



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

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## 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 EB Graft 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 and 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 is 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 (Oct 31, 2023 11:08 GMT)

**Sharmila Nikapota**

*James Collins*

**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](http://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  
Date: .....



## Consolidated Statement of Financial Activities Incorporating Income and Expenditure account

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

## Balance Sheets

	Notes	Group		Charity	
		2022	2021	2022	2021
		£	£	£	£
<b>Fixed Assets</b>		428,891	428,891	428,991	428,991
Investments	5				
<b>Current assets</b>					
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
<b>Creditors</b>					
Amounts falling due within one year- Project costs	7	912,297	169,374	912,397	169,474
<b>Total net assets</b>					
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
<b>Total Funds</b>		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)

Sharmila Nikapota

*James Collins*

James Collins



## Consolidated cash flow statement for the year ended 31 December 2022

	2022 £	2021 £
<b>Net cash inflow/(outflow) from operating activities</b>	(121,282)	706,541
(Increase)/decrease in debtors	(70,516)	(13,767)
(Decrease)/Increase in creditors	742,923	(246,181)
<b>Net cash inflow from operations</b>	551,225	446,593
<b>Cash flow from investing activities</b>		
Fixed asset investment additions	-	-
<b>Net cash (outflow) from investing activities</b>	-	-
<b>Increase/(decrease) in cash at bank</b>	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**

	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
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
	<b>1,033,130</b>	<b>820,811</b>

**4. Raising funds**

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

5. Fixed Asset Investments – Held by group & charity

	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
Social Investments - unlisted		
Cost at 1 January 2022	428,891	402,928
Additions/transfers	-	25,963
Cost at 31 December 2022	<u>428,891</u>	<u>428,891</u>
Net book value		
At 31 December 2022	<u>428,891</u>	<u>428,891</u>
Shares in group undertakings		
Held by charity		
	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
Cost at 1 January 2022	100	100
Cost at 31 December 2022	<u>100</u>	<u>100</u>
Net book value		
At 31 December 2022	<u>100</u>	<u>100</u>

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

	<b>%</b>
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 Bonus Limited, a company registered in Ireland.

6. Debtors

	<b>Group</b>		<b>Charity</b>	
	<b>2022</b>	<b>2021</b>	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
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

**Cure EB formerly Sohana Research Fund (Charity number 1158672)**  
**Report and Financial Statements for the year ended 31 December 2022**

	<b>Group</b>		<b>Charity</b>	
	<b>2022</b>	<b>2021</b>	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
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
	<b>912,297</b>	<b>169,374</b>	<b>912,397</b>	<b>169,474</b>

**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.