

Registered number: 07278507  
Charity number: 1136809

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**REVERSE RETT**  
(A company limited by guarantee)

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**TRUSTEES' REPORT AND FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 DECEMBER 2015**

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**REFERENCE AND ADMINISTRATIVE DETAILS OF THE COMPANY, ITS TRUSTEES AND ADVISERS  
FOR THE YEAR ENDED 31 DECEMBER 2015**

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**Trustees**

Monica Coenraads, Executive Director  
Rachael Stevenson, Executive Director  
Andrew J Stevenson, Treasurer  
Kelly Phillips  
Helen Simmonds  
Thomas Carroll (resigned 15 June 2015)  
Marc Souter (resigned 20 January 2016)  
John Sharpe, Chair  
Ortensia Martinotti (appointed 2 December 2015)

**Company registered number**

07278507

**Charity registered number**

1136809

**Registered office**

The Old Parsonage, Stenner Lane, Didsbury, Manchester, M20 2RQ

**Independent auditor**

Hillier Hopkins LLP, Radius House, 51 Clarendon Road, Watford, Herts, WD17 1HP

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**TRUSTEES' REPORT**  
**FOR THE YEAR ENDED 31 DECEMBER 2015**

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The Trustees present their annual report together with the audited financial statements of for the year 1 January 2015 to 31 December 2015.

Since the charity qualifies as small under section 383, the strategic report required of medium and large companies under The Companies Act 2006 (Strategic Report and Director's Report) Regulations 2013 is not required.

**Objectives and Activities**

**a. PUBLIC BENEFIT**

In setting objectives and planning for activities, the Trustees have given due consideration to general guidance published by the charity commission relating to public benefit.

**b. OBJECTIVES AND ACTIVITIES FOR ACHIEVING OBJECTIVES**

**Rett Syndrome is a neurological condition which most often strikes previously healthy little girls between their first and second birthday and leaves them with multiple disabilities and medical complexities for life.**

Most people with Rett are unable to speak, walk or use their hands. Breathing problems, feeding tubes, seizures, anxiety, gastrointestinal and orthopaedic issues are common.

Research has shown that girls with Rett do not have brain damage. They know and understand much more than their bodies allow them to show - but they are locked in, trapped by a body that cannot obey signals from their brain.

Whilst there is currently no treatment for Rett Syndrome, there is hope.

In 1999 scientists identified the genetic mutation that causes Rett Syndrome. In 2007, they unexpectedly reversed the condition in mouse models of even late stage disease.

At Reverse Rett, our research efforts are focused on translating these research developments into treatments and cures for our children living with Rett Syndrome today.

The last few years have brought unprecedented attention to Rett Syndrome by academic scientists, researchers and executives of pharmaceutical and biotech companies and more recently, life sciences investors. The interest stems from the advantages enjoyed by the Rett field: a known and single genetic cause, and the expectation of reversibility.

Since Rett Syndrome is caused by defective *MECP2* it stands to reason that approaches that attack the root cause, *MECP2* itself, hold the greatest promise of significantly improving symptoms.

Recent data from a number of labs suggests that there may also be many ways to improve Rett symptoms pharmacologically in mice. These approaches are treatments rather than cures but if successful could have a significant impact on the lives of patients with Rett who are struggling with difficult symptoms today.

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**TRUSTEES' REPORT (continued)**  
**FOR THE YEAR ENDED 31 DECEMBER 2015**

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**There is only one route to treatments and cures for Rett Syndrome: research.**

Fundraising to enable research to happen is the primary activity of Reverse Rett.

The main strength of the charity lies in the support given by families of girls with Rett who form the backbone of our fundraising activities.

Investment in resource to enable stronger community fundraising enabled us to raise £816,540 through community fundraising in 2015, which represents 85% of the overall income of the charity, compared to 80% in the previous reporting period.

The other 15% of the charity's income in 2015 was generated from regular monthly giving, our annual London event and funds drawn from trusts and foundations with the support of our much-appreciated Voluntary Grants Writer, Sarah Starbuck.

In 2015, in an effort to boost income, we tried to stimulate supporters into new fundraising activities through specific events. This was not as successful as we would have liked.

In 2016, we have decided to concentrate on a small number of key campaigns and events which have been historically strong, instead of trying to provide a wider variety of opportunities for supporters to get involved with.

**Achievements and performance**

**a. REVIEW OF ACTIVITIES**

Our Strategic Priorities

- 1) Funding research into basic science, clinical treatments and clinical trials.
- 2) Facilitating the development of clinical treatment centers in the UK which would also be capable of running clinical trials.
- 3) Developing Reverse Rett's organizational capabilities so it can fulfill its Mission and Vision in the longer term.

1. Funding research

Reverse Rett works in partnership with RSRT US to fund an international research program focused on treatment, reversal and better understanding the basic science underlying Rett Syndrome and related MECP2 disorders.

The shared use of a common Scientific Advisory Board enables us to ensure a coordinated, concerted and consistent effort in terms of the identification, monitoring and review of appropriate research projects.

Reverse Rett Executive Director, Rachael Stevenson serves on the Board of Trustees of the Rett Syndrome Research Trust and is an active part of the decision making process of the organization.

Between January 1st 2015 and December 31st 2015, Reverse Rett was RSRT's biggest international donor, providing financial support to 19 RSRT research projects, £694,141 to the international research program at RSRT.

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**TRUSTEES' REPORT (continued)**  
**FOR THE YEAR ENDED 31 DECEMBER 2015**

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International research funding is allocated to specific projects on a quarterly basis. Payments for the international projects are sent to the Reverse Rett account in the USA and subsequently distributed directly to the research projects we support.

Reverse Rett is prudently run and research funding is only approved if funds are already held.

The *MECP2* Duplication Fund at Reverse Rett

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 by families of children with *MECP2* Duplication Syndrome and their supporters in the UK are committed to *MECP2* specific projects via RSRT US.

Between January 1st 2015 and December 31st 2015, a total of £43,659.34 was delivered to *MECP2* Duplication projects via the Rett Syndrome Research Trust.

**The Trustees of Reverse Rett extend their deepest appreciation to all the fundraisers, supporters, donors and families of children with Rett and *MECP2* Duplication Syndrome, who have made this level of research funding possible in 2015.**

2. Facilitating the development of clinical treatment centers in the UK which would also be capable of running clinical trials.

Developing the infrastructure required to ensure that people with Rett Syndrome and related *MECP2* disorders in the UK have access to emerging treatments and/or clinical trials remains a priority to this organisation.

In 2015, we continued to work closely with allied organisations and clinicians to further this objective.

Reverse Rett also continues to work closely on national issues pertaining to the development of treatment pathways with key groups and patient organisations, including Findacure, Genetic Alliance UK, NHS England, NICE, Eurordis, Rare Disease UK, Rett UK and the wider Rett Disorders Alliance.

UK Clinical treatment

In 2015, Reverse Rett funded the Centre for Interventional Paediatric Pharmacology and Rare Diseases (CIPPRD)/King's College London, to develop new and improved outcome measures for patients with Rett Syndrome.

CIPPRD is a national specialist clinic whose focus is on managing the secondary symptoms of a variety of conditions, with the use of medications or other approaches as appropriate.

Better outcome measures for people with Rett will mean that doctors and researchers can more accurately measure improvements when they are trying new and existing medications and treatments in people with the condition. The new outcome measures include a combination of online parent/caregiver reports and round the clock physiological measures.

In 2015 the CIPPRD team were able to start utilising the new technology supported by Reverse Rett, within the CIPPRD clinical provision. A new informational booklet about this provision and how it can benefit patients with Rett can be found on our website [reverserett.org.uk](http://reverserett.org.uk).

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A focus group working to fine tune the development of online caregiver reporting was held in early 2016 facilitated by Reverse Rett.

Between January 1st 2015 and December 31st 2015, Reverse Rett delivered £22,500 to the CIPPRD Research Team/King's College London with respect to this work.

#### Rett Disorders Alliance

The Rett Disorders Alliance of the UK was formed in late 2014 to enable UK Rett organisations to work more effectively alongside each other as well as together, collaborating where appropriate on shaping a more positive future for people with Rett Disorders in the UK.

The group consists of UK charities or official patient groups which have direct or indirect involvement with issues relating to the management of symptoms, treatments or general condition of people with Rett Disorders in the UK.

Reverse Rett continues to be a strong voice within the Rett Disorders Alliance of the UK, with Reverse Rett Chairman, John Sharpe, holding the position of Chairman of the Rett Disorders Alliance throughout 2015 and into 2016.

In 2015, the RDA drew plans to develop the first UK Working Group for Rett Disorders which met for the first time in early 2016.

Much work needs to be done within the UK to improve the quality and consistency of clinical services for people with Rett Syndrome of all ages across the UK.

The formation of the Rett Disorders Working Group will form the basis of a new, stronger clinical network of UK clinicians with special interest and/or expertise in Rett Syndrome.

In 2016, Reverse Rett will continue to work with colleagues at Rett UK and the wider Rett Disorders Alliance to facilitate the development of such a network within the UK.

Reverse Rett will also continue to work actively to identify new UK based clinicians with a special interest and/or expertise in Rett Syndrome.

#### Reverse Rett Registry

Reverse Rett runs the only current and accurate basic registry of individuals with Rett Syndrome and related MECP2 disorders in the UK.

This registry can be completed on line on the charity website:

<http://www.reverserett.org.uk/what-we-do/research/register-your-child>

In 2015, 101 new patients were added to the Reverse Rett Registry.

In 2016, we need to find ways to increase registry sign-ups and will explore this as a potential option with other relevant organisations.

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3. Developing Reverse Rett's organizational capabilities so it can fulfil its Mission and Vision in the longer term.

John Sharpe has served as Chairman of Reverse Rett since September 2014, with Helen Simmonds serving as Vice-Chair.

An annual plan for 2016 was developed by the Chairman and approved by the Board of Trustees and will subsequently be implemented at the operational level.

Resources Costs Benefits

The organization remains in good shape with low costs and a good fundraising record.

In terms of financial size, Reverse Rett must now be considered as a medium-size charity. In income terms it is now in the top 7% of UK charities. In terms of numbers of people in the organization, it is still a small charity.

In 2015, we planned to recruit additional Part-time staff to support fundraising activities around the country. These changes were partly successful.

We recruited Beth Johnsson as Part-time Field Coordinator for the South. Beth has settled well into her role and has helped to generate growth in community fundraising at Reverse Rett. Beth will take up a FT position at the organization in Q4 2016.

In January 2015, we changed book-keeping provision from remote and flexible to in house half a day per week. This has removed a significant load of clerical accounting tasks from F&C Manager and enabled a more responsive and effective book-keeping process. Hayley Rose Rutherford continues in this role to date.

The three Full-time employees at Reverse Rett had performance appraisal reviews in the Spring of 2015. Salaries were reviewed and adjusted and a pension scheme was implemented.

We were not successful in recruiting a Part-time field Co-ordinator in the North. This has led us to reconsider the kind of resource that could be most useful to us.

In 2016, we will recruit a Part-time Office Manager for the Reverse Rett office in Manchester to enable increased administrative efficiency in support of our mission.

Policies

The following policies have been reviewed and/or developed and implemented since the last reporting period: Child Protection Policy, Financial and Fundraising Policy, Conflict of Interest Policy.

Reverse Rett also has the following policies in place: Confidentiality Policy, Donor Privacy Policy.

Information/Database

In 2014, we worked in close collaboration with Symphony-Online and Reverse Rett Professional Advisory Board member and Analytics advisor, David Greatrex to develop and implement an effective bespoke database to meet the needs of our growing organization.

In 2015, our main goal was to improve the effectiveness of our mailshot communications through database segmentation.

At the beginning of 2015 the CRM developers (Symphony) and Professional Advisory board member David Greatrex collaborated to enable us to target our e-newsletter more effectively by using segmentation-marketing techniques commonly deployed by corporations and business to increase engagement and revenue streams.



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This approach allows us to talk to the supporters on our database through mailshots in a way that is relevant to them; the objective being to communicate with people in as personal a way as is possible, creating an ongoing dialogue with supporters regarding campaigns, research and general Reverse Rett news and developments.

Engagement has subsequently doubled in terms of the amount of people reading the newsletter and the click through rates to the website.

CRM (database) growth has seen an increase from 2K at the beginning of 2015 to 3K.

In 2015 we sent out:

- 103 mailshots to five different segmented groups.
- Mailshots sent out to the targeted groups have an average open rate of 43.1% compared to 22% open rate for non-targeted.
- They have a click through rate of 4.7% compared to 2.86% for non-targeted.

In 2015, the mailshot was read over 30,000 times, more than double the previous year.

In the build-up to the hugely successful 2015 'Big Give Christmas Challenge,' fifty mailshots were sent out over the year to prime people for the challenge, garner support and inform them of what to do on the day to get the money they had collected doubled. Due to these improved mailshot communications and social media support, supporters were primed and ready on their devices at exactly the right time, leading to 100K being raised in a matter of minutes.

Our main goal in 2016 is to recruit more supporters into our database. This will give us a wider impact from all of our mailshot communications.

We will also apply lessons learning from our experience of communications in 2015.

We will need to review alternative online marketing solutions as the database grows to ensure ongoing effectiveness.

#### Communications

Reverse Rett communications can be broadly split into four categories:

- Interpersonal communications
- Mailshot
- Website
- Social media

**Interpersonal communications** happen via telephone, letter, personal email, enquiries email, 3 different website forms and via social media, both through personal and direct to the charity messaging.

Interpersonal communications are very effective in terms of supporter care but they are time-consuming and rely much of the time, on initiation from the supporter.

**Mail shot** As described above, in 2015, we aimed to personalize our broader communications so that they are effectively drawing more individual engagement with the charity.

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**Website** Visits to the website in 2015 significantly increased compared to 2014 figures:

2014: 30K sessions, 21K users, 69K page views

2015: 42K sessions, 32K users, 85K page views

In 2015 we wrote over 100 news articles for the Reverse Rett website.

In 2016, we will complete a thorough content update of the Reverse Rett website, rewriting all static copy in Q1.

We have identified that the most popular articles are research-focused and will endeavor to increase the number of research-focused articles by increasing the number of guest bloggers who are able to make this kind of contribution.

#### Social media

Social media is constantly evolving. Reaching people without paying for boosted posts is becoming more and more difficult. We have strategies at present that allow us to work around some of these issues. In 2016, we need to continue to find ways to address this and seek professional advice/training where appropriate.

In 2015, Reverse Rett gained:

- 900 new followers on Facebook.
- 987 new followers on Twitter

We sent out:

- 1500 posts on the Reverse Rett Facebook page
- 818 Reverse Rett Tweets

In 2015 we trialed an October awareness campaign which resulted in a Facebook reach of 219,837 compared with previous month's reach of 70,773.

#### **Financial review**

##### **a. DIRECT COSTS**

Direct costs refer to expenditure by the charity.

Total direct costs in 2015 were £751,956

£694,141 included payment to the Rett Syndrome Research Trust US for subsequent distribution to the international research projects we support.

- £650,481.66 Rett Syndrome projects
- £43,659.34 *MECP2* Duplication projects

A table showing the breakdown of research projects funded by quarter is available on our website here: <http://www.reverserett.org.uk/what-we-do/about-us/our-finances/>

£22,500 included payment to King's College London for clinical research work.

£9,497 travel costs

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**TRUSTEES' REPORT (continued)**  
**FOR THE YEAR ENDED 31 DECEMBER 2015**

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**b. TRUSTEE'S REMUNERATION**

Two of the charity's Trustees are full-time employees of the organisation and thus receive a salary for their work.

**c. RESERVES POLICY**

Research funding is only approved and made by the trustees if funds are already held. The aim is to hold an amount equivalent to 6 months operating costs in reserves at the year end.

**Structure, governance and management**

**a. CONSTITUTION**

The company is constituted under a Memorandum of Association dated 9 June 2010 and is a registered charity number 1136809.

Reverse Rett is a national charity.

Our Mission

Our mission is to speed treatments and cures for Rett Syndrome and related *MECP2* disorders by funding research that will have a practical and positive effect on our children's lives.

We fund research from basic science to clinical trials, and work to facilitate the translation of this work to clinical applications for our children with Rett Syndrome and related *MECP2* disorders.

Our Vision

Our vision is a world where girls with Rett Syndrome are diagnosed much quicker and earlier than they are at the moment. A world where we know much more about the progression of the condition and the factors that affect that progression. A world where at every stage of development treatments are available to mitigate against the distressing symptoms which can occur and ultimately a world where treatments are available which cure the condition and allow the girls to live normal lives.

The charity operates in England, Wales, Scotland and Northern Ireland.

The Charity's objectives are:

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.

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**TRUSTEES' REPORT (continued)**  
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**b. METHOD OF APPOINTMENT OR ELECTION OF TRUSTEES**

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 of the Charity who served during the year ended December 31st 2015 are shown on page 1.

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 Bloom (now Rachael Stevenson,) Monica Coenraads and Andrew Stevenson were involved in the founding of the Charity and the remaining Trustees are directly involved in the continued work of the organisation.

**c. POLICIES ADOPTED FOR THE INDUCTION AND TRAINING OF TRUSTEES**

To ensure best practise, all Trustees have worked through the NCVO publication, 'The Good Trustee Guide,' and have been encouraged to read the Charity Commission publication, 'The Essential Trustee.'

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

All Board members at Reverse Rett are parents or grandparents of an individual with Rett Syndrome.

**d. ORGANISATIONAL STRUCTURE AND DECISION MAKING**

Rachael Stevenson, (previously Rachael Bloom) Founding Trustee and Executive Director of Reverse Rett, maintains operational control of the organisation.

Since the inception of the organisation in 2010, Rachael has been responsible for implementing the charity's strategic priorities and for the day-to-day running of the organisation, including communications, fundraising and administration.

Rachael became a formal employee of the Charity in April 2012 and now reports to the Board of Trustees of Reverse Rett.

There are two full-time and one part-time member(s) of staff who report to the Executive Director.

Founding Trustee, Andrew Stevenson became a formal employee of the organisation on September 1st 2012. He continues in the role of Fundraising and Communications Manager to date.

Thomas Johnston became an employee of the organisation on January 10th 2014 and continues in his role of Insights and Information Officer to date.

Beth Johnsson became employed by the organisation on February 23rd 2015 and continues in her role to date.

All staff members have regular and open communication with the Chairman of Reverse Rett, John Sharpe.

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.

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**TRUSTEES' REPORT (continued)**  
**FOR THE YEAR ENDED 31 DECEMBER 2015**

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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.

**e. RISK MANAGEMENT**

The Trustees have assessed the major risks to which the charity is exposed, in particular those related to the operations and finances of the charity, and are satisfied that systems and procedures are in place to mitigate our exposure to the major risks.

**Plans for future periods**

**a. FUTURE DEVELOPMENTS**

Reverse Rett works to speed the time it takes to deliver treatments and a cure for Rett Syndrome and related *MECP2* Disorders.

In 2015, the organization had aimed to increase our international research commitment by 10% per quarter, up to \$275,000 per quarter.

Although this proved difficult, in Qs 1,2, and 4 we did achieve this goal, delivering \$275,000 per quarter plus *MECP2* Duplication funds to the International Research Program at RSRT. In Q3, (September) we delivered \$200,000 plus *MECP2* Duplication funds to RSRT.

We are already aware that for a number of reasons, our projected income in 2016 is likely to be less than in 2015. However, Community Fundraising continues to grow.

In 2016:

- We will work to further improve our Community Fundraising performance and raise as much money as we can to contribute to the International Research Program at RSRT.
- We will continue to work with the UK medical community and other allied organisations to ensure that emerging treatments and therapies can be implemented within the UK.
- We will continue to develop Reverse Rett's organizational capabilities so we can fulfill our vision and mission in the longer term.

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**TRUSTEES' REPORT (continued)**  
**FOR THE YEAR ENDED 31 DECEMBER 2015**

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**The Board of Trustees of Reverse Rett would like to thank the following Trusts, Foundations, Companies and Community Groups who generously supported our work in 2015:**

Access UK Ltd  
Actuaries  
AFTS-AFTS RA 617004  
An gbol  
Arnold Clark  
Aurora Sparkle  
Ballamic Sports Club  
Bank of Scotland  
BG Internation  
Billy's Basement  
Carmel Clothing  
CIDER  
Cotgrave  
Cure for Dylan  
D Henderson-Hope for Nell  
David Ford Milk & Cookies Gig  
Eaton House School  
Fawcett Stairlift  
GAM UK  
GFK NOP Fund  
Goldman Sachs Grant Research Medical  
Grove House  
H & Askham  
Henry JJ  
Hope for Eliza  
Intermarketing Agency  
J A C A Andrews  
J Alpha Charitable Trust  
James & Heidi Paradise  
Kelly Phillips  
Langton  
Like Technologies  
McKinney Calendars  
Mrs Sharpe-John Sharpe  
Northwood Lodge  
PH Group Media  
Prism the Gift  
The Rowse Family Trust  
Sing Healthy  
Sky Bet-Sky Bet Auctions  
St Oswald's School  
The Sylvia Aitken Trust  
The Marple Charity

In 2015, Reverse Rett income generated online via Just Giving was £244,680.

The Board of Trustees of Reverse Rett would like to take this opportunity to acknowledge the significant contribution of individuals and community groups who have donated to or fundraised for Reverse Rett via Just Giving and other online giving facilities in 2015.

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**TRUSTEES' REPORT (continued)**  
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**TRUSTEES' RESPONSIBILITIES STATEMENT**

The Trustees (who are also directors of Reverse Rett for the purposes of company law) are responsible for preparing the Trustees' 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. Under company law the Trustees must not approve the financial statements unless they are satisfied that they 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 judgments and accounting estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in operation.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company's transactions and 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.

**DISCLOSURE OF INFORMATION TO AUDITOR**

Each of the persons who are Trustees at the time when this Trustees' report is approved has confirmed that:

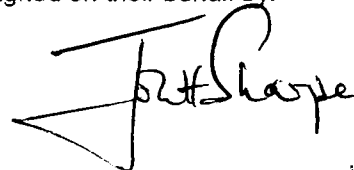
- so far as that Trustee is aware, there is no relevant audit information of which the charitable company's auditor is unaware, and
- that Trustee has taken all the steps that ought to have been taken as a Trustee in order to be aware of any information needed by the charitable company's auditor in connection with preparing its report and to establish that the charitable company's auditor is aware of that information.

In preparing this report, the Trustees have taken advantage of the small companies exemptions provided by section 415A of the Companies Act 2006.

This report was approved by the Trustees on

and signed on their behalf by:

John Sharpe, Chairman



18/08/2016

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**INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF REVERSE RETT**

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We have audited the financial statements of Reverse Rett for the year ended 31 December 2015 set out on pages 16 to 27. The financial reporting framework that has been applied in their preparation is applicable law and the Financial Reporting Standard for Smaller Entities (effective January 2015) (United Kingdom Generally Accepted Accounting Practice applicable to Smaller Entities).

This report is made solely to the charitable company's members, as a body, in accordance with section 145 of the Charities Act 2011 and regulations made under section 154 of that Act. 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 its members, as a body, for our audit work, for this report, or for the opinion we have formed.

**RESPECTIVE RESPONSIBILITIES OF TRUSTEES AND AUDITOR**

As explained more fully in the Trustees' responsibilities statement, 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.

The Trustees have elected for the financial statements to be audited in accordance with the Charities Act 2011 rather than the Companies Act 2006. Accordingly we have been appointed as auditor under section 145 of the Charities Act 2011 and report to you in accordance with regulations made under section 154 of that Act. Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's Ethical Standards for Auditors.

**SCOPE OF THE AUDIT OF THE FINANCIAL STATEMENTS**

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the company's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the Trustees; and the overall presentation of the financial statements. In addition, we read all the financial and non-financial information in the Trustees' report to identify material inconsistencies with the audited financial statements and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by us in the course of performing the audit. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

**OPINION ON FINANCIAL STATEMENTS**

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 2015 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 applicable to Smaller Entities; and
- have been prepared in accordance with the requirements of the Companies Act 2006.



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**INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF REVERSE RETT**

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**MATTERS ON WHICH WE ARE REQUIRED TO REPORT BY EXCEPTION**

We have nothing to report in respect of the following matters where the Charities Act 2011 requires us to report to you if, in our opinion:

- the information given in the Trustees' report is inconsistent in any material respect with the financial statements; or
- the company has not kept adequate accounting records; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

*Hillier Hopkins LLP*

**Hillier Hopkins LLP**

Chartered Accountants  
Statutory Auditor

Radius House  
51 Clarendon Road  
Watford  
Herts  
WD17 1HP

Date: *31 AUGUST 2016*

Hillier Hopkins LLP is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

**REVERSE RETT**  
(A company limited by guarantee)

**STATEMENT OF FINANCIAL ACTIVITIES INCORPORATING INCOME AND EXPENDITURE ACCOUNT  
FOR THE YEAR ENDED 31 DECEMBER 2015**

	Note	Restricted funds 2015 £	Unrestricted funds 2015 £	Total funds 2015 £	Total funds 2014 £
<b>INCOME FROM:</b>					
Donations and capital grants	2	53,600	710,810	764,410	607,136
Charitable activities	3	10,006	181,493	191,499	249,046
<b>TOTAL INCOME</b>		<b>63,606</b>	<b>892,303</b>	<b>955,909</b>	<b>856,182</b>
<b>EXPENDITURE ON:</b>					
Raising funds		-	79,534	79,534	59,907
Charitable activities	6	32,781	801,178	833,959	937,952
<b>TOTAL EXPENDITURE</b>	7	<b>32,781</b>	<b>880,712</b>	<b>913,493</b>	<b>997,859</b>
<b>NET INCOME / (EXPENDITURE) AND MOVEMENT IN FUNDS</b>		<b>30,825</b>	<b>11,591</b>	<b>42,416</b>	<b>(141,677)</b>
<b>RECONCILIATION OF FUNDS:</b>					
Total funds brought forward		17,495	50,569	68,064	209,741
<b>TOTAL FUNDS CARRIED FORWARD</b>		<b>48,320</b>	<b>62,160</b>	<b>110,480</b>	<b>68,064</b>

The notes on pages 18 to 27 form part of these financial statements.

**REVERSE RETT**  
**(A company limited by guarantee)**  
**REGISTERED NUMBER: 07278507**

**BALANCE SHEET**  
**AS AT 31 DECEMBER 2015**

	Note	£	2015 £	£	2014 £
<b>FIXED ASSETS</b>					
Tangible assets	10		1,564		810
<b>CURRENT ASSETS</b>					
Debtors	11	955		750	
Cash at bank and in hand		121,364		71,904	
		<u>122,319</u>		<u>72,654</u>	
<b>CREDITORS:</b> amounts falling due within one year	12	(13,403)		(5,400)	
<b>NET CURRENT ASSETS</b>			<u>108,916</u>		67,254
<b>NET ASSETS</b>			<u>110,480</u>		<u>68,064</u>
<b>CHARITY FUNDS</b>					
Restricted funds	13		48,320		17,495
Unrestricted funds	13		62,160		50,569
<b>TOTAL FUNDS</b>			<u>110,480</u>		<u>68,064</u>

The Trustees consider that the company is entitled to exemption from the requirement to have an audit under the provisions of section 477 of the Companies Act 2006 ("the Act") and members have not required the company to obtain an audit for the year in question in accordance with section 476 of the Act. However, an audit is required in accordance with section 145 of the Charities Act 2011.

The Trustees acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and for preparing financial statements which give a true and fair view of the state of affairs of the company as at 31 December 2015 and of its net incoming resources for the year in accordance with the requirements of sections 394 and 395 of the Act and which otherwise comply with the requirements of the Act relating to financial statements, so far as applicable to the company.

The financial statements have been prepared in accordance with the provisions applicable to small companies within Part 15 of the Companies Act 2006 and in accordance with the Financial Reporting Standard for Smaller Entities (effective January 2015).

The financial statements were approved by the Trustees on 15<sup>th</sup> August 2016 and signed on their behalf, by:

*Rachael Stevenson*

**Rachael Stevenson**

The notes on pages 18 to 27 form part of these financial statements.

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**REVERSE RETT**  
**(A company limited by guarantee)**

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**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 DECEMBER 2015**

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**1. ACCOUNTING POLICIES**

**1.1 Basis of preparation of financial statements**

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 for Smaller Entities published on 16 July 2014, the Financial Reporting Standard for Smaller Entities (effective January 2015) and the Companies Act 2006.

Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy.

**1.2 Company status**

The company is a company limited by guarantee. The members of the company are the Trustees named on page 1. In the event of the company being wound up, the liability in respect of the guarantee is limited to £10 per member of the company.

**1.3 Fund accounting**

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the company and which have not been designated for other purposes.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the company for particular purposes. The costs of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements.

**1.4 Income**

All income is recognised once the company has entitlement to the income, it is probable that the income will be received and the amount of income receivable can be measured reliably.

For legacies, entitlement is taken as the earlier of the date on which either: the company is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the Trust 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 company has been notified of the executor's intention to make a distribution. Where legacies have been notified to the company, or the company 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 tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

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**REVERSE RETT**  
**(A company limited by guarantee)**

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**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 DECEMBER 2015**

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**1. ACCOUNTING POLICIES (continued)**

**1.5 Expenditure**

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use.

Fundraising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of the charitable activities. Support costs are those costs incurred directly in support of expenditure on the objects of the company and include project management carried out at Headquarters. Governance costs are those incurred in connection with administration of the company and compliance with constitutional and statutory requirements.

Costs of generating funds are costs incurred in attracting voluntary income, and those incurred in trading activities that raise funds.

Charitable activities and Governance costs are costs incurred on the academy trust's educational operations, including support costs and costs relating to the governance of the academy trust apportioned to charitable activities.

**1.6 Tangible fixed assets and depreciation**

All assets costing more than £1,000 are capitalised.

Tangible fixed assets are carried at cost, net of depreciation and any provision for impairment. Depreciation is provided at rates calculated to write off the cost of fixed assets, less their estimated residual value, over their expected useful lives on the following bases:

Office equipment	-	25% straight line
Computer equipment	-	25% straight line

**REVERSE RETT**  
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**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 DECEMBER 2015**

**2. INCOME FROM DONATIONS AND LEGACIES**

	Restricted funds 2015 £	Unrestricted funds 2015 £	Total funds 2015 £	Total funds 2014 £
Donations	43,600	707,810	751,410	607,136
Grants	10,000	3,000	13,000	-
	<u>53,600</u>	<u>710,810</u>	<u>764,410</u>	<u>607,136</u>

In 2014, of the total income from donations and legacies, £607,136 was to unrestricted funds and £ NIL was to restricted funds

**3. INCOME FROM CHARITABLE ACTIVITIES**

	Restricted funds 2015 £	Unrestricted funds 2015 £	Total funds 2015 £	Total funds 2014 £
The Big Give	-	117,492	117,492	74,945
London Event 2015	-	64,001	64,001	42,077
Lifeline Project	-	-	-	5,000
MECP2 Fund	5,381	-	5,381	117,774
Roald Dahl	4,625	-	4,625	9,250
	<u>10,006</u>	<u>181,493</u>	<u>191,499</u>	<u>249,046</u>

In 2014, of the total income from charitable activities, £117,022 was to unrestricted funds and £132,024 was to restricted funds.

**4. DIRECT COSTS**

	Project funding £	Total 2015 £	Total 2014 £
Transfer to Rett Syndrome Research Trust USA	694,141	694,141	794,445
Travel and accomodation	9,497	9,497	12,900
Brand redevelopment	582	582	2,016
Kings College Grant	22,500	22,500	22,500
Healthtracker Grant	-	-	23,100
Wages and salaries	23,552	23,552	17,500
National insurance	1,684	1,684	1,375
	<u>751,956</u>	<u>751,956</u>	<u>873,836</u>

**REVERSE RETT**  
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**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 DECEMBER 2015**

**5. SUPPORT COSTS**

	<b>Project funding £</b>	<b>Total 2015 £</b>	<i>Total 2014 £</i>
Misc expenditure	785	785	4,630
Telephone	1,034	1,034	616
Postage	3,673	3,673	5,224
Administration cost	1,687	1,687	1,000
Professional fees	1,265	1,265	2,093
Bank charges	1,401	1,401	544
Operating lease payments	1,277	1,277	-
Office rental costs	7,625	7,625	7,551
Insurance	453	453	-
Wages and salaries	37,537	37,537	16,958
National insurance	2,684	2,684	954
Depreciation	522	522	270
	<u>59,943</u>	<u>59,943</u>	<u>39,840</u>

**6. GOVERNANCE COSTS**

	<b>Restricted funds 2015 £</b>	<b>Unrestricted funds 2015 £</b>	<b>Total funds 2015 £</b>	<i>Total funds 2014 £</i>
Auditors' remuneration	-	5,400	5,400	5,400
Accountancy costs	-	3,172	3,172	-
Meeting expenses	-	249	249	-
Governance expense - wages & salaries	4,625	7,730	12,355	17,500
Governance expense - NI	-	884	884	1,376
	<u>4,625</u>	<u>17,435</u>	<u>22,060</u>	<u>24,276</u>

**REVERSE RETT**  
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**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 DECEMBER 2015**

**7. ANALYSIS OF RESOURCES EXPENDED BY EXPENDITURE TYPE**

	Staff costs 2015 £	Depreciation 2015 £	Other costs 2015 £	Total 2015 £	Total 2014 £
Expenditure on fundraising trading	36,151	-	43,383	79,534	59,907
<b>Costs of generating funds</b>	<b>36,151</b>	<b>-</b>	<b>43,383</b>	<b>79,534</b>	<b>59,907</b>
Project funding	65,457	522	745,920	811,899	913,676
Expenditure on governance	13,239	-	8,821	22,060	24,276
	<b>114,847</b>	<b>522</b>	<b>798,124</b>	<b>913,493</b>	<b>997,859</b>

**8. NET INCOMING RESOURCES/(RESOURCES EXPENDED)**

This is stated after charging:

	2015 £	2014 £
Depreciation of tangible fixed assets:		
- owned by the charity	522	270
Auditor's remuneration	5,400	5,400

During the year, 2 Trustees received remuneration totalling £71,250 (2014 - £60,000).

During the year, no Trustees received any benefits in kind (2014 - £NIL).

1 Trustee received reimbursement of travel expenses amounting to £184 in the current year, (2014 - 4 Trustees - £6007).



**REVERSE RETT**  
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**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 DECEMBER 2015**

**9. STAFF COSTS**

Staff costs were as follows:

	2015 £	2014 £
Wages and salaries	107,181	76,958
Social security costs	7,665	5,442
	114,846	82,400

The average number of persons employed by the company during the year was as follows:

	2015 No.	2014 No.
	5	3
	5	3

No employee received remuneration amounting to more than £60,000 in either year.

**10. TANGIBLE FIXED ASSETS**

	Office equipment £	Computer equipment £	Total £
<b>Cost</b>			
At 1 January 2015	-	1,080	1,080
Additions	227	1,049	1,276
	227	2,129	2,356
At 31 December 2015			
<b>Depreciation</b>			
At 1 January 2015	-	270	270
Charge for the year	57	465	522
	57	735	792
At 31 December 2015			
<b>Net book value</b>			
At 31 December 2015	170	1,394	1,564
At 31 December 2014	-	810	810

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**REVERSE RETT**  
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**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 DECEMBER 2015**

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**11. DEBTORS**

	<b>2015</b>	<b>2014</b>
	£	£
Other debtors	<b>750</b>	<b>750</b>
Prepayments and accrued income	<b>205</b>	<b>-</b>
	<u><b>955</b></u>	<u><b>750</b></u>
	<u><u><b>955</b></u></u>	<u><u><b>750</b></u></u>

**12. CREDITORS: Amounts falling due within one year**

	<b>2015</b>	<b>2014</b>
	£	£
Trade creditors	<b>4,126</b>	<b>-</b>
Other taxation and social security	<b>2,785</b>	<b>-</b>
Other creditors	<b>1,092</b>	<b>-</b>
Accruals and deferred income	<b>5,400</b>	<b>5,400</b>
	<u><b>13,403</b></u>	<u><b>5,400</b></u>
	<u><u><b>13,403</b></u></u>	<u><u><b>5,400</b></u></u>

**REVERSE RETT**  
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**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 DECEMBER 2015**

**13. STATEMENT OF FUNDS**

	Brought Forward £	Income £	Expenditure £	Transfers in/out £	Carried Forward £
<b>Unrestricted funds</b>					
Reserves	50,569	892,303	(880,712)	-	62,160
<b>Restricted funds</b>					
Gene Therapy Consortium	3,825	10,000	-	-	13,825
Lifeline Project	8,510	-	-	(8,510)	-
MECP2 Duplication Fund	(40)	5,381	(5,341)	-	-
Roald Dahl	-	4,625	(4,625)	-	-
Use in Farringdon	200	-	-	-	200
Parent 2 Parent Programme	5,000	-	(315)	8,510	13,195
Clinical Research Funds	-	43,600	(22,500)	-	21,100
	<u>17,495</u>	<u>63,606</u>	<u>(32,781)</u>	<u>-</u>	<u>48,320</u>
Total of funds	<u><u>68,064</u></u>	<u><u>955,909</u></u>	<u><u>(913,493)</u></u>	<u><u>-</u></u>	<u><u>110,480</u></u>

**MECP2 Duplication Fund**

*MECP2 Duplication Syndrome* is caused by problems with the same gene as Rett Syndrome and mostly affects boys.

The symptoms are similar to those we see in Rett; developmental delay with no or very little speech, floppiness, difficulties with feeding, seizures, mobility issues and compromised immune functioning.

The *MECP2 Duplication Fund* at Reverse Rett is driven by a group of like-minded research-focused *MECP2* families in the UK who are working to impact the effort to speed treatment for *MECP2 Duplication Syndrome*.

Reverse Rett supports the efforts of these families by holding a designated fund for *MECP2 Duplication Syndrome* research.

100% of funds which are raised for Reverse *MECP2* through Reverse Rett are delivered to *MECP2* research focused projects every quarter.

Incoming resources referred to in the Statement of Funds, refers to off-line donations received directly by Reverse Rett with regards to the *MECP2 Duplication Fund* and does not represent the total donations or sponsorship received for the fund in a given year.

**Roald Dahl Fund**

Grant payments received from Roald Dahl's Marvelous Children's Charity were restricted to the Executive Director's salary.

Income to this fund in 2015 constitutes the last payment from the grant from Roald Dahl Fund.

**Gene Therapy Workshop fund**

The Gene Therapy Workshop Fund was comprised of a donation of £10,000, which came to Reverse Rett, whereby the donors, The Jomati Foundation, requested that funds be spent only on the development

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**REVERSE RETT**  
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**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 DECEMBER 2015**

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**13. STATEMENT OF FUNDS (continued)**

of research projects in the UK and Europe. At the time there were no relevant research projects in need of funding within the UK.

These funds were deployed with regards to networking events with UK based researchers and scientists via Reverse Rett sponsorship of the British Society of Gene and Cell Therapy Conference and the Rett Syndrome Europe European Convention in Maastricht in 2013.

Remaining funds should now be allocated to the Gene Therapy Consortium, specifically to the Gene Therapy program at the Cobb Lab at the University of Glasgow.

**Lifeline project**

The Lifeline Project was the original name for our Changemakers Project.

When the Trusts Team wrote for funding for this project, they called it 'Lifeline' but we later renamed it, 'Changemakers.'

Both projects are now closed and therefore we can now close these funds.

**Parent 2 Parent**

Reverse Rett Parent 2 Parent offers 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.

Through the project, Reverse Rett provides on-going training and support for mentors and materials for both mentor and mentee. Communication between both parties is facilitated by Reverse Rett in the first six weeks of contact and thereafter as required.

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

**Use in Farringdon**

This grant of £200 from The Ammco Trust was mistakenly received for the Changemakers Project for use in Farringdon, which is a very small market town in Oxfordshire. As it is very unlikely this will be used in the town, the funds have now been returned.

**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.

**SUMMARY OF FUNDS**

	Brought Forward £	Income £	Expenditure £	Transfers in/out £	Carried Forward £
General funds	50,569	892,303	(880,712)	-	62,160
Restricted funds	17,495	63,606	(32,781)	-	48,320
	<u>68,064</u>	<u>955,909</u>	<u>(913,493)</u>	<u>-</u>	<u>110,480</u>

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**REVERSE RETT**  
(A company limited by guarantee)

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**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 DECEMBER 2015**

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**14. ANALYSIS OF NET ASSETS BETWEEN FUNDS**

	Restricted funds 2015 £	Unrestricted funds 2015 £	Total funds 2015 £	Total funds 2014 £
Tangible fixed assets	-	1,564	1,564	810
Current assets	48,320	74,000	122,320	72,654
Creditors due within one year	-	(13,404)	(13,404)	(5,400)
	<u>48,320</u>	<u>62,160</u>	<u>110,480</u>	<u>68,064</u>

**15. OPERATING LEASE COMMITMENTS**

At 31 December 2015 the total of the Charity's future minimum lease payments under non-cancellable operating leases was:

	2015 £	2014 £
Within 1 year	<u>2,417</u>	<u>2,417</u>