

Report and Financial statements Period Ended 31 December 2017 Charity Number 1158672

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"The enthusiasm, dedication and tireless commitment from Cure EB to raise awareness, to find a treatment, and ultimately a cure, for EB keeps us all going. They shine a light in the dark places and give hope to families like ours affected by this cruel skin disorder. It's difficult to imagine the challenges posed by EB without the support of the Cure EB.

It is thanks to Cure EB funded research that there have been so many substantial advances in understanding EB and its causes. We are incredibly grateful to them for giving us this hope and the opportunity for a positive future."

RACHEL GRIST Mum of Isla, age 7

# 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. Also known as: SRF
  - 1.3. Type of entity: Charitable Incorporated Organisation
  - 1.4. Date of incorporation: 25 September 2014
  - 1.5. Registered Charity Number: 1158672
  - 1.6. Governing document: Constitution
  - 1.7. 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

Bankers Barclays Bank PLC

14 Upper Street

Islington London N1 0PQ

Auditors The Gallagher Partnership LLP, P O Box 698

Second Floor Titchfield House

69-85 Tabernacle Street

London EC2A 4RR

# Summary

### Our Mission Statement

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

# **Our Commitments**

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

To strive for maximum research spend.

To raise awareness of EB.



# 2017 Highlights

'Bond with Research' - Research update meeting at the Bond Museum attended by Damian Lewis

### Fundraising Highlights

- Virgin London Marathon raised £23,491
- Silver Butterfly Dinner raised £250,000
- Charity of the year for REDBURN partners, donations in 2017 totalling £27,600
- Dodington Opera £55,000
- Goldman Sachs Gives donations totalling £60,000
- Big Give £39,090 in total (£28,085 received in 2017)

### Project Highlights

- ADSTEM trial ending and LENTICOL F trial (both funded via SRF Debra) due to end early 2018
- Two new US projects funded in collaboration with two US research funding organisations
- · Funding MSC cell production for cell treatments for children at GOSH
- Committing to an editing project at UCL
- Ongoing ocular regeneration of the ocular surfaces on Minnesota



### 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.

In 2017, we made good progress with fundraising with about £853,000 raised in total. This allowed us to make significant research commitments.

We had a very successful research update meeting at the Bond Museum in London preceding our RIBA fundraising dinner in May.

In research, we made exciting progress. We have two SRF Debra-funded clinical trials ending. We await analysis of the results. Our project in Minnesota involving gene editing limbal stem cells and regenerating the corneal surface in RDEB patients is progressing well. We are pleased to be funding two projects in collaboration with two US research funding organisations and are progressing projects at UCL and Kings in the UK.

As far as raising awareness is concerned, we started a new social media awareness campaign called "EBpop" – "Play #EBpop to make the blisters stop", which involves popping waterballoons, the idea being that they are like fluid filled blisters that sufferers with EB need to have popped with a needle. We participated in Parallel London again, bringing the EB community together afterwards at SRF Family Day to listen to Professor Jakub Tolar and Professor McGrath. We had a grant from Jeans for Genes Day towards this. This informal setting allowed EB families to take part in discussion and understand our research funding drive as well as giving them an opportunity to speak to world leading researchers. We will further strive to fund research aiming to change the lives of people with EB.

In the meantime, we hope that you will find this Trustees' Report informative.



### Report of the Trustees

The Trustees present their report along with the financial statements of the charity for the period ended 31 December 2017

### A. Introduction

- Cure EB then known as the Sohana Research Fund C.I.O. ("SRF") was established on 25 September 2014 with Registered Charity Number 1158672. Prior to that, the founders (Sharmila Nikapota and James Collins) had operated the "Sohana Research Fund" as a restricted fund within Debra (Registered Charity Number 1084958) ("SRF Debra").
- 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 2017 is as follows:
  - 3.1 FUNDRAISING SRF raised more than £850,000. This was a reasonable return.
  - 3.2 RESEARCH RESULTS The ADSTEM trial closed in July 2017 with data analysis and write up to follow. LENTICOL F is closing in 2018. Good progress was made on the eye project with a very favourable report review. Lenticol M work is ongoing with the project due to end in 2018. We are collaborating in the funding of two projects in the US looking at gene editing and induced pluripotent stem cell work. MSC production has been started at Kings and cells are being banked for use in RDEB patients at GOSH. We are starting a gene editing project at UCL.
  - 3.3 RESEARCH FUNDING Our research funding spend this year was £893,360.
  - 3.4 RESEARCH COMMITMENTS We started a collaboration with two US based funding organisations to fund two large projects in the US in which we take equal share over a number of years provided milestones are met. This funding is reviewed on a yearly basis. Cure EB has also committed to funding MSC production at Kings and delivery of cells to patients at GOSH and has allocated funding for gene editing at UCL as well as continuing limbal stem cells work.
  - 3.5 AWARENESS AND OTHER EVENTS This was the year of our biennial fundraising dinner at RIBA. We saw an increase in individual and small group led events and following a successful Butterfly Brunch Club meeting a number of smaller satellite brunches hosted by supporters to their friends.

- We aim to build on this network in subsequent years. We had good sporting event participation this year which we hope to improve on.
- 3.6 Looking ahead, 2018 will be a year without our main fundraising event: our biennial Silver Butterfly Dinner. Consequently, we expect income to be lower. However, we hope to be able to develop other revenue streams so that we end up with an income somewhere between that for 2016 and that for 2017.
- 3.7 We look forward to identifying, committing to and funding further projects and, in doing so, cementing Cure EB's position as one of the leading funders of RDEB research and trials.

### B. Objectives and Activities

- 4. As set out in Cure EB's Constitution, Cure EB's objects are "For the public benefit, (a) the advancement of health and (b) the relief and assistance of people in need who are suffering from Recessive Dystrophic 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 resident in the United Kingdom who are suffering from Epidermolysis Bullosa".
- 5. Cure EB's objectives during 2017 were limited to:
  - 5.1 Raising funds (including raising awareness of EB and Cure EB in order to assist with fundraising);
  - 5.2 Identifying and developing projects for funding; and
  - 5.3 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.

- 8. Sharmila was nominated for an award which led to a substantial press piece, we were also referenced in pieces about 'Jeans for Genes' Day as we had a grant from them towards our family day. We had TV appearances in pieces re gene editing and gene therapy skin graft. Damian Lewis attended and spoke at 'Bond with Research', with Sharmila. Sharmila made speeches at the RIBA dinner and within offices, as well as having an increased presence at big events such as runs.
- 9. Cure EB has an active social media presence with over 32,000 followers on Facebook and over 2400 on twitter. We are gradually building our Instagram follower network with 937 followers. The Cure EB website has also been 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.
- 10. Our community outreach and awareness events included a major donor scientific update dinner at the Bond Museum in London named 'Bond with Research' with professor Francesco Dazzi, associate professor Andrew South and Dr Anastasia Petrova and at the Olympic Park for EB families as well as donors and their families with a scientific update from professor McGrath and professor Jakub Tolar.
- 11. Our main fundraising event in 2017 was the biennial Silver Butterfly Dinner at RIBA. We were charity of the year for Redburn and were chosen for GFI charity day in September. We were chosen to benefit from an Opera evening hosted by our patrons Sir James and Lady Deirdre Dyson. Substantial amounts were raised through celebrations, school donations and Goldman Sachs donations of nearly £60,000. We were very pleased to be part of the 'Big Give' in December and double our target of nearly £20,000.
- 12. Social Media continues to be an important tool to raise awareness of the condition and charity. We started a new social media campaign called #EBpop "Play #EBpop to make the blisters stop" which involves popping balloons and challenging others to do the same which helped raise awareness and donations.
- 13. Sponsorship events which included a team running at the Vitality London run and two London Marathon participants raised significant funds. Individuals running for us in smaller events themselves also impacted our general reach and increased these smaller revenues streams. Hikes, concerts, birthday donations, cycle rides, Butterfly Brunch Club donations, 'Lock up choc' challenge are some of the examples.
- 14. Looking ahead, we have a number of events planned for 2018, including a major donor research update meeting at the House of Lords, Butterfly Brunch Club Lunch in London, marathon places, Opera evening, runs and continuing our #EBpop social media campaign. We are keen to continue building regular donations and our online giving.

# B(2). Projects

- 15. 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.
- 16. We currently evaluate projects on a rolling basis (rather than in formal funding rounds at fixed intervals) and invite applications that meet our priority areas of research. An initial outline of the project is evaluated and if deemed to be within an area of interest a full grant application is asked for. The project is then externally reviewed and scored. If the scores are sufficiently high the project is presented to the trustees for approval. If approved, Cure EB negotiates and concludes formal funding agreements with the body that is to carry out the research. We are opening one fixed funding round along with keeping the door open to project evaluation during the year. This will ease collaboration with other organisations.
- 17. During 2017, we cemented our relationship with two U.S. based EB research funding charities EBRP and EBMRF by joining together to fund two projects in the US. This will lead to increased sharing of information about potential new projects, evaluation of them and continued collaborative funding.



"My daughter Poppy is now 6 years old and has never experienced a day in her life without pain.

EB leaves little time for play. Poppy misses out on so much of the childhood experiences that most of us take for granted.

This is life with EB everyday, there's no break and you can't take a holiday away from it. We desperately want to be able to change it, not just for Poppy but for the 5000 people living with EB."

Kate Gee Mum of Poppy, age 6

### C. Achievements and Performance

- 18. During 2017 the total research spend was £893,360, the main research achievements were as follows:
  - 18.1 ADSTEM Trial Understanding how allogeneic mesenchymal stromal cells given intravenously can modify disease severity in epidermolysis bullosa patients. Recruitment and infusions completed in a number of patients who will be followed up for a twelve month period.
  - 18.2 Lenticol F Lentiviral-mediated COL7A1 gene-modified therapy for RDEB. Patients have been recruited and the trial started and will run into 2018
  - 18.3 Second year of regeneration of the ocular surfaces which was a \$500,000 project (\$250,000 spent in 2017)
  - 18.4 EB iPS Consortium. Grants to Colorado, Stanford and Columbia totalling £331,754
  - 18.5 Next generation genome editing project Minnesota £238,680
  - 18.6 Lenticol M Workpackage 1 is ongoing with £67,857 spend in 2017. This work has suffered some delays and we have not reached the clinical trial phase as expected. Grants that had been restricted to the trial have, with donor consent, been assigned to different projects. MSC generation King's College London Project cost 50k in 2017 with a further 140k still committed
- 19. Looking beyond 2017, Cure EB has already committed a total of £1,291,000 research spend. The remainder has been reserved.
- 20. Looking ahead, our aim is to continue our focus on (1) translational research i.e. projects aimed at "translating" fundamental research into treatments for patients; but also (2) some of the critical fundamental research (eg. in relation to gene editing and the causes of squamous cell carcinoma mechanisms of RDEB) that underpins the translational work. We will also continue looking at emerging technologies to determine translational benefit.
- 21. To this end we aim to continue to build our relationships with other potential funders and investors and with the RDEB research community.

### D. Financial Review

- 22. The accounts show the financial affairs of Cure EB for 2017 and as at 31 December 2017. The key figures, together with commentary, are as follows:
  - 22.1 Gross Income: £853,166. This is significantly higher than the amount raised in the prior period for the reasons anticipated at paragraph 25 of our 2016 Report, in particular the hosting of the biennial Silver Butterfly Dinner (which raised about £250,000 in 2017). It was in line with expectation.
  - 22.2 Costs of Fundraising and Awareness (excluding Office and Administration): £82,501
    - (1) As a general rule, Cure EB focuses its fundraising efforts on activities that are likely to produce immediate and substantial returns. Exceptions to this are events that are aimed at securing long term engagement with Cure EB (rather than immediate financial return) or raise awareness of Cure EB, EB and the research that Cure EB funds.
    - (2) As a rule of thumb, Cure EB aims to raise £10 for every £1 spent across all of these activities, but recognises that fluctuating income is likely to mean that this is not achieved every year. For 2014-15 this target was comfortably exceeded. For 2016 it was exceeded. For 2017 it was exceeded (just!).
  - 22.3 Office and Administration Costs: £21,676.92
    - (1) During 2016, Cure EB did not have any office costs. It was run from the home of two of the Trustees. However, this model was not sustainable. There was no dedicated Cure EB office and no space for any support staff. Consequently, during 2017 it was determined that Cure EB should acquire office space. It did so in the last quarter.
    - (2) As a result, the Office and Administration Costs have increased. They will increase further in 2018 due to (a) the full-year cost of the office; and (b) the engagement of support staff.
  - 22.4 Expenditure on charitable activities: £893,360. This has increased as the project pipeline has matured.
  - 22.5 Reserves: £1,966,076. Of this sum:
    - (1) As set out in the Financial Statements (1) £120,929 is in restricted funds; and (2) £1,804,340 has been designated as

- being available for expenditure on charitable purposes only (i.e. excluding cost of fundraising or administration).
- (2) Of these restricted and designated funds £1,291,000 has been provisionally allocated to ongoing and new research aimed at treating epidermolysis bullosa
- (3) The unrestricted and undesignated funds which are used to cover cost of fundraising and administration – are currently made up entirely of donations by the Founders. As at 31 December 2017, these unrestricted reserves totalled £40,807.

#### 23. Looking ahead to 2018:

- 23.1 Gross income are likely to be lower as we will not be hosting our biennial Silver Butterfly Dinner.
- 23.2 Cost of fundraising and awareness is likely to be lower. The Silver Butterfly Dinner is a significant source of cost (as well as income).
- 23.3 Office and Administrative costs will likely be significantly higher. Cure EB acquired a small permanent office in 2017 which it plans to keep. Furthermore, Cure EB plans to recruit part-time but permanent assistance to help run Cure EB. Cure EB anticipates that office and administrative cost will be about £50-60,000 during 2018.
- 23.4 Expenditure on projects will likely stabilise. During 2014-17 Cure EB sought to build up the pipeline of projects. It should now stabilise as the cost of new projects is offset, to an extent, by the cost-saving of other projects ending. Cure EB plans to maintain expenditure slightly above income (on average, if not in every year) in order to reduce the cash reserves recorded in the balance sheet.
- 24. The trustees as at the date of this report (the "Trustees") are:
  - 24.1 Ms. Sharmila Nikapota
  - 24.2 Mr. James Collins
  - 24.3 Mr. Michael de Lathauwer
  - 24.4 Ms. Tazim Hall
  - 24.5 Prof. David Kelsell
  - 24.6 Mr. Duncan Wales
- 25. There were no other trustees during 2017. These Trustees may be reappointed at the expiry of their current terms and/or further trustees may be appointed by resolution passed at a properly convened meeting of the trustees. Pursuant to the

terms of the Constitution, the minimum number of trustees is 3 and the maximum is 9. The Trustees are selected for their experience and expertise.

- 26. The Trustees are not and were not compensated for performing their roles as trustees.
- 27. Management and Administration:
  - 27.1 Management of Cure EB's fundraising and awareness activities has been delegated (subject to a financial cap) to Sharmila Nikapota and James Collins. They in turn report to the other Trustees. In particular:
    - (1) Sharmila Nikapota has primary responsibility for conceiving, developing and performing all fundraising and awareness activities. This includes the identification of suitable contractors to provide goods or services and negotiation with those contractors.
    - (2) Costs of goods and services are approved by, and payment for goods and services is arranged by, James Collins.
    - (3) Sharmila Nikapota and James Collins are authorised to jointly incur costs of up to £10,000 per month in relation to fundraising and awareness activities without further authorisation from the Trustees. For major events, Sharmila Nikapota and James Collins must seek the prior approval of the Trustees.
  - 27.2 Management of the administration of Cure EB has been delegated (subject to a financial cap) to Sharmila Nikapota and James Collins. They in turn report to the other Trustees. In particular:
    - (1) Sharmila Nikapota and James Collins are primarily responsible for identifying the services that need to be performed and finding suitable contractors to assist with the provision of those services.
    - (2) Sharmila Nikapota and James Collins are authorised to jointly incur costs of up to £2,500 per month in relation to the administration of Cure EB without further authorisation from the Trustees. Financial oversight and record keeping is performed by Rachel Lesiter.

#### 27.3 In relation to projects and funding:

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

- (2) The process for the evaluation of potential projects depends on the nature and size of the project. Prof. David Kelsell provides guidance in relation to both the process and the evaluation. He is also responsible for identifying external reviewers to evaluate the projects and collecting comments and scores from those reviewers.
- (3) All funding decisions (including identification of the project to be funded and the amount of funding to be provided) are made by the Trustees (as a whole).
- (4) Having decided "in principle" to fund a project, negotiation of documentation is led by James Collins and Tazim Hall.
- (5) Project invoices that conform with the funding agreements are approved by, and payment is arranged by, James Collins.

#### 28. Professional Services:

- 28.1 Cure EB has no ongoing or general relationship with any firm of solicitors. However 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 (eg.for advice on aspects of foreign law when relevant to funding agreements).
- 28.2 Cure EB has not retained any investment advisor. However, Michael de Lathauwer comes from an investment banking background and is currently a fund manager.

#### 29. Remuneration:

- 29.1 The Trustees are not and were not compensated for their management roles (described above) nor for any other role that they perform.
- 29.2 Cure EB has no employees.
- 29.3 Cure EB has benefited from, and relies on, substantial support from a team of volunteers. In particular:
  - (1) The fundraising and awareness events are supported by a substantial team of engaged and dedicated volunteers. They provided assistance with the development of the event, attracting supporters to the event, graphic design, logistics and in many other ways. Without their support, many of these services would have to be bought in at considerable cost to Cure EB.

(2) The administration of Cure EB has been greatly assisted by volunteers, again saving Cure EB substantial cost. The it will be necessary to increase spending on administration in 2017, we look forward to the continued support of these volunteers.

#### **Investment policy**

Funds are currently held as short term bank balances.

The charity will consider alternative investments during 2018.

#### **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 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 2017 this risk was entirely mitigated by ensuring that reserves substantially exceeded commitments. Whilst the Trustees will maintain expenditure higher than income for the next few years, (1) substantial reserved will be retained; and (2) when reduced to suitable level, the Trustees will seek to ensure that on average (but not each individual year) income and expenditure are balanced.

#### **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.

**James Collins** 

Approved by the Trustees and signed on their behalf by:

**Sharmila Nikapota** 

Date: 22 October 2018

# Report of the Independent Auditors

We have audited the financial statements of Cure EB for the period ended 31 December 2017 which comprise the Statement of Financial Activities, the Balance Sheet, Cash Flow and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) including FRS 102.

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

#### Respective responsibilities of Trustees and auditor

As explained more fully in the Trustees' Responsibilities Statement, the Trustees are responsible for the preparation of financial statements which give a true and fair view.

We have been appointed as auditor under section 144 of the Charities Act 2011 and report in accordance with regulations made under section 154 of that Act. Our responsibility is to audit an opinion of the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's (APB's) Ethical Standards for Auditors.

#### Scope of the audit of the financial statements

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

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#### **Opinion on financial statements**

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 December 2017 and of its incoming resources and application of resources, for the period ended;
- have been property prepared in accordance with United Kingdom Generally Accepted Accounting Practice, and
- have been prepared in accordance with the requirements of the Charities Act 2011

#### Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities Act 2011 requires us to report to you if, in the opinion:

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

Gallagher Partnership LLP

69-85 Tabernacle Street
London EC2A 4RR

24 October 2018

The Gallagher Partnership LLP is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

# Statements of Financial Activities

### **Incorporating Income and Expenditure account**

	Note	<b>2017</b> £	<b>2017</b> £	2017	2016
Income		Unrestricted	Restricted	Total	Total
Income from donations	2	783,079	70,087	853,166	513,444
Total		783,079	70,087	853,166	513,444
<b>Expenditure</b> Raising funds		104,178	0	104,178	34,430
Charitable activities	3	0	893,360	893,360	422,796
Total		104,178	893,360	997,538	457,226
Net movement in funds		678,901	(823,273)	(144,372)	56,218
Transfer of funds		177,227	(177,227)	0	
Funds brought forward		989,019	1,121,429	2,110,448	2,054,230
Funds carried forward		1,845,147	120,929	1,966,076	2,110,448

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# **Balance Sheet**

Balance Sheet	Notes	2017	2016
Current assets Cash at bank		1,966,076	2,110,448
Total net assets		1,966,076	2,110,448
Unrestricted Undesignated Funds	2	40,807	101,110
Unrestricted Designated funds	2	1,804,340	887,909
Restricted Funds	4	120,929	1,121,429
Total Funds		1,966,076	2,110,448

These Financial Statements were approved by the Trustees on 12 October 2018

**Sharmila Nikapota** 

**James Collins** 

### Cash Flow Statement

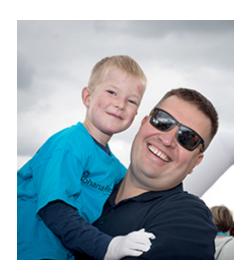
#### Cash flow statement for the period ended 31 December 2017

	2017 £
Net cash outflow from operating activities	(144,372)
Decrease in cash at bank	(144,372)
Cash at the beginning of the year	2,110,448
Cash at the end of the year	1,966,076

"It is really hard to describe in a few sentences how important research is.

The daily routine of dressing changes, pain and challenges a child has to go through is heart-breaking. I don't have enough words to describe it; you need to see it to appreciate this horrible condition. I'm not even mentioning what tremendous work parents do to keep your child healthy and happy. As a parent, all you want for your child is to be happy, to be able to do normal activities, run, swim, kick the ball, be able to develop normally, with EB you don't have that. And the most frightening thing is that tomorrow will be no different.

That's why the research is one of the most important things to us and Gabrielius, it gives us a chance, even if it is one in a million, but it is still a chance, a hope, that one day we will defeat EB and we are very very thankful to Cure EB for that chance."



Linus Misurenkovas Father of Gabrielius, age 4

# Notes Forming Part of the Financial Statements

#### Notes to the financial statements

- 1. Principal accounting policies
- (a) Accounting convention

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

(b) Donation and grant Income

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

- (c) Expenditure is included on an accruals basis.
- (d) Taxation- as a charity the income is exempt from taxation
- (e) 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.
- (f) Going concern

The accounts are prepared on the basis that the Trustees has adequate resources to continue to operate.

(g) Financial instruments and Critical accounting estimates and judgements

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

Basic financial instruments such as bank balances are recognised at transaction value.

- 2. The unrestricted funds include (1) designated funds (which are unrestricted funds but which have been designated by the Trustees for research projects in pursuit of the charitable activities) and (2) undesignated funds (which may be used for any of the activities of the charity, including administration and fundraising).
- 3. Expenditure on raising funds includes costs of administration

		Balance	Income	Expenditure	Inter	Balance
		brought			fund	carried
4.	Restricted fund balances	forward			transfer	forward
		£				
		1,121,429	70,087	(893,360)	(177,227)	120,929

Restricted fund balance carried forward represents 2 research projects in progress.

All funds are held as bank balances

- 5. No Trustees received remuneration or were reimbursed for expenses in the period.
- 6. There are no related party transactions other than donations to the charity from Trustees
- 7. There are no employees
- 8. There are no contingent liabilities