

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
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CAMBRIDGE
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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 Eattris, 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	4				
Patient Support		62,091	340,033	402,124	204,455
Total		163,086	360,215	523,301	324,211
EXPENDITURE ON					
Raising funds	5	22,171	18,881	41,052	49,152
Charitable activities	6				
Patient Support		176,549	261,227	437,776	340,358
Total		198,720	280,108	478,828	389,510
NET INCOME/(EXPENDITURE)		(35,634)	80,107	44,473	(65,299)
Transfers between funds	16	(1,377)	1,377	-	-
Net movement in funds		(37,011)	81,484	44,473	(65,299)
RECONCILIATION OF FUNDS					
Total funds brought forward		111,624	35,387	147,011	212,310
TOTAL FUNDS CARRIED FORWARD		74,613	116,871	191,484	147,011

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)
		<u>70,601</u>	<u>116,871</u>	<u>187,472</u>	<u>142,836</u>
NET CURRENT ASSETS					
		<u>74,613</u>	<u>116,871</u>	<u>191,484</u>	<u>147,011</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>74,613</u>	<u>116,871</u>	<u>191,484</u>	<u>147,011</u>
FUNDS	16				
Unrestricted funds				74,613	111,624
Restricted funds				<u>116,871</u>	<u>35,387</u>
TOTAL FUNDS				<u>191,484</u>	<u>147,011</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

- 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.

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		48,403	(61,973)
Cash flows from investing activities			
Purchase of tangible fixed assets		(3,361)	(5,315)
Net cash used in investing activities		(3,361)	(5,315)
Change in cash and cash equivalents in the reporting period		45,042	(67,288)
Cash and cash equivalents at the beginning of the reporting period		146,871	214,159
Cash and cash equivalents at the end of the reporting period		191,913	146,871

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
	<hr/>	<hr/>
Net cash provided by/(used in) operations	<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
	<hr/>	<hr/>	<hr/>
	146,871	45,042	191,913
	<hr/>	<hr/>	<hr/>
Total	<u>146,871</u>	<u>45,042</u>	<u>191,913</u>

The notes form part of these financial statements

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.

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

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	<u>24,725</u>	<u>26,896</u>
Aggregate amounts	<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	<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	Totals
	£	£	costs	£
	£	£	£	£
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

15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024	2023
	£	£
Other creditors	-	242
Accrued expenses	4,800	4,200
	4,800	4,442

16. MOVEMENT IN FUNDS

	At 1/2/23	Net movement in funds	Transfers between funds	At 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
	111,624	(35,634)	(1,377)	74,613
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
	35,387	80,107	1,377	116,871
TOTAL FUNDS	147,011	44,473	-	191,484

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	-
	<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 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)
	<u>99,228</u>	<u>(83,335)</u>	<u>15,893</u>
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
	<u>224,983</u>	<u>(306,175)</u>	<u>(81,192)</u>
TOTAL FUNDS	<u><u>324,211</u></u>	<u><u>(389,510)</u></u>	<u><u>(65,299)</u></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.

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.

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

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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
	<u>478,828</u>	<u>389,510</u>
Total resources expended		
Net income/(expenditure)	<u>44,473</u>	<u>(65,299)</u>

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