CURE EB (FORMERLY KNOWN AS SOHANA RESEARCH FUND)

England & Wales · Charity number 1158672

Details

Other names	SOHANA RESEARCH FUND, SRF
Status	Registered
Legal form	CIO
Registered	2014-09-25
Register	View on the Charity Commission register

Contact

Address	10 Huntingdon Street London N1 1BU
Phone	02034058433
Email	contact@cure-eb.org
Website	www.cure-eb.org

Activities

Objects: FOR THE PUBLIC BENEFIT, (A) THE ADVANCEMENT OF HEALTH AND (B) THE RELIEF AND ASSISTANCE OF PEOPLE IN NEED WHO ARE SUFFERING FROM EPIDERMOLYSIS BULLOSA, IN PARTICULAR BUT NOT EXCLUSIVELY BY MAKING GRANTS: (1) TO FUND MEDICAL RESEARCH AND/OR CLINICAL TRIALS ANYWHERE IN THE WORLD FOR THE PURPOSE OF DISCOVERING, DEVELOPING AND DELIVERING TREATMENTS FOR EPIDERMOLYSIS BULLOSA; AND (2) TO FUND THE TREATMENT OF PATIENTS WHO ARE SUFFERING FROM EPIDERMOLYSIS BULLOSA. NOTHING IN THIS CONSTITUTION SHALL AUTHORISE AN APPLICATION OF THE PROPERTY OF THE CIO FOR THE PURPOSES WHICH ARE NOT CHARITABLE IN ACCORDANCE WITH SECTION 7 OF THE CHARITIES AND TRUSTEE INVESTMENT (SCOTLAND) ACT 2005 OR SECTION 2 OF THE CHARITIES ACT (NORTHERN IRELAND) 2008.

Activities: SRF seeks to assist those suffering from Epidermolysis Bullosa ("EB"), in particular but not exclusively by making grants:(1) to fund medical research and/or clinical trials anywhere in the world for the purpose of discovering, developing and delivering treatments for EB; and(2) to fund the treatment of patients who are suffering from EB.

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Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** People With Disabilities, Other Defined Groups

Geography

- France
- Spain
- United States
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£4,850,763	£1,410,954	£5,125,552	0
2023-12-31	£730,918	£1,552,666	£1,685,743	0
2022-12-31	£1,000,863	£1,122,145	£2,507,444	1
2021-12-31	£1,565,380	£858,839	£2,628,726	0
2020-12-31	£796,938	£759,771	£1,922,185	0

Trustees

Name	Role	Appointed
Duncan Wales		2017-06-26
JAMES DOUGLAS COLLINS		2014-09-25
MICHAEL GEORGES DE LATHAUWER		2014-09-25
PROFESSOR DAVID KELSELL		2014-09-25
Rachel Lesiter		2022-10-17
SHARMILA VIJAYANTHI NIKAPOTA		2014-09-25
TAZIM HALL		2014-09-25

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CURE EB (FORMERLY KNOWN AS SOHANA RESEARCH FUND)

England & Wales - Charity number 1158672

Accounts

REPORT AND FINANCIAL STATEMENTS

Year-ended 31 December 2024

Charity Number: 1158672

Cure EB

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Year ended 31 December 2024

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Legal and Administrative Information
Year ended 31 December 2024

1. The structural and administrative details for the Charity are as follows:

   1.1. Name: Cure EB (formerly known as Sohana Research Fund)

   1.2. Type of entity: Charitable Incorporated Organisation

   1.3. Date of incorporation: 25 September 2014

   1.4. Registered Charity Number: 1158672

   1.5. Governing document: Constitution

   1.6. Registered and principal office: 10 Huntingdon Street, London, N1 1BU

2. The Trustees as at the date of this report (the "Trustees") are:

   2.1. Ms Sharmila Nikapota

   2.2. Mr James Collins

   2.3. Mr Michael de Lathauwer

   2.4. Ms Tazim Hall

   2.5. Prof. David Kelsell

   2.6. Mr Duncan Wales

   2.7. Rachel Lesiter

3. The bankers are: Barclays Bank PLC

   14 Upper Street
   Islington
   London
   N1 0PQ

4. The auditors are: Mitchell Charlesworth (Audit) Limited

   3rd Floor
   44 Peter Street
   Manchester
   M2 5GP

Cure EB

Summary
Year ended 31 December 2024

Our Mission Statement

Our mission is to find effective treatments and ultimately a cure for Epidermolysis Bullosa ("EB").

Our Commitments

To fund translational research and clinical trials for the benefit of people with EB.

To maximise research spend.

To raise awareness of EB.

Cure EB

2024 Highlights
Year ended 31 December 2024

Fundraising Highlights

- Building the translational fund
- Silver Butterfly Dinner
- Chosen by Bain Capital to be a Children's Fund for Europe charity
- Butterfly Brunch Speaker event
- BGC Charity Day
- Big Give Christmas Challenge
- London Marathon
- Goldman Sachs Gives donations
- Team Abe's walk for EB
- Team EB's cycle to Paris
- Butterfly Lunch

Project highlights

- Poster presentation at ESDR of siRNA project
- Publication in JID re editing RDEB fibroblasts
- Nanocol project publication in ACS nano
- Mission EB trial at Great Ormond Street interim results published and Inmune Bio begin commercialising CORDstrom
- EB graft trial work ongoing
- mRNA base-editing project started
- Bespoke therapy for RDEB starting in Australia
- Collaboration with Debra UK on JEB airways disease

Cure EB

Founder's Statement
Year ended 31 December 2024

Epidermolysis Bullosa ("EB") is a group of genetic skin blistering conditions that vary in severity depending on the subtype. Some forms are fatal in infancy and others lead to progressive deformity and are severely life limiting. Recessive Dystrophic Epidermolysis Bullosa ("RDEB") is a very severe form that leads to scarring, contractures, oesophageal restriction, corneal abrasions, malignant skin cancer and many more painful and life-altering symptoms.

Cure EB exists to find treatments and a cure for EB. To this end, we fund predominantly translational medical research aiming to deliver quality-of-life changing relief and eventually a cure to those afflicted by EB.

Following a very well received research update evening at the Royal Insitution in March we held our Silver Butterfly Gala dinner in May, which was attended by Patron Damian Lewis and was a great success. We were very lucky to be chosen for BGC charity day again with Patron Damian Lewis attending. We were extremely fortunate to be chosen by Bain Capital as their Children's Fund for Europe grant recipient. This in turn helped us with our butterfly run and family day. These were held at the Olympic Park and we were pleased with increased numbers attending, the fun it was and the excellent presentations given by some of our researchers.

At the time of writing this there are now three approved EB treatments on the market in the US, all for topical wound treatment. Only one of these has been approved by the UK, with one going through the NICE process. We are gearing up towards a whole body treatment trial and building a translational fund to make that possible.

As ever we are incredibly grateful to our many wonderful long-term donors, supporters, friends and EB patients who have faith and have stayed with us for many years and for new families joining in our mission to Cure EB.

Sharmila Nikapota

Sharmila Nikapota
Founder Trustee

Report of the Trustees
Year ended 31 December 2024

The Trustees present their report along with the financial statements of the Charity for the year ended 31 December 2024.

Introduction

1. Cure EB - then known as the Sohana Research Fund C.I.O. ("SRF") - was established on 25 September 2014 with Registered Charity Number 1158672.

2. Cure EB's principal purpose is to fund medical research and clinical trials aimed at discovering, developing and delivering treatments for Epidermolysis Bullosa ("EB").

Objectives and activities

3. As set out in Cure EB's Constitution, Cure EB's objects are "*For the public benefit, (a) the advancement of health and (b) the relief and assistance of people in need who are suffering from Epidermolysis Bullosa, in particular but not exclusively by making grants:*

   3.1. *to fund medical research and/or clinical trials anywhere in the world for the purpose of discovering, developing and delivering treatments for Epidermolysis Bullosa; and*

   3.2. *to fund the treatment of patients who are suffering from Epidermolysis Bullosa"*

4. Cure EB's objectives during 2024 were limited to:

   4.1. Raising funds;

   4.2. Raising awareness;

   4.3. Identifying and developing projects for funding; and

   4.4. Funding of projects.

5. The Trustees confirm that in determining what activities Cure EB carries out, they have had regard to the Charity Commission's guidance on public benefit.

Fundraising and awareness

6. We started the year with a major donor dinner with a particular focus on building a translational fund towards taking a whole body treatment to a proof of principle clinical trial. We are extremely lucky to have long standing and committed supporters who have kickstarted this in a significant way.

7. We also had a very successful fundraising dinner in May raising £585,000 and a successful Butterfly Brunch Speaker event in London with Hadley Freeman in Conversation with Mishal Husain. These events introduced the charity to new supporters as well as being successful fundraising events

Fundraising and awareness [Continued]

8. As a rare genetic skin condition public knowledge of the condition is limited. This impacts Cure EB's ability to raise money for research and support. Consequently, we see increased awareness of the condition as something that has a direct influence on our ability to raised funds. We have an active social media presence with over 30,000 followers on Facebook, approximately 2500 on X (formerly known as twitter) and over 2200 on Instagram. We are working on building our Linkedin profile. High profile supporters like Damian Lewis, Jason Isaacs, Tom Holland and The Brothers Trust have helped spread the word via their social media profiles and we were extremely grateful to have our logo featured on Tom Hollands and his brothers shirts for the BMW PGA golf tournament. In print media reference was made to Cure EB by the Team Abe fundraisers doing their 100km walk. Our website continues to be a very important tool when fundraising and educating the public as to our aims and ambitions. It holds all information regarding projects and press as well as event information. We strive to keep it up to date and continue to improve its features.

9. We have an online campaign running called #CoffeeetoCure EB but need to make it more impactful. The ask is simple in encouraging people to donate the cost of a coffee by text number. We hope to continue to build this in an effort to raise awareness but also small value donations from as many people as possible.

10. Our main community outreach and awareness event, the Butterfly Run and Family Day, took place in September 2024. We had increased participation in the run and even had West Ham footballer Thomas Soucek appear but we need to build on numbers. At Family Day four of our researchers gave excellent presentations and we had good participation from the EB families and supporters who attended, with a lively discussion at the end. We were very grateful to have Bain Capital support through their Children's Fund for Europe grant for both these events. We were chosen for BGC charity day which was attended by Damian Lewis and beneficiaries and we also had a very good Big Give Christmas challenge raising £80,000. Fundraisers included very successful marathon and half marathon runners, a team EB cycle to Paris, golf days, styling day, half marathons, Facebook fundraisers and birthday and anniversary celebrations, plant sales and Ride London.

11. We have two restricted funds within Cure EB, the JT fund and the Abe fund. The Abe Fund had a very successful walk in June raising funds towards investing in companies engaged in EB research.

12. We had substantial donations from the James and Deirdre Dyson Trust, The Maria Marina Foundation, The Brothers Trust, CAH Philanthropy, Sharegift, The Medicor Foundation, MDL Philanthropy, W and C Pot Philanthropy The Maurice Hatter Foundation, The William Howarth Trust, Cure EB Charity Foundation Australia, The Lily Foundation, The Sheridan Foundation, I and J Mukherjee Trust, Stanley and Zea Lewis family foundation, Spears Stutz charitable trust, Loftus charitable trust, EC Sosnow charitable trust, Marks family charitable trust, Esfandi charitable foundation, Rubin foundation. Harold and Nicola Pasha charitable trust. We also had sponsorship from Bain Capital, Krystal Bio and Constant Therapeutic for our run and family Day. Other corporate donors include Goldman Sachs Gives, Intermediate Capital Group, BGC, Jarmany Ltd, Sanibel Investments, Gartner, Artemis Fund, Salon 13, Chiesi Ltd, Salon 13, AFC energy, Mackrell solicitors and the Buchanan programme.

13. We are building our regular giving through the Kaleidoscope friends scheme and online platforms but this continues to be an area that we have to grow.

Achievements and performance

14. Cure EB funds a range of projects. However, Cure EB's principal focus is on translational research – i.e. the preclinical research and clinical trials that will (we hope) translate fundamental (laboratory based) research into effective treatments for RDEB. We are assisted by an experienced independent expert panel who evaluate projects and advise on research strategies and priorities.

Achievements and performance [Continued]

15. We currently evaluate projects on a rolling basis (rather than in formal funding rounds at fixed intervals) and invite applications that meet our priority areas of research. An initial outline of the project is evaluated and if deemed to be within an area of interest a full grant application is asked for. The project is then externally reviewed and scored by a scientific advisory panel (SAP), whose members are world leading scientific experts in medical related research. That external review process is coordinated by one of our Trustees, Professor David Kelsell, who is himself an expert in human skin genetics and part of the SAP. If the scores are sufficiently high the project is presented to the Trustees for approval. If approved, Cure EB negotiates and concludes formal funding agreements with the body that is to carry out the research

16. To highlight our research we hosted a research update meeting at the Royal Institution in March. Dr Matthias Titeux from Paris, Professor John McGrath from Kings College London and Dr Ciro Chiappini from Kings College, London all gave excellent and exciting presentations highlighting the progress in the EB gene therapy space.

17. During 2024, published research included a poster at the ESDR on siRNA for EBS, Editing of RDEB fibroblasts in the JID and around Nanoneedles in ACS nano.

18. New projects included mRNA base editing at Kings College London, Bespoke therapy for RDEB in Australia, Therapy for JEB airway disease at Great Ormond Street Hospital. Projects progressed and funded included EB graft (France), Nanocol (US and UK), Editing of RDEB fibroblasts (UK), Paste mediated super exon replacement (UK). Other projects included base and prime editing of RDEB fibroblasts in France, Gene and cell therapy in RDEB at the University of Minnesota and oligonucleotide work in Paris.

19. Looking ahead, we have a particular focus on taking a whole body treatment technology through to clinical trial as well as progressing translational research for local approaches. We will also continue looking at emerging technologies to determine translational benefit

20. To this end we aim to continue to carry on building our relationships with other potential funders (we have a good track record of collaborating) and investors and with the RDEB research community.

Financial review

21. The accounts show the financial affairs of Cure EB and its wholly owned subsidiary, EB Therapeutics Ltd, for 2024. The key figures, together with commentary, are as follows:

    21.1. Gross Income: £4,850,763. This was very much higher than 2023 due in large part to a small number of very substantial donations. In addition, the Butterfly Dinner and other fundraising channels were also successful.

    21.2. Expenditure on charitable activities (including support costs) was slightly lower than the previous year at £1,247,666. This was in line with our target for 2024. The substantial difference between income and expenditure enabled us to build our Translational Fund.

    21.3. Costs of Fundraising: £163,288. Expenditure was higher than the prior period largely due to the cost of the biennial Butterfly Dinner. As a rule of thumb, Cure EB aims to raise £10 for every £1 spent on fundraising activities. Cure achieved this comfortably in 2023.

    21.4 Reserves at year end were £5,125,552. This is much higher than 2023 largely due to the very substantial donations referred to in 21.1 above.

    21.5 Cash at year end was £1,852,797. In addition, Cure EB purchased and held Treasury Bonds of £2,500,000 in order to generate (modest) income from the cash reserves. The other major asset consisted of donations and gift aid receivable in the sum of £2,119,345.

Financial review [Continued]

22. Looking ahead to 2025:

22.1. Gross income is likely to be very much lower than 2025 due to a number of factors, including:

(1) Further major donations towards the Translational Fund are anticipated but not on the scale seen in 2024.

(2) There will be no Butterfly Dinner in 2025.

22.2. Cost of fundraising is also likely to be lower, due to the absence of the Butterfly Dinner.

22.3. Expenditure on projects is likely to be within the range established over the past few years. This will increase sharply when one of the projects supported by the Translational Fund moves into its next phase, but it is not yet clear whether that will be in late 2025 or in 2026.

23. The trustees as at the date of this report (the "Trustees") were:

23.1. Ms. Sharmila Nikapota

23.2. Mr James Collins

23.3. Mr Michael le Lathauwer

23.4 Ms. Tazim Hall

23.5 Prof. David Kelsell

23.6 Mr Duncan Wales

23.7 Ms. Rachel Lesiter

24. There were no other Trustees during 2024. These Trustees may be reappointed at the expiry of their current terms and/or further trustees may be appointed by resolution passed at a properly convened meeting of the trustees. Pursuant to the terms of the Constitution, the minimum number of trustees is 3 and the maximum is 9. The Trustees are selected for their experience and expertise.

25. The Trustees are not and were not compensated for performing their roles as trustees.

26. Management and Administration:

26.1. Management of Cure EB's fundraising and awareness activities has been delegated (subject to a financial cap) to Sharmila Nikapota and James Collins. They in turn report to the other Trustees. In particular:

(1) Sharmila Nikapota has primary responsibility for conceiving, developing and performing all fundraising and awareness activities. This includes the identification of suitable contractors to provide goods or services and negotiation with those contractors.

Financial review [Continued]

(2) Costs of goods and services are approved by, and payment is arranged by, James Collins or Rachel Lesiter.

(3) Sharmila Nikapota and James Collins are authorised to jointly incur costs of up to £10,000 per month in relation to fundraising and awareness activities without further authorisation from the Trustees. For major events, Sharmila Nikapota and James Collins must seek the prior approval of the Trustees.

26.2. Management of the administration of Cure EB has been delegated (subject to a financial cap) to Sharmila Nikapota, Rachel Lesiter and James Collins. They in turn report to the other Trustees. In particular:

(1) Sharmila Nikapota, Rachel Lesiter and James Collins are primarily responsible for identifying the services that need to be performed and finding suitable contractors to assist with the provision of those services.

(2) Sharmila Nikapota and James Collins are authorised to jointly incur costs of up to £2,500 per month in relation to the administration of Cure EB without further authorisation from the Trustees. Financial oversight and record keeping is performed by Rachel Lesiter.

26.3. In relation to projects and funding:

(1) Sharmila Nikapota is in regular direct communication with leading researchers and clinicians and with other potential funding bodies. She has primary responsibility for the initial identification of projects that may merit funding on grounds that they (i) further the objects of Cure EB; and (ii) are (weighing the work that is to be performed and the potential benefits of the research against the cost) cost-effective.

(2) The process for the evaluation of potential projects depends on the nature and size of the project. Prof. David Kelsell provides guidance in relation to both the process and the evaluation. He is also responsible for coordinating the reviews by Cure EB's scientific advisory panel (SAP) whose members are world leading scientific experts in medical related research. They evaluate, comment on and score the projects for Cure EB.

(3) All funding decisions (including identification of the project to be funded and the amount of funding to be provided) are made by the Trustees (as a whole).

(4) Funds in one of the restricted funds (the Abe Fund, year-end balance £412,807) can only be spent on projects approved by the founder of that fund, but the funding decision must still be made by the Trustees.

(5) Having decided "in principle" to fund a project, negotiation of documentation is led by James Collins.

(6) Project invoices that conform with the funding agreements are approved by, and payment is arranged by, James Collins and Rachel Lesiter.

Financial review [Continued]

27. Professional services:

27.1 James Collins in a commercial barrister and Tazim Hall was a solicitor and partner at a substantial international law firm. Cure EB buys in additional legal services as and when required.

27.2 Cure EB has not retained any investment advisor. However, Michael de Lathauwer comes from an investment banking background and is currently a fund manager.

28. Remuneration:

28.1 The Trustees are not and were not compensated for their management roles (described above) nor for any other role that they perform.

28.2 Cure EB has a part-time Administrator and a part-time Research Officer. Both are self-employed, but the time they provide adds up to about 1 FTE (full time equivalent). In addition, Cure EB has established relationships with a number of individuals and organisations that provide services on a contractor or self-employed basis.

28.3 Cure EB has benefited from, and relies on, substantial support from a team of volunteers. In particular:

(1) The fundraising and awareness events are supported by a substantial team of engaged and dedicated volunteers. They provide assistance with the development of the event, attracting supporters to the event, graphic design, logistics and in many other ways. Without their support, many of these services would have to be bought in at considerable cost to Cure EB.

(2) The administration of Cure EB has been greatly assisted by volunteers, again saving Cure EB substantial cost.

Investment policy

Funds are held as short-term bank balances and (if and when rates justify it) longer term treasury deposits. The only other investments made by Cure EB are Social Investments (rather than financial investments).

Social Investments

These investments are payments made to further the aims of the charity – i.e. to advance research – rather than to secure a financial return. However, because they are structured as investments there is potential for return. In 2024 Cure EB made two further Social Investments, but due to the risks inherent in very early stage research, impaired the value of one of those Social Investments by 50%.

EB Therapeutics

At the end of 2018, Cure EB established a subsidiary: EB Therapeutics Ltd ("EBT"). The purpose of this subsidiary is to further develop some of the technologies supported by Cure EB with the aim of assisting with the transition from research to market, so that effective treatments become as widely available as possible. EBT was dormant until 2020. During 2020 it (1) took a license of IP related to one of the projects that Cure EB is supporting; and (2) concluded a research service agreement for a new project. During 2021 this new project generated encouraging laboratory results. This continued through 2022 with the focus shifting (1) to the identification of the best compounds to progress towards an in-human trials; and (2) (for some compounds) from in-vitro to early in-vivo testing. In 2023, work to identify the best compounds continued, and in-vivo testing of those compounds was substantially progressed.
In 2024 distribution tests were conducted and further toxicity testing progressed.

Reserves policy

Policy: Because the charity has a low-cost operating base it does not require a significant unrestricted reserve fund to meet its operating costs. However, Cure EB aims to maintain and build a substantial restricted reserve fund to meet the cost of future projects. This is for two reasons. First, Cure EB wants to be able to fund the best projects irrespective of its income in any particular year (which will fluctuate for reasons beyond its control). Second, Cure EB is building a Development Fund to progress one project through the final steps towards, and then into, human trials.
Forward looking statement: The Trustees are confident that there are adequate reserves to fund the research that Cure EB had committed to fund and to cover the anticipated future costs.

Risk management

The principal risk to the charity is the ability to continue to raise funds sufficient to meet the commitments made to fund projects and operating costs.

The Trustees have (above) highlighted the facts relevant to this risk. During 2024 this risk was entirely mitigated by ensuring that reserves substantially exceeded commitments.

Whilst the Trustees expenditure will exceed income in certain years, the Trustees intend (1) to retain substantial reserves (for the reasons given above); and (2) only commit to projects where Cure EB (i) already has sufficient funding for the project; or (ii) is confident that funds will be raised well in advance of any payment dates falling due.

Public benefit

The Trustees are conscious of the Charity Commission guidelines on public benefit and these guidelines are applied when grants are considered.

Report of the Trustees [Continued]
Year ended 31 December 2024

Trustees' responsibilities in relation to the financial statements

The Trustees are responsible for preparing the Trustees Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Law applicable to charities in England and Wales requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the Charity's financial activities during the year and of its financial position at the end of the year. In preparing those financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Make judgements and estimates that are reasonable and prudent;
- Observe the methods and principles in the Charity SORP;
- State whether applicable accounting standards and statement of recommended practice have been followed subject to any departures disclosed and explained in the financial statements; and
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Charity will continue in operation.

The Trustees are responsible for keeping accounting records which disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Charities Act 2011. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by the Trustees and signed on their behalf by:

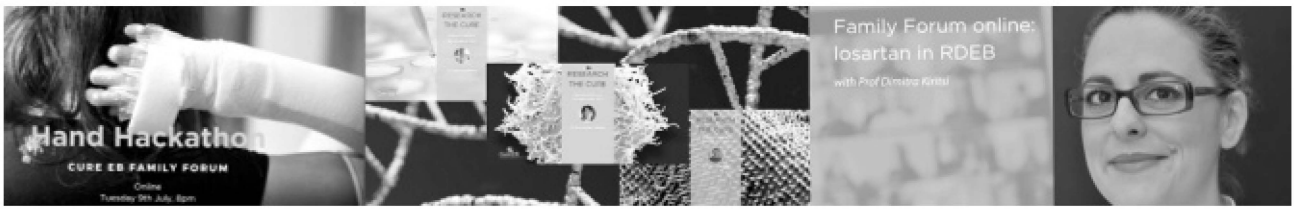
Sharmila Nikapota

James Collins

Sharmila Nikapota

James Collins

Date: 23/10/2025



Report of the Auditors to the Trustees of Cure EB
Year ended 31 December 2024

Opinion

We have audited the financial statements of Cure EB (the 'Charity') for the year ended 31 December 2024 which comprise the Consolidated Statement of Financial Activities, the Consolidated and Charity Balance Sheet, the Consolidated Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the Charity's affairs as at 31 December 2024 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the Charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the Charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

Other information

The Trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- the information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of Trustees

As explained more fully in the Statement of Trustees' Responsibilities, the Trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the Charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the Charity or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists.

Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud.

The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

We gained an understanding of the legal and regulatory framework applicable to the Charity and the industry in which it operates, and considered the risk of acts by the Charity that were contrary to applicable laws and regulations, including fraud. We discussed with the Trustees the policies and procedures in place regarding compliance with laws and regulations. We discussed amongst the audit team the identified laws and regulations, and remained alert to any indications of non-compliance.

During the audit we focused on laws and regulations which could reasonably be expected to give rise to a material misstatement in the financial statements, including, but not limited to, the UK Companies Act and UK tax legislation. Our tests included agreeing the financial statement disclosures to underlying supporting documentation and enquiries with management.

Report of the Auditors to the Trustees of Cure EB [Continued]
Year ended 31 December 2024

Our responsibilities for the audit of the financial statements [Continued]

Our procedures in relation to fraud included but were not limited to: inquires of management whether they have any knowledge of any actual, suspected or alleged fraud, and discussions amongst the audit team regarding risk of fraud such as opportunities for fraudulent manipulation of financial statements. We determined that the principal risks related to posting manual journal entries to manipulate financial performance and management bias through judgements in accounting estimates. We also addressed the risk of management override of internal controls, including testing journals and evaluating whether there was evidence of bias by the directors that represented a risk of material misstatement due to fraud.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

Eligibility for appointment as auditor

Mitchell Charlesworth (Audit) Limited is eligible for appointment as auditor of the Charity by virtue of its eligibility for appointment as auditor of a company under section 1212 of the Companies Act 2006.

Use of our report

This report is made solely to the Charity's Trustees, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the Charity's Trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Charity and the Charity's Trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Mitchell Charlesworth

Alison Buckley (Senior Statutory Auditor)
Mitchell Charlesworth (Audit) Limited
Statutory Auditor

3rd Floor
44 Peter Street
Manchester
M3 5GP

Dated: 23/10/2025

Mitchell Charlesworth (Audit) Limited is eligible to act as auditors in terms of Section 1212 of the Companies Act 2006

Consolidated Statement of Financial Activities (Incorporating Income and Expenditure Account)
Year ended 31 December 2024

	Notes	Unrestricted £	Restricted £	2024 Total £	Unrestricted £	Restricted £	2023 Total £
Income							
Income from donations	2	**257,450**	**4,550,018**	**4,807,468**	250,000	480,918	730,918
Income from investments		**-**	**43,295**	**43,295**	-	47	47
Total		**257,450**	**4,593,313**	**4,850,763**	250,000	480,965	730,965
Expenditure							
Charitable activities	3	**92,494**	**1,155,172**	**1,247,666**	149,718	1,332,052	1,481,770
Raising funds	4	**129,499**	**33,789**	**163,288**	70,896	-	70,896
Total		**221,993**	**1,188,961**	**1,410,954**	220,614	1,332,052	1,552,666
Net movement in funds		**35,457**	**3,404,352**	**3,439,809**	29,386	(851,087)	(821,701)
Transfer of funds	8	**-**	**-**	**-**	(29,189)	29,189	-
Funds brought forward		**199,920**	**1,485,823**	**1,685,743**	199,723	2,307,721	2,507,444
Funds carried forward		**235,377**	**4,890,175**	**5,125,552**	199,920	1,485,823	1,685,743

Balance Sheet
As at 31 December 2024

	Notes	Group 2024 £	Group 2023 £	Charity 2024 £	Charity 2023 £
Fixed assets					
Investments	5	**317,752**	118,427	**317,852**	118,527
Current assets					
Cash at bank		**1,852,797**	1,342,509	**1,675,292**	1,319,809
Other debtors	6	**2,119,345**	155,447	**2,119,345**	178,147
Current asset investments	7	**2,500,000**	1,500,000	**2,500,000**	1,500,000
		6,472,142	2,997,956	**6,294,637**	2,997,956
Creditors: Amounts falling due within one year	8	**(1,169,204)**	(820,521)	**(991,799)**	(820,621)
Net current assets		**5,302,938**	2,177,435	**5,302,838**	2,177,335
Total assets less current liabilities		**5,620,690**	2,295,862	**5,620,690**	2,295,862
Creditors: amounts falling due after more than one year	9	**(495,138)**	(610,119)	**(495,138)**	(610,119)
Total net assets		**5,125,552**	1,685,743	**5,125,552**	1,685,743
The funds of the charity					
Unrestricted income funds		**235,377**	199,920	**267,074**	231,617
Restricted income funds		**4,890,175**	1,485,823	**4,858,478**	1,454,126
Total funds		**5,125,552**	1,685,743	**5,125,552**	1,685,743

These financial statements were approved by the Trustees on 23/10/2025 and were signed on its behalf by:

Sharmila Nikapota

Sharmila Nikapota

James Collins

James Collins

Consolidated Cash Flow Statement
For the year ended 31 December 2024

	2024 £	2023 £
Net movement of funds from operating activities	**3,439,809**	(821,701)
Impairment of fixed asset investments	**100,000**	310,464
Purchase of fixed asset investments	**(299,325)**	-
Increase in debtors / investments (Notes 6 and 7)	**(2,963,898)**	(1,465,237)
Increase in creditors (Notes 8 and 9)	**233,702**	518,343
Net cash inflow from operations	**510,288**	(1,458,131)
Cash at the beginning of the year	**1,342,509**	2,800,640
Cash at the end of the year	**1,852,797**	1,342,509

1. Principal accounting policies

(a) Accounting convention

The financial statements of the Charity, 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 Charities Act 2011. The financial statements have been prepared under the historical cost convention.

Cure EB meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

(b) Group accounts

The financial statements consolidate the results of the Charity and its wholly owned subsidiary EB Therapeutic Ltd on a line-by-line basis. A separate Statement of Financial Activities and Income and Expenditure Account for the Charity has not been presented because it has taken advantage of the exemption afforded by section 408 of the Companies Act 2006.

The consolidated statement of financial activities, balance sheet and cash flow include the financial statements of the Charity and its subsidiary undertaking made up to 31 December 2024. The results of the subsidiary are included in the statement of financial activities and inter group transactions are eliminated fully on consolidation.

The Charity has taken advantage of exemption, under the terms of Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland', not to disclose related party transactions with wholly owned subsidiaries within the Group. Due to EB Therapeutics Ltd current activities and how it is funded, the consolidated statement of charitable financial activities and the consolidated cash flow statement are materially the same as the individual parent Charity's statement of financial activities and individual cash flow statement.

(c) Critical accounting judgements and key sources of estimation uncertainty

Due to the straightforward nature of Cure EB's activities, the Trustees do not believe that there are any estimation uncertainties or accounting judgments that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next financial year.

The investments are held at cost less impairment as the fair value cannot be reliably measured. The Trustees are not aware of any material impairments in the investments other than those disclosed.

(d) Donation and grant income

Income is accounted for in the period in which the Charity is entitled to receipt, the receipt is probable and measurable.

(e) Expenditure

Expenditure is included on an accruals basis.

1. Principal accounting policies [Continued]

(f) Taxation

The Charity is exempt from tax on its charitable activities.

(g) Fixed asset investments

Fixed asset investments are held to generate income, for their investment potential, and/or for their research potential.

Investments include 'social investments' where the purpose in making the investment is wholly or partly to further the Charity's aims. The social investments are stated at cost less impairment unless it can be measured at fair value which can be reliably measured.

The investment in a subsidiary company is held at cost less accumulated impairment losses.

(h) Funds structure

The restricted funds represent donations made where the donor has placed a restriction on the use of the funds. All donations other than specific donations by the Trustees are treated as restricted to research costs and (unless the donor has placed a specific restriction on the use) classed as "Unassigned Research Funds". Unrestricted funds can be used as the Trustees see fit in line with the charitable objectives.

(i) Going concern

The accounts are prepared on the basis that the Trustees have adequate resources to continue to operate. The Trustees have informally discussed expected future cash flows and the future expected incoming and outgoing resources in making their assessment for a period of at least 12 months from the signing of the accounts. Based on these assessments the Trustees have concluded that they can continue to adopt the going concern basis in preparing the annual report and accounts.

(j) Financial instruments

Financial assets and liabilities are recognised when the Charity becomes party to the contractual provisions of the financial instrument. The company holds basic financial instruments which comprise cash at bank, trade and other receivables and trade and other payables.

Basic financial instruments such as social investments, debtors, bank balances and creditors are recognised at transaction value.

2. Donations

All incoming resources related to general donations from individuals and other institutions. There was no legacy income in the year.

All donations received (other than the specific donations from the Trustees) are used to further the Charity's aims, and so are classed as restricted and shown in the Restricted Funds.

3.	Charitable activities	2024	2023
		£	£
	Research projects:		
	University of Minnesota - Nanocol	-	200
	Gene Editing Trial – UC3 Madrid	**38,802**	-
	Base & Prime Editing strategies for RDEB	**350,730**	-
	Kings College London - Nanocol	-	13,685
	Kings College London - Base Editing of RDEB fibroblasts	-	49,457
	PASTE – Superexon Replacement	-	95,437
	University of Colorado – Spray on Skin	**(558,897)**	703,000
	EB Cancer Therapy	**147,033**	-
	Oligo	**638,664**	50,000
	EB Graft	**66,767**	-
	Inserm - SIRNA	-	154,809
	JEB Airway Disease	**80,000**	-
	Decorin	**16,951**	-
	Bespoke Therapy	**267,198**	
	Other costs:		
	Impairment losses	**100,000**	310,464
	Support costs:		
	Administration costs	**80,490**	92,410
	Bank charges	**274**	401
	Audit	**10,532**	10,802
	Charitable Events - restricted	**6,625**	-
	Research Events - restricted	**1,300**	-
	Insurance	**1,197**	1,105
		1,247,666	1,481,770

4.	Raising funds	2024	2023
		£	£
	Fund raising and marketing	**34,518**	38,253
	Fundraising administration costs	**128,770**	32,643
		163,288	70,896

5. Fixed asset investments - held by Group and Charity	2024	2023
	£	£
Social investments - unlisted		
Cost at 1 January 2024	**118,427**	428,891
Additions	**299,325**	-
Cost at 31 December 2024	**417,752**	428,891
Impairment		
Charge for the year	**(100,000)**	(310,464)
Net book value		
At 31 December 2024	**317,752**	118,427
At 31 December 2023	**118,427**	428,891

	2024	2023
	£	£
Shares in Group undertakings held by Charity		
Cost at 1 January 2024	**100**	100
Cost at 31 December 2024	**100**	100
Net book value		
Cost at 31 December 2024	**100**	100

The Group or the Charity's investments at the Balance Sheet date in the share capital of companies include the following:

Subsidiaries

EB Therapeutics Ltd
Registered office: England & Wales
Nature of business: Furthering research for human health

	%
Class of shares	Holding
Ordinary	100.00

Social investments are made to fund companies who undertake research that further the aims of the Charity. Material social investments have been made in Phoenicis Therapeutics, Inc., a US Corporation and Branca Bunus Limited, a company registered in Ireland.

6. Debtors	Group		Charity	
	2024	2023	**2024**	2023
	£	£	**£**	£
Other debtors	**2,119,345**	155,447	**2,119,345**	178,147

Other debtors are donations receivable and gift aid receivable on donations received and receivable during the year.

7. Current Asset investments	Group		Charity	
	2024	2023	**2024**	2023
	£	£	**£**	£
Treasury Bonds	**2,500,000**	1,500,000	**2,500,000**	1,500,000

8. Creditors: amounts falling due within one year	Group		Charity	
	2024	2023	**2024**	2023
	£	£	**£**	£
Trade creditors	**258,473**	16,912	**15,005**	16,912
Amounts owed to intercompany	**-**	-	**65,963**	-
Unpaid share capital	**-**	-	**100**	100
Committed grants	**910,731**	803,609	**910,731**	803,609
	1,169,204	820,521	**991,799**	820,621

9. Creditors: amounts falling due after more than one year	Group		Charity	
	2024	**2023**	**2024**	**2023**
	£	**£**	**£**	**£**
Committed grants	495,138	610,119	495,138	610,119
	495,138	610,119	**495,138**	610,119

10. Fund balances – Current year	Unrestricted Funds £	Restricted Funds £	Total £
Balance brought forward	199,920	1,485,823	1,685,743
Income	257,450	4,593,313	4,850,763
Expenditure	(221,993)	(1,188,961)	(1,410,954)
Inter fund transfer	-	-	-
Balance carried forward	235,377	4,890,175	5,125,552
Represented by:			
Fixed assets	-	317,752	317,752
Cash at bank	235,377	1,617,420	1,852,797
Other net assets/liabilities	-	2,955,003	2,955,003
	235,377	4,890,175	5,125,552

Current year	Brought Forward £	Income £	Expenditure £	Gains/Losses £	Transfers £	Carried Forward £
Research Projects						
Therapy for RDEB SCC	50,000	-	-	-	-	**50,000**
EB Graft	-	-	(66,767)	-	66,767	**-**
Gene Editing Trial	-	-	(38,802)	-	38,802	**-**
Spray on Skin	-	37,103	558,897	-	(596,000)	**-**
Base & prime editing strategies for RDEB	-	108,631	(350,730)	-	242,099	**-**
EB Cancer Therapy	-	-	(147,033)	-	147,033	**-**
Bespoke Therapy	-	-	(267,198)	-	267,198	**-**
JEB Airway Disease	-	-	(80,000)	-	80,000	**-**
Decorin	-	-	(16,951)	-	16,951	**-**
SIRNA	-	37,103	-	-	-	**37,103**
Social Investments						
Nonsense Therapeutics (ABE Fund)	-	200,000	-	(100,000)	-	**100,000**
Other Social Investments	118,427	-	-	-	-	**118,427**
Nova Anchora	-	99,325	-	-	-	**99,325**
Other Research Funds						
Unassigned Research Funds	198,300	621,910	-	-	(262,850)	**557,360**
Other Restricted Funds						
ABE Fund	26,818	412,807	(14,869)	-	-	**424,756**
Translational Fund	1,086,078	3,025,134	(638,663)	-	-	**3,472,549**
Funds for Fundraiser	6,200	-	(920)	-	-	**5,280**
Research Events	-	1,300	(1,300)	-	-	**-**
Children's Fund	-	50,000	(24,625)	-	-	**25,375**
	1,485,823	4,593,313	(1,088,961)	(100,000)	-	**4,890,175**

10. Fund balances [Continued] Previous Year	Unrestricted Funds £	Restricted Funds £	Total £
Balance brought forward	199,723	2,307,721	2,507,444
Income	250,000	480,965	730,965
Expenditure	(222,104)	(1,330,562)	(1,552,666)
Inter fund transfer	(27,699)	27,699	-
Balance carried forward	199,920	1,485,823	1,685,743
Represented by:			
Fixed assets	-	118,427	118,427
Cash at bank	179,928	1,162,581	1,342,509
Other net assets/liabilities	19,992	204,815	224,807
	199,920	1,485,823	1,685,743

Previous year	Brought Forward £	Income £	Expenditure £	Gains/Losses £	Transfers £	Balance Carried Forward £
Research Projects						
SIRNA Interference in EBS	-	-	(154,809)		154,809	-
Nanocol		-	(13,885)	-	13,885	-
KCL Editing of RDEB Fibroblasts	-	-	(49,457)	-	49,457	-
PASTE – mediated Superexon Replacement of COL7A1	-	-	(93,947)	-	93,947	-
Spray on Skin	-	102,331	(703,000)	-	600,669	-
Gene & Cell (Cancer) Therapy for EBT	-	50,000	-	-	-	**50,000**
Social Investments						
ABE Fund	-	26,818	-	-	-	**26,818**
Other Social Investments	401,192	-	-	(310,464)	27,699	**118,427**
Other Restricted Funds						
Funds for fundraiser	6,200	-	-	-	-	**6,200**
EB Family Day	-	5,000	(5,000))	-	-	**-**
Unassigned Research Funds	1,900,329	296,816	-	-	(912,767)	**1,284,378**
	2,307,721	480,965	(1,020,098)	(310,464)	27,699	**1,485,823**

11. Related party disclosures and Trustees' remuneration and benefits

No Trustees received remuneration or were reimbursed for expenses in the period.

During the year the Charity introduced £638,664 (2023: £50,000) of support to its subsidiary EB Therapeutics Ltd.

In the year there were donations to the Charity from the Trustees amounting to £1,247,865 (2023: £230,175) (which are increased by Cure EB claiming Gift Aid).

12. Staff costs

There were no employees (2023: none).

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

No Trustee expenses have been incurred and no Trustees were re-imbursed for any expenses during the year (2023: None).

13. Contingent liabilities and capital commitments

The Trustees are not aware of any contingent liabilities or capital commitments.

14. Subsequent events

The Trustees are not aware of any material adjusting or non-adjusting post balance sheet events.

CURE EB (FORMERLY KNOWN AS SOHANA RESEARCH FUND)

England & Wales - Charity number 1158672

Accounts

REPORT AND FINANCIAL STATEMENTS

Year-ended 31 December 2023

Charity Number: 1158672

Cure EB

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Year ended 31 December 2023

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Cure EB

Legal and Administrative Information
Year ended 31 December 2023

1. The structural and administrative details for the Charity are as follows:

   1.1. Name: Cure EB (formerly known as Sohana Research Fund)

   1.2. Type of entity: Charitable Incorporated Organisation

   1.3. Date of incorporation: 25 September 2014

   1.4. Registered Charity Number: 1158672

   1.5. Governing document: Constitution

   1.6. Registered and principal office: 10 Huntingdon Street, London, N1 1BU

2. The Trustees as at the date of this report (the "Trustees") are:

   2.1. Ms Sharmila Nikapota

   2.2. Mr James Collins

   2.3. Mr Michael de Lathauwer

   2.4. Ms Tazim Hall

   2.5. Prof. David Kelsell

   2.6. Mr Duncan Wales

   2.7. Rachel Lesiter

3. The bankers are: Barclays Bank PLC

   14 Upper Street
   Islington
   London
   N1 0PQ

4. The auditors are: Mitchell Charlesworth (Audit) Limited

   3rd Floor
   44 Peter Street
   Manchester
   M2 5GP

Cure EB

Summary
Year ended 31 December 2023

Our Mission Statement

Our mission is to find effective treatments and ultimately a cure for Epidermolysis Bullosa ("EB").

Our Commitments

To fund translational research and clinical trials for the benefit of people with EB.

To maximise research spend.

To raise awareness of EB.

Cure EB

2023 Highlights
Year ended 31 December 2023

Fundraising highlights

- Radio 4 appeal
- Butterfly Brunch Speaker event
- Dodington Opera
- BGC Charity Day
- Big Give Christmas Challenge
- London Marathon
- Goldman Sachs donation
- Butterfly Run

Project highlights

- Regulatory paperwork submission for gene editing trial
- Gene therapy for airway disease project finished
- Nanocol final report and publication
- Mission EB trial at Great Ormond Street in data analysis phase
- EB graft trial work ongoing
- New multiyear commitment to iPSC project leading up to trial in US
- New cancer immunotherapy project started in Minnesota

Cure EB

Founder's Statement
Year ended 31 December 2023

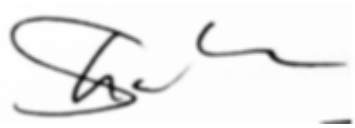
Epidermolysis Bullosa ("EB") is a group of genetic skin blistering conditions that vary in severity depending on the subtype. Some forms are fatal in infancy and others lead to progressive deformity and are severely life limiting. Recessive Dystrophic Epidermolysis Bullosa ("RDEB") is a very severe form that leads to scarring, contractures, oesophageal restriction, corneal abrasions, malignant skin cancer and many more painful and life-altering symptoms.

Cure EB exists to find treatments and a cure for EB. To this end, we fund predominantly translational medical research aiming to deliver quality-of-life changing relief and eventually a cure to those afflicted by EB.

2023 started with our first in person research update evening since the pandemic. We had a very successful Radio 4 appeal in May, bringing EB to a new radio audience. We were very lucky to be chosen for BGC charity day again with Patron Damian Lewis attending. Our butterfly run and family day at the Olympic Park were well attended and great fun with excellent presentations by some of our researchers.

We are buoyed by progress across the gene therapy space and particularly with results coming out of our projects in these areas. The world has seen two approved topical treatments for EB come on the market and we continue to look for systemic treatments to follow.

As ever we are incredibly grateful to our many wonderful long-term donors, supporters, friends and EB patients who have faith and have stayed with us for many years.



25/10/2024

Sharmila Nikapota
Founder Trustee

Cure EB

Report of the Trustees
Year ended 31 December 2023

The Trustees present their report along with the financial statements of the Charity for the year ended 31 December 2023.

Introduction

1. Cure EB - then known as the Sohana Research Fund C.I.O. ("SRF") - was established on 25 September 2014 with Registered Charity Number 1158672.

2. Cure EB's principal purpose is to fund medical research and clinical trials aimed at discovering, developing and delivering treatments for Epidermolysis Bullosa ("EB").

Objectives and activities

3. As set out in Cure EB's Constitution, Cure EB's objects are "*For the public benefit, (a) the advancement of health and (b) the relief and assistance of people in need who are suffering from Epidermolysis Bullosa, in particular but not exclusively by making grants:*

    3.1. *to fund medical research and/or clinical trials anywhere in the world for the purpose of discovering, developing and delivering treatments for Epidermolysis Bullosa; and*

    3.2. *to fund the treatment of patients who are suffering from Epidermolysis Bullosa"*

4. Cure EB's objectives during 2023 were limited to:

    4.1. Raising funds;

    4.2. Raising awareness;

    4.3. Identifying and developing projects for funding; and

    4.4. Funding of projects.

5. The Trustees confirm that in determining what activities Cure EB carries out, they have had regard to the Charity Commission's guidance on public benefit.

Fundraising and awareness

6. As a rare genetic skin condition public knowledge of the condition is limited. This impacts Cure EB's ability to raise money for research and support. Consequently, we see increased awareness of the condition as something that has a direct influence on our ability to raised funds. Our Radio 4 appeal, read by Sharmila in May, raised £85,000 and was one of the top five appeals in 2023. A new radio public were made aware of the horrors of EB and research towards a trial to replace the missing protein.

7. We did not have a fundraising dinner in May as it is a biennial event but had a very successful Butterfly Brunch Speaker event in London with Hadley Freeman in Conversation with Amelia Gentleman. This introduced the charity to new supporters as well as being a successful fundraising event

8. In print media we were referenced in a Bloomberg article 'Sky diving for Butterfly Children' and quoted in a Times article 'Birch Bark treatment for 'butterfly syndrome' given NHS approval'. We have an active social media presence with over 30,000 followers on Facebook, approximately 2500 on X (formerly known as twitter) and over 2000 on Instagram. We are working on building our Linkedin profile. Our website continues to be a very important tool when fundraising and educating the public as to our aims and ambitions. It holds all information regarding projects and press as well as event information. We strive to keep it up to date and continue to improve its features.

Fundraising and awareness [Continued]

9. We launched a new online campaign called #CoffeeetoCure EB which Damian Lewis helped kick off in October, encouraging people to donate the cost of a coffee by text number. We hope to build that over the next year in an effort to raise awareness but also small value donations from as many people as possible.

10. Our main community outreach and awareness event, the Butterfly Run and Family Day, took place in September 2023. We had increased participation in the run, which we need to build on. Four of our researchers gave excellent presentations and we had good participation from the EB families and supporters who attended, with a lively discussion at the end. We were chosen for BGC charity day which was attended by Damian Lewis and beneficiaries and we also had a very good Big Give Christmas challenge raising £80,000. Fundraisers included three very successful marathon runners, a wonderful evening at Dodington Opera, a sky dive, golf days, boogie evening, Facebook fundraisers and birthday and anniversary celebrations and Ride London.

11. Much work went towards building a Development Fund which will become visible and important over the next few years. We have also established two new restricted funds within Cure EB, the JT fund and the Abe fund which are to be used for particular avenues of research.

12. We had substantial donations from the James and Deirdre Dyson Trust, The Brothers Trust, The Reed Foundation, The Tides Foundation, The Maria Marina Foundation, The MDL Trust2, The Maurice Hatter Foundation, The William Howarth Trust, The Ward Family Trust, The Lily Foundation, The Michael and Anna Wix Charitable Trust, Amazon Smile, The fellows Hyde Trust. We also had sponsorship from Krystal Bio, Constant Therapeutics and Flenn Health for our run and family Day and a grant from Amryt Pharma for family day

13. We are building our regular giving through the Kaleidoscope friends scheme and online platforms but this is still an area that we have to work on.

Achievements and performance

14. Cure EB funds a range of projects. However, Cure EB's principal focus is on translational research – i.e. the preclinical research and clinical trials that will (we hope) translate fundamental (laboratory based) research into effective treatments for RDEB. We are assisted by an experienced independent expert panel who evaluate projects and advise on research strategies and priorities.

15. We currently evaluate projects on a rolling basis (rather than in formal funding rounds at fixed intervals) and invite applications that meet our priority areas of research. An initial outline of the project is evaluated and if deemed to be within an area of interest a full grant application is asked for. The project is then externally reviewed and scored by a scientific advisory panel (SAP), whose members are world leading scientific experts in medical related research. That external review process is coordinated by one of our Trustees, Professor David Kelsell, who is himself an expert in human skin genetics and part of the SAP. If the scores are sufficiently high the project is presented to the Trustees for approval. If approved, Cure EB negotiates and concludes formal funding agreements with the body that is to carry out the research

16. To highlight our research we hosted our first research update meeting since the pandemic at the Shard, which was donated to us for the evening. Professor Alain Hovnanian from Inserm, Paris, Professor John McGrath from Kings College London and Dr Joanna Jackow from Kings College, London all gave excellent and exciting presentations highlighting the progress in the EB gene therapy space.

17. During 2023, published research included the Rigosertib pilot study in the Journal of clinical Oncology, Cytosine base editing in JID innovations, and a paper on Restoring airway adhesion in JEB in Molecular Therapy.

Achievements and performance [Continued]

18. Projects progressed and funded included EB graft (France), Nanocol (US and UK), Editing of RDEB fibroblasts (UK), Paste mediated super exon replacement (UK). We also committed to new projects including 'Spray on skin', a large project on the path to clinical trial in the US in which we and other EB charities are match-funding a federal grant. Other projects included base and prime editing of RDEB fibroblasts in France, Gene and cell therapy in RDEB at the University of Minnesota and an extension of the editing of RDEB fibroblasts at Kings College in London.

19. Looking ahead, our aim is to continue our focus on translational research. We will also continue looking at emerging technologies to determine translational benefit.

20. To this end we aim to continue to carry on building our relationships with other potential funders (we have a good track record of collaborating) and investors and with the RDEB research community.

Financial review

21. The accounts show the financial affairs of Cure EB and its wholly owned subsidiary, EB Therapeutics Ltd, for 2023. The key figures, together with commentary, are as follows:

21.1. Gross Income: £730,965. This was (as expected) lower than 2023 due to the fact that it is not a Butterfly Dinner year. Fundraising continued to be challenging in 2023 and income was further depressed by the timing of some donations (which is unpredictable) meaning that whilst 2023 was slightly disappointing, 2024 got off to a very good start.

21.2. Expenditure on charitable activities (including support costs) was higher than the previous year at £1,481,770. This was in line with our aim to increase research funding but distorted upwards by two matters that had a major impact on recognised expenditure but much smaller impact on cash-flow. These were:

(1) Cure EB committed to support a major project at the University of Colorado. Funding for this will be provided over up to 5 years. Whilst the total amount of support to be provided is not yet certain, and much of it will not fall due for 2, 3 or 4 years, we considered it prudent to recognise the likely maximum support to be provided over the entire duration of the project.

(2) We previously structured support for two projects (Fibrx Derm and RNA Derm) as social investments (with Cure EB receiving financial instruments in return for that support). Those social investments were held at cost until 2023. In 2023 we determined that it was prudent to impair those investments by £310,464 (100%). As payment for those projects was made several years ago, this has no impact on Cure EB's cash flow.

21.3. Costs of Fundraising: £70,896. Expenditure was lower than the prior period largely due to the absence of the cost of the biennial Butterfly Dinner. As a rule of thumb, Cure EB aims to raise £10 for every £1 spent on fundraising activities. 2023 Cure achieved this in 2023.

21.4 Reserves at year end were £1,685,743. This is down from £2,507,444 largely for the reasons identified at 21.2 above.

21.5 Cash at year end was £1,342,509. In addition, Cure EB purchased and held Treasury Bonds of £1,500,000 in order to generate (modest) income from the cash reserves. The cash and bonds total of £2,842,509 was slightly higher than the 2022 year-end figure for cash at bank: £2,800,640.

Financial review [Continued]

22. Looking ahead to 2024:

22.1. Gross income is likely to be very much higher than 2023 due to a number of factors, including:

(1) Major progress with fundraising for Cure EB's Development Fund. This is fund that is intended to take a promising treatment through the remaining safety testing and regulatory steps and into human trials. One requirement for regulatory approval is proof of funding.

(2) A very successful Butterfly Dinner.

(3) Increased corporate support.

(4) Substantial fundraising by the Abe Fund (a restricted fund within Cure EB).

22.2. Cost of fundraising is likely to be marginally higher, due to the cost of the Butterfly Dinner.

22.3. Expenditure on projects is likely to be within the range established over the past few years. A number of projects have been approved or reviewed, but it is not yet clear how many of those will be contracted before year-end.

23. The trustees as at the date of this report (the "Trustees") were:

23.1. Ms. Sharmilla Nikapota

23.2. Mr James Collins

23.3. Mr Michael le Lathauwer

23.4 Ms. Tazim Hall

23.5 Prof. David Kelsell

23.6 Mr Duncan Wales

23.7 Ms. Rachel Lesiter

24. There were no other Trustees during 2023. These Trustees may be reappointed at the expiry of their current terms and/or further trustees may be appointed by resolution passed at a properly convened meeting of the trustees. Pursuant to the terms of the Constitution, the minimum number of trustees is 3 and the maximum is 9. The Trustees are selected for their experience and expertise.

25. The Trustees are not and were not compensated for performing their roles as trustees.

26. Management and Administration:

26.1. Management of Cure EB's fundraising and awareness activities has been delegated (subject to a financial cap) to Sharmila Nikapota and James Collins. They in turn report to the other Trustees. In particular:

(1) Sharmila Nikapota has primary responsibility for conceiving, developing and performing all fundraising and awareness activities. This includes the identification of suitable contractors to provide goods or services and negotiation with those contractors.

Financial review [Continued]

(2) Costs of goods and services are approved by, and payment is arranged by, James Collins or Rachel Lesiter.

(3) Sharmila Nikapota and James Collins are authorised to jointly incur costs of up to £10,000 per month in relation to fundraising and awareness activities without further authorisation from the Trustees. For major events, Sharmila Nikapota and James Collins must seek the prior approval of the Trustees.

26.2. Management of the administration of Cure EB has been delegated (subject to a financial cap) to Sharmila Nikapota, Rachel Lesiter and James Collins. They in turn report to the other Trustees. In particular:

(1) Sharmila Nikapota, Rachel Lesiter and James Collins are primarily responsible for identifying the services that need to be performed and finding suitable contractors to assist with the provision of those services.

(2) Sharmila Nikapota and James Collins are authorised to jointly incur costs of up to £2,500 per month in relation to the administration of Cure EB without further authorisation from the Trustees. Financial oversight and record keeping is performed by Rachel Lesiter.

26.3. In relation to projects and funding:

(1) Sharmila Nikapota is in regular direct communication with leading researchers and clinicians and with other potential funding bodies. She has primary responsibility for the initial identification of projects that may merit funding on grounds that they (i) further the objects of Cure EB; and (ii) are (weighing the work that is to be performed and the potential benefits of the research against the cost) cost-effective.

(2) The process for the evaluation of potential projects depends on the nature and size of the project. Prof. David Kelsell provides guidance in relation to both the process and the evaluation. He is also responsible for coordinating the reviews by Cure EB's scientific advisory panel (SAP) whose members are world leading scientific experts in medical related research. They evaluate, comment on and score the projects for Cure EB.

(3) All funding decisions (including identification of the project to be funded and the amount of funding to be provided) are made by the Trustees (as a whole).

(4) Funds in two restricted funds (the Abe Fund, year-end balance £26,818; and the JT Fund, year-end balance £0) can only be spent on projects approved by the founders of those restricted funds, but the funding decision must still be made by the Trustees.

(5) Having decided "in principle" to fund a project, negotiation of documentation is led by James Collins.

(6) Project invoices that conform with the funding agreements are approved by, and payment is arranged by, James Collins and Rachel Lesiter.

Financial review [Continued]

27. Professional services:

27.1 James Collins in a commercial barrister and Tazim Hall was a solicitor and partner at a substantial international law firm. Cure EB buys in additional legal services as and when required.

27.2 Cure EB has not retained any investment advisor. However, Michael de Lathauwer comes from an investment banking background and is currently a fund manager.

28. Remuneration:

28.1 The Trustees are not and were not compensated for their management roles (described above) nor for any other role that they perform.

28.2 Cure EB has a part-time Administrator and a part-time Research Officer. Both are self-employed, but the time they provide adds up to about 1 FTE (full time equivalent). In addition, Cure EB has established relationships with a number of individuals and organisations that provide services on a contractor or self-employed basis.

28.3 Cure EB has benefited from, and relies on, substantial support from a team of volunteers. In particular:

(1) The fundraising and awareness events are supported by a substantial team of engaged and dedicated volunteers. They provide assistance with the development of the event, attracting supporters to the event, graphic design, logistics and in many other ways. Without their support, many of these services would have to be bought in at considerable cost to Cure EB.

(2) The administration of Cure EB has been greatly assisted by volunteers, again saving Cure EB substantial cost.

Investment policy

Funds are held as short-term bank balances and (if and when rates justify it) longer term treasury deposits. The only other investments made by Cure EB are Social Investments (rather than financial investments).

Social Investments

These investments are payments made to further the aims of the charity – i.e. to advance research – rather than to secure a financial return. However, because they are structured as investments there is potential for return. In 2023 Cure EB made no further Social Investments, but impaired the value of two previous Social Investments.

EB Therapeutics

At the end of 2018, Cure EB established a subsidiary: EB Therapeutics Ltd ("EBT"). The purpose of this subsidiary is to further develop some of the technologies supported by Cure EB with the aim of assisting with the transition from research to market, so that effective treatments become as widely available as possible. EBT was dormant until 2020. During 2020 it (1) took a license of IP related to one of the projects that Cure EB is supporting; and (2) concluded a research service agreement for a new project. During 2021 this new project generated encouraging laboratory results. This continued through 2022 with the focus shifting (1) to the identification of the best compounds to progress towards an in-human trials; and (2) (for some compounds) from in-vitro to early in-vivo testing. In 2023, work to identify the best compounds continued, and in-vivo testing of those compounds was substantially progressed.

Reserves policy

Policy: Because the charity has a low-cost operating base it does not require a significant unrestricted reserve fund to meet its operating costs. However, Cure EB aims to maintain and build a substantial restricted reserve fund to meet the cost of future projects. This is for two reasons. First, Cure EB wants to be able to fund the best projects irrespective of its income in any particular year (which will fluctuate for reasons beyond its control). Second, Cure EB is building a Development Fund to progress one project through the final steps towards, and then into, human trials.
Forward looking statement: The Trustees are confident that there are adequate reserves to fund the research that Cure EB had committed to fund and to cover the anticipated future costs.

Risk management

The principal risk to the charity is the ability to continue to raise funds sufficient to meet the commitments made to fund projects and operating costs.

The Trustees have (above) highlighted the facts relevant to this risk. During 2023 this risk was entirely mitigated by ensuring that reserves substantially exceeded commitments.

Whilst the Trustees expenditure will exceed income in certain years, the Trustees intend (1) to retain substantial reserves (for the reasons given above); and (2) only commit to projects where Cure EB (i) already has sufficient funding for the project; or (ii) is confident that funds will be raised well in advance of any payment dates falling due.

Public benefit

The Trustees are conscious of the Charity Commission guidelines on public benefit and these guidelines are applied when grants are considered.

Trustees' responsibilities in relation to the financial statements

The Trustees are responsible for preparing the Trustees Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Law applicable to charities in England and Wales requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the Charity's financial activities during the year and of its financial position at the end of the year. In preparing those financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Make judgements and estimates that are reasonable and prudent;
- Observe the methods and principles in the Charity SORP;
- State whether applicable accounting standards and statement of recommended practice have been followed subject to any departures disclosed and explained in the financial statements; and
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Charity will continue in operation.

The Trustees are responsible for keeping accounting records which disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Charities Act 2011. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by the Trustees and signed on their behalf by:

Sharmila Nikapota **James Collins**

Date: 25/10/2024

Report of the Auditors to the Trustees of Cure EB
Year ended 31 December 2023

Opinion

We have audited the financial statements of Cure EB (the 'Charity') for the year ended 31 December 2023 which comprise the Consolidated Statement of Financial Activities, the Consolidated and Charity Balance Sheet, the Consolidated Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the Charity's affairs as at 31 December 2023 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the Charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the Charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

Other information

The Trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- the information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of Trustees

As explained more fully in the Statement of Trustees' Responsibilities, the Trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the Charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the Charity or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists.

Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud.

The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

We gained an understanding of the legal and regulatory framework applicable to the Charity and the industry in which it operates, and considered the risk of acts by the Charity that were contrary to applicable laws and regulations, including fraud. We discussed with the Trustees the policies and procedures in place regarding compliance with laws and regulations. We discussed amongst the audit team the identified laws and regulations, and remained alert to any indications of non-compliance.

During the audit we focused on laws and regulations which could reasonably be expected to give rise to a material misstatement in the financial statements, including, but not limited to, the Charities Act 2011 and UK tax legislation. Our tests included agreeing the financial statement disclosures to underlying supporting documentation and enquiries with management.

Our responsibilities for the audit of the financial statements [Continued]

Our procedures in relation to fraud included but were not limited to: inquires of management whether they have any knowledge of any actual, suspected or alleged fraud, and discussions amongst the audit team regarding risk of fraud such as opportunities for fraudulent manipulation of financial statements. We determined that the principal risks related to posting manual journal entries to manipulate financial performance and management bias through judgements in accounting estimates. We also addressed the risk of management override of internal controls, including testing journals and evaluating whether there was evidence of bias by the directors that represented a risk of material misstatement due to fraud.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

Eligibility for appointment as auditor

Mitchell Charlesworth (Audit) Limited is eligible for appointment as auditor of the Charity by virtue of its eligibility for appointment as auditor of a company under section 1212 of the Companies Act 2006.

Use of our report

This report is made solely to the Charity's Trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the Charity's Trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Charity and the Charity's Trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Alison Buckley (Senior Statutory Auditor)
Mitchell Charlesworth (Audit) Limited
Statutory Auditor

3rd Floor
44 Peter Street
Manchester
M3 5GP

Dated: 28/10/2024

Mitchell Charlesworth (Audit) Limited is eligible to act as auditors in terms of Section 1212 of the Companies Act 2006

Cure EB

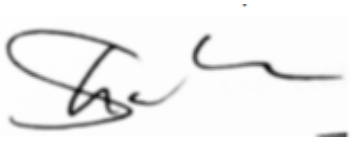
Consolidated Statement of Financial Activities (Incorporating Income and Expenditure Account)
Year ended 31 December 2023

	Notes	Unrestricted £	Restricted £	2023 Total £	Unrestricted £	Restricted £	2022 Total £
Income							
Income from donations	2	**250,000**	**480,918**	**730,918**	182,000	818,852	1,000,852
Income from investments		**-**	**47**	**47**	-	11	11
Total		**250,000**	**480,965**	**730,965**	182,000	818,863	1,000,863
Expenditure							
Charitable activities	3	**149,718**	**1,332,052**	**1,481,770**	90,205	942,925	1,033,130
Raising funds	4	**70,896**	**-**	**70,896**	82,591	6,424	89,015
Total		**220,614**	**1,332,052**	**1,552,666**	172,796	949,349	1,122,145
Net movement in funds		**29,386**	**(851,087)**	**(821,701)**	9,204	(130,486)	(121,282)
Transfer of funds	8	**(29,189)**	**29,189**	**-**	(2,281,980)	2,281,980	-
Funds brought forward		**199,723**	**2,307,721**	**2,507,444**	2,472,499	156,227	2,628,726
Funds carried forward		**199,920**	**1,485,823**	**1,685,743**	199,723	2,307,721	2,507,444

Balance Sheet
As at 31 December 2023

	Notes	Group 2023 £	Group 2022 £	Charity 2023 £	Charity 2022 £
Fixed assets					
Investments	5	**118,427**	428,891	**118,527**	428,991
Current assets					
Cash at bank		**1,342,509**	2,800,640	**1,319,809**	2,779,430
Other debtors	6	**155,447**	190,210	**178,147**	211,420
Current asset investments	7	**1,500,000**	-	**1,500,000**	-
		2,997,956	2,990,850	**2,997,956**	2,990,850
Creditors:					
Amounts falling due within one year	8	**(820,521)**	(912,297)	**(820,621)**	(912,397)
Net current assets		**2,177,435**	2,078,553	**2,177,335**	2,078,453
Total assets less current liabilities		**2,295,862**	2,507,444	**2,295,862**	2,507,444
Creditors: amounts falling due after more than one year	9	**(610,119)**	-	**(610,119)**	-
Total net assets		**1,685,743**	2,507,444	**1,685,743**	2,507,444
The funds of the charity					
Unrestricted income funds		**199,920**	199,723	**231,617**	203,721
Restricted income funds		**1,485,823**	2,307,721	**1,454,126**	2,303,723
Total funds		**1,685,743**	2,507,444	**1,685,743**	2,507,444

These financial statements were approved by the Trustees on 25 October 2024 and were signed on its behalf by:



Sharmila Nikapota

James Collins

Cure EB

Consolidated Cash Flow Statement
For the year ended 31 December 2023

	2023	2022
	£	£
Net movement of funds from operating activities	**(821,701)**	(121,282)
Impairment of fixed asset investments	**310,464**	-
Increase in debtors / investments (Notes 6 and 7)	**(1,465,237)**	(70,516)
Increase in creditors (Notes 8 and 9)	**518,343**	742,923
Net cash inflow from operations	**(1,458,131)**	551,225
Cash at the beginning of the year	**2,800,640**	2,249,515
Cash at the end of the year	**1,342,509**	2,800,640

1. Principal accounting policies

(a) Accounting convention

The financial statements of the Charity, 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 Charities Act 2011. The financial statements have been prepared under the historical cost convention.

Cure EB meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

(b) Group accounts

The financial statements consolidate the results of the Charity and its wholly owned subsidiary EB Therapeutic Ltd on a line-by-line basis. A separate Statement of Financial Activities and Income and Expenditure Account for the Charity has not been presented because it has taken advantage of the exemption afforded by section 408 of the Companies Act 2006.

The consolidated statement of financial activities, balance sheet and cash flow include the financial statements of the Charity and its subsidiary undertaking made up to 31 December 2023. The results of the subsidiary are included in the statement of financial activities and inter group transactions are eliminated fully on consolidation.

The Charity has taken advantage of exemption, under the terms of Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland', not to disclose related party transactions with wholly owned subsidiaries within the Group. Due to EB Therapeutics Ltd current activities and how it is funded, the consolidated statement of charitable financial activities and the consolidated cash flow statement are materially the same as the individual parent Charity's statement of financial activities and individual cash flow statement.

(c) Critical accounting judgements and key sources of estimation uncertainty

Due to the straightforward nature of Cure EB's activities, the Trustees do not believe that there are any estimation uncertainties or accounting judgments that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next financial year.

The investments are held at cost less impairment as the fair value cannot be reliably measured. The Trustees are not aware of any material impairments in the investments other than those disclosed.

(d) Donation and grant income

Income is accounted for in the period in which the Charity is entitled to receipt, the receipt is probable and measurable.

(e) Expenditure

Expenditure is included on an accruals basis.

1. Principal accounting policies [Continued]

(f) Taxation

The Charity is exempt from tax on its charitable activities.

(g) Fixed asset investments

Fixed asset investments are held to generate income, for their investment potential, and/or for their research potential.

Investments include 'social investments' where the purpose in making the investment is wholly or partly to further the Charity's aims. The social investments are stated at cost less impairment unless it can be measured at fair value which can be reliably measured.

The investment in a subsidiary company is held at cost less accumulated impairment losses.

(h) Funds structure

The restricted funds represent donations made where the donor has placed a restriction on the use of the funds. All donations other than specific donations by the Trustees are treated as restricted to research costs and (unless the donor has placed a specific restriction on the use) classed as "Unassigned Research Funds". Unrestricted funds can be used as the Trustees see fit in line with the charitable objectives.

(i) Going concern

The accounts are prepared on the basis that the Trustees have adequate resources to continue to operate. The Trustees have informally discussed expected future cash flows and the future expected incoming and outgoing resources in making their assessment for a period of at least 12 months from the signing of the accounts. Based on these assessments the Trustees have concluded that they can continue to adopt the going concern basis in preparing the annual report and accounts.

(j) Financial instruments

Financial assets and liabilities are recognised when the Charity becomes party to the contractual provisions of the financial instrument. The company holds basic financial instruments which comprise cash at bank, trade and other receivables and trade and other payables.

Basic financial instruments such as social investments, debtors, bank balances and creditors are recognised at transaction value.

2. Donations

All incoming resources related to general donations from individuals and other institutions. There was no legacy income in the year.

3.	Charitable activities	2023	2022
		£	£
	Research projects:		
	University of Minnesota - Nanocol	**200**	82,986
	Universidad Carlos III de Madrid - Gene Editing Trial	**-**	27,137
	UCL Gene Editing	**-**	17,908
	Kings College London - Nanocol	**13,685**	82,176
	Kings College London - Base Editing of RDEB fibroblasts	**49,457**	208,414
	PASTE – Superexon Replacement	**95,437**	-
	University of Colorado – Spray on Skin	**703,000**	-
	Inserm - Oligo	**-**	139,911
	Inserm - EB Graft	**50,000**	77,489
	Inserm - SIRNA	**154,809**	-
	Great Ormond Street - Gene Therapy	**-**	32,481
	Thomas Jefferson - Rigosertib	**-**	151,285
	St Thomas' Hospital, London - Rigosertib	**-**	127,279
	Support costs:		
	Administration costs	**92,410**	57,085
	Impairment losses	**310,464**	-
	Governance costs	**-**	9,300
	Bank charges	**401**	147
	Audit	**10,802**	12,308
	Web hosting and social media consulting	**-**	2,331
	Insurance	**1,105**	2,661
	Professional fees	**-**	2,233
		1,481,770	1,033,130

4.	Raising funds	2023	2022
		£	£
	Fund raising and marketing	**38,253**	62,170
	Web hosting	**-**	752
	Fundraising administration costs	**32,643**	26,093
		70,896	89,015

5.	Fixed asset investments - held by Group and Charity	2023	2022
		£	£
	Social investments - unlisted		
	Cost at 1 January 2023 and 31 December 2023	**428,891**	428,891
	Impairment		
	Charge for the year	**(310,464)**	-
	Net book value		
	At 31 December 2023	**118,427**	428,891
	At 31 December 2022	**428,891**	428,891

5. Fixed asset investments - held by Group and Charity [Continued]	2023	2022
	£	£
Shares in Group undertakings held by Charity		
Cost at 1 January 2023	**100**	100
Cost at 31 December 2023	**100**	100
Net book value		
Cost at 31 December 2023	**100**	100

The Group or the Charity's investments at the Balance Sheet date in the share capital of companies include the following:

Subsidiaries

EB Therapeutics Ltd

Registered office: England & Wales

Nature of business: Furthering research for human health

	%
Class of shares	Holding
Ordinary	100.00

Social investments are made to fund companies who undertake research that further the aims of the Charity. Material social investments have been made in Phoenicis Therapeutics, Inc., a US Corporation and Branca Bunus Limited, a company registered in Ireland.

6. Debtors	Group		Charity	
	2023	2022	2023	2022
	£	£	£	£
Other debtors	**155,447**	190,210	**178,147**	221,420

Other debtors are donations receivable and gift aid receivable on donations received and receivable during the year

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7. Current Asset investments	Group		Charity	
	2023	2022	2023	2022
	£	£	£	£
Treasury Bonds	**1,500,000**	-	**1,500,000**	-

8. Creditors: amounts falling due within one year	Group		Charity	
	2023	2022	2023	2022
	£	£	£	£
Trade creditors	**16,912**	-	**16,912**	-
Accruals	**-**	12,662	**-**	12,662
Unpaid share capital	**-**	-	**100**	100
Committed grants	**803,609**	899,635	**803,609**	899,635
	820,521	912,297	**820,621**	912,397

9. Creditors: amounts falling due after more than one year	Group		Charity	
	2023 £	2022 £	2023 £	2022 £
Committed grants	**610,119**	-	**610,119**	-
	610,119	-	**610,119**	-

10. Fund balances	Unrestricted Funds £	Restricted Funds £	Total £
Balance brought forward	199,723	2,307,721	2,507,444
Income	250,000	480,965	730,965
Expenditure	(220,614)	(1,332,052)	(1,552,666)
Inter fund transfer	(29,189)	29,189	-
Balance carried forward	199,920	1,485,823	1,685,743
Represented by:			
Fixed assets	-	118,427	118,427
Cash at bank	179,928	1,162,581	1,342,509
Other net assets/liabilities	19,992	204,815	224,807
	199,920	1,485,823	1,685,743

10. Fund balances [Continued]

	Brought Forward £	Income £	Expenditure £	Gains/Losses £	Transfers £	Balance Carried Forward £
Research Projects						
SIRNA Interference in EBS	-	-	(154,809)		154,809	**-**
Nanocol		-	(13,885)	-	13,885	**-**
KCL Editing of RDEB Fibroblasts	-	-	(49,457)	-	49,457	**-**
PASTE	-	-	(95,437)	-	95,437	**-**
Spray on Skin	-	102,331	(703,000)	-	600,669	**-**
Therapy for RDEB SCC	-	50,000	-	-	-	**50,000**
Social Investments						
ABE Fund	-	26,818	-	-	-	**26,818**
Other Social Investments	428,891	-	-	(310,464)	-	**118,427**
Other Restricted Funds						
Funds for fundraiser	6,200	-	-	-	-	**6,200**
EB Family Day	-	5,000	(5,000)	-	-	**-**
Development and Unassigned Research Funds	1,822,630	296,816	-	-	(885,068)	**1,234,378**
	2,307,721	480,965	(1,021,588)	(310,464)	29,189	**1,485,823**

Historically the Board recognised donations without implicit terms as unrestricted donations, but allocated all donations not from Trustees to the "designated" fund, so as to ensure sufficient funds were being allocated to further the Charity's aims. Similarly, a portion of the grants made were allocated against the designated fund. This process was reassessed in 2022. As the Charity publish that all donations received will be used to further its aims, it was decided that these donations (i.e. all donations other than specific donations from Trustees) would be better represented as restricted and classed as Unassigned Research Funds.

11. Related party disclosures and Trustees' remuneration and benefits

No Trustees received remuneration or were reimbursed for expenses in the period.

During the year the Charity introduced £50,000 (2022: £100,000) of support to its subsidiary EB Therapeutics Ltd.

In the year there were donations to the Charity from the Trustees amounting to £230,175 (2022: £259,000) (which are increased by Cure EB claiming Gift Aid).

12. Staff costs

There were no employees (2022: one).

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

No Trustee expenses have been incurred and no Trustees were re-imbursed for any expenses during the year (2022: None).

13. Contingent liabilities and capital commitments

The Trustees are not aware of any contingent liabilities or capital commitments.

14. Subsequent events

The Trustees are not aware of any material adjusting or non-adjusting post balance sheet events.

CURE EB (FORMERLY KNOWN AS SOHANA RESEARCH FUND)

England & Wales - Charity number 1158672

Accounts

Report and Financial statements
Period Ended 31 December 2022
Charity Number 1158672

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23. **Notes forming part of the financial statements**

Legal and Administrative Information

1. The structural and administrative details for the charity are as follows:
   - 1.1. Name: Cure EB (formerly known as Sohana Research Fund)
   - 1.2. Type of entity: Charitable Incorporated Organisation
   - 1.3. Date of incorporation: 25 September 2014
   - 1.4. Registered Charity Number: 1158672
   - 1.5. Governing document: Constitution
   - 1.6. Registered and principal office: 10 Huntingdon Street, London, N1 1BU

2. The trustees as at the date of this report (the "Trustees") are:
   - 2.1. Ms. Sharmila Nikapota
   - 2.2. Mr. James Collins
   - 2.3. Mr. Michael de Lathauwer
   - 2.4. Ms. Tazim Hall
   - 2.5. Prof. David Kelsell
   - 2.6. Mr. Duncan Wales
   - 2.7. Rachel Lesiter

3. The Bankers are Barclays Bank PLC

   14 Upper Street
   Islington
   London
   N1 0PQ

4. The Auditors are Haines Watts London LLP

   New Derwent House,
   69-73 Theobalds Road,
   London
   WC1X 8TA

Summary

Our Mission Statement

Our mission is to find effective treatments and ultimately a cure for Epidermolysis Bullosa ("EB").

Our Commitments

To fund translational research and clinical trials for the benefit of people with EB.

To maximise research spend.

To raise awareness of EB.

2022 Highlights

Fundraising Highlights

- Silver Butterfly Dinner
- London Marathon
- Triathlon Team
- BGC Charity Day
- Big Give Christmas Challenge
- Dyson Trust Donation
- Thames Paddleboard Challenge
- Windermere Swim
- Butterfly Run
- Goldman Sachs Gives Donation

Project Highlights

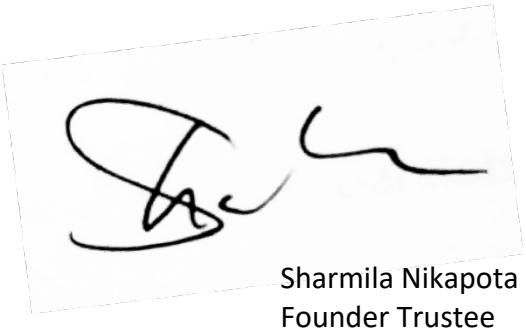
- The EB graft trial using gene corrected skin equivalent grafts is active in France
- Pre-Clinical work towards a gene-edited skin equivalent graft trial completes
- Mission EB, the first large-scale stem cell clinical trial for children with EB is ongoing at Great Ormond Street Hospital
- Took over funding of a Rigosertib trial towards treating RDEB SCC
- Grants made towards newest base editing technology generate a publication in Nature

Founder's Statement

Epidermolysis Bullosa ("EB") is a group of genetic skin blistering conditions that vary in severity depending on the subtype. Some forms are fatal in infancy and others lead to progressive deformity and are severely life limiting. Recessive Dystrophic Epidermolysis Bullosa ("RDEB") is a very severe form that leads to scarring, contractures, oesophageal restriction, corneal abrasions, malignant skin cancer and many more painful and life- altering symptoms.

Cure EB exists to find treatments and a cure for EB. To this end, we fund predominantly translational medical research aiming to deliver quality-of-life changing relief and eventually a cure to those afflicted by EB.

2022 started well with a successful Silver Butterfly Dinner at RIBA. We were also thrilled to get back to hosting our Butterfly Run and Family Day at the Olympic Park after a Covid related break since 2019. We were lucky to be chosen for BGC Charity Day, with Patron Damian Lewis attending on our behalf. Projects suffered delays due to the pandemic, but we were able to commit to new projects. We were thrilled to be successful with a BBC Radio 4 Appeal application with a transmission date in early 2023. We are pleased with progress towards translation of two of our projects and are encouraged by biotech interest in the EB space. We are extremely grateful for the commitment of many of our donors who have helped us over many years.



Sharmila Nikapota
Founder Trustee

Report of the Trustees

The Trustees present their report along with the financial statements of the charity for the period ended 31 December 2022.

A. Introduction

1. Cure EB – then known as the Sohana Research Fund C.I.O. ("SRF") – was established on 25 September 2014 with Registered Charity Number 1158672.

2. Cure EB's principal purpose is to fund medical research and clinical trials aimed at discovering, developing and delivering treatments for Epidermolysis Bullosa ("EB").

3. Key information for 2022 is as follows:

   3.1. FUNDRAISING – Cure EB raised over £1 million in 2022.

   3.2. RESEARCH FUNDING – In 2022, Cure EB spent £947k (excluding support costs) on research projects. £859k of this was made by way of grant, and £88k for a license agreement via Cure EB's wholly owned subsidiary, EB Therapeutics.

   3.3. EB THERAPEUTICS LTD – In 2020, Cure EB's wholly owned subsidiary, EB Therapeutics Ltd ("EBT') concluded 2 agreements: (1) a license agreement related to one of the projects that Cure EB has been supporting; and (2) a research services agreement, for the testing of experimental compounds for the systemic treatment of EB. During 2022, work on the project to which the license relates is ongoing and the research services agreement is generating very good results.

   3.4. RESEARCH COMMITMENTS AND RESULTS – Work on the EB graft trial in Paris is continuing. A gene editing project linked to this work completed its preclinical phase. Mission EB, a stem cell treatment for all children in the UK with recessive dystrophic EB continued at Great Ormond Street Hospital. This was funded with a substantial award from the NIHR with our collaboration. We also entered into two new agreements. One with Kings College London on a base editing project and one at Jefferson University in the United States for an RDEB skin cancer trial. The Nanocol project at Kings College London and Minnesota started its final year as did the Gene therapy for airway disease project at Great Ormond Street Hospital. Projects in France and Spain progressed satisfactorily. We have had less involvement in projects in the United States this year as our substantial work around Gene Editing at the University of Minnesota has paused. Work in Colorado is ongoing from existing contributions.

3.5. AWARENESS AND OTHER EVENTS – Our biennial fundraising dinner held in May at RIBA raised £366,303, which we were very pleased with.

We were extremely lucky to be the chosen charity for the Dodington Opera evening hosted by Sir James and Lady Dyson in June. We also held our Butterfly Run and Family Day for the first time since the pandemic at the Olympic Park. Both events were very well attended. Professor John McGrath from Kings College, Professor Andy South from Jefferson University in the US and Dr Gabriela Petrof from Great Ormond Street Hospital and the Great Ormond Street Nurses came to speak at family day.

We were very lucky to be chosen again for BGC Charity Day which was held in October, and we were enormously grateful to Patron Damian Lewis for attending again on our behalf.

Sharmila spoke at the British Society for gene and Cell Therapy webinar in November which was well attended. We met our Big Give challenge match funding campaign target in late November and December and ended the first year in public since the pandemic with positivity.

B. Objectives and Activities

4. As set out in Cure EB's Constitution, Cure EB's objects are *"For the public benefit, (a) the advancement of health and (b) the relief and assistance of people in need who are suffering from Epidermolysis Bullosa, in particular but not exclusively by making grants:*

   (1) to fund medical research and/or clinical trials anywhere in the world for the purpose of discovering, developing and delivering treatments for Epidermolysis Bullosa; and

   (2) to fund the treatment of patients who are suffering from Epidermolysis Bullosa".

5. Cure EB's objectives during 2022 were limited to:

   5.1. Raising funds;

   5.2. Raising awareness;

   5.3. Identifying and developing projects for funding; and

   5.4. Funding of projects.

6. The Trustees confirm that in determining what activities Cure EB carries out, they have had regard to the Charity Commission's guidance on public benefit.

B(1) Fundraising and Awareness

7. As a rare genetic skin condition public knowledge of the condition is limited. This impacts Cure EB's ability to raise money for research and support. Consequently, we see increased awareness of the condition as something that has a direct influence on our ability to raise funds. As an aid to raising awareness we are developing a game which will have information on EB and the charity. Our book 'Binky's Time to Fly' is now available in six different languages and has a paragraph about EB at the back. All of the sales proceeds of the exclusive hardback edition benefit the charity and all author royalties from the paperback editions (which are controlled by the publisher) are donated to the charity. Flyaway books in the US have released a US version and French publisher Elcy have recently released a French version.

8. We had a very successful Silver Butterfly Dinner at RIBA in May raising over £366,000 which connected us to longstanding and new supporters for the first time since the pandemic.

9. We did not have a good year in print media but continue to build our social media platforms and engagement with the public. Cure EB has an active social media presence with over 30,000 followers on Facebook and approximately 2,500 on twitter. We continue to build our Instagram follower network with 1,585 followers and are working to increase our presence on LinkedIn. The Cure EB website continues to be a very important tool when fundraising and educating the public as to our aims and ambitions. It holds all information regarding projects and press as well as event information. Our recent updates have been very well received and we strive to keep it up to date.

10. Our main community outreach and awareness event, the Butterfly Run and Family Day took place in September 2022. We were chosen for BGC charity day which was attended in person with beneficiaries attending. We had four very successful marathon runners raising £25,000 and other sporting challenges included a Windermere swim £5,229, Hall Triathlon team at Blenheim £46,859, Thames paddleboarders £12,063, golf days, dance academy performance, charity lunches, Arnold House charity Day £5,661, Art sales and in memorium and office fundraising events. We received a substantial Goldman Sachs Gives donation and were part of the Big Give Christmas which raised over £36,000. We had substantial donations from the Sir James and Deirdre Dyson Trust, BGC, The Reed Foundation, The MDL 2 Trust and Maria Marina Foundation. We also had donations from Lloyds Football Club, The Sir James Roll Charitable Trust, Frank Litchfield Charitable Trust, CML Family Foundation, PwC Foundation, the Michael and Anna Wix Charitable Trust, The Mimosa Trust, Eastern Baptist Association, Glovers Integrated Healthcare. We were also happy to have sponsorship from Krystal Bio, Polymem, Constant Therapeutics and Flenn Health for our Run and Family Day and a grant from Amryt Pharma for Family Day. We continue to work at regular giving through our Kaleidoscope scheme and online donations as well as text message giving but there is work to be done to increase these streams.

B(2) Projects

11. Cure EB funds a range of projects. However, Cure EB's principal focus is on translational research – i.e. the preclinical research and clinical trials that will (we hope) translate fundamental (laboratory based) research into effective treatments for RDEB. We are assisted by an experienced independent expert panel who evaluate projects and advise on research strategies and priorities.

12. We currently evaluate projects on a rolling basis (rather than in formal funding rounds at fixed intervals) and invite applications that meet our priority areas of research. An initial outline of the project is evaluated and if deemed to be within an area of interest a full grant application is asked for. The project is then externally reviewed and scored by a scientific advisory panel (SAP), whose members are world leading scientific experts in medical related research. That external review process is coordinated by one of our Trustees, Professor David Kelsell, who is himself an expert in human skin genetics and part of the SAP. If the scores are sufficiently high the project is presented to the Trustees for approval. If approved, Cure EB negotiates and concludes formal funding agreements with the body that is to carry out the research.

13. During 2021, researchers from Great Ormond Street Hospital and Children's Charity (GOSH) began the largest ever stem cell clinical trial for children with EB. The study, in collaboration with clinicians from Birmingham's Children's Hospital, aims to treat 36 children who have Recessive Dystrophic EB (RDEB) – one of the most severe forms of the condition – with infusions of stem cells derived from umbilical cord tissue. It is hoped these infusions will reduce pain and inflammation for months at a time. The trial has been made possible thanks to over £4.5 million in funding from the National Institute for Health Research (NIHR) in partnership with NHS England and NHS Improvement as well as a grant from Cure EB. The University of Sheffield Clinical Trials Research Unit (CTRU) has been overseeing the study and working closely with the GOSH research team over the past 3 years. This trial is ongoing.

14. During 2022, we saw continuation of work on the EB graft trial and conclusion of the preclinical work on a project linked to this. We were able to continue existing projects and increase our portfolio of projects taking on a cancer trial and base editing project. We are continuing clinical translation of projects through EBT.

C. Achievements and Performance

15. During 2022 the total research spend was more than £947k (including project related investments and license fees). Details are set out in Notes 3 and 4 to the Financial Statements.

16. Projects progressed and funded include the EBGraft trial, Gene editing in Madrid and UCL, Nanocol and the Butler project at Great Ormond Street. Our collaboration on Mission EB started with the first child being dose at the end of 2021 which was ongoing in 2022. We also committed to new projects at Kings on base editing and Jefferson for an RDEB skin cancer trial.

17. Looking ahead, our aim is to continue our focus on translational research. We will also continue looking at emerging technologies to determine translational benefit.

18. To this end we aim to continue to carry on building our relationships with other potential funders and investors and with the RDEB research community.

D. Financial Review

19. The accounts show the financial affairs of Cure EB for 2022. The key figures, together with commentary, are as follows:

    19.1. Gross Income: £1,000,863. This was (as expected) down on 2021 due the impact of a very large donation from the IGY Foundation in that year. Fundraising continued to be challenging in 2022, but the Trustee were satisfied with the total achieved.

    19.2. Costs of Fundraising: £89,015. Expenditure was higher than the prior period largely due to the cost of the biennial Butterfly Dinner. As a rule of thumb, Cure EB aims to raise £10 for every £1 spent on fundraising activities. For 2022 this was exceeded.

    19.3. Expenditure on charitable activities (including support costs) was a little higher than the previous year at £1,033,130. This was in line with our aim to increase research funding.

    19.4. Reserves at year end were £2,507,444; and cash at year end was £2,779,430. During 2021 Cure EB started to build a development fund to take specific projects from the laboratory into trial. The IGY Foundation donation helped to kick-start this. For that reason both of these figures are substantially higher than 2020 and remain high in 2022.

20. Looking ahead to 2023:

    20.1. Gross income is likely to be lower than 2022 largely due to the fact that it is not a Butterfly Dinner year. However, we anticipate that a combination of regular and substantial one-off donations will mean that 2023 income will be roughly in line with 2020.

    20.2. Cost of fundraising is also likely to be lower, as the Butterfly Dinner is a source of cost as well as revenue.

    20.3. It is currently too early to make an accurate projection of the likely expenditure on projects. A number of promising projects are being reviewed, but it is not yet clear how many of those will be approved and contracted before year-end.

21. The trustees as at the date of this report (the "Trustees") are:

    21.1. Ms. Sharmila Nikapota

    21.2. Mr. James Collins

    21.3. Mr. Michael de Lathauwer

    21.4. Ms. Tazim Hall

    21.5. Prof. David Kelsell

    21.6. Mr. Duncan Wales

    21.7. Ms. Rachel Lesiter

22. There were no other Trustees during 2022. These Trustees may be reappointed at the expiry of their current terms and/or further trustees may be appointed by resolution passed at a properly convened meeting of the trustees. Pursuant to the terms of the Constitution, the minimum number of trustees is 3 and the maximum is 9. The Trustees are selected for their experience and expertise.

23. The Trustees are not and were not compensated for performing their roles as trustees.

24. Management and Administration:

    24.1. Management of Cure EB's fundraising and awareness activities has been delegated (subject to a financial cap) to Sharmila Nikapota and James Collins. They in turn report to the other Trustees. In particular:

        (1) Sharmila Nikapota has primary responsibility for conceiving, developing and performing all fundraising and awareness activities. This includes the identification of suitable contractors to provide goods or services and negotiation with those contractors.

        (2) Costs of goods and services are approved by, and payment is arranged by, James Collins or Rachel Lesiter.

        (3) Sharmila Nikapota and James Collins are authorised to jointly incur costs of up to £10,000 per month in relation to fundraising and awareness activities without further authorisation from the Trustees. For major events, Sharmila Nikapota and James Collins must seek the prior approval of the Trustees.

    24.2. Management of the administration of Cure EB has been delegated (subject to a financial cap) to Sharmila Nikapota and James Collins, assisted (very substantially) by Rachel Lesiter. They in turn report to the other Trustees. In particular:

        (1) Sharmila Nikapota, James Collins are Rachel Lesiter are primarily responsible for identifying the services that need to be performed and finding suitable

contractors to assist with the provision of those services.

(2) Sharmila Nikapota and James Collins are authorised to jointly incur costs of up to £2,500 per month in relation to the administration of Cure EB without further authorisation from the Trustees. Financial oversight and record keeping is performed by Rachel Lesiter.

24.3. In relation to projects and funding:

(1) Sharmila Nikapota is in regular direct communication with leading researchers and clinicians and with other potential funding bodies. She has primary responsibility for the initial identification of projects that may merit funding on grounds that they (i) further the objects of Cure EB; and (ii) are (weighing the work that is to be performed and the potential benefits of the research against the cost) cost-effective.

(2) The process for the evaluation of potential projects depends on the nature and size of the project. Prof. David Kelsell provides guidance in relation to both the process and the evaluation. He is also responsible for coordinating the reviews by Cure EB's scientific advisory panel (SAP) whose members are world leading scientific experts in medical related research. They evaluate, comment on and score the projects for Cure EB.

(3) All funding decisions (including identification of the project to be funded and the amount of funding to be provided) are made by the Trustees (as a whole).

(4) Having decided "in principle" to fund a project, negotiation of documentation is led by James Collins.

(5) Project invoices that conform with the funding agreements are approved by, and payment is arranged by, James Collins and Rachel Lesiter.

25. Professional Services:

25.1. James Collins in a commercial barrister and Tazim Hall was a solicitor and partner at a substantial international law firm. Cure EB buys in additional legal services as and when required.

25.2. Cure EB has not retained any investment advisor. However, Michael de Lathauwer comes from an investment banking background and is currently a fund manager.

26. Remuneration:

26.1. The Trustees are not and were not compensated for their management roles (described above) nor for any other role that they perform.

26.2. Cure EB has one part-time employee, operating as Research Officer. In addition, Cure EB has established relationships with a number of individuals and organisations that provide services on a contractor or self-employed basis.

26.3. Cure EB has benefited from, and relies on, substantial support from a team of volunteers. In particular:

(1) The fundraising and awareness events are supported by a substantial team of engaged and dedicated volunteers. They provide assistance with the development of the event, attracting supporters to the event, graphic design, logistics and in many other ways. Without their support, many of these services would have to be bought in at considerable cost to Cure EB.

(2) The administration of Cure EB has been greatly assisted by volunteers, again saving Cure EB substantial cost.

Investment policy

Funds are held as short-term bank balances and (if and when rates justify it) longer term treasury deposits. The only other investments made by Cure EB are Programme Related Investments (rather than financial investments).

Programme Related Investments

In 2022 Cure EB made no further Programme Related Investments. These investments are payments made to further the aims of the charity – i.e. to advance research – rather than to secure a financial return. However, because they are structured as investments there is potential for return.

EB Therapeutics

At the end of 2018, Cure EB established a subsidiary: EB Therapeutics Ltd ("EBT"). The purpose of this subsidiary is to further develop some of the technologies supported by Cure EB with the aim of assisting with the transition from research to market, so that effective treatments become as widely available as possible. EBT was dormant until 2020. During 2020 it (1) took a license of IP related to one of the projects that Cure EB is supporting; and (2) concluded a research service agreement for a new project. During 2021 this new project generated encouraging laboratory results. This continued through 2022, with the focus shifting (1) to the identification of the best compounds to progress towards an in-human trials; and (2) (for some compounds) from in-vitro to early in-vivo testing.

Reserves policy

Policy: Because the charity has a low-cost operating base it does not require a significant unrestricted reserve fund to meet its operating costs. However, Cure EB aims to maintain and build a substantial restricted reserve fund to meet the cost of future projects. This is for two reasons. First, Cure EB wants to be able to fund the best projects irrespective of its income in any particular year (which will fluctuate for reasons beyond its control). Second, Cure EB is building a development fund to meet the anticipated cost of taking one project down the (very expensive) path towards in-human trials.

Forward looking statement: The Trustees are confident that there are adequate reserves to fund the research to be undertaken and cover the anticipated future costs.

Risk management

The principal risk to the charity is the ability to continue to raise funds sufficient to meet the commitments made to fund projects and operating costs.

The Trustees have (above) highlighted the facts relevant to this risk. During 2022 this risk was entirely mitigated by ensuring that reserves substantially exceeded commitments.

Whilst the Trustees expenditure will exceed income in certain years, the Trustees intend (1) to retain substantial reserves (for the reasons given above); and (2) only commit to projects where Cure EB (i) already has sufficient funding for the project; or (ii) is confident that funds will be raised well in advance of any payment dates falling due.

Ukraine and Cost of Living

The Trustees acknowledge the war in Ukraine and the cost of living challenges in the UK and the potentially adverse economic impact on the charity of all of these. These are additional risk factors which could impact the operations of the charity after year end. There is a high degree of uncertainty and it may have a significant impact on the way in which we operate. The Trustees are monitoring developments and have the flexibility to amend future commitments for lower than anticipated income. We are focused on protecting the long-term strategy of the charity to enable it to meet forthcoming commitments.

Public Benefit

The Trustees are conscious of the Charity Commission guidelines on public benefit and these guidelines are applied when grants are considered.

Trustees' Responsibilities in relation to the financial statement

The Trustees are responsible for preparing the Trustees Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Law applicable to charities in England and Wales requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the charity's financial activities during the year and of its financial position at the end of the year. In preparing those financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Make judgements and estimates that are reasonable and prudent;
- Observe the methods and principles in the Charity SORP;
- State whether applicable accounting standards and statement of recommended practice have been followed subject to any departures disclosed and explained in the financial statements; and
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The Trustees are responsible for keeping accounting records which disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by the Trustees and signed on their behalf by:

Sharmila
Sharmila (Oct 31, 2023 11:08 GMT)

James Collins

Sharmila Nikapota **James Collins**

Date 31 October 2023

Report of the Independent Auditors to the Trustees of Cure EB

Opinion

We have audited the financial statements of Cure EB (the 'charity') for the year ended 31 December 2022 which comprise the Consolidated Statement of Financial Activities, the Consolidated and Charity Balance Sheet, the Consolidated Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 December 2022 and of its incoming resources and application of resources, for the year then ended;

- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and

- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent

otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations

2008 requires us to report to you if, in our opinion:

- the information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or

- sufficient accounting records have not been kept; or

- the financial statements are not in agreement with the accounting records and returns; or

- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the Statement of Trustees' Responsibilities, the trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists.

Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud.

The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

We gained an understanding of the legal and regulatory framework applicable to the charity and the industry in which it operates, and considered the risk of acts by the charity that were contrary to applicable laws and regulations, including fraud. We discussed with the trustees the policies and procedures in place regarding compliance with laws and regulations. We discussed amongst the audit team the identified laws and regulations, and remained alert to any indications of non-compliance.

During the audit we focused on laws and regulations which could reasonably be expected to give rise to a material misstatement in the financial statements, including, but not limited to, the Charities Act 2011 and UK tax legislation. Our tests included agreeing the financial statement disclosures to underlying supporting documentation and enquiries with management.

Our procedures in relation to fraud included but were not limited to: inquires of management whether they have any knowledge of any actual, suspected or alleged fraud, and discussions amongst the audit team regarding risk of fraud such as opportunities for fraudulent manipulation of financial statements. We determined that the principal risks related to posting manual journal entries to manipulate financial performance and management bias through judgements in accounting estimates. We also addressed the risk of management override of internal controls, including testing journals and evaluating whether there was evidence of bias by the directors that represented a risk of material misstatement due to fraud.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

Eligibility for appointment as auditor

Haines Watts London LLP is eligible for appointment as auditor of the charity by virtue of its eligibility for appointment as auditor of a company under section 1212 of the Companies Act 2006.

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Haines Watts

Jane Wills FCCA (Senior Statutory Auditor)
For and on behalf of Haines Watts London LLP
Statutory Auditor
New Derwent House
69-73 Theobalds Road
London
WC1X 8TA

Date: 31 October 2023

Consolidated Statement of Financial Activities
Incorporating Income and Expenditure account

	Note	2022 £ Unrestricted	2022 £ Restricted	2022 £ Total	2021 £ Total
Income					
Income from donations	2	182,000	818,852	1,000,852	1,565,378
Income from investments		-	11	11	2
Total		182,000	818,863	1,000,863	1,565,380
Expenditure					
Charitable activities	3	90,205	942,925	1,033,130	820,811
Raising funds	4	82,591	6,424	89,015	38,028
Total		172,796	949,349	1,122,145	858,839
Net movement in funds		9,204	(130,486)	(121,282)	706,541
Transfer of funds	8	(2,281,980)	2,281,980	-	-
Funds brought forward		2,472,499	156,227	2,628,726	1,922,185
Funds carried forward		199,723	2,307,721	2,507,444	2,628,726

Balance Sheets

	Notes	Group 2022	Group 2021	Charity 2022	Charity 2021
		£	£	£	£
Fixed Assets		428,891	428,891	428,991	428,991
Investments	5				
Current assets					
Cash at bank		2,800,640	2,249,515	2,779,430	2,236,332
Other debtors	6	190,210	119,694	211,420	132,877
		2,990,850	2,369,209	2,990,850	2,369,209
Creditors					
Amounts falling due within one year- Project costs	7	912,297	169,374	912,397	169,474
Total net assets					
Unrestricted Funds	8	199,723	428,496	203,721	428,496
Restricted Funds	8	2,307,721	156,227	2,303,723	156,227
Designated funds	8	-	2,044,003	-	2,044,003
Total Funds		2,507,444	2,628,726	2,507,444	2,628,726

These Financial Statements were approved by the Trustees on 31 October 2023 and were signed on its behalf by:

Sharmila
Sharmila (Oct 31, 2023 11:08 GMT)

James Collins

Sharmila Nikapota **James Collins**

Consolidated cash flow statement for the year ended 31 December 2022

	2022 £	2021 £
Net cash inflow/(outflow) from operating activities	(121,282)	706,541
(Increase)/decrease in debtors	(70,516)	(13,767)
(Decrease)/Increase in creditors	742,923	(246,181)
Net cash inflow from operations	551,225	446,593
Cash flow from investing activities		
Fixed asset investment additions	-	-
Net cash (outflow) from investing activities	-	-
Increase/(decrease) in cash at bank	551,125	446,593
Cash at the beginning of the year	2,249,515	1,802,922
Cash at the end of the year	2,800,640	2,249,515

Notes to the financial statements

1. Principal accounting policies

(a) Accounting convention

The financial statements of the charity, 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 Charities Act 2011. The financial statements have been prepared under the historical cost convention.

Cure EB meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

(b) Group accounts

The financial statements consolidate the results of the charity and its wholly owned subsidiary EB Therapeutic Ltd on a line-by-line basis. A separate Statement of Financial Activities and Income and Expenditure Account for the charity has not been presented because it has taken advantage of the exemption afforded by section 408 of the Companies Act 2006.

The consolidated statement of financial activities, balance sheet and cash flow include the financial statements of the charity and its subsidiary undertaking made up to 31 December 2021. The results of the subsidiary is included in the statement of financial activities and inter group transactions are eliminated fully on consolidation.

The Charity has taken advantage of exemption, under the terms of Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland', not to disclose related party transactions with wholly owned subsidiaries within the group.

Due to EB Therapeutics Ltd current activities and how it is funded, the consolidated statement of charitable financial activities and the consolidated cash flow statement are materially the same as the individual parent charity's statement of financial activities and individual cash flow statement.

(c) Critical accounting judgements and key sources of estimation uncertainty

Due to the straight forward nature of Cure EB's activities, the Trustees do not believe that there are any estimation uncertainties or accounting judgments that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next financial year.

The investments are held at cost less impairment as the fair value cannot be reliably measured. The trustees are not aware of any material impairments in the investments.

(d) Donation and grant Income

Income is accounted for in the period in which the charity is entitled to receipt, the receipt is probable and measurable.

(e) Expenditure

Expenditure is included on an accruals basis.

(f) Taxation

The charity is exempt from tax on its charitable activities.

(g) Fixed asset investments

Fixed asset investments are held to generate income, for their investment potential, and/or for their research potential.

Investments include 'social investments' where the purpose in making the investment is wholly or partly to further the charity's aims. The social investments are stated at cost less impairment unless it can be measured at fair value which can be reliably measured.

The investment in a subsidiary company is held at cost less accumulated impairment losses.

(h) Funds structure

The restricted funds represent donations made where the donor has placed a restriction on the use of the funds. Unrestricted funds can be used as the Trustees see fit in line with the charitable objectives.

(i) Going concern

The accounts are prepared on the basis that the Trustees have adequate resources to continue to operate. The Trustees have informally discussed expected future cash flows and the future expected incoming and outgoing resources in making their assessment for a period of at least 12 months from the signing of the accounts. Based on these assessments the Trustees have concluded that they can continue to adopt the going concern basis in preparing the annual report and accounts.

(j) Financial instruments

Financial assets and liabilities are recognised when the charity becomes party to the contractual provisions of the financial instrument. The company holds basic financial instruments which comprise cash at bank, trade and other receivables and trade and other payables.

Basic financial instruments such as social investments, debtors, bank balances and creditors are recognised at transaction value.

2. Donations

All incoming resources related to general donations from individuals and other institutions. There was no legacy income in the year.

3. Charitable activities

	2022	2021
	£	£
Research projects:		
University of Minnesota - Nanocol	82,986	113,424
Universidad Carlos III de Madrid - Gene Editing Trial	27,137	105,996
UCL Gene Editing	17,908	35,566
Kings College London - Nanocol	82,176	-
Kings College London – Base Editing of RDEB fibroblasts	208,414	-
Great Ormond Street - Mission EB	-	150,000
Stanford University - EB IPS Cell Consortium	-	194,752
Oligo	139,911	100,000
EB Graft	77,489	65,030
Debra UK – Gene therapy	32,481	-
Thomas Jefferson - Rigosertib	151,285	-
St Thomas' Hospital, London - Rigosertib	127,279	-
Support costs:		
Admin costs	57,085	36,927
Governance costs	9,300	8,729
Bank charges	147	2,079
Audit	12,308	4,800
Web hosting & Social Media consulting	2,331	1,740
Insurance	2,661	-
Professional fees	2,233	1,768
	1,033,130	820,811

4. Raising funds

	2022	2021
	£	£
Fund raising & marketing	62,170	21,898
Web hosting	752	580
Fundraising admin costs	26,093	15,550
	89,015	38,028

5. Fixed Asset Investments – Held by group & charity

	2022 £	2021 £
Social Investments - unlisted		
Cost at 1 January 2022	428,891	402,928
Additions/transfers	-	25,963
Cost at 31 December 2022	428,891	428,891
Net book value		
At 31 December 2022	428,891	428,891

Shares in group undertakings
Held by charity

	2022 £	2021 £
Cost at 1 January 2022	100	100
Cost at 31 December 2022	100	100
Net book value		
At 31 December 2022	100	100

The group or the charity's investments at the Balance Sheet date in the share capital of companies include the following:

Subsidiaries

EB Therapeutics Ltd
Registered office : England & Wales
Nature of business: Furthering research for human health

Class of shares	% holding
Ordinary	100.00

Social investments are made to fund companies who undertake research that further the aims of the charity. Material social investments have been made in Phoenicis Therapeutics, Inc., a US Corporation and Branca Bunus Limited, a company registered in Ireland.

6. Debtors

	Group		Charity	
	2022 £	2021 £	2022 £	2021 £
Other debtors	190,210	119,694	221,420	132,877

Other debtors are donations receivable and gift aid receivable on donations received and receivable during the year.

7. Creditors

	Group		Charity	
	2022	**2021**	**2022**	**2021**
	£	**£**	**£**	**£**
Accruals	12,662	6,050	12,662	6,050
Unpaid share capital	-	-	100	100
Committed grant payments	899,635	163,324	899,635	163,324
	912,297	169,374	912,397	169,474

8. Fund balances

	Unrestricted Funds	Restricted Funds	Designated funds	Total
	£	£	£	£
Balance brought forward	428,496	156,227	2,044,003	2,628,726
Income	182,000	818,863	-	1,000,863
Expenditure	(172,796)	(949,349)	-	(1,122,145)
Inter fund transfer	(237,977)	2,281,980	(2,044,003)	-
Balance carried forward	199,723	2,307,721	-	2,507,444
Represented by				
Fixed assets	-	428,891	-	428,891
Cash at bank	181,385	2,619,255	-	2,800,640
Other net assets/liabilities	18,338	(740,425)	-	(722,087)
	199,723	2,307,721	-	2,507,444

	Brought forward	Reallocation	Income	Expenditure	Balance carried forward
Funds for fundraiser	7,400	-	-	(1,200)	6,200
EB family day	-	-	5,000	(5,000)	-
EB Graft Trial	63,967	-	-	(63,967)	-
Nanocol	20,500	-	-	(20,500)	-
Gene Editing	64,360	-	51,994	(116,354)	-
Restricted research	-	2,281,980	761,869	(742,328)	2,301,521
	156,227	2,281,980	818,863	(949,349)	2,307,721

Historically the Board recognised donations without implicit terms as unrestricted donations, but allocated all donations not from trustees to the designated fund, so as to ensure sufficient funds were being allocated to further the Charity's aims. Similarly, a portion of the grants made were allocated against the designated fund. This process was reassessed in the year. As the Charity publish that all donations received will be used to further it's aims, it was decided that these donations (i.e. all donations other than from trustees) would be better represented as restricted. As such a transfer was undertaken to align to the new policy in the year.

9. Related party disclosures and trustees' remuneration and benefits

No Trustees received remuneration or were reimbursed for expenses in the period.

During the year the charity introduced £100,000 of support to its subsidiary EB Therapeutics Ltd.

In the year there were donations to the charity from the Trustees amounting to £259,000 (2021 - £203,000).

10. Staff costs

There was one part-time employee (2021 - one).

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

11. Contingent liabilities and capital commitments

The trustees are not aware of any contingent liabilities or capital commitments.

12. Subsequent events

The trustees are not aware of any material adjusting or non-adjusting post balance sheet events.

CURE EB (FORMERLY KNOWN AS SOHANA RESEARCH FUND)

England & Wales - Charity number 1158672

Accounts

Report and Financial statements

Period Ended 31 December 2021

Charity Number 1158672

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23. **Notes forming part of the financial statements**

Legal and Administrative Information

1. The structural and administrative details for the charity are as follows:
   - 1.1. Name: Cure EB (formerly known as Sohana Research Fund)
   - 1.2. Type of entity: Charitable Incorporated Organisation
   - 1.3. Date of incorporation: 25 September 2014
   - 1.4. Registered Charity Number: 1158672
   - 1.5. Governing document: Constitution
   - 1.6. Registered and principal office: 10 Huntingdon Street, London, N1 1BU

2. The trustees as at the date of this report (the "Trustees") are:
   - 2.1. Ms. Sharmila Nikapota
   - 2.2. Mr. James Collins
   - 2.3. Mr. Michael de Lathauwer
   - 2.4. Ms. Tazim Hall
   - 2.5. Prof. David Kelsell
   - 2.6. Mr. Duncan Wales
   - 2.7. Rachel Lesiter

3. The Bankers are Barclays Bank PLC

   14 Upper Street
   Islington
   London
   N1 0PQ

4. The Auditors are Haines Watts (City) LLP

   New Derwent House,
   69-73 Theobalds Road,
   London
   WC1X 8TA

Summary

Our Mission Statement

Our mission is to find effective treatments and ultimately a cure for Epidermolysis Bullosa ("EB").

Our Commitments

To fund translational research and clinical trials for the benefit of people with EB.

To maximise research spend.

To raise awareness of EB.

2021 Highlights

Fundraising Highlights

- Walk on the Wild Side event at London Zoo
- London Marathon
- IGY Foundation Donation
- BGC Charity Day
- Big Give Christmas Challenge
- Dyson Trust Donation
- Goldman Sachs Gives Donation

Project Highlights

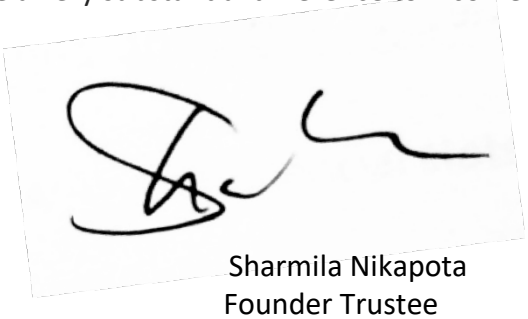
- The EB graft trial using gene corrected skin equivalent grafts is active in France
- Our match funding assists Colorado researchers groundbreaking IPSC work
- The first child is dosed on Mission EB, the first large-scale stem cell clinical trial for children with EB
- Cure EB researcher Prof. Alain Hovnanian wins Scientific Award
- Grants made towards newest base editing technology and gene therapy for airway disease in junctional EB

Founder's Statement

Epidermolysis Bullosa ("EB") is a group of genetic skin blistering conditions that vary in severity depending on the subtype. Some forms are fatal in infancy and others lead to progressive deformity and are severely life limiting. Recessive Dystrophic Epidermolysis Bullosa ("RDEB") is a very severe form that leads to scarring, contractures, oesophageal restriction, corneal abrasions, malignant skin cancer and many more painful and life-altering symptoms.

Cure EB exists to find treatments and a cure for EB. To this end, we fund predominantly translational medical research aiming to deliver quality-of-life changing relief and eventually a cure to those afflicted by EB.

2021 was a year blighted by uncertainty as the pandemic continued to make in person events hazardous. An event scheduled for June had to be moved to September which continued to challenge our fundraising capabilities. One of our biggest fundraisers, the Silver Butterfly Dinner, had to be rescheduled to 2022. We were lucky to have an in person BGC Charity Day, with Patron Damian Lewis attending. Despite delays, research continued and we were able to commit to two new projects whilst continuing others. We are thrilled that Mission EB started at Great Ormond Street Hospital and await results eagerly. We were extremely grateful for a large donation from the IGY Foundation towards our development fund for translational projects which made a very substantial difference to income in 2021.



Sharmila Nikapota
Founder Trustee

Report of the Trustees

The Trustees present their report along with the financial statements of the charity for the period ended 31 December 2021.

A. Introduction

1. Cure EB – then known as the Sohana Research Fund C.I.O. ("SRF") – was established on 25 September 2014 with Registered Charity Number 1158672.

2. Cure EB's principal purpose is to fund medical research and clinical trials aimed at discovering, developing and delivering treatments for Epidermolysis Bullosa ("EB").

3. Key information for 2021 is as follows:

   3.1. FUNDRAISING – Cure EB raised over £1.5 million in 2021.

   3.2. RESEARCH FUNDING – In 2021, Cure EB spent more than £750k (excluding support costs) on research projects. £650k of this was made by way of grant, and £100k for a license agreement via Cure EB's wholly owned subsidiary, EB Therapeutics.

   3.3. EB THERAPEUTICS LTD – In 2020, Cure EB's wholly owned subsidiary, EB Therapeutics Ltd ("EBT') concluded 2 agreements: (1) a license agreement related to one of the projects that Cure EB has been supporting; and (2) a research services agreement, for the testing of experimental compounds for the systemic treatment of EB. During 2021, progress of the project to which the license relates was slow, but the research services agreement has produced very positive laboratory results.

   3.4. RESEARCH COMMITMENTS AND RESULTS – Despite ongoing delays due to Covid, work has continued on the EB graft trial in Paris. The most significant achievement this year was a first child being dosed on Mission EB, a stem cell treatment for all children in the UK with recessive dystrophic EB. This received a substantial award from the NIHR with our collaboration. The Colorado team, with match-funding from ourselves and two US based charities are continuing their important work on induced pluripotent stem cells. We also entered into two new agreements with Kings College London and a collaboration on a junctional EB gene therapy project being conducted at Great Ormond Street Hospital.

   3.5. AWARENESS AND OTHER EVENTS – Our biennial fundraising dinner should have been held in May 2021 but due to the pandemic we decided to postpone it till 2022. We hosted a smaller scale research update and fundraising event in September 2021 called 'Walk on the Wild side' at London Zoo. Following an introduction by Trustee Duncan Wales, Professor McGrath from Kings College London delivered a fantastic update on current research trends worldwide and

particularly advances in base editing technology. Sharmila spoke of Cure EB's work and vision for the future. The event allowed us the opportunity to reconnect with many of our core supporters whilst also reflecting on our ten years funding research into treatments for EB. We did not hold the Butterfly Run in 2021 but we were very fortunate to be chosen again for BGC charity Day with celebrity Patrons Damian Lewis appearing in person and Sean Bean appearing virtually for the charity. Whilst Sir James and Lady Dyson were not able to have an Opera event they nevertheless made a generous donation around Sharmila's #Marathonamonth challenge. The Big Give Christmas challenge ended our fundraising year, exceeding our target by almost double and gaining donations from new supporters as a result of being part of this large online event. Our very committed supporters made all the difference, in particular the IGY Foundation in what would otherwise have been a difficult year.

B. Objectives and Activities

4. As set out in Cure EB's Constitution, Cure EB's objects are *"For the public benefit, (a) the advancement of health and (b) the relief and assistance of people in need who are suffering from Epidermolysis Bullosa, in particular but not exclusively by making grants:*

   (1) to fund medical research and/or clinical trials anywhere in the world for the purpose of discovering, developing and delivering treatments for Epidermolysis Bullosa; and

   (2) to fund the treatment of patients who are suffering from Epidermolysis Bullosa".

5. Cure EB's objectives during 2021 were limited to:

   5.1. Raising funds;

   5.2. Raising awareness;

   5.3. Identifying and developing projects for funding; and

   5.4. Funding of projects.

6. The Trustees confirm that in determining what activities Cure EB carries out, they have had regard to the Charity Commission's guidance on public benefit.

B(1) Fundraising and Awareness

7. As a rare genetic skin condition public knowledge of the condition is limited. This impacts Cure EB's ability to raise money for research and support. Consequently, we see increased awareness of the condition as something that has a direct influence on our ability to raise funds. As an aid to raising awareness we are developing a game which will have information on EB and the charity. Our book 'Binky's Time to Fly' is

now available in six different languages and has a paragraph about EB at the back. All of the sales proceeds of the exclusive hardback edition benefit the charity and all author royalties from the paperback editions (which are controlled by the publisher) are donated to the charity. Flyaway books in the US have released a US version and French publisher Elcy have recently released a French version.

8. We had a wonderful "Walk on the Wild Side" fundraising event at London Zoo in September 2021, with a research update from Professor John McGrath and a reflection on ten years of Cure EB. With The Jazz Spatz and delicious food it was fabulous to see so many supporters again after quite a while.

9. Gabrielius, age 9, was featured in a Times newspaper article about Mission EB. Mission EB is a pilot treatment project in collaboration with the NIHR founded on our EBSTEM and ADSTEM clinical trial funding. The study is aiming to treat 36 children who have recessive dystrophic epidermolysis bullosa with infusions of stem cells derived from umbilical cord tissue. The potential for a first EB treatment in the UK is truly exciting with the first patients having already had their infusions.

10. Cure EB has an active social media presence with over 30,000 followers on Facebook and over 2,500 on twitter. We continue to build our Instagram follower network with 1,454 followers and are planning to increase our presence on LinkedIn. The Cure EB website continues to be an important tool when fundraising and educating the public as to our aims and ambitions. It holds all information regarding projects and press as well as event information. A substantial piece of work is being done to update and improve navigation.

11. Our community outreach and awareness events were not possible in 2021 due to ongoing fears within the community regarding Covid. As a result the Butterfly run and family day did not take place in September and we were unable to hold our usual speaker brunch club event. We were chosen for BGC charity day which was attended both in person and virtually but beneficiaries could not take part in 2021. We benefitted from a very generous donation from the IGY Foundation which made a huge difference to our fundraising. Community fundraising was more difficult due to the pandemic but we were lucky to have support from walking sponsorships, golf days, celebration and a photo exhibition. We received a Goldman Sachs Gives donation and were part of the Big Give Christmas Challenge where we raised almost double our target. We had substantial donations from the Sir James and Deirdre Dyson Trust, The Reed Foundation, The MDL 2 Trust, The Phoebe Research Fund, Hobson Trust and Premier League. Social media continues to be an important tool to raise awareness of the condition and charity. We did not play our social media campaign called #EBpop – "Play #EBpop to make the blisters stop" but are developing a game around this theme.

12. The London Marathon did take place in October both as a mass participation event and virtually. Cure EB had four runners taking part who raised £34,000.

13. Looking ahead, we are planning to hold a Silver Butterfly Dinner at RIBA in May 2022 and the Cure EB Butterfly Run and Family Day at the Olympic Park in September. We continue to work at regular giving and online donations as well as text message giving.

B(2) Projects

14. Cure EB funds a range of projects. However, Cure EB's principal focus is on translational research – i.e. the preclinical research and clinical trials that will (we hope) translate fundamental (laboratory based) research into effective treatments for RDEB. We are assisted by an experienced independent expert panel who evaluate projects and advise on research strategies and priorities.

15. We currently evaluate projects on a rolling basis (rather than in formal funding rounds at fixed intervals) and invite applications that meet our priority areas of research. An initial outline of the project is evaluated and if deemed to be within an area of interest a full grant application is asked for. The project is then externally reviewed and scored by a scientific advisory panel (SAP), whose members are world leading scientific experts in medical related research. That external review process is coordinated by one of our Trustees, Professor David Kelsell, who is himself an expert in human skin genetics and part of the SAP. If the scores are sufficiently high the project is presented to the Trustees for approval. If approved, Cure EB negotiates and concludes formal funding agreements with the body that is to carry out the research. We had hoped to open a funding round but will progress this post pandemic.

16. During 2021, researchers from Great Ormond Street Hospital and Children's Charity (GOSH) began the largest ever stem cell clinical trial for children with EB. The study, in collaboration with clinicians from Birmingham's Children's Hospital, aims to treat 36 children who have Recessive Dystrophic EB (RDEB) – the one of most severe forms of the condition – with infusions of stem cells derived from umbilical cord tissue. It is hoped these infusions will reduce pain and inflammation for months at a time. The trial has been made possible thanks to over £4.5 million of funding from the National Institute for Health Research (NIHR) in partnership with NHS England and NHS Improvement as well as a grant from Cure EB. The University of Sheffield Clinical Trials Research Unit (CTRU) has been overseeing the study and working closely with the GOSH research team over the past 3 years.

17. During 2021, we saw continuation of work on the EB graft trial. We also were able to continue existing projects and increase our portfolio of projects including translational research collaborations with the biotech industry and collaborations with our US funding partners and also a project with Debra UK.

18. We are continuing clinical translation of projects through EBT, and working towards licensing on another project which we are funding through a research service agreement.

C. Achievements and Performance

19. During 2021 the total research spend was more than £750k (including project related investments and licence fees). Details are set out in Notes 3 and 4 to the Financial Statements.

20. Projects progressed and funded include the EBGraft trial, Gene editing in Madrid and UCL, Nanocol at Kings and projects at Colorado. Our collaboration on Mission EB started with the first child being dose at the end of 2021. We also committed to new projects at Kings on base editing and Great Ormond Street Hospital on gene therapy for Junctional EB.

21. Looking ahead, our aim is to continue our focus on translational research. We will also continue looking at emerging technologies to determine translational benefit.

22. To this end we aim to continue to carry on building our relationships with other potential funders and investors and with the RDEB research community.

D. Financial Review

23. The accounts show the financial affairs of Cure EB for 2021. The key figures, together with commentary, are as follows:

    23.1. Gross Income: £1,565,380. Covid continued to impact income streams but a very large donation from the IGY Foundation more than balanced out the Covid-19 effect.

    23.2. Costs of Fundraising: £38,028. Expenditure was higher than the prior period due to the cocktail reception fundraising event at Regents Park. As a rule of thumb, Cure EB aims to raise £10 for every £1 spent on fundraising activities. For 2021 this was comfortably exceeded.

    23.3. Expenditure on charitable activities (including support costs) was a little higher than the previous year at £820,811.

    23.4. Reserves at year end were £2,628,726; and cash at year end was £2,249,515. During 2021 Cure EB started to build a development fund to take specific projects from the laboratory into trial. The IGY Foundation donation helped to kick-start this. For that reason both of these figures are substantially higher than 2020.

24. Looking ahead to 2022:

    24.1. Gross income is likely to be lower than 2021 largely due to (1) the unease following Covid and then war in Ukraine; (2) the cost of living crisis and economic instability; and (3) the inflation of the 2021 figure by the IGY Foundation donation. However, we anticipate that a combination of regular and substantial one-off donations will mean that Cure EB's income will not be as badly affected as that of many other charities.

    24.2. Cost of fundraising is also likely to be higher due to the rescheduling of the Silver Butterfly Dinner to May 2022.

    24.3. It is currently too early to make an accurate projection of the likely expenditure

on projects. However, Covid-19 has led to requests for no-cost extensions to a number of existing projects and a slow-down of new project flow.

25. The trustees as at the date of this report (the "Trustees") are:

    25.1. Ms. Sharmila Nikapota

    25.2. Mr. James Collins

    25.3. Mr. Michael de Lathauwer

    25.4. Ms. Tazim Hall

    25.5. Prof. David Kelsell

    25.6. Mr. Duncan Wales

    25.7. Ms. Rachel Lesiter

26. There were no other Trustees during 2021. These Trustees may be reappointed at the expiry of their current terms and/or further trustees may be appointed by resolution passed at a properly convened meeting of the trustees. Pursuant to the terms of the Constitution, the minimum number of trustees is 3 and the maximum is 9. The Trustees are selected for their experience and expertise.

27. The Trustees are not and were not compensated for performing their roles as trustees.

28. Management and Administration:

    28.1. Management of Cure EB's fundraising and awareness activities has been delegated (subject to a financial cap) to Sharmila Nikapota and James Collins. They in turn report to the other Trustees. In particular:

        (1) Sharmila Nikapota has primary responsibility for conceiving, developing and performing all fundraising and awareness activities. This includes the identification of suitable contractors to provide goods or services and negotiation with those contractors.

        (2) Costs of goods and services are approved by, and payment is arranged by, James Collins.

        (3) Sharmila Nikapota and James Collins are authorised to jointly incur costs of up to £10,000 per month in relation to fundraising and awareness activities without further authorisation from the Trustees. For major events, Sharmila Nikapota and James Collins must seek the prior approval of the Trustees.

    28.2. Management of the administration of Cure EB has been delegated (subject to a financial cap) to Sharmila Nikapota and James Collins. They in turn report to the other Trustees. In particular:

(1) Sharmila Nikapota and James Collins are primarily responsible for identifying the services that need to be performed and finding suitable contractors to assist with the provision of those services.

(2) Sharmila Nikapota and James Collins are authorised to jointly incur costs of up to £2,500 per month in relation to the administration of Cure EB without further authorisation from the Trustees. Financial oversight and record keeping is performed by Rachel Lesiter (who was appointed a Trustee after year-end).

28.3. In relation to projects and funding:

(1) Sharmila Nikapota is in regular direct communication with leading researchers and clinicians and with other potential funding bodies. She has primary responsibility for the initial identification of projects that may merit funding on grounds that they (i) further the objects of Cure EB; and (ii) are (weighing the work that is to be performed and the potential benefits of the research against the cost) cost-effective.

(2) The process for the evaluation of potential projects depends on the nature and size of the project. Prof. David Kelsell provides guidance in relation to both the process and the evaluation. He is also responsible for coordinating the reviews by Cure EB's scientific advisory panel (SAP) whose members are world leading scientific experts in medical related research. They evaluate, comment on and score the projects for Cure EB.

(3) All funding decisions (including identification of the project to be funded and the amount of funding to be provided) are made by the Trustees (as a whole).

(4) Having decided "in principle" to fund a project, negotiation of documentation is led by James Collins and Tazim Hall.

(5) Project invoices that conform with the funding agreements are approved by, and payment is arranged by, James Collins.

29. Professional Services:

29.1. James Collins in a commercial barrister and Tazim Hall was a solicitor and partner at a substantial international law firm. Cure EB buys in additional legal services as and when required.

29.2. Cure EB has not retained any investment advisor. However, Michael de Lathauwer comes from an investment banking background and is currently a fund manager.

30. Remuneration:

30.1. The Trustees are not and were not compensated for their management roles (described above) nor for any other role that they perform.

30.2. Cure EB has one part-time employee, operating as Research Officer. In addition, Cure EB has established relationships with a number of individuals and organisations that provide services on a contractor or self-employed basis.

30.3. Cure EB has benefited from, and relies on, substantial support from a team of volunteers. In particular:

(1) The fundraising and awareness events are supported by a substantial team of engaged and dedicated volunteers. They provided assistance with the development of the event, attracting supporters to the event, graphic design, logistics and in many other ways. Without their support, many of these services would have to be bought in at considerable cost to Cure EB.

(2) The administration of Cure EB has been greatly assisted by volunteers, again saving Cure EB substantial cost.

Investment policy

Funds are held as short-term bank balances and (if and when rates justify it) longer term treasury deposits. The only other investments made by Cure EB are Programme Related Investments (rather than financial investments).

Programme Related Investments

In 2021 Cure EB made further Programme Related Investments. These are payments made to further the aims of the charity – i.e. to advance research – rather than to secure a financial return. However, because they are structured as investments there is potential for return.

EB Therapeutics

At the end of 2018, Cure EB established a subsidiary: EB Therapeutics Ltd ("EBT"). The purpose of this subsidiary is to further develop some of the technologies supported by Cure EB with the aim of assisting with the transition from research to market, so that effective treatments become as widely available as possible. EBT was dormant until 2020. During 2020 it (1) took a license of IP related to one of the projects that Cure EB is supporting; and (2) concluded a research service agreement for a new project. During 2021 this new project generated encouraging laboratory results and EBT hopes to able to make progress towards an in-human trial in 2022 and 2023.

Reserves policy

Policy: Because the charity has a low-cost operating base it does not require a significant unrestricted reserve fund.

Forward looking statement: The Trustees are confident that there are adequate reserves to fund the research to be undertaken and cover the anticipated future costs.

Risk management

The principal risk to the charity is the ability to continue to raise funds sufficient to meet the commitments made to fund projects and operating costs.

The Trustees have (above) highlighted the facts relevant to this risk. During 2021 this risk was entirely mitigated by ensuring that reserves substantially exceeded commitments.

Whilst the Trustees expenditure will exceed income in certain years, the Trustees intend (1) to retain substantial reserves; and (2) only commit to projects where Cure EB (i) already has sufficient funding for the project; or (ii) is confident that funds will be raised well in advance of any payment dates falling due.

Covid 19, Ukraine and Cost of Living

The Trustees acknowledge the outbreak of Covid-19, the war in Ukraine and the cost of living challenges in the UK and the potentially adverse economic impact on the charity of all of these. These are additional risk factor which could impact the operations of the charity after year end. There is a high degree of uncertainty and it may have a significant impact on the way in which we operate. The Trustees are monitoring developments and have the flexibility to amend future commitments for lower than anticipated income. We are focused on protecting the long-term strategy of the charity to enable it to meet forthcoming commitments.

Public Benefit

The Trustees are conscious of the Charity Commission guidelines on public benefit and these guidelines are applied when grants are considered.

Trustees' Responsibilities in relation to the financial statement

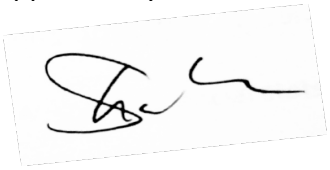
The Trustees are responsible for preparing the Trustees Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Law applicable to charities in England and Wales requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the charity's financial activities during the year and of its financial position at the end of the year. In preparing those financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Make judgements and estimates that are reasonable and prudent;
- Observe the methods and principles in the Charity SORP;
- State whether applicable accounting standards and statement of recommended practice have been followed subject to any departures disclosed and explained in the financial statements; and
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The Trustees are responsible for keeping accounting records which disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by the Trustees and signed on their behalf by:



Sharmila Nikapota **James Collins**

Date 31 October 2022

Report of the Independent Auditors to the Trustees of Cure EB

Opinion

We have audited the financial statements of Cure EB (the 'charity') for the year ended 31 December 2021 which comprise the Consolidated Statement of Financial Activities, the Consolidated and Charity Balance Sheet, the Consolidated Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 December 2021 and of its incoming resources and application of resources, for the year then ended;

- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and

- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations

2008 requires us to report to you if, in our opinion:

- the information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or

- sufficient accounting records have not been kept; or

- the financial statements are not in agreement with the accounting records and returns; or

- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the Statement of Trustees' Responsibilities, the trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- We obtained an understanding of the legal and regulatory requirements applicable to the charity and considered that the most significant are the Charities Act 2011, and UK taxation legislation.

- We obtained an understanding of how the charity complies with these requirements by discussions with management and those charged with governance.

- We assessed the risk of material misstatement of the financial statements, including the risk of material misstatement due to fraud and how it might occur, by holding discussions with management and those charged with governance.

- We inquired of management and those charged with governance as to any known instances of non-compliance or suspected non-compliance with laws and regulations.

- Based on this understanding, we designed specific appropriate audit procedures to identify instances of on-compliance with laws and regulations. This included making enquiries of management and those charged with governance and obtaining additional corroborative evidence as required. As part of an audit in accordance with ISAs (UK) we exercise professional judgement and maintain professional scepticism throughout the audit.

- Identify and assess the risks of material misstatements of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.

- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purposes of expressing an opinion on the effectiveness of the charity's internal control.

- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the trustees.

- Conclude on the appropriateness of the trustees' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the charity's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the charity to cease to continue as a going concern.

- Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieve fair presentation.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

Eligibility for appointment as auditor

Haines Watts (City) LLP is eligible for appointment as auditor of the charity by virtue of its eligibility for appointment as auditor of a company under section 1212 of the Companies Act 2006.

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Haines Watts (City) LLP

Haines Watts (City) LLP

Statutory Auditor

New Derwent House

69-73 Theobalds Road

London

WC1X 8TA

Date: 31 October 2022

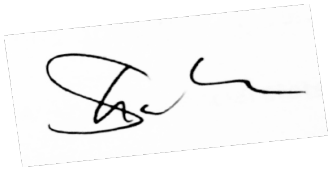
Consolidated Statement of Financial Activities Incorporating Income and Expenditure account

	Note	2021 £ Unrestricted	2021 £ Restricted	2021 £ Total	2020 £ Total
Income					
Income from donations	2	1,507,052	58,326	1,565,378	791,354
Income from investments		2	-	2	5,584
Total		1,507,054	58,326	1,565,380	796,938
Expenditure					
Charitable activities	3	820,811	-	820,811	735,498
Raising funds	4	38,028	-	38,028	24,273
Total		858,839	-	858,839	759,771
Net movement in funds		648,215	58,326	706,541	37,167
Transfer of funds		-	-	-	-
Funds brought forward		1,824,284	97,901	1,922,185	1,885,018
Funds carried forward		2,472,499	156,227	2,628,726	1,922,185

Balance Sheets

		Group		Charity	
	Notes	**2021**	**2020**	**2021**	**2020**
		£	**£**	**£**	**£**
Fixed Assets					
Investments	5	428,891	402,928	428,991	403,028
Current assets					
Cash at bank		2,249,515	1,802,922	2,236,332	1,730,335
Debtors – promissory loan		-	25,963	-	25,963
Other debtors	6	119,694	105,927	132,877	183,931
		2,369,209	1,934,812	2,369,209	1,940,229
Creditors					
Amounts falling due within one year- Project costs		169,374	415,555	169,474	415,655
Total net assets		2,628,726	1,922,185	2,628,726	1,927,602
Unrestricted Funds		428,496	171,988	428,496	171,988
Restricted Funds	7	156,227	97,901	156,227	97,901
Designated funds		2,044,003	1,652,296	2,044,003	1,657,713
Total Funds		2,628,726	1,922,185	2,628,726	1,927,602

These Financial Statements were approved by the Trustees on 31 October 2022 and were signed on its behalf by:



Sharmila Nikapota **James Collins**

Consolidated cash flow statement for the year ended 31 December 2021

	2021 £	2020 £
Net cash inflow/(outflow) from operating activities	706,541	37,167
Increase in debtors	(13,767)	(15,838)
(Decrease)/Increase in creditors	(246,181)	121,159
Net cash inflow from operations	446,593	142,488
Cash flow from investing activities		
Fixed asset investment additions	-	(285,362)
Net cash (outflow) from investing activities	-	(285,362)
Increase/(decrease) in cash at bank	446,593	(142,874)
Cash at the beginning of the year	1,802,922	1,945,796
Cash at the end of the year	2,249,515	1,802,922

Notes to the financial statements

1. Principal accounting policies

(a) Accounting convention

The financial statements of the charity, 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 Charities Act 2011. The financial statements have been prepared under the historical cost convention.

Cure EB meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

(b) Group accounts

The financial statements consolidate the results of the charity and its wholly owned subsidiary EB Therapeutic Ltd on a line-by-line basis. A separate Statement of Financial Activities and Income and Expenditure Account for the charity has not been presented because it has taken advantage of the exemption afforded by section 408 of the Companies Act 2006.

The consolidated statement of financial activities, balance sheet and cash flow include the financial statements of the charity and its subsidiary undertaking made up to 31 December 2021. The results of the subsidiary is included in the statement of financial activities and inter group transactions are eliminated fully on consolidation.

Due to EB Therapeutics Ltd current activities and how it is funded, the consolidated statement of charitable financial activities and the consolidated cash flow statement are materially the same as the individual parent charity's statement of financial activities and individual cash flow statement.

(c) Critical accounting judgements and key sources of estimation uncertainty

Due to the straight forward nature of Cure EB's activities, the Trustees do not believe that there are any estimation uncertainties or accounting judgments that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next financial year.

The investments are held at cost less impairment as the fair value cannot be reliably measured. The trustees are not aware of any material impairments in the investments.

(d) Donation and grant Income

Income is accounted for in the period in which the charity is entitled to receipt, the receipt is probable and measurable.

(e) Expenditure

Expenditure is included on an accruals basis.

(f) Taxation

The charity is exempt from tax on its charitable activities.

(g) Fixed asset investments

Fixed asset investments are held to generate income, for their investment potential, and/or for their research potential.

Investments include 'social investments' where the purpose in making the investment is wholly or partly to further the charity's aims. The social investments are stated at cost less impairment unless it can be measured at fair value which can be reliably measured.

The investment in a subsidiary company is held at cost less accumulated impairment losses.

(h) Funds structure.

The restricted funds represent donations made where the donor has placed a restriction on the use of the funds. Unrestricted funds can be used as the Trustees see fit in line with the charitable objectives.

(i) Going concern

The accounts are prepared on the basis that the Trustees have adequate resources to continue to operate. The Trustees have informally discussed expected future cash flows and the future expected incoming and outgoing resources in making their assessment for a period of at least 12 months from the signing of the accounts. Based on these assessments the Trustees have concluded that they can continue to adopt the going concern basis in preparing the annual report and accounts.

(j) Financial instruments

Financial assets and liabilities are recognised when the charity becomes party to the contractual provisions of the financial instrument. The company holds basic financial instruments which comprise cash at bank, trade and other receivables and trade and other payables.

Basic financial instruments such as social investments, debtors, bank balances and creditors are recognised at transaction value.

2. Donations and designated funds

All incoming resources related to general donations from individuals and other institutions. There was no legacy income in the year.

Designated funds are unrestricted funds designated by the Trustees for research projects in pursuit of the charitable activities.

3. Charitable activities

	2021	2020
	£	£
Research projects:		
University of Minnesota - Next Gene Genome Sequencing/Nanocol	113,424	248,019
Universidad Carlos III de Madrid - Gene Editing Trial	105,996	136,374
Colorado Gates	-	106,569
UCL Gene Editing	35,566	59,543
Kings College London - Nanocol	-	41,088
Great Ormond Street - Mission EB	150,000	-
Stanford University - EB IPS Cell Consortium	194,752	-
EB Therapeutics	100,000	-
EB Graft	65,030	-
License fees	-	91,996
Support costs:		
Admin costs	36,927	29,203
Governance costs	8,729	9,920
Bank charges	2,079	109
Audit	4,800	4,200
Events	-	1,572
Web hosting & Social Media consulting	1,740	2,175
Insurance	-	4,730
Professional fees	1,768	-
	820,811	735,498

4. Raising funds

	2021	2020
	£	£
Fund raising & marketing	21,898	16,371
Web hosting	580	1,009
Fundraising admin costs	15,550	6,893
	38,028	24,273

5. Fixed Asset Investments – Held by group & charity

	2021 £	2020 £
Social Investments - unlisted		
Cost at 1 January 2021	402,928	95,724
Additions/transfers	25,963	307,204
Cost at 31 December 2021	428,891	402,928
Net book value		
At 31 December 2021	428,891	402,928

Shares in group undertakings

Held by charity

	2021 £	2020 £
Cost at 1 January 2021	100	100
Cost at 31 December 2021	100	100
Net book value		
At 31 December 2021	100	100

The group or the charity's investments at the Balance Sheet date in the share capital of companies include the following:

Subsidiaries

EB Therapeutics Ltd
Registered office : England & Wales
Nature of business: Furthering research for human health

Class of shares	% holding
Ordinary	100.00

In previous years material social investments have been made in:
RNADerm Therapeutics Inc, a US Corporation, to further the aims of the charity by the funding of relevant research.

Branca Bunus Limited, a company registered in Ireland, to further the aims of the charity by the funding of relevant research.

Fibrix Derm, Inc. a US company, to further the aims of the charity by the funding of relevant

research.

During the year Fibrix Derm Inc. merged with RNA Derm Therapeutics Inc (and other companies) to become Phoenicis Therapeutics, Inc.

6. Debtors

Other debtors are donations receivable and gift ad receivable on donations received and receivable during 2021.

7. Restricted fund balances

Balance brought forward	Income	Expenditure	Inter fund transfer	Balance carried forward
£	£	£	£	£
97,901	58,326	-	-	156,227

Restricted fund balance carried forward represents 3 research projects in progress and are held as cash balances.

Unrestricted and designated funds are held as bank balances, social investments and current assets.

8. Related party disclosures and trustees' remuneration and benefits

No Trustees received remuneration or were reimbursed for expenses in the period.

During the year the charity introduced £100,000 of support to its subsidiary EB Therapeutics Ltd.

In the year there were donations to the charity from the Trustees amounting to £203,000 (2020 - £115,000).

10. Staff costs

There was one part-time employee (2020 - none).

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

11. Contingent liabilities and capital commitments

The trustees are not aware of any contingent liabilities or capital commitments.

12. Subsequent events

The trustees are not aware of any material adjusting or non-adjusting post balance sheet events.

CURE EB (FORMERLY KNOWN AS SOHANA RESEARCH FUND)

England & Wales - Charity number 1158672

Accounts

Report and Financial statements
Period Ended 31 December 2020
Charity Number 1158672

Contents

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24. Cash Flow statement

25. Notes forming part of the financial statements

Legal and Administrative Information

1. The structural and administrative details for the charity are as follows:
   - 1.1. Name: Cure EB (formerly known as Sohana Research Fund)
   - 1.2. Type of entity: Charitable Incorporated Organisation
   - 1.3. Date of incorporation: 25 September 2014
   - 1.4. Registered Charity Number: 1158672
   - 1.5. Governing document: Constitution
   - 1.6. Registered and principal office: 10 Huntingdon Street, London, N1 1BU

2. The trustees as at the date of this report (the "Trustees") are:
   - 2.1. Ms. Sharmila Nikapota
   - 2.2. Mr. James Collins
   - 2.3. Mr. Michael de Lathauwer
   - 2.4. Ms. Tazim Hall
   - 2.5. Prof. David Kelsell
   - 2.6. Mr. Duncan Wales

3. The Bankers are Barclays Bank PLC

   14 Upper Street
   Islington
   London
   N1 0PQ

4. The Auditors are Haines Watts (City) LLP

   New Derwent House,
   69-73 Theobalds Road,
   London
   WC1X 8TA

Summary

Our Mission Statement

Our mission is to find effective treatments and ultimately a cure for Epidermolysis Bullosa ("EB").

Our Commitments

To fund translational research and clinical trials for the benefit of people with EB.

To maximise research spend.

To raise awareness of EB.

2020 Highlights

Fundraising Highlights

- James and Deirdre Dyson Trust Donation
- Virtual BGC Charity Day
- Big Give Christmas Challenge
- Goldman Sachs Gives Donation

Project Highlights

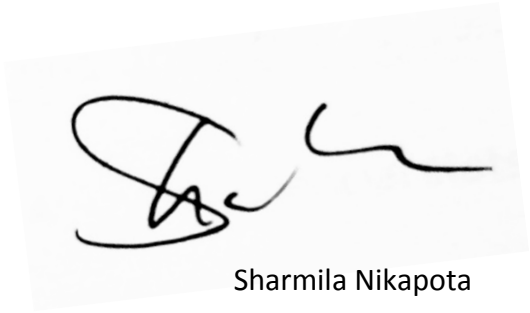
- First patient grafted on the EB graft trial
- Match funding unlocks US NIH grant for Colorado researchers
- Mission EB receives NIHR funding
- New projects include Nanocol and Fibrx Derm
- 4th year of Next Generation Genome Sequencing project

Founder's Statement

Epidermolysis Bullosa ("EB") is a group of genetic skin blistering conditions that vary in severity depending on the subtype. Some forms are fatal in infancy and others lead to progressive deformity and are severely life limiting. Recessive Dystrophic Epidermolysis Bullosa ("RDEB") is a very severe form that leads to scarring, contractures, oesophageal restriction, corneal abrasions, malignant skin cancer and many more painful and life-altering symptoms.

Cure EB exists to find treatments and a cure for EB. To this end, we fund predominantly translational medical research aiming to deliver quality-of-life changing relief and eventually a cure to those afflicted by EB.

2020 was an extremely challenging year, with the Covid 19 pandemic having a major impact both on fundraising and project progress. All in-person events were cancelled and we had to resort to raising awareness online and on virtual events such as BGC Charity Day which we participated in again. Despite Covid related delays the EB graft trial did start in France and we were able to make commitments to two new projects. We were extremely grateful for a large donation from Sir James and Lady Dyson which made a very substantial difference to income in 2020.



Sharmila Nikapota

Founder Trustee

Report of the Trustees

The Trustees present their report along with the financial statements of the charity for the period ended 31 December 2020.

A. Introduction

1. Cure EB – then known as the Sohana Research Fund C.I.O. ("SRF") – was established on 25 September 2014 with Registered Charity Number 1158672.

2. Cure EB's principal purpose is to fund medical research and clinical trials aimed at discovering, developing and delivering treatments for Epidermolysis Bullosa ("EB").

3. Key information for 2020 is as follows:

   3.1. FUNDRAISING – Cure EB raised nearly £800k in 2020.

   3.2. RESEARCH FUNDING – In 2020, Cure EB spent nearly £1m (excluding support costs) on research projects. Most of this (approximately £592k) was made by way of grant, but in 2020 Cure EB also supported research through programme related investments (approximately £307k) and (via Cure EB's wholly owned subsidiary) a license agreement (approximately £92k).

   3.3. EB THERAPEUTICS LTD – In 2020, Cure EB's wholly owned subsidiary, EB Therapeutics Ltd ("EBT') concluded 2 agreements: (1) a license agreement related to one of the projects that Cure EB has been supporting; and (2) a research services agreement, for the testing of experimental compounds for the systemic treatment of EB.

   3.4. RESEARCH COMMITMENTS AND RESULTS – Despite lab closures and therefore delays to projects, the most significant achievement was the EB graft trial starting in Paris. Mission EB, a stem cell treatment for all children in the UK with recessive dystrophic epidermolysis bullosa, received a substantial award from the NIHR with our collaboration and we expect children to be treated in 2021. The Colorado team were successful in obtaining a significant award from the NIH in the US with match-funding from ourselves and two US based charities. We also entered into two new agreements with Kings College London and a programme related investment in Fibrx Derm in the US

   3.5. AWARENESS AND OTHER EVENTS – In January 2020 we were partners on EB2020, the inaugural EB World Congress event in London. There were 730 delegates, 215 organisations and participants from 50 countries. It was an opportunity to bring together the worlds experts to share and discuss global EB research. As partners we had a significant presence in all materials, a speaking slot in the programme, and a stall in the exhibition space where we were able

to highlight the research we are funding. As part of the congress we hosted a dinner at the House of Lords bringing researchers, biotech, representatives of other EB charities and major donor supporters together. There were speeches from Lord Redesdale, Professor McGrath and Sharmila. Feedback from the event was extremely positive. The pandemic hit very shortly after so events like our run had to be cancelled. We did have a bit of fun with the EBpop challenge in the summer raising awareness on social media channels. We were also lucky to be chosen again for BGC Charity Day with celebrity ambassadors Damian Lewis and Jodie Comer appearing for the charity. Whilst Sir James and Lady Dyson were not able to have an Opera event they nevertheless made a donation and in addition made a very substantial donation to us following a libel win which also generated publicity for the charity. The Big Give Christmas challenge ended the year, where we exceeded our target and also gained donations from new supporters as a result of being part of this large online event. Our committed supporters made all the difference in what was a very difficult year.

3.6. Looking ahead, we already know that 2021, like 2020, will not be a good year for fundraising due to Covid 19. However, as Cure EB has substantial net assets (including substantial cash at bank) going into 2021, this will not adversely affect research spending. Whether Covid 19 has any longer term impact on Cure EB will turn on how quickly fundraising rebounds in late-2021 and thereafter.

3.7. We look forward to identifying, committing to and funding further projects and, in doing so, cementing Cure EB's position as one of the leading funders of EB research and trials.

B. Objectives and Activities

4. As set out in Cure EB's Constitution, Cure EB's objects are *"For the public benefit, (a) the advancement of health and (b) the relief and assistance of people in need who are suffering from Epidermolysis Bullosa, in particular but not exclusively by making grants:*

(1) to fund medical research and/or clinical trials anywhere in the world for the purpose of discovering, developing and delivering treatments for Epidermolysis Bullosa; and

(2) to fund the treatment of patients who are suffering from Epidermolysis Bullosa".

5. Cure EB's objectives during 2020 were limited to:

5.1. Raising funds;

5.2. Raising awareness

5.3. Identifying and developing projects for funding; and

5.4. Funding of projects.

6. The Trustees confirm that in determining what activities Cure EB carries out, they have had regard to the Charity Commission's guidance on public benefit.

B(1). Fundraising and Awareness

7. As a rare genetic skin condition public knowledge of the condition is limited. This impacts Cure EB's ability to raise money for research and support. Consequently, we see increased awareness of the condition as something that has a direct influence on our ability to raise funds. As an aid to raising awareness Sharmila wrote and published a book (illustrated by Carolina Rabei) called 'Binky's Time to Fly' with a paragraph about EB at the back. 100% of the sales of the exclusive hardback edition benefit the charity and all author royalties from the paperback editions (which are controlled by the publisher) are donated to the charity. We were pleased that this has now been published in a number of different languages. We were able to sell the book at EB2020, as well as on the website and we hope to able to use the book more when the pandemic impact allows in person events. Flyaway books in the US have released a US version and there have been online book readings as a result.

8. We were partners on EB2020, the inaugural global EB research conference which generated significant awareness of the condition and the charity which was held in Jan 2020 in London. Around this event we hosted a dinner at the House of Lords bringing together researchers, biotech, research funding EB charities and major donors.

9. Cure EB has an active social media presence with over 31,000 followers on Facebook and over 2,520 on twitter. We are continuing building our Instagram follower network with 1,389 followers. The Cure EB website continues to be an important tool when fundraising and educating the public as to our aims and ambitions. It holds all information regarding projects and press as well as event information. We aim to improve and update this in 2021

10. Our community outreach and awareness events had to be cancelled due to the pandemic after the first lockdown in March. As a result the Butterfly run and family day planned for September had to be cancelled, and we were unable to hold a speaker brunch club event. In September, we were chosen for BGC charity day which was attended virtually. We benefitted from a very generous donation in lieu of the Dodington Opera evening from the Sir James and Lady Deirdre Dyson Trust. Community fundraising was understandably curtailed due to the pandemic but we were lucky to have support from celebrations and through online giving. We had a Goldman Sachs Gives donation and were part of the Big Give Christmas Challenge. We had very substantial donations from the Sir James and Deirdre Dyson Trust and also the Maria Marina Foundation, The Roan Charitable Trust, The Reed Foundation, The

Grace Trust, The Sir James Roll Charitable Trust, The MDL 2 Trust, The Phoebe Research Fund, Walk the Talk Foundation and William Howarth Trust.

11. Social Media continues to be an important tool to raise awareness of the condition and charity. We did play our social media campaign called #EBpop – "Play #EBpop to make the blisters stop" and challenging others to do the same though we were not able to get groups together due to Covid. Donations raised through this were much reduced and it was really a tool to try and raise awareness and bind the community together.

12. Organised sponsorship events were all cancelled due to the pandemic. Sharmila started a marathon a month challenge around the Virtual London Marathon in an effort to raise funds

13. Looking ahead, we anticipated that our biennial dinner would not be possible in May 2021 due to the pandemic and other events would be difficult to plan until restrictions were lifted. We continue to work at regular giving and online donations as well as text message giving.

B(2). Projects

14. Cure EB funds a range of projects. However, Cure EB's principal focus is on translational research – i.e. the preclinical research and clinical trials that will (we hope) translate fundamental (laboratory based) research into effective treatments for RDEB. We are assisted by an experienced independent expert panel who evaluate projects and advise on research strategies and priorities.

15. We currently evaluate projects on a rolling basis (rather than in formal funding rounds at fixed intervals) and invite applications that meet our priority areas of research. An initial outline of the project is evaluated and if deemed to be within an area of interest a full grant application is asked for. The project is then externally reviewed and scored. If the scores are sufficiently high the project is presented to the trustees for approval. If approved, Cure EB negotiates and concludes formal funding agreements with the body that is to carry out the research. We had hoped to open a funding round but will progress this post pandemic.

16. During 2020, despite the pandemic we saw the start of the EB graft trial. We also were able to continue existing projects and increase our portfolio of projects including translational research collaborations with the biotech industry.

17. We have taken steps to aid clinical translation of projects through EBT, taking one license and concluding a research service agreement through the subsidiary

C. Achievements and Performance

18. During 2020 the total research spend was nearly £1 million (including project related investments and licence fees). Details are set out in Notes 3 and 4 to the Financial Statements.

19. Projects progressed and funded include the EBgraft trial, Next generation Sequencing in Minnesota, Gene editing in Madrid and UCL, Nanocol at Kings and projects at Stanford and Colorado.

20. Looking ahead, our aim is to continue our focus on translational research. We will also continue looking at emerging technologies to determine translational benefit.

21. To this end we aim to continue to carry on building our relationships with other potential funders and investors and with the RDEB research community.

D. Financial Review

22. The accounts show the financial affairs of Cure EB for 2020 and as at 31 December 2020. The key figures, together with commentary, are as follows:

    22.1. Gross Income: £796,938. This is lower than the amount raised in the prior period (as anticipated in our 2019 Report). The main reason for this was that we did not host our biennial Silver Butterfly Dinner (as these were held in 2017 and 2019). Covid 19 also impacted other revenue streams but a large donation from Sir James and Lady Dyson more than balanced out the Covid 19 effect.

    22.2. Costs of Fundraising: £24,273. This is lower than the prior period as the Silver Butterfly Dinner is a significant source of cost (as well as income). As a rule of thumb, Cure EB aims to raise £10 for every £1 spent on fundraising activities. For 2020 this was comfortably exceeded.

    22.3. Expenditure (on an accrual basis) on charitable activities (including support costs): £735,498. In addition, Cure EB supported research through programme related investments totalling about £307,204. Both of these figures are higher than the prior period and slightly ahead of expectation.

    22.4. Reserves: £1,922,185. This is up on the prior period notwithstanding that expenditure exceeded income. This is because a substantial part of Cure EB's support for projects was structured as (programme related) investments. Cash at year end was £1,802,922. This is down on the prior period but (1) in line with Cure EB's medium-term plan that expenditure on projects should exceed income; and (2) leaves Cure EB in a financially secure position.

23. Looking ahead to 2021:

    23.1. Gross income is likely to be similar to or lower than 2020 largely due to (1) the continuing impact of Covid-19; and (2) the resulting cancellation of the planned 2021 Silver Butterfly Dinner. However, we anticipate that a combination of regular and substantial one-off donations will mean that Cure EB's income will not be as badly affected as that of many other charities.

    23.2. Cost of fundraising is also likely to be higher (as we resume fundraising activities) but lower than previously anticipated due to the cancellation of the Silver Butterfly Dinner.

    23.3. It is currently too early to make an accurate projection of the likely expenditure on projects. However, Covid 19 has led to requests for no-cost extensions to a number of existing projects and a slow-down of new project flow. As a result, we anticipate reduced expenditure on projects in 2021.

24. The trustees as at the date of this report (the "Trustees") are:

    24.1. Ms. Sharmila Nikapota

    24.2. Mr. James Collins

    24.3. Mr. Michael de Lathauwer

    24.4. Ms. Tazim Hall

    24.5. Prof. David Kelsell

    24.6. Mr. Duncan Wales

25. There were no other trustees during 2020. These Trustees may be reappointed at the expiry of their current terms and/or further trustees may be appointed by resolution passed at a properly convened meeting of the trustees. Pursuant to the terms of the Constitution, the minimum number of trustees is 3 and the maximum is 9. The Trustees are selected for their experience and expertise.

26. The Trustees are not and were not compensated for performing their roles as trustees.

27. Management and Administration:

    27.1. Management of Cure EB's fundraising and awareness activities has been delegated (subject to a financial cap) to Sharmila Nikapota and James Collins. They in turn report to the other Trustees. In particular:

        (1) Sharmila Nikapota has primary responsibility for conceiving, developing and performing all fundraising and awareness activities. This includes the identification of suitable contractors to provide goods or services and negotiation with those contractors.

(2) Costs of goods and services are approved by, and payment for goods and services is arranged by, James Collins.

(3) Sharmila Nikapota and James Collins are authorised to jointly incur costs of up to £10,000 per month in relation to fundraising and awareness activities without further authorisation from the Trustees. For major events, Sharmila Nikapota and James Collins must seek the prior approval of the Trustees.

27.2. Management of the administration of Cure EB has been delegated (subject to a financial cap) to Sharmila Nikapota and James Collins. They in turn report to the other Trustees. In particular:

(1) Sharmila Nikapota and James Collins are primarily responsible for identifying the services that need to be performed and finding suitable contractors to assist with the provision of those services.

(2) Sharmila Nikapota and James Collins are authorised to jointly incur costs of up to £2,500 per month in relation to the administration of Cure EB without further authorisation from the Trustees. Financial oversight and record keeping is performed by Rachel Lesiter.

27.3. In relation to projects and funding:

(1) Sharmila Nikapota is in regular direct communication with leading researchers and clinicians and with other potential funding bodies. She has primary responsibility for the initial identification of projects that may merit funding on grounds that they (i) further the objects of Cure EB; and (ii) are (weighing the work that is to be performed and the potential benefits of the research against the cost) cost-effective.

(2) The process for the evaluation of potential projects depends on the nature and size of the project. Prof. David Kelsell provides guidance in relation to both the process and the evaluation. He is also responsible for identifying external reviewers to evaluate the projects and collecting comments and scores from those reviewers.

(3) All funding decisions (including identification of the project to be funded and the amount of funding to be provided) are made by the Trustees (as a whole).

(4) Having decided “in principle” to fund a project, negotiation of documentation is led by James Collins and Tazim Hall.

(5) Project invoices that conform with the funding agreements are approved by, and payment is arranged by, James Collins.

28. Professional Services:

    28.1. James Collins in a commercial barrister and Tazim Hall was a solicitor and partner at a substantial international law firm. Cure EB buys in additional legal services as and when required.

    28.2. Cure EB has not retained any investment advisor. However, Michael de Lathauwer comes from an investment banking background and is currently a fund manager.

29. Remuneration:

    29.1. The Trustees are not and were not compensated for their management roles (described above) nor for any other role that they perform.

    29.2. Cure EB has no employees but has established relationships with a number of individuals and organisations that provide services on a contractor or self-employed basis.

    29.3. Cure EB has benefited from, and relies on, substantial support from a team of volunteers. In particular:

        (1) The fundraising and awareness events are supported by a substantial team of engaged and dedicated volunteers. They provided assistance with the development of the event, attracting supporters to the event, graphic design, logistics and in many other ways. Without their support, many of these services would have to be bought in at considerable cost to Cure EB.

        (2) The administration of Cure EB has been greatly assisted by volunteers, again saving Cure EB substantial cost.

Investment policy

Funds are held as short term bank balances and (if and when rates justify it) longer term treasury deposits. The only other investments made by Cure EB are Programme Related Investments (rather than financial investments).

Programme Related Investments

In 2020 Cure EB made further Programme Related Investments. These are payments made to further the aims of the charity – i.e. to advance research – rather than to secure a financial return. However, because they are structured as investments there is potential for return.

EB Therapeutics

At the end of 2018, Cure EB established a subsidiary: EB Therapeutics Ltd ("EBT"). The purpose of this subsidiary is to further develop some of the technologies supported by Cure EB with the aim of assisting with the transition from research to market, so that effective treatments become as widely available as possible. EBT was dormant until 2020. During 2020 it (1) took a license of IP related to one of the projects that Cure EB is supporting; and (2) concluded a research service agreement for a new project.

Reserves policy

Policy: Because the charity has a low cost operating base it does not require a significant unrestricted reserve fund.

Forward looking statement: The Trustees are confident that there are adequate reserves to fund the research to be undertaken and cover the anticipated future costs.

Risk management

The principal risk to the charity is the ability to continue to raise funds sufficient to meet the commitments made to fund projects and operating costs.

The Trustees have (above) highlighted the facts relevant to this risk. During 2020 this risk was entirely mitigated by ensuring that reserves substantially exceeded commitments. Whilst the Trustees aim to maintain expenditure higher (on average) than income for the next few years, (1) substantial reserves will be retained; and (2) when reduced to a suitable level, the Trustees will seek to ensure that on average (but not each individual year) income and expenditure are balanced.

Covid 19

The Trustees acknowledge the current outbreak of Covid-19 (which is causing economic disruption in most countries) and its potentially adverse economic impact on the charity. This is an additional risk factor which could impact the operations of the charity after year end. Given the nature of the outbreak and the on-going developments, there is a high degree of uncertainty and it may have a significant impact on the way in which we operate.

The Trustees are monitoring developments closely and have the flexibility to amend future grant commitments for lower than anticipated income. We are focussed on protecting the long-term strategy of the charity to enable it to meet forthcoming commitments.

Public Benefit

The Trustees are conscious of the Charity Commission guidelines on public benefit and these guidelines are applied when grants are considered.

Trustees' Responsibilities in relation to the financial statement

The Trustees are responsible for preparing the Trustees Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

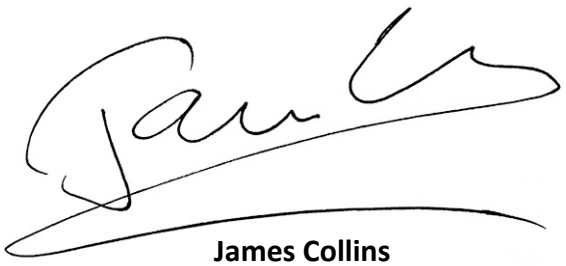
Law applicable to charities in England and Wales requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the charity's financial activities during the year and of its financial position at the end of the year. In preparing those financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Make judgements and estimates that are reasonable and prudent;
- Observe the methods and principles in the Charity SORP;
- State whether applicable accounting standards and statement of recommended practice have been followed subject to any departures disclosed and explained in the financial statements; and
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The Trustees are responsible for keeping accounting records which disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by the Trustees and signed on their behalf by:

Sharmila Nikapota



James Collins

Date: 29 October 2021

Report of the Independent Auditors

Opinion

We have audited the consolidated financial statements and standalone charity balance sheet of Cure EB (the 'parent') and its subsidiaries (the 'group') for the year ended 31 December 2020 which comprise the Consolidated Statement of Financial Activities, the Consolidated Balance Sheet, Consolidated Cash Flow and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) including FRS 102.

This report is made solely to the charity's Trustees, as a body, in accordance with section 144 of the Charities Act 2011 and the regulations made under section 154 of that Act. Our audit work has been undertaken so that we might state to the charity's Trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity's Trustees as a body, for our audit work, for this report, or for the opinions we have formed.

In our opinion the financial statements:

- give a true and fair view of the state of the group's and of the parent charity company affairs as at 31 December 2020 and of the group's incoming resources and application of resources, for the year ended;

- have been property prepared in accordance with United Kingdom Generally Accepted Accounting Practice, and

- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the group in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or

- the Trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charity's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

However, not all future events or conditions can be predicted. The COVID-19 viral pandemic is one of the most significant economic events for the UK with unprecedented levels of uncertainty of outcomes. It is therefore difficult to evaluate all of the potential implications on the Charities income and donations and wider economy. The Trustees' view on the impact of COVID-19 is disclosed in the accounting policies note.

Other information
The Trustees are responsible for the other information. The other information comprises the information in the Trustees' Report, but does not include the financial statements and our Auditors' Report thereon.

Scope of the audit of the financial statements
An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the company's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the trustees; and the overall presentation of the financial statements. In addition, we read all the financial and non-financial information in the Annual Report to identify material inconsistencies with the audited financial statements and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by us in the course of performing the audit. If we become aware of any apparent material misstatements or inconsistencies, we consider the implications for our report.

Matters on which we are required to report by exception
We have nothing to report in respect of the following matters in relation to which the Charities (Accounts and Reports) Regulations 2008 require us to report to you if, in our opinion:

- the information given in the Trustees' Annual Report is inconsistent in any material respect with the financial statements; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records; or
- we have not received all the information and explanations we require for our audit

Responsibilities of Trustees

As explained more fully in the Trustees' Responsibilities Statement, the Trustees are responsible for the preparation of financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determine necessary to enable the preparation of group financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the group financial statements, the Trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so

Auditors' responsibilities for the audit of the financial statements

We have been appointed as auditor under section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an Auditors' Report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- The engagement partner ensured that the engagement team collectively had the appropriate competence, capabilities and skills to identify or recognised non-compliance with applicable laws and regulations;
- we identified the laws and regulations applicable to the charity through discussions with the trustees and other management, and from our commercial knowledge;
- we focused on specific laws and regulations which we considered may have a direct material effect on the financial statements or the operations of the group, including the Charities Act 2011, employment, data protection and fund requirements;
- we assessed the extent of compliance with the laws and regulations identified above through making enquires of management and inspecting correspondence;
- identified laws and regulations were communicated within the audit team regularly and the team remained alert to instances of non-compliance throughout the audit.

We assessed the susceptibility of the charity's material misstatement, including obtaining an understanding of how fraud might occur by;

- making enquiries of management as to where they considered there was susceptibility to fraud, their knowledge of actual, suspected and alleged fraud;
- considering the internal controls in place to mitigate risks of fraud and non-compliance with laws and regulations.

To address the risk of fraud through management bias and override of controls, we:

- performed analytical procedures to identify any unusual or unexpected relationships;
- tested journal entries to identify unusual transactions;
- assess whether judgement and assumptions made in determining the accounting estimates set out in note 1 were indicative of potential bias; and
- Investigate the rationale behind significant or unusual transactions.

In response to the risk of irregularities and non-compliance with laws and regulations, we designed procedures which included, but were not limited to:

- agreeing financial statement disclosure to underlying supporting documentation;
- reading the minutes of meetings of those charged with governance; and
- reviewing correspondence.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Auditors' Report.

Use of our report

This report is made solely to the Trustees, as a body. Our audit work has been undertaken so that we might state to the Trustees those matters we are required to state to them in an Auditors' Report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and its Trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Haines Watts

Haines Watts (City) LLP
Statutory Auditor
69-73 Theobalds Road
London WC1X 8TA

29 October 2021

Haines Watts (City) LLP is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

Consolidated Statement of Financial Activities

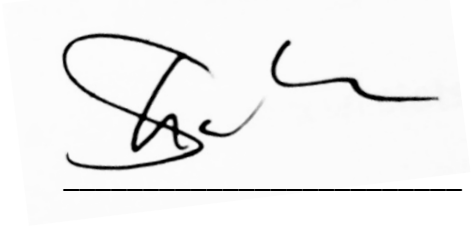
Incorporating Income and Expenditure account

	Note	2020 £ Unrestricted	2020 £ Restricted	2020 £ Total	2019 £ Total
Income					
Income from donations	2	715,962	75,392	791,354	1,056,977
Income from investments		5,584	0	5,584	4,771
Total		721,546	75,392	796,938	1,061,748
Expenditure					
Charitable activities	3	735,498	0	735,498	696,927
Raising funds	3	24,273	0	24,273	58,345
Total		759,770	0	759,771	755,272
Net movement in funds		(38,225)	75,392	37,167	306,476
Transfer of funds		0	0	0	0
Funds brought forward		1,862,509	22,509	1,885,018	1,578,542
Funds carried forward		1,824,284	97,901	1,922,185	1,885,018

Balance Sheets

	Notes	Group 2020	Group 2019	Charity 2020	Charity 2019
		£	£	£	£
Fixed Assets					
Investments	4	402,928	95,724	403,028	95,824
Current assets					
Cash at bank		1,802,922	1,945,796	1,730,335	1,945,796
Debtors – promissory loan	5	25,963	47,805	25,963	47,805
Other debtors- donations receivable		105,927	90,089	183,931	90,089
		1,934,812	2,083,690	1,940,299	2,083,690
Creditors					
Amounts falling due within one year- Project costs		415,555	294,396	415,655	294,496
Total net assets		1,922,185	1,885,018	1,927,602	1,885,018
Unrestricted Funds		171,988	152,752	171,988	152,752
Restricted Funds	6	97,901	22,509	97,901	22,509
Designated funds		1,652,296	1,709,757	1,657,713	1,709,757
Total Funds		1,922,185	1,885,018	1,927,545	1,885,018

These Financial Statements were approved by the Trustees on 29 October 2021



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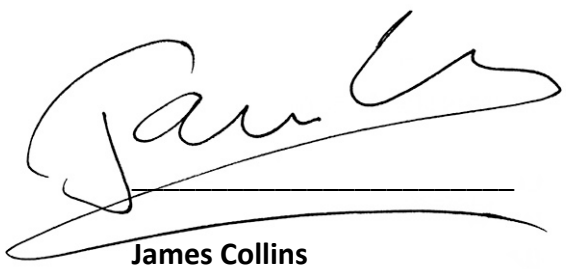

James Collins

Consolidated cash flow statement for the year ended 31 December 2020

	2020 £	2019 £
Net cash inflow/(outflow) from operating activities	37,167	306,476
(Increase)/Decrease in debtors	(15,838)	(31,133)
Increase/(Decrease) in creditors	121,159	(103,271)
Net cash inflow/(outflow) from operations	142,488	172,072
Cash flow from investing activities		
Fixed asset investment additions	(307,204)	(95,724)
Promissory loan repaid	21,842	(47,805)
Net cash (outflow) from investing activities	(285,362)	(143,529)
Increase/(decrease) in cash at bank	(142,874)	28,543
Cash at the beginning of the year	1,945,796	1,917,253
Cash at the end of the year	1,802,922	1,945,796

Notes to the financial statements

1. Principal accounting policies

(a) Accounting convention
The consolidated financial statements are prepared under the historical cost convention and in preparing the financial statements the charity follows best practice as laid down in the Statement of Recommended Practice "Accounting and Reporting by Charities" SORP 2015. The charity presents its accounts under FRS 102.

Basis of consolidation - The consolidated statement of financial activities, balance sheet and cash flow include the financial statements of the charity and its subsidiary undertaking made up to 31 December 2020. The results of the subsidiary is included in the statement of financial activities and inter group transactions are eliminated fully on consolidation.

(b) Donation and grant Income
Income is accounted for in the period in which the charity is entitled to receipt, the receipt is probable and measurable.

(c) Expenditure is included on an accruals basis.

(d) Taxation - as a charity the income is exempt from taxation.

(e) Fixed asset investments are held to generate income or for their investment potential, or both. Investments may include 'social investments' where the purpose in making the investment is wholly or partly to further the charity's aims. The social investments are stated at cost less impairment unless it can be measured at fair value which can be reliably measured.

The investment in a subsidiary company is held at cost less accumulated impairment losses.

(f) Funds structure. The restricted funds represent donations made where the donor has placed a restriction on the use of the funds. Unrestricted funds can be used as the Trustees see fit in line with the charitable objectives.

(g) Going concern
The accounts are prepared on the basis that the Trustees have adequate resources to continue to operate. The Trustees have informally discussed expected future cash flows and the future expected incoming and outgoing resources in making their assessment for a period of at least 12 months from the signing of the accounts. In particular, in response to the COVID-19 pandemic, they have taken into account the impact on the group and Charity and measures they can take to mitigate the impact. Based on these assessments the Trustees have concluded that they can continue to adopt the going concern basis in preparing the annual report and accounts.

(h) Financial instruments and Critical accounting estimates and judgements

Estimates and judgements are continually evaluated and are based on the experience and understanding of the Trustees. The Trustees do not believe that there are any significant estimates and judgements that have a material impact on the financial statements.

Basic financial instruments such as social investments, debtors and bank balances are recognised at transaction value.

2. Designated funds are unrestricted funds designated by the Trustees for research projects in pursuit of the charitable activities.

3. Charitable activities

	2020	2019
	£	£
Research projects:		
Next Gene Genome Sequencing (University of Minnesota)	248,019	270,515
Gene Editing Trial - Madrid	136,374	-
Colorado Gates	106,569	102,978
UCL Gene Editing	59,543	133,977
Kings College London - Nanocol	41,088	-
UCL Lenticol M	-	47,670
DEBRA - Lenticol F clinical trial	-	65,550
Constant Pharma	-	47,805
License fees	91,996	-
Support costs:		
Admin costs	29,203	17,520
Governance costs	9,920	7,912
Bank charges (Net Refund from bank)	109	-
Audit	4,200	3,000
Events	1,572	-
Web hosting & Social Media consulting	2,175	-
Insurance	4,730	-
	735,498	696,927

3.

	2020	2019
Raising funds:	£	£
Fund raising & marketing	16,371	53,357
Web hosting	1,009	-
Fundraising admin costs	6,893	4,988
	24,273	58,345

4. Fixed Asset Investments – Held by group

	2020	2019
	£	£
Social Investments - unlisted		
Cost at 1 January 2020	95,724	95,724
Additions	307,204	-
Cost at 31 December 2020	402,928	95,724

Fixed Asset Investments – Held by charity

	2020	2019
	£	£
Social Investments - unlisted		
Cost at 1 January 2020	95,724	95,724
Additions	307,204	-
Cost at 31 December 2020	402,928	95,724

Shares in group undertakings

Held by charity

	2020	2019
	£	£
Cost at 1 January 2020	100	100
Cost at 31 December 2020	100	100
Net book value		
At 31 December 2020	403,028	95,824

The group or the company's investments at the Balance Sheet date in the share capital of companies include the following:
Subsidiaries

EB Therapeutics Ltd
Registered office : England & Wales
Nature of business: Furthering research for human health

Class of shares	% holding
Ordinary	100.00

In the year a social investment has been made of £92,282 €100,000 in Branca Bunus Limited, a company registered in Ireland, to further the aims of the charity by the funding of relevant research.

Also in the year a social investment has been made of £214,922 $275,000 in Fibrix Derm, Inc. a US company, to further the aims of the charity by the funding of relevant research.

5. Debtors
Included in debtors is a promissory loan of US$30,000 - £25,963 (2019: US$60,000 - £47,805) made in Constant Pharmaceuticals LLC, a US Corporation, at a coupon nil interest rate, in order to further the aims of the charity by the funding of relevant research.

6. Restricted fund balances

	Balance brought forward	Income	Expenditure	Inter fund transfer	Balance carried forward
	£	£	£	£	£
	22,509	75,392	0	0	97,901

Restricted fund balance carried forward represents 3 research projects in progress and are held as cash balances.

Unrestricted and designated funds are held as bank balances, social investments and current assets.

7. No Trustees received remuneration or were reimbursed for expenses in the period.

8. In the year capital and funds were provided of £170,000 to EB Therapeutics Ltd a subsidiary of Cure EB. In the year there were donations to the charity from the Trustees amounting to £115,000 (2019 - £207,200).

9. There are no employees (2019 - none).

10. There are no contingent liabilities.