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

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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.

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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.

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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.

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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.

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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.

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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.

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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 Pharmacogenesis.

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.

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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.

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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.

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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.

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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, 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	4				
Patient Support		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	6				
Patient Support		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)		15,893	(81,192)	(65,299)	(48,478)
Transfers between funds	16	4,186	(4,186)	-	-
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><u>111,624</u></u>	<u><u>35,387</u></u>	<u><u>147,011</u></u>	<u><u>212,310</u></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)
		<u>107,449</u>	<u>35,387</u>	<u>142,836</u>	<u>210,403</u>
NET CURRENT ASSETS					
		<u>111,624</u>	<u>35,387</u>	<u>147,011</u>	<u>212,310</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				<u>35,387</u>	<u>120,765</u>
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

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	Online training modules, video production, event support, and	70,317	72,327
Consulting	graphic design work		
		<u>70,317</u>	<u>72,327</u>

4. INCOME FROM CHARITABLE ACTIVITIES

	2023	2022
	£	£
Grants	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	<u>26,896</u>	<u>8,190</u>
Aggregate amounts	<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	<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 £
TOTAL FUNDS CARRIED FORWARD	91,545	120,765	212,310

13. TANGIBLE FIXED ASSETS

	Plant and machinery £
COST	
At 1 February 2022	9,610
Additions	5,315
At 31 January 2023	14,925
DEPRECIATION	
At 1 February 2022	7,703
Charge for year	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

	2023 £	2022 £
Prepayments	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
	<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>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)
	<u>84,208</u>	<u>(93,317)</u>	<u>(9,109)</u>
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)
	<u>185,657</u>	<u>(225,026)</u>	<u>(39,369)</u>
TOTAL FUNDS	<u><u>269,865</u></u>	<u><u>(318,343)</u></u>	<u><u>(48,478)</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. 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, Transcrip 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.

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).