

# REVERSE RETT

England & Wales · Charity number 1136809

## Details

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Other names	RETT SYNDROME RESEARCH TRUST UK, REVERSE RETT, RSRT UK
Status	Registered
Legal form	Charitable company
Company number	<a href="#">07278507</a>
Registered	2010-07-12
Register	<a href="#">View on the Charity Commission register</a>

## Contact

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Address	Reverse Rett Beehive Mill Jersey Street Manchester M4 6JG
Phone	01615525001
Email	<a href="mailto:enquiries@reverserett.org.uk">enquiries@reverserett.org.uk</a>
Website	<a href="http://www.reverserett.org.uk">http://www.reverserett.org.uk</a>

## Activities

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**Objects:** THE CHARITY'S OBJECTS (THE OBJECTS) ARE:4.1 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:4.1.1 FUNDING RESEARCH PROJECTS;4.1.2 ORGANISING AND SPONSORING SCIENTIFIC WORKSHOPS;4.1.3 COLLATING INFORMATION FROM EXPERTS IN THE FIELD AND PROVIDING ACCESS TO IT; AND4.1.4 INCREASING GENERAL PUBLIC AWARENESS AND KNOWLEDGE OF RETT SYNDROME AND RELATED MECP2 DISORDERS.

**Activities:** Reverse Rett is a patient advocacy and research organisation focused on delivering treatments and a cure for Rett syndrome and related MECP2 disorders.

## Classification

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- **How:** Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** People With Disabilities

## Geography

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- **Area of benefit:** UNDEFINED. IN PRACTICE, LOCAL
- Northern Ireland
- Scotland
- Throughout England And Wales

## Finances

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Period end	Income	Expenditure	Assets	Employees
2024-12-31	£809,095	£764,346	£-97,625	5
2023-12-31	£674,276	£764,346	£-95,957	5
2022-12-31	£766,038	£1,065,830	£-5,887	7
2021-12-31	£716,294	£853,343	£293,905	7
2020-12-31	£651,424	£679,401	£430,954	7

## Trustees

Name	Role	Appointed
John Harald Sharpe	Chair	2014-03-24
ANDREW JOHN STEVENSON		2010-07-09
Catherine McKinney		2018-03-02
Helen Kay Simmonds		2012-06-28
Joanna K L Snyder		2020-09-28
Jocelyn LeBlanc Ph.D		2023-02-10
Kate McMaster		2018-04-26
Matthew James Billingsley		2024-09-19
Michael Christopher Jones		2022-11-16
Natalia Larmer		2025-10-31
Oliver Freeman		2023-12-05
Rachael Stevenson		2010-07-09

**REVERSE RETT**

England & Wales - Charity number 1136809

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# Accounts

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**Report and financial statements for the year ended 31 December 2024**

Registered charity in England & Wales (1136809) and in Scotland (SC046735)  
Registered in England & Wales Company number: 07278507

Reverse Rett  
Reference and Administrative details  
For the year ended 31st December 2024

**Company number** 07278507

**Charity number** 1136809 in England and Wales, SC046735 in Scotland

**Registered office and operational address**

Reverse Rett, Beehive Mill, Jersey Street, 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 Harald Sharpe	Chair
Helen Kay Simmonds	Vice Chair
Rachael Emma Stevenson*	
Andrew John Stevenson*	
Michael Christopher Jones	
Dr Ruksana Ahmed	*resigned 22.04.25
Joanna K L Snyder	
Kate McMaster	
Catherine McKinney	
Ortensia Martinotti	*resigned 22.04.25
Jocelyn LeBlanc Ph.D	
Oliver Freeman	
Matthew Billingsley	*joined 19.09.24

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

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

<b>Key management</b>	Chief Executive	Rachael Stevenson
<b>Personnel</b>	Operations Manager	Catherine Sim

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

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

The trustees present their report and the audited/unaudited 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 10

## **Objectives and Activities**

**Mission:** Reverse Rett is a patient advocacy and research organisation focused on delivering treatments and a cure for Rett Syndrome.

### **Charity Objectives (as per governing document):**

- Fund laboratory and clinical research projects.
- Advocate for access to treatments and therapies.
- Disseminate research and health information.
- Raise public awareness of Rett Syndrome and MECP2 disorders.

### **Main Activities in Relation to Objectives:**

#### **Rett Registry UK**

- Launched in 2014 to support UK clinical trial readiness; now holds data on 813 patients.
- Redesigned as an independently hosted app, enhancing usability, security, and patient control over data.
- Enables efficient clinical trial recruitment and strengthens advocacy for treatment access.
- Recruitment of 94 patients in 2024: and 101 patients in 2025

#### **Clinical Care Funding**

##### **CIPP Rett Centre, King's College London:**

- 2024 funding: £332,586 (£296,586 plus £36,000 for HealthTracker)
- Centre currently manages 200+ complex patients with Rett syndrome.
- Reverse Rett supported clinical stabilisation amid increased need post pandemic.
- Funding ends 1 August 2025.

##### **HealthTracker Licensing:**

- £36,000 (2024), £36,000 (2023).
- CIPP Rett CCIPP Rett Centre Platform enables real-time symptom tracking and group-level analysis.

#### **International Research**

- Over £8 million delivered to RSRT since 2010, enabling gene therapy development.
- Reverse Rett expects to resume funding RSRT projects in late 2025/early 2026.

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### **UK Research**

- All research peer-reviewed per AMRC standards.
- 2024: One £30,000 grant approved, restricted donation of £30,000 to fund Singh project.

### **MECP2 Duplication Syndrome Research (via RSRT)**

- 2024: £2250 community fundraising income.
- Ongoing funding dependent on Cure MDS UK family fundraising.

### **LEAP Education Day**

- Annual community education conference, cost in 2024: £17,108.51
- Sponsorship received for 2024 LEAP Education Day: £32,500

### **Community Education and Network**

#### **Parent 2 Parent / Rett Connect:**

- 2023: £0 spent, £3,056 remaining.
- Initiated in 2012, evolved to include 20 WhatsApp groups, Reverse Rett Community Facebook Group, and Reverse Rett Bitesize on line workshops.

#### **Reverse Rett Bitesize Workshops (2024):**

- 5 sessions, 352 sign-ups, **975 views on YouTube**

#### **Top-performing topics:**

*"An Easy Intro to Gene Therapy for Rett"* Rachael Stevenson (250 views)

*"Taysha Gene Therapies lets us look inside"* (238 views)

*"Dr Jay Shetty talks gene therapy and seizures"* (220 views)

Indicating strong audience interest in foundational gene therapy education and expert-led insights into current research.

### **Industry Support**

- Collaboration with partners on program development, regulatory applications, community surveys, and patient communication.

### **Health Checklist**

- Developed in 2019 with Rett UK and FOXG1; shared with families and clinicians. Plans to update in 2025 are underway.

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**Rett Disorders Alliance Fund:**

- Printing, postage and publication costs for the Health Checklist for the period 2019 – 2025 - £5000 (Printing/Postage costs - £3500, Online Publication costs - £1500)

**Public Benefit**

- Trustees review aims annually and align with Charity Commission guidance.

**Governance & Support Costs (2024):**

- Audit and accountancy required for charities with income over £500,000.
- Staff support split:
  - CEO: 90% charitable, 10% support.
  - Clinical trial lead: 90% charitable, 10% support.
  - Admin/coordinator: 80% charitable, 20% support.
  - Marketing: 20% charitable, 80% support.
  - Fundraiser (ended): 100% fundraising (0.4 FTE).
  - Events/Outreach (ended Feb 2023): 100% charitable.
  - Finance Officer (ended Mar 2023): 100% charitable.
  - Operations Manager (joined Jun 2023): 30% charitable, 70% support.

**Achievements and Performance**

Reverse Rett continues to lead the drive for treatments for Rett syndrome in the UK. Since 2010, it has supported key milestones including the 2024 MHRA approval of UK clinical trials for Neurogene and Taysha programs.

Reverse Rett remains committed to driving UK equality in access to emerging treatments for all patients regardless of age or gender.

**Membership and Credibility**

- Reverse Rett is a Full AMRC member; meets rigorous research funding standards.
- Continues comprehensive outreach programs to register more UK patients.
- Has provided 6 years of core funding to the CIPP Rett Centre, advancing complex UK patient care and research.

Reverse Rett remains proud of its achievements and optimistic about future breakthroughs.

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## **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.

There are currently no approved treatments in the UK, either to delay progression or ameliorate symptoms. At Reverse Rett, we work to accelerate treatments whilst empowering families and carers to keep their child, young person or adult with Rett syndrome as healthy as possible for as long as possible.

Our number one focus is on enabling these patients to access to emerging treatments as soon as they become available. We empower our community to take action in support of this work to help improve the lives of everyone affected, both now and in the future.

The Board of Trustees gratefully acknowledges the generosity of individuals, companies, and community groups who have raised funds for Reverse Rett through online platforms including JustGiving, the Big Give Christmas Challenge, Facebook birthdays, and other fundraising campaigns.

## **Financial Overview:**

### **2023 Background**

In 2023, Reverse Rett reported a **£95,957 deficit**, a **68% reduction** from the previous year, despite a **16% drop in income**. This was largely due to ongoing funding commitments to the CIPP Rett Centre and revised billing from King's College London (KCL), following pandemic-related delays in payment processing.

Although gala income declined and staff transitions disrupted event planning, a special appeal and strong community support helped partially offset these losses. However, the charity's **reserves were significantly depleted**, raising concerns about long-term financial stability.

## 2024 Financial Recovery and Growth

In 2024, the charity made significant progress:

- **Income increased by 17%** to **£809,095** (2023: £674,276).
- **Expenditure rose modestly by 4%** to **£793,670** (2023: £764,346), reflecting inflation and cost-of-living pressures.
- As a result, the **deficit narrowed by £15,425**, marking a continued trend towards financial recovery.

Key actions taken include:

- **Renegotiating the CIPP Rett Centre contract**, reducing funding by **56% from September 2024**.
- **Hiring a Senior Development Officer**, funded by a **£60,000 grant**, to enhance fundraising capacity.

## Outlook for 2025

With CIPP Rett Centre funding due to conclude on **1 September 2025**, Reverse Rett is on track to return to financial surplus. The charity is **projected to end 2025 with an £112,000 surplus**, restoring financial stability to pre-pandemic levels.

## Fundraising in 2024

Reverse Rett's fundraising is primarily driven by families and friends of those affected by Rett or *MECP2* Duplication Syndrome (MDS). The charity does not use professional fundraisers.

Reverse Rett is registered with the **Fundraising Regulator** and fully compliant with its standards, displaying the Regulator badge on all fundraising materials. Reverse Rett has **three published fundraising policies**, and **no failures** to comply with these policies or standards occurred in 2024.

Key fundraising practices:

- No cold calling, mailing, or street solicitation is undertaken or permitted.
- Fundraisers are supported directly by our Fundraising Manager from the outset.
- Online fundraising workshops are provided throughout the year.
- Fundraisers are advised not to place undue pressure on potential donors or to persistently solicit.

## Fundraising Oversight and Complaints

- All fundraising activity is monitored through direct relationships with supporters.
- The charity received **zero complaints** about its fundraising activities in 2024.
- Reverse Rett did **not act as a custodian trustee** during the reporting period.

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## Reverse Rett Fundraising Summary – 2024

2024 was a strong year for Reverse Rett fundraising, with income growth across multiple streams:

- **JustGiving income** rose by **131%**, reaching **£284,987** (2023: £217,101).
- The **London Event** raised **£72,677**, up from **£47,179** in 2023.
- **Big Give Christmas Challenge** income increased by **29%** to **£92,607** (2023: £71,973). Reverse Rett has already secured the full £25,000 match funding required for the 2025 campaign.
- **365 Club**, the monthly digital prize draw, grew modestly, bringing in **£13,590** (2023: £12,660).
- **Trusts and Foundations** income rose by **38%**, from **£14,500** to **£20,000**, supported by the appointment of a dedicated fundraiser in September 2024. Since then, **38 funding applications** have been submitted.

These gains reflect a year of renewed momentum and capacity-building, positioning the charity for sustained growth into 2025.

### Regular monthly giving 2024

- **42 donors - JustGiving (19 Anonymous)**
- **40 donors - Donorfy**
- **8 donors - Bank account**

**The Reverse Rett 365 Club** currently has 263 members which is an increase from 244 in 2024 (7%). There is scope for the charity to increase membership with a targeted campaign in 2025. The club can accommodate 365 members.

### Financial Position and Reserves

The charity currently holds no free reserves as laid out in Note 1B to the accounts.

Per our reserves policy, Reverse Rett aims to hold **six months of operating costs** at the end of each year, to cover redundancy liabilities, lease agreements, and other key obligations should the charity cease operations.

- **Cash held at year-end 2024:** £64,184.97
- **Cash balance projection at the end of 2025:** £112,000

## Strategic Direction

Reverse Rett's 5-year strategy, "**Change is Within Reach**" (2021–2026), continued to guide the charity's Annual Plan in 2024 and 2025. A new strategy is under development and will be shared in Q1 2026.

### Key Focus Areas in 2024:

**CIPP Rett Centre** tapering of funding with a view to completing Centre funding to a close in 2025.

- ✓ Growth of the **Rett Registry UK**.
- ✓ Support for **industry partners** delivering gene therapy trials.
- ✓ Support for industry-led UK and international **burden-of-illness surveys**.
- ✓ Build tools and resources to support **UK regulatory submissions**.
- ✓ Raised **public awareness of Rett and MECP2 Duplication** Syndromes.
- ✓ Targeted **outreach to undiagnosed or unregistered** individuals.
- ✓ Targeted **health information** to families.
- ✓ **Online Bitesize education sessions** focused on managing health complexities.
- ✓ **National conference** bringing patients, families, clinicians and industry together to learn.

Fundraising enables all the work we do at Reverse Rett. In 2024, the charity implemented the following key fundraising goals as well as implementing the London Gala, Big Give Christmas Challenge and 365 Club throughout 2024. Each of the below challenges was led by Reverse Rett Co-founder/Senior Management.

- 100K Jurassic Trek
- 100K Lake District Challenge
- Manchester Marathon

### Reverse Rett: Focus Areas for 2025

In 2025, Reverse Rett continues its mission to accelerate treatments and improve outcomes for people with Rett syndrome. Key areas of focus for the year include:

- **Expanding Rett Registry UK**

Through regular seasonal campaigns and personalised outreach, the charity aims to grow the Registry to ensure more individuals are trial-ready as new treatments become available.

- **Building the UK Cost of Illness Model**

In partnership with Costello Medical, Reverse Rett is developing a UK-specific cost of illness model to support future Health Technology Assessments and improve access to emerging treatments.

- **Conducting a UK Mortality Survey**

A nationwide survey will be undertaken to better understand early mortality in Rett syndrome and strengthen the evidence base for health policy and resource planning.

- **Developing an Emergency Alert Card**

A new tool will be introduced to help frontline healthcare professionals identify key clinical risks when individuals with Rett syndrome present at A&E.

- **Delivering Targeted Education on Respiratory Care**

Focused community education initiatives will address respiratory complications, a leading contributor to poor outcomes in Rett syndrome.

- **Transitioning the CIPP Rett Centre**

After six years of funding the Centre, Reverse Rett will begin to step back, while continuing to support families to access services through NHS funding where appropriate.

- **Supporting Clinical Trials and Industry Research**

The charity will continue working closely with industry partners delivering gene therapy trials and contributing to UK and global studies on the burden of Rett syndrome.

- **Raising Awareness and Reaching the Undiagnosed**

Reverse Rett will increase public awareness of both Rett syndrome and MECP2 Duplication Syndrome and conduct targeted outreach to under-represented and undiagnosed individuals to ensure inclusion in future treatment opportunities.

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## Acknowledgements

The Trustees thank our tremendous Reverse Rett community; in particular, our Reverse Rett Ambassadors and all individuals, families, fundraisers and donors whose ongoing support makes our work possible.

Our special appreciation goes out to each and every one of our children, young people and adults with Rett syndrome who inspire this support

### Individual

Andrews, Julie  
Bird, Albert  
Bird, Jennifer and Derek  
Darby, Martin  
Fraser, Craig  
Gruber, Carol  
Hamilton, J  
Jones, Sally  
Snaith, Ben  
Wainwright, David  
Snaith, Ben  
Wainwright, David  
Walls, Claire

### Companies

A Star Experience,  
Acadia Pharmaceutical,  
Ballymore,  
Black Bridge,  
Enthuse,  
Glastonbury Festival,  
Global E,  
Group Metropolitan  
Harris & Trotter,  
Bolton Ladies Rounders  
Buxton Ladies Group

### Trusts & Foundations

Opé Rett,  
Charities Aid Foundation,  
Highcliffe Charity HCP,  
MECP2 Research,

## Ambassadors

- **Gareth O'Brien** – Rugby League Player (Leigh Leopards / Castleford Tigers)
- **David Ford** – Musician
- **Rhea Kara** – Artist and Pride of Britain Award Winner
- **Gary Chambers** – Director of Rugby at Warrington Wolves
- **Karl Morris** – Founder of The Mind Factor
- **Dominic Laurie** – BBC Presenter
- **Giles Coren** – TV and Radio Presenter
- **Carl Greaves** – Boxing Promoter and Trainer
- **Erin Eaves** – Award W-inning Fundraiser
- **David Rouse** – Former Professional Footballer & Goalkeeping Coach
- **Mark "Mavis" Reilly** – Former Professional Footballer, Ultra Athlete & Author
- **Richard Marshall** – Assistant Coach at Warrington Wolves

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**Regional Ambassadors**

Baine, Glenn	Lashbrooke, Ben	Ross, Rita
Baine, Tara	Lashbrooke, Debbie	Rutherford, Hayley
Billingsley, Louise	Lilly, Sarah	Sargent, Kerry
Buckley, Kate	Lishomwa, Mary	Sawyers, Dan
Buckley, Neil	Lishomwa, Siseho	Selby, Eylem
Coles, Catherine	Lorimer, Amanda	Sharpe, John
Connolly, Jim	Louden, Rhiannon	Simmonds, Helen
Coverley, Caren	Mackenzie, Brendon	Sloan, Scott
Cozic, Bertrand	Marsden, Emily	Smith, Julie
Crookes, Simone	Martinotti, Ortensia	Smith, Katherine
Davidson, Mary	McCready, Katherine	Smith, Liam
Davidson, Melise	McDonald, Jamie	Snyder, Joanna
Douglas-Hamilton, Ely	McGregor-Sims, Deucalion	Spence, Jill
Ellis, Stephanie	Mckendrick, Bonnie	Starbuck, Sarah
Etherington, Andrew	McKinney, Angus	Stevenson, Andy
Freeman, Rodrigo	McKinney, Catherine	Stevenson, Rachael
Fullbrook, Georgie	McKinney, Ross	Taylor, Sarah
Fullbrook, Jayne	Mcmaster, Kate	Tree, Myfanwy
Havill, Wesley	McMaster, Scott	Wainwright, David J
Hodgson, Dan	Monti, Pamela	Wainwright, Louise
Hodgson, Eva Claire	Moore, Allan	Walls, Claire
Hunt, Donna	Morrison, Anna	Walls, Mark
Johnson, Jo	Nightingale, Jill	Walsh, Mark
Jones, Kylie	Owen, Sion	Warne, Gareth
Kensington, Kate	Prebble, Victoria	Wasowska, Ewelina
Langhorne, Shazza	Rajan, Lisa	White, Tanya
Larmer, Jackie	Read, Denise	Wood, Al
Larmer, Natalia	Reilly, Mark	Wood, Stephanie
Reilly, Sylvia	Ricketts, Josh	

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## **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 2024 was 11.

The Trustees of the Charity who served during the year ended December 31, 2024 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. 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.*

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

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

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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. These salaries are highlighted under **Trustee remuneration and expenses, and related party transactions** due to AS and RES Trustee status.

These figures reflect **salary only** and are not additional expenses recovered by AS and RES in relation to their employment at Reverse Rett.

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 detailed below under **Trustee remuneration and expenses, and related party transactions**.

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

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

- Acadia
- Anavex Life Sciences Corp.
- Neurogene Inc.
- Taysha Gene Therapies

## Risk Management

At the 2024 annual in-person meeting, trustees reviewed key risks, including:

1. **Sudden drop in fundraising** – mitigated by a six-month reserve policy
2. **Key personnel changes** – especially as two senior staff are related and parents of children with Rett Syndrome

To reduce risk, an **Operations Manager** was appointed in 2023, easing workload and improving continuity. The charity also holds **key personnel insurance** for the CEO. **Trustee Recruitment and Board Composition**

Proposed trustees are invited to attend a board meeting to introduce themselves, after which a vote is held. In 2022, the Trustees prioritised diversifying the Board by recruiting members not directly affected by Rett Syndrome. As of July 2025, **9 of Trustees** are personally affected, compared to **8 in July 2023**.

## Fundraising Standards and Complaints

Reverse Rett is registered with the **Fundraising Regulator** and adheres to the **Code of Fundraising Practice** and the **Fundraising Promise**. All fundraisers receive clear policies outlining acceptable practices.

- No telephone, mail, or street solicitations are used or permitted.
- Personal data is securely managed via **Donorfy** and GDPR-compliant systems.
- In 2022, the charity received **three complaints** relating to the #FreeFromRett campaign.

## Governance and Oversight

- No external party may appoint Trustees.
- Trustees receive induction through one-to-one sessions with the Chair and relevant support materials.
- Daily operations are delegated to the CEO.
- All expenditure over **£20,000** must be approved by both the **CEO** and **Board Chair**.

The Board reviews and approves:

- New or amended policies
- Research project funding
- Salary changes for the CEO and related parties
- Remuneration policy for senior staff

**Conflict of Interest declarations** are signed annually by all Trustees.

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**Remuneration and Related Party Transactions**

Two Trustees, **Rachael Stevenson** and **Andrew Stevenson**, are full-time employees. As Founding Trustees, they are recused from decisions relating to their employment. Salary adjustments are made by the remaining Board members.

Employment of Trustees is permitted under **Article 6.4.2** of the charity's Articles of Association, provided the majority of trustees do not receive financial benefit.

All other Trustees serve voluntarily and receive no remuneration. Reimbursed expenses (if any) are disclosed in **Note 10** of the accounts.

### **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 24/09/2025 and signed on their behalf by

Rachael Stevenson CEO

# 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 2024, 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 2024, 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 £46,925 during the year ended 31 December 2024 and, of that date, the charitable company's net liabilities exceeded its total assets by £97,625. 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 17, 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

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

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/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.

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: 25/09/2025

Reverse Rett  
Statement of Financial Activities  
(including Income and Expenditure account)  
for the year ended 31 December 2024

	Note	Unrestricted funds £	Restricted funds £	Total funds 2024 £	Total funds 2023 £
<b>Income from:</b>					
Donations and legacies	3	450,088	67,093	517,181	454,358
Charitable activities:	4	289,664	2,250	291,914	219,918
<b>Total income</b>		<b>739,752</b>	<b>69,343</b>	<b>809,095</b>	<b>674,276</b>
<b>Expenditure on:</b>					
Raising funds	5	294,155	3,824	297,979	228,230
Charitable activities:	6	492,522	20,262	512,784	536,116
<b>Total expenditure</b>		<b>786,677</b>	<b>24,086</b>	<b>810,763</b>	<b>764,346</b>
<b>Net income/(expenditure) for the year</b>	8	<b>(46,925)</b>	<b>45,257</b>	<b>(1,668)</b>	<b>(90,070)</b>
Transfer between funds		-	-	-	-
<b>Net movement in funds for the year</b>		<b>(46,925)</b>	<b>45,257</b>	<b>(1,668)</b>	<b>(90,070)</b>
<b>Reconciliation of funds</b>					
Total funds brought forward		(136,899)	40,942	(95,957)	(5,887)
<b>Total funds carried forward</b>		<b>(183,824)</b>	<b>86,199</b>	<b>(97,625)</b>	<b>(95,957)</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 2024

	Note	2024	2023
		£	£
<b>Fixed assets</b>			
Tangible assets	12	2,415	2,071
		<b>2,415</b>	<b>2,071</b>
<b>Current assets</b>			
Debtors	13	96,404	40,995
Cash at bank and in hand		64,496	46,375
		<b>160,900</b>	<b>87,370</b>
<b>Liabilities</b>			
Creditors: amounts falling due in less than one year	14	(260,940)	(185,398)
		<b>(97,625)</b>	<b>(95,957)</b>
<b>Net assets</b>			
		<b>(97,625)</b>	<b>(95,957)</b>
<b>The funds of the charity:</b>			
Restricted income funds	15	86,199	40,942
Unrestricted income funds	16	(183,824)	(136,899)
		<b>(97,625)</b>	<b>(95,957)</b>
<b>Total charity funds</b>			
		<b>(97,625)</b>	<b>(95,957)</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 23 to 37 form part of these accounts.

Approved by the trustees on 24/09/2025 and signed on their behalf by:

.....  
John H Sharpe (Chair)

Reverse Rett  
Statement of Cash Flows  
for the year ending 31 December 2024

	Note	2024 £	2023 £
<b>Cash provided by/(used in) operating activities</b>	19	<b>19,672</b>	<b>(146,102)</b>
<i>Cash flows from investing activities:</i>			
Purchase of tangible fixed assets		(1,551)	(1,728)
<b>Cash provided by/(used in) investing activities</b>		<b>(1,551)</b>	<b>(1,728)</b>
Increase/(decrease) in cash and cash equivalents in the year		18,121	(147,830)
Cash and cash equivalents at the beginning of the year		46,375	194,205
<b>Cash and cash equivalents at the end of the year</b>		<b>64,496</b>	<b>46,375</b>

# Reverse Rett

## Notes to the accounts for the year ended 31 December 2024

### 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 Trustees have assessed the ability of Reverse Rett to continue as a going concern for the period December 2024 to December 2025.

Following a significant deficit in 2023 (£95,957), the charity implemented measures to reduce expenditure and strengthen income streams. In 2024, income increased by 17% to £809,095, while expenditure rose by only 4% to £793,670. The annual deficit narrowed to £15,425, reflecting improved fundraising performance and the successful renegotiation of the CIPP Rett Centre contract, which will conclude on 31 August 2025.

Looking forward, the ending of this funding commitment places the charity on course to return to surplus, with a projected £82,925 surplus in 2025. Fundraising performance has remained in line with projections to date, with strong growth across community fundraising, trusts and foundations, and key events.

The Trustees have considered the principal risks to going concern, including loss of staff and loss of key supporters. Mitigation steps include subcontracting finance functions, investing in operational capacity, and recruiting a Senior Development Officer funded by a three-year grant. While the wider cost-of-living crisis continues to challenge family fundraising, Reverse Rett has diversified income streams and maintained a strong supporter base, including the 365 Club and ongoing legacy campaigns.

The charity has no material liabilities beyond manageable lease commitments and the tapered conclusion of the CIPP Rett Centre funding. Cash flow forecasts indicate the charity will be able to meet its obligations as they fall due. The Trustees are confident that Reverse Rett will continue to operate as a going concern for the period under review and into 2026 and therefore have considered it appropriate to prepare these accounts on a going concern basis.

## Reverse Rett

### Notes to the accounts for the year ended 31 December 2024 (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 2024 (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 2024 (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 2024 (continued)

### 3 Income from donations and legacies

	Unrestricted £	Restricted £	Total 2024 £
Donations	398,092	17,093	415,185
Grants	1,996	-	1,996
Legacies	50,000	50,000	100,000
	450,088	67,093	517,181
<b>Total</b>	<b>450,088</b>	<b>67,093</b>	<b>517,181</b>

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

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

## Reverse Rett

Notes to the accounts for the year ended 31 December 2024 (continued)

### 4 Income from charitable activities

	Unrestricted £	Restricted £	Total 2024 £
The Big Give	92,607	-	92,607
MECP2 Fund	-	2,250	2,250
London Event	72,677	-	72,677
Event Income	5,950	-	5,950
Gift Aid	104,716	-	104,716
365 Income	13,590	-	13,590
Other income	124	-	124
	289,664	2,250	291,914
<b>Total</b>	289,664	2,250	291,914

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

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

### 5 Cost of raising funds

	2024 £	2023 £
Staff costs	168,449	143,975
Fundraiser's fees	13,470	14,909
365 Prizes	3,676	4,219
Event costs	112,384	65,127
	297,979	228,230
	297,979	228,230

All expenditure on cost of raising funds is unrestricted except for £3,824 of event costs which are restricted (2023:£Nil).

## Reverse Rett

Notes to the accounts for the year ended 31 December 2024 (continued)

### 6 Analysis of expenditure on charitable activities

	Unrestricted £	Restricted £	Total 2024 £
Staff costs	81,884	-	81,884
Travel and accommodation	1,886	-	1,886
Kings College Grant	296,583	-	296,583
Clinical trial expense	491	3,169	3,660
CPMRS	36,000	-	36,000
MECP2	-	17,093	17,093
Governance costs (see note 7)	9,444	-	9,444
Support costs (see note 7)	66,234	-	66,234
	492,522	20,262	512,784
	492,522	20,262	512,784

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

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

## Reverse Rett

Notes to the accounts for the year ended 31 December 2024 (continued)

### 7 Analysis of governance and support costs

	Support £	Governance £	Total 2024 £
Office rental cost	13,001	-	13,001
Office costs	32,887	-	32,887
Audit fees	-	4,320	4,320
Accountancy services	15,794	-	15,794
Legal and professional	4,525	5,124	9,649
Advertising and marketing	27	-	27
	66,234	9,444	75,678
	66,234	9,444	75,678

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

	2024 £	2023 £
This is stated after charging/(crediting):		
Depreciation	1,207	1,625
Auditor's remuneration - audit fees	3,400	3,240
Auditor's remuneration - accountancy fees	1,850	1,750
	6,457	6,615

## Reverse Rett

### Notes to the accounts for the year ended 31 December 2024 (continued)

#### 9 Staff costs

Staff costs during the year were as follows:

	2024 £	2023 £
Wages and salaries	221,820	193,881
Social security costs	19,642	14,606
Pension costs	8,871	7,058
	<hr/>	<hr/>
	250,333	215,545
	<hr/> <hr/>	<hr/> <hr/>
<b>Allocated as follows:</b>		
Cost of raising funds	168,449	143,975
Charitable activities	81,884	71,570
Support costs	-	-
	<hr/>	<hr/>
	250,333	215,545
	<hr/> <hr/>	<hr/> <hr/>

One employee has employee benefits in excess of £60,000 (2023: Nil).

The average number of staff employed during the period was 5.3 (2023: 6).

The key management personnel of the charity comprise the trustees, the Chief Executive Officer and the Operations Manager (employed from July 2023). The total employee benefits of the key management personnel of the charity were £114,169 (2023: £88,895).

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

Two of the trustees Rachael Stevenson (Chief Executive) and Andrew Stevenson received remuneration totalling £114,169 during the year (2023: £100,400).

Three trustees received travel and subsistence expenses during the year of £942.95. (2023: nil).

Aggregate donations from related parties were £34,000 (2023: £34,000).

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

The Chief Executive and a director of Reverse Rett, Rachael Stevenson is on the Board of Rett Syndrome Research Trust USA.

Reverse Rett did not make charitable grant to Rett Syndrome USA this year. (2023: £8,428).

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 (2023: nil).

## Reverse Rett

### Notes to the accounts for the year ended 31 December 2024 (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 2024	10,802
Additions	1,551
Disposals	-
	<hr/>
At 31 December 2024	12,353
	<hr/> <hr/>
<b>Depreciation</b>	
At 1 January 2024	8,731
Charge for the year	1,207
Disposals	-
	<hr/>
At 31 December 2024	9,938
	<hr/> <hr/>
<b>Net book value</b>	
At 31 December 2024	2,415
	<hr/> <hr/>
<i>At 31 December 2023</i>	<i>2,071</i>
	<hr/> <hr/>

## Reverse Rett

Notes to the accounts for the year ended 31 December 2024 (continued)

### 13 Debtors

	2024	2023
	£	£
Other debtors	3,645	1,140
Prepayments and accrued income	26,816	25,156
Trade Debtors	600	4,699
Gift Aid Debtor	20,343	-
Big Give debtor	45,000	10,000
	96,404	40,995
	96,404	40,995

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

	2024	2023
	£	£
Trade creditors	218,985	165,536
Other creditors and accruals	29,183	8,138
Taxation and social security costs	12,772	11,724
	260,940	185,398
	260,940	185,398

## Reverse Rett

Notes to the accounts for the year ended 31 December 2024 (continued)

### 15 Analysis of movements in restricted funds

	Balance at 1 January 2024 £	Income £	Expenditure £	Transfers £	As at 31 December 2024 £
<i>MECP2</i>					
Duplication Fund	2,630	19,343	(17,093)	-	4,880
Rett disorder alliance	4,861	-	-	-	4,861
The Fitton Trust	-	20,000	-	-	20,000
Singh Research	-	30,000	-	-	30,000
Clinical Research Funds	33,451	-	(6,993)	-	26,458
Pears Grant	-	-	-	-	-
<b>Total</b>	<b>40,942</b>	<b>69,343</b>	<b>(24,086)</b>	<b>-</b>	<b>86,199</b>

<b>Previous reporting period</b>	<i>Balance at 1 January 2023 £</i>	<i>Income £</i>	<i>Expenditure £</i>	<i>Transfers £</i>	<i>As at 31 December 2023 £</i>
<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>Name of restricted fund</b>	<b>Description, nature and purposes of the fund</b>
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## Reverse Rett

### Notes to the accounts for the year ended 31 December 2024 (continued)

MECP2 Duplication Fund (Cure MDS)	The MECP2 Duplication Fund at Reverse Rett is a restricted fund. The fund exclusively supports projects devoted to the study and means of treatment of MECP2 Duplication/Triplication Syndrome. 100% of funds raised and contributed to Reverse Rett by families of children with MECP2 Duplication Syndrome and their supports in the UK are committed to MECP2 Duplication projects via RSRT 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 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. <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 2024 £	Income £	Expenditure £	Transfers £	As at 31 December 2024 £
General fund	(136,899)	739,752	(786,677)	-	(183,824)
	(136,899)	739,752	(786,677)	-	(183,824)
	(136,899)	739,752	(786,677)	-	(183,824)
<b>Previous reporting period</b>	<i>Balance at 1 January 2023 £</i>	<i>Income £</i>	<i>Expenditure £</i>	<i>Transfers £</i>	<i>As at 31 December 2023 £</i>
General fund	(81,788)	669,626	(735,993)	11,256	(136,899)
	(81,788)	669,626	(735,993)	11,256	(136,899)
	(81,788)	669,626	(735,993)	11,256	(136,899)

**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 2024 (continued)

### 17 Analysis of net assets between funds

	General fund £	Designated funds £	Restricted funds £	Total £
Tangible fixed assets	2,415	-	-	2,415
Net current assets/(liabilities)	(186,239)	-	86,199	(100,040)
Total	(183,824)	-	86,199	(97,625)

### 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	
	2024 £	2023 £	2024 £	2023 £
Less than one year	-	-	-	-
One to five years	-	-	-	-
	-	-	-	-

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

	2024 £	2023 £
<b>Net income/(expenditure) for the year</b>	(1,668)	(90,070)
<b>Adjustments for:</b>		
Depreciation charge	1,207	1,625
Decrease/(increase) in debtors	(55,409)	68,914
Increase/(decrease) in creditors	75,542	(126,571)
<b>Net cash provided by/(used in) operating</b>	19,672	(146,102)

**REVERSE RETT**

England & Wales - Charity number 1136809

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# Accounts

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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 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	Lentospace	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 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.

Reverse Rett  
Trustees Annual Report  
Financial year end 31 December 2023

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.

Taysha 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

Reverse Rett  
Trustees Annual Report  
Financial year end 31 December 2023

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.

Reverse Rett  
Trustees Annual Report  
Financial year end 31 December 2023

**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.

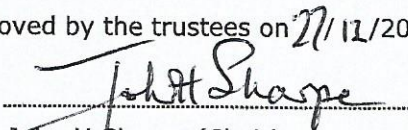
Reverse Rett  
Company number 07278507  
Balance sheet as at 31 December 2023

	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 27/11/2024 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>

# Reverse Rett

## 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.

## Reverse Rett

### 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.

## Reverse Rett

### 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%

## Reverse Rett

### 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
	454,358	-	454,358
<b>Total</b>	<b>454,358</b>	<b>-</b>	<b>454,358</b>

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

	Unrestricted £	Restricted £	Total 2022 £
<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>
	436,744	-	436,744
<b>Total</b>	<b>436,744</b>	<b>-</b>	<b>436,744</b>

## 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
	215,268	4,650	219,918
<b>Total</b>	215,268	4,650	219,918

### *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
	294,183	35,111	329,294
<b>Total</b>	294,183	35,111	329,294

### 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
	228,230	154,464
	228,230	154,464

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
	507,763	28,353	536,116
	507,763	28,353	536,116

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

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

## Reverse Rett

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
	80,179	-	80,179
	80,179	-	80,179

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

	2023 £	2022 £
This is stated after charging/(crediting):		
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
	1,750	1,750

## 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/>	<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/>	<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).

## Reverse Rett

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

<b>Cost</b>	Computer equipment £
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/>
<i>At 31 December 2022</i>	<i>1,968</i>
	<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/>	<hr/>
	40,995	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/>	<hr/>
	185,398	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>	<i>Balance at 1 January 2022 £</i>	<i>Income £</i>	<i>Expenditure £</i>	<i>Transfers £</i>	<i>31 December 2022 £</i>
<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>
<b>Name of restricted fund</b>	<b>Description, nature and purposes of the fund</b>				

## 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)
	(81,788)	669,626	(735,993)	11,256	(136,899)
	(81,788)	669,626	(735,993)	11,256	(136,899)
<b>Previous reporting period</b>					
	Balance at 1 January 2022 £	Income £	Expenditure £	Transfers £	As at 31 December 2022 £
General fund	216,726	730,927	(1,029,441)	-	(81,788)
	216,726	730,927	(1,029,441)	-	(81,788)
	216,726	730,927	(1,029,441)	-	(81,788)

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 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)
Total	(136,899)	-	40,942	(95,957)

### 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	-	-	-	-
	-	-	-	-

### 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
<b>Net cash provided by/(used in) operating</b>	(146,102)	(150,170)

**REVERSE RETT**

England & Wales - Charity number 1136809

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# Accounts

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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.

## Reverse Rett

### Trustees' annual report

For the year ended 31st December 2021

#### 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).

## Reverse Rett

### Trustees' annual report

For the year ended 31st December 2021

#### 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.

## Reverse Rett

### Trustees' annual report

For the year ended 31st December 2021

#### 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

## Reverse Rett

### Trustees' annual report

For the year ended 31st December 2021

#### **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

Reverse Rett

Trustees' annual report

For the year ended 31st December 2021

**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.

## **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  
Greenergy  
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

## Reverse Rett

### Trustees' annual report

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>

Reverse Rett

Trustees' annual report

For the year ended 31st December 2021

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.

## Reverse Rett

### Trustees' annual report

For the year ended 31st December 2021

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.

## Reverse Rett

### Trustees' annual report

For the year ended 31st December 2021

#### **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.

## Reverse Rett

### Trustees' annual report

For the year ended 31st December 2021

#### **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>

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>	326,458	36,152	362,610

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

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

### 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
	155,571	110,401

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
	<u>645,369</u>	<u>52,403</u>	<u>697,772</u>

\* 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>
	<u><i>531,077</i></u>	<u><i>37,923</i></u>	<u><i>569,000</i></u>

## 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

	2021 £	2020 £
This is stated after charging/(crediting):		
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
	10,019	8,417

## 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
	<hr/>	<hr/>
	50,803	109,163

### 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
	<hr/>	<hr/>
	104,977	91,691

## 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
----------------------------	--

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

**REVERSE RETT**

England & Wales - Charity number 1136809

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# Accounts

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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 2020

Reverse Rett  
Trustees' Annual Report  
For the year ended 31<sup>st</sup> December 2020

Reference and Administrative details for the year ended 31<sup>st</sup> December 2020

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  
Rachael Stevenson\*  
Andrew J Stevenson\*  
Monica Coenraads\* resigned 08.11.20  
Ortensia Martinotti  
Catherine McKinney  
Kate McMaster  
Rita Ross  
Neil Buckley  
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 Leicester LE87 2BB

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

Reverse Rett  
Trustees' Annual Report  
For the year ended 31<sup>st</sup> December 2020

The trustees present their report and the audited financial statements for the year ended 31 December 2020. 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 research projects;
- organising and sponsoring scientific workshops;
- collating information from experts in the field and providing access to it;  
and
- increasing general public awareness and knowledge of Rett Syndrome and related *MECP2* disorders.

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

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.

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**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.

Reverse Rett  
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For the year ended 31<sup>st</sup> December 2020

## Activities and projects

### 1. **CIPP Rett Centre, King's College London, £311,137**

In 2019, after comprehensive external peer review, Reverse Rett committed to funding the UK's first specialist Rett Syndrome clinical treatment and research Centre based in London for a period of three years.

The CIPP Rett Centre (formerly CPMRS) was established by Professor Santosh at the Maudsley Hospital and King's College London.

The CIPP Rett Centre is the world's first Centre for personalized medicine in Rett Syndrome that 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 2020: Funds delivered to CIPP Rett Centre totaled: £311,137

### 2. **CIPP Rett Database £12,000**

£12,000 is the pro rata sum (2020) 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 2020: Funds delivered to RSRT *MECP2* Duplication projects totaled £25,625

### 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. Contributions to RSRT lab research were drastically impacted by the impact of the Covid pandemic on charity fundraising.

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**In 2020:** Funds delivered to the RSRT international research program totaled £445. These funds were gifted to Reverse Rett by the French organisation, Opé Rett, with respect to RSRT programs in progress at the University of Edinburgh.

**5. Clinical trial expenses £11,247**

In 2020 we provided on-going support for the UK clinical trial of Cannabidiol sponsored by GW Pharmaceuticals and new support for Anavex for their clinical trial of Anavex 2-73. Reverse Rett provided identification, recruitment and retention services to support both trials. The Clinical trial expenses detailed on p 27 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 2020:** No RDA funds were spent in 2020 and the fund balance is £3,211.

**7. Parent 2 Parent program £1050.54**

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.

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

In 2020, two more Discovery Days were planned in Oxford and Warrington. Both had to be cancelled due to the pandemic.

£1050.54 funded an online app which enabled us to switch these in person events to digital events.

**In 2020:** £1050.54 was spent on switching in person events to digital format so that Discovery Days could go on.

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**8. Governance costs £5640**

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 2019 audit and related accountancy services.

**9. Support costs (note 7, p 28) £147,914**

In 2020, support costs included the above governance costs, office rental, general office costs including phone, internet, printing and postage and staff costs of £95,143.

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

Staff costs under fundraising costs include: Fundraising Manager (0.5 FTE), Events and Campaigns Co-ordinator (0.5 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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For the year ended 31<sup>st</sup> December 2020

## 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.

### 2012

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

### 2014

- ✓ Reverse Rett Co-Founder and CEO joins the Board of Trustees of the Rett Syndrome Research Trust.
- ✓ Reverse Rett begin seed-funding King's College London Research Team at CIPPRD, for work focused on developing new outcome measures (TRIAL Database) for patients with Rett Syndrome under Professor Paramala Santosh.

### 2015

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

### 2016

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

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For the year ended 31<sup>st</sup> December 2020

**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.

Reverse Rett  
Trustees' Annual Report  
For the year ended 31<sup>st</sup> December 2020

**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 development of a UK Rett Syndrome Patient Registry, our recruitment, pre-screening and retention support for clinical trials and in 2019, the commitment to fund the CIPP Rett Centre (formerly CPMRS), the UK's first national clinical treatment and research centre for Rett Syndrome based at King's College Hospital.

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 trials coming to fruition in 2021-2022, are happening as a direct result of work which Reverse Rett has heavily financially supported over the last decade.

Only time will tell, if and how these gene therapies will be safe and effectively a 'cure' in children and adults with Rett Syndrome. It may be that those who are able to access cures earlier in life recover most effectively. At Reverse Rett, our mission now goes beyond our original goal of curing Rett Syndrome. We need to focus also on enabling access to these emerging therapies for patients with Rett Syndrome of all ages and to ensuring that no one is left behind, when treatments that can drastically improve lives become possible.

Reverse Rett  
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For the year ended 31<sup>st</sup> December 2020

**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 2020:**

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  
Stephanie Zinser  
David Ford  
Sean Forde  
Friends of  
Holly  
Colin  
Gordon  
Greenery  
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

**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

Reverse Rett  
Trustees' Annual Report  
For the year ended 31<sup>st</sup> December 2020

**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 the Reverse Rett Covid Resilience Fund in 2020.**

#### 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.

Funds which had been set in reserve for 2020 payments to the newly funded CIPP Rett Centre (formerly CPMRS) kept the charity afloat. This meant that we did not have an immediate cashflow problem when the pandemic struck, however, it also meant that we had to restrict any additional research payments over and above the CIPP Rett Centre until the situation stabilized re fundraising.

Here are some examples of the dramatic income changes:

- Just Giving (our main online fundraising platform) income decreased by 24% compared to a 38% increase from 2018-2019. (2020: £163,395 2019: £212,831.89 2018: £163,754)
- London gala income decreased by 34% compared to a 37% increase from 2018-2019 (2020: £91,317; 2019, £138,758; 2018: £101,203.) This year's gala was a virtual as opposed to in person event.
- The Big Give Christmas Challenge is always a virtual event. This year income from this event increased by 11% compared to a 20% increase from 2018-2019 (2020: £82,502, 2019: £74,238, 2018: £62,108)

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

## Reverse Rett Trustees' Annual Report For the year ended 31<sup>st</sup> December 2020

### **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 and reduced contributions to the international research program at RSRT 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 £430,954 of which £85,430 was restricted.

As the fundraising situation continues to stabilize, contributions to the international research program at RSRT have cautiously resumed.

### **Plans for the future**

A Reverse Rett Annual Plan is developed every autumn for the following year. During 2020, the initial annual plan, developed pre- pandemic, was revised in March 2020 to adjust to the evolving situation with Covid.

That plan remained dynamic and was readjusted several times during the year due to new developments which affected in person fundraising capacity.

A plan for 2021 written in autumn of 2020 had to be revised several times due to more changes.

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:

- Ensuring the stability of Reverse Rett throughout 2021 and into 2022, so that we can continue with our mission and vision in the long term.
- Rebuilding fundraising efforts with the on-going constraints of social distancing.

### **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.

### **Advocacy:**

Providing medical information and resources to families shielding vulnerable family members during the crisis.

Reverse Rett  
Trustees' Annual Report  
For the year ended 31<sup>st</sup> December 2020

**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> 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 31<sup>st</sup> December 2020

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 2020 was 10.

The Trustees of the Charity who served during the year ended December 31, 2020 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.

Reverse Rett  
Trustees' Annual Report  
For the year ended 31<sup>st</sup> December 2020

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.

Reverse Rett  
Trustees' Annual Report  
For the year ended 31<sup>st</sup> December 2020

**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 2020 financial year:**

Douces Rett Association  
Opé Rett

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

GW Pharmaceuticals Anavex Life  
Sciences Corp

Newron Pharmaceuticals  
Taysha Gene Therapies  
Novartis Gene Therapies

**Risk management**

During the annual in person board meeting 2020, 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 2021, Reverse Rett is working to broaden the management base to deliver more protection for the charity against the loss of key personnel.

Reverse Rett  
Trustees' Annual Report  
For the year ended 31<sup>st</sup> December 2020

## **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 2020 was 0.
- In 2018-2019, the charity completed a full GDPR audit to ensure that the privacy of all current and previous donors and fundraisers is secure and that individual consent to hold a limited amount of information re supporters is accounted for.
- Reverse Rett does not engage in telephone, mail or on the street cold solicitations and these actions by another person on behalf of the charity are not permitted.
- The charity has not acted as custodian trustee during the reporting period.

Reverse Rett  
Trustees' Annual Report  
For the year ended 31<sup>st</sup> December 2020

**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 \_\_\_\_\_  
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 2020, 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 2020, 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: \_\_\_\_\_

Reverse Rett  
Statement of Financial Activities  
(including Income and Expenditure account)  
for the year ended 31 December 2020

	Note	Unrestricted funds £	Restricted funds £	Total funds 2020 £	Total funds 2019 £
<b>Income from:</b>					
Donations and legacies	3	333,808	23,650	357,458	526,345
Charitable activities:	4	262,700	31,266	293,966	367,320
<b>Total income</b>		<b>596,508</b>	<b>54,916</b>	<b>651,424</b>	<b>893,665</b>
<b>Expenditure on:</b>					
Raising funds	5	110,401	-	110,401	152,538
Charitable activities:	6	531,077	37,923	569,000	477,190
<b>Total expenditure</b>		<b>641,478</b>	<b>37,923</b>	<b>679,401</b>	<b>629,728</b>
<b>Net income/(expenditure) for the year</b>	8	<b>(44,970)</b>	<b>16,993</b>	<b>(27,977)</b>	<b>263,937</b>
Transfer between funds		(16,000)	16,000	-	-
<b>Net movement in funds for the year</b>		<b>(60,970)</b>	<b>32,993</b>	<b>(27,977)</b>	<b>263,937</b>
<b>Reconciliation of funds</b>					
Total funds brought forward		406,494	52,437	458,931	194,994
<b>Total funds carried forward</b>		<b>345,524</b>	<b>85,430</b>	<b>430,954</b>	<b>458,931</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 2020

	Note	2020		2019	
		£	£	£	£
<b>Fixed assets</b>					
Tangible assets	12		3,504		2,355
<b>Total fixed assets</b>			<b>3,504</b>		<b>2,355</b>
<b>Current assets</b>					
Debtors	13	109,163		106,775	
Cash at bank and in hand		409,978		365,123	
<b>Total current assets</b>		<b>519,141</b>		<b>471,898</b>	
<b>Liabilities</b>					
Creditors: amounts falling due in less than one year	14	(91,691)		(15,322)	
<b>Net assets</b>			<b>430,954</b>		<b>458,931</b>
<b>The funds of the charity:</b>					
Restricted income funds	15		85,430		52,437
Unrestricted income funds	16		345,524		406,494
<b>Total charity funds</b>			<b>430,954</b>		<b>458,931</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 \_\_\_/\_\_\_/2021 and signed on their behalf by:

John Sharpe (Chair)

Reverse Rett  
Statement of Cash Flows  
for the year ending 31 December 2020

	Note	2020 £	2019 £
<b>Cash provided by/(used in) operating activities</b>	19	<b>47,353</b>	<b>144,657</b>
Increase/(decrease) in cash and cash equivalents in the year		44,855	141,759
Cash and cash equivalents at the beginning of the year		365,123	223,364
<b>Cash and cash equivalents at the end of the year</b>		<b>409,978</b>	<b>365,123</b>

## Reverse Rett

### Notes to the accounts for the year ended 31 December 2020

#### **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 2020 (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 2020 (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 2020 (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 2020 (continued)

**3 Income from donations and legacies**

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

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

	Unrestricted £	Restricted £	Total 2019 £
Donations	458,619	-	458,619
Grants Charterhouse Charitable Trust	5,000	-	5,000
Sylvia Aiken Trust	8,000	-	8,000
Lawson Trust	-	35,000	35,000
Mazars	-	9,726	9,726
The Patrick and Helena Trust	10,000	-	10,000
	<hr/>	<hr/>	<hr/>
<b>Total</b>	<b>481,619</b>	<b>44,726</b>	<b>526,345</b>
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

## Reverse Rett

Notes to the accounts for the year ended 31 December 2020 (continued)

**4 Income from charitable activities**

	Unrestricted £	Restricted £	Total 2020 £
The Big Give	82,502	-	82,502
London Event	91,317	-	91,317
MECP2 Fund	665	12,960	13,625
Family events	5,806	-	5,806
Newron Pharmacy	8,874	3,633	12,507
Parent 2 Parent programme	-	14,529	14,529
Gift Aid	71,024	-	71,024
Other income	2,512	144	2,656
	<hr/>	<hr/>	<hr/>
<b>Total</b>	262,700	31,266	293,966
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

**Income from charitable activities - previous year**

	Unrestricted £	Restricted £	Total 2019 £
<i>The Big Give</i>	74,238	-	74,238
<i>London Event</i>	138,758	-	138,758
<i>MECP2 Fund</i>	-	54,737	54,737
<i>Family events</i>	13,791	-	13,791
<i>Newron Pharmacy</i>	-	30,000	30,000
<i>Premier Research</i>	-	10,000	10,000
<i>Gift Aid</i>	42,252	-	42,252
<i>Other income</i>	3,544	-	3,544
	<hr/>	<hr/>	<hr/>
<b>Total</b>	272,583	94,737	367,320
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

**5 Cost of raising funds**

	2020 £	2019 £
Staff costs	63,456	55,629
Fundraiser's fees	5,139	23,161
Event costs	41,806	73,748
	<hr/>	<hr/>
	110,401	152,538
	<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 2020 (continued)

**6 Analysis of expenditure on charitable activities**

	Unrestricted £	Restricted £	Total 2020 £
Staff costs	64,253	-	64,253
Transfer to Rett Syndrome Research Trust USA	445	-	445
Travel and accommodation	1,688	-	1,688
Clinical trial expense	-	11,247	11,247
Parent 2 Parent programme	-	1,051	1,051
CPMRS	311,137	-	311,137
MECP2	-	25,625	25,625
Governance costs (see note 7)	5,640	-	5,640
Support costs (see note 7)	147,914	-	147,914
	<hr/>	<hr/>	<hr/>
	531,077	37,923	569,000
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

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

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

## Reverse Rett

## Notes to the accounts for the year ended 31 December 2020 (continued)

**7 Analysis of governance and support costs**

	Support £	Governance £	Total 2020 £
Office rental cost	5,653	-	5,653
Staff costs	96,695	-	96,695
Office costs	39,045	-	39,045
Audit fees	-	3,600	3,600
Accountancy services	-	2,040	2,040
Legal and professional	3,682	-	3,682
Advertising and marketing	2,839	-	2,839
	<hr/>	<hr/>	<hr/>
	147,914	5,640	153,554
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

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

This is stated after charging/(crediting):	2020 £	2019 £
Depreciation	1,349	543
Operating lease rentals:		
Property	-	7,572
Other	2,568	2,568
Auditor's remuneration - audit fees	3,000	3,480
Auditor's remuneration - accountancy fees	1,600	1,920
	<hr/> <hr/>	<hr/> <hr/>

## Reverse Rett

## Notes to the accounts for the year ended 31 December 2020 (continued)

**9 Staff costs**

Staff costs during the year were as follows:

	2020 £	2019 £
Wages and salaries	198,922	174,643
Social security costs	18,126	14,263
Pension costs	7,356	5,897
	<hr/>	<hr/>
	224,404	194,803
	<hr/> <hr/>	<hr/> <hr/>
<b>Allocated as follows:</b>		
Cost of raising funds	63,456	55,629
Charitable activities	64,253	53,620
Support costs	96,695	85,554
	<hr/>	<hr/>
	224,404	194,803
	<hr/> <hr/>	<hr/> <hr/>

No employees has employee benefits in excess of £60,000 (2019: Nil).

The average number of staff employed during the period was 7 (2019: 6).

The key management personnel of the charity comprise the trustees and the Chief Executive Officer. The total employee benefits of the key management personnel of the charity were £53,040 (2019: £38,234).

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

Two of the trustees Rachael Stevenson (Chief Executive) and Andrew Stevenson (Director) received remuneration totalling £91,831 (2019: £90,438).

No trustee received travel and subsistence expenses during the year. (2019:nil).

Aggregate donations from related parties were £44,650. (2019: £25,550).

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 £445 this year. (2019: £206,095).

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 (2019: nil).

## Reverse Rett

## Notes to the accounts for the year ended 31 December 2020 (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 2020	5,027
Additions	2,498
Disposals	-
	<hr/>
At 31 December 2020	7,525
	<hr/> <hr/>
<b>Depreciation</b>	
At 1 January 2020	2,672
Charge for the year	1,349
Disposals	-
	<hr/>
At 31 December 2020	4,021
	<hr/> <hr/>
<b>Net book value</b>	
At 31 December 2020	3,504
	<hr/> <hr/>
<i>At 31 December 2019</i>	<i>2,355</i>
	<hr/> <hr/>

## Reverse Rett

Notes to the accounts for the year ended 31 December 2020 (continued)

**13 Debtors**

	2020 £	2019 £
Other debtors	6,300	14,980
Prepayments and accrued income	26,672	26,876
Gift aid debtor	25,956	15,784
Big Give debtor	50,235	49,135
	<hr/>	<hr/>
	109,163	106,775
	<hr/> <hr/>	<hr/> <hr/>

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

	2020 £	2019 £
Trade creditors	2,351	1,277
Other creditors and accruals	78,956	8,071
Taxation and social security costs	10,384	5,974
	<hr/>	<hr/>
	91,691	15,322
	<hr/> <hr/>	<hr/> <hr/>

## Reverse Rett

Notes to the accounts for the year ended 31 December 2020 (continued)

**15 Analysis of movements in restricted funds**

	Balance at 1 January 2020 £	Income £	Expenditure £	Transfers £	As at 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 Research Funds	7,107 37,589	14,529 6,352	(1,051) (11,247)	- 16,000	20,585 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>

<b>Previous reporting period</b>	Balance at 1 January 2019 £	Income £	Expenditure £	Transfers £	31 December 2019 £
<i>MECP2</i>					
Duplication	2,680	64,463	(64,463)	-	2,680
Rett disorder alliance	3,072	-	(3,211)	5,000	4,861
Use in Parent 2 Parent Programme Clinical	200 10,952 -	- - 75,000	- (3,845) (37,411)	- - -	200 7,107 37,589
<b>Total</b>	<b>16,904</b>	<b>139,463</b>	<b>(108,930)</b>	<b>5,000</b>	<b>52,437</b>

<b>Name of restricted fund</b>	<b>Description, nature and purposes of the fund</b>
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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 2020 (continued)

Parent 2 Parent	<p>Reverse Rett Parent 2 Parent offers grants parent to parent support as a resource to families of newly diagnosed or struggling children with Rett Syndrome and related <i>MECP2</i> disorders. Through a one to one 'match', experienced parents provide emotional support to families and assist them in finding information and resources.</p> <p>Through the project, Reverse Rett provides on-going training and support for mentors and materials for both mentor and mentee. Communication between both parties is facilitated by Reverse Rett in the first six weeks of contact and thereafter as required.</p> <p>Please find more information here: <a href="http://www.reverserett.org.uk/get-involved/get-connected/">http://www.reverserett.org.uk/get-involved/get-connected/</a></p>
Clinical Research Fund	<p>This is a designated fund which will support UK based clinical research and the implementation of treatment for Rett Syndrome and related <i>MECP2</i> Disorders in the UK.</p>

**16 Analysis of movement in unrestricted funds**

	Balance at 1 January 2020 £	Income £	Expenditure £	Transfers £	As at 31 December 2020 £
General fund	406,494	596,508	(641,478)	(16,000)	345,524
	<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
	406,494	596,508	(641,478)	(16,000)	345,524
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>
<b><i>Previous reporting period</i></b>	<i>Balance at 1 January 2019 £</i>	<i>Income £</i>	<i>Expenditure £</i>	<i>Transfers £</i>	<i>As at 31 December 2019 £</i>
<i>General fund</i>	<i>178,090</i>	<i>754,202</i>	<i>(520,798)</i>	<i>(5,000)</i>	<i>406,494</i>
	<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
	<i>178,090</i>	<i>754,202</i>	<i>(520,798)</i>	<i>(5,000)</i>	<i>406,494</i>
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

**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 2020 (continued)

**17 Analysis of net assets between funds**

	General fund £	Designated funds £	Restricted funds £	Total £
Tangible fixed assets	3,504	-	-	3,504
Net current assets/(liabilities)	342,020	-	85,430	427,450
	<hr/>	<hr/>	<hr/>	<hr/>
Total	345,524	-	85,430	430,954
	<hr/> <hr/>	<hr/> <hr/>	<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:

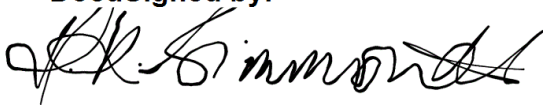
	Property		Equipment	
	2020 £	2019 £	2020 £	2019 £
Less than one year	-	7,572	2,568	2,568
One to five years	-	8,834	6,870	9,438
	<hr/>	<hr/>	<hr/>	<hr/>
	-	16,406	9,438	12,006
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

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

	2020 £	2019 £
<b>Net income/(expenditure) for the year</b>	(27,977)	263,937
<b>Adjustments for:</b>		
Depreciation charge	1,349	543
Decrease/(increase) in debtors	(2,388)	(83,114)
Increase/(decrease) in creditors	76,369	(36,709)
	<hr/>	<hr/>
<b>Net cash provided by/(used in) operating</b>	47,353	144,657
	<hr/> <hr/>	<hr/> <hr/>

On behalf of John Sharp Chair of Trustees

14 September 2021

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