ANNUAL REPORT 2019

MEDICS4RAREDISEASES

A company limited by guarantee and
UK registered charity

Charity number 1183996
Company Number 11119884

M4RD

Report and financial statements

FOR THE YEAR ENDED
31ST DECEMBER 2019

M4RD

TRUSTEE BOARD

Mr Chris France (Chair)
Mrs Tanya Collin-Histed (Vice-Chair)
Dr Debra Fine (Treasurer)
Mr Daniel Jeffries
Dr Olivia Hannah Grant

SECRETARY

Dr Lucy McKay

EMPLOYEES

Dr Lucy McKay (CEO)

INDEPENDENT EXAMINER

Howard Matthews Partnership

BANKERS

Lloyds Bank Plc
CAF Bank

SOLICITORS

Lupton Fawcett

REFERENCE & ADMINISTRATIVE INFORMATION

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.

Charity Name: Medics4RareDiseases
Charity registration number: 1183996
Company registration number: 11119884

Registered Office address:
8 Silver Street,
Dursley,
Gloucestershire,
GL11 4ND.

www.m4rd.org

AIMS & OBJECTIVES

PURPOSE:

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 & 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 organisation's objects are wholly charitable. Any personal benefit arising is legitimately incidental.

DELIVERING OUR AIMS

THE FOCUS

The focus of M4RD continues to be raising awareness of the relevance of rare diseases in clinical medicine.

Our audience is doctors early in their careers e.g. medical students and doctors in training.

The benefit is to those with rare diseases and their communities.

WHY IS M4RD NEEDED?

Rare diseases are individually rare but collectively common. This is a little known fact amongst medical professionals that we have polled. The Department of Health and Social Care made rare diseases a priority with the UK Rare Disease Strategy in 2013 however people with rare conditions continue to report delays in diagnosis, lack of care co-ordination and limited access to research. As demonstrated by Rare Disease UK's Rare Reality report.

M4RD believes that one key foundation block of any strategy is to address medical education - both at undergraduate level and in continued medical education. This starts with raising awareness of the relevance of rare diseases in clinical medicine. M4RD is creating a template for what this education could look like.

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: *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.

ACTIVITIES

2019

HOW DOES M4RD ACHIEVE ITS OBJECTIVES?

M4RD continues to use a combination of in-person and online methods in order to reach medical professionals.

The M4RD annual symposium (known as The Unusual Suspects) is the only event that is organised solely by M4RD. Although it is held in association with The Medical Genetics Section of The Royal Society of Medicine, the agenda and the majority of the event organisation is the responsibility of the M4RD team. The 2019 symposium was a big success with more attendees than ever before. See page 9 for details and feedback.

During the year the M4RD team helped medical students at St George's University produce an event on haemophilia. M4RD also promoted 10s of rare diseases events aimed at medical professionals. The events page started filling up nicely this year which shows a promising trend in medical education on rare diseases.

Lucy McKay spoke at a number of events about the purpose of M4RD and the need for the medical profession to #DareToThinkRare. Her talk at the BPSU received positive feedback from The Deputy Chief Medical Officer who was in attendance. This has led to discussion with the DOH about including specific guidelines on medical education in the next UK Rare Disease Strategy.

M4RD ACTIVITIES

2019

Below outlines some of the activities that M4RD organised or collaborated on in 2019

JANUARY

#MysteryDiseaseMonday started on Instagram to engage medics on their preferred social media platform.

FEBRUARY

The Unusual Suspects, M4RD's annual symposium, held at The Royal Society of Medicine.

RARE DISEASE DAY

M4RD released its new promotional video about the charity and its activities.

APRIL-MAY

M4RD worked with Childhood Tumour Trust to recruit doctors to their medical advisory board.

MAY

M4RD sponsored tickets for medical students to attend a Rare Diseases and The Kidney training day.

20TH JUNE

M4RD entered on to the UK Register of Charities.

JULY

Lucy McKay spoke at the British Paediatric Surveillance Unit annual 'Tea Party' about M4RD.

JULY-AUGUST

M4RD worked with CSF Leak Association to find a doctor to attend an international conference and report back to the charity.

SEPTEMBER

M4RD had its first conference stand at the CRDN Rare Summit.

OCTOBER

New branding created by medical communications company, emotive, revealed.

OCTOBER

Student Voice Prize 2019 launched.

NOVEMBER

Lucy McKay was a guest on BBC Radio 4's Woman's Hour talking about M4RD and the importance that doctors #DareToThinkRare

NOVEMBER

M4RD's work featured on The University of Cambridge's Therapeutic Sciences MPhil course.

DECEMBER

35th condition featured on #MysteryDiseaseMonday

ACTIVITIES

2019

ONLINE ACTIVITIES

People are increasingly expecting their learning materials and activities to be available online. This is a trend that M4RD is keen to accelerate because the diagnostic odyssey is a global issue and while M4RD is UK focused - our work is relevant around the world. The more medical professionals that we can reach the better!

Therefore the team has concentrated on building up their online presence. We now have an established presence on Facebook, Twitter, Instagram and LinkedIn. More content is required to get the M4RD YouTube channel up and running properly.

#MysteryDiseaseMonday is a fun feature that is run on Instagram stories every Monday. It started organically from Lucy's GP colleague texting her to ask "have you heard of Kikuchi-Fukimoto Disease?". The answer was "no" and Lucy decided to put it to the M4RD Instagram followers in a poll on Instagram Stories. 26 followers viewed this Story and of those who voted (number unknown) 82% had NOT heard of this condition. #MDM became a regular feature and 34 different conditions were polled in this way. This regularly engaged medical professionals and promoted the work of the patient groups who were involved. In a year the M4RD Instagram following grew by 325%. M4RD had a poster accepted to The 10th European Conference on Rare Diseases organised by EURORDIS outlining the benefits of running #MDM.

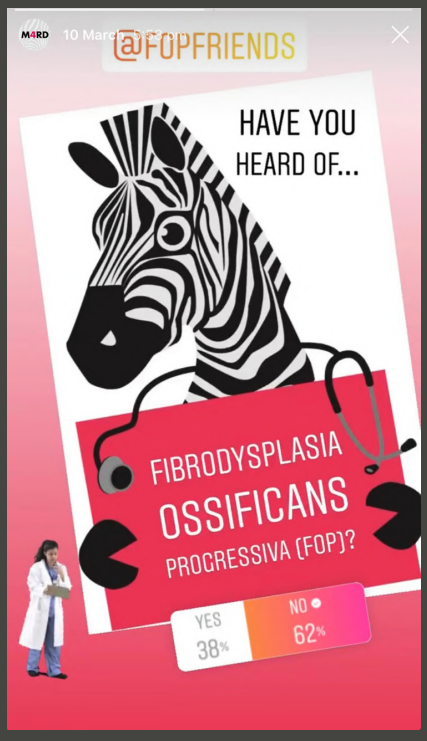
increased Twitter following by 60%

increased Facebook likes by 50%

created an Instagram account & gained 650 followers

increased mailing list subscriptions by 40%

#MDM



Consistent follower engagement on social media can grow your audience and raise awareness of rare diseases

Dr Lucy McKay* - Medics4RareDiseases
Mrs Joanne McPherson - M4RD & IGA

Abstract

Medics4RareDiseases (M4RD) is driving an attitude change towards rare diseases amongst medical students and doctors in training in order to improve the patient experience and reduce the diagnostic odyssey. In 2019 M4RD used Instagram Stories as a platform to reach a global medical audience with a feature known as #MysteryDiseaseMonday (#MDM). Each week M4RD involved a different patient group (PG) to help produce content for a Story about a specific rare condition. M4RD followers were also able to answer a poll asking whether they had or had not heard of that particular condition. 34 different rare diseases were polled in 2019. Haemophilia was the most heard of condition with 90% of voters choosing "yes" whereas none of the voters had heard of neuroferritinopathy. The aim of #MDM was to raise awareness of rare conditions and the pivotal role of PGs. However an exciting bi-product of MDM was the audience growth that M4RD received.

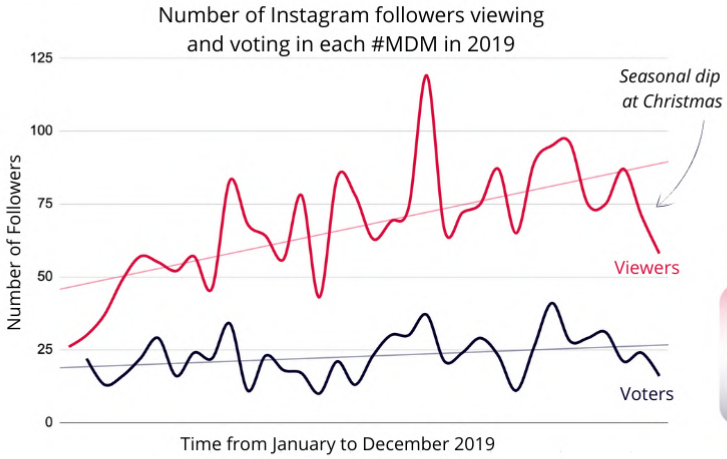
Introduction

M4RD targets rare disease awareness activities at medical professionals in order to reduce the diagnostic odyssey. The activities of the charity do not usually focus on a specific rare disease, rather it focuses on the key message of "rare diseases are collectively common". It is unfeasible for any individual to know the details of over 7000 rare disease. Instead M4RD wants clinicians to understand the relevance of rare disease to their everyday practice and #DareToThinkRare. However an exception to this rule is #MDM - an audience engagement feature that M4RD ran on its Instagram Story throughout 2019. This focused on a specific condition each week and then brought the message back to the common challenges that those with rare diseases face and the need for doctors to #DareToThinkRare.

Methods

1. Recruit a patient group (PG) to take part
2. The PG provides information and media for #MDM which they confirm they have permission to share
3. Provide a date for the #MDM to take place so the PG can share and take part on the day
4. On the set Monday create a 'poll' on Instagram
5. After 2-3 hours start posting information about the condition that was provided by the PG
6. Credit the PG by including its logo, tagging its Instagram handle & including its website URL
7. After 24 hours the Instagram Story disappears
8. The next day post the result of the poll
9. Create a highlight out of the Instagram Story posts

Results



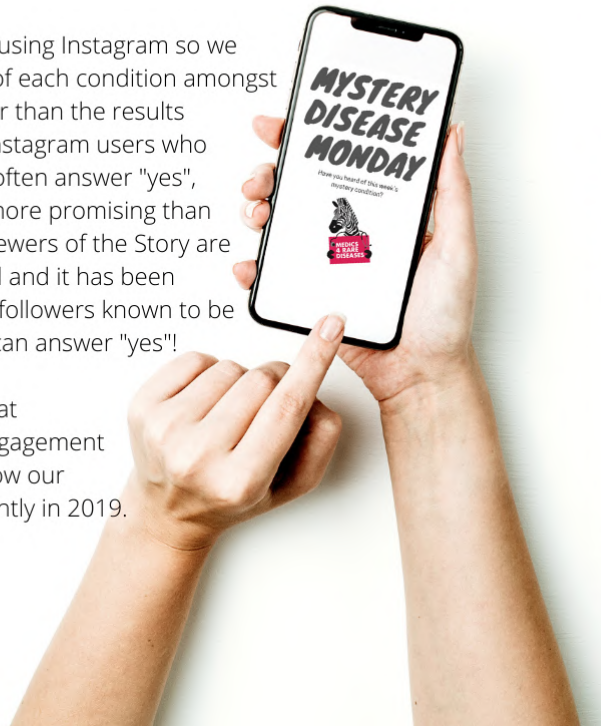
34 different conditions polled in 2019

Most heard of
Haemophilia Type A
Fragile X Syndrome
Bone Sarcoma
DDX3X Syndrome
Fibular Hemimelia
Neuroferritinopathy
Least heard of

Conclusions

The poll is open to everyone using Instagram so we suspect the true awareness of each condition amongst medical professionals is lower than the results suggest. This is because: 1. Instagram users who have the featured condition often answer "yes", making the result look a lot more promising than we suspect the reality is 2. Viewers of the Story are not obliged to vote in the poll and it has been anecdotally noted that often followers known to be doctors will only vote if they can answer "yes"!

However we can conclude that consistent and interactive engagement with our audience helped grow our Instagram followers significantly in 2019.



Instagram following increased by ~325%

Total number of views = 2299
Total number of votes = 733

Voters had heard of the condition	Number of conditions	Conditions in each category
91-100%	0	
81-90%	3	Haemophilia type A; Fragile X, Bone sarcoma
71-90%	5	Kawasaki disease; Hypoparathyroidism; NF1; Spinal CSF leak; Ataxia
60-69%	2	Rett syndrome; 22q Deletion syndrome
50-59%	3	PKU; Cranial CSF leak; Acromegaly
40-49%	4	Gaucher; Cholangiocarcinoma; Pompe; Moyamoya
30-39%	2	Fibromuscular dysplasia; Medulloblastoma
20-29%	7	Wyburn Mason Syndrome; Stiff Person Syndrome; Isolated Congenital Asplenia; SCAD; Acute Necrotizing Encephalopathy; CSID
10-19%	5	Kikuchi-fujimoto; Alström syndrome; CSID; Dyskeratosis; CAPS; Arachnoiditis
0-9%	3	Pitt Hopkins; Fibular hemimelia; Neuroferritinopathy; DDX3X

M4RD is a UK Registered Charity Number 1183996
In 2019 M4RD was sponsored by BioMarin, Inventiva and Sobi
M4RD.org

@medics4rarediseases

ACTIVITIES

2019

WEBSITE

2019 saw the launch of the new M4RD website, created by one of the Trustees, Dan Jeffries.

m4rd.org is a hub for rare disease news, information, videos and resources aimed at medical professionals.

The LEARN tab leads you to the Video Library. This is one of the most popular website features. You can re-watch all the talks from the annual symposium for free here. You can also find disease-specific videos and videos produced by other organisations working in the area of rare diseases.

The LEARN tab also has a Revision section which the M4RD Ambassadors contribute to.

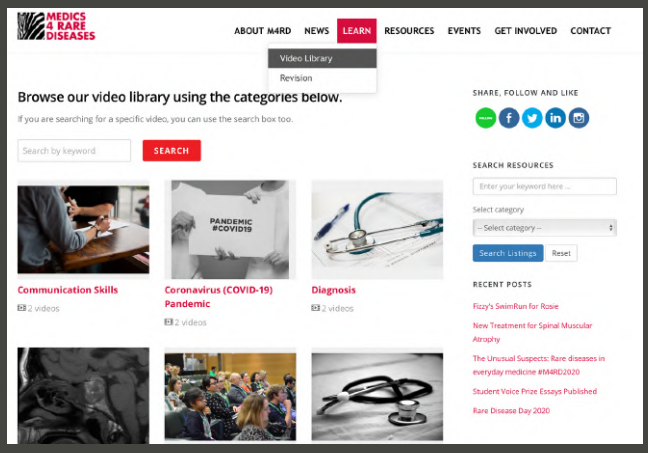
Under the RESOURCES tab you can find rare diseases resources of all sorts:

- Suggested speakers
- Venues for events
- Journal articles
- Guidelines
- Patient Groups

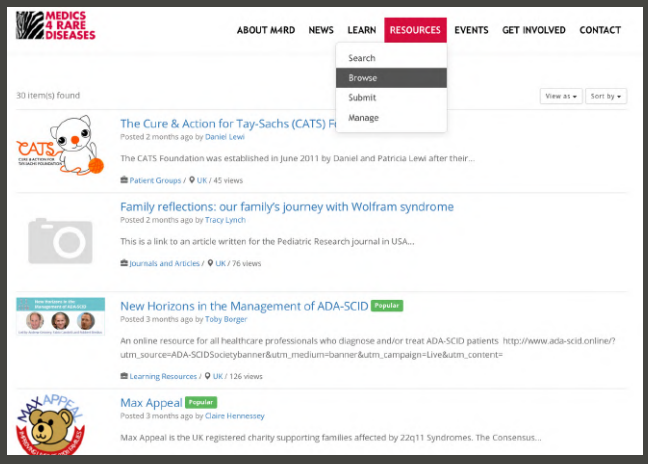
The M4RD team have been actively asking Patient Groups to create their own resources page on the M4RD website so that they can keep it up to date with all their latest information and events.

The EVENTS page is a great place for medical professionals to find out what's happening around the country.

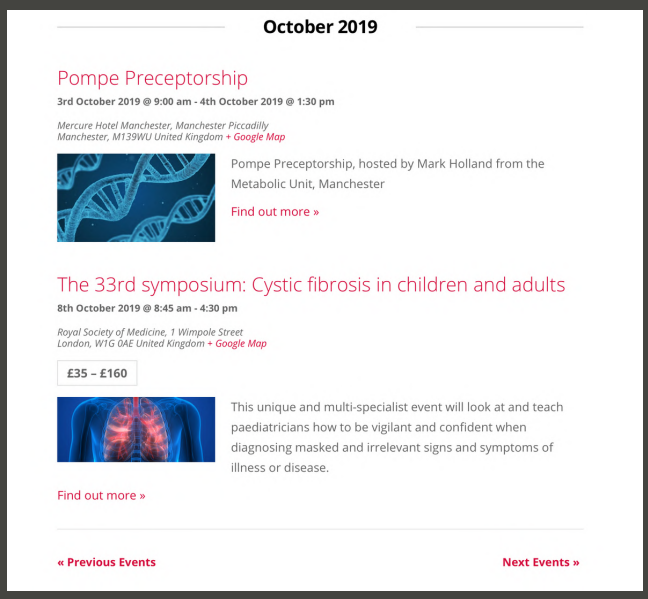
Video Library



Resources



Events



THE UNUSUAL SUSPECTS

THE ANNUAL SYMPOSIUM

The Unusual Suspects: Rare diseases in everyday medicine was held at The Royal Society of Medicine in association with the Medical Genetics Section for the 5th year.

Holding the symposium at this prestigious medical institution is a great honour for M4RD. There were a lot of changes within the RSM during 2018/2019 and so the event organisation was not as straight forward as usual however we were grateful to the Medical Genetics Section for supporting us throughout the process. They also reflected this in the cost of the venue and their services.

The agenda included Dr Will Evans giving his perspective on rare disease in general practice. This is an important area for M4RD to tackle because this is the stage that many patients get delayed in their diagnosis. Will provided pragmatic tips for managing suspected and confirmed rare disease cases. Nicola Miller talked about her experience as a mother of a boy with a very rare dermatological condition. Rudy Benfredj explained how AI will aid doctors to diagnose rare diseases in the future. This talk was extremely well received and has since led to many fruitful opportunities for M4RD. Trustee Dan Jeffries told his story of being diagnosed with one of his rare disease by students during an exam.

For the first time we had the talks professionally recorded so that they can be watched again and again. They have been very useful for producing remote learning materials.

"This conference will empower me to consider rare diseases in the future when making a diagnosis and not shy away from a lack of understanding or knowledge of the specific disease"

100% agreed, or strongly agreed that the event would make them consider a patient may have a rare disease where appropriate in the future.

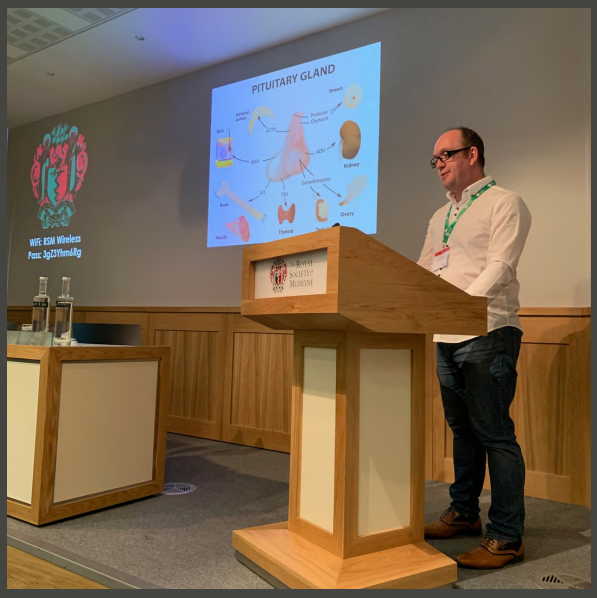
"[This conference] encouraged me to speak to fellow medical students about rare diseases and how to consider them in clinical practice"

100% of relevant delegates said that the conference would impact their clinical practice.

67

DELEGATES

THE UNUSUAL SUSPECTS 2019



ACTIVITIES

THE STUDENT VOICE PRIZE 2019

This year 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 have helped Findacure target medical students.

The aim of the competition is to provide an attractive opportunity (becoming a published author in a journal) to encourage medical students to research rare diseases and engage with the rare disease community. The questions are carefully designed to make this competition accessible across the globe.

This year there were more patient group pairings than last year, when this approach was started. One of the runners-up was involved in a patient group pairing, through which she spoke to a boy with fibrodysplasia ossificans (FOP) and his mother about mental health challenges associated with living with a rare disease; as well as caring for someone with a rare disease.

The winning essay also answered the question on the mental health impact of living with a rare disease. The winner spoke at the M4RD annual symposium in 2020.

QUESTION 1:

Many people living with a rare disease experience a long and arduous journey to diagnosis known as 'The Diagnostic Odyssey'. It involves seeing many different doctors and receiving misdiagnoses.

Explore how current methods of medical education may contribute to this and what changes could be made to improve the experience of those living with a rare disease.

QUESTION 2:

Living with a rare disease is a life-long learning experience which invariably leads to challenges with mental health alongside physical symptoms.

Use a case study to demonstrate how future doctors can learn from patients to improve the management of these complex conditions.

QUESTION 3:

The diagnosis and delivery of treatment for rare diseases can vary greatly between different populations or groups within the same country.

Compare and contrast the experiences of two different groups within a country of your choice, and explore the reasons underlying the inequities of healthcare provision. You may want to focus on a specific disease or stage in the patient journey e.g. newborn screening, diagnosis, or access to treatment.

30

ENTRIES

MEDICS 4 RARE DISEASES

findacure
7,000 rare diseases, 1 common goal

An excerpt from the winning essay of 2019. Medical student, Anna-Lucia, describes a conversation between herself and a patient on the ward who has Neurofibromatosis Type 1:

'Ah. You're the first one who's wanted a chat'

I was surprised, and saddened. How awful it must have been to be David, constantly prodded and gawked at by medical students (most of whom were around his age), but unable to actually have a conversation with any of them. David was an expert patient, but I quickly realised that I'd prefer to hear about how NF1 had affected him than a disease summary I could learn from google.

'So, how are you doing? Mentally, rather than physically?'

I watched as David's eyes filled with tears, which he wiped embarrassedly on the blanket. It became apparent that in the 8 days since his admission, no one had asked him how he was dealing with the mental burden of his condition – something which is all too common for rare disease patients.

-'No Friends 1' by Anna-Lucia Koerling, Student Voice Prize Winner 2019
Published in: Orphanet Journal of Rare Diseases. Volume 15, Article number: 50 (2020)

Anna-Lucia receiving her certificate from Dr Rick Thompson, CEO of Findacure, and Dr Lucy McKay at The Unusual Suspects 2019.

The Student Voice Prize is an excellent opportunity for medical students to learn from those lving with rare diseases. And then to take these lessons through their own medical career while also teching others about them. One audience member who heard Anna-Lucia's talk said:

"[I have gained] an appreciation of the best support for patients with rare diseases."

ACTIVITIES

AMBASSADOR PROGRAMME

After a successful pilot year M4RD decided to continue with the Ambassador Scheme for a second year.

Three clinical ambassadors continued in their positions. All three are Foundation Year 2 doctors and the board felt it important to have a senior clinician involved in the programme. Dr Gisela Wilcox, consultant in Metabolic Medicine at Salford Royal Hospital, generously volunteered her time. Since joining the M4RD family she has organised events for medical trainees at her hospital, raised the profile of M4RD during her work and been available to consult on our activities.

During 2019 the M4RD team received tragic news that Simran, our patient ambassador, had died during an operation for her heart condition. Simran was a founding director of Medics4RareDiseases in December 2017. She lived with a rare condition and despite suffering from severe symptoms she was always sunny and optimistic. She was keen to be involved in the mission of M4RD and was invaluable when advising on our activities. Our sincere condolences were sent to Simran's family and we are deeply grateful for the part she played in M4RD's establishment.

We would like to thank all the M4RD Ambassadors for the free time that they dedicate to achieve M4RD's objects.

THE ROLE OF THE M4RD AMBASSADORS

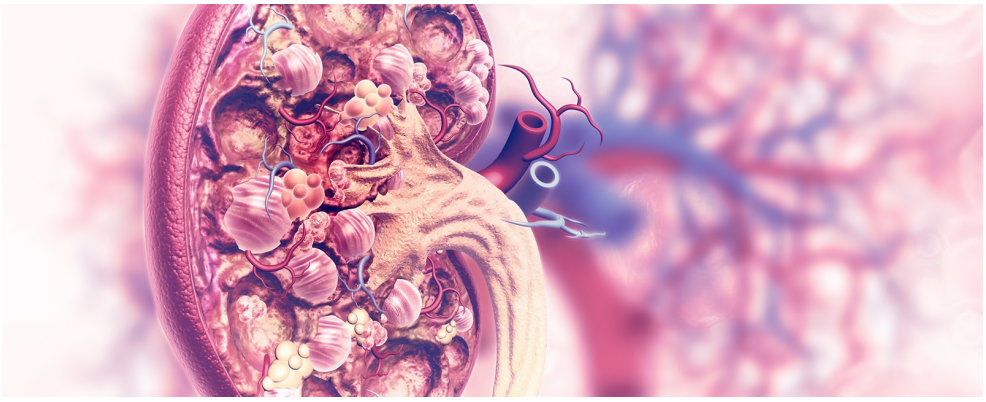
- Advising the M4RD team on how best to achieve the objects of the charity
- Reflecting on their personal experiences in order to improve the work of M4RD
- Support the M4RD team in their aim to raise awareness of rare diseases
- Engage and support medical students to encourage their interest in rare diseases and to get involved with M4RD
- Support rare disease events
- Provide basic education in rare diseases
- Provide content for social media and website

ACTIVITIES

OTHER ACTIVITIES

The official M4RD promotional video was released to mark Rare Disease Day 2019. This video was produced in collaboration with the medical communications agency, emotive. The M4RD team are excited to coninue to work with emotive in 2020.

Medical students sponsored to attend 'Rare Disease and The Kidney' event organised by The RSM Nephrology Section.



M4RD helped CTT to appoint six doctors to their medical advisory board, two of whom were sponsored by CTT to attend the International Conference on Neurofibromatosis in San Francisco so they could report back the latest updates.

Lucy McKay appeared on BBC Radio 4's Woman's Hour during which she spoke of the mission of M4RD alongside Sarah Lippett, author and illustrator of 'A Puff of Smoke'. M4RD have worked closely with Sarah in order to use her memoir as a way of educating medics about life with a rare disease. One listener commented: "It is a great piece of work, the illustrations express things words would not be able to...I will endeavour to remember your story when I am consulting with my patients."

CALL OFF THE SEARCH

MEET THE TWO DOCTORS HEADING TO THE INTERNATIONAL NEUROFIBROMATOSIS CONFERENCE IN SAN FRANCISCO

Earlier this year Medics4RareDiseases (M4RD) helped Childhood Tumour Trust (CTT) search for a doctor that could attend the International Neurofibromatosis Conference in San Francisco this September.

The successful candidate would learn about the latest developments in Neurofibromatosis Type 1, make connections and report back to CTT.

With the help of M4RD, CTT received a number of excellent applications. In fact they couldn't decide between two exceptional candidates so they chose two doctors to attend the conference. After the conference they will become part of the CTT medical advisory board.

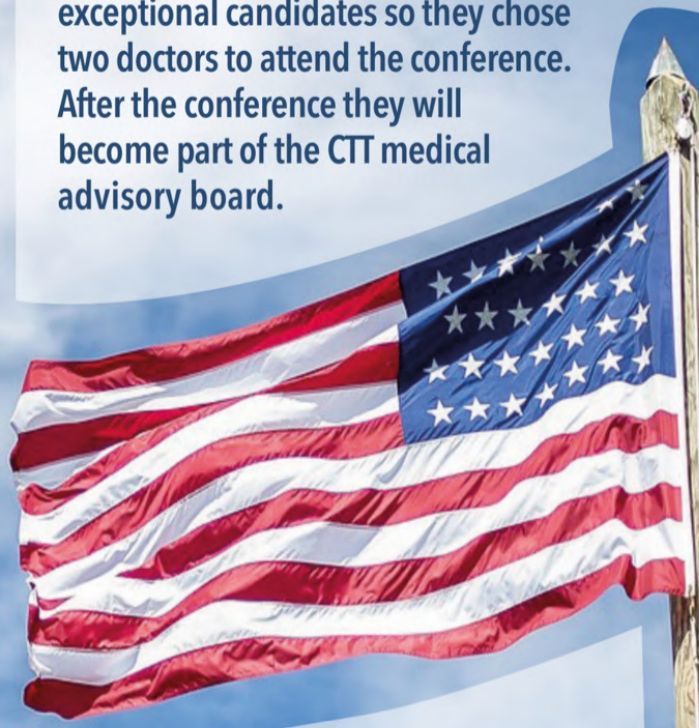
Dr Georgina Bird-Lieberman

Georgina is a Consultant Paediatric Neurologist working in Southampton. She has a specialist interest in Neuro-oncology and is part of the Neuro-oncoloy multi-disciplinary team, where she regularly sees patients with NF1 related optic pathway gliomas and, slightly less commonly, NF2 related schwannomas. She has a long history of working with various charities for children and young people with a variety of medical and physical disadvantages and is very passionate about promoting self-confidence and independence for these young people. Georgina says she is keen to work with Childhood Tumour Trust and understands the importance of early recognition of this distressing condition. She wishes to support them in raising awareness of the condition both within the community and the medical profession.

Dr Sarah Joyce

Sarah is a doctor in Paediatrics in the Kent Surrey Sussex Deanery. She obtained her MSc and PhD in Genetics and then studied Medicine in London. She kept in touch with her interest in Genetics, setting up the university's Genetics Society.

Sarah says she is honoured to be a member of the medical advisory board of Childhood Tumour Trust. She is looking forward to raising awareness about Neurofibromatosis Type 1 amongst health professionals so that more NF1 diagnoses can be made in the critical early stages of children's lives.



In addition they have chosen four more doctors to join their medical advisory board:

Dr Lizzy Charlton, Dr Srinivasa Rambhatla, Dr Katheryn Ferina all from the UK and Dr Kristina Rath from the USA. They will be vital for enabling CTT to support families affected by Neurofibromatosis Type 1.

M4RD and CTT would like to thank all those that applied for these roles and the successful candidates.

Please look out for the conference report in future editions of Rare Revolution Magazine.

www.childhoodtumourtrust.org.uk/
www.ctf.org/get-involved/nf-conference
www.m4rd.org

Childhood Tumour Trust

MEDICS 4 RARE DISEASES

FINANCIAL REVIEW

2018/2019 PLAN

This financial year is the second of a 2 year plan for which funding was secured in late 2017 and received in 2018 and 2019.

In total £36,988 of funding for these two years was secured which supplemented £8,024.58 from the previous year.

The majority of spending occurred in 2019 as 2018 was largely spent organising the company structure and preparing for registering as a charity. Therefore expenses outweigh income in 2019 because the majority of the funding for the two years was received in 2018 but spent in 2019.

2019 INCOME

Total income in 2019 is £9190.

PRINCIPAL FUNDING SOURCES

The principal funding sources for this period were sponsorship and donations from commercial companies. For the 2018/2019 two year plan M4RD received funding from BioMarin, Inventiva, SOBI and Ultragenyx.

M4RD is grateful for this support which enables the Charity to achieve its objects.

2018/2019 OBJECTIVES:

The 2018/2019 project aimed to:

- Become a company limited by guarantee
- Register with the Charity Commission
- Rebrand to Medics4RareDiseases
- Employ staff to ensure objects are met
- Continue to hold annual symposium
- Increasingly use social media as a tool to engage with medical professionals
- Create disease specific infograms for sharing on social media
- Establish an M4RD YouTube channel
- Develop website as a resource centre

M4RD achieved all of these objectives within the 2 year period.

FINANCIAL REVIEW

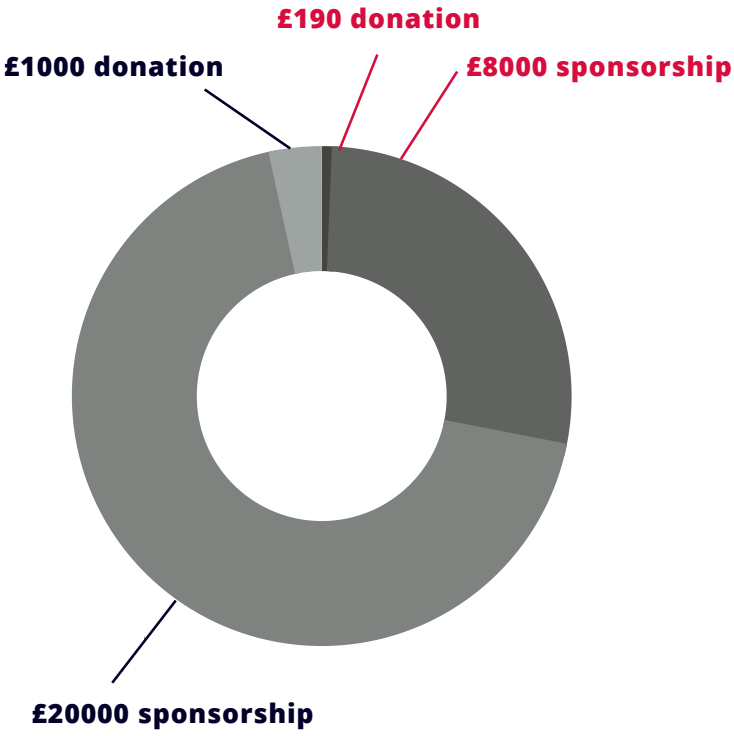
2019 INCOME & DEFERRED FUNDS

£9,000 was received in sponsorship in 2019 (£5000 from SOBI and £3000 from Inventiva). At the end of the financial year a donation of £1000 was received from Ultragenyx in order to aid M4RD to continue its work.

Also at the end of 2019, sponsorship was received from two companies to the total amount of £20,000 which has been deferred because it is for activities taking place in 2020.

Total funds carried forward is £6, 904.

Final cash position is £30,560.



KEY:
- **Income allocated to 2019**
- **Income allocated to 2020**

WORKING WITH COMMERCIAL COMPANIES

M4RD seeks funding from across the industry and does not endorse any companies or products. M4RD is operated independently from these companies and they have no editorial control over M4RD's contents or activities. When working with the pharmaceutical industry M4RD is classed as a patient group and as such follows the ABPI's code of practice.

PRO BONO & VOLUNTARY WORK

M4RD is lucky to have a dedicated and talented Trustee's Board who volunteered a substantial amount of colective time in order to help M4RD achieve its objects. In 2019 the Trustees were estimated to have volunteered X number of hours

Thank you to the M4RD Ambassadors who also support M4RD by volunatrily creating content for the charity and providing guidance for the CEO.

Thank you to emotive who provide their a multi-award winning global healthcare communications experience for free. They created the M4RD promotional video and are responisble for our gorgeous rebranding. This is estimated to equate to £15,000 worth of work.

emotive.

FINANCIAL REVIEW

OUTGOINGS

In 2019 the greatest expenses were the M4RD's employee's salary and the costs involved in the annual symposium. This is reflective of the minimal overheads of the charity as it is an entirely remote organisation without any property or physical assets. Additionally the CEO and Trustee's Board try to do as much work as posisble 'in-house' rather than paying external contractors.

The annual symposium was expected to be a major expense as it is the biggest event of the M4RD calendar where the charity can deliver it's core messages to medical professionals at a prestigious medical institution - The Royal Society of Medicine. Content created at this event is then used for other purposes in the future.

The annual symposium cost less than expected thanks to a discount provided by the venue, only partial use of the travel bursary budget and other smaller savings.

Total expenses for 2019 is £29,070.

FINANCIAL POSITION

The reporting period is 1st January to 31st December 2019. At the end of the reporting period the charity has total funds carried forward of £6,904 and a final cash position of £30,560.

After making appropriate enquiries, the Trustees have a reasonable expectation that the Charity has adequate resources to continue in operational existence for the foreseeable future.

BREAKDOWN OF EXPENSES

Staff salaries, NIC and Pensions	£15,586
Insurance	£228
Legal and professional fees	£1,260
Telephone & computer expenses	£538
Subscriptions	£30
Event costs	£2,913
Administration support	£4,931
Advertising and marketing	£448
Travel	£313

FINANCIAL REVIEW

FINANCIAL RISKS

The risks that M4RD are exposed to are fairly low as its committed spend and running costs are still relatively low. Everyone works remotely and 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. However next year the Charity would like to expand in order to meet its objects more effectively and at a faster rate. A financial software package was implemented in 2019 to support the charity's growth, the aim of which is to help manage its increasing transaction complexity as it expands. The Treasurer, who formally worked as an accountant, has financial oversight.

M4RD is in the process of opening a bank account with CAF Bank in order to allow a deeper level of governance in terms of managing the finances.

The main financial risk is, as always, managing to secure future funding. So far M4RD has relied 100% on commercial donations and sponsorship. However now it is a registered charity the Board of Trustees would like to diversify revenue streams 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.

PAY POLICY FOR KEY MANAGEMENT PERSONNEL

All Trustees give their time voluntarily and receive no benefit from the charity. The charity continues to have one employed member of staff - the CEO. In September 2019 Dr Lucy McKay, CEO, increased her working hours from 2 to 3 days. Lucy's salary was increased in order to reflect this and inflation. This will be reviewed by the Board of Trustees again in August 2020.

RESERVES POLICY

The Trustees agreed that reserves need to be kept and put a Reserves Policy in place 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 would 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.

TRUSTEES

TRUSTEE INDUCTION & TRAINING

Trustees have been appointed to the M4RD 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 the there is not maximum number. Who can 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 and provides a PDF copy of The Charity Commissions document "The Essential Trustee'.

ORGANISATIONAL STRUCTURE & DECISION MAKING POLICIES

The board meets roughly 6 times a year. The CEO, Lucy McKay, is a founding member of the company and has been in role as 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 weekly and to the Treasurer monthly 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.

TRUSTEE SKILLS

The M4RD Board of Trustees greatly contribute to the success of the charity. Two Trustees are GPs and have been involved in M4RD (in its previous incarnations) since 2011. The Treasurer was an Accountant prior to retraining as a doctor. On the board we also have a Patient Organisation representative who helped M4RD establish itself as a charitable company. Our patient representative is also an author and public speaker. As well as doing his day job of creating online interactive educational software, he created the new website at no cost and oversees its proper functioning. The Chair is the founder of a successful online retail company and has been pivotal in getting M4RD's structure established.

DECISION MAKING POLICIES

The aims and objective of the 2018/2019 plan have driven the decision making during this period. The CEO is largely responsible for making decisions about activities that achieve the aims and objectives. 2019 required a lot of organisational change as the board worked with The Charity Commission to register the company as a charity. The Chair was predominantly responsible for this process but was supported by the CEO. Large financial decisions (outside of pre-authorised projects) are taken to the board by the CEO to be discussed. These usually constitute costs over £100.

FUTURE PLANS

FUTURE PLANS

Development of the 'Rare Disease 101 Project':

- Creating an online and interactive learning tool for remote learning use.
- Providing all the materials required for students and doctors to produce their own rare disease training day.
- Create a Rare Disease 101 video

This project is the first step in campaigning for Rare Disease 101 education to be mandatory during medical school studies and in continued medical education.

Complete the Red Flags of Rare Disease Project and submit for publication.

Continue building the resource centre for medics on the website's LEARN page.

Organise the annual symposium at The Royal Society of Medicine in February 2020

Continue developing the 'M4RD Ambassadors' scheme & run it for a third year

Produce the Student Voice Prize 2020 with Findacure

ORGANISATIONAL PLANS

Complete transfer of bank account from Lloyds Bank to CAF Bank

Develop a more diverse fundraising strategy

Hire a Finance Officer

Convert to a Charitable Incorporated Company

FUTURE FUNDING

In 2019 M4RD sent out a funding applications to companies involved in a wide range of rare diseases. The application explained the charity's plans for the future and estimated costs involved. In total the charity hopes to raise £70,000 to achieve the aims and objectives of 2020.

In addition the M4RD team will be looking for a Finance Officer with experience in fundraising.