

BEACON: FOR RARE DISEASES LTD

England & Wales · Charity number 1149646

Details

Other names FINDACURE FOUNDATION

Status Registered

Legal form Charitable company

Company number [08174973](#)

Registered 2012-11-07

Register [View on the Charity Commission register](#)

Contact

Address 66 Devonshire Road
Cambridge
CB1 2BL

Phone 01223222767

Email admin@rarebeacon.org

Website www.rarebeacon.org

Activities

Objects: (1) TO ADVANCE THE EDUCATION OF THE GENERAL PUBLIC IN ALL AREAS RELATING TO FUNDAMENTAL DISEASES AND THEIR CAUSES, EFFECTS AND TREATMENTS; (2) TO PROMOTE AND PROTECT THE PHYSICAL AND MENTAL HEALTH OF SUFFERERS OF FUNDAMENTAL DISEASES AND THEIR CARERS THROUGH THE PROVISION OF SUPPORT, EDUCATION AND PRACTICAL ADVICE; (3) TO SUPPORT RESEARCH INTO THE CAUSES, EFFECTS, TREATMENT AND MANAGEMENT OF FUNDAMENTAL DISEASES AND THEIR APPLICATION TO COMMON DISEASES, AND DISSEMINATE THE USEFUL RESULTS THEREOF.

Activities: Findacure works to: Empower patient groups to build their patient community, develop as a charity, and drive treatment research and development. Promote collaboration between rare disease stakeholders to facilitate treatment development for all.

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities, Other Charities Or Voluntary Bodies, The General Public/mankind

Geography

- **Area of benefit:** NATIONAL
- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-01-31	£691,035	£661,717	£220,802	11
2024-01-31	£523,301	£478,828	£191,484	10
2023-01-31	£324,211	£389,510	-	-
2022-01-31	£269,865	£318,343	-	-
2021-01-31	£324,970	£196,149	-	-

Trustees

Name	Role	Appointed
ANDREW MILLIGAN		2012-10-11
Dr ANTHONY KENT HALL		2012-10-11
Dr Rebecca Godfrey		2025-12-03
Joanne Patra Pisani		2019-10-11
Kamlesh Kanaiyalal Sheth		2025-12-03
Michael Paul Wilbur		2025-12-03
Scott Robin Hutchings		2025-12-03
Shannon Marie Gunn		2025-12-03
Sophie Costello		2019-10-11

BEACON: FOR RARE DISEASES LTD

England & Wales - Charity number 1149646

Accounts

REGISTERED COMPANY NUMBER: 08174973 (England and Wales)
REGISTERED CHARITY NUMBER: 1149646

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 JANUARY 2025
FOR
BEACON: FOR RARE DISEASES LTD

BEACON: FOR RARE DISEASES LTD

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FOR THE YEAR ENDED 31 JANUARY 2025

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BEACON: FOR RARE DISEASES LTD

REFERENCE AND ADMINISTRATIVE DETAILS
FOR THE YEAR ENDED 31 JANUARY 2025

TRUSTEES	A Hall Chief Medical Officer - Biotech Company E Kissmann Strategic Communication Consultant A Milligan Consultant N T Sireau PhD Charity Manager (resigned on 25 November 2024) S Costello Chair of Trustees J Pisani Management Consultant and NED
REGISTERED OFFICE	66 Devonshire Road CAMBRIDGE Cambridgeshire CB1 2BL
REGISTERED COMPANY NUMBER	08174973 (England and Wales)
REGISTERED CHARITY NUMBER	1149646
INDEPENDENT EXAMINER	Archangel Accounting Burnham House Splash Lane Wyton Huntingdon PE28 2AF

BEACON: FOR RARE DISEASES LTD**REPORT OF THE TRUSTEES**
FOR THE YEAR ENDED 31 JANUARY 2025

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 January 2025. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES**Objectives and aims**

Beacon: for rare diseases (hereafter Beacon, and formerly Findacure) aims to transform the way the world views rare diseases. We affect the lives of people with rare diseases and accelerate change in the field by:

- Working directly with patient groups to professionalise their work for impactful results and to build their reputation as the experts in their specific conditions.
- Building a rare disease community that supports, informs, collaborates and advocates for the increased attention by society for the therapeutic and human needs of those affected by any rare condition.

Significant activities**About fundamental diseases**

In the UK and EU, a rare disease is defined as a condition that affects fewer than 1 in 2,000 people. Currently, more than 7,000 rare diseases have been identified, which collectively affect 3.5 million people in the UK. Despite their collective prevalence, each individual condition relates to so few people that they tend to be overlooked by doctors, researchers, funders and the general public. As a result, living with a rare disease can be incredibly isolating; people can be kept from education, work, and their communities. As only 5% of rare diseases have a treatment, many rare disease patients are left with debilitating and degenerative conditions, with little hope for a cure or a modicum of normal living.

This neglect of rare conditions has gone on for too long. Disease prevalence should not be the sole criterion for judging the importance or impact of a condition. The trustees believe that research into even the rarest diseases can benefit us all, since many rare genetic diseases can be viewed as templates for more common ones or teach us a great deal about the fundamentals of human biology. Under the informal banner of Rare is Fundamental, we believe that improving our knowledge of the exceptional conditions will accelerate the identification of treatments for many conditions and the growing knowledge about the way the body functions. Rare diseases are also often at the forefront of new developments in genetic medicine; gene therapies have almost exclusively been developed in this field. Despite this, rare diseases still receive little attention and funding from the research community. They are also significantly less interesting to policy makers and rarely form part of medical training.

Those living with a rare condition are the true experts in their rare disease. They possess valuable insight into the disease's progression and have first-hand experience of symptom management. Above all, they are critical to any pursuit of treatment and have the drive to deliver improved care for themselves. They represent the patient's voice; they understand patient needs for therapy and treatments. As a result, they are a key partner in patient care and research development. They are increasingly being recognised as a key partner by the pharmaceutical industry.

Beacon helps patient groups to form, grow and professionalise. Through our projects, we are building a community of rare disease patient groups that have the skills and knowledge to better support patients, campaign for equal opportunities and drive research. We are committed to helping patient groups learn from one another; and to feel confident in engaging with researchers, pharma, and clinicians on a level footing. A unified rare disease community works much more effectively than each patient group on its own. Alongside the patient empowerment projects, Beacon works to encourage collaborative research into rare diseases by running multi-sector events, such as our annual conference and showcases, which bring patients, clinicians, researchers, and industry together. Beacon also plays a central role in the promotion and development of drug repurposing for rare diseases, primarily through our position within the EC funded consortium, REMEDI4ALL.

BEACON: FOR RARE DISEASES LTD**REPORT OF THE TRUSTEES**
FOR THE YEAR ENDED 31 JANUARY 2025

OBJECTIVES AND ACTIVITIES**Public benefit**

The trustees have complied with Section 17(5) of the Charities Act 2011 and have had due regard to the guidance on Public Benefit by the Charity Commission when exercising relevant powers and duties. See "About Fundamental Diseases" section for details of how the charity provides public benefit.

STRATEGIC REPORT**Achievement and performance****Charitable activities**

Beacon's core aim is to provide support, guidance and connections to the rare disease patient group community. We help them achieve their goals (usually in the areas of patient support, research, and advocacy) and share their experiences so that all can learn from one another. This year has seen the achievement of several notable milestones for the charity's core projects: we secured over 500 registered users for our empowerment program's online learning platform, the Resources Hub; we hosted our first ever international conference in collaboration with REMEDI4ALL and MeRIT; we concluded our work on our first ever European grant with a hybrid conference to close the MCDS-Therapy project in Newcastle. These accomplishments underscore the continual growth of Beacon's reach, the increases in our impact, and the demand for our services – whether direct training, or the creation of unique opportunities for the patient community.

Alongside these hallmarks of our growing reach and impact, 2024/25 has seen continued financial stability, with the award of a new two-year grant to support LifeArc's new Translational Centres for Rare Disease through its coordinating Hub function. Furthermore, our success within the international REMEDI4ALL consortium has continued to grow, both through the launch of the REMEDI4ALL Digital Academy and the delivery of patient engagement work used to support scientific advice for an ultrarare disease clinical trial.

REMEDI4ALL

REMEDI4ALL champions drug repurposing and the necessity of delivering patient impact in repurposing research. Beacon is joint lead on both Training (WP3) and Patient Engagement (WP1) work packages, alongside EURORDIS. Over the last year Beacon has been heavily involved in all aspects of the project. Highlights include partnering with REMEDI4ALL to deliver the first ever International Drug Repurposing Conference, hosting patient focus groups and interviews to collect input for scientific advice in Multisulfatase Deficiency and developing and launching the REMEDI4ALL Digital Academy on drug repurposing. Alongside this we have planned the delivery of our first academic training event – to be hosted in Cambridgeshire in March 2025, and a patient group bootcamp on repurposing to be hosted in Barcelona following the Eurordis Open Academy this summer. There has been a real breadth of work within the consortium, and we are now beginning to see both our training programme and patient engagement activities delivering impact to the wider community.

MCDS-Therapy

In parallel to REMEDI4ALL, our long-term EU funded project, MCDS-Therapy, came to a close in 2024. Beacon led the development and delivery of the project's closing conference, which was held in The Catalyst, Newcastle, on 30th May 2024. This event was Beacon's first ever hybrid event, combining a 37-person virtual audience with 40 attendees in the in-person delegation. The event included talks on the purpose of MCDS-Therapy (including a talk from a young person personally affected by the condition), the challenges of trial delivery for an ultrarare disease during COVID, the clinical trial outcomes, and future prospects. Attended by a mixture of consortium partners, trial participants, and rare bone condition community members, the event helped to summarise the project outcomes and disseminate impact in a meaningful way. Beacon continued to work on communication and dissemination for the project across the year but decided to wrap up communication efforts and channels towards the end of 2024, following grant closure in the summer.

Overall, MCDS-Therapy has been an effective learning experience for Beacon as a charity, representing a unique opportunity for us to understand the workings of EU consortia and engage with a hard-to-reach rare disease patient community. We take many learnings and successes from the project, though there was sadly insufficient evidence to support the successful repurposing of carbamazepine for Metaphyseal chondrodysplasia type Schmid.

BEACON: FOR RARE DISEASES LTD**REPORT OF THE TRUSTEES**
FOR THE YEAR ENDED 31 JANUARY 2025

Conferences and Showcase Events

The decision, made in 2023, to collaborate directly with REMEDI4ALL by combining our long running conference “Drug Repurposing for Rare Diseases” with their proposed conference to create the International Drug Repurposing Conference (iDR) proved to be positive. The first event, iDR24, was delivered in March 2024, in Barcelona with over 50 speakers and 230 delegates in attendance. With three parallel conference streams combined with 4 plenary sessions, the conference represented Beacon’s largest in-person event by far, and had a substantial international impact (including articles in leading Spanish newspaper El País).

Beacon played a major role in the delivery of the conference, leading one of the three conference pathways (focused on rare diseases), supporting the planning, delivery and chairing of the plenary sessions, and making a significant contribution to event logistics and delivery. Our existing event expertise proved invaluable to the consortium, while the large network and international profile of REMEDI4ALL, combined with the collaborative approach of key delivery partners, allowed us to maximise the impact and success of the event. The feedback and community feel of the whole conference were hugely valuable, and we plan to repeat this collaboration, with iDR25 planned for May 2025. The two key learnings are firstly to increase the visibility of the Beacon brand within the conference, maximising the impact and opportunities for Beacon. Second, the financial returns from this conference were far below our usual conference sponsorship income – traditionally a valuable source of core staff funding. Our collaboration in 2025 has already been structured to help Beacon cover more of this financial shortfall associated with the loss of our own independent conference.

With the need to focus on our central role in the iDR Conferences 2024 and 2025, alongside our growing project commitments, we decided to only run a single Showcase event in 2024: The Cambridge Rare Disease Showcase. This evening networking event, running since 2015, saw 90 delegates in attendance, with six lightning talks presented across the evening. These included presentations from our collaborators in the LifeArc Translational Centres for Rare Diseases Hub, Healx, the NIHR BioResource, CamRare, and two patient group beneficiaries. This diversity of speakers and talk types is a core strength of the Showcase series, helping to create new connections across the rare disease ecosystem and highlight excellence in the field.

The Student Voice Prize

Our essay competition collaboration with Medics 4 Rare Disease entered its ninth year in 2024. We received the largest ever number of essay submissions to the Student Voice Prize competition (123), 111 of which we paired with patient group case studies by the Beacon team. This patient pairing scheme has continued to grow year on year and creates a unique opportunity for patient groups to connect with medical students and educate both about their condition and the patient experience. The winning entry to 2023’s competition, “Embracing the unknown: investigating medical communication around uncertainty and the implications on patient and family well-being” by Leisha Devisetti was once again published in Orphanet Journal of Rare Diseases in celebration of rare disease day. It has been accessed over 2400 times and cited twice at the time of writing, highlighting the reach and impact of this project for Beacon and our collaborators.

BEACON: FOR RARE DISEASES LTD**REPORT OF THE TRUSTEES**
FOR THE YEAR ENDED 31 JANUARY 2025

Empowerment program

The growth of the Resources Hub has been a huge success for Beacon this year. We secured 248 new users in 2024 (representing a growth of 89%), with 525 registered users by the start of 2025. This growth reflects our expanding national and international reach, and the increasingly dynamic learning environment of the Hub itself. We released over 15 new resources across 2024, and added more refinements to the platform itself. This growth has been in line with our plans for content creation, spearheaded by a fusion of in-house and *pro bono* developed content. This success in the on-demand training space has been more than matched by our live training offering. We delivered 2 workshops (on charity finance and a series on resilience in rare disease leadership) 3 master classes, and 10 webinars across the year. This included a successful series exploring the diagnostic landscape and the role of rare disease patient groups in supporting the diagnostic journey. Our patient group mentoring program has also continued to flourish, with 21 mentoring pairs completing the scheme this year. This diversity of delivery methods is now key to our strategy, ensuring that there is a form of training to suit everyone's needs and preferences, while also allowing us to deliver training in the most suitable manner for the content.

Overall, 2024/25 has been a year of stabilization and delivery for Beacon. We have reached our goal of a twelve-person team, secured a new multiyear grant, and maintained a stable financial base. We have successfully concluded the MCDS-Therapy project, launched REMEDI4ALL's digital training offering and delivered our first ever international conference. Our patient group training offering has significantly increased its online reach and secured excellent feedback across the board. Our relative team stability has helped us focus more on project delivery, the refinement of internal processes, and the development of more long-term strategic documents to guide our work in the future. We hope to continue this trend in the year ahead and begin to identify new long-term funding and revenue streams to support our core team and operations.

STRATEGIC REPORT**Achievement and performance****Internal and external factors**

Cost inflation, wage growth and the subsequent challenge of creating a competitive employment package remain real challenges for a charity of Beacon's size and means. Costs have continued to rise over the year and are set to further increase with the planned changes to National Insurance later in 2025. We have continued to work to increase staff salaries in a sustainable manner, aiming to ensure a wage structure which exceeds the real living wage, and rewards and recognizes staff experience and dedication. This has been, and will remain a challenge for Beacon, especially when we have seen more corporate funders excluding staff costs from their grant awards.

Staff turnover has been less pronounced in 2024, with two departures and three new appointments within the team during the last year. We have now secured a stable staff team of 12, with new appointments to the role of Events Officer, Projects Officer, and Senior Scientific Projects Officer. We are well placed to deliver our grant commitments while retaining the necessary flexibility to pursue new opportunities to deliver our core mission. With stability in most of our core positions, and the support of a secondment from Costello Medical Consulting Ltd, we have been able to both deliver on our projects and develop new strategic documentation to support our work. This includes a new five-year strategy for Beacon, alongside fundraising and communication strategy documents to help structure our external engagement work. Finally, we have continued to develop more robust internal processes to support our work and define a "Beacon approach" to project delivery, helping to ensure our approaches are retained in our institutional memory, rather than owned exclusively by key staff members.

BEACON: FOR RARE DISEASES LTD**REPORT OF THE TRUSTEES**
FOR THE YEAR ENDED 31 JANUARY 2025

STRATEGIC REPORT**Achievement and performance****Partnerships**

REMEDi4ALL remains Beacon's largest and most significant partnership. As a UK organisation, Beacon is an associated partner in the EU project, receiving funding through the UKRI's Horizon Guarantee Scheme. The consortium now includes 26 distinct member organisations across Europe, all with different expertise in the drug repurposing space. Beacon is working particularly closely with EURORDIS: Rare disease Europe, EATRIS (the European Translational Research Infrastructure), TEAM IT, Syreon Research Institute, the AntiCancer Fund, and the Dutch Funder ZonMW in the delivery of the project, and is involved in eight of the thirteen work packages, with co-leadership of two. This project is of huge strategic significance to both the repurposing community, and to Beacon itself. The experience gained through this consortium has expanded our international reach and helped us to develop further in-house expertise in patient engagement in research, and digital training.

We have continued to develop our working relationship with LifeArc, who officially joined the REMEDi4ALL consortium on the 1st January 2025. In the summer of 2024, we developed an application to be involved in the Hub of LifeArc's new Translational Centres for Rare Diseases, helping to lead the work on patient engagement and involvement, training, and communication. This grant was awarded on a two-year basis in September 2025, with the chance to extend to a full five-year project. Within the Hub, Beacon works in close collaboration with both LifeArc and Genetic Alliance UK, as well as connecting directly with the newly funded Translational centres for rare kidney, mitochondrial, and respiratory diseases, and the centre to accelerate rare disease clinical trials. Although still in its early stages, this represents another exciting opportunity for Beacon to both collaborate more directly with UK rare disease academia, and to influence the approach to patient centred research in the UK rare disease ecosystem.

The EU-funded study, MCDS-Therapy, concluded at the end of May 2024. Beacon organized and delivered the closing conference for the project in May 2024 – hosting our first ever hybrid event – and including both patient talks and targeted communications to the patient community following trial analysis. The project represented a strong collaboration with the University of Newcastle, alongside other international partners, and was a meaningful source of financial stability and education for our team. Overall, MCDS-Therapy has trained us on the delivery of patient engagement and communication project, the challenges of clinical trial working, and the key considerations for consortium working. While the project outcomes were not as impactful as we hoped at the outset, we do believe that the MCDS community is left in a better place than at consortium formation, and Beacon remains committed to further disseminating the outcomes of the project through our own channels.

Beacon and Medics4RareDiseases - a registered charity dedicated to raising awareness about rare diseases within the medical profession - have continued the collaboration on The Student Voice Prize, which saw further growth in entries in 2024. We maintained our partnership with the Orphanet Journal of Rare Diseases and BioMed Central, which once again published the winning entry from our student essay competition in their journal, alongside three other entries on their "On Medicine" blog.

It is also worth noting that the majority of Beacon's training events rely on the support and collaboration of our many friends and partners throughout the rare disease world. Our trainers often come from patient organisations, charities, and industry groups across the sector, providing their knowledge and time to support our work. We also receive regular support in promoting events from Genetic Alliance UK, Rare Revolution Magazine, Cambridge Rare Disease Network and EMIG (The Ethical Medicines Industry Group). Our work would not be possible without this on-going support and collaboration, and we are indebted to everyone who supports our work and mission with their time and expertise.

Finally, Beacon and Costello Medical have continued our fruitful *pro bono* collaboration in 2024 with support spanning the production of new guides for the Resources Hub, and vital *pro bono* support with finance and bookkeeping. Furthermore, in 2024 a member of the Costello Team was seconded to Beacon to support our project work following a staff resignation. This proved invaluable to our team and strengthened the collaboration between the two organisations. Costello Medical have been a long-term supporter of our work and mission, and their high-quality work, and commitment to professional *pro bono* support have been fundamental to our growth and success in the last few years.

BEACON: FOR RARE DISEASES LTD**REPORT OF THE TRUSTEES**
FOR THE YEAR ENDED 31 JANUARY 2025

STRATEGIC REPORT**Financial review****Financial position**

Beacon has continued in a position of financial stability moving from 2023 to 2024. We end the year with a surplus of £29,318, with income significantly up on the prior financial year (£691,035 versus £523,301) but our highest annual spend (£661,717). This growth is mostly driven by a large in kind contribution in 2024-25. Furthermore, at the close of the year Beacon has an outstanding claim of over £20,000 to the UKRI for two months of work on the REMEDI4ALL project, and £6,471.95 owed for work on the now concluded MCDS-Therapy project (funded by the European Commission). This reflects an even more positive relative financial position for the charity, which is key to maintain our stability and success as we move into the second half of both the REMEDI4ALL project and our Nation Lottery Community Fund grant.

Within this financial year we have secured a new multiyear grant from LifeArc, supporting our role as delivery partner within The LifeArc Translational Centres for Rare Disease Hub. This Hub will act as a supportive function between four distinct UK rare disease translational research centres (working in rare kidney disease, rare respiratory disease, rare mitochondrial disease, and the acceleration of clinical trials) encouraging collaboration, and driving forward PPIE, training, and communication efforts. Our grant was initially secured in September 2024 for a two-year period with a value of £113,546.08 and £99,337.68 in years one and two respectively. Excitingly the grant has the potential to extend for a further three years, supporting Beacon's work on the program until September 2030. At this stage the first six months of funding have been delivered to Beacon. Combined with our REMEDI4ALL grant (running until September 2027) and National Lottery grant (running until April 2026) we now hold three long term funds to support the core of our work, and stabilizing our long-term work and impact. This further strengthens our financial position; however, it is worth noting that despite this significant income boost from the LifeArc grant, Beacon's annual income is marginally down on the previous financial year. Rather than supplementing existing funding streams, our LifeArc funding has effectively replaced a funding drop off in other areas – most notably a decline in overall grant funding.

As noted last year, beginning new grants comes with an increase in operational costs. This paired with continued inflation, wage growth, national insurance increases, and the challenging fundraising environment all mean that we need to remain active and driven in developing our fundraising pipeline. Corporate fundraising has proven particularly challenging in the last year. We have developed a new fundraising strategy in the last year and are working to identify new fundraising pathways and services to support Beacon's work in the long term.

Principal funding sources

The principal funding source in this period was grant funding from the UKRI to support our work on the REMEDI4ALL project. This grant is paid in arrears, with payments to Beacon during this period covering work from December 2023 to November 2024 and totaling £157,773.04. The National Lottery Community Fund provided significant support for our Empowerment Program. This funding totaled £136,710.72, equating to payments for the second year of the project. We also secured a £20,000 grant from the National Lottery Awards for All scheme to support our Rare Disease Showcase Series. The LifeArc Translational Centres for Rare Diseases Grant provided payments for work between September 2024 and the end of February 2025 totaling £56,773.04. These major grant payments were supplemented by a further £3,156.32 from the EveryLife Foundation, a grant of £2,000 for our supporting work in the RareCare Project and £68,679.99 in corporate grants. Our major corporate grant supporters included Orchard Therapeutics (£5,000 grant for the Empowerment Program), Amicus Therapeutics (£5,000 grant for the Empowerment Program), Alexion (£13,500 grant funding for the Empowerment Program), Takeda (£10,000 grant for core costs), Vertex Pharmaceuticals (£15,000 grant for the Empowerment Program) and Pharming (£19,179.99 grant for our Advanced Therapies training within the Empowerment Program). We also received corporate donations worth £5,053.55, all through our long-term supporter Whiskers LLP.

Our community events generated a further £34,000 in sponsorships, covering the Rare Disease Showcase Series, International Drug Repurposing Conference, and Rarely Heard Podcast. This included contributions from Bionical, Healx, LifeArc, and Alexion.

Overall, we have seen a growth in corporate grants as compared to last year (reaching £68,679.99 from £36,648), though the absolute level of funding remains below our aspirations. Our sponsorship level was marginally down on 2023-24 and was mostly driven by our podcast project (which will be delivered in over the course of 2025). Clearly our long-term grants are central to Beacon's financial model, though both the REMEDI4ALL and Community Fund grants delivered a lower pre-planned level of income this year than last.

BEACON: FOR RARE DISEASES LTD**REPORT OF THE TRUSTEES**
FOR THE YEAR ENDED 31 JANUARY 2025

STRATEGIC REPORT**Financial Reserves****Policy & review**

At any time, the charity aims to maintain reserves of sufficient levels to meet its contractual obligations for three months. This is through a combination of unrestricted and restricted funding to pay overheads and fulfil grant requirements. At the end of the reporting period, the charity holds £221,671 (2024: £191,913) of which £152,646 (2024: £116,718) is in restricted funds, and £69,025 (2024: £75,195) is in unrestricted funds. The general unrestricted funds, which the Trustees have not designated, of £67,966 (2024: £74,613) are below the cost of maintaining our staff team for three months (a little over £100,000) but does exclude the significant restricted funds held for salaries and overheads.

The restricted funds carried forward are committed to be spent in 2025 on the charity's projects and overheads, including: on-going delivery of the Empowerment Program; support for LifeArc's drug repurposing toolkit; the delivery of Beacon's work on the LifeArc Hub for the Translational Research Centres for Rare Disease; and delivery of the Rarely Heard Podcast series. Note that at the close of the financial year over £20,000 has been allocated to the UKRI R4A core fund (designated for the salary costs associated with the delivery of the REMEDI4ALL project) all of which will be reclaimed from the UKRI in the coming months and further strengthens our financial position.

Going concern

The trustees believe that the Charity has sufficient funding in place to continue for at least the next 12 months, and the accounts have therefore been prepared on a going concern basis.

Future plans

Looking ahead to 2025, we have a few crucial requirements both for our projects and as an organisation:

1. Deliver our first live training events for the REMEDI4ALL consortium, including our Academic Bootcamp, Patient Bootcamp, Hackathon, and Clinical trials webinar series
2. Develop our patient engagement group for the LifeArc Hub project and a detailed training plan for the project.
3. Deliver the iDR25 conference and develop a more streamlined delivery model for iDR26.
4. Develop new funding streams for Beacon, whether new international projects, or new long-term grants to replace the National Lottery Community Fund for the Empowerment Program which will expire in early 2026.
5. Increase our efforts to connect with the UK pharmaceutical industry in order to increase the corporate funding available for our core training programs.
6. The delivery of a daylong Showcase event.
7. Restructuring our internal teams to limit the separation of the science and project teams, allowing the more effective use of our internal expertise across our workstreams and projects.
8. Recruitment of new trustees to grow our board and develop our governance.

As a charity, we are now well regarded in both the UK rare disease ecosystem and the global repurposing environment. This helps us to unlock connections and opportunities for our core patient group beneficiaries. We need to use this position in 2025 to the benefit of our groups, helping to drive patient engagement in rare disease research, and the repurposing of therapies for rare and ultrarare conditions. Furthermore, we plan to use this network to recruit new Trustees to support our existing board. Here we aim to increase the lived experience in the governance of the charity, improve the financial management and oversight of the organisation, and broaden our network to unlock new fundraising opportunities.

BEACON: FOR RARE DISEASES LTD

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2025

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

The charity's objects, as set out in its Articles of Association, are:

- 1 To advance the education of the general public in all areas relating to fundamental diseases and their causes, effects and treatments;
- 2 To promote and protect the physical and mental health of sufferers of fundamental diseases and their carers through the provision of support, education and practical advice;
- 3 To support research into the causes, effects, treatment and management of fundamental diseases and their application to common diseases, and disseminate the useful results thereof.

Since the drafting of the objects the term "fundamental diseases" has been reconsidered and the term "rare diseases" is used in its place.

Charity Constitution

The constitutional provisions relating to appointment and removal of trustees are:

- There should be a minimum of 3 trustees but no maximum.
- Appointment is by Ordinary Resolution
- A third of trustees retire by rotation at each AGM, but may be re-elected.

Trustees cease to hold office if:

- They cease to be a director by virtue of any provision in the Companies Acts or is prohibited by law from being a director
- They are disqualified from acting as a trustee by virtue of sections 178 and 179 of the Charities Act 2011;
- If they cease to be a member of the charity
- If they become incapable by reason of mental disorder, illness or injury of managing and administering their own affairs
- If they resign as a director by notice to the charity (as long as at least two directors will remain in office when the notice takes effect);
- If they are absent without the permission of the directors from all their meetings held within a period of 6 consecutive months and the directors resolve that his or her office be vacated.

Recruitment and appointment of new trustees

Our trustee recruitment process aims to identify candidates with new skills and experience needed for the organisation, and to find candidates with a desire to support our mission. We have a job specification prepared for the role, which is reviewed whenever we need to seek new trustee appointments. Shortlisted applicants are interviewed first over the phone, before face-to-face interviews with the CEO and existing board members. Successful candidates are invited to attend a board meeting before formally accepting the position of trustee, and appointment at the next board meeting.

In November 2024 Beacon's long-time Chair of Trustees and Co-Founder Nick Sireau stepped down from the board. Nick's experience as a parent to two children with a rare disease, as a patient group CEO, and in driving forward a drug repurposing project, has been central to Beacon's journey and mission. His dedication to the rare disease community has been unwavering since our inception, and the whole board and team want to put on record our thanks to him for his work and support. Following Nick's resignation, Sophie Costello was unanimously elected to the position of Chair of Trustees.

BEACON: FOR RARE DISEASES LTD**REPORT OF THE TRUSTEES**
FOR THE YEAR ENDED 31 JANUARY 2025

STRUCTURE, GOVERNANCE AND MANAGEMENT**Organisational structure**

As of November 2024 Beacon has five governing trustees, who meet on a quarterly basis with the Chief Executive Officer (CEO) to discuss the charity's activities and impact. The CEO is the most senior management personnel, and line manages three members of staff: The Chief Operating Officer (COO), Fundraising Manager, and Scientific Projects Manager. The COO line manages our Projects Manager, Digital Resources Manager, and Operations Officer. Our Scientific Projects Manager manages our Senior Scientific Projects Officer and Project Officer, while our Fundraising Manager line manages our Senior Fundraising Officer and Communications Officer. Our Projects Manager manages our Events Officer. All staff members perform ad hoc volunteer management, though this is led by our Digital Resources Manager.

The CEO and COO take advice on rare disease patient empowerment from the Patient Engagement Committee, which comprises of seven advisors. This Committee serves for two years before applications are opened for reappointments and new members, with a majority of advisors having a personal experience of a rare disease.

The trustees delegate day-to-day management of the charity to the CEO. They take legal advice from Hogan Lovells and White & Case, and financial advice from Archangel Accounting Limited.

Decision making

As the responsible managing body for the charity, the board of trustees make decisions on the strategic direction for the charity, as well as decisions relating to significant financial commitments and the hiring of new staff, all in conjunction with the CEO. Operational matters are delegated to staff, with the COO taking and increasing lead in the day-to-day management and administration of the charity. The trustees are kept abreast of developments through monthly updates with the chair of trustees and quarterly trustee meetings.

Induction and training of new trustees

New trustees follow an induction programme to ensure they integrate effectively into the board. They receive an induction pack which contains the charity's governing document, accounts, key policies, strategic plan, overview of the charity's history and ethos, and guiding documents from the Charity Commission on being a trustee. The new trustee then meets individually with all fellow board members and the CEO. They are also introduced to the staff and volunteers to gain a full understanding of the charity and its people.

Key management remuneration

In the fourth quarter of the year, the CEO prepares the budget for the coming year based on secured and projected income. As this time, provisional salaries for the year are calculated, taking performance, inflation rates, and the available budget into consideration. The CEO compiles a business plan for any salary changes, which is put to the board for a unified decision on remuneration.

Wider network

Beacon is a member of Rare Disease International, a global alliance of people living with a rare disease, as well as a member of Rare Disease UK, Genetic Alliance UK, Rare Revolution Magazine, The Cambridge Network, and an associate member of EURORDIS Rare Diseases Europe. Involvement in these networks builds the charity's reputation and allows Beacon to contribute to international efforts to support rare diseases. Membership in EURORDIS requires Beacon to remain financially independent, particularly from the pharmaceutical industry, limiting pharma funding to a maximum of 50% of the charity's revenue. Beacon is also registered with the Fundraising Regulator and as such is committed to best practice in fundraising.

Beacon is part of the REMEDi4ALL consortium, an international collaboration to drive the repurposing of medicines by developing a platform for any project across Europe. We are also a member of the LifeArc Rare Disease Translational Centres for Rare Disease Hub, where we work alongside LifeArc and Genetic Alliance UK to support patient engagement and training in rare disease research across four dedicated research centres in the UK.

Related parties

There are no material related party transactions which were not concluded under normal market conditions.

BEACON: FOR RARE DISEASES LTD**REPORT OF THE TRUSTEES**
FOR THE YEAR ENDED 31 JANUARY 2025

STRUCTURE, GOVERNANCE AND MANAGEMENT**Risk management**

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

The trustees compile a risk register and monitor it on an annual basis to ensure all potential risks are identified and strategies are put in place to manage them. The principal internal risks identified are having insufficient funding to fulfil charitable aims and the potential for fraud. To mitigate insufficient funding, the CEO draws up an annual cash flow forecast to map guaranteed and projected income for the year. This is then monitored on a monthly basis to identify potential shortfalls of funding and guide fundraising strategy. In periods where cash flow is critical, an Executive Committee for Cash Flow formed of three trustees and the CEO monitors cash flow on a weekly basis to ensure continuation of the charity's activities. The trustees and staff aim to diversify the charity's funding portfolio to ensure no one fund is overly relied upon. The charity has recently moved to a new accountant and will be reviewing financial processes and support over the course of the coming financial year, as well as looking to appoint a dedicated treasurer to support his oversight.

Having secured a three-year Community Fund grant in 2023, the REMEDi4ALL consortium in 2022, and with the new LifeArc grant in 2024, a large proportion of our income is now derived from grant funding. To fund our outstanding costs, we are using a mixture of corporate grants, corporate sponsorship, and small trust and foundation applications. This strategy has proved successful, though corporate funding is clearly in decline, and increasingly hard to secure for the organization. Regardless, Beacon has a diverse range of funding sources and grant durations at the present time, and has maintained its income from the previous year. Community fundraising remains a very small source of income for the organisation and remains a low priority. Beacon fundamentally lacks an active base of supporters and donors, as our core beneficiaries are themselves directly involved with small charities. We do, however, continue to see success in securing unrestricted corporate donations. These are often developing into partnerships between companies keen to support our work from a corporate social responsibility perspective. This access to both funding and expertise is proving greatly beneficial to our financial security and flexibility.

To mitigate the risk of fraud, the charity employs an independent bookkeeper who monitors expenses monthly and requires receipts for all expenditure. The charity bank account is backed by several layers of security to ensure only selected senior staff (specifically the CEO and limited access for the COO) can access accounts. All cheques and bank withdrawals require at least two account signatories present, while access to our Community Fund holding account requires all transactions to be authorised by two approved individuals. Furthermore, there are internal systems in place which require large payments to receive approval from at least two signatories of the account. The trustees believe that these strategies have greatly reduced the possibility and impact of these internal risks.

The principal external risk to Beacon is the failure to deliver its commitments to the REMEDi4ALL and LifeArc projects, thus jeopardising long-term funding streams, and potential impact for the charity. This has been well mitigated to date, by building and developing a "science" team dedicated to the delivery of these key projects and developing strong collaborative working practices with project partners. We retain very close working relationships with the EURORDIS team dedicated to REMEDi4ALL, allowing us to share workload and smooth out any resource challenges. Both projects are well managed centrally, with well-managed and defined reporting requirements and interaction with all partners. Beacon's CEO took part in the first project monitoring meeting with the European Commission at the end of the first year of the REMEDi4LL project, which received very positive feedback, and we continue to hold a central position within the project Steering Committee. Though early in development, we have established positive working relationships with both Genetic Alliance UK and LifeArc in the Hib project and are optimistic for similar level of collaboration in this program.

The second external risk identified is public backlash against the charity's work. To ensure that public trust is not lost, the charity is transparent about its work, also maintaining ongoing evaluations of projects to monitor impact. Ongoing work at the charity is shared in weekly blogs and summed up in annual impact reports, which are shared on the website and at events. The Patient Group Engagement Committee was established to allow rare disease advocates independent input on the development and evaluation of projects. They also bring additional rare disease patient and carer perspectives to the charity, in order to ensure our activities, continue to meet the needs of our beneficiaries.

BEACON: FOR RARE DISEASES LTD

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2025

STRUCTURE, GOVERNANCE AND MANAGEMENT

A growing risk to the charity is the risk posed by the loss of staff members. The ever-increasing cost of living has driven up wages – in particular the real living wage which is our base-line target as an employer, making it harder for a small charity to sustain competitive salaries and both attract and retain talented staff. The loss of staff members is clearly difficult in any small team. It increases the challenge of delivering our growing contractual obligations but also removes vital expertise and experience from the team. Beacon has improved our project planning processes to mitigate this and also worked to implement a program of wage growth within the team. This has been paired with the exploration of new staff incentives. This work needs to continue over the coming year, alongside work to streamline our recruitment and onboarding process. This is particularly crucial as Beacon’s model is always likely to rely on hiring a core of staff early in their careers who are looking to explore the charity sector and implement life science skills outside of the laboratory setting. Such an approach will always come with the risk of higher staff turnover, which we must work to manage.

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

Report of the trustees, incorporating a strategic report, approved by order of the board of trustees, as the company directors, on 28th October 2025 and signed on the board's behalf by:

DocuSigned by:

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Sophie Costello - Trustee

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
BEACON: FOR RARE DISEASES LTD**

Independent examiner's report to the trustees of Beacon: For Rare Diseases Ltd ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 January 2025.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts 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 your 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

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales, which is one of the listed bodies.

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 Company as required by Section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts 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 accounts 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.

DocuSigned by:

Julia Jones

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Julia Jones FCA
Archangel Accounting
Burnham House
Splash Lane
Wyton
Huntingdon
PE28 2AF

Date: 28th October 2025

BEACON: FOR RARE DISEASES LTD**STATEMENT OF FINANCIAL ACTIVITIES**
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 JANUARY 2025

	Notes	Unrestricted funds £	Restricted funds £	2025 Total funds £	2024 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	3	204,234	59,516	263,750	121,177
Charitable activities					
Patient Support	4	4,827	422,458	427,285	402,124
Total		<u>209,061</u>	<u>481,974</u>	<u>691,035</u>	<u>523,301</u>
EXPENDITURE ON					
Raising funds	5	-	52,264	52,264	41,052
Charitable activities					
Patient Support	6	190,452	419,000	609,453	437,776
Total		<u>190,452</u>	<u>471,264</u>	<u>661,717</u>	<u>478,828</u>
NET INCOME/(EXPENDITURE)					
Transfers between funds	16	18,609	10,709	29,318	44,473
		<u>(25,255)</u>	<u>25,255</u>	<u>-</u>	<u>-</u>
Net movement in funds		<u>(6,647)</u>	<u>35,965</u>	<u>29,318</u>	<u>44,473</u>
RECONCILIATION OF FUNDS					
Total funds brought forward		74,613	116,871	191,484	147,011
TOTAL FUNDS CARRIED FORWARD		<u><u>67,966</u></u>	<u><u>152,836</u></u>	<u><u>220,802</u></u>	<u><u>191,484</u></u>

The notes form part of these financial statements

BEACON: FOR RARE DISEASES LTD (REGISTERED NUMBER: 08174973)**BALANCE SHEET**
31 JANUARY 2025

	Notes	Unrestricted funds £	Restricted funds £	2025 Total funds £	2024 Total funds £
FIXED ASSETS					
Tangible assets	13	3,741	-	3,741	4,012
CURRENT ASSETS					
Debtors	14	-	231	231	359
Cash at bank		69,025	152,646	221,671	191,913
		<u>69,025</u>	<u>152,877</u>	<u>221,902</u>	<u>192,272</u>
CREDITORS					
Amounts falling due within one year	15	(4,800)	(40)	(4,840)	(4,800)
		<u>64,225</u>	<u>152,836</u>	<u>217,061</u>	<u>187,472</u>
NET CURRENT ASSETS					
TOTAL ASSETS LESS CURRENT LIABILITIES					
		<u>67,966</u>	<u>152,836</u>	<u>220,802</u>	<u>191,484</u>
NET ASSETS					
		<u><u>67,966</u></u>	<u><u>152,836</u></u>	<u><u>220,802</u></u>	<u><u>191,484</u></u>
FUNDS					
Unrestricted funds	16			67,966	74,613
Restricted funds				152,836	116,871
TOTAL FUNDS					
				<u><u>220,802</u></u>	<u><u>191,484</u></u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 January 2025.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 January 2025 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

BEACON: FOR RARE DISEASES LTD (REGISTERED NUMBER: 08174973)

BALANCE SHEET - continued
31 JANUARY 2025

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

The financial statements were approved by the Board of Trustees and authorised for issue on 28th October 2025 and were signed on its behalf by:

DocuSigned by:

Sophie Costello
D28DE01B9D65405:.....
Sophie Costello - Trustee

BEACON: FOR RARE DISEASES LTD**CASH FLOW STATEMENT**
FOR THE YEAR ENDED 31 JANUARY 2025

	Notes	2025 £	2024 £
Cash flows from operating activities			
Cash generated from operations	1	33,689	48,403
Net cash provided by/(used in) operating activities		<u>33,689</u>	<u>48,403</u>
Cash flows from investing activities			
Purchase of tangible fixed assets		(3,931)	(3,361)
Net cash used in investing activities		<u>(3,931)</u>	<u>(3,361)</u>
Change in cash and cash equivalents in the reporting period			
Cash and cash equivalents at the beginning of the reporting period		<u>191,913</u>	<u>146,871</u>
Cash and cash equivalents at the end of the reporting period		<u><u>221,671</u></u>	<u><u>191,913</u></u>

The notes form part of these financial statements

BEACON: FOR RARE DISEASES LTD**NOTES TO THE CASH FLOW STATEMENT**
FOR THE YEAR ENDED 31 JANUARY 2025**1. RECONCILIATION OF NET INCOME/(EXPENDITURE) TO NET CASH FLOW FROM OPERATING ACTIVITIES**

	2025 £	2024 £
Net income/(expenditure) for the reporting period (as per the		
Statement of Financial Activities)	29,318	44,473
Adjustments for:		
Depreciation charges	4,202	3,524
Decrease/(increase) in debtors	129	48
Increase in creditors	40	358
Net cash provided by/(used in) operations	<u>33,689</u>	<u>48,403</u>

2. ANALYSIS OF CHANGES IN NET FUNDS

	At 1/2/24 £	Cash flow £	At 31/1/25 £
Net cash			
Cash at bank	191,913	29,758	221,671
	<u>191,913</u>	<u>29,758</u>	<u>221,671</u>
Total	<u>191,913</u>	<u>29,758</u>	<u>221,671</u>

BEACON: FOR RARE DISEASES LTD**NOTES TO THE FINANCIAL STATEMENTS**
FOR THE YEAR ENDED 31 JANUARY 2025

1. LEGAL FORM

The charity is a registered charity registered in England and Wales number 1149646 and a company limited by guarantee number 08174973 having no share capital incorporated in England and Wales.

Its registered office and principal place of business is at 66 Devonshire Road, Cambridge, CB1 2BL.

2. ACCOUNTING POLICIES**Basis of preparing the financial statements**

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

Going Concern Basis

The Trustees consider that the going concern basis is appropriate as they consider the reserves levels and secured funding to be at sufficient levels to ensure that the charity can meet its financial obligations for the next 12 to 18 months and on that basis the charity is a going concern.

Reconciliation with previous Generally Accepted Accounting Practice

In preparing the accounts, the trustees have considered whether in applying the accounting policies required by FRS102 and the Charities SORP FRS 102 the restatement of comparative items was required. None were required.

Significant judgements

Apart from those judgements involving estimations, the management has not made any judgements in the process of applying the entity's accounting policies that have significant effect on the amounts recognised in the accounts. There are no key assumptions concerning the future or other key sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next reporting period

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Income from government and other grants is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

Donated services and facilities

Donated professional services are recognised as income when the charity has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use by the charity is probable and that economic benefit can be measured reliably. On receipt, donated professional services are recognised on the basis of the value of the gift to the charity which is the amount the charity would have been willing to pay to obtain services of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

BEACON: FOR RARE DISEASES LTD**NOTES TO THE FINANCIAL STATEMENTS - continued**
FOR THE YEAR ENDED 31 JANUARY 2025

2. ACCOUNTING POLICIES - continued**Expenditure**

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Charitable activities

The trustees are of the view that the charity has one main activity - that of the provision of patient support. Charitable activity costs have therefore been allocated to this activity.

Tangible fixed assets

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

Plant and machinery - 33% on cost

Expenditure on capital items in excess of £500 is capitalised and written off over the estimated useful economic life.

Taxation

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

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Pension costs and other post-retirement benefits

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

Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments and accrued income are recognised at the amount prepaid or accrued net of any trade discounts due.

Cash at bank and in hand

Cash at bank and in hand includes cash and short term highly liquid investments with a maturity of 3 months or less from the date of acquisition or opening of the deposit.

Creditors

Creditors are recognised when the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

BEACON: FOR RARE DISEASES LTD**NOTES TO THE FINANCIAL STATEMENTS - continued**
FOR THE YEAR ENDED 31 JANUARY 2025**3. DONATIONS AND LEGACIES**

	2025	2024
	£	£
Donations	25,794	8,154
Admissions	2,548	7,464
Donated services and facilities	184,021	57,059
Sponsorship	51,387	48,500
	<u>263,750</u>	<u>121,177</u>

Donated services and facilities:

<u>Donor</u>	<u>Service donated</u>	<u>2025</u>	<u>2024</u>
Consultancy			
Costello Medical	Online training modules, video production, event support, and	184,021	38,609
Consulting	graphic design work		
Intent Health	Messaging workshop, development of a communications strategy toolkit and ad-hoc strategic counsel.	-	18,450
		<u>184,021</u>	<u>57,059</u>

4. INCOME FROM CHARITABLE ACTIVITIES

	2025	2024
	£	£
Grants	427,285	402,124
	<u>427,285</u>	<u>402,124</u>

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

	2025	2024
	£	£
Consilium Scientific	2,000	-
Amicus Therapeutics	5,000	-
Pharming Technologies BV	19,180	-
EveryLife Foundation	3,156	-
Alexion	25,500	-
Takeda	10,000	-
National Lottery Community Fund	136,711	152,461
LifeArc	28,387	-
Amicus Therapeutics	-	5,000
Illumina	-	19,648
Awards for All	20,000	10,000
Vertex Pharmaceuticals	15,000	-
Alan Boswell Group Charitable Trust	-	11,686
Innovate UK	157,351	181,330
Envision Hope Foundation	-	12,000
Orchard Therapeutics	5,000	9,999
	<u>427,285</u>	<u>402,124</u>

BEACON: FOR RARE DISEASES LTD**NOTES TO THE FINANCIAL STATEMENTS - continued**
FOR THE YEAR ENDED 31 JANUARY 2025**5. RAISING FUNDS****Raising donations and legacies**

	2025	2024
	£	£
Staff costs	52,264	16,327
Entrance fees	-	-
	<u>52,264</u>	<u>16,327</u>

Other trading activities

	2025	2024
	£	£
Event costs	-	24,725
	<u>-</u>	<u>24,725</u>
Aggregate amounts	<u>52,264</u>	<u>41,052</u>

6. CHARITABLE ACTIVITIES COSTS

	Direct Costs (see note 7)	Support costs (see note 8)	Totals
	£	£	£
Patient Support	<u>608,673</u>	<u>780</u>	<u>609,453</u>

7. DIRECT COSTS OF CHARITABLE ACTIVITIES

	2025	2024
	£	£
Staff costs	308,444	292,020
Insurance	426	302
Postage and stationery	2,543	2,330
Advertising	289	839
Training	17,897	15,650
General expenses	7,646	8,855
Travel	11,926	12,573
IT Costs	18,389	9,798
Rent and venue costs	46,201	24,475
Recruitment costs	484	3,274
Consultancy	184,540	58,709
Donations	75	50
Repairs and maintenance	214	2
Telephone	82	-
Bank charges	516	-
Accountancy	4,799	-
Depreciation	4,202	3,524
	<u>608,673</u>	<u>432,401</u>

BEACON: FOR RARE DISEASES LTD**NOTES TO THE FINANCIAL STATEMENTS - continued**
FOR THE YEAR ENDED 31 JANUARY 2025**8. SUPPORT COSTS**

	Management	Finance	Governance	Totals
	£	£	costs	£
	£	£	£	£
Patient travel support	-	780	-	780
	<u> </u>	<u> </u>	<u> </u>	<u> </u>

9. NET INCOME/(EXPENDITURE)

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

	2025	2024
	£	£
Depreciation - owned assets	4,202	3,524
	<u> </u>	<u> </u>

10. TRUSTEES' REMUNERATION AND BENEFITS

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

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 January 2025 nor for the year ended 31 January 2024.

11. STAFF COSTS

	2025	2024
	£	£
Wages and salaries	314,547	267,975
Social security costs	30,184	20,095
Other pension costs	15,977	20,277
	<u> </u>	<u> </u>
	<u>360,708</u>	<u>308,347</u>

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

	2025	2024
CEO	1	1
COO	1	1
Other Officers	9	8
	<u> </u>	<u> </u>
	<u>11</u>	<u>10</u>

No employees received emoluments in excess of £60,000.

Total employee benefit cost in the year relating to Key Management Personnel totalled £100,449 (2024: £50,608).

BEACON: FOR RARE DISEASES LTD**NOTES TO THE FINANCIAL STATEMENTS - continued**
FOR THE YEAR ENDED 31 JANUARY 2025**12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES**

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	100,995	20,182	121,177
Charitable activities			
Patient Support	62,091	340,033	402,124
Total	<u>163,086</u>	<u>360,215</u>	<u>523,301</u>
EXPENDITURE ON			
Raising funds	22,171	18,881	41,052
Charitable activities			
Patient Support	176,549	261,227	437,776
Total	<u>198,720</u>	<u>280,108</u>	<u>478,828</u>
NET INCOME/(EXPENDITURE)	(35,634)	80,107	44,473
Transfers between funds	<u>(1,377)</u>	<u>1,377</u>	<u>-</u>
Net movement in funds	(37,011)	81,484	44,473
RECONCILIATION OF FUNDS			
Total funds brought forward	111,624	35,387	147,011
TOTAL FUNDS CARRIED FORWARD	<u><u>74,613</u></u>	<u><u>116,871</u></u>	<u><u>191,484</u></u>

13. TANGIBLE FIXED ASSETS

	Plant and machinery £
COST	
At 1 February 2024	18,286
Additions	3,931
At 31 January 2025	<u>22,217</u>
DEPRECIATION	
At 1 February 2024	14,274
Charge for year	4,202
At 31 January 2025	<u>18,476</u>
NET BOOK VALUE	
At 31 January 2025	<u><u>3,741</u></u>
At 31 January 2024	<u><u>4,012</u></u>

BEACON: FOR RARE DISEASES LTD**NOTES TO THE FINANCIAL STATEMENTS - continued**
FOR THE YEAR ENDED 31 JANUARY 2025

14. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR		2025	2024	
		£	£	
Prepayments		231	359	
		<u>231</u>	<u>359</u>	
15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR		2025	2024	
		£	£	
Other creditors		-	-	
Accrued expenses		4,840	4,800	
		<u>4,840</u>	<u>4,800</u>	
16. MOVEMENT IN FUNDS				
	At 1/2/24	Net movement in funds	Transfers between funds	At 31/1/25
	£	£	£	£
Unrestricted funds				
General fund	69,960	3,760	(15,907)	57,812
Designated Fixed Asset Fund	651	-	(651)	-
Designated Projects	4,002	14,848	(8,697)	10,153
	<u>74,613</u>	<u>18,608</u>	<u>(25,255)</u>	<u>67,965</u>
Restricted funds				
Core Costs	-	(61,934)	135,712	73,778
Essay Competition	-	(52)	52	-
RD-TRC	-	3,613	-	3,613
E-learning Portal	-	(1,734)	1,734	-
Training Programmes	-	(8,614)	8,614	-
Mentoring	-	(4,525)	4,525	-
Video Transcription	(113)	-	113	-
Conferences	-	(5,487)	7,131	1,644
MCDS EU H2020	18,088	(5,583)	(12,505)	-
Showcases	1,430	5,026	(11)	6,445
Empowerment	79,729	47,201	(84,455)	42,476
Podcast	-	3,708	-	3,708
ReMedi4All	(17,159)	39,091	(21,782)	150
Repurposing	34,896	-	(33,119)	1,777
Additional Overheads	-	-	19,246	19,246
	<u>116,871</u>	<u>10,710</u>	<u>25,255</u>	<u>152,837</u>
TOTAL FUNDS	<u>191,484</u>	<u>29,318</u>	<u>-</u>	<u>220,802</u>

BEACON: FOR RARE DISEASES LTD**NOTES TO THE FINANCIAL STATEMENTS - continued**
FOR THE YEAR ENDED 31 JANUARY 2025**16. MOVEMENT IN FUNDS - continued**

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	194,213	(190,453)	3,760
Designated Fixed Asset Fund	-	-	-
Designated Projects	14,848	-	14,848
	<u>209,061</u>	<u>(190,453)</u>	<u>18,608</u>
Restricted funds			
Core Costs	353,628	(415,563)	(61,935)
Essay Competition	-	(52)	(52)
RD-TRC	3,613	-	3,613
E-learning Portal	-	(1,734)	(1,734)
Training Programmes	-	(8,614)	(8,614)
Mentoring	-	(4,525)	(4,525)
Video Transcription	-	-	-
Conferences	860	(6,347)	(5,487)
MCDS EU H2020	-	(5,583)	(5,583)
Showcases	9,423	(4,397)	5,026
Empowerment	65,520	(18,319)	47,201
Podcast	4,121	(413)	3,708
ReMedi4All	44,809	(5,717)	39,092
Repurposing	-	-	-
Additional Overheads	-	-	-
	<u>481,974</u>	<u>(471,264)</u>	<u>10,710</u>
TOTAL FUNDS	<u>691,035</u>	<u>(661,717)</u>	<u>29,318</u>

BEACON: FOR RARE DISEASES LTD**NOTES TO THE FINANCIAL STATEMENTS - continued**
FOR THE YEAR ENDED 31 JANUARY 2025**16. MOVEMENT IN FUNDS - continued****Comparatives for movement in funds**

	At 1/2/23	Net	Transfers	At
	£	movement	between	31/1/24
		in funds	funds	£
		£	£	
Unrestricted funds				
General fund	34,391	36,946	(1,377)	69,960
Designated Fixed Asset Fund	4,175	(3,524)	-	651
Designated Projects	73,058	(69,056)	-	4,002
	<u>111,624</u>	<u>(35,634)</u>	<u>(1,377)</u>	<u>74,613</u>
Restricted funds				
Essay Competition	-	(252)	252	-
Mentoring	-	(1,765)	1,765	-
Video Transcription	-	(113)	-	(113)
Conferences	(367)	(49)	416	-
MCDS EU H2020	26,617	(8,529)	-	18,088
Showcases	6,000	(4,570)	-	1,430
Empowerment	21,350	60,144	(1,765)	79,729
Podcast	2,342	(3,051)	709	-
ReMedi4All	(55,937)	38,778	-	(17,159)
Repurposing	35,382	(486)	-	34,896
	<u>35,387</u>	<u>80,107</u>	<u>1,377</u>	<u>116,871</u>
TOTAL FUNDS	<u>147,011</u>	<u>44,473</u>	<u>-</u>	<u>191,484</u>

BEACON: FOR RARE DISEASES LTD**NOTES TO THE FINANCIAL STATEMENTS - continued**
FOR THE YEAR ENDED 31 JANUARY 2025**16. MOVEMENT IN FUNDS - continued**

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	159,084	(122,138)	36,946
Designated Fixed Asset Fund	-	(3,524)	(3,524)
Designated Projects	4,002	(73,058)	(69,056)
	<u>163,086</u>	<u>(198,720)</u>	<u>(35,634)</u>
Restricted funds			
Essay Competition	7,500	(7,752)	(252)
Mentoring	-	(1,765)	(1,765)
Video Transcription	-	(113)	(113)
Conferences	(25)	(24)	(49)
MCDS EU H2020	-	(8,529)	(8,529)
Showcases	18,020	(22,590)	(4,570)
Empowerment	164,666	(104,522)	60,144
Podcast	-	(3,051)	(3,051)
ReMedi4All	170,054	(131,276)	38,778
Repurposing	-	(486)	(486)
	<u>360,215</u>	<u>(280,108)</u>	<u>80,107</u>
TOTAL FUNDS	<u>523,301</u>	<u>(478,828)</u>	<u>44,473</u>

Empowerment: Includes lottery funding and corporate funding assigned to the delivery of our patient group empowerment programme.

Core Costs Fund: Funding dedicated to staff costs and overheads from across the charity.

Conferences Fund: Funding secured for our annual drug repurposing conference, Drug Repurposing for Rare Diseases.

Essay Competition: corporate donations to fund prizes, travel and core costs in Beacon's annual essay competition, "The Student Voice Prize" delivered in collaboration with Medics 4 Rare Diseases.

MCDS EU H2020 Grant: Beacon is one of 11 project partners in EU-funded clinical trial testing whether carbamazepine can be repurposed to treat the rare genetic bone disorder, metaphyseal chondrodysplasia type Schmid (MCDS). Money in this fund is assigned to the direct delivery costs for the non-staff costs of the project.

Mentoring: Grant funding specifically assigned to our mentoring programme.

Podcast: Grant funding to support the Podcast project.

BEACON: FOR RARE DISEASES LTD

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 JANUARY 2025

16. MOVEMENT IN FUNDS - continued

ReMEDi4ALL Fund: Grant funding from UKRI as part of a consortium driving forward drug repurposing initiatives by creating an accessible platform that will help guide and educate users involved in the drug repurposing pathway. Money in this fund is assigned exclusively to the non-staff costs of the project.

Repurposing Fund: funding from LifeArc towards the Beacon STEM drug repurposing programme, leading rare disease trials for repurposed drugs.

Showcases Fund: funds raised to deliver Beacon's rare disease showcase series.

Additional Overheads Fund: Holds a reserve of funds dedicated to the delivery of Beacon's work within the REMEDi4ALL consortium.

Designated Funds

Designated Fixed Asset Fund: This represents the net book value of the fixed assets and associated depreciation.

Designated Projects: This represents funds designated by the Trustees to cover the expenditure of projects where restricted funding has not been generated.

RD-TRC: Funding for the delivery of projects and patient focused activities within the LifeArc Translational Centres for Rare Diseases Hub.

E-learning Portal: (Renamed Hub) Funding assigned to the delivery of Beacon's online learning platform, the Resources Hub

Video Transcription: (Should be an empty or closed fund) Funding assigned for the transcription of videos or live Beacon events to improve beneficiary accessibility.

Transfers between funds

Transfers between funds represent the allocation of core funding from within project income and work at the year end to rationalise funds.

17. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 January 2025.

18. INDEPENDENT EXAMINER FEES

Independent examiner fees of £4,000 + VAT were accrued during the year. (2024: £4,000 + VAT).

BEACON: FOR RARE DISEASES LTD

England & Wales - Charity number 1149646

Accounts

REGISTERED COMPANY NUMBER: 08174973 (England and Wales)
REGISTERED CHARITY NUMBER: 1149646

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 JANUARY 2024
FOR
BEACON: FOR RARE DISEASES LTD

Staffords
Chartered Accountants
Unit 1, Cambridge House
Camboro Business Park
Oakington Road, Girton
CAMBRIDGE
Cambridgeshire
CB3 0QH

BEACON: FOR RARE DISEASES LTD

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FOR THE YEAR ENDED 31 JANUARY 2024

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BEACON: FOR RARE DISEASES LTD

REFERENCE AND ADMINISTRATIVE DETAILS
FOR THE YEAR ENDED 31 JANUARY 2024

TRUSTEES	A Hall Chief Medical Officer - Biotech company E Kissmann Strategic Communication Consultant A Milligan Consultant N T Sireau PhD Charity Manager S Costello Company Director J Pisani Management Consultant and NED
REGISTERED OFFICE	66 Devonshire Road CAMBRIDGE Cambridgeshire CB1 2BL
REGISTERED COMPANY NUMBER	08174973 (England and Wales)
REGISTERED CHARITY NUMBER	1149646
INDEPENDENT EXAMINER	Staffords Chartered Accountants Unit 1, Cambridge House Camboro Business Park Oakington Road, Girton CAMBRIDGE Cambridgeshire CB3 0QH

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2024

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 January 2024. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

Beacon: for rare diseases (hereafter Beacon, and formerly Findacure) aims to transform the way the world views rare diseases. We affect the lives of people with rare diseases and accelerate change in the field by:

- Working directly with patient groups to professionalise their work for impactful results, and build their reputation as the experts in their specific conditions.
- Building a rare disease community that supports, informs, collaborates and advocates for the improvement of all rare conditions.

Significant activities

About fundamental diseases

In the UK and EU, a rare disease is defined as a condition that affects fewer than 1 in 2,000 people. Currently, more than 7,000 rare diseases have been identified, which collectively affect 3.5 million people in the UK. Despite their collective prevalence, each individual condition relates to so few people that they tend to be overlooked by doctors, researchers, and the general public. As a result, living with a rare disease can be incredibly isolating; people can be kept from education, work, and their communities. As only 5% of rare diseases have a treatment, many rare disease patients are left with debilitating and degenerative conditions, with little hope for a cure or a modicum of normal living.

This neglect of rare conditions has gone on for too long. Disease prevalence should not be the sole criterion for judging the importance or impact of a condition. The trustees believe that the research into even the rarest of diseases can benefit us all, since many rare genetic diseases can be viewed as templates for more common ones or teach us a great deal about the fundamentals of human biology. Under the informal banner of Rare is Fundamental, we believe that improving our knowledge of the exceptional conditions will accelerate the identification of treatments for many conditions and the growing knowledge about the way the body functions. Rare diseases are also often at the forefront of new developments in genetic medicine; gene therapies have almost exclusively been developed in this field. Despite this, rare diseases still receive little attention and funding from the research community. They are also significantly less interesting to policy makers and rarely form part of medical training.

Those living with a rare condition are the true experts in their rare disease. They possess valuable insight into the disease's progression and have first-hand experience of symptom management. Above all, they are critical to any pursuit of treatment and have the drive to deliver improved care for themselves. They represent the patient's voice; they understand patient needs for therapy and treatments. As a result, they are a key partner in patient care and research development. They are increasingly being recognised as a key partner by the pharmaceutical industry.

Beacon helps patient groups to form, grow and professionalise. Through our projects, we are building a community of rare disease patient groups that has the skills and knowledge needed to better support patients, campaign for equal opportunities and drive research. We are committed to helping patient groups learn from one another; and to feel confident in engaging with researchers, pharma, and clinicians on a level footing. A unified rare disease community works much more effectively than each patient group on its own. Alongside the patient empowerment projects, Beacon works to encourage collaborative research into rare diseases by running multi-sector events, such as our annual conference and showcases, which bring patients, clinicians, researchers, and industry together. Beacon also plays a central role in the promotion and development of drug repurposing for rare diseases, primarily through our position within the EC funded consortium, REMEDi4ALL.

BEACON: FOR RARE DISEASES LTD

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2024

OBJECTIVES AND ACTIVITIES

Public benefit

The trustees have complied with Section 17(5) of the Charities Act 2011 and have had due regard to the guidance on Public Benefit by the Charity Commission when exercising relevant powers and duties. See "About Fundamental Diseases" section for details of how the charity provides public benefit.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2024

STRATEGIC REPORT

Achievement and performance

Charitable activities

Beacon's core aim is to provide support, guidance and connections to the rare disease patient group community. We help them achieve their goals (usually in the areas of patient support, research, and advocacy) and share their experiences so that all can learn from one another. This year has seen the achievement of several notable milestones for the charity's core projects, including our largest ever Cambridge Showcase, and the biggest turn out to an in-person event at the London Showcase. Our online Resources Hub experienced rapid growth, reaching over 280 users and significantly improving our e-learning offering. We also had over 100 entries for The Student Voice Prize from more countries than ever before, with an impressively high standard of writing. These accomplishments underscore Beacon's commitment to building the rare disease community; actively establishing a collaborative network across sectors and bringing together patient groups, industry, medics and life scientists to deliver change for those affected by rare diseases.

Alongside these hallmarks of our growing reach and impact, 2023/24 has also been marked by improved financial security, with the award of a new three-year grant to support our Empowerment Programme from the National Lottery Reaching Communities Fund, sitting alongside our newly established five-year grant from the UKRI Horizon Guarantee Fund for REMEDI4ALL.

REMEDI4ALL

REMEDI4ALL champions drug repurposing and the necessity of delivering patient impact in repurposing research. Beacon's first complete year of work within this EC-funded consortium, has been one of huge positivity. We are joint leads on both Training (WP3) and Patient Engagement (WP1) work packages, alongside EURORDIS. Over the last year Beacon has been heavily involved in all aspects of the project, helping to bring patient input to three different repurposing research programmes, developing patient engagement protocols for the consortium, developing a training landscape map for drug repurposing, conducting research on diverse community training needs, and establishing a detailed drug repurposing training curriculum. The team have worked exceptionally closely with EURORDIS in delivering this work and played a key role in developing new international partnerships for the consortium, including with LifeArc and UCL in the UK.

MCDS-Therapy

In parallel to REMEDI4ALL, our long-term EU funded project, MCDS-Therapy, also continued throughout 2023, following the agreement of an 18-month project extension with the EU. Beacon continues to lead the communication and outreach for the project. The MCDS-Therapy clinical trial closed at the end of January 2024, so we are now leading the planning for the conference to close the project. This will be held in Newcastle in May 2024, and will represent our first hybrid event as a charity.

Conferences and Showcase Events

Given the close collaboration with REMEDI4ALL, the success of our work to date, and the shared mission to promote drug repurposing and patient-led innovation, Beacon has decided to collaborate with REMEDI4ALL in the delivery of a new International Drug Repurposing Conference, which will incorporate Beacon's established conference - Drug Repurposing for Rare Diseases (#iDR24). Consequently, we did not deliver this conference in 2023, with efforts diverted to the planning and delivery of this new event, to be held in Barcelona in March 2024. This represents a significant collaborative effort for the team, and a unique opportunity to widen the knowledge of drug repurposing for rare disease beyond the UK.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2024

While Beacon did not run a conference in 2023, we have had significant success with our Showcase events. As noted, we delivered two Showcase events in 2023 - The Cambridge and London Rare Disease Showcases - and both had landmark attendances. Our Cambridge evening networking event, running since 2015, saw 90 delegates in attendance, with six lightning talks presented across the evening. These included presentations from three other charities in the rare disease space, alongside a clinician, life science consultant, and biotech entrepreneur. The London Rare Disease Showcase, held in November 2023, was a day-long rare disease conference with our biggest ever in-person attendance of 185 delegates. The day featured a full programme of talks, including topics of significant impact to the delivery of rare disease service across the UK: talks on rare disease policy from Genetic Alliance UK, on research networks and funding from LifeArc and the Medical Research Council, and a detailed panel discussion on the challenges of effective industry-patient group collaboration (including speakers from the PMCPA and ABPI). This type of programme highlights Beacon's growing impact in the UK rare disease landscape, and our ability to bring together key decision-makers and actors in the space. Of course, this only delivers true impact if patient groups are part of that environment, and we were proud to feature the work of The Sickle Cell Society in our programme, alongside talks from three patient advocates and three further patient group leaders. We believe the Rare Disease Showcase series fulfils an important and unique niche in the rare disease space and are thrilled to see its growth and impact.

Empowerment programme

As mentioned, securing a new grant from The National Lottery to support our empowerment programme was another big landmark in 2023. This has helped us kick-start the community engagement with the Resources Hub (launched in 2022) by appointing a dedicated manager. The growth of the Hub since they took official charge has been impressive, with over 289 users at year end, the development of 3 new training courses, 5 on-demand recordings and many more in the works. Our initial focus was structural, improving the back-end functionality, standardising formatting, and building accessibility, before beginning a programme of new content launches and communication. Based on this strong foundation, the Hub is primed to form the digital home of Beacon's training offering and a gateway to the charity. Alongside this on-demand training offering, we have continued our live training events. We were able to return to in-person events, through our "Delving into digital fundraising" workshop held in London. Furthermore, we delivered an impressive programme of ten webinars, two masterclasses, an online workshop and the continuation of our peer mentoring programme. This diversity of delivery methods is now key to our strategy, ensuring that there is a form of training to suit everyone's need and preferences, while also allowing us to deliver training in the most suitable manner for the content. A great example of this is our masterclass series, which this year included a training session entitled "Boosting your online presence: SEO for beginners". This small group live training allowed our trainers to work directly with patient leaders, allowing them to practice the skills needed to improve their charities' web engagement.

In addition to our exceptional project performance, we've undergone significant behind-the-scenes changes. The staff team has grown to 11, with new roles in fundraising, communication and scientific projects. The launch of our new and improved website, developed in-house, means finding information and engaging with our projects is easier than ever. Moving forward, leveraging our online presence, especially through the website and Resources Hub, is central to our strategy. This will enable us to expand the availability of training resources and foster connections for patient leaders across the UK and beyond.

The last year represents a significant step forward for Beacon. Our improved funding stability has allowed the charity to grow, which, crucially has led to increased impact both in terms of patient group training, and the development of the rare disease drug repurposing ecosystem. This increased impact is helping to grow our influence and convening power, but more importantly allows us to provide high quality support and opportunities for our rare disease patient group community. Finding ways to leverage Beacon's resources and network to better support patient group development and improve the landscape for them will be a key strategic focus in the years ahead.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2024

STRATEGIC REPORT

Achievement and performance

Internal and external factors

The year 2023-24 represented the first year since COVID where there was limited practical impact on our charitable mission or delivery of our services. None-the-less, it is fair to say that COVID has changed the way that our beneficiaries wish to access our services - we have seen a consistent increase in the level of caution around in-person events, and a new level of expectation for hybrid delivery or online engagement, which we are beginning to work into our planning. Despite this, we have delivered several highly successful in person meetings in 2023, and they will remain a core component of our training in the future.

A more significant impairment to the delivery of such events in 2023 was the persistent train strikes. These led to the direct cancellation of at least two planned Beacon training events, which were subsequently converted to online trainings. Inflation has, undoubtedly been a challenge over the course of the year. All event costs, for both in-person trainings and community events have increased significantly, both stretching our budgets and limiting the ease with which many can attend such events. While Beacon does cover patient travel to training, the ease with which many can afford to miss work or cover caring duties at home has clearly decreased. Inflation has also hit Beacon's staff team, and we have worked wherever possible to provide meaningful pay increases to staff members to account for this.

Staff turnover has emerged as a significant challenge to Beacon over the course of 2023 - though we have managed to deliver impressively on our projects despite this. While the onboarding of the REMEDI4ALL project saw rapid team growth at the end of 2022, 2023 saw the departure of three members from our Projects and Fundraising teams. In response to these departures, we have welcomed four new staff members in 2023: a Communications Officer, a Projects Officer a Scientific Projects Officer, and Fundraising Manager. Our Fundraising Manager, in particular, brings exceptional experience to Beacon, having formerly worked for both the Tuberous Sclerosis Association and Genetic Alliance UK. Such changes in the staff team pose significant challenges but are to be expected in a rapidly growing organisation.

The fundraising environment in the life sciences sector has been less challenging than that seen throughout 2022. Regardless, it is fair to say that the ease with which Beacon can access grants from the pharmaceutical industry has decreased over the last 5 years, and the bureaucracy, restrictions, and payment delays have all increased. While these challenges have been offset by our improved access to multi-year trust and foundation grants, the necessary growth of the charity means a steady flow of corporate grants remains vital to support our work. The appointment of Emma Damian-Grint as Beacon's new Fundraising Manager in September 2023 highlights our commitment to both diversifying our funding streams and developing our strategy to mitigate against these funding challenges.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2024

STRATEGIC REPORT

Achievement and performance

Partnerships

Our new project, REMEDi4ALL, is Beacon's largest and most significant partnership to date. As a UK organisation, Beacon is an associated partner in the EU project, receiving funding through the UKRI's Horizon Guarantee Scheme. The consortium includes 24 distinct member organisations across Europe, all with different expertise in the drug repurposing space. Beacon is working particularly closely with EURORDIS: Rare disease Europe, EATRIS (the European Translational Research Infrastructure) and TEAM IT in the delivery of the project, and is involved in eight of the thirteen work packages, with co-leadership of two. This project is of huge strategic significance to both the repurposing community, and to Beacon itself. Our work on the project during its first complete year, and its impact, has already been detailed when describing our "Charitable Activities". Suffice to say, that the experience gained through this consortium has expanded our international reach and helped us to develop further in-house expertise on patient engagement in research, and digital training.

We have continued to develop our working relationship with LifeArc, building on the funding secured in 2022 to help them develop their Drug Repurposing Toolkit. Our CEO was involved in the grant panel for LifeArc's funding call for Rare Disease Translational Research Centres in the UK, and we are continuing to work closely with LifeArc in the development of this project, as well as the growth of REMEDi4ALL.

We remain committed to the EU-funded study, MCDS-Therapy, which is now entering its final few months following the recent closure of the clinical trial. Beacon is now leading the development and delivery of the project's closing conference, which will be held in Newcastle in May 2024. This project involves close interaction with stakeholders at Newcastle University and Newcastle Hospital's NHS Foundation Trusts, as well as partners across Europe. Beacon and Medics4RareDiseases - a registered charity dedicated to raising awareness about rare diseases within the medical profession - have continued the collaboration on The Student Voice Prize, which saw significant growth in entries in 2023. We maintained our partnership with the Orphanet Journal of Rare Diseases and BioMed Central, which once again published the winning entry from our student essay competition in their journal, alongside three other entries on their "On Medicine" blog.

It is also worth noting that the majority of Beacon's training events rely on the support and collaboration of our many friends and partners throughout the rare disease world. Our trainers often come from patient organisations, charities, and industry groups across the sector, providing their knowledge and time to support our work. We also receive regular support in promoting events from Genetic Alliance UK, Rare Revolution Magazine, Cambridge Rare Disease Network and EMIG (The Ethical Medicines Industry Group). Our work would not be possible without this on-going support and collaboration, and we are indebted to everyone who supports our work and mission with their time and expertise.

Finally, Beacon and Costello Medical have continued our fruitful pro bono collaboration in 2023 with support spanning the production of new guides for the Resources Hub, and vital pro bono support with finance and bookkeeping. Costello Medical have been a long-term supporter of our work and mission, and their high-quality work, and commitment to professional pro bono support have been fundamental to our growth and success in the last few years. Beacon also had the chance to work alongside Intent Health in 2023, who supported the development of a new communication approach and set of "messaging pillars" for the organisation.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2024

STRATEGIC REPORT

Financial review

Financial position

As noted already, and predicted in our last financial report, 2023 has been a year of improved financial performance and increase stability for Beacon. We end the year with a surplus of £44,473, having secured our highest ever income (£523,301) and highest ever annual spend (£478,828). The deficit in the year shown in unrestricted funds reflects expenditure from the designated projects fund, which had an excess of expenditure over income of £69,056 in the year. This was spending of funds designated last year. Furthermore, at the close of the year Beacon has an outstanding claim of over £20,000 to the UKRI for two months of work on the REMEDI4ALL project, reflecting an even more positive relative financial position. Indeed, the REMEDI4ALL project has driven both the increase in income and expenditure for the organisation during this time, with funding totalling £181,330 delivered across this period.

With the REMEDI4ALL grant in place for at least an additional three and half years, and new long term funding agreements with the National Lottery Community Fund, Beacon is in its best-ever financial position. Of course, our growing operational costs, increasing inflation, and the challenging fundraising environment all mean that we need to remain active and driven in developing our fundraising pipeline. Regardless of long-term funding, Beacon relies of corporate support, primarily grants, to fuel its operation. Securing these grants is becoming more challenging. While this is now a relatively smaller component of our annual budget, it remains vital to sustaining our size and impact. To avoid complacency in this regard, our new experienced Fundraising Manager is working with the CEO and Trustees to develop a long-term fundraising strategy for the organisation, with the aim of stabilising and smoothing out our cashflow and opening new income streams.

Principal funding sources

The principal funding source in this period was grant funding from the UKRI to support our work on the REMEDI4ALL project. This grant is paid in arrears, with payments to Beacon during this period covering work from September 2022 to November 2023 and totalling £181,330. The National Lottery Community Fund provided significant support for our empowerment programme. This funding totalled £152,461, equating to payments for the first year of the project. These major grant payments were supplemented by a further £33,686 from trusts and foundations (including The National Lottery Awards for All, Alan Boswell Charitable Trust and Envision Hope Foundation) and £36,648 in corporate grants. Our major corporate grant supporters included Orchard Therapeutics (£10,000 grant for the Empowerment Programme), Amicus Therapeutics (£5,000 grant for the Empowerment Programme), Empowerment Programme), and Illumina (£19,648 grant for our Empowerment Programme). PTC Therapeutics provided sponsorship of £10,000 for this project, and we also received corporate donations worth £3,427, all through our long-term supporter Whiskers LLP.

Our community events generated a further £38,500 in sponsorships, covering the Student Voice Prize and Rare Disease Showcase Series. This included contributions from Pleco Therapeutics, Bionical, Simbec Orion, Dendrite Ltd, LifeArc, Emmotive and the NIHR. Finally, our event ticket sales totalled £7,464, again driven through the Rare Disease Showcase series.

Our sponsorship level was up on 2022-23, though there is still need for growth in this area. More surprising is the drop in corporate grants - down to £36,648, from £99,446.06 in 2022-23. This is partly due to signing annual agreements that were secured in December 2022 and January 2023, leaving little time to secure new funding with those funders in the 2023-24 calendar year. Regardless, it does reflect the wider challenge in the corporate funding pipeline, which is increasingly challenging to access. Clearly our long-term grants are central to Beacon's financial model, and sustaining and replacing them is key to our future success.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2024

STRATEGIC REPORT

Financial review

Reserves policy & review

At any time, the charity aims to maintain reserves of sufficient levels to meet its contractual obligations for three months. This is through a combination of unrestricted and restricted funding to pay overheads and fulfil grant requirements. At the end of the reporting period, the charity holds £191,484 (2023: £147,011) of which £116,871 (2023: £35,387) is in restricted funds, and £74,613 (2023: £111,624) is in unrestricted funds. The general unrestricted funds, which the Trustees have not designated, of £69,960 (2023: £34,391) is slightly in excess of the costs of maintaining our staff team for three months and excludes the significant restricted funds held for salaries and overheads.

The restricted funds carried forward are committed to be spent in 2024 on the charity's projects and overheads, including: on-going delivery of the Empowerment Programme; an outstanding invoice for the delivery of the International Rare Disease Showcase; the delivery of communication and dissemination responsibilities for MCDS-Therapy; support for LifeArc's drug repurposing toolkit. Note that at the close of the financial year over £20,000 had been allocated to the UKRI R4A core fund (designated for the salary costs associated with the delivery of the REMEDI4ALL project) all of which will be reclaimed from the UKRI in the coming months, and further strengthens our financial position.

Going concern

The trustees believe that the Charity has sufficient funding in place to continue for at least the next 12 months and the accounts have therefore been prepared on a going concern basis.

Future plans

The year 2023 was predicted to be a year of consolidation for Beacon, with the need to stabilise and train the staff team a top priority. Unfortunately, this did not prove the case, with significant staff turnover complicating our work. We anticipate that 2024 will provide a period of staff stability for the charity, with new long-term grants and funding allowing us to increase staff reward and responsibility. We aim to develop a new five-year strategy in 2024 and this will include input from the entire team as well as the trustees. The strategy will look critically at sources of growth as well as the workings and improvements needed internally regarding enhanced retention and building a transparent human resource management model. Beacon will also aim to capture our institutional knowledge and use it actively in building new services and connections, as well as secure more administrative support to ensure both the smooth day-to-day operation and long-term stability of the charity. We now represent one of the largest UK charities in the rare disease space, and we are looking to ensure our operations reflect this.

The success of our first full year on the REMEDI4ALL project has been gratifying, but the need to deliver successfully for this project remains paramount. Beacon has taken a leading role in the delivery of the International Drug Repurposing Conference within the consortium, alongside Eatris, and Team IT. Successfully delivering our first in-person, multi-stream, international conference will be a big achievement for the charity and increase our global visibility. Beyond this, Beacon is committed to the development of a comprehensive digital training programme on drug repurposing which we will aim to launch in September 2024. Paired with our first ever hybrid event, delivered for the MCDS-Therapy consortium, we aim to develop our experience and visibility as a leader in community events for the rare disease repurposing sectors in 2024.

Our Empowerment programme in 2024 will see the continued development of the Resources Hub, and a particular focus on the Diagnostic pathway for rare diseases. We are also looking to deliver more collaborative training projects with other organisations in our sector to further enhance the connections between disparate patient groups and the wider rare disease ecosystem. In particular, we hope to combine our events, training, and patient engagement expertise to support the development of LifeArc's Rare Disease Translational Research Centres in 2024. Talks are on-going regarding the role we may be able to play in supporting this project. Such a collaboration would strengthen our connections to UK academia, helping to unify our empowerment, community, and scientific projects and give Beacon a truly representative rare disease network capable of supporting the needs of any patient group we work with.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2024

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

The charity's objects, as set out in its Articles of Association, are:

- 1 To advance the education of the general public in all areas relating to fundamental diseases and their causes, effects and treatments;
- 2 To promote and protect the physical and mental health of sufferers of fundamental diseases and their carers through the provision of support, education and practical advice;
- 3 To support research into the causes, effects, treatment and management of fundamental diseases and their application to common diseases, and disseminate the useful results thereof.

Since the drafting of the objects the term "fundamental diseases" has been reconsidered and the term "rare diseases" is used in its place.

Charity Constitution

The constitutional provisions relating to appointment and removal of trustees are:

- There should be a minimum of 3 trustees but no maximum.
- Appointment is by Ordinary Resolution
- A third of trustees retire by rotation at each AGM, but may be re-elected.

Trustees cease to hold office if:

- They cease to be a director by virtue of any provision in the Companies Acts or is prohibited by law from being a director
- They are disqualified from acting as a trustee by virtue of sections 178 and 179 of the Charities Act 2011;
- If they cease to be a member of the charity
- If they become incapable by reason of mental disorder, illness or injury of managing and administering their own affairs
- If they resign as a director by notice to the charity (as long as at least two directors will remain in office when the notice takes effect);
- If they are absent without the permission of the directors from all their meetings held within a period of 6 consecutive months and the directors resolve that his or her office be vacated.

Recruitment and appointment of new trustees

Our trustee recruitment process aims to identify candidates with new skills and experience needed for the organisation, and to find candidates with a desire to support our mission. We have a job specification prepared for the role, which is reviewed whenever we need to seek new trustee appointments. Shortlisted applicants are interviewed first over the phone, before face-to-face interviews with the CEO and existing board members. Successful candidates are invited to attend a board meeting before formally accepting the position of trustee, and appointment at the next board meeting.

Beacon's board has been stable over the last year, but we may explore the expansion of our board in 2024, with an explicit aim of appointing a dedicated treasurer.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2024

STRUCTURE, GOVERNANCE AND MANAGEMENT

Organisational structure

Beacon has six governing trustees, who meet on a quarterly basis with the Chief Executive Officer (CEO) to discuss the charity's activities and impact. The CEO is the most senior management personnel, and line manages three members of staff: The Chief Operating Officer (COO), Fundraising Manager, and Scientific Projects Manager. The COO line manages our Projects Manager, Digital Resources Manager, Projects Officer and Administrative Officer. Our Scientific Projects Officer manages our Scientific Projects Officer, while our recently appointed Fundraising Manager line manages our Fundraising Officer and Communications Officer. All staff members perform ad hoc volunteer management.

The CEO and COO take advice on rare disease patient empowerment from the Patient Engagement Committee, which comprises of seven advisors. This Committee serves for two years before applications are opened for reappointments and new members, with a majority of advisors having a personal experience of a rare disease.

The trustees delegate day-to-day management of the charity to the CEO. They take legal advice from Hogan Lovells and White & Case, and financial advice from Staffords Chartered Accountants.

Decision making

As the responsible managing body for the charity, the board of trustees make decisions on the strategic direction for the charity, as well as decisions relating to significant financial commitments and the hiring of new staff, all in conjunction with the CEO. Operational matters are delegated to staff, with the COO taking and increasing lead in the day-to-day management and administration of the charity. The trustees are kept abreast of developments through monthly updates with the chair of trustees and quarterly trustee meetings.

Induction and training of new trustees

New trustees follow an induction programme to ensure they integrate effectively into the board. They receive an induction pack which contains the charity's governing document, accounts, key policies, strategic plan, overview of the charity's history and ethos, and guiding documents from the Charity Commission on being a trustee. The new trustee then meets individually with all fellow board members and the CEO. They are also introduced to the staff and volunteers to gain a full understanding of the charity and its people.

Key management remuneration

In the fourth quarter of the year, the CEO prepares the budget for the coming year based on secured and projected income. As this time, provisional salaries for the year are calculated, taking performance, inflation rates, and the available budget into consideration. The CEO compiles a business plan for any salary changes, which is put to the board for a unified decision on remuneration.

Wider network

Beacon is a member of Rare Disease International, a global alliance of people living with a rare disease, as well as a member of Rare Disease UK, Genetic Alliance UK, Rare Revolution Magazine, The Cambridge Network, and an associate member of EURORDIS Rare Diseases Europe. Involvement in these networks builds the charity's reputation and allows Beacon to contribute to international efforts to support rare diseases. Membership in EURORDIS requires Beacon to remain financially independent, particularly from the pharmaceutical industry, limiting pharma funding to a maximum of 50% of the charity's revenue. Beacon is also registered with the Fundraising Regulator and as such is committed to best practice in fundraising.

Beacon is part of the REMEDI4ALL consortium, and the MCDS-Therapy consortium -both international collaborations to drive the repurposing of medicines - the former as a platform for any project across Europe, the latter of a generic drug to treat metaphyseal chondrodysplasia type Schmid.

Related parties

There are no material related party transactions which were not concluded under normal market conditions.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2024

STRUCTURE, GOVERNANCE AND MANAGEMENT

Risk management

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

The trustees compile a risk register and monitor it on an annual basis to ensure all potential risks are identified and strategies are put in place to manage them. The principal internal risks identified are having insufficient funding to fulfil charitable aims and the potential for fraud. To mitigate insufficient funding, the CEO draws up an annual cash flow forecast to map guaranteed and projected income for the year. This is then monitored on a monthly basis to identify potential shortfalls of funding and guide fundraising strategy. In periods where cash flow is critical, an Executive Committee for Cash Flow formed of three trustees and the CEO monitors cash flow on a weekly basis to ensure continuation of the charity's activities. The trustees and staff aim to diversify the charity's funding portfolio to ensure no one fund is overly relied upon.

Having secured involvement in a multi stakeholder EU funded project in 2018, and a three-year Community Fund grant in 2019, the REMEDi4ALL consortium in 2022, and with a new three-year Community Fund grant in 2023, a large proportion of our income is now derived from grant funding. To fund our outstanding costs, we are using a mixture of corporate grants, corporate sponsorship, and small trust and foundation applications. This strategy has proved successful, and leaves Beacon with a diverse range of funding sources and grant durations at the present time, and lead to a significant growth in income across this financial year. Community fundraising remains a very small source of income for the organisation and remains a low priority. Beacon fundamentally lacks an active base of supporters and donors, as our core beneficiaries are themselves directly involved with small charities. We do, however, continue to see success in securing unrestricted corporate donations. These are often developing into partnerships between companies keen to support our work from a corporate social responsibility perspective. This access to both funding and expertise is proving greatly beneficial to our financial security and flexibility.

To mitigate the risk of fraud, the charity employs an independent bookkeeper who monitors expenses on a monthly basis and requires receipts for all expenditure. The charity bank account is backed by several layers of security to ensure only selected senior staff (specifically the CEO and limited access for the COO) can access accounts. All cheques and bank withdrawals require at least two account signatories present, while access to our Community Fund holding account requires all transactions to be authorised by two approved individuals. Furthermore, there are internal systems in place which require large payments to receive approval from at least two signatories of the account. The trustees believe that these strategies have greatly reduced the possibility and impact of these internal risks.

The principal external risk to Beacon is the failure to deliver its commitments to the REMEDi4ALL project, thus jeopardising a long-term funding stream, and potential impact for the charity. This has been well mitigated to date, firstly by the rapid recruitment of an expanded staff team dedicated to the project, and with relevant expertise. Secondly, by establishing very close working relationships with the EURORDIS team dedicated to REMEDi4ALL, allowing us to share workload and smooth out any resource challenges. Thirdly, the project is well managed centrally, and we have developed detailed plans for its delivery. By ensuring regular contact with the key consortium partners, and a collaborative atmosphere, Beacon has proven to be an effective partner in the project to date and remains well placed to deliver on this crucial project.

The second external risk identified is public backlash against the charity's work. To ensure that public trust is not lost, the charity is transparent about its work, also maintaining ongoing evaluations of projects to monitor impact. Ongoing work at the charity is shared in weekly blogs and summed up in annual impact reports, which are shared on the website and at events. The Patient Group Engagement Committee was established to allow rare disease advocates independent input on the development and evaluation of projects. They also bring additional rare disease patient and carer perspectives to the charity, in order to ensure our activities, continue to meet the needs of our beneficiaries.

BEACON: FOR RARE DISEASES LTD

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2024

STRUCTURE, GOVERNANCE AND MANAGEMENT

A growing risk to the charity is the risk posed by the loss of staff members - both due to the increased challenge in delivering our contractual obligations, and the loss of accumulated knowledge and expertise within the charity. Beacon has been working over the past year to establish more robust processes for organisation management, and methods to capture institutional knowledge within the organisation, rather than having key information held by single team members. This is an ongoing process, and we plan to address staff incentives and benefits alongside this in greater detail in the coming year.

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

Report of the trustees, incorporating a strategic report, approved by order of the board of trustees, as the company directors, on and signed on the board's behalf by:

.....
N T Sireau PhD - Trustee

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
BEACON: FOR RARE DISEASES LTD**

Independent examiner's report to the trustees of Beacon: For Rare Diseases Ltd ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 January 2024.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts 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 your 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

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales, which is one of the listed bodies.

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 Company as required by Section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts 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 accounts 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.

Matthew Pettifer FCA

Staffords
Chartered Accountants
Unit 1, Cambridge House
Camboro Business Park
Oakington Road, Girton
CAMBRIDGE
Cambridgeshire
CB3 0QH

Date:

BEACON: FOR RARE DISEASES LTD

STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 JANUARY 2024

	Notes	Unrestricted funds £	Restricted funds £	2024 Total funds £	2023 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	3	100,995	20,182	121,177	119,756
Charitable activities					
Patient Support	4	62,091	340,033	402,124	204,455
Total		<u>163,086</u>	<u>360,215</u>	<u>523,301</u>	<u>324,211</u>
EXPENDITURE ON					
Raising funds	5	22,171	18,881	41,052	49,152
Charitable activities					
Patient Support	6	176,549	261,227	437,776	340,358
Total		<u>198,720</u>	<u>280,108</u>	<u>478,828</u>	<u>389,510</u>
NET INCOME/(EXPENDITURE)					
Transfers between funds	16	(35,634)	80,107	44,473	(65,299)
		<u>(1,377)</u>	<u>1,377</u>	<u>-</u>	<u>-</u>
Net movement in funds		<u>(37,011)</u>	<u>81,484</u>	<u>44,473</u>	<u>(65,299)</u>
RECONCILIATION OF FUNDS					
Total funds brought forward		111,624	35,387	147,011	212,310
TOTAL FUNDS CARRIED FORWARD		<u>74,613</u>	<u>116,871</u>	<u>191,484</u>	<u>147,011</u>

The notes form part of these financial statements

BEACON: FOR RARE DISEASES LTD (REGISTERED NUMBER: 08174973)

BALANCE SHEET
31 JANUARY 2024

	Notes	Unrestricted funds £	Restricted funds £	2024 Total funds £	2023 Total funds £
FIXED ASSETS					
Tangible assets	13	4,012	-	4,012	4,175
CURRENT ASSETS					
Debtors	14	206	153	359	407
Cash at bank		75,195	116,718	191,913	146,871
		<u>75,401</u>	<u>116,871</u>	<u>192,272</u>	<u>147,278</u>
CREDITORS					
Amounts falling due within one year	15	(4,800)	-	(4,800)	(4,442)
NET CURRENT ASSETS		<u>70,601</u>	<u>116,871</u>	<u>187,472</u>	<u>142,836</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>74,613</u>	<u>116,871</u>	<u>191,484</u>	<u>147,011</u>
NET ASSETS		<u><u>74,613</u></u>	<u><u>116,871</u></u>	<u><u>191,484</u></u>	<u><u>147,011</u></u>
FUNDS	16				
Unrestricted funds				74,613	111,624
Restricted funds				116,871	35,387
TOTAL FUNDS				<u><u>191,484</u></u>	<u><u>147,011</u></u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 January 2024.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 January 2024 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

The notes form part of these financial statements

BALANCE SHEET - continued
31 JANUARY 2024

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

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

.....
N T Sireau PhD - Trustee

BEACON: FOR RARE DISEASES LTD

CASH FLOW STATEMENT
FOR THE YEAR ENDED 31 JANUARY 2024

	Notes	2024 £	2023 £
Cash flows from operating activities			
Cash generated from operations	1	48,403	(61,973)
Net cash provided by/(used in) operating activities		<u>48,403</u>	<u>(61,973)</u>
Cash flows from investing activities			
Purchase of tangible fixed assets		(3,361)	(5,315)
Net cash used in investing activities		<u>(3,361)</u>	<u>(5,315)</u>
Change in cash and cash equivalents in the reporting period		<u>45,042</u>	<u>(67,288)</u>
Cash and cash equivalents at the beginning of the reporting period		<u>146,871</u>	<u>214,159</u>
Cash and cash equivalents at the end of the reporting period		<u><u>191,913</u></u>	<u><u>146,871</u></u>

The notes form part of these financial statements

BEACON: FOR RARE DISEASES LTD

NOTES TO THE CASH FLOW STATEMENT
FOR THE YEAR ENDED 31 JANUARY 2024

1. RECONCILIATION OF NET INCOME/(EXPENDITURE) TO NET CASH FLOW FROM OPERATING ACTIVITIES

	2024	2023
	£	£
Net income/(expenditure) for the reporting period (as per the Statement of Financial Activities)	44,473	(65,299)
Adjustments for:		
Depreciation charges	3,524	3,047
Decrease/(increase) in debtors	48	(176)
Increase in creditors	358	455
	<u>48,403</u>	<u>(61,973)</u>

2. ANALYSIS OF CHANGES IN NET FUNDS

	At 1/2/23	Cash flow	At 31/1/24
	£	£	£
Net cash			
Cash at bank	146,871	45,042	191,913
	<u>146,871</u>	<u>45,042</u>	<u>191,913</u>
Total	<u>146,871</u>	<u>45,042</u>	<u>191,913</u>

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 JANUARY 2024

1. LEGAL FORM

The charity is a registered charity registered in England and Wales number 1149646 and a company limited by guarantee number 08174973 having no share capital incorporated in England and Wales.

Its registered office and principal place of business is at 66 Devonshire Road, Cambridge, CB1 2BL.

2. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

Going Concern Basis

The Trustees consider that the going concern basis is appropriate as they consider the reserves levels and secured funding to be at sufficient levels to ensure that the charity can meet its financial obligations for the next 12 to 18 months and on that basis the charity is a going concern.

Reconciliation with previous Generally Accepted Accounting Practice

In preparing the accounts, the trustees have considered whether in applying the accounting policies required by FRS102 and the Charities SORP FRS 102 the restatement of comparative items was required. None were required.

Significant judgements

Apart from those judgements involving estimations, the management has not made any judgements in the process of applying the entity's accounting policies that have significant effect on the amounts recognised in the accounts. There are no key assumptions concerning the future or other key sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next reporting period

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Income from government and other grants is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

Donated services and facilities

Donated professional services are recognised as income when the charity has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use by the charity is probable and that economic benefit can be measured reliably. On receipt, donated professional services are recognised on the basis of the value of the gift to the charity which is the amount the charity would have been willing to pay to obtain services of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2024

2. ACCOUNTING POLICIES - continued

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Charitable activities

The trustees are of the view that the charity has one main activity - that of the provision of patient support. Charitable activity costs have therefore been allocated to this activity.

Tangible fixed assets

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

Plant and machinery - 33% on cost

Expenditure on capital items in excess of £500 is capitalised and written off over the estimated useful economic life.

Taxation

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

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Pension costs and other post-retirement benefits

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

Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments and accrued income are recognised at the amount prepaid or accrued net of any trade discounts due.

Cash at bank and in hand

Cash at bank and in hand includes cash and short term highly liquid investments with a maturity of 3 months or less from the date of acquisition or opening of the deposit.

Creditors

Creditors are recognised when the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2024

3. DONATIONS AND LEGACIES

	2024	2023
	£	£
Donations	8,154	13,446
Admissions	7,464	3,515
Donated services and facilities	57,059	70,317
Sponsorship	48,500	31,428
Fundraising income	-	1,050
	<u>121,177</u>	<u>119,756</u>

Donated services and facilities:

<u>Donor</u>	<u>Service donated</u>	<u>2024</u>	<u>2023</u>
Consultancy			
Costello Medical	Online training modules, video production, event support, and	38,609	70,317
Consulting	graphic design work		
Intent Health	Messaging workshop, development of a communications strategy	18,450	-
	toolkit and ad-hoc strategic counsel.		
		<u>57,059</u>	<u>70,317</u>

4. INCOME FROM CHARITABLE ACTIVITIES

	2024	2023
	£	£
Grants	402,124	204,455
	<u>402,124</u>	<u>204,455</u>

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

	2024	2023
	£	£
Takeda	-	20,000
Chiesi	-	15,000
National Lottery Community Fund	152,461	45,168
LifeARC	-	47,419
Amicus Therapeutics	5,000	-
Illumina	19,648	19,446
Awards for All	10,000	-
Evolution Education Trust	-	5,000
Vertex Pharmaceuticals	-	20,000
Ipsen Pharma	-	15,000
UCB Biopharma	-	10,000
Cambridge Healthcare Research	-	2,000
Genetic Alliance	-	5,422
Alan Boswell Group Charitable Trust	11,686	-
Innovate UK	181,330	-
Envision Hope Foundation	12,000	-
Orchard Therapeutics	9,999	-
	<u>402,124</u>	<u>204,455</u>

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2024

5. RAISING FUNDS

Raising donations and legacies

	2024	2023
	£	£
Staff costs	16,327	22,221
Entrance fees	-	35
	<u>16,327</u>	<u>22,256</u>

Other trading activities

	2024	2023
	£	£
Event costs	24,725	26,896
	<u>41,052</u>	<u>49,152</u>

6. CHARITABLE ACTIVITIES COSTS

	Direct Costs (see note 7) £	Support costs (see note 8) £	Totals £
Patient Support	432,401	5,375	437,776
	<u>432,401</u>	<u>5,375</u>	<u>437,776</u>

7. DIRECT COSTS OF CHARITABLE ACTIVITIES

	2024	2023
	£	£
Staff costs	292,020	204,218
Insurance	302	319
Postage and stationery	2,330	2,172
Advertising	839	4,509
Staff training	15,650	6,822
General expenses	8,855	4,541
Travel	12,573	8,937
IT Costs	9,798	11,341
Rent	24,475	16,992
Recruitment costs	3,274	2,230
Consultancy	58,709	70,661
Donations	50	55
Repairs and maintenance	2	100
Depreciation	3,524	3,047
	<u>432,401</u>	<u>335,944</u>

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2024

8. SUPPORT COSTS

	Management	Finance	Governance costs	Totals
	£	£	£	£
Patient Support	90	172	5,113	5,375
	<u> </u>	<u> </u>	<u> </u>	<u> </u>

9. NET INCOME/(EXPENDITURE)

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

	2024	2023
	£	£
Depreciation - owned assets	3,524	3,047
	<u> </u>	<u> </u>

10. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 January 2024 nor for the year ended 31 January 2023.

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 January 2024 nor for the year ended 31 January 2023.

11. STAFF COSTS

	2024	2023
	£	£
Wages and salaries	267,975	202,510
Social security costs	20,095	13,833
Other pension costs	20,277	10,096
	<u> </u>	<u> </u>
	308,347	226,439
	<u> </u>	<u> </u>

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

	2024	2023
CEO	1	1
COO	1	1
Other Officers	8	6
	<u> </u>	<u> </u>
	10	8
	<u> </u>	<u> </u>

No employees received emoluments in excess of £60,000.

Total employee benefit cost in the year relating to Key Management Personnel totalled £50,608 (2023: £45,148).

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2024

12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	89,228	30,528	119,756
Charitable activities			
Patient Support	10,000	194,455	204,455
Total	<u>99,228</u>	<u>224,983</u>	<u>324,211</u>
EXPENDITURE ON			
Raising funds	22,256	26,896	49,152
Charitable activities			
Patient Support	61,079	279,279	340,358
Total	<u>83,335</u>	<u>306,175</u>	<u>389,510</u>
NET INCOME/(EXPENDITURE)	15,893	(81,192)	(65,299)
Transfers between funds	4,186	(4,186)	-
Net movement in funds	20,079	(85,378)	(65,299)
RECONCILIATION OF FUNDS			
Total funds brought forward	91,545	120,765	212,310
TOTAL FUNDS CARRIED FORWARD	<u><u>111,624</u></u>	<u><u>35,387</u></u>	<u><u>147,011</u></u>

13. TANGIBLE FIXED ASSETS

	Plant and machinery £
COST	
At 1 February 2023	14,925
Additions	3,361
At 31 January 2024	<u>18,286</u>
DEPRECIATION	
At 1 February 2023	10,750
Charge for year	3,524
At 31 January 2024	<u>14,274</u>
NET BOOK VALUE	
At 31 January 2024	<u><u>4,012</u></u>
At 31 January 2023	<u><u>4,175</u></u>

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2024

14. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024	2023
	£	£
Prepayments	359	407
	<u>359</u>	<u>407</u>

15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024	2023
	£	£
Other creditors	-	242
Accrued expenses	4,800	4,200
	<u>4,800</u>	<u>4,442</u>

16. MOVEMENT IN FUNDS

	At 1/2/23	Net movement	Transfers between	At
	£	in funds	funds	31/1/24
	£	£	£	£
Unrestricted funds				
General fund	34,391	36,946	(1,377)	69,960
Designated Fixed Asset Fund	4,175	(3,524)	-	651
Designated Projects	73,058	(69,056)	-	4,002
	<u>111,624</u>	<u>(35,634)</u>	<u>(1,377)</u>	<u>74,613</u>
Restricted funds				
Essay Competition	-	(252)	252	-
Mentoring	-	(1,765)	1,765	-
Video Transcription	-	(113)	-	(113)
Conferences	(367)	(49)	416	-
MCDS EU H2020	26,617	(8,529)	-	18,088
Showcases	6,000	(4,570)	-	1,430
Community Fund	21,350	60,144	(1,765)	79,729
Podcast	2,342	(3,051)	709	-
ReMedi4All	(55,937)	38,778	-	(17,159)
Repurposing	35,382	(486)	-	34,896
	<u>35,387</u>	<u>80,107</u>	<u>1,377</u>	<u>116,871</u>
TOTAL FUNDS	<u>147,011</u>	<u>44,473</u>	<u>-</u>	<u>191,484</u>

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2024

16. MOVEMENT IN FUNDS - continued

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	159,084	(122,138)	36,946
Designated Fixed Asset Fund	-	(3,524)	(3,524)
Designated Projects	4,002	(73,058)	(69,056)
	<hr/>	<hr/>	<hr/>
	163,086	(198,720)	(35,634)
Restricted funds			
Essay Competition	7,500	(7,752)	(252)
Mentoring	-	(1,765)	(1,765)
Video Transcription	-	(113)	(113)
Conferences	(25)	(24)	(49)
MCDS EU H2020	-	(8,529)	(8,529)
Showcases	18,020	(22,590)	(4,570)
Community Fund	164,666	(104,522)	60,144
Podcast	-	(3,051)	(3,051)
ReMedi4All	170,054	(131,276)	38,778
Repurposing	-	(486)	(486)
	<hr/>	<hr/>	<hr/>
	360,215	(280,108)	80,107
	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	<u>523,301</u>	<u>(478,828)</u>	<u>44,473</u>

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2024

16. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1/2/22 £	Net movement in funds £	Transfers between funds £	At 31/1/23 £
Unrestricted funds				
General fund	36,475	1,014	(3,098)	34,391
Designated Fixed Asset Fund	1,907	(3,047)	5,315	4,175
Designated Projects	45,238	27,820	-	73,058
Designated Project Admin fund	7,925	(9,894)	1,969	-
	<hr/>	<hr/>	<hr/>	<hr/>
	91,545	15,893	4,186	111,624
Restricted funds				
Essay Competition	1,048	(1,048)	-	-
Resources Hub	84	(3,746)	3,746	84
Mentoring	6,350	(6,350)	-	-
Conferences	2,158	(2,525)	-	(367)
MCDS EU H2020	52,525	(25,909)	-	26,616
Showcases	11,369	(5,369)	-	6,000
Community Fund	45,269	(17,048)	(6,955)	21,266
Podcast	1,962	380	-	2,342
Webinars	-	(1,060)	1,060	-
ReMedi4All	-	(55,936)	-	(55,936)
Repurposing	-	37,419	(2,037)	35,382
	<hr/>	<hr/>	<hr/>	<hr/>
	120,765	(81,192)	(4,186)	35,387
TOTAL FUNDS	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>
	212,310	(65,299)	-	147,011

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2024

16. MOVEMENT IN FUNDS - continued

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	76,828	(75,814)	1,014
Designated Fixed Asset Fund	-	(3,047)	(3,047)
Designated Projects	22,400	5,420	27,820
Designated Project Admin fund	-	(9,894)	(9,894)
	<hr/>	<hr/>	<hr/>
	99,228	(83,335)	15,893
Restricted funds			
Essay Competition	4,850	(5,898)	(1,048)
Resources Hub	-	(3,746)	(3,746)
Mentoring	-	(6,350)	(6,350)
Conferences	10,963	(13,488)	(2,525)
MCDS EU H2020	-	(25,909)	(25,909)
Showcases	19,715	(25,084)	(5,369)
Workshops	5,422	(5,422)	-
Community Fund	144,614	(161,662)	(17,048)
Podcast	2,000	(1,620)	380
Webinars	-	(1,060)	(1,060)
ReMedi4All	-	(55,936)	(55,936)
Repurposing	37,419	-	37,419
	<hr/>	<hr/>	<hr/>
	224,983	(306,175)	(81,192)
	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	324,211	(389,510)	(65,299)
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

Community Fund: Funding from the National Lottery Community Fund to bring together patient groups, clinicians and researchers to build a cohesive community.

Conferences Fund: Funding secured for our annual drug repurposing conference, Drug Repurposing for Rare Diseases.

Essay Competition: corporate donations to fund prizes, travel and core costs in Beacon's annual essay competition, "The Student Voice Prize" delivered in collaboration with Medics 4 Rare Diseases.

MCDS EU H2020 Grant: Beacon is one of 11 project partners in EU-funded clinical trial testing whether carbamazepine can be repurposed to treat the rare genetic bone disorder, metaphyseal chondrodysplasia type Schmid (MCDS).

Resources Hub: Grant funding specifically for the Online Portal.

Peer Mentoring: Grant funding specifically assigned to our mentoring programme.

Podcast: Grant funding from Illumina, Alexion, Takeda and Cambridge Healthcare research to support the Podcast project.

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued **FOR THE YEAR ENDED 31 JANUARY 2024**

16. MOVEMENT IN FUNDS - continued

ReMEDi4ALL Fund: Grant funding from UKRI as part of a consortium driving forward drug repurposing initiatives by creating an accessible platform that will help guide and educate users involved in the drug repurposing pathway.

Repurposing Fund: funding from LifeArc towards the Beacon STEM drug repurposing programme, leading rare disease trials for repurposed drugs.

Showcases Fund: funds raised to deliver The Cambridge Rare Disease Showcase, and The London Rare Disease Showcase in 2023.

Designated Funds

Designated Fixed Asset Fund: This represents the net book value of the fixed assets and associated depreciation.

Designated Projects: This represents funds designated by the Trustees to cover the expenditure of projects where restricted funding has not been generated.

Designated Project Admin Fund: This represents funds designated by the Trustees to cover the first year of costs associated with employing a project administrator.

Transfers between funds

Transfers between funds represent the allocation of core funding from within project income.

17. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 January 2024.

18. INDEPENDENT EXAMINER FEES

Independent examiner fees of £4,000 + VAT were accrued during the year. (2023: £3,500 + VAT).

BEACON: FOR RARE DISEASES LTD

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 JANUARY 2024

	2024	2023
	£	£
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	8,154	13,446
Admissions	7,464	3,515
Donated services and facilities	57,059	70,317
Sponsorship	48,500	31,428
Fundraising income	-	1,050
	<hr/>	<hr/>
	121,177	119,756
Charitable activities		
Grants	402,124	204,455
	<hr/>	<hr/>
Total incoming resources	523,301	324,211
EXPENDITURE		
Raising donations and legacies		
Wages	14,732	20,270
Social security	858	938
Pensions	737	1,013
Entrance fees	-	35
	<hr/>	<hr/>
	16,327	22,256
Other trading activities		
Event costs	24,725	26,896
Charitable activities		
Wages	253,243	182,240
Social security	19,237	12,895
Pensions	19,540	9,083
Insurance	302	319
Postage and stationery	2,330	2,172
Advertising	839	4,509
Staff training	15,650	6,822
General expenses	8,855	4,541
Travel	12,573	8,937
IT Costs	9,798	11,341
Rent	24,475	16,992
Recruitment costs	3,274	2,230
Consultancy	58,709	70,661
Donations	50	55
Repairs and maintenance	2	100
Carried forward	428,877	332,897

This page does not form part of the statutory financial statements

BEACON: FOR RARE DISEASES LTD

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 JANUARY 2024

	2024	2023
	£	£
Charitable activities		
Brought forward	428,877	332,897
Computer equipment	3,524	3,047
	<u>432,401</u>	<u>335,944</u>
Support costs		
Management		
Telephone	90	249
Finance		
Bank charges	172	216
Governance costs		
Accountancy	5,113	3,949
Total resources expended	<u>478,828</u>	<u>389,510</u>
Net income/(expenditure)	<u><u>44,473</u></u>	<u><u>(65,299)</u></u>

This page does not form part of the statutory financial statements

BEACON: FOR RARE DISEASES LTD

England & Wales - Charity number 1149646

Accounts

REGISTERED COMPANY NUMBER: 08174973 (England and Wales)
REGISTERED CHARITY NUMBER: 1149646

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 JANUARY 2023
FOR
BEACON: FOR RARE DISEASES LTD

Staffords
Chartered Accountants
Unit 1, Cambridge House
Camboro Business Park
Oakington Road, Girton
CAMBRIDGE
Cambridgeshire
CB3 0QH

BEACON: FOR RARE DISEASES LTD

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FOR THE YEAR ENDED 31 JANUARY 2023

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REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2023

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 January 2023. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

Beacon: for rare diseases (hereafter Beacon, and formerly Findacure) aims to transform the way the world views rare diseases. We affect the lives of people with rare diseases and accelerate change in the field by:

- Working directly with patient groups to professionalise their work for impactful results, and build their reputation as the experts in their specific conditions.
- Building a rare disease community that supports, informs, collaborates and advocates for the improvement of all rare conditions.

Significant activities

About fundamental diseases

In the EU, a rare disease is defined as a condition that affects fewer than 1 in 2,000 people. Currently, more than 7,000 rare diseases have been identified, which collectively affect 3.5 million people in the UK. Despite their collective prevalence, each individual condition relates to so few people that they tend to be overlooked by doctors, researchers, and the general public. As a result, living with a rare disease can be incredibly isolating; people can be kept from education, work, and their communities. As only 5% of rare diseases have a treatment, many rare disease patients are left with debilitating and degenerative conditions, with little hope for a cure or a modicum of normal living.

This neglect of rare conditions has gone on for too long. Disease prevalence should not be the sole criterion for judging the importance or impact of a condition. The trustees believe that the research into even the rarest of diseases can benefit us all, since many rare genetic diseases can be viewed as templates for more common ones, or teach us a great deal about the fundamentals of human biology. Under the informal banner of Rare is Fundamental, we believe that improving our knowledge of the exceptional conditions, will accelerate the identification of treatments for many conditions and the growing knowledge about the way the body functions. Rare diseases are also often at the forefront of new developments in genetic medicine; gene therapies have almost exclusively been developed in this field. Despite this, rare diseases still receive little attention and funding from the research community. They are also significantly less interesting to policy makers and rarely form part of medical training.

Those living with a rare condition are the true experts in their rare disease. They possess valuable insight into the disease's progression and have first-hand experience of symptom management. Above all, they are critical to any pursuit of treatment and have the drive to deliver improved care for themselves. They represent the patient's voice; they understand patient needs for therapy and treatments. As a result, they are a key partner in patient care and research development. They are increasingly being recognised as a key partner by the pharmaceutical industry.

Beacon helps patient groups to form, grow and professionalise. Through our projects, we are building a community of rare disease patient groups that has the skills and knowledge needed to better support patients, campaign for equal opportunities and drive research. We are committed to helping patient groups learn from one another; and to feel confident in engaging with researchers, pharma, and clinicians on a level footing. A unified rare disease community works much more effectively than each patient group on its own. Alongside the patient empowerment projects, Beacon works to encourage collaborative research into rare diseases by running multi-sector events, such as our annual conference and showcases, which bring patients, clinicians, researchers, and industry together.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2023

OBJECTIVES AND ACTIVITIES

Public benefit

The trustees have complied with Section 17(5) of the Charities Act 2011 and have had due regard to the guidance on Public Benefit by the Charity Commission when exercising relevant powers and duties. See "About Fundamental Diseases" section for details of how the charity provides public benefit.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2023

STRATEGIC REPORT

Achievement and performance

Charitable activities

The financial year 2022-23 was a significant year for Beacon - the first full year of operation under our new name and brand; the year where we secured a place in the EC funded drug repurposing consortium REMEDI4ALL; and the year where we delivered our first truly international event.

Beacon's core aim is to provide support, guidance and connections to the rare disease patient group community. We help them achieve their goals and share their experiences so that all can learn from one another. By the start of 2022 the COVID situation had clearly normalised and the rare disease community was more comfortable with in person interaction. While this change has eased some of the pressures on our patient community, the impacts of COVID on fundraising, research and rare disease awareness remain significant. The changes have, at least allowed Beacon to return to the delivery of some work in person over the course of the year, helping to strengthen patient community connections and addressing a prevalent sense of "zoom-fatigue" within the community. 2022-23 has seen 2 in person workshops delivered by Beacon with a total of 49 live attendees. While we aim to continue to expand our in-person activities, the delivery of virtual and on demand training remains crucial to our success, reach, and impact. In total we delivered 5 workshops, with 190 attendees, and 7 webinars with 259 attendees in 2022 alone.

2022 marked the final year of our National Lottery Community Fund grant, which has supported the development and delivery of our Rare Disease Patient Group Empowerment Programme. Across the final year of this programme Beacon supported 238 patient organisations. Of these, at least 54 represented groups new to Beacon. Furthermore, we were able to launch our newly redeveloped Resources Hub thanks to the funding of the National Lottery. This new platform offers increased accessibility to our on-demand training, both through the implementation of the Reach Deck platform to enable translations, screen reading etc. and the integration of a curated set of our live event recordings. The Resources Hub saw 50 new registrants within the first month and represents a new and improved tool to both support the community and drive engagement with our services.

Over the course of the last year, under the auspices of our National Lottery Community fund grant, and supported by other corporate funders after its completion, Beacon delivered the following training as part of our Patient Group Empowerment Programme:

- * Four webinars, three as part of a series entitled "Developing your team" including sessions on volunteers, staff and succession planning, and a final stand alone webinar entitled "Increasing your visibility".
- * Continued the delivery of our community catch up project "RareChat", and the patient group mentoring cohort launched in 2021-22. The latter featured four mentoring-exclusive trainings covering marketing and communication, an introduction to individual giving, developing your case for support, and our closing celebration.
- * Launched our new e-learning platform, The Resources Hub.
- * Delivered five workshops entitled "Engaging and involving your community"; "Understanding access and reimbursement"; "Demonstrating Impact"; "Building positive partnerships between patient groups and industry" and "Building Rare Resilience", the latter in partnership with Genetic Alliance UK and RareMinds. Two of these workshops were delivered in person in London.
- * Continued to roll out our new Masterclass programme, with a second cohort attending our two-session programme on public speaking and a new training on creating videos on your smart phone delivered later in 2022.

This work represents real success for the charity - both reintroducing face-to-face training, closure of the Lottery Funding with the launch of a new e-learning platform, and the continuation of the Empowerment Programme independent of Lottery support. Over the course of the third and final year of our empowerment programme, we had 866 event attendances for the empowerment programme. This is a fantastic reach for our projects. It highlights the need for our services, and Beacon's continued impact.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2023

Beacon's Uniting Communities projects have also grown over the last year. The International Rare Disease Showcase was held on the 1st to the 3rd February 2022, to mark both Rare Disease Day and the launch of our new brand. This virtual conference was our biggest ever event, spanning three days, with 53 speakers for over 20 countries, and 449 delegates engaging with us. Featuring talks from all around the globe, all via the SwapCard platform, we were able to introduce Beacon and our aims and values to the global rare disease community. This virtual event was followed by the return of the Cambridge Rare Disease Showcase, our evening networking event designed to connect the life science ecosystem with Rare Diseases in Cambridge. Held on the 6th of July, this was our first major in-person event since COVID and our re-brand. Our largest ever audience of 70 people created an engaging and celebratory atmosphere, highlighting the importance of face-to-face engagement to our community building mission. This Showcase was followed by our 9th annual Drug Repurposing for Rare Diseases Conference on the 10th October. This event served as the launch for both the LifeArc drug repurposing toolkit, and the EU funded REMEDi4ALL consortium in the UK. Attended by 103 delegates, from across the patient, clinical, research, and life science community, the event was a big success.

In addition to our events programme, The Student Voice Prize annual essay competition continued to mature in 2022, with an all-time high of 67 entries from around the globe. We are also on the verge of launching our second season of the Rarely Heard Podcast. This series captures the stories of people personally affected by rare conditions, and tries to understand their mental health challenges, and how they have overcome them. We hope this will evolve into a powerful tool for public engagement on rare diseases, and a great way for people in the world of rare diseases to share their thoughts and needs in an engaging and meaningful way.

The MCDS-Therapy project continued through 2022, having secured an extension from the EU to account for COVID enforced delays. Trial recruitment closed and we have been working to maintain visibility and engagement with the project. Excitingly, Beacon became a member of the newly funded REMEDi4ALL consortium in 2022. The project launched in September 2022, with the aim of creating a drug repurposing platform to help accelerate drug repurposing projects across Europe to deliver increased patient impact. Beacon is working as joint-leader (with EURORDIS) of two of the project's thirteen work packages, which focus on patient engagement and the development of a new drug repurposing curriculum. This five-year project provides significant long-term funding for the charity, cements our position as a leading charity in the rare disease and drug repurposing space, and increases our international visibility and impact. Repurposing has long been a focus for the charity, but REMEDi4ALL gives us a clear pathway to impact the field, and support patient groups on their journey to create new rare disease treatments. While the award of this grant is hugely exciting for Beacon, it is essentially funding new work for the charity, and necessitated team growth. While CEO, Rick Thompson, is leading the project directly, we have also hired a new Senior Scientific Officer, Scientific Projects Officer, and Administrative Officer to support the work, leading to significant growth in both Beacon's team size and annual wage bill.

Beacon has continued to increase its capacity and output over the course of this year, driven by our new UKRI grant in support of REMEDi4ALL, the final stage of the National Lottery Community Fund grant, and an increased international outlook (engendered by COVID enforced virtual working and our re-brand). We now have the chance to deliver significant impact in the field of drug repurposing and patient engagement in research thanks to the REMEDi4ALL programme, and the opportunity to develop much more in-house expertise in these areas. Our new Resources Hub offers a powerful tool to train patient groups globally and connect them with Beacon's mission, thus maximising the impact of our increasingly diverse empowerment programme. However, it is fair to say that the financial environment in 2022 has been challenging, with our corporate fundraising providing very little income over the course of 2022. Thanks to significant fundraising success in the last quarter of the financial year, the charity has been able to turn this situation around and enter 2023-24 in a much more robust financial position than was predicted in our third quarter. While we have ultimately posted a significant loss this year, the vast majority of this is accounted for by REMEDi4ALL project, which will be paid to the organisation in arrears by the UKRI each quarter. Subsequently, the CEO and board of trustees believe that Beacon enters the new financial year well resourced, and optimistic about the continued opportunities ahead.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2023

STRATEGIC REPORT

Achievement and performance

Internal and external factors

The impact of COVID-19 has lessened in 2022, and the increased confidence of the rare disease community has allowed us to deliver a number of in-person events this year. We have continued to refine our skills in the virtual space, and the International Rare Disease Showcase and new Resources Hub both reflect our ability to deliver meaningful impact in the virtual world.

There has, however, been a clear impact of COVID on the life sciences sector in 2022, and this has impacted our ability to raise funds through our traditional corporate grants and partnerships. Beacon's corporate income has traditionally been delivered throughout the year; however, 2022 saw very little income in the first nine months. This limited cash flow, coupled with the need to expand the scientific expertise within the staff team did create financial challenges. During this time Beacon produced a high volume of good quality applications and worked on a new National Lottery Community Fund Application. Thankfully, this fundraising effort paid off for the charity, with significant grants from Takeda and LifeArc amongst others secured in the final quarter, along with confirmation of success in our application for another three-years of Lottery funding. While money from the UKRI (for the REMEDi4ALL project) and National Lottery Community Fund is still to be delivered, we end the year with much more confidence in our financial future, and with a significant yet manageable deficit.

Despite the financial uncertainty of the year, the opportunity afforded to Beacon through engagement with the REMEDi4ALL project needed to be maximised. Subsequently we have invested significant time and resources into recruitment and expansion over the course of the year. We hired a new Fundraising Officer, Faith Walpole, to replace Sophia Rodrigues who departed Beacon earlier in the year. We also recruited Eve Scott (in October) and Chloe Eyre (in November) as Senior Scientific Officer and Scientific Projects Officer respectively, to deliver the day-to-day work on the REMEDi4ALL programme. Finally, Will May joined the team to support the administration of the organisation, in particular the operation of the REMEDi4ALL project. This expansion is significant for Beacon, taking us to a staff team of ten, and foreshadowing a significant increase in turnover for the 2023-24 financial year.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2023

STRATEGIC REPORT

Achievement and performance

Partnerships

Our new project, REMEDI4ALL, is Beacon's largest and most significant partnership to date. As a UK organisation, Beacon is an associated partner in the EU project, receiving funding through the UKRI's Horizon Guarantee Scheme. The consortium includes 24 distinct member organisations across Europe, all with different expertise in the drug repurposing space. Beacon is working particularly closely with EURORDIS: Rare disease Europe, EATRIS (the European Translational Research Infrastructure) and TEAM IT in the delivery of the project, and is involved in eight of the thirteen work packages, with co-leadership of two. This project is of huge strategic significance to both the repurposing community, and to Beacon itself. The experience gained through this consortium will help expand our reach globally, but also enhance our internal expertise. Through REMEDI4ALL, Beacon will grow its credentials as a leading expert in patient centred research, drug repurposing education, and the role of repurposing in securing new treatments in the world of rare diseases. The project has the potential to benefit rare disease communities globally, and, as such, Beacon will be committed to its successful delivery and growth for the coming years.

Off the back of securing the REMEDI4ALL project, we have also developed a close working relationship with LifeArc, and secured funding from them to help highlight and develop their Drug Repurposing Toolkit. This collaboration has led to support for our conference, a collaborative webinar series entirely focussed of the drug repurposing pathway, and open engagement around LifeArc's future plans for funding and support in the drug repurposing field between Beacon, LifeArc, UCL and REMEDI4ALL.

Outside of REMEDI4ALL, we remain committed to the EU-funded study, MCDS-Therapy. Beacon plays a key role in the communication, dissemination, and recruitment of patients for the project's clinical trial. This project involves close interaction with stakeholders at Newcastle University and Newcastle Hospital's NHS Foundation Trusts, as well as partners across Europe. Beacon and Medics4RareDiseases - a registered charity dedicated to raising awareness about rare diseases within the medical profession - have continued the collaboration on The Student Voice Prize. We maintained our partnership with the Orphanet Journal of Rare Diseases and BioMed Central, which once again published the winning entry from our student essay competition in their journal, alongside three other entries on their "On Medicine" blog.

Beacon and Costello Medical have continued our fruitful pro bono collaboration in 2022 with support spanning the production of new animations for the Resources Hub, placement of a design intern to complete the rebrand project, support of the International Rare Disease Showcase, development of Hub modules and support with finance and bookkeeping.

It is also worth noting that the majority of Beacon's training events rely on the support and collaboration of our many friends and partners throughout the rare disease world. Our trainers come from patient organisations, charities, and industry groups across the sector, providing their knowledge and time to support our work. We also receive regular support in promoting events from Genetic Alliance UK, Rare Revolution Magazine, Cambridge Rare Disease Network and EMIG (The Ethical Medicines Industry Group). Our work would not be possible without this on-going support and collaboration, and we are indebted to everyone who supports our work and mission with their time and expertise.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2023

STRATEGIC REPORT

Financial review

Financial position

While a loss of over £60,000 across a financial year is never pleasant reading, it is fair to say that Beacon enters the year 2023-24 with renewed optimism. Firstly, it is crucial to note that over £55,000 of that deficit can be accounted for by our work to date for the REMEDi4ALL consortium, £40,000 was paid to us in February and the balance in April. Secondly, Beacon is currently finalising the agreement for a new National Lottery Community Fund bid worth over £400,000 for the next three years, which will cover roughly half of the cost of our patient empowerment programme during that period. Thirdly, there has been a significant and rapid improvement in our corporate fundraising pipeline in the last quarter, which has both prevented a much more damaging loss for 2022-23 and promises to generate further income in the coming months.

Long term funding agreements with MCDS-Therapy, the UKRI, and the National Lottery Community Fund, all give Beacon a sound footing for 2023 and beyond. While it is fair to say that Beacon will need to significantly grow its income and increase its financial reserves to meet its growing size, impact and commitments, the trustees believe we are in the position to do this. Our dedicated fundraising team and CEO experienced in the rare disease field, combined with our strong existing relationships in the life sciences space should allow Beacon to stabilise and grow its income in the more favourable fundraising environment of 2023.

Principal funding sources

The principal funding source in this period was grant funding from the National Lottery Community Fund to support our empowerment programme. This funding totalled £45,168, equating to payments for the second half of year three. This payment was supplemented by a further £57,841.11 from trusts and foundations (including LifeArc), and £99,446.06 in corporate grants. LifeArc provided a grant of £47,419.35 to support both the Drug Repurposing Conference and our work supporting their Drug Repurposing Toolkit. This was supplemented by a grant of £5421.76 from Genetic Alliance UK for the delivery of our collaborative project - Building Rare Resilience - and £5,000 from the Evolution Education Trust to support our drug repurposing conference. Our major corporate grant supporters included Illumina (£19,446.06 grant for the Empowerment Programme), Ipsen (£15,000 grant for the Empowerment Programme), Takeda (£20,000 grant support for our Empowerment Programme), Vertex (£20,000 grant for our Empowerment Programme), UCB (£10,000 grant funding for the Empowerment Programme), Chiesi (£15,000 for the Empowerment Programme) and Cambridge Healthcare Research (£2,000 funding for second season of beacon podcast). We also received corporate donations worth £12,400. This included a £10,000 donation from Costello Medical Consulting to support our fundraising team, along with donations of £2,000 from Ergomed, and £400 from Oxford Pharmagenesis.

We received a further £29,900 in sponsorships, covering the Student Voice Prize, International Rare Disease Showcase, Cambridge Rare Disease Showcase, Drug Repurposing for Rare Disease 2022, and the Rarely Heard Podcast. This included contributions from The Envision Hope Foundation, Healx, Costello Medical, Pharmacomedics, Alexion, Simbec Orion, Rhythm Pharmaceuticals, EUSA Pharma, PTC Therapeutics, Roche, PulseInfoframe, Gilead, and Cambridge Healthcare Research.

Overall, our sponsorship level was down on the previous year, though this will be partly due to the funding for the International Rare Disease Showcase fall across two financial years. Corporate funding was actually strong, but heavily skewed to the final quarter of the financial year, creating a challenging cash flow situation for 2022-23. It is worth noting that no income from the REMEDi4ALL project was received in this financial year, despite the project starting in September 2022.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2023

STRATEGIC REPORT

Financial review

Reserves policy & review

At any time, the charity aims to maintain reserves of sufficient levels to meet its contractual obligations for three months.

This is through a combination of unrestricted and restricted funding to pay overheads and fulfil grant requirements.

At the end of the reporting period, the charity holds £147,011 (2022: £212,310) of which £35,387 (2022: £120,765) is in restricted funds, and £111,624 (2022: £91,545) is in unrestricted funds. The general unrestricted funds, which the Trustees have not designated, of £34,391 (2022: £36,475) fall roughly £20,000 short of the costs of maintaining our staff team for three months and excludes the significant restricted funds held for salaries and overheads.

The restricted funds carried forward are committed to be spent in 2023 on the charity's projects and overheads, including: on-going delivery of the Empowerment Programme; an outstanding invoice for the delivery of the International Rare Disease Showcase, the delivery of the Rarely Heard Podcast series; the delivery of communication and dissemination responsibilities for MCDS-Therapy. Note that at the close of the financial year £55,936 had been allocated to the UKRI R4A core fund (designated for the salary costs associated with the delivery of the REMEDi4ALL project) all of which will be reclaimed from the UKRI in the coming months, and further strengthens our financial position.

Going concern

The trustees believe that the Charity has sufficient funding in place to continue for at least the next 12 months and the accounts have therefore been prepared on a going concern basis.

Future plans

The next year will need to be a year of consolidation for Beacon. Firstly, we need to consolidate the staff team. We have recruited a significant number of new staff in 2022, and our new Lottery grant, when confirmed, will necessitate further expansion. We will need to complete this growth, train, and embed new team members, and ensure a strong working environment with processes fit for a larger organisation. Secondly, having secured the REMEDi4ALL grant, we need to establish ourselves as an active and effective member of the consortium, and deliver impactful work for our patient communities in the project. This will initially be tested in our planned curriculum setting meeting, which we will be hosting with EURORDIS in March 2023. Thirdly, we will need to improve our cash flow across the year, attempt to grow our reserves, and establish a new stable level of income for the charity. Our long-term grants leave us well positioned to achieve this, but much work is needed with our corporate partners, and community collaborators to ensure success. Fourth, we will need to maximise the benefits of our new Resources Hub, our ability to deliver in-person events, and our redeveloped operating procedures to broaden our impact on our patient group community. We must improve our ability to measure our impact, and identify our patient group's needs, in order to truly redevelop our patient group training to better suit patient group resources, and requirements in the UK and beyond.

Partnerships will be key to all of this work, as will developing and maximising the skills of our young but talented staff team. We enter 2023 with great positivity after a challenging but successful year. If we achieve our aims Beacon will enter 2024 established as one of the UK's largest rare disease charities, expert in patient engagement in research and patient groups support, and with a burgeoning international reputation.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2023

The charity's objects, as set out in its Articles of Association, are:

- 1 To advance the education of the general public in all areas relating to fundamental diseases and their causes, effects and treatments;
- 2 To promote and protect the physical and mental health of sufferers of fundamental diseases and their carers through the provision of support, education and practical advice;
- 3 To support research into the causes, effects, treatment and management of fundamental diseases and their application to common diseases, and disseminate the useful results thereof.

Since the drafting of the objects the term "fundamental diseases" has been reconsidered and the term "rare diseases" is used in its place.

Charity Constitution

The constitutional provisions relating to appointment and removal of trustees are:

- There should be a minimum of 3 trustees but no maximum.
- Appointment is by Ordinary Resolution
- A third of trustees retire by rotation at each AGM, but may be re-elected.

Trustees cease to hold office if:

- They cease to be a director by virtue of any provision in the Companies Acts or is prohibited by law from being a director
- They are disqualified from acting as a trustee by virtue of sections 178 and 179 of the Charities Act 2011;
- If they cease to be a member of the charity
- If they become incapable by reason of mental disorder, illness or injury of managing and administering their own affairs
- If they resign as a director by notice to the charity (as long as at least two directors will remain in office when the notice takes effect);
- If they are absent without the permission of the directors from all their meetings held within a period of 6 consecutive months and the directors resolve that his or her office be vacated.

Recruitment and appointment of new trustees

Our trustee recruitment process aims to identify candidates with new skills and experience needed for the organisation, and to find candidates with a desire to support our mission. We have a job specification prepared for the role, which is reviewed whenever we need to seek new trustee appointments. Shortlisted applicants are interviewed first over the phone, before face to face interviews with the CEO and existing board members. Successful candidates are invited to attend a board meeting before formally accepting the position of trustee, and appointment at the next board meeting.

Beacon's board has been stable over the last year, but we may explore the expansion of our board in 2022.

Organisational structure

Beacon has six governing trustees, who meet on a quarterly basis with the Chief Executive Officer (CEO) to discuss the charity's activities and impact. The CEO is the most senior management personnel, and line manages six members of staff: the COO, Senior Corporate Fundraiser, Fundraising Officer, Marketing and Engagement Manager, Senior Scientific Officer and Scientific Officer. The COO manages both the Senior Projects Officers, and Administrative Officer.

The CEO takes advice on rare disease patient empowerment from the Patient Engagement Committee, which comprises of seven advisors. This Committee serves for two years before applications are opened for reappointments and new members, with a majority of advisors having a personal experience of a rare disease.

The CEO takes scientific advice from the Scientific Advisory Committee.

The trustees delegate day-to-day management of the charity to the CEO. They take legal advice from Hogan Lovells and White & Case, and financial advice from Staffords Chartered Accountants.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2023

STRUCTURE, GOVERNANCE AND MANAGEMENT

Decision making

As the responsible managing body for the charity, the board of trustees make decisions on the strategic direction for the charity, as well as decisions relating to significant financial commitments and the hiring of new staff. Operational matters are delegated to staff, and trustees are kept abreast of developments in monthly updates and quarterly trustee meetings.

Induction and training of new trustees

New trustees follow an induction programme to ensure they integrate effectively into the board. They receive an induction pack which contains the charity's governing document, accounts, key policies, strategic plan, overview of the charity's history and ethos, and guiding documents from the Charity Commission on being a trustee. The new trustee then meets individually with all fellow board members and the CEO. They are also introduced to the staff and volunteers to gain a full understanding of the charity and its people.

Key management remuneration

In the fourth quarter of the year, the CEO prepares the budget for the coming year based on secured and projected income. As this time, provisional salaries for the year are calculated, taking performance, inflation rates, and the available budget into consideration. The CEO compiles a business plan for any salary changes, which is put to the board for a unified decision on remuneration.

Wider network

Beacon is a member of Rare Disease International, a global alliance of people living with a rare disease, as well as a member of Rare Disease UK, Genetic Alliance UK, Rare Revolution Magazine, The Cambridge Network, and an associate member of EURORDIS Rare Diseases Europe. Involvement in these networks builds the charity's reputation and allows Beacon to contribute to international efforts to support rare diseases. Membership in EURORDIS requires Beacon to remain financially independent, particularly from the pharmaceutical industry, limiting pharma funding to a maximum of 50% of the charity's revenue. Beacon is also registered with the Fundraising Regulator and as such is committed to best practice in fundraising.

Beacon is part of the REMEDI4ALL consortium, and the MCDS-Therapy consortium -both international collaborations to drive the repurposing of medicines - the former as a platform for any project across Europe, the latter of a generic drug to treat metaphyseal chondrodysplasia type Schmid.

Related parties

There are no material related party transactions which were not concluded under normal market conditions.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2023

STRUCTURE, GOVERNANCE AND MANAGEMENT

Risk management

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

The trustees compile a risk register and monitor it on an annual basis to ensure all potential risks are identified and strategies are put in place to manage them. The principal internal risks identified are having insufficient funding to fulfil charitable aims and the potential for fraud. To mitigate insufficient funding, the CEO draws up an annual cash flow forecast to map guaranteed and projected income for the year. This is then monitored on a monthly basis to identify potential shortfalls of funding and guide fundraising strategy. In periods where cash flow is critical, an Executive Committee for Cash Flow formed of three trustees and the CEO monitors cash flow on a weekly basis to ensure continuation of the charity's activities. The trustees and staff aim to diversify the charity's funding portfolio to ensure no one fund is overly relied upon.

Having secured involvement in a multi stakeholder EU funded project in 2018, and a three-year Community Fund grant in 2019, the REMEDi4ALL consortium in 2022, and with a new three-year Community Fund grant pending, a large proportion of our income is now derived from grant funding. To fund our outstanding costs, we are using a mixture of corporate grants, corporate sponsorship, and small trust and foundation applications. This strategy has proved successful, and leaves Beacon with a diverse range of funding sources and grant durations at the present time. Indeed, while 2022 proved challenging from a cash flow perspective, we were able to ensure that the charity was holding enough funds to fulfil its obligations throughout the year, and ultimately secure significant corporate grant funding. Community fundraising remains a very small source of income for the organisation and remains a low priority. Beacon fundamentally lacks an active base of supporters and donors, as our core beneficiaries are themselves directly involved with small charities. We do, however, continue to see success in securing unrestricted corporate donations. These are often developing into partnerships between companies keen to support our work from a corporate social responsibility perspective. This access to both funding and expertise is proving greatly beneficial to our financial security and flexibility.

To mitigate the risk of fraud, the charity employs an independent bookkeeper who monitors expenses on a monthly basis and requires receipts for all expenditure. The charity bank account is backed by several layers of security to ensure only selected senior staff (specifically the CEO and limited access for the COO) can access accounts. All cheques and bank withdrawals require at least two account signatories present, while access to our Community Fund holding account requires all transactions to be authorised by two approved individuals. Furthermore, there are internal systems in place which require large payments to receive approval from at least three signatories of the account. The trustees believe that these strategies have greatly reduced the possibility and impact of these internal risks.

The principal external risk to Beacon is the failure to deliver its commitments to the REMEDi4ALL project, thus jeopardising a long-term funding stream, and potential impact for the charity. This has been well mitigated to date, firstly by the rapid recruitment of an expanded staff team dedicated to the project, and with relevant expertise. Secondly, by establishing very close working relationships with the EURORDIS team dedicated to REMEDi4ALL, allowing us to share workload and smooth out any resource challenges. Thirdly, the project is well managed centrally, and we have developed detailed plans for its delivery. By ensuring regular contact with the key consortium partners, and a collaborative atmosphere, we believe Beacon is well placed to deliver on this crucial project.

The second external risk identified is public backlash against the charity's work. To ensure that public trust is not lost, the charity is transparent about its work, also maintaining ongoing evaluations of projects to monitor impact. Ongoing work at the charity is shared in weekly blogs and summed up in annual impact reports, which are shared on the website and at events. The Patient Engagement was established to allow rare disease advocates independent input on the development and evaluation of projects. They also bring additional rare disease patient and carer perspectives to the charity, in order to ensure our activities continue to meet the needs of our beneficiaries.

Last year, our rebrand was identified as a major risk to the organisation - we are pleased to report that the new name and identity has been well received by the community and our plans to manage this transition have proved successful for the charity as a whole.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2023

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number

08174973 (England and Wales)

Registered Charity number

1149646

Registered office

66 Devonshire Road
CAMBRIDGE
Cambridgeshire
CB1 2BL

Trustees

A Hall Chief Medical Officer - Biotech company
E Kissmann Strategic Communication Consultant
A Milligan Consultant
N T Sireau PhD Charity Manager
S Costello Company Director
J Pisani Management Consultant and NED

Independent Examiner

Matthew Pettifer FCA
Staffords
Chartered Accountants
Unit 1, Cambridge House
Camboro Business Park
Oakington Road, Girton
CAMBRIDGE
Cambridgeshire
CB3 0QH

Solicitors

White & Case LLP, 5 Old Broad Street, London, EC2N 1DW
Hogan Lovells, Atlantic House, Holborn Viaduct, London, EC1A 2FG

Bankers

Co-operative Bank plc
PO Box 250
Delf House
Skelmersdale
WN8 6WT

Unity Trust Bank
PO Box 7193
Planetary Road
Willenhall
WV1 9DG

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2023

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

Report of the trustees, incorporating a strategic report, approved by order of the board of trustees, as the company directors, on and signed on the board's behalf by:

.....
N T Sireau PhD - Trustee

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
BEACON: FOR RARE DISEASES LTD**

Independent examiner's report to the trustees of Beacon: For Rare Diseases Ltd ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 January 2023.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts 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 your 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

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales, which is one of the listed bodies.

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 Company as required by Section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts 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 accounts 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.

Matthew Pettifer FCA

Staffords
Chartered Accountants
Unit 1, Cambridge House
Camboro Business Park
Oakington Road, Girton
CAMBRIDGE
Cambridgeshire
CB3 0QH

Date:

BEACON: FOR RARE DISEASES LTD

STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 JANUARY 2023

	Notes	Unrestricted funds £	Restricted funds £	2023 Total funds £	2022 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	3	89,228	30,528	119,756	128,844
Charitable activities					
Patient Support	4	10,000	194,455	204,455	141,021
Total		<u>99,228</u>	<u>224,983</u>	<u>324,211</u>	<u>269,865</u>
EXPENDITURE ON					
Raising funds	5	22,256	26,896	49,152	39,725
Charitable activities					
Patient Support	6	61,079	279,279	340,358	278,618
Total		<u>83,335</u>	<u>306,175</u>	<u>389,510</u>	<u>318,343</u>
NET INCOME/(EXPENDITURE)					
Transfers between funds	16	15,893 4,186	(81,192) (4,186)	(65,299) -	(48,478) -
Net movement in funds		<u>20,079</u>	<u>(85,378)</u>	<u>(65,299)</u>	<u>(48,478)</u>
RECONCILIATION OF FUNDS					
Total funds brought forward		91,545	120,765	212,310	260,788
TOTAL FUNDS CARRIED FORWARD		<u>111,624</u>	<u>35,387</u>	<u>147,011</u>	<u>212,310</u>

The notes form part of these financial statements

BEACON: FOR RARE DISEASES LTD (REGISTERED NUMBER: 08174973)

BALANCE SHEET
31 JANUARY 2023

	Notes	Unrestricted funds £	Restricted funds £	2023 Total funds £	2022 Total funds £
FIXED ASSETS					
Tangible assets	13	4,175	-	4,175	1,907
CURRENT ASSETS					
Debtors	14	233	174	407	231
Cash at bank		111,416	35,455	146,871	214,159
		<u>111,649</u>	<u>35,629</u>	<u>147,278</u>	<u>214,390</u>
CREDITORS					
Amounts falling due within one year	15	(4,200)	(242)	(4,442)	(3,987)
NET CURRENT ASSETS		<u>107,449</u>	<u>35,387</u>	<u>142,836</u>	<u>210,403</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>111,624</u>	<u>35,387</u>	<u>147,011</u>	<u>212,310</u>
NET ASSETS		<u>111,624</u>	<u>35,387</u>	<u>147,011</u>	<u>212,310</u>
FUNDS	16				
Unrestricted funds				111,624	91,545
Restricted funds				35,387	120,765
TOTAL FUNDS				<u>147,011</u>	<u>212,310</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 January 2023.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 January 2023 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

BALANCE SHEET - continued
31 JANUARY 2023

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

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

.....
N T Sireau PhD - Trustee

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 JANUARY 2023

1. LEGAL FORM

The charity is a registered charity registered in England and Wales number 1149646 and a company limited by guarantee number 08174973 having no share capital incorporated in England and Wales.

Its registered office and principal place of business is at 66 Devonshire Road, Cambridge, CB1 2BL.

2. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

Going Concern Basis

The Trustees consider that the going concern basis is appropriate as they consider the reserves levels and secured funding to be at sufficient levels to ensure that the charity can meet its financial obligations for the next 12 to 18 months and on that basis the charity is a going concern.

Reconciliation with previous Generally Accepted Accounting Practice

In preparing the accounts, the trustees have considered whether in applying the accounting policies required by FRS102 and the Charities SORP FRS 102 the restatement of comparative items was required. None were required.

Significant judgements

Apart from those judgements involving estimations, the management has not made any judgements in the process of applying the entity's accounting policies that have significant effect on the amounts recognised in the accounts. There are no key assumptions concerning the future or other key sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next reporting period

Financial reporting standard 102 - reduced disclosure exemptions

The charitable company has taken advantage of the following disclosure exemptions in preparing these financial statements, as permitted by FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland':

- the requirements of Section 7 Statement of Cash Flows.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Income from government and other grants is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

Donated services and facilities

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2023

2. ACCOUNTING POLICIES - continued

Income

Donated professional services are recognised as income when the charity has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use by the charity is probable and that economic benefit can be measured reliably. On receipt, donated professional services are recognised on the basis of the value of the gift to the charity which is the amount the charity would have been willing to pay to obtain services of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Charitable activities

The trustees are of the view that the charity has one main activity - that of the provision of patient support. Charitable activity costs have therefore been allocated to this activity.

Tangible fixed assets

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

Plant and machinery - 33% on cost

Expenditure on capital items in excess of £500 is capitalised and written off over the estimated useful economic life.

Taxation

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

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Pension costs and other post-retirement benefits

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

Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments and accrued income are recognised at the amount prepaid or accrued net of any trade discounts due.

Cash at bank and in hand

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2023

2. ACCOUNTING POLICIES - continued

Cash at bank and in hand includes cash and short term highly liquid investments with a maturity of 3 months or less from the date of acquisition or opening of the deposit.

Creditors

Creditors are recognised when the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

3. DONATIONS AND LEGACIES

	2023	2022
	£	£
Donations	13,446	11,016
Admissions	3,515	586
Donated services and facilities	70,317	72,327
Sponsorship	31,428	44,915
Fundraising income	1,050	-
	<u>119,756</u>	<u>128,844</u>

Donated services and facilities:

<u>Donor</u>	<u>Service donated</u>	<u>2023</u>	<u>2022</u>
Consultancy			
Costello Medical Consulting	Online training modules, video production, event support, and graphic design work	70,317	72,327
		<u>70,317</u>	<u>72,327</u>

4. INCOME FROM CHARITABLE ACTIVITIES

		2023	2022
	Activity	£	£
Grants	Patient Support	204,455	141,021
		<u>204,455</u>	<u>141,021</u>

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

		2023	2022
		£	£
Takeda		20,000	10,000
EU H2020		-	31,353
Chiesi		15,000	-
National Lottery Community Fund		45,168	45,168
Abbvie		-	5,000
LifeARC		47,419	-
Amicus Therapeutics		-	5,000
illumina		19,446	-
Alexion		-	19,500
		<u>147,033</u>	<u>116,021</u>
Carried forward		147,033	116,021

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2023

4. INCOME FROM CHARITABLE ACTIVITIES - continued

	2023	2022
	£	£
Brought forward	147,033	116,021
Awards for All	-	10,000
Evolution Education Trust	5,000	5,000
Vertex Pharmaceuticals	20,000	10,000
Ipsen Pharma	15,000	-
UCB Biopharma	10,000	-
Cambridge Healthcare Research	2,000	-
Genetic Alliance	5,422	-
	<u>204,455</u>	<u>141,021</u>

5. RAISING FUNDS

Raising donations and legacies

	2023	2022
	£	£
Staff costs	22,221	31,491
Entrance fees	35	44
	<u>22,256</u>	<u>31,535</u>

Other trading activities

	2023	2022
	£	£
Event costs	26,896	8,190
	<u>49,152</u>	<u>39,725</u>

6. CHARITABLE ACTIVITIES COSTS

	Direct Costs (see note 7)	Support costs (see note 8)	Totals
	£	£	£
Patient Support	335,944	4,414	340,358
	<u>335,944</u>	<u>4,414</u>	<u>340,358</u>

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2023

7. DIRECT COSTS OF CHARITABLE ACTIVITIES

	2023	2022
	£	£
Staff costs	204,218	141,414
Insurance	319	306
Postage and stationery	2,172	307
Advertising	4,509	832
Staff training	6,822	2,410
General expenses	4,541	1,164
Travel	8,937	2,147
IT Costs	11,341	10,935
Rent	16,992	6,643
Recruitment costs	2,230	335
Consultancy	70,661	105,696
Donations	55	75
Repairs and maintenance	100	-
Depreciation	3,047	1,647
	<u>335,944</u>	<u>273,911</u>

8. SUPPORT COSTS

	Management	Finance	Governance	Totals
	£	£	costs £	£
Patient Support	<u>249</u>	<u>216</u>	<u>3,949</u>	<u>4,414</u>

9. NET INCOME/(EXPENDITURE)

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

	2023	2022
	£	£
Depreciation - owned assets	<u>3,047</u>	<u>1,647</u>

10. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 January 2023 nor for the year ended 31 January 2022.

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 January 2023 nor for the year ended 31 January 2022.

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2023

11. STAFF COSTS

	2023	2022
	£	£
Wages and salaries	202,510	155,353
Social security costs	13,833	10,104
Other pension costs	10,096	7,448
	<u>226,439</u>	<u>172,905</u>

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

	2023	2022
CEO	1	1
Head of Operations	1	1
Other Officers	6	4
	<u>8</u>	<u>6</u>

No employees received emoluments in excess of £60,000.

Total employee benefit cost in the year relating to Key Management Personnel totalled £45,148 (2022: £41,143).

12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	84,208	44,636	128,844
Charitable activities			
Patient Support	-	141,021	141,021
Total	<u>84,208</u>	<u>185,657</u>	<u>269,865</u>
EXPENDITURE ON			
Raising funds	34,248	5,477	39,725
Charitable activities			
Patient Support	59,069	219,549	278,618
Total	<u>93,317</u>	<u>225,026</u>	<u>318,343</u>
NET INCOME/(EXPENDITURE)	(9,109)	(39,369)	(48,478)
RECONCILIATION OF FUNDS			
Total funds brought forward	100,654	160,134	260,788

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2023

12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

Unrestricted funds £	Restricted funds £	Total funds £
91,545	120,765	212,310

TOTAL FUNDS CARRIED FORWARD

13. TANGIBLE FIXED ASSETS

Plant and
machinery
£

COST

At 1 February 2022
Additions

9,610
5,315

At 31 January 2023

14,925

DEPRECIATION

At 1 February 2022
Charge for year

7,703
3,047

At 31 January 2023

10,750

NET BOOK VALUE

At 31 January 2023

4,175

At 31 January 2022

1,907

14. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

Prepayments

2023 £	2022 £
407	231

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2023

15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2023	2022
	£	£
Other creditors	242	123
Accrued expenses	4,200	3,864
	<u>4,442</u>	<u>3,987</u>

16. MOVEMENT IN FUNDS

	At 1/2/22	Net movement	Transfers between	At
	£	in funds	funds	31/1/23
	£	£	£	£
Unrestricted funds				
General fund	36,475	1,014	(3,098)	34,391
Designated Fixed Asset Fund	1,907	(3,047)	5,315	4,175
Designated Projects	45,238	27,820	-	73,058
Designated Project Admin fund	7,925	(9,894)	1,969	-
	<u>91,545</u>	<u>15,893</u>	<u>4,186</u>	<u>111,624</u>
Restricted funds				
Essay Competition	1,048	(1,048)	-	-
Resources Hub	84	(3,746)	3,746	84
Mentoring	6,350	(6,350)	-	-
Conferences	2,158	(2,525)	-	(367)
MCDS EU H2020	52,525	(25,909)	-	26,616
Showcases	11,369	(5,369)	-	6,000
Community Fund	45,269	(17,048)	(6,955)	21,266
Podcast	1,962	380	-	2,342
Webinars	-	(1,060)	1,060	-
ReMedi4All	-	(55,936)	-	(55,936)
Repurposing	-	37,419	(2,037)	35,382
	<u>120,765</u>	<u>(81,192)</u>	<u>(4,186)</u>	<u>35,387</u>
TOTAL FUNDS	<u>212,310</u>	<u>(65,299)</u>	<u>-</u>	<u>147,011</u>

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2023

16. MOVEMENT IN FUNDS - continued

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	76,828	(75,814)	1,014
Designated Fixed Asset Fund	-	(3,047)	(3,047)
Designated Projects	22,400	5,420	27,820
Designated Project Admin fund	-	(9,894)	(9,894)
	<hr/>	<hr/>	<hr/>
	99,228	(83,335)	15,893
Restricted funds			
Essay Competition	4,850	(5,898)	(1,048)
Resources Hub	-	(3,746)	(3,746)
Mentoring	-	(6,350)	(6,350)
Conferences	10,963	(13,488)	(2,525)
MCDS EU H2020	-	(25,909)	(25,909)
Showcases	19,715	(25,084)	(5,369)
Workshops	5,422	(5,422)	-
Community Fund	144,614	(161,662)	(17,048)
Podcast	2,000	(1,620)	380
Webinars	-	(1,060)	(1,060)
ReMedi4All	-	(55,936)	(55,936)
Repurposing	37,419	-	37,419
	<hr/>	<hr/>	<hr/>
	224,983	(306,175)	(81,192)
	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	<u>324,211</u>	<u>(389,510)</u>	<u>(65,299)</u>

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2023

16. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1/2/21 £	Net movement in funds £	Transfers between funds £	At 31/1/22 £
Unrestricted funds				
General fund	38,814	(444)	(1,895)	36,475
Designated Fixed Asset Fund	1,659	(1,647)	1,895	1,907
Designated Projects	30,630	14,608	-	45,238
Designated Project Admin fund	29,551	(21,626)	-	7,925
	<hr/>	<hr/>	<hr/>	<hr/>
	100,654	(9,109)	-	91,545
Restricted funds				
Essay Competition	-	1,048	-	1,048
Resources Hub	-	(11,757)	11,841	84
Mentoring	6,818	(468)	-	6,350
Conferences	-	2,158	-	2,158
MCDS EU H2020	45,156	7,369	-	52,525
Showcases	6,790	4,579	-	11,369
Workshops	-	(2,440)	2,440	-
Community Fund	98,620	(38,614)	(14,737)	45,269
Podcast	2,750	(788)	-	1,962
Webinars	-	(456)	456	-
	<hr/>	<hr/>	<hr/>	<hr/>
	160,134	(39,369)	-	120,765
	<hr/>	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	<u>260,788</u>	<u>(48,478)</u>	<u>-</u>	<u>212,310</u>

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2023

16. MOVEMENT IN FUNDS - continued

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	73,704	(74,148)	(444)
Designated Fixed Asset Fund	-	(1,647)	(1,647)
Designated Projects	10,504	4,104	14,608
Designated Project Admin fund	-	(21,626)	(21,626)
	<hr/>	<hr/>	<hr/>
	84,208	(93,317)	(9,109)
Restricted funds			
Essay Competition	7,400	(6,352)	1,048
Resources Hub	-	(11,757)	(11,757)
Mentoring	-	(468)	(468)
Conferences	20,741	(18,583)	2,158
MCDS EU H2020	31,353	(23,984)	7,369
Showcases	30,295	(25,716)	4,579
Workshops	-	(2,440)	(2,440)
Community Fund	77,168	(115,782)	(38,614)
Podcast	18,700	(19,488)	(788)
Webinars	-	(456)	(456)
	<hr/>	<hr/>	<hr/>
	185,657	(225,026)	(39,369)
	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	<u>269,865</u>	<u>(318,343)</u>	<u>(48,478)</u>

Community Fund: Funding from the National Lottery Community Fund to bring together patient groups, clinicians and researchers to build a cohesive community.

Conferences Fund: Funding secured for our annual drug repurposing conference, Drug Repurposing for Rare Diseases. This year including corporate sponsorship from Healx, Pharmacomedics, Pulse Inframe, and Purposeful, sponsorship from LifeArc, and grant support from the Evolution Education Trust.

Essay Competition: corporate donations to fund prizes, travel and core costs in Beacon's annual essay competition, "The Student Voice Prize" delivered in collaboration with Medics 4 Rare Diseases. Sponsorship was received from Costello Medical Consulting Ltd, Dolon Ltd, Linguamatics, TranScript LLP and EUSA Pharma.

MCDS EU H2020 Grant: Beacon is one of 11 project partners in EU-funded clinical trial testing whether carbamazepine can be repurposed to treat the rare genetic bone disorder, metaphyseal chondrodysplasia type Schmid (MCDS).

Resources Hub: Grant funding specifically for the Online Portal.

Peer Mentoring: Grant funding specifically assigned to our mentoring programme.

Podcast: Grant funding from Illumina, Alexion, Takeda and Cambridge Healthcare research to support the Podcast project.

BEACON: FOR RARE DISEASES LTD

NOTES TO THE FINANCIAL STATEMENTS - continued **FOR THE YEAR ENDED 31 JANUARY 2023**

16. MOVEMENT IN FUNDS - continued

ReMEDi4ALL Fund: Grant funding from UKRI as part of a consortium driving forward drug repurposing initiatives by creating an accessible platform that will help guide and educate users involved in the drug repurposing pathway.

Repurposing Fund: funding from LifeArc towards the Beacon STEM drug repurposing programme, leading rare disease trials for repurposed drugs.

Showcases Fund: funds raised to deliver The International Rare Disease Showcase a virtual multiday conference on rare disease projects across the globe in February 2022, and the Cambridge Rare Disease Showcase, an evening networking event in the summer of 2022.

Webinars Fund: Funding to cover the costs of running webinars. This was combined with the empowerment community fund at the end of the year.

Workshops Fund: Any grant funding specifically assigned to the Beacon patient group training workshops.

Designated Funds

Designated Fixed Asset Fund: This represents the net book value of the fixed assets and associated depreciation.

Designated Projects: This represents funds designated by the Trustees to cover the expenditure of projects where restricted funding has not been generated.

Designated Project Admin Fund: This represents funds designated by the Trustees to cover the first year of costs associated with employing a project administrator.

Transfers between funds

Transfers between funds represent the allocation of core funding from within project income.

17. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 January 2023.

18. INDEPENDENT EXAMINER FEES

Independent examiner fees of £3,500 + VAT were accrued during the year. (2022: £3,220 + VAT).

BEACON: FOR RARE DISEASES LTD

England & Wales - Charity number 1149646

Accounts

REGISTERED COMPANY NUMBER: 08174973 (England and Wales)
REGISTERED CHARITY NUMBER: 1149646

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 JANUARY 2022

FOR

BEACON: FOR RARE DISEASES LTD

PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

Staffords
Chartered Accountants
Unit 1, Cambridge House
Camboro Business Park
Oakington Road, Girton
CAMBRIDGE
Cambridgeshire
CB3 0QH

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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FOR THE YEAR ENDED 31 JANUARY 2022

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BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2022

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 January 2022. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

Beacon aims to transform the way the world views rare diseases. We positively transform the lives of people affected by rare diseases and accelerate change in the field by:

- Working directly with patient groups to empower them, giving them the skills to professionalise their work, and the confidence to recognise their own expertise in their conditions.
- Building a rare disease community that supports, informs, and collaborates together for the betterment of all rare conditions.

Significant activities

About fundamental diseases

In the EU, a rare disease is defined as a condition that affects fewer than 1 in 2,000 people. Currently, more than 7,000 rare diseases have been identified, which collectively affect 3.5 million people in the UK. Despite their collective prevalence, each individual condition relates to so few people that they tend to be overlooked by doctors, researchers, and the general public. As a result, living with a rare disease can be incredibly isolating; people can be kept from education, work, and their communities. As only 5% of rare diseases have a treatment, many rare disease patients are left with debilitating and degenerative conditions, with little hope for a cure or a modicum of normal living.

This neglect of rare conditions has gone on for too long. Disease prevalence should not be the sole criterion for judging the importance or impact of a condition. The trustees believe that the research into even the rarest of diseases can benefit us all, since many rare genetic diseases can be viewed as templates for more common ones, or teach us a great deal about the fundamentals of human biology. Under the informal banner of Rare is Fundamental, we believe that improving our knowledge of the exceptional conditions, will accelerate the identification of treatments for many conditions and the growing knowledge about the way the body functions. Rare diseases are also often at the forefront of new developments in genetic medicine; gene therapies have almost exclusively been developed in this field. Despite this, rare diseases still receive little attention and funding from the research community. They are also significantly less interesting to policy makers and rarely form part of medical training.

Those living with a rare condition are the true experts in their rare disease. They possess valuable insight into the disease's progression and have first-hand experience of symptom management. Above all, they are critical to any pursuit of treatment and have the drive to deliver improved care for themselves. They represent the patient's voice; they understand patient needs for therapy and treatments. As a result, they are a key partner in patient care and research development. They are increasingly being recognised as a key partner by the pharmaceutical industry.

Findacure helps patient groups to form, grow and professionalise. Through our projects, we are building a community of rare disease patient groups that has the skills and knowledge needed to better support patients, campaign for equal opportunities and drive research. We are committed to helping patient groups learn from one another; and to feel confident in engaging with researchers, pharma, and clinicians on a level footing. A unified rare disease community works much more effectively than each patient group on its own. Alongside the patient empowerment projects, Findacure works to encourage collaborative research into rare diseases by running multi-sector events, such as our annual conference and showcases, which bring patients, clinicians, researchers, and industry together.

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2022

OBJECTIVES AND ACTIVITIES

Public benefit

The trustees have complied with Section 17(5) of the Charities Act 2011 and have had due regard to the guidance on Public Benefit by the Charity Commission when exercising relevant powers and duties. See "About Fundamental Diseases" section for details of how the charity provides public benefit.

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2022

STRATEGIC REPORT

Achievement and performance

Charitable activities

Findacure's core aim is to provide support, guidance and connections to the rare disease patient group community. We help them achieve their goals and share their experiences so that all can learn from one another. With the continuation of the COVID-19 pandemic, and the fluctuations in national restrictions, the year 2021 has remained exceptionally challenging to our community. Over the course of the year, Findacure has continued to deliver all of our work in the virtual world, and we are only now beginning to plan in-person events. Despite the challenges of working in a purely virtual environment, our work has seen significant success and impact: over 160 patient organisations were supported directly by our empowerment programme during its second year, with an increased reach beyond the UK, thanks to our online delivery. Due to the significant underspend in our grant funding in the first year of the pandemic, which made it near impossible to spend funds allocated on event delivery, we have also had the ability to reallocate funding to the development of new virtual empowerment projects. The necessity of spending these funds has led to loss over this financial year. Despite this, we have increased the impact of our work, while retaining a healthy level of funding for the year ahead.

Over the course of the last year, under the auspices of our National Lottery Community fund grant (and supported by other corporate funders), Findacure delivered the following training as part of our patient group empowerment programme:

- * Launched and delivered a new edition of the patient group mentoring programme, including masterclass-style training in the leadership of small charities.
- * Delivered 5 webinars entitled "Ensuring inclusive communications around genetics"; "Understanding Health Economics"; "Navigating HTA"; "Measuring Quality of Life"; and "Working with healthcare professionals".
- * Continued the delivery of our new community catch up project "RareChat". We ran ten sessions across the year, using the informal discussion as a way to connect the rare community, and to directly understand their needs, in aid of our event planning and delivery.
- * Continued the redevelopment of our new e-learning resource, The Resources Hub.
- * Delivered 4 online workshops entitled "Supporting your community: mental health and wellbeing"; "Data collection"; "Community Fundraising"; and "Patient group research and trial design".
- * Launched a new programme of Masterclasses. This new type of training focusses on small group interactions and practical training. We hope to develop this programme so that attendees will be supported to create a specific deliverable during the training - our first sessions in November focussed on public speaking.
- * Launched a new trustee recruitment programme "Recruiting a Rare Board". This six-month programme is designed to support small patient groups to professionally recruit volunteer trustees to support their growth and development.

This work package represents a significant development of our empowerment programme, and was aided by the recruitment of a new Projects Administrator into the team at the start of the year. Over the course of the second year of our empowerment programme, we had 598 attendees for the empowerment programme. This is a fantastic reach for our projects. It highlights the need for our services, and Findacure's continued impact.

Findacure's Uniting Communities projects have also grown over the last year. Our 8th annual Drug Repurposing for Rare Diseases Conference was held in June as a virtual conference. For the first time, we delivered the event over two days. The event fully embraced the power of a digital platform (SwapCard) to engage our audience with lectures, discussion, networking, and interactive sessions. We welcomed 202 delegates across the event, representing our largest ever audience. The challenge of planning and delivering large virtual events meant that we decided to delay our annual Showcase series in 2021. The International Rare Disease Showcase will instead be held on the 1st February 2022, to mark both Rare Disease Day and the launch of our new brand.

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In addition to our events programme, The Student Voice Prize annual essay competition continued to mature in 2021, with 50 entries from around the globe. We also launched our new podcast, Rarely Heard, in collaboration with Same But Different. This series captures the stories of people personally affected by rare conditions, and tries to understand their mental health challenges, and how they have overcome them. We hope this will evolve into a powerful tool for public engagement on rare diseases, and a great way for people in the world of rare diseases to share their thoughts and needs in an engaging and meaningful way.

The MCDS-Therapy project continued to strengthen through 2021. We saw the clinical trial recover from COVID-19 shut down, and the launch of our first international sites. Alongside this, Findacure's work on community engagement has helped to significantly grow our online following, as well as supporting recruitment onto one of the first health economic studies into this rare skeletal dysplasia. Indeed, our communications work has continued to develop as a charity. Our social media followings have continued to grow, and we have been invited to write a series of articles on the topics of rare diseases in the mainstream media. During 2021, Findacure appeared in Media Planet's Rare Disease Campaign (distributed in the Guardian), The PharmaTimes, Rare Revolution Magazine, and The Times and Sunday Times. Findacure's founders, Dr Nick Sireau and Dr Tony Hall were also recognised by the Prime Minister with the Points of Light Award.

Fundraising activities

Findacure has continued to increase its capacity and output over the course of this year, driven by our more stable and flexible funding position, and COVID-19 induced underspend in 2020. Our work has become more diverse, with more projects focussed on tailored support to patient groups, and broader rare disease education and outreach. Despite the financial deficit this year, we are currently well resourced, and in an excellent position to continue to strengthen the charity in 2022.

Internal and external factors

COVID-19 has remained a significant external factor governing our activity in 2021. After our work in 2020 establishing a new, virtual way of working, we have been able to continue to deliver a high standard of virtual support for rare disease patient organisations, alongside our first virtual Drug Repurposing for Rare Disease conference. All work has remained online to date, primarily to protect our patient community, with many of our beneficiaries more vulnerable to COVID infection. Internal work practices have been gradually evolving over the course of the year, with an aim to strike a balance between COVID security and the protection of the mental health and well-being of the staff team. While many staff have returned to office working part-time, under COVID restrictions, others have remained home-based, and a new hybrid working model has evolved throughout the charity.

Due to our pre-pandemic financial stability, our stable staff and trustee team, and limited reliance on community fundraising, we have been well placed to ride out the pandemic financially. Over the course of this year, our main challenge has been to ensure that we meet our long-term grant spending commitments, and find effective use for the excess funding that rolled over from our 2020 grants. This has allowed us to grow our staff team, develop new online training resources and launch a series of new projects across 2021, increasing our charitable impact. This drive to spend funding has also resulted in a net loss of funds over the course of 2020-21, though our reserves and dedicated project funding remain at a sufficient level for the year ahead.

Over the course of 2021, we have also been conducting research and organising for a potential change in branding of the organisation that would better reflect its focus and future growth plans. The new name - Beacon: for rare diseases - will be officially launched at the start of the new financial year, and represents a significant evolution in the charity. The development of this new identity has been a significant undertaking, using substantial staff time as well as pro bono creative resources provided by Costello Medical and voluntary branding advice from trustee Andy Milligan. We have been developing a suite of new materials for the organisation, alongside a new website with clear messaging and a stronger focus on the patient groups that we support.

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REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2022

STRATEGIC REPORT

Achievement and performance

Partnerships

Our on-going involvement in the EU-funded study, MCDS-Therapy, remains our largest collaborative project. Findacure plays a key role in the communication, dissemination, and recruitment of patients for the project's clinical trial. This project involves close interaction with stakeholders at Newcastle University and Newcastle Hospital's NHS Foundation Trusts, as well as partners across Europe. It is an exceptional learning opportunity for our team.

Findacure and Medics4RareDiseases - a registered charity dedicated to raising awareness about rare diseases within the medical profession - have continued the collaboration on The Student Voice Prize. We maintained our partnership with the Orphanet Journal of Rare Diseases and BioMed Central, which once again published the winning entry from our student essay competition in their journal, alongside three other entries on their "On Medicine" blog. This collaborative model has been extended and developed for the delivery of our new podcast, Rarely Heard, in collaboration with Same But Different.

Much like our work in the Ardent consortium in 2020, we have been supporting a collaborative policy project in 2021, focussed on the transition of rare disease patients from paediatric to adult services. This project, delivered with Cambridge Rare Disease Network and Costello Medical Consulting, brought together leaders in the field of rare disease transition from across the UK. It ultimately led to the production of a new report with a series of recommendations to improve the transition process for rare patients. This represents just one of the areas of collaboration between Findacure and Costello Medical, who have continued to be a significant support to our work and mission over 2021. Indeed, Costello have provided significant pro bono design support to facilitate our rebranding, including seconding a design intern to the organisation for the last six months of the year. Such a contribution has been transformative to our organisation and highlights the huge potential of such stable collaborations between charity and corporate partners.

It is also worth noting that the majority of Findacure's training events rely on the support and collaboration of our many friends and partners throughout the rare disease world. Our trainers come from patient organisations, charities, and industry groups across the sector, providing their knowledge and time to support our work. We also receive regular support in promoting events from Genetic Alliance UK, Rare Revolution Magazine, Cambridge Rare Disease Network and EMIG (The Ethical Medicines Industry Group). Our work would not be possible without this on-going support and collaboration, and we are indebted to everyone who supports our work and mission with their time and expertise.

Finally, we note that our CEO has dedicated significant time this year in developing a new collaboration with a European-level drug repurposing consortium, resulting in a grant application to the Horizon EU fund. We await the outcome of this application and new potential formal collaboration.

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REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2022

STRATEGIC REPORT

Financial review

Financial position

Findacure remains on sound financial footing as we enter the new financial year. While we reported a loss over the course of 2021-22, this was primarily due to a build up of funds over the preceding year, which we were unable to spend effectively with the advent of COVID-19. By working closely with our funders, in particular the National Lottery Community Fund, we have identified new ways to spend the fund rolling over from 2020-21. This has helped to build the charity's ability to deliver long-term digital training, and engage with the community.

We currently hold the necessary funds for the completion of our National Lottery Grant, with significant funding to carry us through 2022. We have been actively developing new long-term funding streams over the course of 2021, with the potential of a new European Commission project launching in 2022, and new National Lottery Community Fund and Partnerships Fund bids in development. Furthermore, we have recently appointed a new Fundraising Officer to the team to increase our fundraising capacity, which we feel is a sensible move for a growing organisation in the more challenging fundraising environment. We believe this additional resource, combined with our strong existing relationships in the life sciences space should allow a continued stable position for Findacure, or Beacon as it will be known, across 2022.

Principal funding sources

The principal funding source in this period was grant funding from the National Lottery Community Fund to support our empowerment programme. This funding totalled £45,168, equating to payments for the first half of year three only (the second half of year two's payment falling at the close of the last financial year, another reason for our effective loss across 2021-22). We received £31,353 for our work on MCDS-Therapy (a project funded by the European Union Horizon 2020 grant). These payments were supplemented by a further £15,000 from trusts and foundations, and £49,500 in corporate grants. Grant funding included £10,000 from the National Lottery Awards for All scheme, a £5,000 grant from the Evolution Education Trust to support our drug repurposing conference. Our major corporate grant supporters included Alexion (£19,500 in total including a £12,000 grant in support for our empowerment programme and £7,500 support for the podcast), Takeda (£10,000 support for our podcast programme), Abvie (£5,000 support for our empowerment programme), Amicus (£5,000 grant for our empowerment programme) and Vertex (£10,000 grant for our empowerment programme). We received a further £44,915 in sponsorships, including contributions from Cambridge Healthcare Research, Bionical EMAS, Pharmacomedics, Open Health, Purposeful, LifeArc, PulseInfotrame, Healx, Dolon, Costello Medical, Linguamatics, TranScrip, Aparito and EUSA Pharma.

Reserves policy & review

At any time, the charity aims to maintain reserves of sufficient levels to meet its contractual obligations for three months. This is through a combination of unrestricted and restricted funding to pay overheads and fulfil grant requirements.

At the end of the reporting period, the charity holds £212,310 (2021: £260,788) of which: £120,765 (2021: £160,134) is in restricted funds, and £91,545 (2021: £100,654) is in unrestricted funds.

£36,475 of the latter is explicitly assigned to our strategic reserve, which falls roughly £10,000 short of the costs of maintaining our staff team for three months and excludes the significant restricted funds held for salaries and overheads. The restricted funds carried forward are committed to be spent in 2022 on the charity's projects and overheads, including: on-going delivery of the Empowerment Programme (including the E-learning portal, patient group workshops, webinars, and mentoring scheme); the delivery of the Drug Repurposing for Rare Disease Conference 2022 and Rare Disease Showcase; the establishment of a new rare disease podcast series; the delivery of communication and dissemination responsibilities for MCDS-Therapy.

Going concern

The trustees believe that the Charity has sufficient funding in place to continue for at least the next 12 months and the accounts have therefore been prepared on a going concern basis.

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STRATEGIC REPORT

Future plans

The successful launch of our new identity and brand will be a major focus of early 2022. Ensuring recognition within our community will be key, as well as stewarding existing funding relationships during the transition period. The new brand will be launched at our first ever explicitly international event - the International Rare Disease Showcase - in February 2022, alongside the launch of our new website. This has huge strategic importance for the organisation.

Across 2021 and moving forward, we have had a strong focus on securing new long-term grant funding for the organisation. We are part of a consortium bidding for Horizon Europe funding for a new drug repurposing platform, the results of which will be announced in early 2022. This project has the potential to create a new, well defined scientific repurposing project within the organisation, and will lead to significant new work, requiring new team members within the organisation. Alongside this, we have been developing a new application for funding from the National Lottery Community Fund, and are working in collaboration with Genetic Alliance UK and Breaking Down Barriers to develop a new collaborative grant to better support the UK rare disease patient group community. These sizeable grants are a crucial focus for the organisation going forward, with the aim of further stabilising our charity and confirming our organisational maturity.

Alongside our focus on identity and financial security, we will also be delivering the final stages of our National Lottery Community Fund grant, with a core focus on the completion of our new e-learning platform, the Resources Hub. This should increase the accessibility and flexibility of this platform, and we hope it can take centre stage in our Empowerment work as we close out the next year.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

The charity's objects, as set out in its Articles of Association, are:

- 1 To advance the education of the general public in all areas relating to fundamental diseases and their causes, effects and treatments;
- 2 To promote and protect the physical and mental health of sufferers of fundamental diseases and their carers through the provision of support, education and practical advice;
- 3 To support research into the causes, effects, treatment and management of fundamental diseases and their application to common diseases, and disseminate the useful results thereof.

Since the drafting of the objects the term "fundamental diseases" has been reconsidered and the term "rare diseases" is used in its place.

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STRUCTURE, GOVERNANCE AND MANAGEMENT

Charity Constitution

The constitutional provisions relating to appointment and removal of trustees are:

- There should be a minimum of 3 trustees but no maximum.
- Appointment is by Ordinary Resolution
- A third of trustees retire by rotation at each AGM, but may be re-elected.

Trustees cease to hold office if:

- They cease to be a director by virtue of any provision in the Companies Acts or is prohibited by law from being a director
- They are disqualified from acting as a trustee by virtue of sections 178 and 179 of the Charities Act 2011;
- If they cease to be a member of the charity
- If they become incapable by reason of mental disorder, illness or injury of managing and administering their own affairs
- If they resign as a director by notice to the charity (as long as at least two directors will remain in office when the notice takes effect);
- If they are absent without the permission of the directors from all their meetings held within a period of 6 consecutive months and the directors resolve that his or her office be vacated.

Recruitment and appointment of new trustees

In 2019 Findacure implemented a new Trustee recruitment process, with the aim of identifying candidates with new skills and experience needed for the organisation, and to find candidates with a desire to support our mission. We created a job specification and position, advertised it widely and accepted applications for a fixed time period. This was followed by phone and face to face interviews with the CEO and existing board members. Successful candidates were invited to attend a board meeting before formally accepting the position of trustee, and appointment at the next board meeting.

Organisational structure

Beacon has six governing trustees, who meet on a quarterly basis with the Chief Executive Officer (CEO) to discuss the charity's activities and impact. The CEO is the most senior management personnel, and line manages two members of staff: The Head of Operations and Fundraising Manager. The Head of Operations line manages our Projects Officer, and all staff members perform ad hoc volunteer management.

The CEO takes advice on rare disease patient empowerment from the Patient Engagement Committee, which comprises of seven advisors. This Committee serves for two years before applications are opened for reappointments and new members, with a majority of advisors having a personal experience of a rare disease.

The CEO takes scientific advice from the Scientific Advisory Committee. This Committee has biennial rotating membership, with at least one member having a personal experience of a rare disease.

The trustees delegate day-to-day management of the charity to the CEO. They take legal advice from Hogan Lovells and White & Case, and financial advice from Staffords Chartered Accountants.

Decision making

As the responsible managing body for the charity, the board of trustees make decisions on the strategic direction for the charity, as well as decisions relating to significant financial commitments and the hiring of new staff. Operational matters are delegated to staff, and trustees are kept abreast of developments in monthly updates and quarterly trustee meetings.

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STRUCTURE, GOVERNANCE AND MANAGEMENT

Induction and training of new trustees

New trustees follow an induction programme to ensure they integrate effectively into the board. They receive an induction pack which contains the charity's governing document, accounts, key policies, strategic plan, overview of the charity's history and ethos, and guiding documents from the Charity Commission on being a trustee. The new trustee then meets individually with all fellow board members and the CEO. They are also introduced to the staff and volunteers to gain a full understanding of the charity and its people.

Key management remuneration

In the fourth quarter of the year, the CEO prepares the budget for the coming year based on secured and projected income. As this time, provisional salaries for the year are calculated, taking performance, inflation rates, and the available budget into consideration. The CEO compiles a business plan for any salary changes, which is put to the board for a unified decision on remuneration.

Wider network

Beacon is a member of Rare Disease International, a global alliance of people living with a rare disease, as well as a member of Rare Disease UK, Genetic Alliance UK, Rare Revolution Magazine, The Cambridge Network, and an associate member of EURORDIS Rare Diseases Europe. Involvement in these networks builds the charity's reputation and allows Beacon to contribute to international efforts to support rare diseases. Membership in EURORDIS requires Beacon to remain financially independent, particularly from the pharmaceutical industry, limiting pharma funding to a maximum of 50% of the charity's revenue. Beacon is also registered with the Fundraising Regulator and as such is committed to best practice in fundraising.

Beacon is part of the MCDS-Therapy consortium, an international collaboration to drive the repurposing of a generic drug to treat metaphyseal chondrodysplasia type Schmid. This group includes universities, hospitals, and SME's around the world.

Related parties

There are no material related party transactions which were not concluded under normal market conditions.

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STRUCTURE, GOVERNANCE AND MANAGEMENT

Risk management

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

The trustees compile a risk register and monitor it on an annual basis to ensure all potential risks are identified and strategies are put in place to manage them. The principal internal risks identified are having insufficient funding to fulfil charitable aims and the potential for fraud. To mitigate insufficient funding, the CEO draws up an annual cash flow forecast to map guaranteed and projected income for the year. This is then monitored on a monthly basis to identify potential shortfalls of funding and guide fundraising strategy. In periods where cash flow is critical, an Executive Committee for Cash Flow formed of three trustees and the CEO monitors cash flow on a weekly basis to ensure continuation of the charity's activities. The trustees and staff aim to diversify the charity's funding portfolio to ensure no one fund is overly relied upon.

Having secured involvement in a multi stakeholder EU funded project in 2018, and a three-year Community Fund grant in 2019, a large proportion of our income is now derived from grant funding. To fund our outstanding costs, we are using a mixture of corporate grants, corporate sponsorship, and small trust and foundation applications. This strategy has proved successful, particularly since the appointment of our Fundraising Manager, and leaves Findacure with a diverse range of funding sources and grant durations at the present time. Community fundraising remains a very small source of income for the organisation and remains a low priority. Findacure fundamentally lacks an active base of supporters and donors, as our core beneficiaries are themselves directly involved with small charities. We do, however, continue to see success in securing unrestricted corporate donations. These are often developing into partnerships between companies keen to support our work from a corporate social responsibility perspective. This access to both funding and expertise is proving greatly beneficial to our financial security and flexibility.

To mitigate the risk of fraud, the charity employs an independent bookkeeper who monitors expenses on a monthly basis and requires receipts for all expenditure. The charity bank account is backed by several layers of security to ensure only selected senior staff (specifically the CEO and limited access for the Head of Operations) can access accounts. All cheques and bank withdrawals require at least two account signatories present, while access to our Community Fund holding account requires all transactions to be authorised by two approved individuals. Furthermore, there are internal systems in place which require large payments to receive approval from at least three signatories of the account. The trustees believe that these strategies have greatly reduced the possibility and impact of these internal risks.

The principal external risk to the organisation is clearly the response of our community - whether beneficiaries or funders - to COVID-19 and the return to restriction-free life. It remains unclear how the rare disease community will respond to the return to in-person events, though we predict a phased return within this vulnerable community. While COVID response is hard to predict, our actions over 2021, detailed above, combined with flexibility from our funders, have left Findacure in a strong position to deliver virtual training, with scope to deliver in-person events as demanded. Access to grants, both corporate and foundation-based has remained challenging, and the evolution of the funding landscape remains uncertain.

The second external risk identified is public backlash against the charity's work. To ensure that public trust is not lost, the charity is transparent about its work, also maintaining ongoing evaluations of projects to monitor impact. Ongoing work at the charity is shared in weekly blogs and summed up in annual impact reports, which are shared on the website and at events. The Patient Engagement and Scientific Advisory Committees were established to allow rare disease advocates independent input on the development and evaluation of projects. They also bring additional rare disease patient and carer perspectives to the charity, in order to ensure activities continue to meet the needs of beneficiaries.

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STRUCTURE, GOVERNANCE AND MANAGEMENT

Our rebrand also represents a risk to the organisation - as loss of recognition and brand identity could impact both our fundraising performance and beneficiary reach. Crucially, we have worked hard to inform a wide range of stakeholders about our rebranding process, engaging with them about the concept, and creating the new concepts alongside them. By launching the new brand in February 2022 at our largest ever event, we are confident that our core audience will be well aware of our new name and activities in 2022.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number

08174973 (England and Wales)

Registered Charity number

1149646

Registered office

66 Devonshire Road
CAMBRIDGE
Cambridgeshire
CB1 2BL

Trustees

A Hall Chief Medical Officer - Biotech company
E Kissmann Strategic Communication Consultant
A Milligan Consultant
N T Sireau PhD Charity Manager
S Costello Company Director
J Pisani Management Consultant and NED

Independent Examiner

Matthew Pettifer FCA
Institute of Chartered Accountants in England and Wales
Staffords
Chartered Accountants
Unit 1, Cambridge House
Camboro Business Park
Oakington Road, Girton
CAMBRIDGE
Cambridgeshire
CB3 0QH

Solicitors

White & Case LLP, 5 Old Broad Street, London, EC2N 1DW
Hogan Lovells, Atlantic House, Holborn Viaduct, London, EC1A 2FG

BEACON: FOR RARE DISEASES LTD
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REFERENCE AND ADMINISTRATIVE DETAILS

Bankers

Co-operative Bank plc
PO Box 250
Delf House
Skelmersdale
WN8 6WT

Unity Trust Bank
PO Box 7193
Planetary Road
Willenhall
WV1 9DG

CHANGE OF NAME

The charitable company passed a special resolution on 14 January 2022 changing its name from Findacure Foundation to Beacon: For Rare Diseases Ltd.

STATEMENT OF TRUSTEES' RESPONSIBILITIES

The trustees (who are also the directors of Beacon: For Rare Diseases Ltd for the purposes of company law) are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) including Financial Reporting Standard 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland"

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the trustees are required to

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

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

Report of the trustees, incorporating a strategic report, approved by order of the board of trustees, as the company directors, on and signed on the board's behalf by:

.....
N T Sireau PhD - Trustee

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION**

Independent examiner's report to the trustees of Beacon: For Rare Diseases Ltd ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 January 2022.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts 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 your 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

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a registered member of Institute of Chartered Accountants in England and Wales which is one of the listed bodies.

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 Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts 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 accounts 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.

Matthew Pettifer FCA
Institute of Chartered Accountants in England and Wales
Staffords
Chartered Accountants
Unit 1, Cambridge House
Camboro Business Park
Oakington Road, Girton
CAMBRIDGE
Cambridgeshire
CB3 0QH

Date:

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

	Notes	Unrestricted funds £	Restricted funds £	2022 Total funds £	2021 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	3	84,208	44,636	128,844	88,473
Charitable activities					
Patient Support		-	141,021	141,021	236,497
Total		84,208	185,657	269,865	324,970
EXPENDITURE ON					
Raising funds	5	34,248	5,477	39,725	45,231
Charitable activities					
Patient Support	6	59,069	219,549	278,618	150,918
Total		93,317	225,026	318,343	196,149
NET INCOME/(EXPENDITURE)		(9,109)	(39,369)	(48,478)	128,821
RECONCILIATION OF FUNDS					
Total funds brought forward		100,654	160,134	260,788	131,967
TOTAL FUNDS CARRIED FORWARD		91,545	120,765	212,310	260,788

The notes form part of these financial statements

BEACON: FOR RARE DISEASES LTD (REGISTERED NUMBER: 08174973)
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

BALANCE SHEET
31 JANUARY 2022

	Notes	Unrestricted funds £	Restricted funds £	2022 Total funds £	2021 Total funds £
FIXED ASSETS					
Tangible assets	13	1,907	-	1,907	1,659
CURRENT ASSETS					
Debtors	14	231	-	231	229
Cash at bank		93,394	120,765	214,159	263,385
		93,625	120,765	214,390	263,614
CREDITORS					
Amounts falling due within one year	15	(3,987)	-	(3,987)	(4,485)
NET CURRENT ASSETS		89,638	120,765	210,403	259,129
TOTAL ASSETS LESS CURRENT LIABILITIES		91,545	120,765	212,310	260,788
NET ASSETS		91,545	120,765	212,310	260,788
FUNDS					
	16			91,545	100,654
Unrestricted funds				120,765	160,134
Restricted funds				212,310	260,788
TOTAL FUNDS				212,310	260,788

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 January 2022.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 January 2022 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

The notes form part of these financial statements

BEACON: FOR RARE DISEASES LTD (REGISTERED NUMBER: 08174973)
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

BALANCE SHEET - continued
31 JANUARY 2022

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

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

.....
N T Sireau PhD - Trustee

The notes form part of these financial statements

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 JANUARY 2022

1. LEGAL FORM

The charity is a registered charity registered in England and Wales number 1149646 and a company limited by guarantee number 08174973 having no share capital incorporated in England and Wales.

Its registered office and principal place of business is at 66 Devonshire Road, Cambridge, CB1 2BL.

2. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

Going Concern Basis

The Trustees consider that the going concern basis is appropriate as they consider the reserves levels and secured funding to be at sufficient levels to ensure that the charity can meet its financial obligations for the next 12 to 18 months and on that basis the charity is a going concern.

Reconciliation with previous Generally Accepted Accounting Practice

In preparing the accounts, the trustees have considered whether in applying the accounting policies required by FRS102 and the Charities SORP FRS 102 the restatement of comparative items was required. None were required.

Significant judgements

Apart from those judgements involving estimations, the management has not made any judgements in the process of applying the entity's accounting policies that have significant effect on the amounts recognised in the accounts. There are no key assumptions concerning the future or other key sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next reporting period

Financial reporting standard 102 - reduced disclosure exemptions

The charitable company has taken advantage of the following disclosure exemptions in preparing these financial statements, as permitted by FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland':

- the requirements of Section 7 Statement of Cash Flows.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Income from government and other grants is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

Donated services and facilities

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

2. ACCOUNTING POLICIES - continued

Income

Donated professional services are recognised as income when the charity has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use by the charity is probable and that economic benefit can be measured reliably. On receipt, donated professional services are recognised on the basis of the value of the gift to the charity which is the amount the charity would have been willing to pay to obtain services of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Charitable activities

The trustees are of the view that the charity has one main activity - that of the provision of patient support. Charitable activity costs have therefore been allocated to this activity.

Tangible fixed assets

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

Plant and machinery - 33% on cost

Expenditure on capital items in excess of £500 is capitalised and written off over the estimated useful economic life.

Taxation

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

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Pension costs and other post-retirement benefits

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

Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments and accrued income are recognised at the amount prepaid or accrued net of any trade discounts due.

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

2. ACCOUNTING POLICIES - continued

Cash at bank and in hand

Cash at bank and in hand includes cash and short term highly liquid investments with a maturity of 3 months or less from the date of acquisition or opening of the deposit.

Creditors

Creditors are recognised when the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

3. DONATIONS AND LEGACIES

	2022	2021
	£	£
Donations	11,016	28,923
Admissions	586	5,089
Donated services and facilities	72,327	18,734
Sponsorship	44,915	34,042
Fundraising income	-	1,685
	128,844	88,473
	128,844	88,473

Donated services and facilities:

<u>Donor</u>	<u>Service donated</u>	<u>2022</u>	<u>2021</u>
Consultancy			
Costello Medical	Online training modules, video production, event support, and graphic design work	72,327	15,544
Consulting			
Little Robot	Support of running and updating the E-learning Portal	-	1,320
		72,327	16,864
		72,327	16,864
Publication			
Orphanet Journal	Pro bono publication of 'Student Voice' essay competition.	-	1,870
		-	1,870
		-	1,870
Total		72,327	18,734

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

4. INCOME FROM CHARITABLE ACTIVITIES

	Activity	2022	2021
		£	£
Grants	Patient Support	141,021	236,497

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

	2022	2021
	£	£
Takeda	10,000	-
EU H2020	31,353	-
Rhythm	-	3,000
National Lottery Community Fund	45,168	181,997
Abbvie	5,000	-
Amicus Therapeutics	5,000	5,000
Cello Health	-	5,000
Coronavirus Support Grant	-	5,000
Illumina	-	17,000
Alexion	19,500	7,000
Awards for All	10,000	10,000
Edward Gostling Foundation	-	2,500
Evolution Education Trust	5,000	-
Vertex Pharmaceuticals	10,000	-
	141,021	236,497

5. RAISING FUNDS

Raising donations and legacies

	2022	2021
	£	£
Staff costs	31,491	30,997
Entrance fees	44	-
	31,535	30,997

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

5. RAISING FUNDS - continued

Other trading activities

	2022	2021
	£	£
Event costs	8,190	14,234
Aggregate amounts	39,725	45,231

6. CHARITABLE ACTIVITIES COSTS

	Direct Costs (see note 7)	Support costs (see note 8)	Totals
	£	£	£
Patient Support	273,911	4,707	278,618

7. DIRECT COSTS OF CHARITABLE ACTIVITIES

	2022	2021
	£	£
Staff costs	141,414	98,173
Insurance	306	306
Postage and stationery	307	421
Advertising	832	545
Staff training	2,410	180
General expenses	1,164	482
Travel	2,147	2,365
IT Costs	10,935	8,623
Rent	6,643	7,796
Recruitment costs	335	490
Consultancy	105,696	25,712
Donations	75	50
Depreciation	1,647	1,015
	273,911	146,158

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

8. SUPPORT COSTS

	Management £	Finance £	Governance costs £	Totals £
Patient Support	<u>60</u>	<u>202</u>	<u>4,445</u>	<u>4,707</u>

9. NET INCOME/(EXPENDITURE)

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

	2022 £	2021 £
Depreciation - owned assets	<u>1,647</u>	<u>1,015</u>

10. TRUSTEES' REMUNERATION AND BENEFITS

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

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 January 2022 nor for the year ended 31 January 2021.

11. STAFF COSTS

	2022 £	2021 £
Wages and salaries	155,353	114,407
Social security costs	10,104	6,605
Other pension costs	7,448	8,158
	<u>172,905</u>	<u>129,170</u>

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

	2022	2021
CEO	1	1
Head of Operations	1	1
Other Officers	4	3
	<u>6</u>	<u>5</u>

No employees received emoluments in excess of £60,000.

Total employee benefit cost in the year relating to Key Management Personnel totalled £41,143 (2021: £39,663).

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	26,608	61,865	88,473
Charitable activities			
Patient Support	7,500	228,997	236,497
Total	<u>34,108</u>	<u>290,862</u>	<u>324,970</u>
EXPENDITURE ON			
Raising funds	30,997	14,234	45,231
Charitable activities			
Patient Support	(52,616)	203,534	150,918
Total	<u>(21,619)</u>	<u>217,768</u>	<u>196,149</u>
NET INCOME	55,727	73,094	128,821
Transfers between funds	700	(700)	-
Net movement in funds	56,427	72,394	128,821
RECONCILIATION OF FUNDS			
Total funds brought forward	44,227	87,740	131,967
TOTAL FUNDS CARRIED FORWARD	<u><u>100,654</u></u>	<u><u>160,134</u></u>	<u><u>260,788</u></u>

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

13. TANGIBLE FIXED ASSETS

Plant and
machinery
£

COST

At 1 February 2021
Additions

7,715
1,895

At 31 January 2022

9,610

DEPRECIATION

At 1 February 2021
Charge for year

6,056
1,647

At 31 January 2022

7,703

NET BOOK VALUE

At 31 January 2022

1,907

At 31 January 2021

1,659

14. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

2022
£

2021
£

Prepayments

231

229

15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

2022
£

2021
£

Trade creditors

-

84

Other creditors

123

723

Accrued expenses

3,864

3,678

3,987

4,485

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

16. MOVEMENT IN FUNDS

	At 1/2/21 £	Net movement in funds £	Transfers between funds £	At 31/1/22 £
Unrestricted funds				
General fund	38,814	(444)	(1,895)	36,475
Designated Fixed Asset Fund	1,659	(1,647)	1,895	1,907
Designated Projects	30,630	14,608	-	45,238
Designated Project Admin fund	29,551	(21,626)	-	7,925
	<u>100,654</u>	<u>(9,109)</u>	<u>-</u>	<u>91,545</u>
Restricted funds				
Essay Competition	-	1,048	-	1,048
Resources Hub	-	(11,757)	11,841	84
Mentoring	6,818	(468)	-	6,350
Conferences	-	2,158	-	2,158
MCDS EU H2020	45,156	7,369	-	52,525
Showcases	6,790	4,579	-	11,369
Workshops	-	(2,440)	2,440	-
Community Fund	98,620	(38,614)	(14,737)	45,269
Podcast	2,750	(788)	-	1,962
Webinars	-	(456)	456	-
	<u>160,134</u>	<u>(39,369)</u>	<u>-</u>	<u>120,765</u>
TOTAL FUNDS	<u><u>260,788</u></u>	<u><u>(48,478)</u></u>	<u><u>-</u></u>	<u><u>212,310</u></u>

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

16. MOVEMENT IN FUNDS - continued

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	73,704	(74,148)	(444)
Designated Fixed Asset Fund	-	(1,647)	(1,647)
Designated Projects	10,504	4,104	14,608
Designated Project Admin fund	-	(21,626)	(21,626)
	<hr/>	<hr/>	<hr/>
	84,208	(93,317)	(9,109)
Restricted funds			
Essay Competition	7,400	(6,352)	1,048
Resources Hub	-	(11,757)	(11,757)
Mentoring	-	(468)	(468)
Conferences	20,741	(18,583)	2,158
MCDS EU H2020	31,353	(23,984)	7,369
Showcases	30,295	(25,716)	4,579
Workshops	-	(2,440)	(2,440)
Community Fund	77,168	(115,782)	(38,614)
Podcast	18,700	(19,488)	(788)
Webinars	-	(456)	(456)
	<hr/>	<hr/>	<hr/>
	185,657	(225,026)	(39,369)
	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	269,865	(318,343)	(48,478)
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

16. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1/2/20 £	Net movement in funds £	Transfers between funds £	At 31/1/21 £
Unrestricted funds				
General fund	25,315	3,479	10,020	38,814
Designated Fixed Asset Fund	742	(1,015)	1,932	1,659
Designated Projects	18,170	53,263	(40,803)	30,630
Designated Project Admin fund	-	-	29,551	29,551
	<u>44,227</u>	<u>55,727</u>	<u>700</u>	<u>100,654</u>
Restricted funds				
Essay Competition	233	(233)	-	-
Resources Hub	502	(4,064)	3,562	-
Mentoring	4,061	370	2,387	6,818
Video Transcription	325	(340)	15	-
Conferences	1,595	(1,595)	-	-
MCDS EU H2020	63,717	(18,561)	-	45,156
Showcases	6,000	790	-	6,790
Workshops	-	(4,568)	4,568	-
Community Fund	11,307	98,958	(11,645)	98,620
Podcast	-	2,750	-	2,750
Webinars	-	(413)	413	-
	<u>87,740</u>	<u>73,094</u>	<u>(700)</u>	<u>160,134</u>
TOTAL FUNDS	<u><u>131,967</u></u>	<u><u>128,821</u></u>	<u><u>-</u></u>	<u><u>260,788</u></u>

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

16. MOVEMENT IN FUNDS - continued

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	7,895	(4,416)	3,479
Designated Fixed Asset Fund	-	(1,015)	(1,015)
Designated Projects	26,213	27,050	53,263
	<hr/>	<hr/>	<hr/>
	34,108	21,619	55,727
Restricted funds			
Essay Competition	7,251	(7,484)	(233)
Resources Hub	16,864	(20,928)	(4,064)
Mentoring	13,000	(12,630)	370
Video Transcription	-	(340)	(340)
Conferences	21,000	(22,595)	(1,595)
MCDS EU H2020	-	(18,561)	(18,561)
Showcases	16,750	(15,960)	790
Workshops	-	(4,568)	(4,568)
Community Fund	205,997	(107,039)	98,958
COVID Support	5,000	(5,000)	-
Podcast	5,000	(2,250)	2,750
Webinars	-	(413)	(413)
	<hr/>	<hr/>	<hr/>
	290,862	(217,768)	73,094
	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	<u>324,970</u>	<u>(196,149)</u>	<u>128,821</u>

Community Fund: Funding from the National Lottery Community Fund to bring together patient groups, clinicians and researchers to build a cohesive community.

Conferences Fund: Funding secured for our annual drug repurposing conference, Drug Repurposing for Rare Diseases. This year including corporate sponsorship from Healx, Pharmacomedics, Pulse Inframe, and Purposeful, sponsorship from LifeArc, and grant support from the Evolution Education Trust.

COVID Fund: Grant towards additional costs incurred as a result of the global coronavirus pandemic.

Essay Competition: corporate donations to fund prizes, travel and core costs in Findacure's annual essay competition, "The Student Voice Prize" delivered in collaboration with Medics 4 Rare Diseases. Sponsorship was received from Costello Medical Consulting Ltd, Dolon Ltd, Linguamatics, TranScript LLP and EUSA Pharma.

MCDS EU H2020 Grant: Findacure is one of 11 project partners in EU-funded clinical trial testing whether carbamazepine can be repurposed to treat the rare genetic bone disorder, metaphyseal chondrodysplasia type Schmid (MCDS).

Resources Hub: Grant funding specifically for the Online Portal.

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

16. MOVEMENT IN FUNDS - continued

Peer Mentoring: Grant funding specifically assigned to our mentoring programme - Rhythm Pharmaceuticals, Alexion, Sobi.

Podcast: Grant funding from Illumina, Alexio, Takeda nad Cambridge Healthcare research to support the Podcast project.

Showcases Fund: funds raised to deliver The International Rare Disease Showcase, a virtual multiday conference on rare disease projects across the globe in Feb 22.

Video Transcription: Funding to cover the costs of video transcription.

Webinars Fund: Funding to cover the costs of running webinars. This was combined with the empowerment community fund at the end of the year.

Workshops Fund: Any grant funding specifically assigned to the findacure patient group training workshops.

Designated Funds

Designated Fixed Asset Fund: This represents the net book value of the fixed assets and associated depreciation.

Designated Projects: This represents funds designated by the Trustees to cover the expenditure of projects where restricted funding has not been generated.

Designated Project Admin Fund: This represents funds designated by the Trustees to cover the first year of costs associated with employing a project administrator.

Transfers between funds

Transfers between funds represent the allocation of core funding from within project income.

17. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 January 2022.

18. INDEPENDENT EXAMINER FEES

Independent examiner fees of £3,220 + VAT were accrued during the year. (2021: £3,060 + VAT).

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 JANUARY 2022

	2022 £	2021 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	11,016	28,923
Admissions	586	5,089
Donated services and facilities	72,327	18,734
Sponsorship	44,915	34,042
Fundraising income	-	1,685
	<u>128,844</u>	<u>88,473</u>
Charitable activities		
Grants	141,021	236,497
	<u>141,021</u>	<u>236,497</u>
Total incoming resources	269,865	324,970
EXPENDITURE		
Raising donations and legacies		
Wages	28,325	28,133
Social security	1,750	1,457
Pensions	1,416	1,407
Entrance fees	44	-
	<u>31,535</u>	<u>30,997</u>
Other trading activities		
Event costs	8,190	14,234
Charitable activities		
Wages	127,028	86,274
Social security	8,354	5,148
Pensions	6,032	6,751
Insurance	306	306
Postage and stationery	307	421
Advertising	832	545
Staff training	2,410	180
General expenses	1,164	482
Travel	2,147	2,365
IT Costs	10,935	8,623
Rent	6,643	7,796
Recruitment costs	335	490
Carried forward	166,493	119,381

This page does not form part of the statutory financial statements

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 JANUARY 2022

	2022	2021
	£	£
Charitable activities		
Brought forward	166,493	119,381
Consultancy	105,696	25,712
Donations	75	50
Computer equipment	1,647	1,015
	<hr/> 273,911	<hr/> 146,158
Support costs		
Management		
Telephone	60	127
Finance		
Bank charges	202	197
Governance costs		
Accountancy	3,665	3,693
Bookkeeping	780	743
	<hr/> 4,445	<hr/> 4,436
Total resources expended	<hr/> 318,343	<hr/> 196,149
Net (expenditure)/income	<hr/> (48,478) <hr/>	<hr/> 128,821 <hr/>

This page does not form part of the statutory financial statements

BEACON: FOR RARE DISEASES LTD

England & Wales - Charity number 1149646

Accounts

REGISTERED COMPANY NUMBER: 08174973 (England and Wales)
REGISTERED CHARITY NUMBER: 1149646

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 JANUARY 2021
FOR
FINDACURE FOUNDATION

Staffords
Chartered Accountants
Unit 1, Cambridge House
Camboro Business Park
Oakington Road, Girton
CAMBRIDGE
Cambridgeshire
CB3 0QH

FINDACURE FOUNDATION

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FOR THE YEAR ENDED 31 JANUARY 2021

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Detailed Statement of Financial Activities	26 to 27

FINDACURE FOUNDATION

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 JANUARY 2021**

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 January 2021. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

Findacure aims to transform the way the world views rare diseases. We positively transform the lives of people affected by rare diseases and accelerate change in the field by:

- Working directly with patient groups to empower them, giving them the skills to professionalise their work, and the confidence to recognise their own expertise in their conditions.
- Building a rare disease community that supports, informs, and collaborates together for the betterment of all rare conditions.

Significant activities

About fundamental diseases

In the EU, a rare disease is defined as a condition that affects fewer than 1 in 2,000 people. Currently, more than 7,000 rare diseases have been identified, which collectively affects 3.5 million people in the UK. Despite their collective prevalence, each individual condition affects so few people that they tend to be overlooked by doctors, researchers, and the general public. As a result, living with a rare disease can be incredibly isolating; people can be kept from education, work, and their communities. As only 5% of rare diseases have a treatment, many rare disease patients are left with debilitating and degenerative conditions, with little hope for a cure.

This neglect of rare conditions has gone on for too long. Disease prevalence does not equate to the importance or impact of a condition. Many rare genetic diseases can be a template for more common illnesses or teach us about the fundamentals of human biology. By improving our knowledge of these exceptional conditions, we can identify treatments for many conditions or learn more about the way the body functions. Rare diseases are also often at the forefront of new developments in genetic medicine; gene therapies have almost exclusively been developed in this field. In this way, research into the rarest of diseases can benefit us all. Rare is fundamental. Despite this, rare diseases still receive little attention and funding from the research community. They also receive limited policy interest and are rarely part of medical training.

Those living with a rare condition are the true experts in their rare disease. They possess valuable insight into the disease's progression and have first-hand experience of symptom management. Above all, they are critical to any pursuit of treatment and have the drive to deliver improved care for themselves. They represent the patient voice; they understand patient needs for therapy and treatments. As a result, they are a key partner in patient care and research development. They are increasingly being recognised as a key partner by the pharmaceutical industry.

Findacure helps patient groups to form as well as existing groups to grow and professionalise. Through our projects, we are building a community of rare disease patient groups that has the skills and knowledge needed to better support patients, campaign for equal opportunities and drive research. We are committed to helping patient groups learn from one another, and to feel confident in engaging with researchers, pharma, and clinicians on a level footing. A unified rare disease community works much more effectively than the sum of its parts. Alongside our patient empowerment projects, Findacure works to encourage collaborative research into rare diseases by running events, such as our annual conference and showcases, which bring patients, clinicians, researchers, and industry together.

Public benefit

The trustees have complied with Section 17(5) of the Charities Act 2011 and have had due regard to the guidance on Public Benefit by the Charity Commission when exercising relevant powers and duties. See "About Fundamental Diseases" section for details of how the charity provides public benefit.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2021

ACHIEVEMENT AND PERFORMANCE

Charitable activities

Findacure's core aim is to provide support and guidance to the rare disease patient group community. We help them achieve their goals and share their experiences so that all can learn from one another. The year 2020 has presented some of the biggest challenges to that community to date. COVID-19 shut down the ability to meet other people and dramatically reduced community funding, directing most grant funding to schemes working to directly deal with the impact of the pandemic. Over the course of the year Findacure has had to rapidly evolve its own working model, while providing advice and support to patient organisations trying to do the same. This transition has been aided by two factors. First, our funding stability and flexibility. This allowed us to redirect our training efforts to platforms and topics that are most appropriate to the time. Second, a hugely dedicated and creative staff team. They have found ways to rapidly adapt their work and ideas to a new virtual world and continue to deliver meaningful services and support to patients.

Over the course of the 2020 COVID-19 pandemic, under the auspices of our National Lottery Community fund grant, Findacure delivered the following projects:

- Launched and delivered an online patient group mentoring programme, including masterclass style training in "talking heads" video production
- Ran a focus group on the impact of COVID-19 on rare diseases.
- Delivered 6 webinars on the role of drug repurposing in COVID-19 and rare diseases, the recruitment and management of trustees, funding opportunities with the National Lottery during COVID-19, early access to medicines, building your patient group data, and natural history studies.
- Launched a new community catch up project called RareChat. This ran every three weeks across the year.
- Released e-learning guides on leading a rare patient group, running virtual events, fundraising, recruiting, and managing trustees.
- Developed a new online workshop format delivering four events to date covering fundraising, online communications, collaborations, and diversity in rare diseases.
- Began the development of a new WordPress-based e-learning hub to replace our old online portal.

This work package represents a significant expansion of our planned deliverables for our first year of the empowerment programme grant. During this time, we maintained a mixture of trainings: some tailored to support our community through its COVID-19 response, and the rest following our pre-COVID plans. Over the course of the first year of our empowerment programme, we had 482 attendees at our webinar and workshop programme alone. This is a fantastic reach for our projects. It highlights the need for our services, and Findacure's impact during the COVID pandemic.

Outside of our Empowerment Programme, Findacure's Uniting Communities projects, which include our annual conference, showcase series, and essay competition, continue to go from strength to strength. The 7th annual Drug Repurposing for Rare Diseases Conference was held in February to mark Rare Disease Day and was one of the last pre-lockdown events in the UK Rare Disease calendar. It was our largest ever conference, with over 130 delegates in attendance. It was also our largest total sponsorship and most-extensive exhibition. Due to COVID-19, our annual Showcase series became a single online event, the Virtual Rare Disease Showcase. This was our first ever multi-day conference, delivered over 3 days on the Swapcard platform. We saw over 300 people attending the event, including many delegates from beyond the UK. This was by far and away our largest ever showcase. It fully embraced the power of a digital platform to engage our audience with lectures, discussion, networking, and interactive sessions. These two events have helped to grow awareness about Findacure, increased our reputation for professionalism and engagement, and created hundreds of opportunities for novel conversations and connections within the rare disease community.

In addition to the success of our events programme, The Student Voice Prize annual essay competition matured into a truly collaborative project with Medics 4 Rare Diseases (M4RD) in 2020. We created a new shared identity for the programme, and delivered the work in a completely new, more collaborative manner. The significant effort put into this project proved hugely beneficial, with over 60% more entries than our previous high and the highest standard of writing in our shortlist to date. We will work closely with M4RD to continue the growth and professionalism of this programme in the future.

FINDACURE FOUNDATION

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 JANUARY 2021**

The MCDS-Therapy project saw significant progress in 2020 due to the appointment of a new Marketing and Engagement Manager to lead the day-to-day work. She has revamped and re-engaged with our social media audience, worked to update and refine the website, and has recently been working to support recruitment to a satellite study on Health Economics in achondroplasia. Our broader promotion of the project and drug repurposing in general has continued, with our CEO Rick Thompson once again teaching at the Eurordis Winter School and chairing a panel on patient engagement in research at the World Orphan Drug Congress, Europe 2020.

Internal and external factors

COVID-19 has been the single biggest external factor influencing the running of the charity since its inception. National lockdown in March 2020 caused a hard stop on our face-to-face events, which we do not expect to resume until 2022. As such, the organisation had to rapidly adapt to a new model of working and service delivery.

Our staff team were all transitioned to home working, with additional expenditure on computing equipment and software to facilitate remote communication. We also worked to rapidly develop new online training structures. We developed a new multi-day virtual format to replace our patient group training workshops. Alongside this, the organisation sought to consult our community as to their most pressing needs during COVID-19. This led to the delivery of many COVID-related training events in spring and summer 2020.

These changes to our working practices have been dramatic, but the transition to the virtual world has been successful. We have seen a high level of engagement across our events, alongside continued positive feedback. Due to our pre-existing financial stability, our stable staff and trustee team, and limited reliance on community fundraising, we have been extraordinarily well placed to ride out the pandemic. Furthermore, our existing project funding included significant budget for live events, which we have been unable to spend as planned. This has left a significant underspend in our budgets that we are working to reassign and rectify with funders. We have already been able to take on a new permanent Marketing and Engagement Manager to improve our online presence and event outreach. We will appoint a new Projects Administrator using a new ring-fenced fund at the start of the next financial year.

Therefore, despite the hugely challenging nature of 2020, Findacure has emerged in its strongest ever position both financially and structurally. We are ready to roll our work out on a bigger scale, in new ways, and to help the rare disease community that has been disproportionately impacted by COVID-19.

FINDACURE FOUNDATION

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 JANUARY 2021**

ACHIEVEMENT AND PERFORMANCE

Partnerships

Our on-going involvement in the EU-funded study, MCDS-Therapy, remains our largest collaborative project. Findacure is taking a key role in the communication, dissemination, and recruitment of patients for the project's clinical trial. This project involves close interaction with stakeholders at Newcastle University and Newcastle Hospital's NHS Foundation Trusts, as well as partners across Europe. It is an exceptional learning opportunity for our team.

Findacure and Medics4RareDiseases - now a registered charity dedicated to raising awareness about rare diseases within the medical profession - have continued the collaboration on our rebranded essay competition, The Student Voice Prize. This was particularly successful in 2020, with increased collaboration between the teams, new branding, and improved social media helping to drastically increase both number and quality of entrants. We maintained our partnership with the Orphanet Journal of Rare Diseases and BioMed Central, which once again published the winning entry from our student essay competition in their journal alongside three other entries on their "On Medicine" blog.

From the start of the COVID-19 pandemic, Findacure also engaged with the cross-sector rare disease group, ARDEnt, which aimed to capture and chronicle the impact of the pandemic on rare disease patients and service. While our role was minimal, we were proud to engage in research and discussions on this topic and look forward to the report's publication in 2021. This type of collaboration has strengthened the links between the rare disease community and will provide fruitful ground for collaborative projects in the years ahead.

We have maintained several relationships with corporate partners that have provided pro bono support to Findacure over the year, as well as some financial support. Costello Medical Consulting, Cello Health, Kudos Health and Little Robot have all provided valuable support to our work over the year.

It is also worth noting that the majority of Findacure's training events rely on the support and collaboration of our many friends and partners throughout the rare disease world. Our trainers come from patient organisations, charities, and industry groups across the sector, providing their knowledge and time to support our work. We also receive regular support in promoting events from Genetic Alliance UK, Rare Revolution Magazine, Cambridge Rare Disease Network and EMIG (The Ethical Medicines Industry Group).

FINANCIAL REVIEW

Financial position

With long term grants secured and a strengthening relationship with our corporate partners thanks to the work of our dedicated fundraising manager, Findacure is in a strong financial position at the end of this financial year. COVID-19 has created an incredibly challenging environment for charities, but with our funding streams well developed prior to its emergence, we have been able to remain secure. In fact, COVID-19 has severely limited our capacity to spend funds, as we have been unable to deliver face-to-face events. Consequently, we are holding significant funds for our empowerment programme, which were earmarked for project delivery in 2020. We have had productive conversations with our funders during this time, and are working on a range of projects, including a revamp of our e-learning portal, to maximise the impact of this funding in the virtual environment. We have also been able to create a ring-fenced fund to cover a sixth member of staff, who will begin with the organisation at the start of the new financial year.

Our current focus is on the completion of fundraising for the year three empowerment programme. We will then switch our attention to long-term grants that will take us beyond the Community Fund grant, which ends in July 2022.

FINDACURE FOUNDATION

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 JANUARY 2021**

FINANCIAL REVIEW

Principal funding sources

The principal funding source in this period was grant funding from the National Lottery Community Fund to support our empowerment programme. Payments totalled £182,468.44, equating to payments for the second half of year one and the entirety of year two. These payments were supplemented by a further £17,500 grant funding, and £94,448.05 in corporate grants, donations, and sponsorships. Grant funding included £10,000 from the National Lottery Awards for All scheme, a £5000 grant from the Coronavirus Community Fund for our COVID response projects, and a £2500 grant from the Edward Gosling Foundation. Our major corporate supporters included Illumina (£12,000 grant for our empowerment programme; £5,000 support for our podcast project, and a donation in excess of £9000), Healx (£8,000 grant supporting Findacure's patient engagement activities), Sobi (£10,000 grant supporting our patient group mentoring programme), Cello Health (£10,000 donation), Alexion (£7,000 grant in support of our training on mental health for rare disease patient groups) and Amicus (£5,000 grant for our empowerment programme). This all totalled to make it our most successful year for funding to date.

Reserves policy & review

At any time, the charity aims to maintain reserves of sufficient levels to meet its contractual obligations for three months. This is through a combination of unrestricted and restricted funding to pay overheads and fulfil grant requirements.

At the end of the reporting period, the charity holds £260,788 (2020: £131,967) of which: £160,134 (2020: £87,740) is in restricted funds, and £100,654 (2020: £44,227) is in unrestricted funds.

£38,814 of the latter is explicitly assigned to our strategic reserve, which falls roughly £1,000 short of the costs of maintaining our staff team for three months and excludes the significant restricted funds held for salaries and overheads. The restricted funds carried forward are committed to be spent in 2021 on the charity's projects and overheads, including: on-going delivery of the Empowerment Programme (including the E-learning portal, patient group workshops, webinars, and mentoring scheme); the delivery of the Drug Repurposing for Rare Disease Conference 2021 and Rare Disease Showcase; the establishment of a new rare disease podcast series; the delivery of communication and dissemination responsibilities for MCDS-Therapy.

Going concern

The trustees believe that the Charity has sufficient funding in place to continue for at least the next 12 months and the accounts have therefore been prepared on a going concern basis.

FUTURE PLANS

With a strong financial position at the end of 2020, our attention has turned to securing grants to support Findacure beyond the end of our National Lottery Community Fund grant in 2022. We are looking to develop a number of new projects within the empowerment programme and want to use this innovation to drive further corporate support, and to instigate collaborative grants with other organisations in the sector. In the post-COVID funding environment, collaborative applications are likely to be viewed favourably by funders and we are well placed to develop such applications in 2021.

Alongside this development of the empowerment programme, we plan to turn our attention to the branding and messaging of the organisation. This has not been reviewed since our launch, and we plan to review it to ensure we are projecting the best and most accurate message to our key stakeholders. Alongside this we will look to firm up our mission in the repurposing field, ensuring that our role in this area goes beyond our annual conference.

As noted already, Findacure's sixth staff member will begin with the organisation at the start of the 2021/22 financial year, and we will continue to explore options to expand our staff team to address the growing needs of our beneficiaries post-COVID. We also expect to focus on the development and promotion of our e-learning platform, rebranded the "resource Hub" in 2021, as a vital tool to increase the reach of our work and the skills of our community. The increasing staff team and online reach will also allow us to promote training that highlights the role of important social issues, such as mental health and diversity in the field of rare diseases, and to explore options to help patient groups take the difficult step to secure their first paid employees.

FINDACURE FOUNDATION

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 JANUARY 2021**

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

The charity's objects, as set out in its Articles of Association, are:

- 1 To advance the education of the general public in all areas relating to fundamental diseases and their causes, effects and treatments;
- 2 To promote and protect the physical and mental health of sufferers of fundamental diseases and their carers through the provision of support, education and practical advice;
- 3 To support research into the causes, effects, treatment and management of fundamental diseases and their application to common diseases, and disseminate the useful results thereof.

Since the drafting of the objects the term "fundamental diseases" has been reconsidered and the term "rare diseases" is used in its place.

Charity Constitution

The constitutional provisions relating to appointment and removal of trustees are:

- There should be a minimum of 3 trustees but no maximum.
- Appointment is by Ordinary Resolution
- A third of trustees retire by rotation at each AGM, but may be re-elected.

Trustees cease to hold office if:

- They cease to be a director by virtue of any provision in the Companies Acts or is prohibited by law from being a director
- They are disqualified from acting as a trustee by virtue of sections 178 and 179 of the Charities Act 2011;
- If they cease to be a member of the charity
- If they become incapable by reason of mental disorder, illness or injury of managing and administering their own affairs
- If they resign as a director by notice to the charity (as long as at least two directors will remain in office when the notice takes effect);
- If they are absent without the permission of the directors from all their meetings held within a period of 6 consecutive months and the directors resolve that his or her office be vacated.

Recruitment and appointment of new trustees

In 2019 Findacure implemented a new Trustee recruitment process, with the aim of identifying candidates with new skills and experience needed for the organisation, and to find candidates with a desire to support our mission. We created a job specification and position, advertised it widely and accepted applications for a fixed time period. This was followed by phone and face to face interviews with the CEO and existing board members. Successful candidates were invited to attend a board meeting before formally accepting the position of trustee, and appointment at the next board meeting.

FINDACURE FOUNDATION

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 JANUARY 2021**

STRUCTURE, GOVERNANCE AND MANAGEMENT

Organisational structure

Findacure has six governing trustees, who meet on a quarterly basis with the Chief Executive Officer (CEO) to discuss the charity's activities and impact. The CEO is the most senior management personnel, and line manages two members of staff: The Head of Operations and Fundraising Manager. The Head of Operations line manages our Projects Officer, and all staff members perform ad hoc volunteer management.

The CEO takes advice on rare disease patient empowerment from the Patient Engagement Committee, which comprises of seven advisors. This Committee serves for two years before applications are opened for reappointments and new members, with a majority of advisors having a personal experience of a rare disease.

The CEO takes scientific advice from the Scientific Advisory Committee. This Committee has biennial rotating membership, with at least one member having a personal experience of a rare disease.

The trustees delegate day-to-day management of the charity to the CEO. They take legal advice from Hogan Lovells and White & Case, and financial advice from Staffords Chartered Accountants.

Decision making

As the responsible managing body for the charity, the board of trustees make decisions on the strategic direction for the charity, as well as decisions relating to significant financial commitments and the hiring of new staff. Operational matters are delegated to staff, and trustees are kept abreast of developments in monthly updates and quarterly trustee meetings.

Induction and training of new trustees

New trustees follow an induction programme to ensure they integrate effectively into the board. They receive an induction pack which contains the charity's governing document, accounts, key policies, strategic plan, overview of the charity's history and ethos, and guiding documents from the Charity Commission on being a trustee. The new trustee then meets individually with all fellow board members and the CEO. They are also introduced to the staff and volunteers to gain a full understanding of the charity and its people.

Key management remuneration

In the fourth quarter of the year, the CEO prepares the budget for the coming year based on secured and projected income. As this time, provisional salaries for the year are calculated, taking performance, inflation rates, and the available budget into consideration. The CEO compiles a business plan for any salary changes, which is put to the board for a unified decision on remuneration.

Wider network

Findacure is a member of Rare Disease International, a global alliance of people living with a rare disease, as well as a member of Rare Disease UK, Genetic Alliance UK, Rare Revolution Magazine, The Cambridge Network, and an associate member of EURORDIS Rare Diseases Europe. Involvement in these networks builds the charity's reputation and allows Findacure to contribute to international efforts to support rare diseases. Membership in EURORDIS requires Findacure to remain financially independent, particularly from the pharmaceutical industry, limiting pharma funding to a maximum of 50% of the charity's revenue. Findacure is also registered with the Fundraising Regulator and as such is committed to best practice in fundraising.

Findacure is part of the MCDS-Therapy consortium, an international collaboration to drive the repurposing of a generic drug to treat metaphyseal chondrodysplasia type Schmid. This group includes universities, hospitals, and SME's around the world.

Related parties

There are no material related party transactions which were not concluded under normal market conditions.

FINDACURE FOUNDATION

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 JANUARY 2021**

STRUCTURE, GOVERNANCE AND MANAGEMENT

Risk management

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

The trustees compile a risk register and monitor it on an annual basis to ensure all potential risks are identified and strategies are put in place to manage them. The principal internal risks identified are having insufficient funding to fulfil charitable aims and the potential for fraud. To mitigate insufficient funding, the CEO draws up an annual cash flow forecast to map guaranteed and projected income for the year. This is then monitored on a monthly basis to identify potential shortfalls of funding and guide fundraising strategy. In periods where cash flow is critical, an Executive Committee for Cash Flow formed of three trustees and the CEO monitors cash flow on a weekly basis to ensure continuation of the charity's activities. The trustees and staff aim to diversify the charity's funding portfolio to ensure no one fund is overly relied upon.

Having secured involvement in a multi stakeholder EU funded project in 2018, and a three-year Community Fund grant in 2019, a large proportion of our income is now derived from grant funding. To fund our outstanding costs, we are using a mixture of corporate grants, corporate sponsorship, and small trust and foundation applications. This strategy has proved successful, particularly since the appointment of our new Fundraising Manager, and leaves Findacure with a diverse range of funding sources and grant durations at the present time. Community fundraising remains a very small source of income for the organisation and remains a low priority. Findacure fundamentally lacks an active base of supporters and donors, as our core beneficiaries are themselves directly involved with small charities. We do, however, continue to see success in securing unrestricted corporate donations. These are often developing into partnerships between companies keen to support our work from a corporate social responsibility perspective. This access to both funding and expertise is proving greatly beneficial to our financial security and flexibility.

To mitigate the risk of fraud, the charity employs an independent bookkeeper who monitors expenses on a monthly basis and requires receipts for all expenditure. The charity bank account is backed by several layers of security to ensure only selected senior staff (specifically the CEO and limited access for the Head of Operations) can access accounts. All cheques and bank withdrawals require at least two account signatories present, while access to our Community Fund holding account requires all transactions to be authorised by two approved individuals. Furthermore, there are internal systems in place which require large payments to receive approval from at least three signatories of the account. The trustees believe that these strategies have greatly reduced the possibility and impact of these internal risks.

The principal external risk to the organisation is clearly the emergence of the COVID-19 global pandemic and the significant uncertainty and instability it has created. Such risks are hard to predict, but our actions over 2020, detailed above, combined with flexibility from our funders have left Findacure in a strong position after the first year of COVID. Moving forward, we are well insulated from the clear reduction in community fundraising caused by COVID-19, as this forms a small part of our income. Access to grants has become more challenging, but we hope that over the coming year our strong performance in 2020, combined with our growing visibility and impact will make us an attractive prospect for grant funders. Aside from funding, we have proven in 2020 that our projects and benefit can be delivered in an impactful manner in a virtual world, and we will continue with this model for as long as it benefits patient groups.

The second external risk identified is public backlash against the charity's work. To ensure that public trust is not lost, the charity is transparent about its work, also maintaining ongoing evaluations of projects to monitor impact. Ongoing work at the charity is shared in weekly blogs and summed up in annual impact reports, which are shared on the website and at events. The Patient Engagement and Scientific Advisory Committees were established to allow rare disease advocates independent input on the development and evaluation of projects. They also bring additional rare disease patient and carer perspectives to the charity in order to ensure activities continue to meet the needs of beneficiaries.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number

08174973 (England and Wales)

Registered Charity number

1149646

FINDACURE FOUNDATION

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 JANUARY 2021

Registered office

66 Devonshire Road
CAMBRIDGE
Cambridgeshire
CB1 2BL

Trustees

A Hall Chief Medical Officer - Biotech company
E Kissmann Strategic Communication Consultant
A Milligan Consultant
N T Sireau PhD Charity Manager
S Costello Company Director
J Pisani Management Consultant and NED

Independent Examiner

Matthew Pettifer FCA
Institute of Chartered Accountants in England and Wales
Staffords
Chartered Accountants
Unit 1, Cambridge House
Camboro Business Park
Oakington Road, Girton
CAMBRIDGE
Cambridgeshire
CB3 0QH

Solicitors

White & Case LLP, 5 Old Broad Street, London, EC2N 1DW
Hogan Lovells, Atlantic House, Holborn Viaduct, London, EC1A 2FG

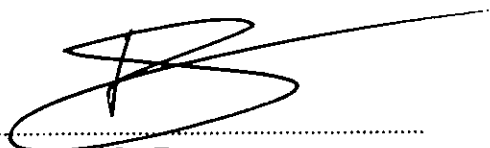
Bankers

Co-operative Bank plc
PO Box 250
Delf House
Skelmersdale
WN8 6WT

Unity Trust Bank
PO Box 7193
Planetary Road
Willenhall
WV1 9DG

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

Approved by order of the board of trustees on 29/10/2021 and signed on its behalf by:


.....
N T Sireau PhD - Trustee

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
FINDACURE FOUNDATION**

Independent examiner's report to the trustees of Findacure Foundation ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 January 2021.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts 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 your 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

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a registered member of Institute of Chartered Accountants in England and Wales which is one of the listed bodies.

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 Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts 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 accounts 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.



Matthew Pettifer FCA
Institute of Chartered Accountants in England and Wales
Staffords
Chartered Accountants
Unit 1, Cambridge House
Camboro Business Park
Oakington Road, Girton
CAMBRIDGE
Cambridgeshire
CB3 0QH

Date: 29/10/21

FINDACURE FOUNDATION

STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 JANUARY 2021

	Notes	Unrestricted funds £	Restricted funds £	2021 Total funds £	2020 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	3	26,608	61,865	88,473	75,827
Charitable activities	4				
Patient Support		7,500	228,997	236,497	110,838
Total		<u>34,108</u>	<u>290,862</u>	<u>324,970</u>	<u>186,665</u>
EXPENDITURE ON					
Raising funds	5	30,997	14,234	45,231	40,157
Charitable activities	6				
Patient Support		(52,616)	203,534	150,918	154,138
Total		<u>(21,619)</u>	<u>217,768</u>	<u>196,149</u>	<u>194,295</u>
NET INCOME/(EXPENDITURE)		<u>55,727</u>	<u>73,094</u>	<u>128,821</u>	<u>(7,630)</u>
Transfers between funds	16	700	(700)	-	-
Net movement in funds		<u>56,427</u>	<u>72,394</u>	<u>128,821</u>	<u>(7,630)</u>
RECONCILIATION OF FUNDS					
Total funds brought forward		44,227	87,740	131,967	139,597
TOTAL FUNDS CARRIED FORWARD		<u><u>100,654</u></u>	<u><u>160,134</u></u>	<u><u>260,788</u></u>	<u><u>131,967</u></u>

The notes form part of these financial statements

FINDACURE FOUNDATION (REGISTERED NUMBER: 08174973)

BALANCE SHEET
31 JANUARY 2021

	Notes	Unrestricted funds £	Restricted funds £	2021 Total funds £	2020 Total funds £
FIXED ASSETS					
Tangible assets	13	1,659	-	1,659	742
CURRENT ASSETS					
Debtors	14	229	-	229	229
Cash at bank		102,567	160,818	263,385	136,056
		<u>102,796</u>	<u>160,818</u>	<u>263,614</u>	<u>136,285</u>
CREDITORS					
Amounts falling due within one year	15	(3,801)	(684)	(4,485)	(5,060)
NET CURRENT ASSETS		<u>98,995</u>	<u>160,134</u>	<u>259,129</u>	<u>131,225</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>100,654</u>	<u>160,134</u>	<u>260,788</u>	<u>131,967</u>
NET ASSETS		<u>100,654</u>	<u>160,134</u>	<u>260,788</u>	<u>131,967</u>
FUNDS	16				
Unrestricted funds				100,654	44,227
Restricted funds				160,134	87,740
TOTAL FUNDS				<u>260,788</u>	<u>131,967</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 January 2021.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 January 2021 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

The notes form part of these financial statements

BALANCE SHEET - continued

31 JANUARY 2021

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

The financial statements were approved by the Board of Trustees and authorised for issue on29/10/2021..... and were signed on its behalf by:



.....
N T Sireau PhD - Trustee

The notes form part of these financial statements

FINDACURE FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 JANUARY 2021

1. LEGAL FORM

The charity is a registered charity registered in England and Wales number 1149646 and a company limited by guarantee number 08174973 having no share capital incorporated in England and Wales.

Its registered office and principal place of business is at 66 Devonshire Road, Cambridge, CB1 2BL.

2. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

Going Concern Basis

The Trustees consider that the going concern basis is appropriate as they consider the reserves levels and secured funding to be at sufficient levels to ensure that the charity can meet its financial obligations for the next 12 to 18 months and on that basis the charity is a going concern.

Reconciliation with previous Generally Accepted Accounting Practice

In preparing the accounts, the trustees have considered whether in applying the accounting policies required by FRS102 and the Charities SORP FRS 102 the restatement of comparative items was required. None were required.

Significant judgements

Apart from those judgements involving estimations, the management has not made any judgements in the process of applying the entity's accounting policies that have significant effect on the amounts recognised in the accounts. There are no key assumptions concerning the future or other key sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next reporting period

Financial reporting standard 102 - reduced disclosure exemptions

The charitable company has taken advantage of the following disclosure exemptions in preparing these financial statements, as permitted by FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland':

- the requirements of Section 7 Statement of Cash Flows.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Income from government and other grants is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

Donated services and facilities

FINDACURE FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 JANUARY 2021

2. ACCOUNTING POLICIES - continued

Income

Donated professional services are recognised as income when the charity has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use by the charity is probable and that economic benefit can be measured reliably. On receipt, donated professional services are recognised on the basis of the value of the gift to the charity which is the amount the charity would have been willing to pay to obtain services of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Charitable activities

The trustees are of the view that the charity has one main activity - that of the provision of patient support. Charitable activity costs have therefore been allocated to this activity.

Tangible fixed assets

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

Plant and machinery - 33% on cost

Expenditure on capital items in excess of £500 is capitalised and written off over the estimated useful economic life.

Taxation

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

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Pension costs and other post-retirement benefits

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

Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments and accrued income are recognised at the amount prepaid or accrued net of any trade discounts due.

Cash at bank and in hand

Cash at bank and in hand includes cash and short term highly liquid investments with a maturity of 3 months or less from the date of acquisition or opening of the deposit.

Creditors

FINDACURE FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2021

2. ACCOUNTING POLICIES - continued

Creditors are recognised when the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

3. DONATIONS AND LEGACIES

	2021	2020
	£	£
Donations	28,923	8,389
Admissions	5,089	7,491
Donated services and facilities	18,734	24,911
Sponsorship	34,042	33,700
Fundraising income	1,685	1,336
	88,473	75,827
	88,473	75,827
 Donated services and facilities:		
<u>Donor</u>	<u>Service donated</u>	
Venue Hire		
White & Case LLP	Pro bono venue for Findacure's workshop on Online Communications	- 1,171
		- 1,171
Consultancy		
Costello Medical Consulting	Online training modules, video production, event support, and graphic design work	15,544 19,870
Little Robot	Support of running and updating the E-learning Portal	1,320 1,320
		16,864 21,190
Publication		
Orphanet Journal	Pro bono publication of 'Student Voice' essay competition.	1,870 1,870
		1,870 1,870
Legal Fees		
Weightmans	Production of employment contracts	- 680
		- 680
Total		18,734 24,911

FINDACURE FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2021

4. INCOME FROM CHARITABLE ACTIVITIES

		2021	2020
	Activity	£	£
Grants	Patient Support	236,497	110,838

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

	2021	2020
	£	£
EU H2020	-	30,851
Rhythm	3,000	-
National Lottery Community Fund	181,997	64,487
Amicus Therapeutics	5,000	3,000
Swedish Orphan Biovitrum	-	5,000
Cello Health	5,000	7,500
Coronavirus Support Grant	5,000	-
Illumina	17,000	-
Alexion	7,000	-
Awards for All	10,000	-
Edward Gostling Foundation	2,500	-
	236,497	110,838

5. RAISING FUNDS

Raising donations and legacies

	2021	2020
	£	£
Staff costs	30,997	13,601
Entrance fees	-	1,116
	30,997	14,717

Other trading activities

	2021	2020
	£	£
Event costs	14,234	25,440
	45,231	40,157

FINDACURE FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2021

6. CHARITABLE ACTIVITIES COSTS

	Direct Costs (see note 7) £	Support costs (see note 8) £	Totals £
Patient Support	<u>146,158</u>	<u>4,760</u>	<u>150,918</u>

7. DIRECT COSTS OF CHARITABLE ACTIVITIES

	2021 £	2020 £
Staff costs	98,173	91,693
Insurance	306	306
Postage and stationery	421	1,909
Advertising	545	950
Staff training	180	640
General expenses	482	2,027
Travel	2,365	8,040
IT Costs	8,623	2,585
Rent	7,796	11,097
Recruitment costs	490	5,494
Consultancy	25,712	23,574
Donations	50	-
Depreciation	1,015	569
	<u>146,158</u>	<u>148,884</u>

8. SUPPORT COSTS

	Management £	Finance £	Governance costs £	Totals £
Patient Support	<u>127</u>	<u>197</u>	<u>4,436</u>	<u>4,760</u>

9. NET INCOME/(EXPENDITURE)

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

	2021 £	2020 £
Depreciation - owned assets	<u>1,015</u>	<u>569</u>

FINDACURE FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2021

10. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 January 2021 nor for the year ended 31 January 2020.

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 January 2021 nor for the year ended 31 January 2020.

11. STAFF COSTS

	2021	2020
	£	£
Wages and salaries	114,407	92,842
Social security costs	6,605	5,520
Other pension costs	8,158	6,932
	<u>129,170</u>	<u>105,294</u>

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

	2021	2020
CEO	1	1
Head of Operations	1	1
Other Officers	3	2
	<u>5</u>	<u>4</u>

No employees received emoluments in excess of £60,000.

Total employee benefit cost in the year relating to Key Management Personnel totalled £39,663 (2020: £35,652).

12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	46,873	28,954	75,827
Charitable activities			
Patient Support	13,214	97,624	110,838
Total	<u>60,087</u>	<u>126,578</u>	<u>186,665</u>
EXPENDITURE ON			
Raising funds	14,769	25,388	40,157
Charitable activities			
Patient Support	45,550	108,588	154,138

FINDACURE FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2021

12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

	Unrestricted funds £	Restricted funds £	Total funds £
	<u> </u>	<u> </u>	<u> </u>
Total	60,319	133,976	194,295
NET INCOME/(EXPENDITURE)	(232)	(7,398)	(7,630)
Transfers between funds	2,096	(2,096)	-
Net movement in funds	1,864	(9,494)	(7,630)
RECONCILIATION OF FUNDS			
Total funds brought forward	42,363	97,234	139,597
TOTAL FUNDS CARRIED FORWARD	<u>44,227</u>	<u>87,740</u>	<u>131,967</u>

13. TANGIBLE FIXED ASSETS

	Plant and machinery £
COST	
At 1 February 2020	5,783
Additions	1,932
At 31 January 2021	<u>7,715</u>
DEPRECIATION	
At 1 February 2020	5,041
Charge for year	1,015
At 31 January 2021	<u>6,056</u>
NET BOOK VALUE	
At 31 January 2021	<u>1,659</u>
At 31 January 2020	<u>742</u>

FINDACURE FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2021

14. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR				
		2021	2020	
		£	£	
Prepayments		229	229	
		<u> </u>	<u> </u>	
15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR				
		2021	2020	
		£	£	
Trade creditors		84	572	
Other creditors		723	730	
Accrued expenses		3,678	3,758	
		<u> </u>	<u> </u>	
		4,485	5,060	
		<u> </u>	<u> </u>	
16. MOVEMENT IN FUNDS				
	At 1/2/20	Net movement in funds	Transfers between funds	At 31/1/21
	£	£	£	£
Unrestricted funds				
General fund	25,315	3,479	10,020	38,814
Designated Fixed Asset Fund	742	(1,015)	1,932	1,659
Designated Projects	18,170	53,263	(40,803)	30,630
Designated Project Admin fund	-	-	29,551	29,551
	<u> </u>	<u> </u>	<u> </u>	<u> </u>
	44,227	55,727	700	100,654
Restricted funds				
Essay Competition	233	(233)	-	-
Online e-learning Portal	502	(4,064)	3,562	-
Mentoring	4,061	370	2,387	6,818
Video Transcription	325	(340)	15	-
Conferences	1,595	(1,595)	-	-
MCDS EU H2020	63,717	(18,561)	-	45,156
Showcases	6,000	790	-	6,790
Workshops	-	(4,568)	4,568	-
Community Fund	11,307	98,958	(11,645)	98,620
Podcast	-	2,750	-	2,750
Webinars	-	(413)	413	-
	<u> </u>	<u> </u>	<u> </u>	<u> </u>
	87,740	73,094	(700)	160,134
	<u> </u>	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	131,967	128,821	-	260,788
	<u> </u>	<u> </u>	<u> </u>	<u> </u>

FINDACURE FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2021

16. MOVEMENT IN FUNDS - continued

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	7,895	(4,416)	3,479
Designated Fixed Asset Fund	-	(1,015)	(1,015)
Designated Projects	26,213	27,050	53,263
	<u>34,108</u>	<u>21,619</u>	<u>55,727</u>
Restricted funds			
Essay Competition	7,251	(7,484)	(233)
Online e-learning Portal	16,864	(20,928)	(4,064)
Mentoring	13,000	(12,630)	370
Video Transcription	-	(340)	(340)
Conferences	21,000	(22,595)	(1,595)
MCDS EU H2020	-	(18,561)	(18,561)
Showcases	16,750	(15,960)	790
Workshops	-	(4,568)	(4,568)
Community Fund	205,997	(107,039)	98,958
COVID Support	5,000	(5,000)	-
Podcast	5,000	(2,250)	2,750
Webinars	-	(413)	(413)
	<u>290,862</u>	<u>(217,768)</u>	<u>73,094</u>
TOTAL FUNDS	<u><u>324,970</u></u>	<u><u>(196,149)</u></u>	<u><u>128,821</u></u>

FINDACURE FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2021

16. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1/2/19 £	Net movement in funds £	Transfers between funds £	At 31/1/20 £
Unrestricted funds				
General fund	32,370	1,516	(8,571)	25,315
Designated Fixed Asset Fund	198	(569)	1,113	742
Designated Projects	9,795	(1,179)	9,554	18,170
	<u>42,363</u>	<u>(232)</u>	<u>2,096</u>	<u>44,227</u>
Restricted funds				
Rare Cancer Research Fund	119	-	(119)	-
Essay Competition	-	233	-	233
Online e-learning Portal	638	(604)	468	502
Mentoring	15,480	(8,905)	(2,514)	4,061
Video Transcription	420	(95)	-	325
Conferences	10,387	(8,792)	-	1,595
MCDS EU H2020	61,267	2,450	-	63,717
Showcases	2,108	3,206	686	6,000
Workshops	6,815	(4,698)	(2,117)	-
Community Fund	-	9,807	1,500	11,307
	<u>97,234</u>	<u>(7,398)</u>	<u>(2,096)</u>	<u>87,740</u>
TOTAL FUNDS	<u>139,597</u>	<u>(7,630)</u>	<u>-</u>	<u>131,967</u>

FINDACURE FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 JANUARY 2021

16. MOVEMENT IN FUNDS - continued

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	27,877	(26,361)	1,516
Designated Fixed Asset Fund	-	(569)	(569)
Designated Projects	32,210	(33,389)	(1,179)
	<u>60,087</u>	<u>(60,319)</u>	<u>(232)</u>
Restricted funds			
Essay Competition	2,103	(1,870)	233
Online e-learning Portal	1,700	(2,304)	(604)
Mentoring	2,287	(11,192)	(8,905)
Video Transcription	-	(95)	(95)
Conferences	6,825	(15,617)	(8,792)
MCDS EU H2020	30,851	(28,401)	2,450
Showcases	17,154	(13,948)	3,206
Workshops	1,171	(5,869)	(4,698)
Community Fund	64,487	(54,680)	9,807
	<u>126,578</u>	<u>(133,976)</u>	<u>(7,398)</u>
TOTAL FUNDS	<u><u>186,665</u></u>	<u><u>(194,295)</u></u>	<u><u>(7,630)</u></u>

Community Fund: Income raised to bring together patient groups, clinicians and researchers to build a cohesive community.

Conferences Fund: Corporate sponsorship raised for our annual Drug Repurposing for Rare Diseases Conference - Life Arc, Ergomed, Healx, Sobi, PharmacoMedics, Newron and Roche.

COVID Fund: Grant towards additional costs incurred as a result of the global coronavirus pandemic.

Essay Competition: corporate donations to fund prizes, travel and core costs in Findacure's annual "Student Voice" essay competition. Sponsorship was received from Costello Medical Consulting Ltd, Dolon Ltd, Linguamatics and TranScrip LLP.

MCDS EU H2020 Grant: Findacure is one of 11 project partners in EU-funded clinical trial testing whether carbamazepine can be repurposed to treat the rare genetic bone disorder, metaphyseal chondrodysplasia type Schmid (MCDS).

Online Portal: Grant funding specifically for the Online Portal.

Peer Mentoring: Grant funding specifically assigned to our mentoring programme - Rhythm Pharmaceuticals, Alexion, Sobi.

Podcast: Grant funding from Illumina to support the Podcast project.

Showcases Fund: Corporate sponsorship for the Rare Disease showcase series - Healx, Apartio, Open Health, Roche, Bionical. Also grant funding from Awards For All. Can use the same description of the activity, but note it was delivered in a virtual setting in 2020.

FINDACURE FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 JANUARY 2021

16. MOVEMENT IN FUNDS - continued

Video Transcription: Funding to cover the costs of video transcription.

Webinars Fund: Funding to cover the costs of running webinars. This was combined with the empowerment community fund at the end of the year.

Workshops Fund: Any grant funding specifically assigned to the findacure patient group training workshops.

Designated Funds

Designated Fixed Asset Fund : This represents the net book value of the fixed assets and associated depreciation.

Designated Projects: This represents funds designated by the Trustees to cover the expenditure of projects where restricted funding has not been generated.

Designated Project Admin Fund: This represents funds designated by the Trustees to cover the first year of costs associated with employing a project administrator.

Transfers between funds

Transfers between funds represent the allocation of core funding from within project income; together with funds designated by Trustees to specific projects.

17. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 January 2021.

18. INDEPENDENT EXAMINER FEES

Independent examiner fees of £3,060 + VAT were accrued during the year. (2020: £2,920 + VAT).

FINDACURE FOUNDATION

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 JANUARY 2021

	2021	2020
	£	£
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	28,923	8,389
Admissions	5,089	7,491
Donated services and facilities	18,734	24,911
Sponsorship	34,042	33,700
Fundraising income	1,685	1,336
	<u>88,473</u>	<u>75,827</u>
Charitable activities		
Grants	236,497	110,838
	<u>324,970</u>	<u>186,665</u>
EXPENDITURE		
Raising donations and legacies		
Wages	28,133	12,231
Social security	1,457	820
Pensions	1,407	550
Entrance fees	-	1,116
	<u>30,997</u>	<u>14,717</u>
Other trading activities		
Event costs	14,234	25,440
Charitable activities		
Wages	86,274	80,611
Social security	5,148	4,700
Pensions	6,751	6,382
Insurance	306	306
Postage and stationery	421	1,909
Advertising	545	950
Staff training	180	640
General expenses	482	2,027
Travel	2,365	8,040
IT Costs	8,623	2,585
Rent	7,796	11,097
Recruitment costs	490	5,494
Consultancy	25,712	23,574
Donations	50	-
Computer equipment	1,015	569
	<u>146,158</u>	<u>148,884</u>

This page does not form part of the statutory financial statements

FINDACURE FOUNDATION

**DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 JANUARY 2021**

	2021	2020
	£	£
Support costs		
Management		
Telephone	127	318
Finance		
Bank charges	197	52
Governance costs		
Accountancy	3,693	3,969
Legal fees	-	680
Bookkeeping	743	235
	<u>4,436</u>	<u>4,884</u>
Total resources expended	<u>196,149</u>	<u>194,295</u>
Net income/(expenditure)	<u>128,821</u>	<u>(7,630)</u>

This page does not form part of the statutory financial statements

