

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

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 JANUARY 2022
FOR
BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

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REPORT OF THE TRUSTEES
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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 2022. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

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

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

Significant activities

About fundamental diseases

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

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

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

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

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OBJECTIVES AND ACTIVITIES

Public benefit

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

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STRATEGIC REPORT

Achievement and performance

Charitable activities

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

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

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

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

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

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

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

Fundraising activities

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

Internal and external factors

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

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

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

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Achievement and performance

Partnerships

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

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

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

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

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

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STRATEGIC REPORT

Financial review

Financial position

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

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

Principal funding sources

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

Reserves policy & review

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

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

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

Going concern

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

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STRATEGIC REPORT

Future plans

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

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

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

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

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

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

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

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

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STRUCTURE, GOVERNANCE AND MANAGEMENT

Charity Constitution

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

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

Trustees cease to hold office if:

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

Recruitment and appointment of new trustees

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

Organisational structure

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

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

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

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

Decision making

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

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STRUCTURE, GOVERNANCE AND MANAGEMENT

Induction and training of new trustees

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

Key management remuneration

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

Wider network

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

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

Related parties

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

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STRUCTURE, GOVERNANCE AND MANAGEMENT

Risk management

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

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

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

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

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

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

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STRUCTURE, GOVERNANCE AND MANAGEMENT

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

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number

08174973 (England and Wales)

Registered Charity number

1149646

Registered office

66 Devonshire Road
CAMBRIDGE
Cambridgeshire
CB1 2BL

Trustees

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

Independent Examiner

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

Solicitors

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

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REFERENCE AND ADMINISTRATIVE DETAILS

Bankers

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

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

CHANGE OF NAME

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

STATEMENT OF TRUSTEES' RESPONSIBILITIES

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

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

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

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

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

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

.....
N T Sireau PhD - Trustee

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

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

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

Responsibilities and basis of report

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

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

Independent examiner's statement

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

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

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

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

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

Date:

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

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

The notes form part of these financial statements

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

BALANCE SHEET
31 JANUARY 2022

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

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

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

The trustees acknowledge their responsibilities for

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

The notes form part of these financial statements

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

BALANCE SHEET - continued
31 JANUARY 2022

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

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

.....
N T Sireau PhD - Trustee

The notes form part of these financial statements

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

1. LEGAL FORM

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

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

2. ACCOUNTING POLICIES

Basis of preparing the financial statements

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

Going Concern Basis

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

Reconciliation with previous Generally Accepted Accounting Practice

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

Significant judgements

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

Financial reporting standard 102 - reduced disclosure exemptions

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

- the requirements of Section 7 Statement of Cash Flows.

Income

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

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

Donated services and facilities

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

2. ACCOUNTING POLICIES - continued

Income

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

Expenditure

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

Charitable activities

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

Tangible fixed assets

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

Plant and machinery - 33% on cost

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

Taxation

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

Fund accounting

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

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

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

Pension costs and other post-retirement benefits

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

Debtors

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

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

2. ACCOUNTING POLICIES - continued

Cash at bank and in hand

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

Creditors

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

3. DONATIONS AND LEGACIES

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

Donated services and facilities:

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

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

4. INCOME FROM CHARITABLE ACTIVITIES

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

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

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

5. RAISING FUNDS

Raising donations and legacies

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

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

5. RAISING FUNDS - continued

Other trading activities

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

6. CHARITABLE ACTIVITIES COSTS

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

7. DIRECT COSTS OF CHARITABLE ACTIVITIES

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

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

8. SUPPORT COSTS

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

9. NET INCOME/(EXPENDITURE)

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

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

10. TRUSTEES' REMUNERATION AND BENEFITS

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

Trustees' expenses

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

11. STAFF COSTS

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

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

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

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

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

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

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

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

13. TANGIBLE FIXED ASSETS

	Plant and machinery £
COST	
At 1 February 2021	7,715
Additions	1,895
	<hr/>
At 31 January 2022	9,610
	<hr/>
DEPRECIATION	
At 1 February 2021	6,056
Charge for year	1,647
	<hr/>
At 31 January 2022	7,703
	<hr/>
NET BOOK VALUE	
At 31 January 2022	1,907
	<hr/> <hr/>
At 31 January 2021	1,659
	<hr/> <hr/>

14. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022	2021
	£	£
Prepayments	231	229
	<hr/> <hr/>	<hr/> <hr/>

15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022	2021
	£	£
Trade creditors	-	84
Other creditors	123	723
Accrued expenses	3,864	3,678
	<hr/>	<hr/>
	3,987	4,485
	<hr/> <hr/>	<hr/> <hr/>

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

16. MOVEMENT IN FUNDS

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

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

16. MOVEMENT IN FUNDS - continued

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

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

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

16. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

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

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

16. MOVEMENT IN FUNDS - continued

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

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

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

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

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

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

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

Resources Hub: Grant funding specifically for the Online Portal.

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

16. MOVEMENT IN FUNDS - continued

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

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

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

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

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

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

Designated Funds

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

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

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

Transfers between funds

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

17. RELATED PARTY DISCLOSURES

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

18. INDEPENDENT EXAMINER FEES

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

BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

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

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BEACON: FOR RARE DISEASES LTD
PREVIOUSLY KNOWN AS FINDACURE FOUNDATION

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

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

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