

Report and Financial statements Period Ended 31 December 2021 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 OPQ

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

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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.
- 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

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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.

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- 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

jant

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.

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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:

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- 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.

Harries Watts (City) LLP

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

Statutory Auditor

New Derwent House

69-73 Theobalds Road

London

WC1X8TA

Consolidated Statement of Financial Activities Incorporating Income and Expenditure account

	Note	2021 f	2021 f	2021 £	2020 £
Income		Unrestricted	Restricted	Total	Total
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
			55,525		7.00,000
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
Command accepts					
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		169,374	415,555	169,474	415,655
year- Project costs					
Tatal nat accets		2 620 726	1 022 105	2 (20 72(1 027 602
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
iviai rulius		2,020,720	1,322,103	2,020,720	1,327,002

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	<u>-</u>	(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 Cash at the end of the year	1,802,922	1,945,796
eash 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

Cure EB formerly Sohana Research Fund (Charity number 1158672) Report and Financial Statements for the year ended 31 December 2021

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.

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

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

3.

	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		
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				Balance
brought			Inter fund	carried
forward	Income	Expenditure	transfer	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.