

Registered charity in England & Wales (1136809) and in Scotland (SC046735)

Registered in England & Wales Company number: 07278507

# Reverse Rett

Report and financial statements

For the year ended 31 December 2016

Reverse Rett  
Reference and administrative information  
for the year ended 31 December 2016

**Company number** 07278507

**Charity number** 1136809 (England & Wales) and SC046735 (Scotland)

**Registered office and operational address** Suite 2B, Paragon House  
Seymour Grove  
Manchester  
M16 0LN

**Trustees** Trustees, who are also directors under company law, who served during the year and up to the date of this report were as follows:

John Sharpe	Chair
Helen Simmonds	Vice-Chair
Andrew J Stevenson*	
Rachael Stevenson*	
Monica Coenraads*	
Kelly Phillips	(resigned 14 May 2017)
Helen Simmonds	
Marc Souter	(resigned 20 January 2016)
Ortensia Martinotti	(appointed 2 December 2015)
Neil Fowler	(appointed 21 April 2016)

\*Trustees who are also Directors of the charitable company.

**Key management** Rachael Stevenson Executive Director

**Bankers** Barclays Bank  
102 High Street, Thame, Oxon, OX9 3DU

**Independent auditors** Slade & Cooper Limited  
Greenfish Resource Centre, 46-50 Oldham St, Manchester, M4 1LE

Reverse Rett  
Trustees' annual report  
for the year ended 31 December 2016

The trustees present their report and the audited financial statements for the year ended 31 December 2016. Included within the trustees' report is the directors' report as required by company law.

Reference and administrative information set out on page 1 forms part of this report. The financial statements comply with current statutory requirements, the memorandum and articles of association and the Statement of Recommended Practice - Accounting and Reporting by Charities: SORP applicable to charities preparing their accounts in accordance with FRS 102.

**Objectives and activities**

Reverse Rett is a UK medical research charity working to accelerate treatments and a cure for Rett Syndrome.

Rett Syndrome is a neurological condition which most often strikes previously healthy little girls between their first and second birthday and leaves them with multiple disabilities and medical complexities for life.

Most people with Rett are unable to speak, walk or use their hands. Breathing problems, feeding tubes, seizures, anxiety, gastrointestinal and orthopaedic issues are common.

There are currently no FDA or EMA approved drugs or treatments for Rett Syndrome.

But there is hope.

In 2007, scientists at the University of Edinburgh were unexpectedly able to reverse the condition in mouse models of even late stage disease.

In 2013, successful gene therapy experiments in Rett mice, supported by Reverse Rett, provided a tangible way to reverse symptoms in humans with the disease.

Since then, our efforts have been focused on driving these spectacular research developments into a cure for Rett Syndrome and on research projects focused on bringing about treatments to mitigate some of the distressing symptoms of the disorder, to provide relief for patients until we can deliver a cure.

*Purposes and aims*

The purposes of the charity as set out in our governing document are:

to relieve sickness and preserve health for the public benefit by developing treatments and cures for Rett Syndrome and related MECP2 disorders.

The main activities undertaken in relation to those purposes are:

- i. FUNDING RESEARCH PROJECTS
- ii. DEVELOPING CLINICAL CAPACITY TO ENABLE IMPLEMENTATION OF TREATMENTS AND CURES IN THE UK
- iii. ORGANISING AND SPONSORING SCIENTIFIC WORKSHOPS
- iv. COLLATING INFORMATION FROM EXPERTS IN THE FIELD AND PROVIDING ACCESS TO IT
- v. INCREASING GENERAL PUBLIC AWARENESS AND KNOWLEDGE OF RETT SYNDROME AND RELATED MECP2 DISORDERS.

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Reverse Rett exists to relieve sickness and preserve health for the public benefit of people with Rett Syndrome and related *MECP2* disorders. We do this primarily by:

- (i) Funding research into treatments and a cure.
- (ii) Facilitating the development of clinical provision in the UK with the capacity to 1. run clinical trials 2. Deliver emerging treatments and cures as and when they become available.
- (iii) Developing the charity's organisational capacity so that we can continue to execute our mission in the long term.

In 2016 the main activities undertaken to further the charity's purposes for the public benefit were:

- (i) Funding research into treatments and a cure: In 2016 Reverse Rett contributed £585,728 to the international research program at RSRT and £53,500 to the work of Dr Santosh and team at the CIPPRD clinic, a total of £639,228 of research funding.

The majority of research funds were raised through community fundraising, driven by the families and friends of children and adults with Rett Syndrome in the UK. Much of this fundraising happens on an individual level supported by the charity.

In 2016 Reverse Rett also:

Implemented two new charity-wide events, 'Running for Change 5K' in North Berwick in May and the 'Change is Possible Virtual Run' in October Both of these events were well-attended and successful events.

Held our 7<sup>th</sup> Annual London Gala in November raising £62,557 net.

Ran our 7<sup>th</sup> consecutive Big Give Christmas Challenge Campaign, encouraging supporters to save their change throughout the year and donate in December. The campaign raised £122,761.12.

Implemented a new campaign, 'Pledge your birthday' whereby supporters can ask for donations to Reverse Rett in lieu of presents and cards.

- (ii) Developing clinical capacity:  
In 2016, Reverse Rett provided £50,000 to King's College London CIPPRD Research Team for one FT post Doc researcher to further develop the team's work on the TRIAL database. We provided £3500 to the CIPPRD research team for the purchase of additional wearable technology devices for patients with Rett Syndrome. (100% of funds delivered to KCL in 2016, were donated or raised as restricted funds for UK clinical research use only.)  
We provided logistical support, recruited participants for and participated in the Focus Groups which were held to inform this work.

We provided written feedback on the TRIAL database questionnaire due to go into use by families in Q2 2017.

We provided £20,000 OF continuation funding for HealthTrackerIR infrastructure software for the TRIAL Database.



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We worked collaboratively with the CIPPRD RT in the development of a Breathing Profile Questionnaire to demonstrate to pharma and regulators the impact of breathing irregularities on UK patients with Rett and their families.

We recruited families to participate in completing that questionnaire, collated that information and co-presented some of the information collected to the Rett Disorders Working Group to highlight breathing irregularities in Rett Syndrome as an urgent unmet medical need in the UK health system.

In Q3 2016, we committed £50,000 of funding for one FT Clinical Trial Coordinator to facilitate the implementation of the first UK clinical trial for patients with Rett.

In Q4 2016, Reverse Rett Executive Director, Rachael Stevenson, gave evidence at the Research Ethics Committee hearing at Chelsea and Westminster Hospital for the first UK clinical trial and helped to carry this work successfully through approval.

(iii) Raising awareness of Rett Syndrome and the potential for treatments and a cure:

Often families fundraising for Reverse Rett simultaneously drive awareness alongside their fundraising efforts.

In 2016, we were also able to successfully raise awareness of our work through concentrated social media campaigns; one of these campaigns involved asking supporters to vote for Reverse Rett to win a bucket collection opportunity at Chelsea Football Club and one involved asking supporters to vote for Reverse Rett to be finalists in the Just Giving Charity of the Year competition. Both campaigns were successful.

We also managed to raise the profile of Rett Syndrome and the work of Reverse Rett by nominating one of our young fundraisers for a Pride of Britain Award, which she won in November, resulting in tremendous publicity in the national press and on live television.

The trustees of Reverse Rett review the aims, objectives and activities of the charity each year. This report looks at what the charity has achieved and the outcomes of its work in the reporting period. The trustees report the success of each key activity and the benefits the charity has brought to those groups of people that it is set up to help. The review also helps the trustees ensure the charity's aims, objectives and activities remained focused on its stated purposes.

The trustees have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives and in planning its future activities. In particular, the trustees consider how planned activities will contribute to the aims and objectives that have been set.

**Income from charitable activities explained (as detailed in the accounts, p.22)**

- (i) The Big Give £122,761-these are funds raised through the Big Give Christmas Challenge campaign
- (ii) London event £62,558-these are funds raised at the 7<sup>th</sup> Annual London Gala Event
- (iii) *MECP2* Fund-£49,073-The *MECP2* fund is a restricted fund at Reverse Rett, via which, UK families of children with *MECP2* Duplication Syndrome are able to raise funds to accelerate treatments and cures for the condition which are sent via Reverse Rett to Rett Syndrome Research Trust *MECP2* Duplication projects.  
*MECP2* Duplication Syndrome is closely related to Rett as the condition is caused by the same gene. However, targets for treating the condition are different; in Rett, patients do

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not have enough Mecp2 protein, in Duplication, patients have too much. Research efforts therefore are separate but collaborative.

As *MECP2* Duplication Syndrome has a much lower incidence than Rett, there are less affected families and ergo less families fundraising. Reverse Rett supports the efforts of *MECP2* Duplication families by delivering 100% of funds raised to Duplication projects with no overhead.

- (iv) Roald Dahl-Reverse Rett are grateful to have previously been the recipient of a grant from the Roald Dahl's Marvellous Children's Charity in support of our Parent 2 Parent project. This grant period has now ended and so Roald Dahl can be removed as an income source under this heading.

**Costs of raising funds explained (as detailed in the accounts p.22)**

- (i) Staff costs £34,091-this is the net pay for fundraising support staff, 1.5 FTE.  
(ii) Fundraiser's fees £10,668-These are costs for generating voluntary income; design, marketing and printing of fundraising materials, mailchimp fees, plus costs for Running for Change 5K and Virtual Run.  
(iii) Event costs £8308 -These are costs for individuals participating in events, t-shirts, posters and event entry fees.

**Analysis of expenditure on charitable activities (as detailed in the accounts p.23)**

- (i) Staff costs £36,903 -this is the net pay for Executive Director of Reverse Rett.  
(ii) Transfer to Rett Syndrome Research Trust USA £585,728 -these are funds which are delivered to the international research program at RSRT. These funds are held in a dedicated US bank account and are subsequently distributed each quarter to the appropriate research projects each quarter.  
(iii) Travel and accommodation £12,848-These are travel costs for Reverse Rett staff, primarily the Executive Director, traveling to 2 RSRT US Trustee Board meetings in 2016, as well as regular travel to meetings, workshops and focus groups in London re developing UK clinical capacity. Other travel and accommodation costs are for Reverse Rett staff supporting nationwide fundraising events.  
(iv) Brand redevelopment £0-No brand redevelopment in 2016.  
(v) King's College grant £43,710-These are funds delivered to King's College London for one FT post-doc researcher for continued work on the TRIAL Project at the Centre for Interventional Paediatric Psychopharmacology and Rare Diseases (CIPPRD) led by Dr Paramala Santosh.  
(vi) Governance costs £6000-These are audit fees and associated accountancy costs.  
(vii) Support costs £80,908-These are remaining staff costs, associated HMRC costs, book-keeping costs and office rental fees.

**Volunteers**

The Trustees of Reverse Rett would like to acknowledge the significant contribution of our volunteers and the in kind contributions of professional individuals and companies who support the organisation.

Key elements of the work of Reverse Rett are implemented or supported by volunteers. These include the design and hosting of our website, marketing segmentation, event production, Professional Advisory Board and more.

Events such as the 7<sup>th</sup> Annual London Gala event and the Running for Change 5K would not have been possible without volunteer support. Volunteers at the London Gala are critical to the smooth running of the event. Each year they are involved in event set up, fundraising, auction support, payment processing and more.

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In this year's Running for Change 5K, 18 volunteer stewards were needed to ensure the health and safety of 288 participants and their families and 7 volunteers helped to run stalls raising money on the day.

Special thanks to Symphony Online, The Greatrex Group, Talbot Productions, DT Impact, David Ford, Kate Quigley, Archerfield Walled Garden, our Ambassadors and everyone who has given freely of their time and resources to benefit the work of Reverse Rett.

### **Achievements and performance**

The charity's main activities and who it tries to help are described below. All its charitable activities focus on accelerating treatments and cures for Rett Syndrome and are undertaken to further Reverse Rett's charitable purposes for the public benefit.

Reverse Rett was launched in July 2010, by a small group of parents who wanted to impact the speed at which treatments and cures could be delivered for people living with Rett Syndrome today. These goals remain the same in 2017. Here are the main achievements of the charity to date:

#### **Organisational Achievements**

2011

- ✓ Winners of 'Best New Charity' at the Charity Times Awards

2012

- ✓ Reverse Rett passes first million dollar mark, delivering over \$1m to Rett Syndrome research mid year.
- ✓ Winners of 'Best New Charity' at the Just Giving Awards

2013

- ✓ Reverse Rett initiates a UK Patient Registry for UK patients with Rett Syndrome to ensure readiness for UK clinical trials
- ✓ Reverse Rett Co-Founder and CEO joins the Board of Trustees of the Rett Syndrome Research Trust

2014

- ✓ Reverse Rett provides seed funding to Dr Paramala Santosh for clinical research focused on developing the TRIAL database and wearable technology for patients with Rett Syndrome based at King's College London

2015

- ✓ The first family focus groups are held to inform KCL work on the TRIAL database.
- ✓ Reverse Rett passes \$5 million dollar mark

2016

- ✓ Reverse Rett facilitates the implementation of the first UK clinical trial for an emerging treatment for Rett Syndrome, committing funding for a FT Clinical Trials Coordinator based at King's College London
- ✓ Reverse Rett CEO gives evidence at Ethics Committee hearing for first UK clinical trial for an emerging treatment for Rett Syndrome
- ✓

2017

- ✓ The first UK clinical trial is launched in Q1 under the leadership of Dr Paramala Santosh at King's College Hospital, London
- ✓ Reverse Rett providing logistical support to trial site via pre-screening and referral for trial and supporting retention through arranging travel and accommodation for participating families

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**Scientific developments**

Through our commitment to the international research program at RSRT, Reverse Rett has financially contributed to work leading to the following scientific developments.

**Basic scientific discoveries**

Discovery that the Rett protein MeCP2 is required throughout life to maintain healthy brain function. (Adrian Bird, Huda Zoghbi)

Discovery that the genes disrupted in Rett are much longer (over 100 nucleotide bases) than the average length of <https://www.ncbi.nlm.nih.gov/pubmed/25762136> a gene (20 nucleotide bases) Labs are now testing drugs that downregulate long genes. (Michael Greenberg via MECP2 Consortium)  
Identification of a critical novel domain on the Rett protein (NCoR/ SMRT interaction domain) that could have therapeutic implications for Rett and MECP2 Duplication Syndrome. (Adrian Bird via MECP2 Consortium)

**Translational discoveries-Could lead to new cures and therapies**

Dramatic symptom reversal in mice using Gene Therapy treatment. (Gail Mandel and Adrian Bird)

Discovery that MECP2 Duplication Syndrome is reversible.

Supporting the establishment of two novel areas of Rett research:

- 1) Activating the silent MECP2 gene.
- 2) Modifier genes.

Contributing to three clinical trials (Ketamine, Copaxone and Statin)

**Enabling technology**

Financially supporting the RSRT Gene Therapy Consortium to advance gene therapy treatment to clinical trials asap.

**Financial review**

At the beginning of 2016, we were aware that income for the year was likely to be less than the income for 2015.

This is because we knew that two major annual donations were going to be reduced by £65,000 and one of two major events usually bringing in approx. £100,000 would not occur. A number of smaller, yet lucrative annual events also did not happen.

Despite these shortfalls, Reverse Rett went on to have a fairly successful fundraising year. Although annual income decreased by £152,420 overall, Reverse Rett Community Fundraising showed growth for the fourth consecutive year with online donation income up by approximately £40,000 on 2015.

Income from charitable events has gone down overall but income from the London event has increased by 50% on 2015. The shortfall in events overall is due to the loss of the Cure for Dylan event and no regional gala events being held in 2016.

The organisation's running costs increased slightly, largely due to the employment of an admin assistant, one PT fundraising coordinator moving from PT to FT hours, mandatory pension contributions and the provision of a childcare voucher scheme for staff.

Fundraising costs decreased by £12,000, despite the fact that in 2016, we held two new charity wide events.

Post Brexit, with the reduced value of sterling, our money buys less dollars and therefore less research. This Board will need to give due consideration to different ways we can continue to support the International Research Program at RSRT whilst ensuring that we maximize the value of the funds we raise.



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In conclusion, although we have raised less money in 2016 than in 2015, Community Fundraising and associated communications (including adaptations to online giving facilities) has made up for a reasonably large proportion of the loss in income. It will be important to continue to invest in Community Fundraising as this a strong and consistent area of growth for Reverse Rett.

**Reserves policy**

Reverse Rett is a parent-driven, patient organisation. Our children are waiting for treatments and cures for this condition. Due to the brutal nature of Rett, they need to be able to access these treatments and cures as quickly as possible.

That's why Reverse Rett deliberately holds no endowment or excessive reserves, instead seeking to deploy funds raised as quickly and wisely as possible.

Donor contributions/funds raised are typically deployed to research projects within three months or less.

The organisation holds six months of running costs in reserves, which equates to approximately £70,000.

**Structure, governance and management**

Reverse Rett is a company limited by guarantee, company number 07278507 incorporated on 9<sup>th</sup> June 2010. The company was established under a memorandum of association which established the objects and powers of the charitable company and is governed under its articles of association.

Members of the charity guarantee to contribute an amount not exceeding £1 to the assets of the charity in the event of winding up. The total number of such guarantees at 31 December 2016 was 8. The trustees are members of the charity but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

Two of the Charity's Founding Trustees are now employees of the Charity and thus receive a salary for their work.

All remaining trustees give their time voluntarily and receive no benefits from the charity. Any expenses reclaimed from the charity by these Trustees are set out in note 10 to the accounts.

Reverse Rett is a charity registered in England and Wales, charity number 1136809 and a charity registered in Scotland, charity number SC046735.

The management of the company is the responsibility of the Trustees who are elected and co-opted under the terms of the Articles of Association.

The Trustees of the Charity who served during the year ended December 31<sup>st</sup> 2016 are shown on p1.

The first Trustees are those persons notified to Companies House as the first Directors of the Charity. The Charity may by ordinary resolution, appoint a person who is willing to act as a Director and determine the length of rotation in which any additional directors are to retire.

Rachael Stevenson, Monica Coenraads and Andrew Stevenson were involved in the founding of the Charity and remain Trustees to date.

The Trustees meet in person, once annually and by telephone on a quarterly and as needed basis.

The Reverse Rett Conflict of Interest Policy is signed annually by all Trustees.

All current Board members of Reverse Rett are parents or grandparents of an individual with Rett Syndrome.

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for the year ended 31 December 2016

**Remuneration policy for key management personnel**

Two of the charity's Trustees are FT employees of the organisation and thus receive a salary for their work.

As Founding Trustees of the organisation, Rachael Stevenson and Andrew Stevenson are recused from any Board meetings to discuss the details of their employment at Reverse Rett. Adjustments in remuneration for both parties are decided by the Board of Trustees.

Employment of Directors of the Charity is permitted by Article 6.4.2 of the Memorandum and Articles of Association of the Charity which provides that Directors of the Charity may be employed providing that the majority of Directors do not benefit in this way.

The Board of Trustees of Reverse Rett would like to thank the following companies, community groups, trusts and individuals who generously supported our work in 2016:

Archerfield Estate  
B1 Edinburgh  
Crear Hotels Trist  
Cure for Dylan  
David Starbuck  
Cure Rett  
David Ford Milk and Cookies Gig 2015  
Enterprise Rent-A-Car  
Find a cure for Frankie  
Friends for Fundraising, Thurso  
Gam UK  
Harry Nash  
Hope for Eliza  
Hope for Harriet  
John and Maureen Sharpe  
Knightswood Football Club  
Nicholas White & Ortensia Martinotti  
Prism the Gift- Bianca & Stuart Roden  
Reverse Festival, Cotgrave  
Reykjavik Marathon c/o Guðrún's Research Trust, Iceland  
Rhea Kara and Family  
Royal Albert Lodge  
Sandhurst Town Hall

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Shepperd and Wedderburn

Simon Cowell

SkyBet Auctions

Louis Tomlinson

Steve Truby

The Childwick Trust

WR Millar

We would also like to take this opportunity to acknowledge the significant contribution of individuals and community groups who have given to Reverse Rett via online giving facilities such as Just Giving and the Big Give Christmas Challenge in 2016.

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for the year ended 31 December 2016

**Statement of responsibilities of the trustees**

The trustees (who are also directors of Reverse Rett for the purposes of company law) 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).

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

- Select suitable accounting policies and then apply them consistently
- Observe the methods and principles in the Charities SORP
- Make judgements and estimates that are reasonable and prudent
- State whether applicable UK Accounting Standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements
- 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 proper accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the trustees are aware:

- There is no relevant audit information of which the charitable company's auditors are unaware
- The trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information

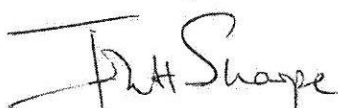
The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

**Auditors**

Slade & Cooper Ltd were appointed as the charitable company's auditors during the year and have expressed their willingness to continue in that capacity.

This report has been prepared in accordance with the provisions applicable to companies subject to the small companies' regime of the Companies Act 2006.

The trustees' annual report has been approved by the trustees on 14<sup>th</sup> August 2017 and signed on their behalf by



John Sharpe  
Chair



## Independent auditors' report

to the members of

Reverse Rett

We have audited the financial statements of Reverse Rett for the year ended 31 December 2016, which comprise the Statement of Financial Activities (including the income and expenditure account), the Balance Sheet, the Statement of Cash Flows and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (Financial Reporting Standard 102) (United Kingdom Generally Accepted Accounting Practice applicable to Smaller Entities).

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members 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 charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

### **Respective responsibilities of trustees and auditors**

As explained more fully in the Trustees' Responsibilities Statement set out on page 10, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view.

We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with regulations under those Acts.

Our responsibility is to audit and express an opinion on 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**

A description of the scope of an audit of financial statements is provided on the FRC's website at [www.frc.org.uk/apb/scope/private.cfm](http://www.frc.org.uk/apb/scope/private.cfm).

### **Opinion on financial statements**

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2016, and of its incoming resources and application of resources, including its income and expenditure, 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 Companies Act 2006.

### **Opinion on other matter prescribed by the Companies Act 2006**

In our opinion the information given in the Trustees' Annual Report for the financial year for which the financial statements are prepared is consistent with the financial statements.

*(continued)*

**Independent Auditor's Report  
(continued)**

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

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

- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies exemption in preparing the Trustees' Annual Report and take advantage of the small companies exemption from the requirement to prepare a strategic report.



Chinwe Jennifer Daniel FCCA DChA

Senior Statutory Auditor

*for and on behalf of*

Slade & Cooper Limited  
Statutory Auditors  
Green Fish Resource Centre  
46-50 Oldham Street  
Manchester  
M4 1LE

Date: 01/09/2017

Reverse Rett  
Statement of Financial Activities  
(including Income and Expenditure account)  
for the year ended 31 December 2016

	Note	Unrestricted funds £	Restricted funds £	Total funds 2016 £	Total funds 2015 £
<b>Income from:</b>					
Donations and legacies	3	557,083	3,959	561,042	764,410
Charitable activities: Optional subheading	4	185,319	49,073	234,392	191,499
<b>Total income</b>		<b>742,402</b>	<b>53,032</b>	<b>795,434</b>	<b>955,909</b>
<b>Expenditure on:</b>					
Raising funds	5	53,067	-	53,067	79,534
Charitable activities: Optional subheading	6	676,248	89,849	766,097	833,959
<b>Total expenditure</b>		<b>729,315</b>	<b>89,849</b>	<b>819,164</b>	<b>913,493</b>
<b>Net income/(expenditure) before net gains/(losses) on investments</b>		13,087	(36,817)	(23,730)	42,416
Realised gains/(losses) on investments		-	-	-	-
Unrealised gains/(losses) on investments		-	-	-	-
<b>Net income/(expenditure) for the year</b>	8	<b>13,087</b>	<b>(36,817)</b>	<b>(23,730)</b>	<b>42,416</b>
Transfer between funds		(22,610)	22,610	-	-
<b>Net movement in funds for the year</b>		<b>(9,523)</b>	<b>(14,207)</b>	<b>(23,730)</b>	<b>42,416</b>
<b>Reconciliation of funds</b>					
Total funds brought forward		62,160	48,320	110,480	68,064
<b>Total funds carried forward</b>		<b>52,637</b>	<b>34,113</b>	<b>86,750</b>	<b>110,480</b>

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

Reverse Rett  
Company number 7278507  
Balance sheet as at 31 December 2016

	Note	2016		2015	
		£	£	£	£
<b>Fixed assets</b>					
Tangible assets	12		728		1,564
<b>Total fixed assets</b>			<b>728</b>		<b>1,564</b>
<b>Current assets</b>					
Debtors	13	11,412		955	
Cash at bank and in hand		85,509		121,364	
<b>Total current assets</b>		<b>96,921</b>		<b>122,319</b>	
<b>Liabilities</b>					
Creditors: amounts falling due in less than one year	14	(10,899)		(13,403)	
<b>Net assets</b>			<b>86,750</b>		<b>110,480</b>
<b>The funds of the charity:</b>					
Restricted income funds	15		34,113		48,320
Unrestricted income funds	16		52,637		62,160
<b>Total charity funds</b>			<b>86,750</b>		<b>110,480</b>

These accounts are prepared in accordance with the special provisions of part 15 of the Companies Act 2006 relating to small companies and constitute the annual accounts required by the Companies Act 2006 and are for circulation to members of the company.

The notes on pages 17 to 29 form part of these accounts.

Approved by the trustees on 14 / 08 /2017 and signed on their behalf by:

*Rachael Stevenson*

Rachael Stevenson (Trustee)

Reverse Rett  
Statement of Cash Flows  
for the year ending 31 December 2016

	Note	2016 £	2015 £
<b>Cash provided by/(used in) operating activities</b>	19	<b>(36,025)</b>	<b>50,736</b>
<i>Cash flows from investing activities:</i>			
Purchase of tangible fixed assets		-	(1,276)
<b>Cash provided by/(used in) investing activities</b>		<b>-</b>	<b>(1,276)</b>
Increase/(decrease) in cash and cash equivalents in the year		(36,025)	49,460
Cash and cash equivalents at the beginning of the year		121,364	71,904
<b>Cash and cash equivalents at the end of the year</b>		<b>85,339</b>	<b>121,364</b>

## Reverse Rett

### Notes to the accounts for the year ended 31 December 2016

#### **1 Accounting policies**

The principal accounting policies adopted, judgments and key sources of estimation uncertainty in the preparation of the financial statements are as follows:

##### **a Basis of preparation**

The financial statements have been prepared in accordance with 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) issued on 16 July 2014 (as updated through Update Bulletin 1 published on 2 February 2016) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

Reverse Rett meets the definition of a public benefit entity under FRS102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note.

##### **b Reconciliation with previous Generally Accepted Accounting Practice**

In preparing the accounts, the trustees have considered whether in applying the accounting policies required by FRS 102 and the Charities SORP FRS 102 the restatement of comparative items was required. No Restatements were required.

##### **c Preparation of the accounts on a going concern basis**

The trustees consider that there are no material uncertainties about the charitable company's ability to continue as a going concern.

The trustees have made no key judgments which have a significant effect on the accounts.

The trustees do not consider that there are any sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amount of assets and liabilities within the next reporting period.

Notes to the accounts for the year ended 31 December 2016 (continued)

**d Income**

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and the amount can be measured reliably.

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

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the charity that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

Income received in advance of a provision of a specified service is deferred until the criteria for income recognition are met.

**e Donated services and facilities**

Donated professional services and donated facilities are recognised as income when the charity has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use by the charity of the item is probable and that economic benefit can be measured reliably. In accordance with the Charities SORP (FRS 102), general volunteer time is not recognised; refer to the trustees' annual report for more information about their contribution.

On receipt, donated professional services and donated facilities are recognised on the basis of the value of the gift to the charity which is the amount the charity would have been willing to pay to obtain services or facilities of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

**f Interest receivable**

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the Bank.

Notes to the accounts for the year ended 31 December 2016 (continued)

**g Fund accounting**

Unrestricted funds are available to spend on activities that further any of the purposes of charity.

Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose.

Restricted funds are donations which the donor has specified are to be solely used for particular areas of the charity's work or for specific projects being undertaken by the charity.

**h Expenditure and irrecoverable VAT**

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

**i Allocation of support costs**

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Support costs include back office costs, finance, personnel, payroll and governance costs which support the charity's programmes and activities.

**j Operating leases**

Operating leases are leases in which the title to the assets, and the risks and rewards of ownership, remain with the lessor. Rental charges are charged on a straight line basis over the term of the lease.

**k Tangible fixed assets**

Individual fixed assets costing £1,000 or more are capitalised at cost and are depreciated over their estimated useful economic lives on a straight line basis as follows:

Office equipment	25%
Computer equipment	25%



Notes to the accounts for the year ended 31 December 2016 (continued)

**l Debtors**

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

**m Cash at bank and in hand**

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

**n Creditors and provisions**

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

**o Financial instruments**

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

## Reverse Rett

Notes to the accounts for the year ended 31 December 2016 (continued)

### p Pensions

Employees of the charity are entitled to join a defined contribution 'money purchase' scheme. The charity's contribution is restricted to the contributions disclosed in note 9. There were no outstanding contributions at the year end.

### 2 Legal status of the charity

The charity is a company limited by guarantee registered in England and Wales and has no share capital. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity. The registered office address is disclosed on page 1.

### 3 Income from donations and legacies

	Unrestricted £	Restricted £	Total 2016 £	Total 2015 £
Donations	537,083	3,959	541,042	751,410
Grants	20,000	-	20,000	13,000
<b>Total</b>	<b>557,083</b>	<b>3,959</b>	<b>561,042</b>	<b>764,410</b>
<i>Total by fund 31 December 2015</i>	<i>710,810</i>	<i>53,600</i>	<i>764,410</i>	

Reverse Rett

Notes to the accounts for the year ended 31 December 2016 (continued)

**4 Income from charitable activities**

	Unrestricted £	Restricted £	Total 2016 £	Total 2015 £
The Big Give	122,761	-	122,761	117,492
London Event	62,558	-	62,558	64,001
MECP2 Fund	-	49,073	49,073	5,381
Roald Dahl	-	-	-	4,625
<b>Total</b>	<b>185,319</b>	<b>49,073</b>	<b>234,392</b>	<b>191,499</b>
<i>Total by fund 31 December 2015</i>	<i>181,493</i>	<i>10,006</i>	<i>191,499</i>	

**5 Cost of raising funds**

	2016 £	2015 £
Staff costs	34,091	79,534
Fundraiser's fees	10,668	-
Event costs	8,308	-
	<b>53,067</b>	<b>79,534</b>

All expenditure on cost of raising funds is unrestricted.

## Reverse Rett

Notes to the accounts for the year ended 31 December 2016 (continued)

### 6 Analysis of expenditure on charitable activities

	Unrestricted £	Restricted £	Total 2016 £	Total 2015 £
Staff costs	36,903	-	36,903	25,236
Transfer to Rett Syndrome Research Trust USA	539,589	46,139	585,728	694,141
Travel and accomodation	12,848	-	12,848	9,497
Brand redevelopment	-	-	-	582
Kings College Grant	-	43,710	43,710	22,500
Governance costs (see note 7)	6,000	-	6,000	22,060
Support costs (see note 7)	80,908	-	80,908	59,943
	<u>676,248</u>	<u>89,849</u>	<u>766,097</u>	<u>833,959</u>
			2016 £	2015 £
Restricted expenditure			89,849	32,781
Unrestricted expenditure			676,248	801,178
			<u>766,097</u>	<u>833,959</u>

### 7 Analysis of governance and support costs

	Support £	Governance £	Total 2016 £
Office rental cost	9,223	-	9,223
Staff costs	52,135	-	52,135
Office costs	14,278	-	14,278
Audit fees	-	3,780	3,780
Accountancy services	3,975	2,220	6,195
Legal and professional	1,297	-	1,297
	<u>80,908</u>	<u>6,000</u>	<u>86,908</u>

## Reverse Rett

Notes to the accounts for the year ended 31 December 2016 (continued)

### 8 Net income/(expenditure) for the year

This is stated after charging/(crediting):	2016 £	2015 £
Depreciation	666	522
Operating lease rentals:		
Property	-	-
Other	918	1,074
Auditor's remuneration - audit fees	3,780	3,600
Auditor's remuneration - accountancy fees	2,220	2,000
	123,130	158,230

### 9 Staff costs

Staff costs during the year were as follows:

	2016 £	2015 £
Wages and salaries	112,553	150,564
Social security costs	8,089	7,666
Pension costs	2,488	-
	123,130	158,230
<b>Allocated as follows:</b>		
Cost of raising funds	34,091	79,534
Charitable activities	36,903	25,236
Support costs	52,135	40,221
Governance costs	-	13,239
	123,129	158,230

No employees has employee benefits in excess of £60,000 (2015: Nil).

The average number of staff employed during the period was 4 (2015: 5).

The key management personnel of the charity comprise the trustees and the Chief Executive Officer. The total employee benefits of the key management personnel of the charity were £43,512 (2015: £43,512).

## Reverse Rett

Notes to the accounts for the year ended 31 December 2016 (continued)

### 10 Trustee remuneration and expenses, and related party transactions

During the year two trustees who are employed by the charity received remuneration totalling £70,596 (2015: £71,250).

No trustee received travel and subsistence expenses during the year (2015:£184).

Aggregate donations from related parties were £43,450 (2015: £85,400).

There are no donations from related parties which are outside the normal course of business and no restricted donations from related parties.

The Chief Executive and a director of Reverse Rett, Rachael Stevenson is on the Board of Rett Syndrome Research Trust USA. Reverse Rett made a charitable grant of £585,728 to Rett Syndrome USA in support of the aims of both charities (2015: £676,231).

No trustee or other person related to the charity had any personal interest in any contract or transaction entered into by the charity, including guarantees, during the year (2015: nil).

### 11 Corporation tax

The charity is exempt from tax on income and gains falling within Chapter 3 of Part 11 of the Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects. No tax charges have arisen in the charity.

### 12 Fixed assets: tangible assets

<b>Cost</b>	Office equipment £	Computer equipment £	Total £
At 1 January 2016	227	2,129	2,356
Additions	-	-	-
Disposals	(227)	-	(227)
	<hr/>	<hr/>	<hr/>
At 31 December	-	2,129	2,129
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>
<b>Depreciation</b>			
At 1 January 2016	57	735	792
Charge for the year	-	666	666
Disposals	(57)	-	(57)
	<hr/>	<hr/>	<hr/>
At 31 December	-	1,401	1,401
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>
<b>Net book value</b>			
At 31 December	-	728	728
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>
<i>At 31 December</i>	<i>170</i>	<i>1,394</i>	<i>1,564</i>
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

Reverse Rett

Notes to the accounts for the year ended 31 December 2016 (continued)

**13 Debtors**

	2016 £	2015 £
Other debtors	750	750
Prepayments and accrued income	210	205
Gift aid debtor	10,452	-
	<hr/>	<hr/>
	11,412	955
	<hr/> <hr/>	<hr/> <hr/>

**14 Creditors: amounts falling due within one year**

	2016 £	2015 £
Trade creditors	495	4,126
Short term compensated absences (holiday pay)	-	-
Other creditors and accruals	6,860	6,492
Deferred income	-	-
Taxation and social security costs	3,544	2,785
	<hr/>	<hr/>
	10,899	13,403
	<hr/> <hr/>	<hr/> <hr/>

## Reverse Rett

Notes to the accounts for the year ended 31 December 2016 (continued)

### 15 Analysis of movements in restricted funds

	Balance at 1 January 2016 £	Income £	Expenditure £	Transfers £	31 December 2016 £
Gene Therapy Consortium <i>MECP2</i>	13,825	726	-	-	14,551
Duplication Fund	-	49,073	(46,139)	-	2,934
Rett disorder	-	3,233	-	-	3,233
Use in Farringdon	200	-	-	-	200
Parent 2 Parent	13,195	-	-	-	13,195
Clinical Research Funds	21,100	-	(43,710)	22,610	-
<b>Total</b>	<b>48,320</b>	<b>53,032</b>	<b>(89,849)</b>	<b>22,610</b>	<b>34,113</b>

**Name of restricted fund**

**Description, nature and purposes of the fund**

Gene Therapy Workshop fund	<p>The Gene Therapy Workshop Fund was comprised of a donation of £10,000 which came to Reverse Rett, whereby the donors, The Jomati Foundation, requested that funds be spent only on the development of research projects in the UK and Europe. At the time there were no relevant research projects in need of funding within the UK.</p> <p>These funds were deployed with regards to network events with UK based researchers and scientist via Reverse Rett sponsorship of the British Society of Gene and Cell Therapy Conference and the Rett Syndrome Europe European Convention in Maastricht in 2013. Remaining funds should now be allocated to the Gene Therapy Consortium, specifically to the Gene Therapy program at the Cobb Lab at the University of Glasgow.</p>
Parent 2 Parent	<p>Reverse Rett Parent 2 Parent offers grants parent to parent support as a resource to families of newly diagnosed or struggling children with Rett Syndrome and related <i>MECP2</i> disorders. Through a one to one 'match', experienced parents provide emotional support to families and assist them in finding information and resources.</p> <p>Through the project, Reverse Rett provides on-going training and support for mentors and materials for both mentor and mentee. Communication between both parties is facilitated by Reverse Rett in the first six weeks of contact and thereafter as required.</p> <p>Please find more information here: <a href="http://www.reverserett.org.uk/get-involved/get-connected/">http://www.reverserett.org.uk/get-involved/get-connected/</a></p>
Clinical Research Fund	<p>This is a designated fund which will support UK based clinical research and the implementation of treatment for Rett Syndrome and related <i>MECP2</i> Disorders in the UK.</p>
<i>MECP2</i>	<p>The <i>MECP2</i> Duplication Fund at Reverse Rett is a restricted fund. The fund exclusively supports projects devoted to the study and means of treatment of <i>MECP2</i> Duplication/Triplication Syndrome. 100% of funds raised and contributed to Reverse Rett by families of children with <i>MECP2</i> Duplication Syndrome and their supports in the UK are committed to <i>MECP2</i> Duplication projects via RSRT US.</p>



## Reverse Rett

Notes to the accounts for the year ended 31 December 2016 (continued)

### 16 Analysis of movement in unrestricted funds

	Balance at 1 January 2016 £	Income £	Expenditure £	Transfers £	As at 31 December 2016 £
General fund	62,160	742,402	(751,925)	-	52,637
	<u>62,160</u>	<u>742,402</u>	<u>(751,925)</u>	<u>-</u>	<u>52,637</u>

Name of unrestricted fund	Description, nature and purposes of the fund
General fund	The free reserves after allowing for all designated funds

### 17 Analysis of net assets between funds

	General fund £	Designated funds £	Restricted funds £	Total £
Tangible fixed assets	728	-	-	728
Net current assets/(liabilities)	51,909	-	34,113	86,022
	<u>52,637</u>	<u>-</u>	<u>34,113</u>	<u>86,750</u>

## Notes to the accounts for the year ended 31 December 2016 (continued)

**18 Operating lease commitments**

The charity's total future minimum lease payments under non-cancellable operating leases is as

	Equipment	
	2016	2015
	£	£
Less than one year	918	918
One to five years	2,753	3,671
Over five years	-	-
	<u>3,671</u>	<u>4,589</u>

**19 Reconciliation of net movement in funds to net cash flow from operating activities**

	2016	2015
	£	£
<b>Net income/(expenditure) for the year</b>	(23,730)	42,416
<b>Adjustments for:</b>		
Depreciation charge	666	522
Decrease/(increase) in debtors	(10,457)	(205)
Increase/(decrease) in creditors	(2,504)	8,003
	<u>(36,025)</u>	<u>50,736</u>