

www.reverserett.org.uk

Report and financial statements for the year ended 31 December 2022

Reverse Rett Reference and Administrative details For the year ended 31st December 2022

Company number 07278507 Charity number 1136809 (England & Wales) and SC046735 (Scotland)

Registered office and operational address:

Beehive Mill, Jersey Street, Ancoats, Manchester, M4 6JG

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:

Chairman John H. Sharpe Vice-Chair Helen K. Simmonds

Ortensia Martinotti

Catherine McKinney
Kate McMaster
Joanna Snyder
*Rachael Stevenson
*Andrew Stevenson
Rita Ross
Dr Ruksana Ahmed
Mo Lishomwa-resigned 06.03.23
Mike Jones-joined 16.11.22

Jocelyn LeBlanc-joined on 10.02.23

Key management: Rachael Stevenson, CEO

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

Independent auditors: Slade & Cooper Limited, Beehive Mill, Jersey St, Manchester,

M4 6JG

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

The trustees present their report and the audited financial statements for the year ended 31 December 2022. 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, 2022 £465,000 (2021: £315,836) (includes note 2. below £36,000)

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.

Reverse Rett originally committed to providing core funding to the CIPP Rett Centre at a cost of £998,000 over three years from September 2019-September 2022.

The remit of the Centre was to develop digital health strategies to monitor and manage patients whilst conducting translational research using the HealthTracker platform, providing complex clinical care and conducting clinical trials.

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.

By September 2022, the CIPP Rett team were managing in excess of 150+ patients. Clinical demand on the team was high due to long term repercussions of successive lock downs. Many UK patients with Rett Syndrome became increasingly complex during the pandemic because of lack of access to services, therapies and clinical management. This coupled with the increased demand on NHS services across the Board meant that more patients and families were turning to the Centre than ever before. Not only did the lockdowns impact the individual patients with Rett Syndrome, they affected the families as well with a number of families requiring psychological support and families breaking up under the pressure of isolating at close quarters whilst looking after a family member with Rett Syndrome at the same time.

Reverse Rett worked with the CIPP Rett team to identify ways of decreasing pressure on the team whilst still meeting their clinical remit and ethical obligations. It was decided that at this point, the team should focus on stabilising the clinical provision.

For 2023-2024, Reverse Rett funding for the Centre will move to a one-year rolling contract. The CIPP Rett team will also focus on identifying additional and alternate funding streams moving forward.

In 2022: Funds committed to CIPP Rett Centre totalled: £465,000 (£315,836-2021).

2. CIPP Rett Database/HealthTrackerTM licensing £36,000

The 2022 cost for the software license for the HealthTracker platform was £36,000. The CIPP Rett Database, also known as the Multi System Symptoms Profile or REST questionnaire 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) £7474

Reverse Rett funds MECP2 Duplication research through our longstanding partnership with the US-based, Rett Syndrome Research Trust (RSRT). All funds delivered to MECP2 Duplication Fund projects at RSRT are raised by MECP2 Duplication Syndrome families in the UK.

In 2022, funds raised and delivered to RSRT MECP2 Duplication projects totalled £7474 (2021-£14,484)

4. Contributions to the international research program at the Rett Syndrome Research Trust (USA) £99,992

Since Reverse Rett was founded in 2010, the charity has delivered over £7 million to RSRT research projects internationally. Reverse Rett contributions to the international research program at 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, Reverse Rett contributions to RSRT resumed at the end of the year with a £100,000 contribution. In 2022, we matched that with a further £100,000 contribution at the end of the year.

2022: funds raised and delivered to RSRT Rett research programs totalled £99,992 these funds are yet to be deployed by RSRT (2021: £100,000 These funds supported the Bird and Cobb Labs at the University of Edinburgh)

5.Clinical trial income (unrestricted payments for Reverse Rett Clinical Trial Support Services= £46,779, Clinical trial expenses: Restricted £28,915, Total = £75,694

In 2021, Reverse Rett provided recruitment and clinical trial support services for the UK clinical trial of Anavex 2-73 in children and some patients on the adults' extension period. 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.

5. Rett Disorders Alliance £0 spent, £4861 remaining

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.

2021: £0 spent, balance £4861. In 2022: No RDA funds were spent in 2022 and the fund balance is £4,861.

6. Parent 2 Parent program 2022: £0 spent, £3056 remaining

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 Marvellous 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.

In 2021: £17,529 from Contact/The Pears Foundation supported this work.

In 2022: 0 spent, 0 remaining

7. Rett Registry UK 2022: £ 8400 (2021: £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 2021, it was simply a locked spreadsheet which had no immediate benefit for families. The overall purpose of the Registry is to provide the Reverse Rett with the logistical information, demographics and necessary consents to contact families regarding research opportunities and to recruit patients for clinical trials as needed.

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.

During 2022, this bespoke Registry required further adaptation, trouble-shooting and amendments at a cost of £8400.

The Rett Registry UK was built by the Mather Group IO and can be found here https://www.rettregistry.uk/

In 2022: £8400 (2021-£12,400)

8. Governance costs 2022: £5988 (2021: £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 2022 audit and related accountancy services.

9. Support costs (2021 note 7, p 23) 2022: £179,158, (2021: £169,900)

CEO (RES) 80% charitable activities 20% support costs

Clinical trial lead and supporter care (AS) 0.5 fundraising, 0.5 charitable activities Office admin/Clinical Trial/registry co-ordinator (EW) 0.5 charitable activities, 0.5 support costs

Design and marketing (WH) 25% fundraising support 75% support costs Special events fundraiser (HB) 100% fundraising (0.4FTE) Events and Outreach Lead (BKJ) 100% fundraising

Finance Officer 100% support cost

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 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 13 years, Reverse Rett has been tightly focused on research funding. Change is now within reach. The first gene therapy trial in adults in Canada is underway. A second trial for children is due to start in the USA in the next few months. A UK clinical trial in children is projected to start in 2024. As an organisation, this gives us more work than ever in order to ensure that everyone with Rett Syndrome in the UK can access these emerging disease

modifying treatments either through UK clinical trials or subsequent clinical delivery in UK hospitals.

At Reverse Rett, 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.

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.
- ✓ Reverse Rett Co-Founder and CEO joins the Board of Trustees of the Rett Syndrome
 Research Trust

2014

✓ Reverse Rett begin seed-funding King's College London Research Team at CIPPRD, for work focused on developing new outcome measures (TRIAL Database) for patients with Rett Syndrome under Professor Paramala Santosh.

2015

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

2016

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

2019

- ✓ 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.
- ✓ 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

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

2022

- ✓ Reverse Rett supports the implementation of 4th 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 imminently.

2023

- ✓ Neurogene receives FDA approval for their first in human clinical trial to start in the USA, this time in children.
- ✓ Taysha Gene Therapies announce that their first adult patient has been dosed with TSHA 102
- ✓ Taysha Gene Therapies confirm that plans to submit a CTA for a UK clinical trial in children is on track for mid-2023.
- ✓ FDA approves Trofinitide/Daybue as first licensed treatment for Rett Syndrome worldwide
- ✓ Taysha Gene Therapies confirm that a CTA for a UK children's trial has now been submitted
- ✓ Taysha Gene Therapies report 2nd adult patient with Rett Syndrome dosed with TSHA-102 in Canada.

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 redevelopment 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.

With the dosing of the very first-ever patient with Rett Syndrome with TSHA-102 this year, we have reached a pivotal moment in the Rett community. Data gleaned from this first patient and those adults who follow will enable much learning to inform the further development of gene therapies and will hopefully enable the company to progress to paediatric trials.

In this very early stage of the first in human clinical trial of Rett gene therapy, the focus is on patient safety which is why adults with Rett Syndrome are the very first patients, rather than children. At Reverse Rett, we continue to work to ensure that emerging treatments including

gene therapies are accessible to patients with Rett Syndrome of all ages, stages and genders. We believe that no one should left behind, when treatments that can drastically improve lives become available.

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.

Individuals	Companies	Trusts and Foundations
Four in a Row		
Hazel & Lloyd Beiny	Archerfield Estates	CVC Philanthropy
Derek & Jenny Bird	Blackridge Communications	Givergy Ltd
Josh Bottomley	Busy - Bean Accounting	Hope for Eliza
Stephanie & Alvin Wood	Caleywater Ltd	KD Wright Financial
Martin Darby	Charity Ball	Murphy-Neumann
David Ford	GCU Students' Association	OPE Rett
Ray Holden	Greenergy International Ltd	Taysha Gene Therapies
Core Marketing	House Mouse Music	The Big Give
PE McCall	Internet Lodge No 9659	The Patrick & Helen Frost Foundation
Catherine & Ross McKinney	Kate Noble Photography	The Rockely Charity
Christopher Missling	MD Communications	The Sylvia Aitken Charitable Trust
Pamela Monti	Media Spaces	The Taylor Charitable Trust
Lindsey Pringle	Much Loved	The TK Maxx and Homesense
	Thomas McMaster & Son	
	Hannah Rainback	PMSF UK
Zillah & Michael Rainback	Royal Albert Edward	
John & Maureen Sharpe	Slade & Cooper Ltd	
Anthony & Joanna Snyder	St Quintin Park Lodge 4863	
Paris Steele	Surbiton High School	
Charlie Talbot	Talbot Productions	
James Terry	The Rotary Club North Berwick	
David & Louise Wainwright	The Round Table Tonbridge	
Kyle Wilcox		
Thrill Collins Band		
Warrington Wolves		
Ellie Douglas-Hamilton		
Rita & Gavin Ross		

Financial review

Like many charities and non-profit organisations, Reverse Rett has faced some significant challenges over the last several years. During this time, the charity has continued to operate, to implement its charitable objectives and work towards the organisation's goal of delivering treatments and a cure for Rett Syndrome and related MECP2 Disorders.

Here you can find key insights from the Charities Aid Foundation report on post-pandemic giving in 2021 and 2022 which showed that giving levels remained subdued and had not returned to pre-pandemic levels.

In 2022, income at Reverse Rett continued to be lower than pre-pandemic levels as was typical for UK charities across the board. However, there was a 8% increase in income compared to 2021 and an increase in 22% in 2021 compared to 2020.

This shows that income is rising albeit slowly and incrementally despite ongoing public concern about the state of the economy, the cost-of-living crisis, the war in Ukraine, the price of fuel, rising interest rates, etc.

Reverse Rett projections for 2022 remained conservative throughout the year, with a projected year-end result of £689K, vs actual £753,538. This 8% increase on 2021 income (£716,294) happened despite income from our largest event of the year, the London Gala, decreasing by approx. 25%.

Community fundraising income actually grew by 28 %; the strength of key community support for the charity somewhat mitigated the decrease in support from more removed supporters, e.g. friends of friends supporting charity-wide events and campaigns such as the London Gala and Big Give Christmas Challenge, rather than individuals with family members directly affected by Rett Syndrome taking on personal events and challenges.

Despite this slow but sure increase in income, the charity finished 2022 in deficit by £236,607 for two main reasons:

1. Inconsistencies in billing from KCL concerning the CIPP Rett Centre

The initial funding period for the CIPP Rett Centre was Sept 2019-Sept 2022. KCL invoicing did not begin until April 2020, which meant that the initial payment and all subsequent payments were six months in arrears. As the KCL research payments team split the initial grant into 13 payments with the last payment due in Sept 2022, the invoicing schedule was already planned to run 3 months in arrears. KCL has agreed that the discrepancies in billing are their responsibility/error and will continue to invoice Reverse Rett retroactively at quarterly intervals. Due to accounting policies, however, at the end of 2022, any funds due concerning 2022, show as a debt in 2022, even if the respective payments were not expected in 2022.

2. RSRT international research program payment of £100,000 in Dec 2022

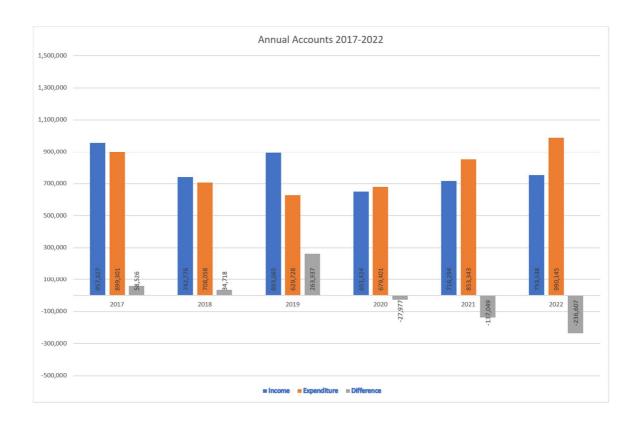
Reverse Rett contributions to the international research program at RSRT over 13 years totalling over £7 million. Those contributions were made based on the availability of funds. Due to the pandemic and the commitment to the CIPP Rett Centre in 2020, Reverse Rett halted RSRT voluntary contributions to ensure that the charity remained stable and the CIPP Rett Centre payments could be paid as and when invoiced.

In 2021, Reverse Rett was able to resume contributions, delivering £100,000 in the year. In 2022, although income had only modestly increased, we were able to maintain the annual contribution to the international research program at the same level as the previous year and therefore delivered a further £100,000 to RSRT in December 2022.

3. Overall fundraising and income situation

At this point, it is important to look at the situation within the context of the last five years which included the Covid-19 pandemic and a multitude of other challenges which are now facing many businesses and organisations of all sizes.

Figure 1 shows the initial drop in income in 2020 followed by a gradual improvement in the Reverse Rett income since 2020 in terms of recovery from the Covid pandemic and the effects of successive lockdowns on the charity's community fundraising, particularly as the charity's key supporter base of <100 ambassadors are 85% parents of children and adults with Rett Syndrome who were shielding for a large part of 2020-2021 and even in some cases, into 2022.



During the pandemic in 2020, 2021 and 2022, Reverse Rett fundraising was seriously compromised. Our reserves were used.

In 2023, our reserves are depleted but our fundraising showing signs of a healthy recovery.

Because of the improved fundraising situation, this year we doubled up on CIPP payments in March 2023 to try to bring invoicing back in line with the current calendar year. The majority of payments due in 2023 will hereafter relate to work that happened in the 2022-2023 extension period, rather than in the previous year, which will help to reduce the deficit at year end.

Fundraising in 2023

Despite the fact that the main lockdowns took place in 2020 and 2021, social distancing remained in place throughout all the non-lockdown periods and into 2022, which continued to affect in-person events and group gatherings well into 2022.

Many families and supporters never emerged in between lockdowns because of long-term shielding issues. Ongoing issues around the cost-of-living crisis in 2021 and 2022 mean that even giving has not returned to pre-pandemic levels.

Despite this, the number of individual donations to Reverse Rett campaigns across a variety of online media shows that support for Reverse Rett is still strong, but individuals are giving less which is reflective of the widespread decrease of surplus income for many people in the UK.

Here are some of the income movements for two of our largest income streams in 2022:

- In 2022, the Reverse Rett Winter Gala was a virtual event as well as an in-person event to mitigate potential COVID-related issues. Overall, the event income was down 26% compared to 2021 with an income of £112,726. (2021: £153,718, 2020: £91,317, 2019: £138,758).
- Just Giving income increased by 28% on 2021 with an income of £236,613.87 (2021: £169,830.43, 2020: £163,395, 2019: £212,831.89) which is even better than the 2019 figure. This demonstrates the significant reinvigoration of Reverse Rett community fundraising efforts post-pandemic and the heart which is behind the charity, despite the downturn in income from other events.

Income from Trusts and Foundations also decreased in 2022. In 2020 and 2021, the charity was eligible for specific grants to support organisations during the Covid pandemic and in the immediate aftermath. Those grants were no longer available in 2022, despite the long-reaching negative impact on fundraising. Reverse Rett is already necessarily limited in terms of grants eligibility due to the medical research focus of the charity, compared to patient organisations who are focused on more immediately tangible programs which help individuals and families in the here and now.

Capacity for Trusts and Foundations fundraising was also higher in 2020 and 2021 due to diminished in-person challenges and events as well as reduced team activities for the CEO, allowing them more time to make applications. In June 2023, a new pivotal team member,

Operations Manager started work to support the CEO with day-to-day operations and management freeing up more time for Trusts and Foundations applications.

With conservative financial projections for 2023 and actions we are taking to reduce costs and mitigate risk, we are confident about the future. Over the last 14 years, Reverse Rett has built a network of committed fundraisers and supporters who even stayed with us during the Pandemic, despite their own personal challenges with isolation and lockdown often whilst caring for a disabled family member as well. Year to date fundraising figures for 2023 show that families old and new continue are 100% behind the charity as continue to work to deliver treatments and a cure for Rett Syndrome to everyone affected.

In summary:

Taking into account all of the above, the charity's conservative financial projections for 2023, the decrease in costs and actions we are taking to mitigate future risk, we do not feel that there are any material uncertainties about the charity's ability to continue operating throughout 2023 and into 2024.

During the pandemic in 2020, 2021 and 2022, our fundraising was compromised and we used our reserves. In 2023, our reserves are depleted but our fundraising showing signs of a healthy recovery.

To mitigate risk, we have made no further commitment to the CIPP Rett Centre beyond Sept 2023 so that we are able to reduce funding as needed. As previously stated contributions to RSRT are voluntary. There will be no further payments to RSRT until Reverse Rett funds delivered in 2022 have been deployed and the charity has met all existing commitments.

Reserves policy:

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

Funds raised and donated are typically deployed to research projects on a quarterly basis. In 2019, the charity held a greater sum in reserve because of the impending new commitment to the CIPP Rett Centre (funding period, Sept 2019-2022). In 2020, the pandemic had a huge impact on all Reverse Rett fundraising events. The charity maintained very conservative projections and almost completely stopped contributions to the US-based Rett Syndrome Research Trust in order to mitigate risk during a period of ongoing financial instability.

In 2022, Reverse Rett maintained international research funding at the same level as in 2021, delivering £100,000 to the US-based Rett Syndrome Research Trust, which kept the commitment but decreased the charity's reserve.

Funds held at year-end 2022 was £176,000 in main Reverse Rett bank account (2021: £297,238 of which £77,179 was restricted).

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 2022/2023 Annual Plans.

In 2022, Reverse Rett was focused on:

Research:

- Continuing to financially support and monitor the CIPP Rett Centre.
- Growing CIPP Rett Database/MPSS uptake.
- 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 regarding emerging diseasemodifying therapies.

Advocacy:

- Building and maintaining a consistent relationship with UK family support organisation, Rett UK in advance of upcoming Health Technology Assessment preparations and access planning.
- 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.

Outreach:

- Improvements and continued trouble-shooting on the Rett Registry UK to ensure an increase in uptake
- 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.
- Increasing the number of patients on Rett Registry UK
- Building a working partnership with Rett UK to promote the Rett Registry UK
- Developing a campaign to reach 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.

Clinical care:

- Improving clinical care and outcomes for complex UK children and adults with Rett Syndrome.
- Support CIPP Rett Centre to disseminate research and clinical best practice information to improve medical management of everyone affected.
- Disseminating research-focused health information to families and caregivers of people with Rett Syndrome in the UK to help improve health outcomes.

Looking ahead in 2023:

From a wider perspective, 2022 was a good year for Reverse Rett in many ways. Gene therapy companies, Taysha Gene Therapies and Neurogene both made strides towards the clinic with their Rett programs. Each of these programs were developed from academic work to which Reverse Rett made significant contributions over the last decade.

Also in 2022, the Anavex paediatric clinical trial was running at five sites across the UK, with recruitment, pre-screening and logistical support from Reverse Rett.

The CIPP Rett Centre continues to manage the health of complex patients from all over the UK and publish best practise health information to benefit Rett patients worldwide.

The new form Rett Registry UK became fully operational and we were able to develop a partnership with Rett UK around the Registry which makes it easier to recruit.

Our partnerships with industry and clinicians continue to grow and we were able to continue to support RSRT curative research programs.

However, fundraising continues to be difficult at Reverse Rett. The Saharan Trek showed us that the will is there. But there is no doubt that the capacity to give has been affected by the combined effects of the pandemic, cost of living crisis, energy issues and the war in Ukraine. In summary, people are still giving to and fundraising for Reverse Rett, but at lower levels.

With economic projections for 2023 UK wide looking increasingly bleak, we are working to reduce expenditure at the charity. We have done this by moving from a full office to shared desks within a serviced office and part-time hybrid working.

Critically, we have been working to strengthen all our events and challenges and the communication around them, so that we make it as easy and desirable as possible for people to give, as much as they can, when they can.

In 2023, we will continue to work on the key areas outlined above. Here some additional areas of focus for this year:

Research

 Publish data from the Rett Registry UK and from the CIPP Database (MPSS) to help build UK datasets and toolkit which will help us to advocate for disease modifying therapies to be recommended for funding across the UK.

• Build Rett Registry UK to include more Natural History questions and measurements of early mortality etc.

Advocacy

- Support the development of centres in all four nations with the capacity to deliver further trials and genetic-based treatments as they become available.
- Establish no cost/low cost screening service to ensure young children have timely access to genetic diagnoses in advance of UK gene therapy clinical trials.
- Work with UK family support organisation, Rett UK to align messaging around Rett Syndrome, the burden of illness and the potential for transformative therapies to alter the course of the disease for young children and significantly improve the quality of life for young people and adults who are already symptomatic.

Outreach

- Timed social media campaigns promoting the Rett Registry UK
- Targeted campaigns to find undiagnosed/unregistered patients in all age groups through the Big Give Count Me In project.
- Implement online Bitesize sessions focused on community education around emerging gene therapies.

Clinical Care

- Work to mitigate clinical pressure on CIPP Rett Centre
- Work with existing Rett clinics to support their drive for increased external funding, building capacity to deliver emerging gene therapies and other new treatments.

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.

Fundraising

- Three big Reverse Rett led team challenges (Jurassic Coast 100K, Lake District 100K and Iceland Fire and Ice Trek are planned for the year in May, June and September respectively.
- The Big Give Christmas Challenge will take place at the end of November/early December 2023.
- The Annual London Gala has had a revamp and will be held at a new venue with a new format.

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. Rita Ross is a Founding Trustee and was a trustee from inception until 2012 and subsequently from 2017 to present.

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 2022 was 11.

The Trustees of the Charity who served during the year ended December 31, 2022 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.

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 July 2023) is 8/11.

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 CLT/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.

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
- Rett Syndrome Ireland

With special thanks to our industry partners:

- Anavex Life Sciences Corp.
- Taysha Gene Therapies

Risk management

During the annual in-person board meeting 2022, 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 at year-end protects the charity in the short term from a major decrease in fundraising which we have now experienced due to the Covid-19 pandemic.

The potential for key personnel changes is 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 2023, Reverse Rett has broadened the management base of the organization to better protect the charity against the loss of key personnel and to ease the load on key personnel mitigating the loss of key personnel due to illness and or burn out.

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 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 about activities by the charity or by a person on behalf of the charity for the purpose of fundraising during 2022 was 3. This was due to an awareness campaign which was called #FreeFromRett which some people found controversial.
- In 2022, Reverse Rett continued to develop and update the Rett Registry UK to make it easier for families to use and to provide the organization with the required features to effectively identify patients for clinical trials and to manage the distribution across the UK. The Rett Registry UK is fully GDPR compliant with an in built suite of safety features. 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 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	
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 2022, 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 2022, 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: <a href="https://www.frc.org.uk/Our-Work/Audit/Audit-and-assurance/Standards-and-guidance-for-auditors-responsibilities-for-auditors-respo

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:

Statement of Financial Activities (including Income and Expenditure account) for the year ended 31 December 2022

	Note	Unrestricted funds	Restricted funds £	Total funds 2022 £	Total funds 2021 £
Income from:		426 744		426 744	252.604
Donations and legacies	3	436,744	-	436,744	353,684
Charitable activities:	4	294,183	35,111	329,294	362,610
Total income		730,927	35,111	766,038	716,294
Expenditure on:			 .		
Raising funds	5	154,464	-	154,464	155,571
Charitable activities:	6	874,977	36,389	911,366	697,772
Total expenditure		1,029,441	36,389	1,065,830	853,343
Net income/(expenditure) for the year	8	(298,514)	(1,278)	(299,792)	(137,049)
Transfer between funds					
Net movement in funds for the year	ar	(298,514)	(1,278)	(299,792)	(137,049)
Reconciliation of funds Total funds brought forward		216,726	77,179	293,905	430,954
Total funds carried forward		(81,788)	75,901	(5,887)	293,905

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 2022

	Note	20	22	202	1
		£	£	£	£
Fixed assets Tangible assets	12		1,968		2,155
Total fixed assets			1,968		2,155
Current assets Debtors Cash at bank and in hand	13	109,909 194,205		<i>50,803</i> 345,924	
Total current assets		304,114		396,727	
Liabilities Creditors: amounts falling due in less than one year	14 _	(311,969)		(104,977)	
Net assets			(5,887)		293,905
The funds of the charity:					
Restricted income funds Unrestricted income funds	15 16		75,901 (81,788)		77,179 216,726
Total charity funds			(5,887)		293,905

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 31 to 44 form part of these accounts.

Approved by the trustees on	/	/2023	and signed on their behalf by:
John H Sharpe (Chair)			

Statement of Cash Flows for the year ending 31 December 2022

	Note	2022 £	2021 £
Cash provided by/(used in) operating activities	19	(150,170)	(64,054)
Cash flows from investing activities:			
Purchase of tangible fixed assets		(1,549)	(2,898)
Cash provided by/(used in) investing activities	-	(1,549)	(2,898)
Increase/(decrease) in cash and cash equivalents in the year		(151,719)	(66,952)
Cash and cash equivalents at the beginning of the year		345,924	365,123
Cash and cash equivalents at the end of the year	-	194,205	298,171

Notes to the accounts for the year ended 31 December 2022

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 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.

During the pandemic in 2020, 2021 and 2022, our fundraising was compromised and we used our reserves. In 2023, our reserves are depleted but our fundraising showing signs of a healthy recovery. To mitigate risk, we have made no further commitment to the CIPP Rett Centre beyond Sept 2023 so that we are able to reduce funding as needed. As previously stated contributions to RSRT are voluntary. There will be no further payments to RSRT until Reverse Rett funds delivered in 2022 have been deployed and the charity has met all existing commitments.

The trustees do not consider that there are any sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amount of assets and liabilities within the next reporting period.

Notes to the accounts for the year ended 31 December 2022 (continued)

c Income

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and the amount can be measured reliably.

Income from government and other grants, whether 'capital' grants or 'revenue' grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the charity that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is a treated as a contingent asset and disclosed if material.

Income received in advance of a provision of a specified service is deferred until the criteria for income recognition are met.

d Donated services and facilities

Donated professional services and donated facilities are recognised as income when the charity has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use by the charity of the item is probable and that economic benefit can be measured reliably. In accordance with the Charities SORP (FRS 102), general volunteer time is not recognised; refer to the trustees' annual report for more information about their contribution.

On receipt, donated professional services and donated facilities are recognised on the basis of the value of the gift to the charity which is the amount the charity would have been willing to pay to obtain services or facilities of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

e Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the Bank.

Notes to the accounts for the year ended 31 December 2022 (continued)

f Fund accounting

Unrestricted funds are available to spend on activities that further any of the purposes of charity.

Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose.

Restricted funds are donations which the donor has specified are to be solely used for particular areas of the charity's work or for specific projects being undertaken by the charity.

g Expenditure and irrecoverable VAT

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

h Allocation of support costs

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Support costs include back office costs, finance, personnel, payroll and governance costs which support the charity's programmes and activities.

i Operating leases

Operating leases are leases in which the title to the assets, and the risks and rewards of ownership, remain with the lessor. Rental charges are charged on a straight line basis over the term of the lease.

j Tangible fixed assets

Individual fixed assets costing £1,000 or more are capitalised at cost and are depreciated over their estimated useful economic lives on a straight line basis as follows:

Office equipment 25% Computer equipment 25%

Notes to the accounts for the year ended 31 December 2022 (continued)

k Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

I Cash at bank and in hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

m Creditors and provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

n Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

o Pensions

Employees of the charity are entitled to join a defined contribution 'money purchase' scheme. The charity's contribution is restricted to the contributions disclosed in note 9. There were no outstanding contributions at the year end.

2 Legal status of the charity

The charity is a company limited by guarantee registered in England and Wales and has no share capital. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity. The registered office address is disclosed on page 1.

Notes to the accounts for the year ended 31 December 2022 (continued)

3 Income from donations and legacies

		Unrestricted £	Restricted $\underline{\pounds}$	Total 2022 £
Donation Grants -	s Sylvia Aiken Trust	413,744 3,000	- -	413,744 3,000
	The Patrick and Helena Trust	20,000		20,000
Total		436,744		436,744

Income from donations and legacies - previous year

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

Notes to the accounts for the year ended 31 December 2022 (continued)

4 Income from charitable activities

5

	Unrestricted £	Restricted £	Total 2022 £
The Big Give London Event MECP2 Fund Family events Anavex germany GmbH Gift Aid Other income	80,427 112,726 - 6,961 46,779 45,732 1,558	- 6,196 - 28,915 - -	80,427 112,726 6,196 6,961 75,694 45,732 1,558
Total	294,183	35,111	329,294
Income from charitable activities -	previous year		
	Unrestricted £	Restricted £	Total 2021 £
The Big Give London Event MECP2 Fund Family events Anavex germany GmbH Gift Aid Other income	110,788 153,718 - 7,048 22,335 31,693 876	- - 15,762 - 20,390 - -	110,788 153,718 15,762 7,048 42,725 31,693 876
Total	326,458	36,152	362,610
Cost of raising funds		2022 £	2021 £
Staff costs Fundraiser's fees Event costs		32,791 12,821 108,852	68,177 3,048 84,346
		154,464	155,571

All expenditure on cost of raising funds is unrestricted.

Notes to the accounts for the year ended 31 December 2022 (continued)

6 Analysis of expenditure on charitable activities

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

^{*} The stated amount includes staff cost of £13,428.

Analysis of expenditure on charitable activities - previous year

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

Notes to the accounts for the year ended 31 December 2022 (continued)

7 Analysis of governance and support costs

	Support £	Governance £	Total 2022 £
Office rental cost Staff costs Office costs Audit fees Accountancy services Legal and professional Advertising and marketing	12,204 93,150 57,393 - - 5,559 4,864	3,888 2,100 - -	12,204 93,150 57,393 3,888 2,100 5,559 4,864
	173,170	5,988	179,158
8 Net income/(expenditure) for the year	ear		
This is stated after charging/(crediting):	2022 £	2021 £	
Depreciation Operating lease rentals: Property	1,736	1,349 -	
Other Auditor's remuneration - audit fees Auditor's remuneration - accountancy fe	3,240 ees 1,750	2,460 3,000 1,600	

Notes to the accounts for the year ended 31 December 2022 (continued)

9 Staff costs

Staff costs during the year were as follows:

stall costs during the year were as follows:	2022 £	2021 £
Wages and salaries Social security costs Pension costs	224,759 18,288 8,598	206,210 18,525 7,843
	251,645	232,578
Allocated as follows: Cost of raising funds Charitable activities Support costs	32,791 125,704 93,150	68,177 67,193 97,208
	251,645	232,578

No employees has employee benefits in excess of £60,000 (2021: Nil).

The average number of staff employed during the period was 7 (2021: 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 £57,512 (2021: £54,453).

10 Trustee remuneration and expenses, and related party transactions

Two of the trustees Rachael Stevenson (Chief Executive) and Andrew Stevenson received remuneration totalling £98,854 during the year (2021:£95,066).

No trustee received travel and subsistence expenses during the year. (2021:nil).

Aggregate donations from related parties were £nil (2021: £35,000).

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

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

Reverse Rett made charitable grant to Rett Syndrome USA of £99,992 this year. (2021: £100,000).

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 (2021: nil).

Notes to the accounts for the year ended 31 December 2022 (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.

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12 Fixed assets: tangible assets

Cost	Computer equipment £
At 1 January 2022 Additions Disposals	7,525 1,549 -
At 31 December 2022	9,074
Depreciation	
At 1 January 2022 Charge for the year Disposals	5,370 1,736 -
At 31 December 2022	7,106
Net book value	
At 31 December 2022	1,968
At 31 December 2021	2,155

Notes to the accounts for the year ended 31 December 2022 (continued)

13 Debtors

		2022 £	2021 £
	Other debtors Prepayments and accrued income Gift aid debtor Big Give debtor	70,427 26,982 - 12,500	10,837 28,208 1,758 10,000
		109,909	50,803
14	Creditors: amounts falling due within one year	2022	2021
		£	£
	Trade creditors Other creditors and accruals Taxation and social security costs	293,621 6,973 11,375	16,297 74,895 13,785
		311,969	104,977

Notes to the accounts for the year ended 31 December 2022 (continued)

15 Analysis of movements in restricted funds

	Balance at 1 January 2022 £	Income £	Expenditure £	Transfers £	As at 31 December 2022 £
<i>MECP2</i> Duplication	12,368	6,196	(7,474)	-	11,090
Rett disorder alliance Use in	4,861	-	-	-	4,861
Farringdon	200	-	-	-	200
Parent 2 Parent Programme Clinical	3,056	-	-	-	3,056
Research Funds Pears Grant	48,694 8,000	-	-	_	48,694 8,000
reals Glaff	6,000				
Total	77,179	6,196	(7,474)	-	75,901
Previous reporting period	Balance at 1 January 2020 £	Income £	Expenditure £	Transfers £	31 December 2020 £
reporting period MECP2 Duplication	January 2020		-		December 2020
mECP2 Duplication Rett disorder alliance	January 2020 £ 11,090 4,861	£	£		December 2020 £ 12,368 4,861
mecp2 Duplication Rett disorder	January 2020 £ 11,090	£	£		December 2020 £ 12,368
MECP2 Duplication Rett disorder alliance Use in Parent 2 Parent Programme	January 2020 £ 11,090 4,861	£	£		December 2020 £ 12,368 4,861
MECP2 Duplication Rett disorder alliance Use in Parent 2 Parent Programme Clinical Research Funds	January 2020 £ 11,090 4,861 200	£	£ (14,484)		December 2020 £ 12,368 4,861 200
MECP2 Duplication Rett disorder alliance Use in Parent 2 Parent Programme Clinical	January 2020 £ 11,090 4,861 200 20,585	£	£ (14,484)		December 2020 £ 12,368 4,861 200 3,056
MECP2 Duplication Rett disorder alliance Use in Parent 2 Parent Programme Clinical Research Funds Anavex	January 2020 £ 11,090 4,861 200 20,585	£ 15,762	£ (14,484) (17,529)		December 2020 £ 12,368 4,861 200 3,056
MECP2 Duplication Rett disorder alliance Use in Parent 2 Parent Programme Clinical Research Funds Anavex Germany GmbH	January 2020 £ 11,090 4,861 200 20,585	£ 15,762 20,390	£ (14,484) (17,529)		December 2020 £ 12,368 4,861 200 3,056 48,694

MECP2

restricted fund

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

Description, nature and purposes of the fund

Notes to the accounts for the year ended 31 December 2022 (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 then 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 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)
Previous reporting period	Balance at 1 January 2021 £	Income £	Expenditure £	Transfers £	As at 31 December 2022 £
General fund	345,524	672,142	(800,940)		216,726
	345,524	672,142	(800,940)	_	216,726

Name of unrestricted

Description, nature and purposes of the fund

General fund

The free reserves after allowing for all designated funds

Notes to the accounts for the year ended 31 December 2022 (continued)

17 Analysis of net assets between funds

	General fund £	Designated funds £	Restricted funds £	Total £
Tangible fixed assets Net current assets/(liabilities)	1,968 (83,756)	- -	- 75,901	1,968 (7,855)
Total	(81,788)	-	75,901	(5,887)

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	
	2022 £	2021 £	2022 £	2021 £
Less than one year One to five years	<u>-</u> -	-	-	2,460 4,410
	-	-	-	6,870

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

2022 £	2021 £
(299,792)	(137,049)
1,736	1,349
. ,	58,360 13,286
200,992	13,200
(150,170)	(64,054)
	£ (299,792) 1,736 (59,106) 206,992