

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 2018

## Reverse Rett

### Reference and administrative information

for the year ended 31<sup>st</sup> December 2018

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\*

Ortensia Martinotti

Neil Fowler -resigned 17<sup>th</sup> February 2018

Catherine McKinney -appointed 2<sup>nd</sup> March 2018

Kate McMaster -appointed 26<sup>th</sup> April 2018

Rita Ross -appointed 19<sup>th</sup> November 2018

\*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<sup>st</sup> December 2018

The trustees present their report and the audited financial statements for the year ended 31 December 2018. 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 deliver 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.

Estimated to affect 1:10,000 live female births, the disorder is rarely seen in males. Most people with Rett Syndrome are unable to speak, walk or use their hands. Breathing problems, feeding tubes, seizures, anxiety, gastrointestinal and orthopaedic issues are common.

Research has shown that people with Rett do not have brain damage. They know and understand much more than their bodies allow them to show – but they are locked in, trapped by a body that cannot obey signals from their brain.

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.

Rett Syndrome is most often caused by mutations on a gene called MECP2 on the X chromosome. The gene makes a protein which everyone needs for their brains to function properly, but people with Rett Syndrome do not have enough of this protein.

In 2007, researchers at Edinburgh University proved that a cure for Rett Syndrome is possible. Their experiments showed that when the protein is replaced at the right level, the symptoms of Rett Syndrome go away.

Gene therapy is one way that the protein can be replaced and human clinical trials are due to start in 2019.

Human clinical trials of treatments for specific symptoms and clusters of symptoms are already underway.

Since the inception of the charity, Reverse Rett has funded laboratory research focused on curing Rett Syndrome, research focused on accelerating treatments for symptoms, basic science working to better understand the underlying causes of the condition and clinical trials and research focused on bringing treatments and cures from bench to bedside.

### **Purposes and aims**

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

# Reverse Rett

## Trustees' annual report

For the year ended 31<sup>st</sup> December 2018

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.

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.

### **Volunteers**

Key elements of the work of Reverse Rett are implemented or supported by volunteers. In 2018, these included the design and hosting of our website, marketing segmentation, event production, Professional Advisory Board, Research Review Committee and more.

Events such as the 9th Annual London Gala event and the 3rd 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.

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

### **Achievements and Performance**

In 2018:

- Reverse Rett deployed a total of £567,288 to medical research projects including the international research program at RSRT, UK clinical research at King's College London and UK clinical trial facilitation.

# Reverse Rett

## Trustees' annual report

For the year ended 31<sup>st</sup> December 2018

- £216,804 was delivered to RSRT Rett Syndrome projects at the Universities of Glasgow and Edinburgh and £52,816 to MECP2 Duplication projects in the USA.
- A human trial of gene therapy for Rett (AVXS-201), was announced by AveXis, a Novartis company and projected to begin in 2019. This work has been developed as a direct result of the work of the Gene Therapy Consortium at RSRT which has been financially supported by Reverse Rett since 2013.
- Reverse Rett continued to support the UK clinical trial of Sarizotan (a potential treatment for breathing irregularities in Rett Syndrome) at King's College Hospital in London.

This trial is on-going with further trials planned for the coming year. Support for the trial included funding for a Clinical Trials Co-ordinator at the trial site, recruitment and pre-screening support, organising travel and accommodation arrangements for participating families.

- Reverse Rett continued to provide low-level funding to Professor Santosh and team at the CIPPRD at the Maudsley Hospital for their work in developing new outcome measures and monitoring systems for patients with Rett via the TRIAL Project and in support of the current and emerging clinical trials for Rett Syndrome at King's College Hospital.
- Reverse Rett worked collaboratively as part of the UK Rett Disorders Alliance, with the UK Rett Disorders Working Group, to develop a Rett Syndrome Health Checklist which will be published online on June 25<sup>th</sup> 2019. This document can be shared with clinicians and families to provide some structure and advisement re how to manage the many symptoms of Rett Syndrome and most critically, emphasising how to avoid adverse events.
- Reverse Rett was granted full membership of the Association of Medical Research Charities (AMRC), a highly revered mark of credibility for UK medical research charities. Full members of AMRC are registered charities that fund health and medical research in the UK as one of their principal activities and meet very stringent membership criteria including the peer review process used in making research awards.

### **Financial Review**

Whilst 2018 was a positive year for Reverse Rett in terms of achievements and performance, it was a difficult financial year.

Total income in 2018 was £757,776 compared to the 2017 year-end income, £957,827. Average income for the three years preceding 2018 was £885,379.

Data from online giving activity through the Just Giving website shows that the number of donations made to Reverse Rett in 2018 was roughly the same as in 2017 but that the amounts donated were lower. It is possible that austerity and concerns over Brexit have caused people to donate less to charity.

In 2018, the Big Give Christmas Challenge (CC) once again arbitrarily reduced Reverse Rett's overall target to £80K, which has affected our overall income capacity for the Challenge.

# Reverse Rett

## Trustees' annual report

For the year ended 31<sup>st</sup> December 2018

(Reverse Rett started in 2010 with a CC target of £10K and increased every year until a high point of £140,000 raised in 2016.

The 9<sup>th</sup> Reverse Rett London Gala was very successful raising in excess of £100,000.

Income from family events has decreased steadily since 2015, with a number of families changing the focus of their event fundraising to fundraising for equipment, therapies, adaptations etc for their child.

A lower overall level of income at Reverse Rett in 2018 has meant a lower financial contribution to the international Rett Syndrome Research Program at RSRT.

At the end of 2018, the charity carried over a higher level of reserves than is typical at year end, due to projected higher-level UK research spend in 2019.

### **Reserves policy**

Reverse Rett is a parent-driven, patient organisation. Children and adults with Rett Syndrome are at the heart of everything we do. The nature of Rett Syndrome demands that they need to be able to access these treatments and cures as quickly as possible.

Funds raised and donated are typically deployed to research projects on a quarterly basis.

The organisation holds six months of running costs in reserves, which equates to approximately £85,000.

### **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 2018 was 7. 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. 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.

# Reverse Rett

## Trustees' annual report

For the year ended 31<sup>st</sup> December 2018

The Trustees of the Charity who served during the year ended December 31<sup>st</sup> 2018 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, Andrew Stevenson and Monica Coenraads 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.

### **Remuneration policy for key management personnel**

Two of the charity's Trustees are full-time 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 2018:**

Allied Office Furniture

All Saints Ben Hilton School

Archerfield Estate

Amazon Media

Kevin Arenson

Altrincham Market

The Baine Family

Jenny Barnett

Barclays Technology

Bruntwood 2000 Alpha Portfolio Ltd Charities aid Foundation

Bothwell Charitable Trust

# Reverse Rett

## Trustees' annual report

For the year ended 31<sup>st</sup> December 2018

BBC Studios

Big Give Christmas Challenge

Hazel Beiny

Church of God Shepherd

Cure Rett Brazil

Charities Trust

Childwick Trust

Cure for Dylan

Dorset Masonic Shooting Association

Dudley Council

Exeter Football Club

Friends of Holly

David Ford

GAM Investments

Nigel Gilbert

The Golden Pheasant, Biggleswade

Hoares Bank

Hope for Eliza

Just Giving

Barnaby Lashbrooke

Sam Lashbrooke

Murphy Newman Charity

MMSO Concert

NPT UK

Newron Pharmaceuticals SPA

OpéRett

Penkeths Limited

Paris Steele

Paypal

Pfizer

The Prebble Family



# Reverse Rett

## Trustees' annual report

For the year ended 31<sup>st</sup> December 2018

Rotary Club of Bramhall

Royal Albert Lodge

RS Macdonald Charitable Trust

John and Maureen Sharpe

Shawbrook Bank

Sylvia Aitken Trust

Trustees of Alison Kaye

David Thomson

The Vides Family

Virgin Money

Winstanley Michael

**The Board of Trustees would like to take this opportunity to acknowledge the significant contribution of individuals and community groups who have raised funds for Reverse Rett via online giving facilities such as Just Giving and the Big Give Christmas Challenge in 2018**

Tim Adams

Jen Benson

Matteo Berlucchi

Ken Burnside

Joanna Clare

Julia Dobbin

Lorna Dale

Laurance Dine

Katie and Oly Freeman

Michael Fowler

Chae Gordon

Colin Gordon

Simon Goodwin

John Goodwin

Jo Hill

Abigail Hall

Helene Hodgson

# Reverse Rett

## Trustees' annual report

For the year ended 31<sup>st</sup> December 2018

Beth and Vincent Johnsson

Martin Kwiatkowski

Nick Kelly

David Lashbrooke

Gunter Loffler

Chris Lowe

Jonathan Lowe

Nicola McGlinchey

Mary McCabe

Greg McKeague

Catherine and Ross McKinney

Kate McMaster

Jill Nightingale

Daniel Owen

Jonny and Kelly Paton

Kelly Phillips

Gill Prett

Jill Simpson

Andy Stevenson

Ben Stewart

Matthew Short

Dan Sawyers

Sophia Schindler

Debbie Strang

Gillian Tree

David Wainwright

Catherine Wilkinson

Andrew Walton

John Wright

# Reverse Rett

## Trustees' annual report

For the year ended 31<sup>st</sup> December 2018

### 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 30/07/2019 and signed on their behalf by

John Sharpe  
Chair

# Independent auditors' report to the members of

## Reverse Rett

For the year ended 31<sup>st</sup> December 2018

### **Opinion**

We have audited the financial statements of Reverse Rett (the 'charitable company') for the year ended 31 December 2018, 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, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

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.

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 2018, 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 requirements of the Companies Act 2006.

### **Basis for opinion**

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

### **Conclusions relating to going concern**

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

- the trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charitable company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

### **Other information**

# Independent auditors' report to the members of

## Reverse Rett

For the year ended 31<sup>st</sup> December 2018

The trustees are responsible for the other information. The other information comprises the information included in the trustees' annual report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. 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.

### **Opinions on other matters prescribed by the Companies Act 2006**

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the trustees' report (incorporating the directors' report) for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the trustees' report has been prepared in accordance with applicable legal requirements.

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

In the light of our knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' report.

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

- 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' exemptions in preparing the Trustees' Annual Report and from the requirement to prepare a strategic report.

### **Responsibilities of trustees**

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, 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.

# Independent auditors' report to the members of

## Reverse Rett

For the year ended 31<sup>st</sup> December 2018

In preparing the financial statements, the trustees are responsible for assessing the charitable company'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 charitable company or to cease operations, or have no realistic alternative but to do so.

### **Auditor's responsibilities for the audit of the financial statements**

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

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our auditor's 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: 28/08/2019

Reverse Rett  
Statement of Financial Activities  
(including Income and Expenditure account)  
for the year ended 31 December 2018

	Note	Unrestricted funds £	Restricted funds £	Total funds 2018 £	Total funds 2017 £
<b>Income from:</b>					
Donations and legacies	3	393,738	25,000	403,738	587,478
Charitable activities: Events income	4	198,643	140,395	339,038	370,349
<b>Total income</b>		<b>592,381</b>	<b>165,395</b>	<b>742,776</b>	<b>957,827</b>
<b>Expenditure on:</b>					
Raising funds	5	140,770	-	140,770	105,676
Charitable activities: Medical research cost	6	385,455	181,833	567,288	793,625
<b>Total expenditure</b>		<b>526,225</b>	<b>181,833</b>	<b>708,058</b>	<b>899,301</b>
<b>Net income/(expenditure) for the year</b>	8	<b>66,156</b>	<b>(16,438)</b>	<b>34,718</b>	<b>58,526</b>
Transfer between funds		(13,941)	13,941	-	-
<b>Net movement in funds for the year</b>		<b>52,215</b>	<b>(2,497)</b>	<b>34,718</b>	<b>58,526</b>
<b>Reconciliation of funds</b>					
Total funds brought forward		125,875	19,401	145,276	86,750
<b>Total funds carried forward</b>		<b>178,090</b>	<b>16,904</b>	<b>179,994</b>	<b>145,276</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 2018

	Note	2018		2017	
		£	£	£	£
<b>Fixed assets</b>					
Tangible assets	12		-		263
<b>Total fixed assets</b>			<b>-</b>		<b>263</b>
<b>Current assets</b>					
Debtors	13	23,661		23,835	
Cash at bank and in hand		223,364		131,516	
<b>Total current assets</b>		<b>247,025</b>		<b>155,351</b>	
<b>Liabilities</b>					
Creditors: amounts falling due in less than one year	14	(52,031)		(10,338)	
<b>Net assets</b>			<b>194,994</b>		<b>145,276</b>
<b>The funds of the charity:</b>					
Restricted income funds	15		16,904		19,401
Unrestricted income funds	16		178,090		125,875
<b>Total charity funds</b>			<b>194,994</b>		<b>145,276</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 32 form part of these accounts.

Approved by the trustees on 30/07/2019 and signed on their behalf by:

John Sharpe (Chair)



Reverse Rett  
Statement of Cash Flows  
for the year ending 31 December 2018

	Note	2018 £	2017 £
<b>Cash provided by/(used in) operating activities</b>	19	<b>76,848</b>	<b>46,007</b>
Increase/(decrease) in cash and cash equivalents in the year		76,848	46,007
Cash and cash equivalents at the beginning of the year		131,516	85,509
<b>Cash and cash equivalents at the end of the year</b>		<b>208,364</b>	<b>131,516</b>

# Reverse Rett

## Notes to the accounts for the year ended 31 December 2018

### **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 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.

## Reverse Rett

### Notes to the accounts for the year ended 31 December 2018 (continued)

#### **c 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.

#### **d 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.

#### **e 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.

## Reverse Rett

### Notes to the accounts for the year ended 31 December 2018 (continued)

#### **f 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.

#### **g 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.

#### **h 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.

#### **i 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.

#### **j 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%

## Reverse Rett

Notes to the accounts for the year ended 31 December 2018 (continued)

### **k 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.

### **l 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.

### **m 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.

### **n 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 2018 (continued)

### o 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 2018 £
Donations	393,738	-	393,738
Grants - The R S McDonalds Trust	-	10,000	10,000
Childwick Trust	-	15,000	15,000
<b>Total</b>	<b>393,738</b>	<b>25,000</b>	<b>403,738</b>

### Income from donations and legacies - previous year

	Unrestricted £	Restricted £	Total 2017 £
Donations	542,478	-	542,478
Grants	-	45,000	45,000
<b>Total</b>	<b>542,478</b>	<b>45,000</b>	<b>587,478</b>

## Reverse Rett

Notes to the accounts for the year ended 31 December 2018 (continued)

### 4 Income from charitable activities

	Unrestricted £	Restricted £	Total 2018 £
The Big Give	62,108	-	62,108
London Event	101,203	-	101,203
MECP2 Fund	-	52,563	52,563
Family events	32,365	-	32,365
Newron Pharmacy	-	80,000	80,000
Other income	2,967	7,832	10,799
	198,643	140,395	339,038
<b>Total</b>	<b>198,643</b>	<b>140,395</b>	<b>339,038</b>

### *Income from charitable activities - previous year*

	Unrestricted £	Restricted £	Total 2017 £
<i>The Big Give</i>	<i>100,397</i>	<i>-</i>	<i>100,397</i>
<i>London Event</i>	<i>96,402</i>	<i>-</i>	<i>96,402</i>
<i>MECP2 Fund</i>	<i>-</i>	<i>142,261</i>	<i>142,261</i>
<i>Family events</i>	<i>31,289</i>	<i>-</i>	<i>31,289</i>
	<i>228,088</i>	<i>142,261</i>	<i>370,349</i>
<b>Total</b>	<b>228,088</b>	<b>142,261</b>	<b>370,349</b>

### 5 Cost of raising funds

	2018 £	2017 £
Staff costs	65,250	38,751
Fundraiser's fees	13,355	9,646
Event costs	62,165	57,279
	140,770	105,676
	<b>140,770</b>	<b>105,676</b>

All expenditure on cost of raising funds is unrestricted.

## Reverse Rett

Notes to the accounts for the year ended 31 December 2018 (continued)

### 6 Analysis of expenditure on charitable activities

	Unrestricted £	Restricted £	Total 2018 £
Staff costs	43,400	-	43,400
Transfer to Rett Syndrome Research Trust USA	216,804	52,816	269,620
Travel and accommodation	13,854	-	13,854
Kings College Grant	-	49,404	49,404
Clinical trial expense	-	77,369	77,369
Rett disorders alliance	-	-	-
Parent 2 Parent programme	-	2,244	2,244
Governance costs (see note 7)	5,400	-	5,400
Support costs (see note 7)	105,997	-	105,997
	385,455	181,833	567,288
	385,455	181,833	567,288

### *Analysis of expenditure on charitable activities - previous year*

	<i>Unrestricted £</i>	<i>Restricted £</i>	<i>Total 2017 £</i>
<i>Staff costs</i>	<i>38,205</i>	<i>-</i>	<i>38,205</i>
<i>Transfer to Rett Syndrome Research Trust USA</i>	<i>377,490</i>	<i>166,812</i>	<i>544,302</i>
<i>Travel and accommodation</i>	<i>6,147</i>	<i>-</i>	<i>6,147</i>
<i>Kings College Grant</i>	<i>-</i>	<i>82,240</i>	<i>82,240</i>
<i>Clinical trial expense</i>	<i>31,036</i>	<i>-</i>	<i>31,036</i>
<i>Rett disorders alliance</i>	<i>-</i>	<i>161</i>	<i>161</i>
<i>Governance costs (see note 7)</i>	<i>5,520</i>	<i>-</i>	<i>5,520</i>
<i>Support costs (see note 7)</i>	<i>86,014</i>	<i>-</i>	<i>86,014</i>
	<i>544,412</i>	<i>249,213</i>	<i>793,625</i>
	<i>544,412</i>	<i>249,213</i>	<i>793,625</i>



## Reverse Rett

Notes to the accounts for the year ended 31 December 2018 (continued)

### 7 Analysis of governance and support costs

	Support £	Governance £	Total 2018 £
Office rental cost	9,336	-	9,336
Staff costs	56,564	-	56,564
Office costs	13,329	-	13,329
Audit fees	-	3,480	3,480
Accountancy services	4,674	1,920	6,594
Legal and professional	2,702	-	2,702
Advertising and marketing	19,392	-	19,392
	105,997	5,400	111,397
	105,997	5,400	111,397

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

	2018 £	2017 £
This is stated after charging/(crediting):		
Depreciation	263	465
Operating lease rentals:		
Property	7,572	5,048
Other	918	918
Auditor's remuneration - audit fees	3,480	3,600
Auditor's remuneration - accountancy fees	1,920	1,920
	105,997	111,397
	105,997	111,397

## Reverse Rett

Notes to the accounts for the year ended 31 December 2018 (continued)

### 9 Staff costs

Staff costs during the year were as follows:

	2018 £	2017 £
Wages and salaries	149,538	107,916
Social security costs	12,065	7,537
Pension costs	3,611	2,853
	<hr/>	<hr/>
	165,214	118,306
	<hr/> <hr/>	<hr/> <hr/>
<b>Allocated as follows:</b>		
Cost of raising funds	65,250	38,751
Charitable activities	43,400	38,205
Support costs	56,564	41,350
	<hr/>	<hr/>
	165,214	118,306
	<hr/> <hr/>	<hr/> <hr/>

No employees has employee benefits in excess of £60,000 (2017: Nil).

The average number of staff employed during the period was 6 (2017: 3.4).

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 £48,500 (2017: £47,361).

## Reverse Rett

Notes to the accounts for the year ended 31 December 2018 (continued)

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

During the year two trustees who are employed by the charity received remuneration totalling £84,000 (2017: £79,458).

One trustee received travel and subsistence expenses during the year of £94.90 (2017:£nil).

Aggregate donations from related parties were £29,000 (2017: £58,000).

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. Monica Coenraads who is also a director of Reverse Rett sits on the Board of Rett Syndrome Research Trust USA.

Reverse Rett made a charitable grant of £269,620 to Rett Syndrome USA in support of the aims of both charities (2017: £544,302).

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 (2017: 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.

## Reverse Rett

Notes to the accounts for the year ended 31 December 2018 (continued)

### 12 Fixed assets: tangible assets

<b>Cost</b>	Computer equipment £
At 1 January 2018	2,129
Additions	-
Disposals	-
	2,129
At 31 December	2,129
 <b>Depreciation</b>	
At 1 January 2018	1,866
Charge for the year	263
Disposals	-
	2,129
At 31 December	2,129
 <b>Net book value</b>	
At 31 December 2018	-
At 31 December 2017	263

## Reverse Rett

Notes to the accounts for the year ended 31 December 2018 (continued)

### 13 Debtors

	2018 £	2017 £
Other debtors	1,465	3,702
Prepayments and accrued income	7,196	3,196
Big Give debtor	15,000	16,937
	23,661	23,835
	23,661	23,835

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

	2018 £	2017 £
Trade creditors	33,029	1,897
Other creditors and accruals	6,138	5,980
Taxation and social security costs	12,864	2,461
	52,031	10,338
	52,031	10,338

## Reverse Rett

Notes to the accounts for the year ended 31 December 2018 (continued)

### 15 Analysis of movements in restricted funds

	Balance at 1 January 2018 £	Income £	Expenditure £	Transfers £	As at 31 December 2018 £
<i>MECP2</i>					
Duplication Fund	2,934	52,563	(52,817)	-	2,680
Rett disorder	3,072	-	-	-	3,072
Use in					
Farringdon	200	-	-	-	200
Parent 2 Parent	13,195	-	(2,243)	-	10,952
Clinical Research Funds	-	112,832	(126,773)	13,941	-
<b>Total</b>	<b>19,401</b>	<b>165,395</b>	<b>(181,833)</b>	<b>13,941</b>	<b>16,904</b>
<b><i>Previous reporting period</i></b>	<i>Balance at 1 January 2017 £</i>	<i>Income £</i>	<i>Expenditur e £</i>	<i>Transfers £</i>	<i>31 December 2017 £</i>
<i>Gene Therapy Consortium</i>	14,551	10,000	(24,551)	-	-
<i>MECP2</i>					
<i>Duplication Fund</i>	2,934	142,261	(142,261)	-	2,934
<i>Rett disorder</i>	3,233	-	(161)	-	3,072
<i>Use in</i>					
<i>Farringdon</i>	200	-	-	-	200
<i>Parent 2 Parent</i>	13,195	-	-	-	13,195
<i>Clinical Research Funds</i>	-	35,000	(82,240)	47,240	-
<b>Total</b>	<b>34,113</b>	<b>187,261</b>	<b>(249,213)</b>	<b>47,240</b>	<b>19,401</b>

## Reverse Rett

Notes to the accounts for the year ended 31 December 2018 (continued)

<b>Name of restricted fund</b>	<b>Description, nature and purposes of the fund</b>
	<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>
Gene Therapy Workshop fund	<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.</p> <p>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 RSPT US.</p>

## Reverse Rett

Notes to the accounts for the year ended 31 December 2018 (continued)

### 16 Analysis of movement in unrestricted funds

	Balance at 1 January 2018 £	Income £	Expenditure £	Transfers £	As at 31 December 2018 £
General fund	125,875	592,381	(526,225)	(13,941)	178,090
	<hr/> 125,875	<hr/> 592,381	<hr/> (526,225)	<hr/> (13,941)	<hr/> 178,090
	<hr/> <hr/> 125,875	<hr/> <hr/> 592,381	<hr/> <hr/> (526,225)	<hr/> <hr/> (13,941)	<hr/> <hr/> 178,090
<b><i>Previous reporting period</i></b>	<i>Balance at 1 January 2017 £</i>	<i>Income £</i>	<i>Expenditure £</i>	<i>Transfers £</i>	<i>As at 31 December 2017 £</i>
General fund	52,637	770,566	(697,328)	-	125,875
	<hr/> 52,637	<hr/> 770,566	<hr/> (697,328)	<hr/> -	<hr/> 125,875
	<hr/> <hr/> 52,637	<hr/> <hr/> 770,566	<hr/> <hr/> (697,328)	<hr/> <hr/> -	<hr/> <hr/> 125,875

**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	-	-	-	-
Net current assets/(liabilities)	178,090	-	16,904	194,994
	<hr/> 178,090	<hr/> -	<hr/> 16,904	<hr/> 194,994
Total	<hr/> <hr/> 178,090	<hr/> <hr/> -	<hr/> <hr/> 16,904	<hr/> <hr/> 194,994



## Reverse Rett

Notes to the accounts for the year ended 31 December 2018 (continued)

### 18 Operating lease commitments

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

	Property		Equipment	
	2018	2017	2018	2017
	£	£	£	£
Less than one year	7,572	7,572	918	918
One to five years	8,834	16,406	1,835	2,753
	16,406	23,978	2,753	3,671
	16,406	23,978	2,753	3,671

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

	2018	2017
	£	£
<b>Net income/(expenditure) for the year</b>	34,718	58,526
<b>Adjustments for:</b>		
Depreciation charge	263	465
Decrease/(increase) in debtors	174	(12,423)
Increase/(decrease) in creditors	41,693	(561)
	76,848	46,007
<b>Net cash provided by/(used in) operating</b>	76,848	46,007