made of the recoverable amount of the cash-generating unit to which the asset belongs. The cash-generating unit is the smallest identifiable group of assets that includes the asset and generates cash inflows that largely independent of the cash inflows from other assets or groups of assets.

For impairment testing of goodwill, the goodwill acquired in a business combination is, from the acquisition date, allocated to each of the cash-generating units that are expected to benefit from the synergies of the combination, irrespective of whether other assets or liabilities of the charity are assigned to those units.

##### Financial instruments

A financial asset or a financial liability is recognised only when the charity becomes a party to the contractual provisions of the instrument.

Basic financial instruments are initially recognised at the amount receivable or payable including any related transaction costs.

Current assets and current liabilities are subsequently measured at the cash or other consideration expected to be paid or received and not discounted.

Debt instruments are subsequently measured at amortised cost.

Where investments in shares are publicly traded or their fair value can otherwise be measured reliably, the investment is subsequently measured at fair value with changes in fair value recognised in income and expenditure. All other such investments are subsequently measured at cost less impairment.

Other financial instruments, including derivatives, are initially recognised at fair value, unless payment for an asset is deferred beyond normal business terms or financed at a rate of interest that is not a market rate, in which case the asset is measured at the present value of the future payments discounted at a market rate of interest for a similar debt instrument.

Other financial instruments are subsequently measured at fair value, with any changes recognised in the statement of financial activities, with the exception of hedging instruments in a designated hedging relationship.

Financial assets that are measured at cost or amortised cost are reviewed for objective evidence of impairment at the end of each reporting date. If there is objective evidence of impairment, an impairment loss is recognised under the appropriate heading in the statement of financial activities in which the initial gain was recognised.

For all equity instruments regardless of significance, and other financial assets that are individually significant, these are assessed individually for impairment. Other financial assets are either assessed individually or grouped on the basis of similar credit risk characteristics.

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 December 2020

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#### 3. Accounting policies *(continued)*

##### Financial instruments *(continued)*

Any reversals of impairment are recognised immediately, to the extent that the reversal does not result in a carrying amount of the financial asset that exceeds what the carrying amount would have been had the impairment not previously been recognised.

##### Defined contribution plans

Contributions to defined contribution plans are recognised as an expense in the period in which the related service is provided. Prepaid contributions are recognised as an asset to the extent that the prepayment will lead to a reduction in future payments or a cash refund.

When contributions are not expected to be settled wholly within 12 months of the end of the reporting date in which the employees render the related service, the liability is measured on a discounted present value basis. The unwinding of the discount is recognised as an expense in the period in which it arises.

#### 4. Limited by guarantee

Medics 4 Rare Disease Ltd is a company limited by guarantee and accordingly does not have a share capital.

Every member of the company undertakes to contribute such amount as may be required not exceeding £1 to the assets of the charitable company in the event of its being wound up while he or she is a member, or within one year after he or she ceases to be a member.

#### 5. Donations and legacies

	Unrestricted Funds £	Total Funds 2020 £	Unrestricted Funds £	Total Funds 2019 £
<b>Donations</b>				
Donations	13,592	13,592	1,190	1,190
<b>Sponsorship</b>				
Sponsorship	45,000	45,000	8,000	8,000
	<u>58,592</u>	<u>58,592</u>	<u>9,190</u>	<u>9,190</u>

#### 6. Investment income

	Unrestricted Funds £	Total Funds 2020 £	Unrestricted Funds £	Total Funds 2019 £
Bank interest receivable	1	1	–	–
	<u>1</u>	<u>1</u>	<u>–</u>	<u>–</u>

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# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

Year ended 31 December 2020

#### 7. Expenditure on charitable activities by fund type

	Unrestricted Funds £	<b>Total Funds 2020 £</b>	Unrestricted Funds £	Total Funds 2019 £
Medical education	36,755	36,755	26,429	26,429
Support costs	2,788	2,788	2,641	2,641
	<u>39,543</u>	<u>39,543</u>	<u>29,070</u>	<u>29,070</u>

#### 8. Expenditure on charitable activities by activity type

	Activities undertaken directly £	Support costs £	<b>Total funds 2020 £</b>	Total fund 2019 £
Medical education	36,755	–	36,755	26,429
Governance costs	–	2,788	2,788	2,641
	<u>36,755</u>	<u>2,788</u>	<u>39,543</u>	<u>29,070</u>

#### 9. Net income/(expenditure)

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

	<b>2020 £</b>	2019 £
Depreciation of tangible fixed assets	<u>307</u>	<u>–</u>

#### 10. Independent examination fees

	<b>2020 £</b>	2019 £
Fees payable to the independent examiner for:		
Independent examination of the financial statements	900	900
Other assurance services	1,888	1,741
	<u>2,788</u>	<u>2,641</u>

#### 11. Staff costs

The total staff costs and employee benefits for the reporting period are analysed as follows:

	<b>2020 £</b>	2019 £
Wages and salaries	20,155	14,570
Social security costs	392	670
Employer contributions to pension plans	654	346
	<u>21,201</u>	<u>15,586</u>

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 December 2020

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#### 11. Staff costs *(continued)*

The average head count of employees during the year was 1 (2019: 1). The average number of full-time equivalent employees during the year is analysed as follows:

	<b>2020</b>	2019
	<b>No.</b>	No.
Charitable activities	<u>1</u>	<u>1</u>

No employee received employee benefits of more than £60,000 during the year (2019: Nil).

#### 12. Trustee remuneration and expenses

No remuneration or other benefits from employment with the charity or a related entity were received by the trustees.

£1,500 was paid to Mr D Jeffries, one of the trustees, for his professional services in setting up e-learning facilities for the charity.

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#### 13. Tangible fixed assets

	<b>Equipment</b>
	<b>£</b>
<b>Cost</b>	
At 1 January 2020	–
Additions	<u>1,228</u>
<b>At 31 December 2020</b>	<u>1,228</u>
<b>Depreciation</b>	
At 1 January 2020	–
Charge for the year	<u>307</u>
<b>At 31 December 2020</b>	<u>307</u>
<b>Carrying amount</b>	
<b>At 31 December 2020</b>	<u>921</u>
At 31 December 2019	<u>–</u>

#### 14. Debtors

	<b>2020</b>	2019
	<b>£</b>	£
Trade debtors	<u>15,000</u>	<u>–</u>

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

#### Year ended 31 December 2020

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#### 15. Creditors: amounts falling due within one year

	<b>2020</b>	2019
	<b>£</b>	£
Accruals and deferred income	16,992	23,279
Social security and other taxes	116	377
	<u>17,108</u>	<u>23,656</u>

#### 16. Deferred income

	<b>2020</b>	2019
	<b>£</b>	£
Amount deferred in year	<u>15,000</u>	<u>20,000</u>

#### 17. Pensions and other post retirement benefits

##### Defined contribution plans

The amount recognised in income or expenditure as an expense in relation to defined contribution plans was £654 (2019: £346).

#### 18. Analysis of charitable funds

##### Unrestricted funds

	At 1 January 202			At 31 December 2020
	0	Income	Expenditure	2020
	£	£	£	£
General funds	<u>6,904</u>	<u>58,593</u>	<u>(39,543)</u>	<u>25,954</u>

	At 1 January 201			At 31 December 2019
	9	Income	Expenditure	2019
	£	£	£	£
General funds	<u>26,784</u>	<u>9,190</u>	<u>(29,070)</u>	<u>6,904</u>

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Financial Statements *(continued)*

Year ended 31 December 2020

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#### 19. Analysis of net assets between funds

	Unrestricted Funds £	Total Funds 2020 £
Tangible fixed assets	921	921
Current assets	42,141	42,141
Creditors less than 1 year	(17,108)	(17,108)
<b>Net assets</b>	<u>25,954</u>	<u>25,954</u>

	Unrestricted Funds £	Total Funds 2019 £
Tangible fixed assets	–	–
Current assets	30,560	30,560
Creditors less than 1 year	(23,656)	(23,656)
<b>Net assets</b>	<u>6,904</u>	<u>6,904</u>

#### 20. Post balance sheet events

A special resolution was agreed and passed on 14 January 2020 to convert the charitable company to a charitable incorporated organisation (CIO) without changes to the organisation's name, details or Memorandum and Articles of Association. The application was not successful and the charity will reapply in 2021.

#### 21. Related parties

There have been no related party transactions during the period that require disclosure.

**Medics 4 Rare Diseases Ltd**

**Company Limited by Guarantee**

**Management Information**

**Year ended 31 December 2020**

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**The following pages do not form part of the financial statements.**

**Medics 4 Rare Diseases Ltd**  
**Company Limited by Guarantee**  
**Detailed Statement of Financial Activities**  
**Year ended 31 December 2020**

	<b>2020</b>	2019
	£	£
<b>Income and endowments</b>		
<b>Donations and legacies</b>		
Donations	13,592	1,190
Sponsorship	45,000	8,000
	<u>58,592</u>	<u>9,190</u>
<b>Investment income</b>		
Bank interest receivable	1	–
	<u>1</u>	<u>–</u>
<b>Total income</b>	<u>58,593</u>	<u>9,190</u>
<b>Expenditure</b>		
<b>Expenditure on charitable activities</b>		
Wages and salaries	20,155	14,570
Employer's NIC	392	670
Pension costs	654	346
Insurance	420	228
Legal and professional fees	2,788	3,901
Telephone	14	31
Depreciation	307	–
Computer costs	811	507
General expenses	31	–
Subscriptions	65	30
Event costs	2,416	3,144
Bank charges	81	3
Administration support	4,972	4,780
Advertising and marketing	917	491
Travelling and entertainment	–	369
Consultancy	5,520	–
	<u>39,543</u>	<u>29,070</u>
<b>Total expenditure</b>	<u>39,543</u>	<u>29,070</u>
<b>Net income/(expenditure)</b>	<u>19,050</u>	<u>(19,880)</u>

# Medics 4 Rare Diseases Ltd

## Company Limited by Guarantee

### Notes to the Detailed Statement of Financial Activities

Year ended 31 December 2020

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	<b>2020</b>	2019
	£	£
<b>Expenditure on charitable activities</b>		
<b>Medical education</b>		
<i>Activities undertaken directly</i>		
Wages and salaries	20,155	14,570
Employer's NIC	392	670
Pension costs	654	346
Insurance	420	228
Legal and professional fees	–	1,260
Telephone	14	31
Depreciation	307	–
Computer expenses	811	507
Sundries	31	–
Subscriptions	65	30
Event costs	2,416	3,144
Bank charges	81	3
Administration support	4,972	4,780
Advertising and marketing	917	491
Travelling and entertainment	–	369
Consultancy	5,520	–
	<u>36,755</u>	<u>26,429</u>
<b>Governance costs</b>		
Accountancy fees	2,788	2,641
	<u>2,788</u>	<u>2,641</u>
<b>Expenditure on charitable activities</b>	<u>39,543</u>	<u>29,070</u>

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