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 2019

Reference and Administrative details

For the year ended 31st December 2019

Company number 07278507

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

Registered office and operational address: Statham Link Suite 1F

Lancastrian Office Centre

Talbot Road

Old Trafford

Manchester

M32 0FP

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

Catherine McKinney

Kate McMaster

Rita Ross

Neil Buckley

*Trustees who are also Directors of the charitable company.

The number of guarantee members is 10.

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

Trustees' annual report

For the year ended 31st December 2019

The trustees present their report and the audited financial statements for the year ended 31 December 2019. 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

Mission

Our mission is to speed treatments and a cure for Rett Syndrome and related *MECP2* disorders by funding research that will have a practical and positive effect on the lives of children and adults living with the conditions today.

We fund research from basic science to developing new clinical treatments and work to facilitate the translation of this work to clinical applications for people with Rett Syndrome and related *MECP2* disorders.

Objects as set out in the charity's governing document

Reverse Rett exists to relieve sickness and to preserve health for the public benefit by developing treatments and cures for Rett Syndrome and related *MECP2* disorders, in particular but not exclusively by:

- funding research projects;
- organising and sponsoring scientific workshops;
- collating information from experts in the field and providing access to it; and
- increasing general public awareness and knowledge of Rett Syndrome and related MECP2 disorders.

Main activities undertaken in relation to objects

- Funding laboratory research (Rett Syndrome and MECP2 Duplication) through longstanding partnership with the US based Rett Syndrome Research Trust (RSRT). This work is largely focused on treating the underlying causes of the disorder and bringing about transformational improvement in patients.
- Funding clinical research at King's College London/The Maudsley Hospital

Trustees' annual report

For the year ended 31st December 2019

This work is focused on improving the current health status of people with Rett Syndrome; Raising standards in prescription of drugs, building a set of comprehensive guidelines to reduce drug to drug interactions, individualising patient care using sensor-based monitoring and developing a deep understanding of patients with a view to drug repurposing for the treatment of Rett symptoms.

Funding the TRIAL Database

The TRIAL database is a comprehensive longitudinal study of disease progression in patients with Rett Syndrome and related disorders by King's College London Research Team. In combination with the clinical research described above, the goal is to marry the use of digital patient reported outcome measures and wearable technology to observe how patterns in physiology predict disease pathology in Rett Syndrome both on an individual and group level.

At this time, there are no FDA validated outcome measures for Rett which can be effectively used in clinical trials which is already hindering progress in vital studies of emerging medications for this patient population. This work is focused on developing new standard outcome measures for Rett.

- Managing the UK Rett Syndrome Patient Registry at Reverse Rett, critical to the
 implementation of UK clinical trials and our ability to demonstrate the on-going clinical need for
 treatments for the condition.
- Enabling UK Clinical Trials through patient identification, pre-screening, referral and retention support with practical logistical arrangements for patients and families re study visits.
- Collaboration via Rett Disorders Alliance UK; partnership with Rett UK and other UK
 Rett charities, to address areas of common interest which benefit the U.K. Rett
 community; including but not limited to, the UK Rett Disorders Working Group, Rett Syndrome
 Health Checklist, clinical trial communications to the community, improving U.K. clinical
 provision, Burden of Illness Study.

Public benefit

The trustees 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.

Trustees' annual report

For the year ended 31st December 2019

Activities and projects

1. International research funding via the Rett Syndrome Research Trust (USA)

We fund Rett Syndrome research at two labs at the University of Edinburgh and international MECP2 Duplication research through our longstanding partnership with the US based, <u>Rett Syndrome Research Trust (RSRT)</u>.

In 2019:

All funds delivered to RSRT Rett projects were delivered to the Cobb Lab at the University of Edinburgh, totalling £141,632. The Cobb lab are focused on treating the underlying cause of Rett

Syndrome by controlling the amount of *MECP2* delivered by gene therapies very precisely, using a range of cutting-edge technologies; from big data computer science to gene manipulation and design control mechanisms that allow healthy *MECP2* to be delivered to Rett patients without damaging side effects.

Funds delivered to RSRT MECP2 Duplication projects totalled £54,737

In July 2019:

Reverse Rett received a restricted grant of £9726 from the Mazars Charitable Trust for the purchase of specialised equipment related to *MECP2* Duplication drug screens at the at the Bird Lab, University of Edinburgh. These funds were submitted accordingly.

Total income into MECP2 Duplication Fund = £54,982

Total funds delivered to MECP2 Duplication projects = £64, 463

2. Clinical research expense £6029.50

Reverse Rett has full membership of the Association of Medical Research Charities (AMRC). AMRC membership requirements are for member organisations to conduct comprehensive and stringent peer review processes for projects under consideration for funding.

In 2019, Reverse Rett conducted a full external peer review of a proposal to fund the new Centre for Personalised Medicine (CPMRS) at King's College Hospital.

CPMRS is the first centre of its kind; a specialist Rett Syndrome clinical research Centre based in London. In Summer 2019, Reverse Rett committed to funding the CPMRS at a cost of £998,000 over three years.

£6029.50 in clinical research expense was allocated to fund an external cost analysis for the CPMRS, as recommended by the Research Review Committee. Additional costs were for accommodation for one Research Review Committee member attending national in person review meeting.

Trustees' annual report

For the year ended 31st December 2019

3. Centre for Personalised Medicine in Rett Syndrome (CPMRS) £12,789

CPMRS is the new Rett Syndrome clinical research Centre at King's College Hospital. In the summer of 2019, Reverse Rett committed to funding the CPMRS at a cost of £998,000 over three years.

£12,789 is the pro rata sum (2019) for the software license for the HealthTracker platform. The HealthTracker is an online digital platform, tailored for patients with Rett Syndrome through which families and caregivers are able to report the patient's symptoms on an ongoing basis.

Data are then analysed on an individual level, to check for changes in the presentation of symptoms in order to alert local clinical teams and on a group level, to assess patterns in presentation across the disease group or sub-groups, elucidating wider learning within the field.

4. Clinical trial expenses £40,073

In 2019 we provided on-going support for the UK clinical trial of Sarizotan, sponsored by Newron Pharmaceuticals. This trial was aimed at reducing respiratory irregularities in patients with Rett Syndrome. Reverse Rett provided identification, recruitment and retention services to support the trial. The expenses detailed on p 22 are the costs for patient travel, accommodation and meal allowances for study visits. These funds were provided to the charity in advance of the study visits and deployed and accounted for accordingly with reports sent back to the sponsor on a quarterly basis.

5. Rett Disorders Alliance £3211

In 2019, the Rett Disorders Alliance, in collaboration with the UK Rett Disorders Working Group, produced the Rett Syndrome Health Checklist; a comprehensive guide to the many symptoms of Rett Syndrome, potential treatment pathways and resources for families and clinicians.

Reverse Rett holds the fund for the Rett Disorders Alliance. In 2018, a grant of £5000 was received from the Bolland Charitable Trust by Reverse Rett and designated to the Rett Disorders Alliance fund.

These funds were used for the production and printing of the Health Checklist so that it could be distributed to families and clinicians across the UK as needed. Remaining funds will be utilised for the production of short videos communicating key safety issues highlighted within the Checklist.

6. Parent 2 Parent programme £3,845

Reverse Rett is a medical research charity and does not formally provide support services to families of patients with Rett Syndrome. The Parent 2 Parent Project was founded in 2012 with support from Roald Dahl's Marvellous Children's Charity, to facilitate connections between parent mentors and newly diagnosed families/those in need of additional support.

In 2019, in order to draw new mentors into the program, we held two 'Discovery Days' to enable like-minded families to come together to support and learn from each other. Both meetings were well attended with over 70 participants in London and Edinburgh respectively.

Trustees' annual report

For the year ended 31st December 2019

7. Governance costs £6,400

All charities registered in England and Wales with an income over £500,000 are mandated to have an annual independent audit. These governance costs represent the cost of our 2018 audit and related accountancy services.

8. Support costs (note 7, p 23) £130,966

In 2019, support costs included the above governance costs, office rental, general office costs including phone, internet, printing and postage and staff costs of £85,554.

Staff costs listed here are for CEO, Clinical Trial Lead, (0.5 FTE) Patient Registry Co-ordinator, Finance Officer and Office Administrator/Clinical Trial Co-ordinator.

Staff costs under fundraising costs include: Fundraising Manager (0.5 FTE), Events and Campaigns Co-ordinator, Regional Fundraiser (0.2 FTE)

Achievements and performance

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

The main achievements of the charity

Reverse Rett exists to bring treatments and a cure closer. We fund research and forge connections between scientists, doctors and those affected by Rett to make this goal a reality.

In 2007, with the successful reversal of Rett in the lab, families living with Rett Syndrome entered a new era for research in which we knew a cure was possible. We are now entering a final era, in which trials for treatments are beginning.

Reverse Rett has been instrumental in facilitating the delivery of UK clinical trials through our work in improving UK clinical provision for patients with Rett, the development of a UK Rett Syndrome Patient Registry, our recruitment, pre-screening and retention support for clinical trials and in 2019, the funding of the UK's first national clinical research centre for Rett Syndrome; the Centre for Personalised Medicine in Rett Syndrome based at King's College Hospital.

The CPMRS effectively manages the health of the UK's most complex patients with the disease, simultaneously generating vital learning about disease progression and management and disseminates this

information more broadly to assist in best practise management and promoting longevity of Rett patients both nationally and worldwide.

Below, you can see a timeline of key milestones that show progress in the field since the reversal experiments of 2007 and in the work of Reverse Rett which was launched in 2010.

Trustees' annual report

For the year ended 31st December 2019

Organisational Achievements

2010

✓ Reverse Rett is founded by five parents from the home of now CEO, Rachael Stevenson.

2011

- ✓ Launch of RSRT's international *MECP2* Consortium to combine global efforts to find a tangible way to reverse Rett in humans.
- ✓ 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

- ✓ Gene therapy work part funded by Reverse Rett demonstrates reversibility of symptoms of Rett Syndrome in mice.
- ✓ The Rett Syndrome Research Trust (RSRT) launch international Gene Therapy Consortium to compound efforts to drive Gene Therapy for Rett into human trials.
- ✓ 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 begin seed-funding King's College London Research Team at CIPPRD, for work focused on developing new outcome measures (TRIAL Database) for patients with Rett Syndrome under Professor Paramala Santosh.

2015

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

2016

✓ Reverse Rett facilitates the implementation of the first UK clinical trial for an emerging treatment (Sarizotan) for Rett Syndrome, committing funding for a FT Clinical Trials Coordinator based at King's College London.

Trustees' annual report

For the year ended 31st December 2019

✓ Reverse Rett CEO gives evidence at Ethics Committee hearing for Sarizotan clinical trial

2017

- ✓ The Sarizotan clinical trial is launched in Q1 under the leadership of Dr Paramala Santosh at King's College Hospital, London. Reverse Rett providing identification, pre-screening, referral and retention services.
- ✓ RSRT/AveXis announcement of development of first human clinical trial for gene therapy in patients with Rett Syndrome.

2018

- ✓ Reverse Rett granted full membership of the UK's Association of Medical Research Charities (AMRC).
- ✓ 2nd UK clinical trial for a potential treatment (cannabidiol) launched at three UK trial sites. Reverse Rett providing identification, pre-screening, referral and retention services.

2019

✓ Reverse Rett CEO gives evidence at London Ethics Committee hearing for 3rd UK clinical trial for an emerging treatment for Rett Syndrome.

2020

✓ 3rd UK clinical trial for a potential treatment (Anavex 2-73) launched at KCL with two other UK trial sites to follow. Reverse Rett providing identification, referral and retention services.

Beneficiaries of our services

The beneficiaries of our services are children and adults with Rett Syndrome and related disorders. Improvements in the symptoms of Rett Syndrome can have far-reaching effects, beyond the individual patient.

There are over 50 reported symptoms of Rett Syndrome; in particular, autonomic disturbances cause significant disruption in the lives of patients and the families who care for them. Amelioration of symptoms

such as sleep difficulties, agitation, breathing problems and anxiety can have a significant impact on the lives of patients and families, increasing stress and isolation and impacting the health and well-being of other family members as well as the patient.

At Reverse Rett, we work to enable patients to access emerging treatments through clinical trials as soon as these treatments become available.

We fund research focused on delivering a cure which will address the underlying cause of the disorder; a faulty gene (MECP2) which leads to a lack of mecp2 protein which is needed for normal brain function.

Trustees' annual report

For the year ended 31st December 2019

Research in mouse models shows that restoration of this protein leads to a reversal of symptoms; proof of concept that a human cure for Rett Syndrome is possible.

Whether this work comes to fruition in this generation of children and adults with Rett Syndrome or the next, our ultimate goal is an all-out cure for the disorder, bringing hope to the lives of many, that the struggles they face today may not be someone else's struggle tomorrow.

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 2019:

A Freeman
Alix Partners UK
Altrincham Market
Alvin and Stephanie Wood

Apex Hotels

Archerfield Estate

Art in Bloom

Bank of Scotland

Banks L A

Derek and Jenny Bird

BM Snacks Ltd

M Brandon

Charlie Talbot

Cartmel YFC

Core Marketing

Cure for Dylan

D & G Group

Danny Clifford

Dame Judi Dench

Darren Onyett

David Ford

David Thompson

Discover Parks

Elly Douglas-Hamilton

East Renfrewshire Golf Club

Trustees' annual report

For the year ended 31st December 2019

Friends of Holly
Future Publishing Ltd
GAM (U.K.) Limited
Gerry Sheridan
L Glacken
Halford MEDIA
The Holt School
Hope for Eliza
IIR Ltd
Jenny Bird
Joanna and Tony Snyder
John and Maureen Sharpe
Kate Bentley
Kate and Joe Kensington
Kate Noble Photography
Keg and Kitchen
The Kilt Walk
The Lawson Trust
McKay Williamson
Michael Winstanley
NDE Technical Services GMBH
Neil and Kate Buckley
Nicholas White and Ortensia Martinotti
Oak Foundation
Opé Rett
Orbis Investment
Paris Steele
Emma Louise Parker <i>In memory of Daisy May Parker</i>

Exeter Football Club

Foundation Scotland

FII Investment

Trustees' annual report

For the year ended 31st December 2019

The Patrick & Helena Frost Foundation

Rebecca Boulton

Rett Syndrome Rannsoknarsjouur

Roger Trevitt

Rudsambee Company

Saracens A.R.F.C

Sarah Taylor

Silvia and Vincenzo Treggiari

Mr G Stacey

St Columba's School

The Stars Group (London)

Stenham Advisors PLC

The Sylvia Aitken Charitable Trust

Treecraft Ltd

Tonbridge Round Table

Whitby Seafoods

Simon Wright

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 2019.

Financial review

2019 year-end income was **£893,665**, which is an 18% increase on 2018.

- Just Giving income increased by 38%. (£212,831.89 2019, £173,657.21 2018)
- London Gala income increased by 90% from £93K in 2018 to £177K in 2019.
- Big Give Christmas Challenge income decreased by 7% due to an arbitrary reduction in the charity's overall target to 75K.

The lengthy peer review process preceding approval of the new CPMRS at KCH necessitated an increased level of reserve throughout 2019 which accounts for a lower overall research spend.

Trustees' annual report

For the year ended 31st December 2019

The overall contribution to international research projects at RSRT was a total of £206,095; £141,632 sent to labs in Edinburgh over the course of 2019 and £64,463 sent to US based *MECP2* duplication projects.

There are no uncertainties about the charity's ability to continue as a going concern.

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 relentless nature of the condition demands that they should be able to access treatments and cures as quickly as possible.

Funds raised and donated are typically deployed to research projects on a quarterly basis. In 2019, the charity held a greater sum in reserve because of the projected 2020 outlay for the Centre for Personalised Medicine in Rett Syndrome at King's College Hospital. A grant of £998,000 over three years was approved by the Board of Trustees of Reverse Rett in September 2019.

The organisation holds six months of running costs in reserves, which equates to approximately £150,000

Plans for the future

A Reverse Rett Annual Plan is developed every autumn for the following year. At the time of writing this report, the Annual Plan for 2020 has necessarily been adapted to accommodate issues arising from the Covid-19 pandemic which has significantly impacted the charity's income.

In summary, for 2020, the charity will focus on:

- Ensuring the survival of Reverse Rett throughout 2020-2021, so that we can continue with our mission and vision in the long term.
- Providing medical information and resources to families shielding vulnerable family members during the crisis.
- Continue to financially support and monitor the CPMRS which remains operational.
- Providing recruitment and retention services for on-going and new clinical trials.
- Rebuilding fundraising efforts with the on-going constraints of social distancing.
- Developing a longer-term strategy for the Charity. So far, Reverse Rett has developed and
 evolved organically. We see the outside world of treatment and trials and industry changing
 rapidly and we need to think about how these and other developments could affect our plans and
 structure for the future. There may be other opportunities to further our mission by broadening
 the scope of our activities.

Trustees' annual report

For the year ended 31st December 2019

Structure, governance and management

Reverse Rett is a company limited by guarantee, company number 07278507 incorporated on 9th 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.

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

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 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 are members of the charity, but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

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 2019 was 9.

The Trustees of the Charity who served during the year ended December 31st 2019 are shown on p1.

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

As a parent-driven, patient organisation, Reverse Rett looks first to the Rett Syndrome community to recruit Trustees. The organisation's founding document states in section 19 that

- A Director must be a natural person aged 16 years or older.
- No one may be appointed a Director if he or she would be disqualified from acting under the provisions of article 21.

Potential trustees are nominated to the Board by one or more of the existing Board members. The validity of the nomination is discussed. The Trustees then vote on whether to approve the membership of the proposed individual.

No other person or external body is permitted to appoint charity trustees.

Induction and training of Trustees is delivered in person through one to one contact with the organisation's Chairman, where Trustee's roles and responsibilities are explained and supporting information is sent to the newly recruited Trustee as appropriate.

Trustees' annual report

For the year ended 31st December 2019

Reverse Rett is a full member of the umbrella organisation, the Association of Medical Research Charities (AMRC). Membership of AMRC requires member organisations to fulfil specific criteria with regards to a high standard of external peer review of proposed research projects and subsequent monitoring.

Detailed information about the established AMRC peer review process at Reverse Rett can be found here. https://www.reverserett.org.uk/what-we-do/how-we-fund-uk-clinical-research/

The Board of Trustees of Reverse Rett delegates day to day operational responsibility of the organisation to the CEO, Rachael Stevenson.

In accordance with the charity's Financial Procedures Policy, expenditure of >£20K must be approved by Board Chairman as well as CEO.

The Board of Trustees must review and approve:

- New organisation policies
- Amendments to existing policies
- Funding of new research projects
- Salary increases for CEO and FM

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

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.

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.

Trustees' annual report

For the year ended 31st December 2019

Related parties and relationships with other organisations

Reverse Rett is a full member of the Association of Medical Research Charities (AMRC)

We work in partnership with the following organisations:

- Rett Syndrome Research Trust (USA) -providing funding for UK based RSRT research projects
- Rett Disorders Alliance UK -working on areas of common interest to benefit the UK Rett community
- Rett UK -UK patient organisation focused on family support for those affected by Rett Syndrome

The following are international organisations from whom we have received donations during the 2019 financial year:

Guðrún's Rett Syndrome Research Trust, Iceland

Opé Rett

Israel Rett Syndrome Research and Treatment Foundation

With special thanks to our industry partners:

Newron Pharmaceuticals

GW Pharmaceuticals

Anavex Life Sciences Corp.

Risk management

During the annual in person board meeting 2019, the charity trustees gave consideration to the major risks to which the charity is exposed.

These include but are not limited to;

- Sudden major decrease in fundraising
- Key personnel changes

Keeping a six-month reserve protects the charity in the short term from a major decrease in fundraising which we have now experienced due to the Covid-19 outbreak.

The potential for key personnel changes will be reviewed on an ongoing basis. The charity is insured against the loss of the Executive Director as recruitment for this post is likely to bring a significantly increased cost for the charity.

Fundraising

Reverse Rett is registered with the Fundraising Regulator and considered to be demonstrating commitment to good fundraising practice.

Trustees' annual report

For the year ended 31st December 2019

Reverse Rett is committed to following the Fundraising Regulator's Code of Fundraising Practice and the Fundraising Promise and is permitted to use the Fundraising Regulator badge on all fundraising materials.

- There has been no failure to comply with the scheme or the standards referred to in (1) above.
- Reverse Rett's approach to fundraising is laid out in our Fundraising Principles and Fundraising Policies for community fundraising and events which are sent out to all new fundraisers.
- The charity monitors activities carried out on behalf of the charity for the purpose of fundraising through on-going interpersonal relationships with fundraisers and supporters of whom we are aware.
- The number of complaints received by the charity or a person acting on its behalf about activities by the charity or by a person on behalf of the charity for the purpose of fundraising during 2019 was 0.
- In 2018-2019, the charity completed a full GDPR audit to ensure that the privacy of all current and previous donors and fundraisers is secure and that individual consent to hold a limited amount of information re supporters is accounted for.
- Reverse Rett does not engage in telephone, mail or on the street cold solicitations and these actions by another person on behalf of the charity are not permitted.
- The charity has not acted as custodian trustee during the reporting period.

Trustees' annual report

For the year ended 31st December 2019

Statement of responsibilities of the trustees

The trustees (who are also directors of Frs102 company charity 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.

The trustees' annual report has been approved by the trustees on 24/08/2020 and signed on their behalf by

John Sharpe

Chair

Independent auditors' report to the members of

Reverse Rett

For the year ended 31st December 2019

Opinion

We have audited the financial statements of Reverse Rett (the 'charitable company') for the year ended 31 December 2019, 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 2019, 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.

Statement of Financial Activities (including Income and Expenditure account) for the year ended 31 December 2019

	Note	Unrestricted funds	Restricted funds £	Total funds 2019 £	Total funds 2018 £
Income from: Donations and legacies	3	481,619	44,726	526,345	418,738
Charitable activities: Events income	4	272,583	94,737	367,320	339,038
Total income		754,202	139,463	893,665	757,776
Expenditure on: Raising funds	5	152,538	-	152,538	140,770
Charitable activities: Medical research cost	6	368,260	108,930	477,190	567,288
Total expenditure		520,798	108,930	629,728	708,058
Net income/(expenditure) for the year	8	233,404	30,533	263,937	49,718
Transfer between funds		(5,000)	5,000	-	-
Net movement in funds for the year	ear	228,404	35,533	263,937	49,718
Reconciliation of funds Total funds brought forward		178,090	16,904	194,994	145,276
Total funds carried forward		406,494	52,437	458,931	194,994

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 07278507

Balance sheet as at 31 December 2019

	Note		2019	201	1.8
Fined seets		£	£	£	£
Fixed assets Tangible assets	12		2,355		
Total fixed assets			2,355		-
Current assets Debtors Cash at bank and in hand	13	106,775 365,123		23,661 223,364	
Total current assets	-	471,898	_	247,025	
Liabilities Creditors: amounts falling due in less than one year	14	(15,322)) 	(52,031)	
Net assets			458,931		194,994
The funds of the charity:					
Restricted income funds Unrestricted income funds	15 16		52,437 406,494		16,904 178,090
Total charity funds			458,931		194,994

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 24 to 39 form part of these accounts.

Approved by the trustees on 24/08/2020 and signed on their behalf by:

John Sharpe (Chair)

Statement of Cash Flows for the year ending 31 December 2019

	Note	2019 £	2018 £
Cash provided by/(used in) operating activities	19	144,657	91,848
Increase/(decrease) in cash and cash equivalents in the year		141,759	91,848
Cash and cash equivalents at the beginning of the year	-	223,364	131,516
Cash and cash equivalents at the end of the year		365,123	223,364

Notes to the accounts for the year ended 31 December 2019

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.

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.

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.

Notes to the accounts for the year ended 31 December 2019 (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 a 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.

Notes to the accounts for the year ended 31 December 2019 (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%

Notes to the accounts for the year ended 31 December 2019 (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.

I 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.

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.

Notes to the accounts for the year ended 31 December 2019 (continued)

3 Income from donations and legacies

		Unrestricted £	Restricted £	Total 2019 £
Donation Grants -	Charterhouse Charitable Trust Sylvia Aiken Trust Lawson Trust Mazars The Patrick and Helena Trust	458,619 5,000 8,000 - - 10,000	- - - 35,000 9,726 -	458,619 5,000 8,000 35,000 9,726 10,000
Total		481,619	44,726	526,345
Income from donations and legacies - previous year				
		Unrestricted £	Restricted £	Total 2018 £
Donation Grants	es	393,738 -	- 25,000	393,738 25,000
Total		393,738	25,000	418,738

Notes to the accounts for the year ended 31 December 2019 (continued)

4 Income from charitable activities

	Unrestricted	Restricted	Total 2019
	£	£	£
The Rig Cive	74 220		74 220
The Big Give London Event	74,238 138,758	-	74,238 138,758
MECP2 Fund	-	54,737	54,737
Family events	13,791	-	13,791
Newron Pharmacy	-	30,000	30,000
Premier Research	-	10,000	10,000
Rett Disorders Alliance	42.252	-	42.252
Gift Aid Other income	42,252 3,544	-	42,252 3,544
Other income	3,344	_	3,344
Total	272 592	04 727	267 220
iotai	272,583	94,737	367,320
Income from charitable activities -	previous year		
	Unvoctristod	Doctrictod	Total 2010
	Unrestricted £	Restricted £	Total 2018 £
	2	2	2
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
Total	198,643	140,395	339,038
Cost of raising funds			
		2019	2018
		£	£
Staff costs		55,629	65,250
Fundraiser's fees		23,161	13,355
Event costs		73,748	62,165
		450 500	1.40.770
		152,538	140,770

All expenditure on cost of raising funds is unrestricted.

5

Notes to the accounts for the year ended 31 December 2019 (continued)

6 Analysis of expenditure on charitable activities

	Unrestricted £	Restricted £	Total 2019 £
Staff costs Transfer to Rett	53,620	-	53,620
Syndrome Research Trust	141,632	64,463	206,095
Travel and accommodation	14,161	_	14,161
Kings College Grant	6,030	-	6,030
Clinical trial expense Rett disorders alliance	2,662 -	37,411 3,211	40,073 3,211
Parent 2 Parent programme CPMRS	- 12,789	3,845 -	3,845 12,789
Governance costs	·		•
(see note 7) Support costs (see	6,400	-	6,400
note 7)	130,966	-	130,966
	368,260	108,930	477,190

Analysis of expenditure on charitable activities - previous year

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

Notes to the accounts for the year ended 31 December 2019 (continued)

7 Analysis of governance and support costs

		Support £	Governance £	Total 2019 £
Office rental cost Staff costs Office costs Audit fees Accountancy services Legal and professions Advertising and mark	al	12,120 85,554 25,095 - - 6,286 1,911	- - 3,480 2,920 - -	12,120 85,554 25,095 3,480 2,920 6,286 1,911
		130,966	6,400	137,366
8 Net income/(experiments is stated after charge)	nditure) for the year narging/(crediting):	2019 £	2018 £	
Depreciation Operating lease renta Property Other Auditor's remuneration		543 7,572 2,568 3,480 1,920	263 7,572 918 3,480 1,920	

Notes to the accounts for the year ended 31 December 2019 (continued)

9 Staff costs

Staff costs during the year were as follows:

ican costs during the year were as follows.	2019 £	2018 £
Wages and salaries Social security costs Pension costs	174,643 14,263 5,897	149,538 12,065 3,611
	194,803	165,214
Allocated as follows: Cost of raising funds Charitable activities Support costs	55,629 53,620 85,554	65,250 43,400 56,564
	194,803	165,214

No employees has employee benefits in excess of £60,000 (2018: Nil).

The average number of staff employed during the period was 6 (2018: 6).

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 £50,373 (2018: £48,500).

Notes to the accounts for the year ended 31 December 2019 (continued)

10 Trustee remuneration and expenses, and related party transactions

During the year two trustees who are employed by the charity received remuneration totalling £87,222 (2018: £84,000).

One trustee received travel and subsistence expenses during the year of nil (2018:£94.90).

Aggregate donations from related parties were £25,550. (2018: £29,000).

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 £206,095 to Rett Syndrome USA in support of the aims of both charities (2018: £269,620).

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 (2018: 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.

Notes to the accounts for the year ended 31 December 2019 (continued)

12 Fixed assets: tangible assets

Cost	Computer equipment £
At 1 January 2019 Additions Disposals	2,129 2,898 -
At 31 December	5,027
Depreciation	
At 1 January 2019 Charge for the year Disposals	2,129 543 -
At 31 December	2,672
Net book value	
At 31 December 2019	2,355
At 31 December 2018	-

Notes to the accounts for the year ended 31 December 2019 (continued)

13 Debtors

		2019 £	2018 £
	Other debtors Prepayments and accrued income Gift aid debtor Big Give debtor	14,980 26,876 15,784 49,135	1,465 7,196 - 15,000
		106,775	23,661
14	Creditors: amounts falling due within one year	2019 £	2018 £
	Trade creditors Other creditors and accruals Taxation and social security costs	1,277 8,071 5,974	33,029 6,138 12,864
		15,322	52,031

Notes to the accounts for the year ended 31 December 2019 (continued)

15 Analysis of movements in restricted funds

	Balance at 1 January 2019 £	Income £	Expenditure £	Transfers £	As at 31 December 2019 £
MECP2 Duplication	2,680	64,463	(64,463)	-	2,680
Rett disorder alliance Use in	3,072	-	(3,211)	5,000	4,861
Farringdon	200	-	-	-	200
Parent 2 Parent Programme Clinical	10,952	-	(3,845)	-	7,107
Research Funds	-	75,000	(37,411)	-	37,589
Total	16,904	139,463	(108,930)	5,000	52,437
Previous reporting period	Balance at 1 January 2018 £	Income £	Expenditure £	Transfers £	31 December 2018 £
MECP2	£	Σ	£	£	£
Duplication Rett disorder	2,934	52,563	(52,817)	-	2,680
alliance Use in Parent 2 Parent	3,072 200	-	- -	-	3,072 200
Programme Clinical	13,195 -	- 112,832	(2,243) (126,773)	- 13,941	10,952 -
Total					

Notes to the accounts for the year ended 31 December 2019 (continued)

Name of	
restricted	fund

Description, nature and purposes of the fund

MECP2

The MECP2 Duplication Fund at Reverse Rett is a restricted fund. The fund exclusively supports projects devoted to the study and means of treatment of MECP2 Duplication/Triplication Syndrome. 100% of funds raised and contributed to Reverse Rett by families of children with MECP2 Duplication Syndrome and their supports in the UK are committed to MECP2 Duplication projects via RSPT US.

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 MECP2 disorders. Through a one to one 'match', experienced parents provide emotional support to families and assist then in finding information and resources.

Parent 2 Parent

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.

Please find more information here: http://www.reverserett.org.uk/getinvolved/get-connected/

Clinical Research Fund

This is a designated fund which will support UK based clinical research and the implementation of treatment for Rett Syndrome and related MECP2 Disorders in the UK.

Notes to the accounts for the year ended 31 December 2019 (continued)

16 Analysis of movement in unrestricted funds

	Balance at 1 January 2019 £	Income £	Expenditure £	Transfers £	As at 31 December 2019 £
General fund	178,090	754,202	(520,798)	(5,000)	406,494
	178,090	754,202	(520,798)	(5,000)	406,494
Previous reporting period	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
	125,875	592,381	(526,225)	(13,941)	178,090
Name of unrestricted	Description, natu	re and purpos	es of the fund		
General fund	The free reserves after allowing for all designated funds				

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)	2,355 404,139	-	- 52,437	2,355 456,576
Total	406,494	-	52,437	458,931

Notes to the accounts for the year ended 31 December 2019 (continued)

18 Operating lease commitments

The charity's total future minimum lease payments under non-cancellable operating leases is as follows for each of the following periods:

Property		Equipment	
2019	2018	2019	2018
£	£	£	£
7,572	7,572	2,568	918
8,834	8,834	9,438	1,835
16,406	16,406	12,006	2,753
	2019 £	2019 2018 £ £ 7,572 7,572 8,834 8,834	2019 2018 2019 £ £ £ 7,572 7,572 2,568 8,834 8,834 9,438

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

	2019 £	2018 £
Net income/(expenditure) for the year Adjustments for:	263,937	49,718
Depreciation charge	543	263
Decrease/(increase) in debtors	(83,114)	174
Increase/(decrease) in creditors	(36,709)	41,693
Net cash provided by/(used in) operating	144,657	91,848