

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

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

**BEACON: FOR RARE DISEASES LTD**

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**FOR THE YEAR ENDED 31 JANUARY 2025**

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**BEACON: FOR RARE DISEASES LTD**

**REFERENCE AND ADMINISTRATIVE DETAILS**  
**FOR THE YEAR ENDED 31 JANUARY 2025**

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

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

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

**OBJECTIVES AND ACTIVITIES****Objectives and aims**

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

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

**Significant activities****About fundamental diseases**

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

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

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

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

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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.

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

Beacon's core aim is to provide support, guidance and connections to the rare disease patient group community. We help them achieve their goals (usually in the areas of patient support, research, and advocacy) and share their experiences so that all can learn from one another. This year has seen the achievement of several notable milestones for the charity's core projects: we secured over 500 registered users for our empowerment program's online learning platform, the Resources Hub; we hosted our first ever international conference in collaboration with REMEDi4ALL and MeRIT; we concluded our work on our first ever European grant with a hybrid conference to close the MCDS-Therapy project in Newcastle. These accomplishments underscore the continual growth of Beacon's reach, the increases in our impact, and the demand for our services – whether direct training, or the creation of unique opportunities for the patient community.

Alongside these hallmarks of our growing reach and impact, 2024/25 has seen continued financial stability, with the award of a new two-year grant to support LifeArc's new Translational Centres for Rare Disease through its coordinating Hub function. Furthermore, our success within the international REMEDi4ALL consortium has continued to grow, both through the launch of the REMEDi4ALL Digital Academy and the delivery of patient engagement work used to support scientific advice for an ultrarare disease clinical trial.

**REMEDi4ALL**

REMEDi4ALL champions drug repurposing and the necessity of delivering patient impact in repurposing research. Beacon is joint lead on both Training (WP3) and Patient Engagement (WP1) work packages, alongside EURORDIS. Over the last year Beacon has been heavily involved in all aspects of the project. Highlights include partnering with REMEDi4ALL to deliver the first ever International Drug Repurposing Conference, hosting patient focus groups and interviews to collect input for scientific advice in Multisulfatase Deficiency and developing and launching the REMEDi4ALL Digital Academy on drug repurposing. Alongside this we have planned the delivery of our first academic training event – to be hosted in Cambridgeshire in March 2025, and a patient group bootcamp on repurposing to be hosted in Barcelona following the Eurordis Open Academy this summer. There has been a real breadth of work within the consortium, and we are now beginning to see both our training programme and patient engagement activities delivering impact to the wider community.

**MCDS-Therapy**

In parallel to REMEDi4ALL, our long-term EU funded project, MCDS-Therapy, came to a close in 2024. Beacon led the development and delivery of the project's closing conference, which was held in The Catalyst, Newcastle, on 30th May 2024. This event was Beacon's first ever hybrid event, combining a 37-person virtual audience with 40 attendees in the in-person delegation. The event included talks on the purpose of MCDS-Therapy (including a talk from a young person personally affected by the condition), the challenges of trial delivery for an ultrarare disease during COVID, the clinical trial outcomes, and future prospects. Attended by a mixture of consortium partners, trial participants, and rare bone condition community members, the event helped to summarise the project outcomes and disseminate impact in a meaningful way. Beacon continued to work on communication and dissemination for the project across the year but decided to wrap up communication efforts and channels towards the end of 2024, following grant closure in the summer.

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

**BEACON: FOR RARE DISEASES LTD****REPORT OF THE TRUSTEES**  
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**Conferences and Showcase Events**

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

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

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

**The Student Voice Prize**

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

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**Empowerment program**

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

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

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

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

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

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

REMEDI4ALL remains Beacon's largest and most significant partnership. As a UK organisation, Beacon is an associated partner in the EU project, receiving funding through the UKRI's Horizon Guarantee Scheme. The consortium now includes 26 distinct member organisations across Europe, all with different expertise in the drug repurposing space. Beacon is working particularly closely with EURORDIS: Rare disease Europe, EATRIS (the European Translational Research Infrastructure), TEAM IT, Syreon Research Institute, the AntiCancer Fund, and the Dutch Funder ZonMW in the delivery of the project, and is involved in eight of the thirteen work packages, with co-leadership of two. This project is of huge strategic significance to both the repurposing community, and to Beacon itself. The experience gained through this consortium has expanded our international reach and helped us to develop further in-house expertise in patient engagement in research, and digital training.

We have continued to develop our working relationship with LifeArc, who officially joined the REMEDI4ALL consortium on the 1<sup>st</sup> January 2025. In the summer of 2024, we developed an application to be involved in the Hub of LifeArc's new Translational Centres for Rare Diseases, helping to lead the work on patient engagement and involvement, training, and communication. This grant was awarded on a two-year basis in September 2025, with the chance to extend to a full five-year project. Within the Hub, Beacon works in close collaboration with both LifeArc and Genetic Alliance UK, as well as connecting directly with the newly funded Translational centres for rare kidney, mitochondrial, and respiratory diseases, and the centre to accelerate rare disease clinical trials. Although still in its early stages, this represents another exciting opportunity for Beacon to both collaborate more directly with UK rare disease academia, and to influence the approach to patient centred research in the UK rare disease ecosystem.

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

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

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

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



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**FOR THE YEAR ENDED 31 JANUARY 2025**

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

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

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

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

**Principal funding sources**

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

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

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

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

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

The restricted funds carried forward are committed to be spent in 2025 on the charity's projects and overheads, including: on-going delivery of the Empowerment Program; support for LifeArc's drug repurposing toolkit; the delivery of Beacon's work on the LifeArc Hub for the Translational Research Centres for Rare Disease; and delivery of the Rarely Heard Podcast series. Note that at the close of the financial year over £20,000 has been allocated to the UKRI R4A core fund (designated for the salary costs associated with the delivery of the REMEDi4ALL project) all of which will be reclaimed from the UKRI in the coming months and further strengthens our financial position.

**Going concern**

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

**Future plans**

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

1. Deliver our first live training events for the REMEDi4ALL consortium, including our Academic Bootcamp, Patient Bootcamp, Hackathon, and Clinical trials webinar series
2. Develop our patient engagement group for the LifeArc Hub project and a detailed training plan for the project.
3. Deliver the iDR25 conference and develop a more streamlined delivery model for iDR26.
4. Develop new funding streams for Beacon, whether new international projects, or new long-term grants to replace the National Lottery Community Fund for the Empowerment Program which will expire in early 2026.
5. Increase our efforts to connect with the UK pharmaceutical industry in order to increase the corporate funding available for our core training programs.
6. The delivery of a daylong Showcase event.
7. Restructuring our internal teams to limit the separation of the science and project teams, allowing the more effective use of our internal expertise across our workstreams and projects.
8. Recruitment of new trustees to grow our board and develop our governance.

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

## **BEACON: FOR RARE DISEASES LTD**

### **REPORT OF THE TRUSTEES** **FOR THE YEAR ENDED 31 JANUARY 2025**

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#### **STRUCTURE, GOVERNANCE AND MANAGEMENT**

##### **Governing document**

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

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

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

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

##### **Charity Constitution**

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

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

Trustees cease to hold office if:

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

##### **Recruitment and appointment of new trustees**

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

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

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**STRUCTURE, GOVERNANCE AND MANAGEMENT****Organisational structure**

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

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

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

**Decision making**

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

**Induction and training of new trustees**

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

**Key management remuneration**

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

**Wider network**

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

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

**Related parties**

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

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

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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. The charity has recently moved to a new accountant and will be reviewing financial processes and support over the course of the coming financial year, as well as looking to appoint a dedicated treasurer to support his oversight.

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

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

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

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

**BEACON: FOR RARE DISEASES LTD**

**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 31 JANUARY 2025**

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**STRUCTURE, GOVERNANCE AND MANAGEMENT**

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

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

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

DocuSigned by:  
  
D28DE01B3D85405.....  
Sophie Costello - Trustee

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

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

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

**Responsibilities and basis of report**

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under Section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under Section 145(5) (b) of the 2011 Act.

**Independent examiner's statement**

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

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the Company as required by Section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of Section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

DocuSigned by:

*Julia Jones*

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

Date: 28<sup>th</sup> October 2025

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

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

The notes form part of these financial statements



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

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

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

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

The trustees acknowledge their responsibilities for

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

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

**BALANCE SHEET - continued**  
**31 JANUARY 2025**

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

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

DocuSigned by:  
  
D28DE01B9D65405:.....  
Sophie Costello - Trustee

**BEACON: FOR RARE DISEASES LTD**

**CASH FLOW STATEMENT**  
**FOR THE YEAR ENDED 31 JANUARY 2025**

|   | Notes | 2025<br>£ | 2024<br>£ |
|---|-------|-----------|-----------|
| <b>Cash flows from operating activities</b>                               |       |           |           |
| Cash generated from operations  | 1     | 33,689    | 48,403    |
| Net cash provided by/(used in) operating activities                       |       | 33,689    | 48,403    |
| <b>Cash flows from investing activities</b>                               |       |           |           |
| Purchase of tangible fixed assets   |       | (3,931)   | (3,361)   |
| Net cash used in investing activities                                     |       | (3,931)   | (3,361)   |
| <b>Change in cash and cash equivalents in the reporting period</b>        |       | 29,758    | 45,042    |
| <b>Cash and cash equivalents at the beginning of the reporting period</b> |       | 191,913   | 146,871   |
| <b>Cash and cash equivalents at the end of the reporting period</b>       |       | 221,671   | 191,913   |

The notes form part of these financial statements

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

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

**2. ANALYSIS OF CHANGES IN NET FUNDS**

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

The notes form part of these financial statements

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

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**1. LEGAL FORM**

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

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

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

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

**Going Concern Basis**

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

**Reconciliation with previous Generally Accepted Accounting Practice**

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

**Significant judgements**

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

**Income**

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

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

**Donated services and facilities**

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

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

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**2. ACCOUNTING POLICIES - continued****Expenditure**

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

**Charitable activities**

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

**Tangible fixed assets**

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

Plant and machinery - 33% on cost

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

**Taxation**

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

**Fund accounting**

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

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

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

**Pension costs and other post-retirement benefits**

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

**Debtors**

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

**Cash at bank and in hand**

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

**Creditors**

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

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

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

Donated services and facilities:

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

**4. INCOME FROM CHARITABLE ACTIVITIES**

|        | Activity        | 2025           | 2024           |
|--------|-----------------|----------------|----------------|
|        |                 | £              | £              |
| Grants | Patient Support | <u>427,285</u> | <u>402,124</u> |

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

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

**BEACON: FOR RARE DISEASES LTD**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 31 JANUARY 2025**

**5. RAISING FUNDS**

**Raising donations and legacies**

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

**Other trading activities**

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

**6. CHARITABLE ACTIVITIES COSTS**

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

**7. DIRECT COSTS OF CHARITABLE ACTIVITIES**

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



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

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

**9. NET INCOME/(EXPENDITURE)**

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

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

**10. TRUSTEES' REMUNERATION AND BENEFITS**

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

**Trustees' expenses**

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

**11. STAFF COSTS**

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

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

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

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

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

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

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

**13. TANGIBLE FIXED ASSETS**

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

**BEACON: FOR RARE DISEASES LTD****NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 31 JANUARY 2025****14. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

|             | 2025 | 2024 |
|-------------|------|------|
|             | £    | £    |
| Prepayments | 231  | 359  |

**15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

|                  | 2025         | 2024         |
|------------------|--------------|--------------|
|                  | £            | £            |
| Other creditors  | -            | -            |
| Accrued expenses | 4,840        | 4,800        |
|                  | <u>4,840</u> | <u>4,800</u> |

**16. MOVEMENT IN FUNDS**

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Mentoring: Grant funding specifically assigned to our mentoring programme.

Podcast: Grant funding to support the Podcast project.

**BEACON: FOR RARE DISEASES LTD**

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

**16. MOVEMENT IN FUNDS - continued**

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

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

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

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

Designated Funds

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

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

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

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

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

**Transfers between funds**

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

**17. RELATED PARTY DISCLOSURES**

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

**18. INDEPENDENT EXAMINER FEES**

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