

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 2021

## Reverse Rett

Trustees' annual report

For the year ended 31st December 2021

Reference and Administrative details for the year ended 31<sup>st</sup> December 2021

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

Trustee/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  
Dr Ruksana Ahmed- *joined 07.07.21*  
Andrew J Stevenson\*  
Rachael Stevenson\*  
Ortensia Martinotti  
Catherine McKinney  
Kate McMaster  
Rita Ross  
Neil Buckley *-resigned 25.03.21*  
Joanna Snyder  
Mwangala Lishomwa *\*joined 04.05.21*

\*Trustees who are also Directors of the charitable company. The number of guarantee members is 11.

**Key management.** Rachael Stevenson CEO

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

**Independent auditors** Slade & Cooper Limited, Beehive Mill, Jersey St, Manchester, M4 6JG

## Reverse Rett

### Trustees' annual report

For the year ended 31st December 2021

The trustees present their report and the audited financial statements for the year ended 31 December 2021. 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**

Reverse Rett is a patient advocacy and research organisation focused on delivering treatments and a cure for Rett Syndrome to everyone affected.

### **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 laboratory and clinical research projects
- Advocating for access to treatments and therapies for all affected patients
- Disseminating research and health information
- increasing general public awareness and knowledge of Rett Syndrome and related *MECP2* disorders.

### **Main activities undertaken in relation to objects**

Children and adults with Rett Syndrome are at the heart of everything we do in line with our mission to deliver treatments and a cure to everyone affected.

Four vital pillars underpin our work:

#### **1. Research**

We fund research projects that will lead to better outcomes for children and adults with Rett Syndrome both now and in the future.

#### **2. Advocacy**

We advocate for access to treatments and therapies for all affected patients.

#### **3. Outreach**

We increase public awareness and knowledge of Rett Syndrome and related *MECP2* disorders so that we can register and contact affected patients who may benefit from emerging treatments.

#### **4. Clinical care**

We improve clinical care and outcomes for complex UK children and adults with Rett Syndrome whilst disseminating research and clinical best practice information to improve management of all those affected.

#### **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.

## Activities and projects

### 1. **CIPP Rett Centre, King's College London, £315,836 (includes note 2. below £12,000)**

Reverse Rett provides core funding for the CIPP Rett Centre, the UK's only Rett Syndrome clinical treatment and research Centre based in South London at the Maudsley Hospital and King's College London and led by Professor PJ Santosh.

The CIPP Rett Centre focuses on developing digital health strategies to monitor and manage patients whilst conducting translational research using the HealthTracker platform, providing holistic specialist care and conducting clinical trials.

Reverse Rett has committed to providing core funding to the CIPP Rett Centre at a cost of £998,000 over three years from September 2019-September 2022. In March 2022, subsequent to a formal review of the Centre's activities, the Board of Trustees of Reverse Rett voted to extend funding for the Centre until September 2023 due to the extenuating circumstances of the effects of the pandemic on the Centre's activities.

In 2021: Funds delivered to CIPP Rett Centre totaled: £315,836

### 2. **CIPP Rett Database**

£12,000 is the pro rata sum (2021) 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 can 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 and 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.

### 3. **MECP2 Duplication Syndrome (MDS) research funding via the Rett Syndrome Research Trust (USA)**

Reverse Rett funds *MECP2* Duplication research through our longstanding partnership with the US based, Rett Syndrome Research Trust (RSRT).

In 2021: Funds delivered to RSRT *MECP2* Duplication projects totaled £14,484

### 4. **Contributions to the international research program at the Rett Syndrome Research Trust (USA)**

Reverse Rett funds laboratory research through our longstanding partnership with the US based RSRT. In 2020, contributions to RSRT were dramatically affected by the pandemic's effect on fundraising. In 2021, with the recommencement of some fundraising activities and adjustment to the changes in fundraising, regular and significant contributions have resumed.

**In 2021:** Funds delivered to the RSRT international research program totaled £100,000. These funds supported the work of the Cobb and Bird Labs at the University of Edinburgh.

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#### 5. **Clinical trial expenses £20,390**

In 2021, Reverse Rett provided support for the UK clinical trial of Anavex 2-73 in adults. Reverse Rett provided identification, recruitment and retention services to Anavex. The Clinical trial expenses detailed 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 sponsors on a quarterly basis.

#### 6. **Rett Disorders Alliance £0**

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.

**In 2021:** No RDA funds were spent in 2021 and the fund balance is £4,861.

#### 7. **Parent 2 Parent program £17,529**

Reverse Rett is a patient advocacy and research organisation 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 Dahls Marvelous Children's Charity, to facilitate connections between parent mentors and newly diagnosed families/those in need of additional support.

Over time and with the influence of the pandemic and the effect of lockdowns on our community, with support from Contact/The Pears Foundation, this program evolved to become Rett Connect. Rett Connect encompasses three projects; Parent 2 Parent, Reverse Rett Bitesize and Reverse Rett Family Forum.

£17,529 from Contact/The Pears Foundation supported this work.

#### 8. **Rett Registry UK £12,400**

In 2021, Reverse Rett started a project to enhance and develop the Rett Registry UK. Rett Registry UK is the most comprehensive registry of children, young people and adults with Rett Syndrome in the UK, but until last year, it was simply a locked spreadsheet which had no real direct benefit for families. The overall purpose of the Registry is to provide the organisation with the logistical information, demographics and necessary consents to contact families re research opportunities and to recruit patients for clinical trials.

The re-development of the Registry into an independently hosted website application has provided parents and carers with a comprehensive suite of features to help reduce admin, link to useful resources, and connect up to the wider community. The app also gives families and carers direct control over their own data and the ability to continuously update the app, download/delete their own data. It has enabled the organisation to more effectively champion the need for new and emerging treatments to be implemented in the UK and given us the tools we need to efficiently manage clinical trial recruitment and retention services. The Rett Registry UK was built by the Mather Group IO and can be found here <https://www.rettregistry.uk/> with kind support from GW Pharmaceuticals (£10,000).

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#### 9. Governance costs £5520

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 2021 audit and related accountancy services.

#### 10. Support costs (note 7, p 23) £291,841

In 2021, support costs included the above governance costs, office rental, general office costs including phone, internet, printing and postage and staff costs of £219,149.

Staff costs listed here are for CEO (FT), Clinical Trial Lead and Supporter Care, (0.5 FTE), Finance Officer, Office Administrator/Clinical Trial Co-ordinator, Design and Marketing Lead and Special events fundraiser.

Staff costs under fundraising costs include: Clinical Trial Lead and Supporter Care (0.5 FTE), Events and Outreach Lead (FT) Special events fundraiser (0.4 FTE)

### Achievements and performance

The charity's main activities and who it tries to help are described below. All its charitable activities focus on delivering 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 has been at the forefront of UK Rett Syndrome laboratory and clinical research funding for more than a decade. The timeline below shows key milestones demonstrating progress in the field since the reversal experiments of 2007 and the work of Reverse Rett which was launched in 2010.

Over the last ten years, Reverse Rett has been tightly focused on research funding. Change is now within reach. Three human gene therapy clinical trials are firmly on the horizon and as an organisation, we need to do more.

Our first principle is equality; that all patients with Rett Syndrome regardless of age or gender, should have access to emerging treatments and cures.

As well as continuing to fund clinical and laboratory research, we continue to seek out and register as many UK patients as possible, wherever they are, so that we can reach them when treatments which will improve their lives become viable. We are doing this in a few ways, through increased provision of health information, through the Rett Connect program and more. We continue to work in support of UK clinical trials of emerging treatments. Reverse Rett provides core funding to the CIPP Rett Centre, which manages the health the most complex Rett patients in the country, extrapolating and disseminating learnings which can improve the health and quality of life of Rett patients of all ages, internationally.

We are proud of our past achievements and positive about the future unfolding before us.

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.

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#### 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 Just Giving Award

##### 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 Award

##### 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



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#### **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.
- ✓ 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.
- ✓ Reverse Rett commits to funding the CIPP Rett Centre for three years. The CIPP Rett Centre is the UK's first dedicated clinical treatment and research centre for children and adults with Rett Syndrome and related disorders and is based in London. The CIPP Rett Centre launched in Sept 2019.

#### **2020**

- ✓ 3<sup>rd</sup> 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.
- ✓ 2021 Three gene therapy companies announce their intention to file IND applications for upcoming clinical trials of gene therapy in Rett Syndrome before the end of 2021.

#### **2021**

- ✓ Reverse Rett supports the implementation of 3<sup>rd</sup> UK clinical trial (Anavex 2-73 adults) at two trial sites

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**2022**

- ✓ Reverse Rett supports the implementation of 4<sup>th</sup> UK clinical trial (Anavex 2-73 paediatric) at up to six trial sites.
- ✓ Taysha Gene Therapies files IND/CTA with Health Canada and receives green light for the first in human gene therapy trial for Rett to start this year.

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### Trustees' annual report

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#### **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.

Reverse Rett has also been instrumental in facilitating the delivery of UK clinical trials through our work in improving UK clinical provision for patients with Rett, the re-development of the Rett Registry UK, our recruitment, pre-screening and retention support for clinical trials and our long-term commitment to fund the CIPP Rett Centre (formerly CPMRS).

The CIPP Rett Database which monitors the condition of patients with Rett Syndrome of all ages and stages, all around the UK, gathering anonymized data about disease progression and burden on patients and families which will be an integral component of driving emerging treatments through the regulatory processes.

Both the patient-centred and digital aspects of the work of the CIPP Rett Centre simultaneously generate learning about disease progression and management that is helping patients today, before treatments and a cure become available.

Ultimately, a treatment focused on repairing the underlying cause of the disorder (a lack of mecp2 protein) is needed to significantly reduce or reverse several existing symptoms. Gene therapy programs which are now being championed by industry are happening as a direct result of laboratory research which Reverse Rett has heavily financially supported over the last decade via the RSRT MECP2 Consortium and RSRT Gene Therapy Consortium.

We hope that this year, we will begin to better understand the effects of gene therapy in people with Rett Syndrome, as the first patients have the tremendous opportunity to trial these products. It may be that those who are able to access cures earlier in life recover most effectively. At Reverse Rett, as well as working to bring treatments for Rett Syndrome to fruition, we are also focused on making sure that emerging treatments are available to patients with Rett Syndrome of all ages, stages and genders. We believe that no one should be left behind, when treatments that can drastically improve lives become our reality.

## Reverse Rett

### Trustees' annual report

For the year ended 31st December 2021

**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 2021:**

Amanda Adams  
Jim Amos  
Archerfield Estate  
Derek and Jenny Bird  
S J Bradbury  
Neil and Kate Buckley  
Kerry Burroughs  
Christopher Cant  
Caterpillar Cares Society  
Charities Trust  
Elisabeth Christopher  
Cleeve Vale Rotary Club  
Jorge Conde  
Core Marketing  
Cure for Dylan  
Keki Dadiseth  
Martin Darby  
Mary Davidson  
Elly Douglas-Hamilton  
DT Impact and Influence  
Flowers by Enchantment % Neil Buckley  
David Ford  
Sean Forde  
Ray Holden  
Friends of Holly  
Colin Gordon  
Greenenergy  
HG Capital  
HR\_Inspire  
Tim Jones  
KDW Financial Planning  
Barnaby Lashbrooke  
David Lashbrooke  
Danielle Ledger  
Chris Lowe  
Masonic Charitable  
Foundation Masons  
Internet Lodge 9659  
Mersey Valley Golf Country club  
Committee Masonic Charitable Foundation  
Patricia McCall  
Scott and Kate McMaster  
Muchloved  
Murphy-Neumann Charity Company Limited  
Nicky McBurney Charity Bootcamp  
Kate Noble  
Northern Ireland Electricity service charities committee

Peter O'Grady  
Peter Meyer Trust  
Kelly Phillips  
Gillian Prett  
Mark Ross  
Rita and Gavin Ross  
Savills  
John and Maureen Sharpe  
Clive Sheridan  
Matt Smith  
Anthony and Joanna Snyder  
David H Starbuck  
St Michael & All Angels Church  
Charlie Talbot  
Thrill Collins  
Thomas McMaster and Son LTD  
Gillian Tree  
Myfanwy Tree  
McKay Williamson  
Alvin and Stephanie Wood  
Stephanie Zinser

#### **From Grants and trusts**

The Pears Foundation  
Mrs F B Laurance Charitable Trust  
The Munro Foundation  
The Patrick & Helena Frost Foundation  
The Sumray Trust  
The Sylvia Aitken Charitable Trust

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For the year ended 31st December 2021

**The Board of Trustees would like to take this opportunity to acknowledge the significant contribution of individuals, companies and community groups who have raised funds for Reverse Rett via online giving facilities such as Just Giving, the Big Give Christmas Challenge and Facebook birthdays as well as other online fundraising challenges and campaigns. We couldn't do what we do without you.**

### Financial review

2020 was a difficult year for Reverse Rett. Income dropped by 27% compared to 2019 due to the Pandemic and sharp decrease in fundraising events and activities. In 2021, despite a lengthy third lockdown and community fundraising not resuming in earnest until June/July, the year ended strongly with a 10% improvement on 2020 and a return to almost pre-pandemic levels.

Projections for 2022 remained conservative and on track to meet year end estimate of £689,000. Here are some of the income movements for our three largest income streams:

In 2021, the Reverse Rett Winter Gala was a virtual event as well as an in-person event to cover all eventualities with the pandemic. The event income surpassed pre-pandemic levels. (2019: £138,758, 2020: £91,317, 2021: £153,718).

The Big Give Christmas Challenge is always a virtual event. This year income from this event increased by 26% on 2020. (2019: £74,238, 2020: £82,502, 2021: £110,788)

Just Giving income has increased by a modest 4% on 2021 (2019: £212,831.89, 2020: £163,395, 2021: £169,830.43). This shows a slight recovery from the pandemic but acknowledging that online fundraising has been through some lasting changes in the last few years which will no doubt continue to evolve, as other more immediately accessible platforms such as Facebook online giving.

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

## Reverse Rett

### Trustees' annual report

For the year ended 31st December 2021

#### **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 2020, the charity held a greater sum in reserve because of the ongoing unpredictability of the fundraising situation during the pandemic and the commitment of £998,000 over three years made to CIPP Rett Centre in September 2019. The charity holds a minimum of 6 months running costs as free reserve. Total funds held at year end was £293,905 of which £77,179 was restricted.

#### **Plans for the future**

In early 2021, the Reverse Rett Board of Trustees set to work to develop a new long-term strategy for the organisation. The strategy document is entitled 'Change is within Reach,' the Reverse Rett Strategy 2021-2026.

This longer-term plan feeds into the current dynamic annual plan and provides helpful longer-term perspective.

In 2021, Reverse Rett is focused on:

#### **Research:**

- Continuing to financially support and monitor the CIPP Rett Centre and CIPP Rett Database.
- Building international research contributions to RSRT to pre-pandemic levels.
- Providing recruitment and retention services for on-going and new clinical trials.
- Developing relationships with industry partners re emerging products.

#### **Advocacy:**

Undergoing audit of HTA preparations and access planning.

#### **Outreach:**

Increasing general public awareness and knowledge of Rett Syndrome and MECP2 Duplication Syndrome so that we are able to register and contact affected patients who many benefit from emerging treatments.

Directly seeking out under-represented groups and unidentified children and adults with Rett Syndrome for the same reason.

#### **Clinical care:**

Improving clinical care and outcomes for complex UK children and adults with Rett Syndrome whilst disseminating research and clinical best practice information to improve medical management of everyone affected.

#### **Structure, governance and management**

Reverse Rett is a company limited by guarantee, company number 07278507 incorporated on 9<sup>th</sup>

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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.

## Reverse Rett

### Trustees' annual report

For the year ended 31st December 2021

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 and Andrew Stevenson 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 on 31 December 2021 was 11.

The Trustees of the Charity who served during the year ended December 31<sup>st</sup> 2021 are shown on p1. The Trustees generally meet in person, once annually and via online conferencing on a bi-monthly basis and as needed basis. Since the pandemic started, Trustees have met more frequently and through online face to face meetings via Zoom!

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.



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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.

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#### **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  
Opé Rett  
Gudrun's Rett Syndrome Research Trust  
Israel Rett Syndrome Research and Treatment Foundation

#### **The following are international organisations from whom we have received donations during the 2021 financial year:**

Opé Rett

#### **With special thanks to our industry partners:**

GW Pharmaceuticals  
Anavex Life Sciences Corp.  
Taysha Gene Therapies  
Neurogene Inc.

#### **Risk management**

During the annual in person board meeting 2021, the charity trustees considered 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. In 2022, Reverse Rett is working to broaden the management base to deliver more protection for the charity against the loss of key personnel.

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#### **Fundraising**

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

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 2021 was 0.
- In 2021, the charity has updated the Rett Registry UK complete with a suite of privacy and data protection tools to ensure that the privacy of all registrants and their families is secure. All fundraiser/supporter personal information is held on a secure third party platform called Donorfy. Consents to hold limited information are secure.
- 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.

## 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 **31/08/2022** and signed on their behalf by

John Sharpe  
Chairman

# Independent Auditors' Report to the Members and Trustees of Reverse Rett

## Opinion

We have audited the financial statements of Reverse Rett (the 'charitable company') for the year ended 31 December 2021, 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). 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 2021, 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

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

## Other information

The trustees are responsible for the other information. The other information comprises the information included in the 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

## Independent Auditors' Report to the Members and Trustees of Reverse Rett

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 18, 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.

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**

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.

## Independent Auditors' Report to the Members and Trustees of Reverse Rett

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The specific procedures for this engagement and the extent to which these are capable of detecting irregularities, including fraud is detailed below:

- enquiry of management and those charged with governance around actual and potential litigation and claims.
- enquiry of the charity's staff, management and those charged with governance to identify any instances of non-compliance with laws and regulations.
- reviewing minutes of meetings of those charged with governance.
- reviewing financial statement disclosures and testing to supporting documentation to assess compliance with applicable laws and regulations.
- auditing the risk of management override of controls, including through testing journal entries and other adjustments for appropriateness, and evaluating the business rationale of significant transactions outside the normal course of business.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities is available on the Financial Reporting Council's website at: <https://www.frc.org.uk/Our-Work/Audit/Audit-and-assurance/Standards-and-guidance/Standards-and-guidance-for-auditors/Auditors-responsibilities-for-audit/Description-of-auditors-responsibilities-for-audit.aspx>. This description forms part of our auditor's report.

### **Use of our report**

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.

Chinwe Jennifer Daniel FCCA DChA

Senior Statutory Auditor

*for and on behalf of*

Slade & Cooper Limited  
Statutory Auditors  
Beehive Mill  
Jersey Street  
Manchester, M4 6JG

Date: **14/09/2022**

Reverse Rett  
Statement of Financial Activities  
(including Income and Expenditure account)  
for the year ended 31 December 2021

	Note	Unrestricted funds £	Restricted funds £	Total funds 2021 £	Total funds 2020 £
<b>Income from:</b>					
Donations and legacies	3	345,684	8,000	353,684	357,458
Charitable activities:	4	326,458	36,152	362,610	293,966
<b>Total income</b>		<b>672,142</b>	<b>44,152</b>	<b>716,294</b>	<b>651,424</b>
<b>Expenditure on:</b>					
Raising funds	5	155,571	-	155,571	110,401
Charitable activities:	6	645,369	52,403	697,772	569,000
<b>Total expenditure</b>		<b>800,940</b>	<b>52,403</b>	<b>853,343</b>	<b>679,401</b>
<b>Net income/(expenditure) for the year</b>	8	<b>(128,798)</b>	<b>(8,251)</b>	<b>(137,049)</b>	<b>(27,977)</b>
Transfer between funds		-	-	-	-
<b>Net movement in funds for the year</b>		<b>(128,798)</b>	<b>(8,251)</b>	<b>(137,049)</b>	<b>(27,977)</b>
<b>Reconciliation of funds</b>					
Total funds brought forward		345,524	85,430	430,954	458,931
<b>Total funds carried forward</b>		<b>216,726</b>	<b>77,179</b>	<b>293,905</b>	<b>430,954</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 07278507  
Balance sheet as at 31 December 2021

	Note	2021	2020
		£	£
<b>Fixed assets</b>			
Tangible assets	12	2,155	3,504
<b>Total fixed assets</b>		<b>2,155</b>	<b>3,504</b>
<b>Current assets</b>			
Debtors	13	50,803	109,163
Cash at bank and in hand		345,924	409,978
<b>Total current assets</b>		<b>396,727</b>	<b>519,141</b>
<b>Liabilities</b>			
Creditors: amounts falling due in less than one year	14	(104,977)	(91,691)
<b>Net assets</b>		<b>293,905</b>	<b>430,954</b>
<b>The funds of the charity:</b>			
Restricted income funds	15	77,179	85,430
Unrestricted income funds	16	216,726	345,524
<b>Total charity funds</b>		<b>293,905</b>	<b>430,954</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 26 to 39 form part of these accounts.

Approved by the trustees on 31/08/2022 and signed on their behalf by:

Helen Simmonds (Vice-Chair)

Reverse Rett  
Statement of Cash Flows  
for the year ending 31 December 2021

	Note	2021 £	2020 £
<b>Cash provided by/(used in) operating activities</b>	19	<b>(64,054)</b>	<b>47,353</b>
Increase/(decrease) in cash and cash equivalents in the year		(64,054)	44,455
Cash and cash equivalents at the beginning of the year		409,978	365,123
<b>Cash and cash equivalents at the end of the year</b>		<b>345,924</b>	<b>409,578</b>

# Reverse Rett

## Notes to the accounts for the year ended 31 December 2021

### 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), second edition - October 2019 (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006 and UK Generally Accepted Accounting Practice.

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.

## Reverse Rett

### Notes to the accounts for the year ended 31 December 2021 (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 2021 (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 2021 (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.

#### **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.

## Reverse Rett

Notes to the accounts for the year ended 31 December 2021 (continued)

### 3 Income from donations and legacies

	Unrestricted £	Restricted £	Total 2021 £
Donations	293,495	-	293,495
Grants - Sylvia Aiken Trust	3,000	-	3,000
The Patrick and Helena Trust	-	-	-
Covid Response and JRS	16,189	-	16,189
HG Foundation	2,000	-	2,000
Childwick Trust	15,000	-	15,000
GW Pharmaceuticals	10,000	-	10,000
Exceed Trust	1,000	-	1,000
The Lawson Trust	5,000	-	5,000
Pears Grant	-	8,000	8,000
	345,684	8,000	353,684
<b>Total</b>	345,684	8,000	353,684

#### *Income from donations and legacies - previous year*

	Unrestricted £	Restricted £	Total 2020 £
<i>Donations</i>	<i>277,897</i>	<i>21,075</i>	<i>298,972</i>
<i>Grants</i> - Sylvia Aiken Trust	<i>6,000</i>	<i>-</i>	<i>6,000</i>
The Patrick and Helena Trust	<i>10,000</i>	<i>-</i>	<i>10,000</i>
Covid Response and JRS	<i>39,311</i>	<i>-</i>	<i>39,311</i>
Others	<i>600</i>	<i>2,575</i>	<i>3,175</i>
	<i>-</i>	<i>-</i>	<i>-</i>
	<i>333,808</i>	<i>23,650</i>	<i>357,458</i>
<b>Total</b>	<i>333,808</i>	<i>23,650</i>	<i>357,458</i>

## Reverse Rett

Notes to the accounts for the year ended 31 December 2021 (continued)

### 4 Income from charitable activities

	Unrestricted £	Restricted £	Total 2021 £
The Big Give	110,788	-	110,788
London Event	153,718	-	153,718
MECP2 Fund	-	15,762	15,762
Family events	7,048	-	7,048
Anavex Germany GmbH	22,335	20,390	42,725
Gift Aid	31,693	-	31,693
Other income	876	-	876
<b>Total</b>	<b>326,458</b>	<b>36,152</b>	<b>362,610</b>

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

	Unrestricted £	Restricted £	Total 2019 £
<i>The Big Give</i>	<i>82,502</i>	<i>-</i>	<i>82,502</i>
<i>London Event</i>	<i>91,317</i>	<i>-</i>	<i>91,317</i>
<i>MECP2 Fund</i>	<i>665</i>	<i>12,960</i>	<i>13,625</i>
<i>Family events</i>	<i>5,806</i>	<i>-</i>	<i>5,806</i>
<i>Newron Pharmacy</i>	<i>8,874</i>	<i>3,633</i>	<i>12,507</i>
<i>Parent 2 Parent programme</i>	<i>-</i>	<i>14,529</i>	<i>14,529</i>
<i>Gift Aid</i>	<i>71,024</i>	<i>-</i>	<i>71,024</i>
<i>Other income</i>	<i>2,512</i>	<i>144</i>	<i>2,656</i>
<b>Total</b>	<b>262,700</b>	<b>31,266</b>	<b>293,966</b>

### 5 Cost of raising funds

	2021 £	2020 £
Staff costs	68,177	63,456
Fundraiser's fees	3,048	5,139
Event costs	84,346	41,806
	<b>155,571</b>	<b>110,401</b>

All expenditure on cost of raising funds is unrestricted.



## Reverse Rett

Notes to the accounts for the year ended 31 December 2021 (continued)

### 6 Analysis of expenditure on charitable activities

	Unrestricted £	Restricted £	Total 2021 £
Staff costs	53,765	-	53,765
Transfer to Rett Syndrome Research Trust USA	100,000	-	100,000
Travel and accommodation	348	-	348
Clinical trial expense	-	20,390	20,390
Parent 2 Parent programme*	-	17,529	17,529
CIPP Rett Centre	315,836	-	315,836
MECP2	-	14,484	14,484
Governance costs (see note 7)	5,520	-	5,520
Support costs (see note 7)	169,900	-	169,900
	645,369	52,403	697,772
	645,369	52,403	697,772

\* The stated amount includes staff cost of £13,428.

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

	<i>Unrestricted</i> £	<i>Restricted</i> £	<i>2,020</i> £
<i>Staff costs</i>	<i>64,253</i>	<i>-</i>	<i>64,253</i>
<i>Transfer to Rett Syndrome Research Trust USA</i>	<i>445</i>	<i>-</i>	<i>445</i>
<i>Travel and accommodation</i>	<i>1,688</i>	<i>-</i>	<i>1,688</i>
<i>Kings College Grant</i>	<i>-</i>	<i>-</i>	<i>-</i>
<i>Clinical trial expense</i>	<i>-</i>	<i>11,247</i>	<i>11,247</i>
<i>Rett disorders alliance</i>	<i>-</i>	<i>-</i>	<i>-</i>
<i>Parent 2 Parent programme</i>	<i>-</i>	<i>1,051</i>	<i>1,051</i>
<i>CIPP Rett Centre</i>	<i>311,137</i>	<i>-</i>	<i>311,137</i>
<i>MECP2</i>	<i>-</i>	<i>25,625</i>	<i>25,625</i>
<i>Governance costs (see note 7)</i>	<i>5,640</i>	<i>-</i>	<i>5,640</i>
<i>Support costs (see note 7)</i>	<i>147,914</i>	<i>-</i>	<i>147,914</i>
	<i>531,077</i>	<i>37,923</i>	<i>569,000</i>
	<i>531,077</i>	<i>37,923</i>	<i>569,000</i>

## Reverse Rett

Notes to the accounts for the year ended 31 December 2021 (continued)

### 7 Analysis of governance and support costs

	Support £	Governance £	Total 2021 £
Office rental cost	10,530	-	10,530
Staff costs	97,208	-	97,208
Office costs	51,506	-	51,506
Audit fees	-	3,500	3,500
Accountancy services	-	2,020	2,020
Legal and professional	9,360	-	9,360
Advertising and marketing	1,296	-	1,296
	169,900	5,520	175,420
	169,900	5,520	175,420

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

This is stated after charging/(crediting):	2021 £	2020 £
Depreciation	1,349	1,349
Operating lease rentals:		
Property	-	-
Other	2,460	2,568
Auditor's remuneration - audit fees	3,000	3,000
Auditor's remuneration - accountancy fees	1,600	1,600
	169,900	175,420

## Reverse Rett

Notes to the accounts for the year ended 31 December 2021 (continued)

### 9 Staff costs

Staff costs during the year were as follows:

	2021 £	2020 £
Wages and salaries	206,210	198,922
Social security costs	18,525	18,126
Pension costs	7,843	7,356
	<hr/>	<hr/>
	232,578	224,404
	<hr/> <hr/>	<hr/> <hr/>
<b>Allocated as follows:</b>		
Cost of raising funds	68,177	63,456
Charitable activities	67,193	64,253
Support costs	97,208	96,695
	<hr/>	<hr/>
	232,578	224,404
	<hr/> <hr/>	<hr/> <hr/>

No employees has employee benefits in excess of £60,000 (2020: Nil).

The average number of staff employed during the period was 7 (2020: 7).

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 £54,453 (2020: £53,040).

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

Two of the trustees Rachael Stevenson (Chief Executive) and Andrew Stevenson received remuneration totalling £95,066 during the year (2020: £91,831).

No trustee received travel and subsistence expenses during the year. (2020: nil).

Aggregate donations from related parties were £35,000 (2020: £44,650).

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 charitable grant to Rett Syndrome USA of £100,000 this year. (2020: £445).

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 (2020: nil).

## Reverse Rett

Notes to the accounts for the year ended 31 December 2021 (continued)

### 11 Corporation tax

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

### 12 Fixed assets: tangible assets

<b>Cost</b>	Computer equipment £
At 1 January 2021	7,525
Additions	-
Disposals	-
	<hr/>
At 31 December 2021	7,525
	<hr/> <hr/>
<b>Depreciation</b>	
At 1 January 2021	4,021
Charge for the year	1,349
Disposals	-
	<hr/>
At 31 December 2021	5,370
	<hr/> <hr/>
<b>Net book value</b>	
At 31 December 2021	2,155
	<hr/> <hr/>
<i>At 31 December 2020</i>	<i>3,504</i>
	<hr/> <hr/>

## Reverse Rett

Notes to the accounts for the year ended 31 December 2021 (continued)

### 13 Debtors

	2021 £	2020 £
Other debtors	10,837	6,300
Prepayments and accrued income	28,208	26,672
Gift aid debtor	1,758	25,956
Big Give debtor	10,000	50,235

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50,803

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109,163

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

	2021 £	2020 £
Trade creditors	16,297	2,351
Other creditors and accruals	74,895	78,956
Taxation and social security costs	13,785	10,384

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104,977

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91,691

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## Reverse Rett

Notes to the accounts for the year ended 31 December 2021 (continued)

### 15 Analysis of movements in restricted funds

	Balance at 1 January 2021 £	Income £	Expenditure £	Transfers £	As at 31 December 2021 £
<i>MECP2</i>					
Duplication	11,090	15,762	(14,484)	-	12,368
Rett disorder alliance	4,861	-	-	-	4,861
Use in Farringdon	200	-	-	-	200
Parent 2 Parent Programme Clinical	20,585	-	(17,529)	-	3,056
Research Funds	48,694	-	-	-	48,694
Anavex Germany GmbH	-	20,390	(20,390)	-	-
Pears Grant	-	8,000	-	-	8,000
<b>Total</b>	<b>85,430</b>	<b>44,152</b>	<b>(52,403)</b>	<b>-</b>	<b>77,179</b>

<b>Previous reporting period</b>	Balance at 1 January 2020 £	Income £	Expenditure £	Transfers £	31 December 2020 £
<i>MECP2</i>					
Duplication	2,680	34,035	(25,625)	-	11,090
Rett disorder alliance	4,861	-	-	-	4,861
Use in Farringdon	200	-	-	-	200
Parent 2 Parent Programme Clinical	7,107	14,529	(1,051)	-	20,585
Research Funds	37,589	6,352	(11,247)	16,000	48,694
<b>Total</b>	<b>52,437</b>	<b>54,916</b>	<b>(37,923)</b>	<b>16,000</b>	<b>85,430</b>

Name of restricted fund	Description, nature and purposes of the fund
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MECP2	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.
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## Reverse Rett

### Notes to the accounts for the year ended 31 December 2021 (continued)

**Parent 2 Parent** 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 them in finding information and resources.

The Reverse Rett Parent 2 Parent project is now housed under Rett Connect umbrella. Please see here for more details.  
<https://www.reverserett.org.uk/rett-connect/>

**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.

#### 16 Analysis of movement in unrestricted funds

	Balance at 1 January 2021 £	Income £	Expenditure £	Transfers £	As at 31 December 2021 £
General fund	345,524	672,142	(800,940)		216,726
	345,524	672,142	(800,940)	-	216,726
	345,524	672,142	(800,940)		216,726

	<i>Previous reporting period</i> Balance at 1 January 2020 £	<i>Income</i> £	<i>Expenditure</i> £	<i>Transfers</i> £	<i>As at 31 December 2020 £</i>
<i>General fund</i>	406,494	596,508	(641,478)	(16,000)	345,524
	406,494	596,508	(641,478)	(16,000)	345,524
	406,494	596,508	(641,478)	(16,000)	345,524

**Name of  
unrestricted**

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

General fund      The free reserves after allowing for all designated funds

## Reverse Rett

Notes to the accounts for the year ended 31 December 2021 (continued)

### 17 Analysis of net assets between funds

	General fund £	Designated funds £	Restricted funds £	Total £
Tangible fixed assets	2,155	-	-	2,155
Net current assets/(liabilities)	214,571	-	77,179	291,750
Total	216,726	-	77,179	293,905

### 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	
	2021 £	2020 £	2021 £	2020 £
Less than one year	-	-	2,460	2,568
One to five years	-	-	4,410	6,870
	-	-	6,870	9,438

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

	2021 £	2020 £
<b>Net income/(expenditure) for the year</b>	(137,049)	(27,977)
<b>Adjustments for:</b>		
Depreciation charge	1,349	1,349
Decrease/(increase) in debtors	58,360	(2,388)
Increase/(decrease) in creditors	13,286	76,369
<b>Net cash provided by/(used in) operating</b>	(64,054)	47,353