

Company number 07278507

Charity Number: 1136809 (England & Wales)

Charity Number: SC046735 (Scotland)

# Reverse Rett

Report and financial statements

For the year ended 31 December 2023

Reverse Rett  
Trustees Annual Report  
Financial year end 31 December 2023

**Company number** 07278507

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

**Registered office and operational address** Beehive Mill, Jersey St, Manchester M4 6JG

**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 H Sharpe            Chair  
Helen Kay Simmonds Vice Chair  
Dr Ruksana Ahmed  
Oliver Freeman \* joined 05.12.23  
Michael Christopher Jones  
Jocelyn LeBlanc Ph.D\* joined 10.02.23  
Ortensia Martinotti  
Catherine McKinney  
Kate McMaster  
Rita Ross \* resigned 30.04.24  
Joanna K L Snyder  
Rachael Emma Stevenson  
Andrew John Stevenson

Trustees who held title to property belonging to the charity during the reporting period or at the date of approval were: NA

**Key management** Rachael Stevenson    Chief Executive  
Catherine Sim            Operations Manager

**Bankers** Barclays Bank UK PLC, Leicester LE87 2BB

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

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The Trustees present their report and the audited financial statements for the year ended 2023. Included within the trustees' report is the directors' report as required by company law.

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

## **Objectives and activities**

Reverse Rett is a patient advocacy organisation focused on accelerating treatments and a cure for Rett syndrome.

Objects as set out in the charity's governing document

Reverse Rett exists to relieve sickness and 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, young people and adults with Rett syndrome are at the heart of everything we do in line with our mission to accelerate treatments and a cure for everyone affected.

## **International research funding:**

Since Reverse Rett's founding in 2010, we've donated over £7 million to RSRT research projects globally, which have led to current gene therapy trials. The pandemic affected our fundraising, causing a temporary halt in contributions. We resumed with £100,000 donations at the end of 2021 and 2022. However, due to delays in deploying these funds and increased payments to the CIPP Rett Centre, we paused our RSRT payments in 2023.

We plan to continue supporting RSRT's International Research program but must pause contributions due to current UK fundraising conditions. As part of our 2025 strategy, we are reassessing our charitable focus and hope to resume support in 2025.

Contributions to the international research program at the Rett Syndrome Research Trust (RSRT) USA £0, 2023, (2022: £100,000).

## **Rett Registry UK:**

Reverse Rett launched the Rett Registry UK in 2014 to support clinical trials and regulatory processes for Rett syndrome treatments in the UK. It's the only UK-specific registry for individuals with Rett syndrome, with 722 participants from the UK and beyond.

In 2021, we upgraded the Registry to an independently hosted app, offering enhanced features for parents and carers. This app reduces administrative tasks, connects users to resources, and allows families to manage their own data. It helps us advocate for new treatments and efficiently manage clinical trial recruitment and retention.

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Cost of Rett Registry UK in 2023, £5625, (2022, £8400).

**Clinical care:**

Reverse Rett funds the CIPP Rett Centre, the UK's sole dedicated Rett Syndrome clinic and research centre, led by Professor PJ Santosh at Maudsley Hospital and King's College London.

Established in 2019 by Professor Santosh at Maudsley Hospital and King's College London, the CIPP Rett Centre is the UK's only service exclusively offering comprehensive care for Rett Syndrome (RTT) patients. Funded mainly by Reverse Rett, the CIPP Rett Centre was the first in the UK to conduct RTT clinical trials and serves as a model for trials and care in rare diseases.

The Centre provides holistic, personalized care for complex patients, focusing on neurobehavioral, emotional, and autonomic dysregulation. It integrates research with clinical practice, using advanced techniques like pharmacogenomics and physiological data to manage and treat RTT effectively.

Initially, Reverse Rett committed £998,000 for three years (September 2019-2022) to support the Centre's digital health strategies, patient management, and clinical trials. Due to the pandemic's impact, we extended funding until September 2023.

By September 2022, the Centre was managing over 150 patients, with increased demand from the pandemic's effects on services and mental health. We worked with the Centre to focus on stabilizing care under these pressures.

The CIPP Centre is the only national facility offering comprehensive care for Rett syndrome patients of all ages and is now managing over 200 patients. It cannot stop operations abruptly and requires significant notice to adjust.

In 2022, changes in billing led to increased payments for Reverse Rett. Reverse Rett has now established a plan to reduce the charity's commitment to the CIPP Rett Centre. From 2023, funding shifted to a one-year rolling contract. Due to the ongoing impact of the CIPP Rett Centre costs on the charity, from September 2024, the cost of the CIPP Rett Centre has reduced to £150,000 (from Sept 2024-Sept 2025) and thereafter will cost £125,000 per year for Reverse Rett.

CIPP Rett Centre (King's College London) costs in 2023, £313,000 (2022: £289,000)

**CIPP Rett Database/HealthTracker TM funding:**

In 2023, the HealthTracker software license cost £36,000. The CIPP Rett Database, also known as the Multi System Symptoms Profile or REST questionnaire, is an online tool for reporting and tracking Rett Syndrome symptoms. It analyzes data both individually and collectively to monitor patient changes and identify broader patterns, playing a crucial role in the care provided by the CIPP Rett Centre.

CIPP Rett Database/HealthTracker TM licensing, £36,000 in 2023, (2022: £36,000).

**Clinical Trial Support:**

Reverse Rett supports clinical trials for Rett syndrome by recruiting participants and providing logistical help. We've assisted with four UK trials of potential drug treatments at six sites, including children and adult trials. Our services include recruiting from the Rett Registry UK, pre-screening, referrals, and covering travel and accommodation for patients.

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In 2023, we supported the UK trial of Anavex 2-73, managing recruitment, retention, and logistical costs for patient visits. We received and accounted for these funds in advance, with quarterly reports sent to sponsors.

Clinical trial support costs in 2023, £21,044

**MECP2 Duplication Fund:**

Reverse Rett funds MECP2 Duplication research through our partnership with the US-based Rett Syndrome Research Trust (RSRT). The money for these projects comes from UK families affected by MECP2 Duplication Syndrome and depends on the funds they raise.

MECP2 Duplication Syndrome (MDS) research funding via the Rett Syndrome Research Trust (USA) (2023: £0) (2022 £7474)

**Community Education programs:**

Reverse Rett Bitesize sessions started in 2019, covering a wide range of topics, drawing on the expertise of clinicians, researchers and parents and sharing a wealth of information and experience with the community. The 2023-2024 season was focused on educating the community about Emerging Gene Therapies and what to expect whilst the first gene therapies for Rett are in clinical trials.

**LEAP Education Day:**

In June 2024, Reverse Rett held its first annual LEAP Education Day, a one-day event where industry professionals and clinicians share the latest information about emerging treatments with patients and families.

**Industry support and partnerships:**

Reverse Rett collaborates with industry partners to support program development. This includes reviewing patient and family materials, assisting with ethics applications, distributing surveys, sharing updates, and advising on incorporating patient feedback both in the UK and internationally.

**Memberships and credibility:**

Reverse Rett is a full member of the Association of Medical Research Charities (AMRC), a prestigious accreditation for UK medical research charities. This membership indicates that we fund health and medical research and meet high standards, including a strict peer review process for research awards.

**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.

**Governance Costs:**

Charities in England and Wales with incomes over £500,000 must have an annual independent audit. These costs cover our 2023 audit and related accountancy services.

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Governance costs in 2023, £2903 (2022 £5988).

**Staff costs:**

CEO (RES) 90% charitable activities 10% support costs

Clinical trial lead and supporter care (AS) 90% charitable activities 10% support costs

Office admin/Clinical Trial/registry co-ordinator (EW) 80% charitable activities 20% support costs

Design and marketing (WH) 20% charitable activities 80% support costs

Special events fundraiser (HB) 100% fundraising (0.4FTE) \* role ended

Events and Outreach Lead (BKJ) 100% support costs \*role ended Feb 2023

Finance Officer 100% support costs \*role ended March 2023

Operations Manager \*joined June 2023 (CS) 30% charitable activities 70% support costs

**Achievements and performance**

The charity's main activities and its beneficiaries 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 led UK funding for Rett Syndrome research for over a decade. Since its launch in 2010, the charity has focused on advancing research, and significant progress is being made with gene therapy trials starting in Canada, the USA, and Australia.

In January 2024, the UK regulator MHRA approved clinical trials for Neurogene and Taysha Gene Therapies in the UK, with the first trial site opening soon. Reverse Rett is committed to ensuring all UK Rett Syndrome patients have access to these new treatments and upholding the principle of equality in healthcare.

Reverse Rett continues to work to register as many UK Rett Syndrome patients as possible which will help us advocate for new treatments to be funded by the NHS. Patients being registered means we can reach families and carers when new treatments become available. We provide health information through the Rett Connect program enabling families to advocate for appropriate healthcare. Our funding of the CIPP Rett Centre enables effective clinical management of complex patients with Rett syndrome whose care cannot be managed at the local level.

We are proud of our progress and optimistic about the future. The timeline below highlights key milestones in Rett Syndrome research and Reverse Rett's work since 2010.

- 2010 Reverse Rett founded by five parents, including now CEO Rachael Stevenson.
- 2011 Reverse Rett wins Best New Charity at the Charity Times and Just Giving Awards and surpasses \$1 million in international Rett Syndrome research funding.
- 2013 Reverse Rett begins funding King's College London Research Team for developing new outcome measures.

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- 2014 Reverse Rett initiates a UK Patient Registry for clinical trial readiness.  
Reverse Rett holds the family focus groups for CIPP Rett Database/HealthTracker project at Kings College London
- 2015 Reverse Rett international research funding exceeds \$5 million.
- 2016 Reverse Rett facilitates the first UK drug clinical trial funding a Clinical Trials Coordinator at Kings College Hospital  
Reverse Rett CEO provides evidence at the Ethics Committee hearing for the first UK drug trial
- 2017 First UK Rett syndrome drug trial started at Kings College Hospital
- 2018 Reverse Rett awarded full membership of UK's Association of Medical Research Charities (AMRC).
- 2019 Second UK Rett syndrome drug trial launched at two trial sites with clinical trial support services (CTSS) provided by Reverse Rett  
Reverse Rett CEO provides ethics committee evidence for a third UK clinical trial.  
Reverse Rett commits to three years of core funding for the CIPP Rett Centre
- 2020 Third UK Rett syndrome drug trial launched at four sites across the UK
- 2021 Reverse Rett provides CTSS for the third UK Rett syndrome drug trial
- 2022 Taysha Gene Therapies files for the first human gene therapy trial in Canada.
- 2023 Gene therapy company, Neurogene gets FDA approval for a US clinical trial in children.  
Taysha Gene Therapies doses the first adult patient with gene therapy in Canada  
FDA approves Trofinetide/Daybue as the first licensed treatment for Rett Syndrome.
- 2024 MHRA approves UK clinical trials for Taysha Gene Therapies TSHA-1012 and Neurogene NGN 401.  
The first UK clinical trial site opens in Sept 2024

**Beneficiaries of our services:**

The beneficiaries of our services are children and adults with Rett Syndrome and related disorders. Children with Rett Syndrome are born apparently healthy. In the first few years of life, they lose many abilities that most people take for granted, such as using their hands, speaking, and walking. This loss affects their ability to communicate, form relationships, and gain independence. Some children may never walk and are confined to a wheelchair, while others may walk but later lose this ability. Those who retain mobility often face anxiety and instability.

Despite appearing less aware due to their physical limitations, people with Rett Syndrome are often very cognizant of their condition. They endure significant pain and discomfort from symptoms like seizures, breathing issues, and muscle problems. Managing these symptoms is challenging, as addressing one often worsens another.

Rett Syndrome brings a range of severe and life-limiting medical issues that greatly impact the lives of patients and their families, causing profound disruption and distress.

At Reverse Rett, we work to enable all affected patients to access emerging treatments as soon as these treatments become available. We empower the community to take action to help improve the lives of everyone affected.

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The Board of Trustees thanks everyone who has supported Reverse Rett through online fundraising platforms like Just Giving, the Big Give Christmas Challenge, Facebook birthdays, and other online campaigns. Your efforts make the ultimate difference:

Individuals	Companies	Trusts and Foundations
Alison Wilkie	A Star Experience	Anavex Life Sciences
Amanda Adams	Archerfield Estates	Charitable Giving Benevity
Andrew Etherington	Bann Hire and Sales	Charities aid Foundation
Anna Morrison	Blackridge Communications	Charities Trust
Brian Taylor	Buth Bheag Ltd	KDW Financial Planning
Carmen Jones	Carl Greaves Boxing	Cure for Dylan
Chester DEO	Promotions	Ixion Lodge
Christopher Mark Heaton	Charlotte Gray Photography	Maurice and Nicola Trust -
David Ford	Core Marketing Partners	Jurassic Coast
Derek & Jenny Bird	Global-e	National Funding Scheme
Diane Rowland	Hobbs Bakery	Neurogene Inc.
Ellie Douglas-Hamilton	Hospitality Sports	The Big Give
Glastonbury Festival	Houghwood Golf Club	The Patrick & Helen Frost
Volunteers	Lentaspace	Foundation
Jenalyn Walton	Liasons UK	Phoenix Fun Events
Joanna and Tony Snyder	Mid Ulster Granite & Stone	Polar Capital
Kate McMaster	Co	South Lanarkshire Council
Lynn Crump	Much Loved	T K Maxx
Mark Reilly	Thomas McMaster and sons	Taysha
Pamela Monti	Oakland Group	The Hospital Saturday Trust
Jackie Larmer	Olivia Grace Home Fragrance	
John & Maureen Sharpe	Ltd	
Martin Darby	Slade & Cooper Ltd	
Mike Gibbons		
Mr John Stevenson		
Mrozowska Agata		
Natalia Larmer		
Nick Jackson		
Photography		
Ortensia Martinotti		
Pim van Wessel		
Rachel Edwards		
Ray Holden		
Riah Fairweather		
Rita Ross		
Sach Hirani		
Stephen Nesbitt		
Teresa Thomas		
Warrington Wolves		



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**Financial review 2023/2024:**

At the end of 2023, Reverse Rett had a £95,957 deficit, which was a 68% reduction from the previous year. However, the charity's reserves were depleted due to a 16% drop in income, raising concerns about its financial stability.

**Key Points:**

1. Deficit Causes:

- The deficit was mainly due to financial commitments to the CIPP Rett Centre and changes in billing from King's College London (KCL).
- The pandemic caused a major income drop, affecting fundraising and delaying payments to KCL.

2. Income Drop in 2023:

- Revenue from the gala decreased and staff changes impacted event planning.
- Despite these challenges, community fundraising and a special appeal improved overall income.

3. Current Situation (December 2024):

- Community fundraising has improved in 2024, with more funds raised than in previous years.
- The charity is taking steps to eliminate the deficit, including reducing support for the CIPP Rett Centre and hiring a new Senior Development Officer funded by a £60,000 grant from a grant giving trust.
- The charity has renegotiated the contract with the CIPP Rett Centre and reduced Centre funding by 56% from Sept 2024, allowing the charity to eliminate the deficit by Dec 2025.

These actions are aimed at restoring financial stability to pre-pandemic levels.

**Fundraising in 2023:**

Reverse Rett's fundraising is driven primarily by the families and friends of those with Rett or MECP2 Duplication syndromes, without the use of professional fundraisers. The charity adheres to the

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standards set by the Fundraising Regulator and displays the Regulator badge on its materials. It has three published fundraising policies and no complaints related to fundraising in 2023.

The charity supports its fundraisers through a Fundraising Manager, who provides guidance and organizes workshops. Reverse Rett does not engage in cold solicitations or aggressive fundraising tactics.

In 2023, income from Just Giving increased by 28% to £236,613.87, surpassing pre-pandemic levels and reflecting a strong revival of community fundraising efforts despite lower income from other events.

### **CIPP Rett Centre Urgent Appeal:**

The CIPP Rett Centre Urgent Appeal launched on July 1, 2023, aimed to rally community support. The appeal highlighted that the Centre, vital for UK clinical treatment and research, relies entirely on funding from Reverse Rett and needs ongoing community backing to continue its work.

### **Annual gala:**

In 2022, income from the Reverse Rett Gala fell by 26% due to the economic downturn. To address this, the charity reduced gala costs for 2023 by changing the venue and lowering capacity. However, with the resignation of the Events Manager early in 2023 and no replacement for the year, gala income dropped by 58% from 2022 to 2023 (£112,726 to £47,179). This significant decrease was largely due to the loss of key personnel.

### **Big Give Christmas Challenge:**

In 2023, income from the annual campaign was £71,973, up slightly from £70,330 in 2022. Growth in the Big Give Christmas Challenge is limited by the availability of matched funding. Donors are motivated by the prospect of their donations being matched, so when matched funds are depleted, donations typically decrease.

### **Community fundraising:**

Income from Just Giving increased by 28% in 2023, reaching £236,613.87, surpassing the 2019 figure. This shows a strong recovery in community fundraising for Reverse Rett after the pandemic, even though other events saw a decline in income.

### **Trusts and Foundations fundraising:**

In 2023, income from trusts and foundations dropped because the staff team was reduced by 40%, leading to fewer grant applications. In June 2024, Reverse Rett secured a grant to hire a full-time Trusts and Foundations fundraiser for three years.

### **In summary:**

At the end of 2023, Reverse Rett faced a deficit, though this was significantly reduced from the previous year. Despite the reduction in the deficit, the charity's reserves were depleted due to a 16% drop in income.

The deficit primarily stemmed from the charity's financial commitments to the CIPP Rett Centre and changes in billing practices from King's College London. The pandemic has also had a significant and long term impact on fundraising. This combination of issues led to the 2023 deficit.

- By September 2024, overall income has strengthened, with more funds raised than in previous years. To address the remaining deficit and restore financial stability, The charity has renegotiated the contract with the CIPP Rett Centre and reduced Centre funding by 56%

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from Sept 2024, allowing the charity to eliminate the deficit by Dec 2025 as well as securing a £60,000 grant to hire a new Senior Development Officer. This SDO is already in place with live applications out to prospective funders. These measures are part of the charity's strategy to return to a stable financial position, comparable to pre-pandemic levels.

### **Reserves Policy:**

Reverse Rett's financial policy dictates that the board of trustees will evaluate the necessary level of reserves for the charity. This assessment will account for factors such as redundancy liabilities, lease agreements, and other significant considerations in the event of the charity's closure. The goal is to maintain reserves equal to six months of operating costs by the end of the year.

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

In 2021, Reverse Rett published a new long-term strategy for the organization, entitled, 'Change is within Reach,' the Reverse Rett Strategy 2021-2026. This long-term strategy provides a foundation for the charity's subsequent Annual Plans including the 2023/2024 Annual Plans.

In 2023, Reverse Rett was focused on:

- Continuation funding of the CIPP Rett Centre
- Growing CIPP Rett Database/MPSS uptake
- Growing, maintaining and improving the Rett Registry UK
- Supporting industry partners currently implementing gene therapy clinical trials
- Providing ongoing clinical trial support services for UK Anavex trial
- Participating in regulatory and ethics applications for UK clinical trials of emerging treatments including direct presentations and provision of supporting materials through a variety of media
- Supporting industry partners with both UK-specific and international survey development re burden of illness in Rett Syndrome to support development of disease modifying treatments
- Access planning and preparation for UK Health Technology Assessments
- 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.
- Outreach to under-represented groups and undiagnosed /unidentified children, young people and adults with Rett Syndrome in order to ensure they are registered when new treatments become available.
- Providing online Bitesize sessions focused on community education around emerging gene therapies.
- Disseminating research-focused health information to families and caregivers of people with Rett Syndrome in the UK to help improve health outcomes.
- Supporting CIPP Rett Centre to disseminate research and clinical best practice information to improve medical management of everyone affected

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## **Fundraising:**

Fundraising enables all the work we do at Reverse Rett. In 2023, the charity worked hard to grow community fundraising and to implement the London Gala, Big Give Christmas Challenge and 365 Club. Each of the below challenges was led by Reverse Rett Co-founders/Senior Management:

- 100K Jurassic Juggernauts Challenge
- 100K Lake District Challenge
- Iceland Fire and Ice Trek 72K

## **2024**

2024 sees the continuation of Reverse Rett's above work to accelerate treatments for Rett syndrome underpinned by the four pillars within the charity's long term strategy, 'Change is within reach.' In 2025, the trustees will work to develop a follow on strategy to this document which runs until 2026.

None of the above work can happen without fundraising. Reverse Rett receives no government funding. The charity has to raise every penny of funds we need to continue our work.

The Trustees of Reverse Rett would like to thank everyone who makes our work possible for their ongoing support and commitment.

## **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 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 2023 was 12.

The Trustees of the Charity who served during the year ended December 31 2023 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.

As a parent-driven, patient organisation, Reverse Rett looks first to the Rett Syndrome community to recruit Trustees. In 2022, the Trustees highlighted the importance of recruiting additional board members who are not directly affected by Rett Syndrome. The current number of individuals personally

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affected on the board of Trustees (as of Sept 2024) is 9/12 compared to 8/11(July 2023). 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.

In 2022, the charity audited the recruitment process for Board members. A new more comprehensive recruitment process was developed. Potential trustees are nominated to the Board by one or more of the existing Board members. The individual is approached and sent an application pack. The individual returns their application. Chairman and CEO discuss and if appropriate, invite the individual to an informal interview. Subsequent to that interview, if it is agreed to be mutually beneficial, the individual is invited to observe a board meeting and to introduce themselves at the meeting.

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.

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.](#)

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 related parties
- Remuneration policy for key management personnel

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

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.

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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.

**Related parties and relationships with other organisations:**

Rett Syndrome Research Trust (USA) -international research funding

Opé Rett -research focused non-profit in France

Gudrun's E Rett Syndrome Research Trust - research focused non-profit in Iceland

Israel Rett Syndrome Research and Treatment Foundation

Rett Syndrome Ireland -Patient advocacy non-profit in Ireland

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

Acadia  
Anavex Life Sciences Corp.  
Neurogene Inc.  
Taysa Gene Therapies

**Risk management:**

During the annual in-person board meeting 2023, the charity trustees considered the major risks to which the charity is exposed.

These include but are not limited to sudden major decreases in income and key personnel changes.

**Sudden major decreases in income:**

In 2024, Reverse Rett received a £60,000 grant from the Fitton Trust to hire a Senior Development Officer. This role will focus on securing grants from trusts and foundations to support various projects, including the ongoing work of the CIPP Rett Centre. By boosting this important income source and simultaneously reducing its commitment to the CIPP Rett Centre, the charity aims to eliminate its deficit and build a financial reserve to handle future income fluctuations.

**Key personnel changes:**

Reverse Rett is run by a small team. Two key team members, CEO and CTL/FM are parents of children with Rett syndrome. There is an increased risk of emotional/physical burnout as well as a high risk of family illness/bereavement. As the two are related parties, any event striking one is likely to affect the other.

In 2023, Reverse Rett broadened the management base of the organization by recruiting an Operations Manager in support of the day to day running of the charity.

Not only does this help protect this small team against the loss of key personnel due to bereavement or illness, it eases the load on key personnel mitigating the loss of key personnel due to illness and or burn out.

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

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charity. The addition of another senior member of staff in the role of SDO will further mitigate the loss of key personnel at Reverse Rett and at no direct cost to the charity.

**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 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 off 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 in 2023 was one.

**Rett Registry UK:**

The Rett Registry UK is the UK's only patient registry for Rett syndrome and related MECP2 disorders. The Rett Registry UK is fully GDPR compliant with an in-built suite of safety features.

All fundraiser/supporter personal information is held separately 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.

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**Statement of responsibilities of the trustees:**

The trustees (who are also directors of Reverse Rett for the purposes of company law) are responsible for preparing the trustees' annual report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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

- Select suitable accounting policies and then apply them consistently
- Observe the methods and principles in the Charities SORP
- Make judgements and estimates that are reasonable and prudent
- State whether applicable UK Accounting Standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the trustees are aware:

There is no relevant audit information of which the charitable company's auditors are unaware.

The trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

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

The trustees annual report has been approved by the trustees on 27.12.24  
and signed on their behalf by:



Rachael Stevenson  
CEO, Reverse Rett



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 2023, 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 2023, 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.

## Material uncertainty relating to going concern

We draw attention to the disclosure in Note 1b in the financial statements, which indicates that the charitable company incurred a net unrestricted deficit of £55,111 during the year ended 31 December 2023 and, of that date, the charitable company's net liabilities exceeded its total assets by £95,957. As stated in Note 1b, these events or conditions, along with other matters as set out on Note 1b, indicate that a material uncertainty exists that may cast significant doubt on the charitable company's ability to continue as a going concern. Our opinion is not modified in respect of this matter.

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 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.

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

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 15, 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.

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:

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

- 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/auditorsresponsibilities>. 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.

*Jennifer Daniel*

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: 30/12/2024

Reverse Rett  
Statement of Financial Activities  
(including Income and Expenditure account)  
for the year ended 31 December 2023

	Note	Unrestricted funds £	Restricted funds £	Total funds 2023 £	Total funds 2022 £
<b>Income from:</b>					
Donations and legacies	3	454,358	-	454,358	436,744
Charitable activities:	4	215,268	4,650	219,918	329,294
<b>Total income</b>		<b>669,626</b>	<b>4,650</b>	<b>674,276</b>	<b>766,038</b>
<b>Expenditure on:</b>					
Raising funds	5	228,230	-	228,230	154,464
Charitable activities:	6	507,763	28,353	536,116	911,366
<b>Total expenditure</b>		<b>735,993</b>	<b>28,353</b>	<b>764,346</b>	<b>1,065,830</b>
<b>Net income/(expenditure) for the year</b>	8	<b>(66,367)</b>	<b>(23,703)</b>	<b>(90,070)</b>	<b>(299,792)</b>
Transfer between funds		11,256	(11,256)	-	-
<b>Net movement in funds for the year</b>		<b>(55,111)</b>	<b>(34,959)</b>	<b>(90,070)</b>	<b>(299,792)</b>
<b>Reconciliation of funds</b>					
Total funds brought forward		(81,788)	75,901	(5,887)	293,905
<b>Total funds carried forward</b>		<b>(136,899)</b>	<b>40,942</b>	<b>(95,957)</b>	<b>(5,887)</b>

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

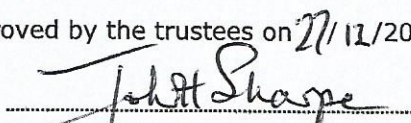
Reverse Rett  
Company number 07278507  
Balance sheet as at 31 December 2023

	Note	2023	2022
		£	£
<b>Fixed assets</b>			
Tangible assets	12	2,071	1,968
<b>Total fixed assets</b>		<b>2,071</b>	<b>1,968</b>
<b>Current assets</b>			
Debtors	13	40,995	109,909
Cash at bank and in hand		46,375	194,205
<b>Total current assets</b>		<b>87,370</b>	<b>304,114</b>
<b>Liabilities</b>			
Creditors: amounts falling due in less than one year	14	(185,398)	(311,969)
<b>Net assets</b>		<b>(95,957)</b>	<b>(5,887)</b>
<b>The funds of the charity:</b>			
Restricted income funds	15	40,942	75,901
Unrestricted income funds	16	(136,899)	(81,788)
<b>Total charity funds</b>		<b>(95,957)</b>	<b>(5,887)</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 22 to 35 form part of these accounts.

Approved by the trustees on 27/12/2024 and signed on their behalf by:

  
John H Sharpe (Chair)

Reverse Rett  
Statement of Cash Flows  
for the year ending 31 December 2023

	Note	2023 £	2022 £
<b>Cash provided by/(used in) operating activities</b>	19	<b>(146,102)</b>	<b>(150,170)</b>
<i>Cash flows from investing activities:</i>			
Purchase of tangible fixed assets		(1,728)	(1,549)
<b>Cash provided by/(used in) investing activities</b>		<b>(1,728)</b>	<b>(1,549)</b>
Increase/(decrease) in cash and cash equivalents in the year		(147,830)	(151,719)
Cash and cash equivalents at the beginning of the year		194,205	345,924
<b>Cash and cash equivalents at the end of the year</b>		<b>46,375</b>	<b>194,205</b>

## Notes to the accounts for the year ended 31 December 2023

### 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.

#### b Preparation of the accounts on a going concern basis

The financial statements have been prepared on a going concern basis which assumes that the charitable company will continue in operational existence for the foreseeable future. At the year end the charity had net current liabilities of £95,957. This is largely due to an ongoing funding commitment of £345,000 per annum made to one of its partners, the CIPP Rett Centre. From September 2024, this commitment has been reduced significantly down to £150,000 for the period September 2024-September 2025. (This is a 56% reduction in costs). From September 2025, the commitment will be £125,000 for the period from September 2025-September 2026.

In 2024, Reverse Rett received a restricted grant from the Fitton Trust enabling the charity to hire a dedicated Trusts and Foundations fundraiser for three years. This staff member is now in place and is targeted to raise £150,000 from trusts and foundations for the CIPP Rett Centre in 2025, further supporting the charity's position in maintaining a lower level of support for the CIPP Rett Centre from September 2024.

At the end of 2024, the charity will owe one outstanding payment to the CIPP Rett Centre with regards to 2024. The current payment schedule states that this payment is not due until March 2025 and an invoice will not be raised until then (£86,000). This credit arrangement will ensure that the charity maintains a healthy cashflow.

Community fundraising at Reverse Rett remains strong with multiple events and challenges planned for 2025.

The trustees have projected that the charity will end 2025 with a surplus of £112,000 due to the renegotiation of the CIPP Rett Centre funding commitment and therefore have considered it appropriate to prepare these accounts on a going concern basis.

Notes to the accounts for the year ended 31 December 2023 (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.



Notes to the accounts for the year ended 31 December 2023 (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 2023 (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 2023 (continued)

### 3 Income from donations and legacies

	Unrestricted £	Restricted £	Total 2023 £
Donations	410,554	-	410,554
Grants	14,500	-	14,500
Legacies	29,304	-	29,304
	<hr/>	<hr/>	<hr/>
<b>Total</b>	454,358	-	454,358
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

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

	<i>Unrestricted £</i>	<i>Restricted £</i>	<i>Total 2022 £</i>
<i>Donations</i>	<i>413,744</i>	<i>-</i>	<i>413,744</i>
<i>Grants</i>			
<i>Sylvia Aiken Trust</i>	<i>3,000</i>	<i>-</i>	<i>3,000</i>
<i>The Patrick and Helena Trust</i>	<i>20,000</i>	<i>-</i>	<i>20,000</i>
	<hr/>	<hr/>	<hr/>
<b>Total</b>	436,744	-	436,744
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

## Reverse Rett

Notes to the accounts for the year ended 31 December 2023 (continued)

### 4 Income from charitable activities

	Unrestricted £	Restricted £	Total 2023 £
The Big Give	71,973	-	71,973
London Event	47,179	-	47,179
Newron Pharmacy	-	4,650	4,650
Event Income	34,864	-	34,864
365 Income	12,660	-	12,660
Gift Aid	44,098	-	44,098
Other income	4,494	-	4,494
	<hr/>	<hr/>	<hr/>
<b>Total</b>	215,268	4,650	219,918
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

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

	Unrestricted £	Restricted £	Total 2022 £
<i>The Big Give</i>	80,427	-	80,427
<i>London Event</i>	112,726	-	112,726
<i>MECP2 Fund</i>	-	6,196	6,196
<i>Family events</i>	6,961	-	6,961
<i>Anavex germany GmbH</i>	46,779	28,915	75,694
<i>Gift Aid</i>	45,732	-	45,732
<i>Other income</i>	1,558	-	1,558
	<hr/>	<hr/>	<hr/>
<b>Total</b>	294,183	35,111	329,294
	<hr/>	<hr/>	<hr/>

### 5 Cost of raising funds

	2023 £	2022 £
Staff costs	143,975	32,791
Fundraiser's fees	14,909	12,821
365 Prizes	4,219	-
Event costs	65,127	108,852
	<hr/>	<hr/>
	228,230	154,464
	<hr/> <hr/>	<hr/> <hr/>

All expenditure on cost of raising funds is unrestricted.

## Reverse Rett

Notes to the accounts for the year ended 31 December 2023 (continued)

### 6 Analysis of expenditure on charitable activities

	Unrestricted £	Restricted £	Total 2023 £
Staff costs	71,570	-	71,570
Travel and accommodation	5,446	-	5,446
Kings College Grant	313,417	-	313,417
Clinical trial expense	1,151	19,893	21,044
CPMRS	36,000	-	36,000
MECP2	-	8,460	8,460
Governance costs (see note 7)	-	-	-
Support costs (see note 7)	80,179	-	80,179
	<hr/>	<hr/>	<hr/>
	507,763	28,353	536,116
	<hr/>	<hr/>	<hr/>

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

	Unrestricted £	Restricted £	2022 £
Staff costs	125,704	-	125,704
Transfer to Rett Syndrome Research Trust USA	99,992	-	99,992
Travel and accommodation	5,123	-	5,123
Clinical trial expense	-	28,915	28,915
CIPP Rett Centre	465,000	-	465,000
MECP2	-	7,474	7,474
Governance costs (see note 7)	5,988	-	5,988
Support costs (see note 7)	173,170	-	173,170
	<hr/>	<hr/>	<hr/>
	874,977	36,389	911,366
	<hr/>	<hr/>	<hr/>

## Notes to the accounts for the year ended 31 December 2023 (continued)

**7 Analysis of governance and support costs**

	Support £	Governance £	Total 2023 £
Office rental cost	14,315	-	14,315
Software Development	4,500	-	4,500
Office costs	35,147	-	35,147
Audit fees	3,888	-	3,888
Accountancy services	11,170	-	11,170
Legal and professional	11,018	-	11,018
Advertising and marketing	141	-	141
	<hr/>	<hr/>	<hr/>
	80,179	-	80,179
	<hr/>	<hr/>	<hr/>

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

This is stated after charging/(crediting):	2023 £	2022 £
Depreciation	1,625	1,736
Operating lease rentals:		
Property	-	-
Other	-	-
Auditor's remuneration - audit fees	3,240	3,240
Auditor's remuneration - accountancy fees	1,750	1,750
	<hr/>	<hr/>

## Reverse Rett

### Notes to the accounts for the year ended 31 December 2023 (continued)

#### 9 Staff costs

Staff costs during the year were as follows:

	2023 £	2022 £
Wages and salaries	193,881	224,759
Social security costs	14,606	18,288
Pension costs	7,058	8,598
	<hr/>	<hr/>
	215,545	251,645
	<hr/>	<hr/>
<b>Allocated as follows:</b>		
Cost of raising funds	143,975	32,791
Charitable activities	71,570	125,704
Support costs	-	93,150
	<hr/>	<hr/>
	215,545	251,645
	<hr/>	<hr/>

No employees has employee benefits in excess of £60,000 (2022: Nil).

The average number of staff employed during the period was 6 (2022: 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 £58,496 (2022: £57,512).

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

Two of the trustees Rachael Stevenson (Chief Executive) and Andrew Stevenson received remuneration totalling £100,400 during the year (2022: £98,854).

No trustee received travel and subsistence expenses during the year. (2022: nil).

Aggregate donations from related parties were £nil (2022: £nil).

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 £8,428 this year. (2022: £99,992).

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 (2022: nil).

## Notes to the accounts for the year ended 31 December 2023 (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**

	Computer equipment £
<b>Cost</b>	
At 1 January 2023	9,074
Additions	1,728
Disposals	-
	<hr/>
At 31 December 2023	10,802
	<hr/> <hr/>
<b>Depreciation</b>	
At 1 January 2023	7,106
Charge for the year	1,625
Disposals	-
	<hr/>
At 31 December 2023	8,731
	<hr/> <hr/>
<b>Net book value</b>	
At 31 December 2023	2,071
	<hr/> <hr/>
At 31 December 2022	1,968
	<hr/> <hr/>



## Reverse Rett

Notes to the accounts for the year ended 31 December 2023 (continued)

### 13 Debtors

	2023 £	2022 £
Other debtors	1,140	70,427
Prepayments and accrued income	25,156	26,982
Trade Debtors	4,699	-
Big Give debtor	10,000	12,500
	<hr/> 40,995	<hr/> 109,909
	<hr/> <hr/>	<hr/> <hr/>

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

	2023 £	2022 £
Trade creditors	165,536	293,621
Other creditors and accruals	8,138	6,973
Taxation and social security costs	11,724	11,375
	<hr/> 185,398	<hr/> 311,969
	<hr/> <hr/>	<hr/> <hr/>

## Reverse Rett

Notes to the accounts for the year ended 31 December 2023 (continued)

### 15 Analysis of movements in restricted funds

	Balance at 1 January 2023 £	Income £	Expenditure £	Transfers £	As at 31 December 2023 £
<i>MECP2</i>					
Duplication Fund	11,090	-	(8,460)	-	2,630
Rett disorder alliance	4,861	-	-	-	4,861
Use in Farringdon	200	-	-	(200)	-
Parent 2 Parent Programme	3,056	-	-	(3,056)	-
Clinical Research Funds	48,694	4,650	(19,893)	-	33,451
Pears Grant	8,000	-	-	(8,000)	-
<b>Total</b>	<b>75,901</b>	<b>4,650</b>	<b>(28,353)</b>	<b>(11,256)</b>	<b>40,942</b>

<b>Previous reporting period</b>	Balance at 1 January 2022 £	Income £	Expenditure £	Transfers £	31 December 2022 £
<i>MECP2</i>					
Duplication Fund	12,368	6,196	(7,474)	-	11,090
Rett disorder alliance	4,861	-	-	-	4,861
Use in Farringdon	200	-	-	-	200
Parent 2 Parent Programme	3,056	-	-	-	3,056
Clinical Research Funds	48,694	28,915	(28,915)	-	48,694
Pears Grant	8,000	-	-	-	8,000
<b>Total</b>	<b>77,179</b>	<b>35,111</b>	<b>(36,389)</b>	<b>-</b>	<b>75,901</b>

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

### Notes to the accounts for the year ended 31 December 2023 (continued)

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.
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 <i>MECP2</i> disorders. Through a one to one 'match', experienced parents provide emotional support to families and assist them in finding information and resources.  The Reverse Rett Parent 2 Parent project is now housed under Rett Connect umbrella. Please see here for more details. <a href="https://www.reverserett.org.uk/rett-connect/">https://www.reverserett.org.uk/rett-connect/</a>
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 <i>MECP2</i> Disorders in the UK.

## 16 Analysis of movement in unrestricted funds

	Balance at 1 January 2023 £	Income £	Expenditure £	Transfers £	As at 31 December 2023 £
General fund	(81,788)	669,626	(735,993)	11,256	(136,899)
	<hr/> (81,788) <hr/>	<hr/> 669,626 <hr/>	<hr/> (735,993) <hr/>	<hr/> 11,256 <hr/>	<hr/> (136,899) <hr/>
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>
<b>Previous reporting period</b>	<b>Balance at 1 January 2022 £</b>	<b>Income £</b>	<b>Expenditure £</b>	<b>Transfers £</b>	<b>As at 31 December 2022 £</b>
General fund	216,726	730,927	(1,029,441)	-	(81,788)
	<hr/> 216,726 <hr/>	<hr/> 730,927 <hr/>	<hr/> (1,029,441) <hr/>	<hr/> - <hr/>	<hr/> (81,788) <hr/>
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>
<b>Name of unrestricted</b>	<b>Description, nature and purposes of the fund</b>				
General fund	The free reserves after allowing for all designated funds				

## Reverse Rett

### Notes to the accounts for the year ended 31 December 2023 (continued)

#### 17 Analysis of net assets between funds

	General fund £	Designated funds £	Restricted funds £	Total £
Tangible fixed assets	2,071	-	-	2,071
Net current assets/(liabilities)	(138,970)	-	40,942	(98,028)
	<hr/>	<hr/>	<hr/>	<hr/>
Total	(136,899)	-	40,942	(95,957)
	<hr/>	<hr/>	<hr/>	<hr/>

#### 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	
	2023 £	2022 £	2023 £	2022 £
Less than one year	-	-	-	-
One to five years	-	-	-	-
	<hr/>	<hr/>	<hr/>	<hr/>
	-	-	-	-
	<hr/>	<hr/>	<hr/>	<hr/>

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

	2023 £	2022 £
<b>Net income/(expenditure) for the year</b>	(90,070)	(299,792)
<b>Adjustments for:</b>		
Depreciation charge	1,625	1,736
Decrease/(increase) in debtors	68,914	(59,106)
Increase/(decrease) in creditors	(126,571)	206,992
	<hr/>	<hr/>
<b>Net cash provided by/(used in) operating</b>	(146,102)	(150,170)
	<hr/>	<hr/>