COMPANY REGISTRATION NUMBER: 11119884
CHARITY REGISTRATION NUMBER: 1183996

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

The following pages do not form part of the financial statements

Medics 4 Rare Diseases Ltd

Company Limited by Guarantee

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

Year ended 31 December 2021

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

Registered charity name	Medics 4 Rare Diseases Ltd
Charity registration number	1183996
Company registration number	11119884
Principal office and registered office	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
Bookkeeping and payroll	Adder Bookkeeping
Company secretary	Dr L M R McKay
Independent examiner	Howard Matthews BA FCA Queensgate House 23 North Park Road Harrogate North Yorkshire HG1 5PD

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.

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.

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.

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.

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.

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 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 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.

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.

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.

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.

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.

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

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

Year ended 31 December 2021

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
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North Yorkshire
HG1 5PD

Statement of Financial Activities (including income and expenditure account)

Year ended 31 December 2021

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

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

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

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

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

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 it's financial statements in compliance with the Charities SORP. There has been no change in the business activity of the company since it's 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.

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.

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

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.

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.

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 £
Donations				
Donations	15,597	15,597	13,592	13,592
Sponsorship				
Sponsorship	85,729	85,729	45,000	45,000
	101,326	101,326	58,592	58,592

6. Investment income

	Unrestricted Funds £	**Total Funds 2021 £**	Unrestricted Funds £	Total Funds 2020 £
Bank interest receivable	1	1	1	1

7. Expenditure on charitable activities by fund type

	Unrestricted Funds £	**Total Funds 2021** **£**	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
	74,702	74,702	39,543	39,543

8. Expenditure on charitable activities by activity type

	Activities undertaken directly £	Support costs £	**Total funds 2021** **£**	Total fund 2020 £
Medical education	71,854	–	71,854	36,755
Governance costs	–	2,848	2,848	2,788
	71,854	2,848	74,702	39,543

9. Net income

Net income is stated after charging/(crediting):

	2021 **£**	2020 £
Depreciation of tangible fixed assets	512	307

10. Independent examination fees

	2021 **£**	2020 £
Fees payable to the independent examiner for:		
Independent examination of the financial statements	900	900
Other assurance services	1,948	1,888
	2,848	2,788

11. Staff costs

The total staff costs and employee benefits for the reporting period are analysed as follows:

	2021 **£**	2020 £
Wages and salaries	43,620	20,155
Social security costs	–	392
Employer contributions to pension plans	1,033	654
	44,653	21,201

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:

	2021 **No.**	2020 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

	Equipment **£**
Cost	
At 1 January 2021	1,228
Additions	1,127
At 31 December 2021	2,355
Depreciation	
At 1 January 2021	307
Charge for the year	512
At 31 December 2021	819
Carrying amount	
At 31 December 2021	1,536
At 31 December 2020	921

14. Debtors

	2021 **£**	2020 £
Trade debtors	–	15,000
Prepayments and accrued income	450	–
	450	15,000

15. Creditors: amounts falling due within one year

	2021 **£**	2020 £
Trade creditors	1,094	–
Accruals and deferred income	2,260	16,992
Social security and other taxes	1,808	116
	5,162	17,108

16. Deferred income

	2021 **£**	2020 £
Amount deferred in year	–	15,000

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 2021 £	Income £	Expenditure £	**At 31 December 2021** £
General funds	25,954	101,327	(74,702)	52,579

	At 1 January 2020 £	Income £	Expenditure £	At 31 December 2020 £
General funds	6,904	58,593	(39,543)	25,954

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)
Net assets	52,579	52,579

	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)
Net assets	25,954	25,954

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.

Management Information

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

	2021 **£**	2020 £
Income and endowments		
Donations and legacies		
Donations	15,597	13,592
Sponsorship	85,729	45,000
	101,326	58,592
Investment income		
Bank interest receivable	1	1
Total income	101,327	58,593
Expenditure		
Expenditure on charitable activities		
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	–
	74,702	39,543
Total expenditure	74,702	39,543
Net income	26,625	19,050

	2021 **£**	2020 £
Expenditure on charitable activities		
Medical education		
Activities undertaken directly		
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	–
	71,854	36,755
Governance costs		
Accountancy fees	2,848	2,788
Expenditure on charitable activities	74,702	39,543