

Annual Report & Accounts 2013/2014



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Foreword from the Chair

We are extremely grateful for our supporters who ran, walked and pedalled their way to raising a brilliant £121,427 last year. Your ingenuity in finding ways to raise funds knows no bounds. It is your tireless support that has enabled us to help 337 families in crisis.

From our many hundreds of phone calls, e-mails and letters asking for help and expert information we know that the programme of hands on support we provide is needed more than ever. We make a difference NOW in assisting people with Rett syndrome to achieve their goals.

It is only through the money you raised that we can respond to requests for help. As a result of those funds our full time specialist Support Workers are available to provide assistance. Besides telephone and email contact, our Support Workers attend clinics and host regional days. They have a wealth of experience and will work incredibly hard to ensure positive outcomes for those in need.

Specialist Clinics, which are funded by the NHS, have been held in London, Nottingham, Manchester and Cardiff. Clinics enable children and adults with medical and management issues to be seen by medical and therapeutic professionals who are experts in the field of Rett syndrome. Members of our support staff are on hand at the clinics to deal with any issues.

Regional days held this year in Cambridge, Chesterfield and Newcastle were very popular and well attended by over 330 people. These day events ensure that parents, carers, siblings and people with Rett syndrome meet each other and professionals. Their feedback tells us that the information, practical help and fellowship has meant so much to our community.

'Talks were relevant, practical and made good use of the time. Open forums provided a great opportunity to ask questions'

Our "Management and Care Guidelines, a handbook for professionals" contains advice from many experts and has been received favourably by both parents and professionals. It was launched at the European Congress in Maastricht in October 2013 has been adopted by other countries and has even been translated into Hungarian.

To ensure that we reach as many people as possible, membership of Rett UK is free. I am delighted to see that numbers are continuing to grow.

In May, after 3 years, Paul Chapman stood down as Chairman. Vice-chair Peter Oliver took over temporarily and I was appointed in September 2013. Our sincere thanks go to Paul and Peter for their hard work, dedication and commitment.

Unfortunately for much of the year our Chief Executive Officer was on sick leave and eventually retired due to ill health. We wish her well. In her absence, our loyal staff team has continued to keep things running smoothly in the office. We give them our grateful thanks.

The new year sees us upbeat and positive about the future. We make a difference NOW and strive to fulfil all of our aims, so that our people with Rett syndrome and their families can have the best possible quality of life.

Lorna Joffar

Lorna Jaffa - Chair of the Trustees Date: 27 September 2014



Report of the Trustees for the Year Ended 31 March 2014

The trustees, who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 March 2014. The trustees have adopted the provisions of the Statement of Recommended Practice (SORP) 'Accounting and Reporting by Charities' issued in March 2005.

Reference and Administrative Details

Registered Company number: 07339522 (England and Wales)

Registered Charity number:

1137820

Registered office:

Langham House West Mill Street Luton Bedfordshire LU12NA

Auditor

Grunberg & Co Limited Chartered Accountants 10-14 Accommodation Road Golders Green London **NW11 8ED**

Bankers

HSBC 18 Ballards Lane Church End Finchley London N3 2BH



Activities for the Public Benefit

We have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing our aims and objectives and in planning our future activities. In particular, the trustees consider how planned activities will contribute to the aims and objectives they have set.

During the course of this year's activities, Rett UK has supported over 520 families, given assistance to over 27 newly diagnosed families and worked extensively with medical professionals and care teams to advance understanding and awareness of Rett syndrome in the UK.

A key decision by the Trustee Board was to open membership to all those within the Rett community and to offer that as a free service.

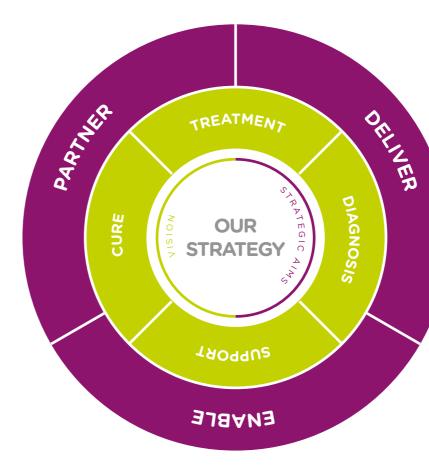
Strategy

About Rett syndrome

When a child with classic Rett syndrome is born, they appear perfectly normal. In the second year of life, the parent's dreams are shattered as regression occurs and the child begins to lose skills they had already developed. The outcome of regression is that the child will be profoundly and multiply disabled and totally dependent on others for the whole of their lives. They may be unable to speak. walk or use their hands; many have epilepsy, reflux and scoliosis. Most of those with classic and atypical Rett syndrome are female. However, recently other variants, some which may involve males have been identified. These are CDKL5, FOXG1 and MECP2.

Who we are

Rett UK is a national charity. We are a membership organisation and welcome members from the UK and abroad.



Our vision is:

- That everyone with Rett syndrome is diagnosed, their symptoms effectively treated and their families, carers and friends inclusively and appropriately supported; and • A cure for Rett syndrome.

Our aims:

- In line with our vision, Rett UK's strategic aims are to:
- Deliver excellent support services to meet the short and long term needs of the Rett community:
- Promote, support and encourage research to enable improvements in identifying new therapies and treatments for Rett people and ultimately a cure;
- Raise awareness of Rett syndrome and its effect on individuals and the families: and
- Pursue a broad range of funding opportunities in order to deliver our objectives.

Support Today

The year 2013/14 saw a dramatic increase in the number of times we are in touch with families with recorded figures in excess of 1300 points of contact, not including social media interactions. enquiries about regional family events or fundraising! This is direct contact by families with members of the family support team. Wow! We seem to be doing it right!

The increase in contact has been for a number of different reasons. The majority of requests for support and information are directly due to the impact of Welfare Reforms. Many of our families' daily lives are made increasingly more complicated and difficult due to changes or reduction in services e.g. requests for payment for services previously received free of charge, such as Blue Badges.

We have also seen an increase in requests from families who are experiencing problems during hospital admissions and those dealing with medical professionals.

Both are complex areas that require the regular and on-ongoing support from the team.

Support is all about helping others and the Rett UK team is always happy to extend its help to those further afield who have received a diagnosis of Rett syndrome and may not have such great information and support networks as we have in the UK. We are seeing an increase in contact from Eastern Europe. We help families to get a better understanding of the syndrome and to improve their expectations for their children.

"Last week we have received the medical report based on our last month's stay in Cardiff. I would like to thank you both for the kind hospitality, support and the attention you've shown to me and my family. We are really grateful to have you on our side for this hard journey. Wish you and the team all the best."

Nikolay, Michaela & Magdalena, Bulgaria

Regional Family Days

We commenced the second round of regional days on 22 March 2014 at New Siblands Secondary School in Thornbury near Bristol. A great day was had by everyone who attended. New professionals who have been added to the programme include a Spinal Surgeon, a Specialist Registrar in Special Care Dentistry and a Music Therapist.

The events are always well attended by families who get lots of information and opportunities to meet other families.



Regional Day

Family Comments

"Very informative and so lovely to meet other families too. Congratulations to the staff and volunteers for making the day the success it was!"

"Easily accessible with great facilities."

"Our granddaughter is newly diagnosed. We received a lot of support and emotional understanding of our immediate needs. We made some new friends as well."

Best Practice Guide

Launched in October 2013 at the European Congress in Maastricht, the Rett UK National Best Practice Management & Care Guidelines, which were funded by a grant from Jeans for Genes, were eagerly received and we are pleased to say that they are providing a great help to families and professionals alike.

This little booklet is packed with useful information about Rett syndrome: on how to manage symptoms and provide good quality care to the individual. It is being welcomed not just in the UK but has reached many families in Europe and is also being translated into different languages and adapted to reflect the services available within that country. This is all credited back to Rett UK!

Transition Project

Many families experience of the transition process can be very difficult and we continue to provide information and support during this time of change. We are working directly with a number of families to ensure they attain the appropriate care/support package to meet with their aspirations for their child's future. We are producing a simple information guide about the key professionals who need to be involved, their roles and what families can do to help transition to be a smooth process.



The Future

Rett UK has developed and evolved into a caring, positive and encouraging charity that I am happy to be associated with. Your dedication and assistance has been invaluable and now 25 years later I actually don't feel alone anymore. So thank you and God bless all you do."

Joanna Tomlin, mother to Keisha

Following on from the increased support for families and the great compliment by Joanna, the Rett UK support team will build good relationships and offer continued support at times of difficulty or concern. We are the friendly voice at the end of the line, when there is nowhere else to turn and will provide practical advice, a listening ear and run the gauntlet for those who have run out of steam.

Our focus for 2014/15 will be to build on the great success of our Family Support groups, developing new self-help groups in your local area. This will be a chance for families to meet up, share experiences and knowledge and be amongst friends who understand all that families are enduring and going through on a day to day basis.







Read All About It

Rett UK is passionate about ensuring that everyone affected by Rett syndrome has access to reliable and accurate information as well as professional advice and support – we do this in many ways.



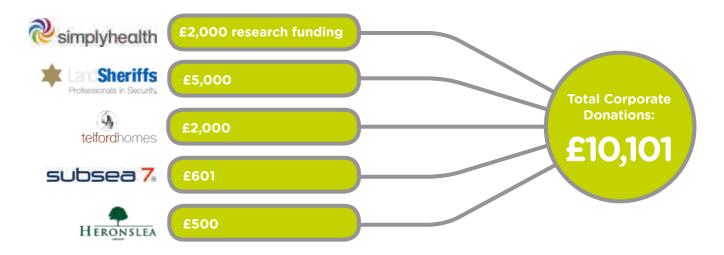
1,600. Our regular postings of news and pictures have remained popular with one parent commenting:

"So very helpful & very informative... fantastic people @ the end of the phone too"

The circulation of Rett News, our free quarterly magazine, continues to grow with a current subscription of 1,200. Families consistently praise Rett News for its mix of information, family stories and inspirational fundraisers. Not wanting to sit on our laurels, we will be reviewing Rett News in 2014/15 and our new Editorial Committee will bring both a wider perspective and new ideas to this much loved magazine.

Fundraising

As a charity we receive no Government or NHS funding to deliver our services and rely on the generosity of our supporters. We have been fortunate this year to receive corporate donations from:



We received £13,000 from the trusts overleaf to help fund our Telephone and Electronic Support Service or TESS for short. TESS is an essential service we provide to support people living with Rett syndrome. We aim to support, inform and empower families and carers to cope with new diagnosis, day-to-day care, management and bereavement. Through TESS we can offer advocacy when families have difficulties accessing services and provision or if those services have been refused. TESS also provides an opportunity to educate professionals who are caring for people with Rett syndrome for the first time to ensure the highest level of interaction with their patients/clients. It is often the families, carers and professionals' sole source of help and is seen as a lifeline by its users.

Our website **www.rettuk.org** has seen nearly 17,000 individual visitors making over 90,000 page views this year. Our most popular pages are those that provide factual information about the symptoms and diagnosis of Rett syndrome and the services we provide. We are further improving our website in 2014/15 by reviewing its style and content to ensure it is easy to use, mobile friendly and cutting edge.

Our use of social media continues to grow with our Facebook likes rising to nearly 2,500 and our Twitter following at over ve remained popular with



The project is supported by grant funding from:

- The Bartle Family Trust
 Souter Charitable Trust
- Swire Charitable Trust
- The Albert Hunt Trust





We received funding for our Transition project from BBC Children In Need and for our Regional Roadshow Programme from Jeans for Genes Day 2013.

Our Charity Champions

As well as grants and donations from companies, we received hundreds of donations from individuals and families to support our work. There are too many to list everyone here, but here are some of the events that have taken place over the year.

Romany's Roughnecks participated in the Tough Mudder in Yorkshire raising over £1,000. Tough Mudder is a 10–12 mile obstacle course designed to test all-around strength, stamina, teamwork, and mental grit. Tough Mudder reckons it's 'Probably the Toughest Event on the Planet'. A huge thank you to Leah Smith-Warren and the team.



Dale Hill undertook a 6-race challenge raising over £750, he completed the Lincoln 10k race, The Grand East Anglia 10k, The Hull 10k, The Humber Bridge Half, The York 10k and the Great North Run – well done Dale!

Rett UK's Chair, Lorna Jaffa, undertook the amazing feat of a free-standing headstand which she sustained for 5 minutes and for which she successfully raised over £2,000 in sponsorship.

Elina Eisler and her friend Elliot from Durham University took part in their annual Jailbreak. Elina and Elliot had to get as far away from Durham University without spending any money - a feat that sounds perfect fundraising for students! In just under 36 hours they managed to reach Amsterdam and raised over £1,600 - what an adventure!

Thank you to all of our donors, whether you have bought Christmas cards, sponsored a friend or sent in a cheque. We have also received nearly £10,000 in anonymous donations. We are unable to thank our mystery donors in person so thank you to everyone for all your hard work, commitment and support over the year. Without you we could not continue to provide support, education and advocacy to families across the UK.



Hope for Tomorrow

Rett syndrome Awareness Month

October is Rett syndrome Awareness Month. The trustees have planned a number of events to launch the beginning of our 30th anniversary year.

Family Companion

We are excited that after a great deal of hard work by staff and trustees, the long awaited Family Companion is ready to be launched at our AGM at Tadworth in September 2014.

This is a handbook for parents and contains many information sheets which have been written by experts in Rett syndrome. It also contains articles on legislation and welfare reforms. As situations change and develop, we will update the folder. All families will receive a copy of the Family Companion.

The Family Companion is funded by The Freemasons' Grand Charity.

Planning for the 30th Anniversary Family Weekend

To celebrate the beginning of our 30th year planning has already begun. The trustees have booked the Hilton Hotel in Northampton and are already looking for speakers and funding streams. Save the date: 9–11 October 2015.

Training Courses

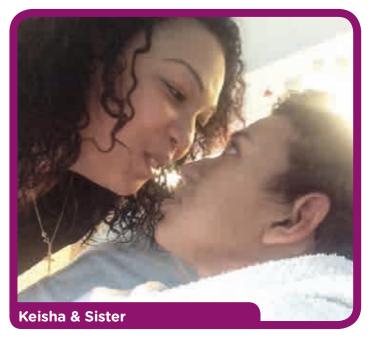
As our population with Rett syndrome gets older, many women will go into residential care or supported living where the members of staff are unfamiliar with Rett syndrome. Our support team has devised a training package which has been positively received by participants.

"Very useful and informative, the training was extremely important to me especially in my working environment. I thought the whole course was very interesting, one of the best I had attended."

Research

Hyland Bursary has been instigated by one of our families, to investigate how those women over 25 cope with Rett syndrome as they get older. Rett UK has liaised with Helen Leonard, an Australian Researcher, over the compiling of a questionnaire which will go out to the carers of women over 25 years.





Financial Review

Principal Funding Sources

Rett UK is funded by donations from individuals, corporations and trusts. The Board of Trustees reviews the funding to limit the exposure to any particular source of funds.

Investment Policy

The Finance Committee will recommend and monitor the investment structure, risk profile and priorities of the Charity's investments and for this purpose may seek appropriate advice from an independent intermediary/adviser who is authorised by the FSA. Recommendations will be brought to the Executive Committee at the next meeting. The Finance Committee has delegated powers to authorise any necessary urgent changes, which will be circulated to Executive Committee members, normally by e-mail, for comment/agreement within 7 days.

Reserves Policy

Rett UK has a policy of maintaining a general (or unrestricted) reserve of between 3 and 6 months running costs, calculated against last year's general expenditure in its audited financial statements. The lower amount is to provide a safe margin for the security of Rett UK's ongoing work. The higher amount is to ensure that funds are consistently disbursed towards the charitable objectives of Rett UK. That range of general reserve also includes an awareness of the likely costs of redundancy payments and other winding up costs should Rett UK decide, or be forced, to cease operations.

Any divergence from holding a general reserve of between 3 and 6 months running costs will be discussed by the Board of Trustees with a clear indication of how and when Rett UK will seek to return to a reserve within its agreed policy range. Rett UK's investments currently comprise cash held on deposit with CCLA Investment Management Limited. This enables easy and speedy access to funds and reflects the Executive Committee's low risk approach to investments.

Rett UK will regularly monitor its reserve via the Honorary Treasurer and Chief Executive who will report the current reserve to each quarterly Finance Committee and Trustee meeting.

This policy will be reviewed at least annually by the Finance Committee, normally in the final quarter of each financial year, as part of the budget setting process for the following financial year. The Finance Committee will bring any recommendations or observations to the Board of Trustees at the following meeting.

Where funds are received from donors with a restriction on their use they are held in separate restricted funds.

Loma Joffa

Lorna Jaffa - Chair of the Trustees

Date: 27 September 2014

Structure, Governance and Management

Governing Document

The charity is controlled by its Memorandum and Articles of Association and was incorporated as a private limited company, limited by guarantee, on 9 August 2010. Copies of the Articles of Association are available at **www.rettuk.org** or from its head office by request.

Appointment of Trustees

The Directors are Charity Trustees as defined by section 97 of the Charities Act 1993. Trustees are appointed by ordinary resolution and at each Annual General Meeting one-third of the Trustees must retire, but may be reappointed. The present Trustees may appoint new Trustees but those Trustees appointed by the Trustees must retire at the next Annual General Meeting.

Prospective members of the Board of Trustees are given a file of introductory papers including planning and strategic documents and other relevant documentation. They will normally attend at least one Trustee meeting as an observer.

Internal Control and Risk Management

The Executive Committee is responsible for the charity's system of internal control and for reviewing its effectiveness. It acknowledges that such a system can only manage and mitigate risk rather than finally eliminate the risk of failure to achieve set objectives. The management of risk is delegated to the Executive Director who has implemented a risk management policy and provides reports to Trustees at each board meeting. Our systems of control include a two-year Business Plan written by the Executive Director and an Annual Budget. Regular consideration is given to monitoring the actual performance against the budget and forecasts and to the formal delegation to spend within clearly defined limits.

Having examined the major strategic, business and operational rules, which the charity faces, the Executive Committee confirms that systems have been established to minimise organisational and financial risks.



The Board of Trustees has established four sub-committees, each with specific terms of reference and chaired by a member of the Board of Trustees:

The Finance Committee discusses and agrees the annual budget (including the salary review) for approval by the Board of Trustees. It monitors the investment structure, risk profile and priorities of the charity's investments and for this purpose may seek appropriate advice from an independent intermediary/adviser who is authorised by the FSA. It reviews the annual audit plan of the external audit firm, which reports subsequently on the audit results. The Committee also considers the organisation's Reserves' Policy and practice and makes appropriate recommendations to the Board of Trustees.

Fundraising Committees are convened for specific purposes, e.g. to raise funds for the 30th Anniversary Family Weekend and to review current fundraising strategies and opportunities.

The Management Committee is convened by the Chair of the Board of Trustees when there is an issue of importance that requires consideration and/or decision before the next Board of Trustees meeting or another specific deadline.

The Research Committee oversees Rett UK's strategic development in respect of research, together with providing a point of reference and expertise in this area. The areas of research that Rett UK will fund; how funding decisions are made and how research is funded are set out in its Research Policy. The Committee will guide the Board of Trustees and staff in making decisions on research funding. In cases where there is no specific guidance, the decision will be left to the discretion of the Board of Trustees, having taken appropriate advice.

On Behalf of the Board.

Lorna Joffar

Lorna Jaffa - Chair of the Trustees

Date: 27 September 2014



Rett UK: Annual Report and Accounts 2014

Fun loving Florrie-Rae

Statement of Trustees' Responsibilities

The trustees (who are also directors of Rett UK 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 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 judgments and estimates that are reasonable and prudent;
- State whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements, and
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping adequate 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. The auditors, Grunberg & Co Limited, will be proposed for reappointment at the forthcoming Annual General Meeting.

In so far as the trustees are aware:

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

Treasurer's Report

I am pleased to present my report to you on the accounts for the year ended 31 March 2014.

As ever we are reliant on the vital funding from our members, friends and associates in addition to grants received from trusts and corporate donors. I would like to thank everyone who has helped Rett UK over the last year, both those donating as well as those organising events and supporting those fundraising. There have been numerous events, many of which have been physical or mental challenges, or in some cases both! Every penny raised is greatly appreciated and we are also very grateful for those who donate their time.

Total funds raised this year amounted to $\pm 197,153$. This was less than the previous year and we have worked hard to reduce costs and make effective use of our funds. This year we had expenditure of $\pm 210,180$.

At 31 March 2014 Rett UK had reserves of £93,984 including £34,419 of restricted funds.

I would like to thank all of our staff and members, as well as my fellow trustees, for all of their hard work over the last year.

Lucy Durn

Lucy Duncan - Honorary Treasurer

Date: 27 September 2014



Report of the Independent Auditors to the Members of Rett UK (Limited by Guarantee)

We have audited the financial statements of Rett UK (Limited by Guarantee) for the year ended 31 March 2014 on pages 20-26. The financial reporting framework that has been applied in their preparation is applicable law and the Financial Reporting Standard for Smaller Entities (effective April 2008) (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 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.

Respective responsibilities of trustees and auditor

As explained more fully in the Statement of Trustees' Responsibilities, 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.

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 charitable 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 Report of the Trustees to identify material inconsistencies with the audited financial statements. 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 March 2014 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.

Opinion on Other Matter prescribed by the Companies Act 2006 In our opinion the information given in the Report of the Trustees for the financial year for which the financial statements are prepared is consistent with the financial statements.

Matters on which we are required to report by exception We have nothing to report in respect of the following matters where 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 exemption in preparing the Report of the Trustees.

Gedalia Waldman BA ACA (Senior Statutory Auditor)

For and on behalf of Grunberg & Co Limited 10-14 Accommodation Road Golders Green London **NW11 8ED**

Date: 29 September 2014

Rett UK: Annual Report and Accounts 2014

Statement of Financial Activities for the year ended 31 March 2014

| | | General | Restricted | Total | Total |
|---------------------------------|-------|----------|------------|----------|----------|
| | Notes | Funds | Funds | Funds | Funds |
| | | 2014 | 2014 | 2014 | 2013 |
| | | £ | £ | £ | £ |
| Incoming Resources | | | | | |
| Voluntary income | 2 | 134,529 | 54,234 | 188,763 | 286,464 |
| Activities for generating funds | 2 | 8,085 | - | 8,085 | 5,696 |
| Investment income | | 305 | - | 305 | 576 |
| Total incoming resources | | 142,919 | 54,234 | 197,153 | 292,736 |
| Resources Expended | | | | | |
| Charitable activities | 3 | 92,836 | 46,059 | 138,895 | 169,842 |
| Costs of generating funds | 3 | 67,508 | 2,260 | 69,768 | 96,981 |
| Governance costs | 3 | 1,517 | - | 1,517 | 1,164 |
| Total Resources Expended | | 161,861 | 48,319 | 210,180 | 267,987 |
| Net movement in funds | | (18,942) | 5,915 | (13,027) | 24,749 |
| Reconciliation of Funds | | | | | |
| Total funds brought forward | | 78,507 | 28,504 | 107,011 | 82,262 |
| Total funds carried forward | | £59,565 | £34,419 | £93,984 | £107,011 |

The notes on pages 22-26 form part of these financial statements.

Balance Sheet at 31 March 2014

| | | 2014 | | 2013 | |
|----------------------------|-------|----------|---------|----------|----------|
| | Notes | £ | £ | £ | £ |
| Fixed assets | | | | | |
| Tangible assets | 5 | | 7,836 | | 13,955 |
| Current assets | | | | | |
| Debtors | 9 | 28,750 | | 15,640 | |
| Cash at bank and in hand | | 74,618 | | 106,576 | |
| | | 103,368 | | 122,216 | |
| Creditors; amounts falling | | | | | |
| due within one year | 10 | (17,220) | | (29,160) | |
| | 10 | (17,220) | | (23,100) | |
| Net current assets | | | 86,148 | | 93,056 |
| Total assets less current | | | | | |
| liabilities | | | £93,984 | | £107,011 |
| Financed by: | | | | | |
| General Fund | | | 59,565 | | 78,507 |
| Restricted Fund | | | 34,419 | | 28,504 |
| Total Funds | 7 | | £93,984 | | £107,011 |

The notes on pages 22-26 form part of these financial statements.

The trustees acknowledge their responsibilities for

- (a) Ensuring that the charitable company keeps accounting records that comply with Section 386 of the Companies Act 2006 and
- (b) Preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies and with the Financial Reporting Standard for Smaller Entities (effective April 2008).

The financial statements were approved by the Board of Trustees on 27 September 2014 and were signed on its behalf by:

Lorna Joffar

Lorna Jaffa - Chair of the Trustees

financial year in accordance with the requirements of Section 393 and which otherwise comply

Notes to the Financial Statements for the Year Ended 31 March 2014

1. ACCOUNTING POLICIES

Accounting convention

The financial statements have been prepared under the historical cost convention, and in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008), the Companies Act 2006 and the requirements of the Statement of Recommended Practice, Accounting and Reporting by Charities.

Incoming resources

All incoming resources are included on the Statement of Financial Activities when the charity is legally entitled to the income and the amount can be quantified with reasonable accuracy.

Resources expended

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources. Grants offered subject to conditions which have not been met at the year-end date are noted as a commitment but not accrued as expenditure.

Tangible fixed assets

Tangible fixed assets are stated at cost or valuation less depreciation. Depreciation is provided at rates calculated to write off the cost or valuation less estimated residual value of each asset over its expected useful life, as follows:

| Office equipment | 25% Straight line |
|--------------------|-------------------|
| Office furniture | 25% Straight line |
| Computer equipment | 25% Straight line |

Leasing

Rentals payable under operating leases are charged against income on a straight-line basis over the lease term.

Staff costs

The Executive Committee considers it appropriate to apportion staff costs between Charitable Activities for generating funds and Governance costs.

Taxation

The charity is exempt from corporation tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

2. INCOMING RESOURCES

| | General Funds 2014 | Restricted Funds 2014 | Total Funds 2014 | Total Funds 2013 |
|---------------------------------|--------------------------|-----------------------------|------------------------|------------------------|
| | £ | £ | £ | £ |
| Voluntary income | | | | |
| Grant income | 3,000 | 36,319 | 39,319 | 61,710 |
| Corporate income | 10,102 | - | 10,102 | 17,850 |
| Donations | 121,427 | 17,915 | 139,342 | 206,904 |
| | £134,529 | £54,234 | £188,763 | £286,464 |
| Activities for generating funds | | | | |
| Sales | 2,981 | - | 2,981 | 2,257 |
| Unity Lottery and 300 Club | 4,471 | - | 4,471 | 3,413 |
| Other receipts | 633 | - | 633 | 26 |
| | £8,085 | £- | £8,085 | £5,696 |
| Investment income | | | | |
| Bank interest | £305 | £- | £305 | £576 |

3. RESOURCES EXPENDED

| | Charitable | Costs of | Governance | Total | Total |
|--|------------|------------------|------------|----------|----------|
| | Activities | Generating Funds | Costs | Funds | Funds |
| | 2014 | 2014 | 2014 | 2014 | 2013 |
| | £ | £ | £ | £ | £ |
| Clinics, research and support services | 14,979 | 2,260 | - | 17,239 | 36,420 |
| Purchases for resale | - | 2,073 | - | 2,073 | 1 |
| Magazine, booklet and information | 4,577 | 3,319 | 450 | 8,346 | 8,964 |
| Family weekend and Regional Day | 6,122 | - | - | 6,122 | 4,512 |
| Event operations | 150 | 8,124 | - | 8,274 | 18,887 |
| Insurance and professional indemnity | 273 | 710 | 855 | 1,838 | 1,894 |
| Legal, professional and accountancy ¹ | 2,855 | 1,903 | - | 4,758 | 4,485 |
| Printing, postage and stationery | 2,100 | 1,284 | - | 3,384 | 4,142 |
| Rent and property expenses | 8,172 | 5,449 | - | 13,621 | 10,482 |
| Repairs and maintenance | 5,439 | 3,383 | - | 8,822 | 9,037 |
| Staff costs (note 4) | 80,202 | 35,886 | 10 | 116,098 | 147,132 |
| Staff recruitment | - | - | - | - | 2,677 |
| Telephone | 3,286 | 1,202 | - | 4,488 | 5,529 |
| IT | 6,245 | 2,823 | - | 9,068 | 8,591 |
| Travel | 2,737 | 279 | - | 3,016 | 2,573 |
| Bank and credit card charges | 570 | 380 | - | 950 | 863 |
| Trustee expenses | - | - | 122 | 122 | 245 |
| General expenses | 1,188 | 693 | 80 | 1,961 | 1,553 |
| | £138,895 | £69,768 | £1,517 | £210,180 | £267,987 |

Included in legal, professional and accountancy is an audit fee of £4,758 (2013 - £4,485)

4. STAFF COSTS

| | 2014 | 2013 |
|--|----------|----------|
| | 3 | £ |
| Wages and salaries | 99,044 | 127,831 |
| Social security | 8,909 | 12,254 |
| | 107,953 | 140,085 |
| Other staff cost | 8,145 | 7,048 |
| | £116,098 | £147,133 |
| The average number of people employed by the | | |
| charity was: | | |
| | No. | No. |
| Charitable activities | 2.5 | 2.5 |
| Costs of generating funds | 1.5 | 2 |
| Governance | - | - |
| | 4 | 4.5 |

5. TANGIBLE FIXED ASSETS

| | Office | Office | Computer | |
|------------------|-----------|-----------|-------------------|---------|
| | equipment | furniture | Hardware/Software | Total |
| | £ | £ | £ | £ |
| Cost | | | | |
| At 1 April 2013 | 3,060 | 2,472 | 18,943 | 24,475 |
| Additions | - | - | - | - |
| At 31 March 2014 | 3,060 | 2,472 | 18,943 | 24,475 |
| Depreciation | | | | |
| At 1 April 2013 | 1,530 | 987 | 8,003 | 10,520 |
| Charge for year | 765 | 618 | 4,736 | 6,119 |
| At 31 March 2014 | 2,295 | 1,605 | 12,739 | 16,639 |
| Net book value | | | | |
| At 31 March 2014 | £765 | £867 | £6,204 | £7,836 |
| At 31 March 2013 | £1,530 | £1,485 | £10,940 | £13,955 |

6. ANALYSIS OF NET ASSETS

| | Unrestricted | Restricted | Total |
|--------------------------|--------------|------------|----------|
| | £ | £ | £ |
| Tangible assets | 7,836 | - | 7,836 |
| Debtors | 15,910 | 12,840 | 28,750 |
| Cash at bank and in hand | 53,039 | 21,579 | 74,618 |
| Creditors | (17,220) | - | (17,220) |
| | £59,565 | £34,419 | £93,984 |

7. SUMMARY OF MOVEMENT OF FUNDS

| | Balance at | | | | Balance at |
|---------------------------------|---------------|-----------|----------|------------|---------------|
| | 31 March 2013 | Transfers | Income | Expenses | 31 March 2014 |
| | Ē | £ | £ | £ | £ |
| General Fund | £78,507 | £- | £142,919 | £(161,861) | £59,565 |
| Restricted Funds | | | | | |
| Research Fund | - | - | 1,220 | - | 1,220 |
| Music Therapy Fund | 106 | - | - | - | 106 |
| North London Support Group Fund | 378 | - | 128 | (155) | 351 |
| Regional Day Fund | - | - | 4,998 | (2,083) | 2,915 |
| TESS Fund | - | - | 13,000 | (13,000) | - |
| Family Guide Fund | 22,000 | - | - | (70) | 21,930 |
| Support Services Fund | - | - | 18,192 | (18,192) | - |
| Care Pathways Fund | 2,663 | - | - | (67) | 2,596 |
| MECP2 Fund | 3,357 | - | 16,696 | (14,752) | 5,301 |
| | £28,504 | £- | £54,234 | £(48,319) | £34,419 |

Where funds are received from donors with a restriction on their use they are held in separate restricted funds.

Research Funds

All monies in the Research Funds are utilised to investigate causes of Rett syndrome and a possible cure.

Music Therapy Fund

The Fund is utilised for the provision of music therapy, for people with Rett syndrome, at events organised by Rett UK such as regional clinics.

North London Support Group Fund

The Fund is used to pay expenses incurred by the North London Support Group.

Regional Day Fund

The Fund is to be used to regional days offering support, guidance and latest information around the country.

TESS (Telephone and Electronic Support Services) Fund

The Fund is used to offer direct support to families via our telephone helpline, email and social media.

Family Guide Fund

The Fund is being used to produce and distribute our new Family Companion.

Support Services Fund

The Fund is utilised to run Rett UK's support services including staff costs to attend clinics and advocacy meetings.

Care Pathways Fund

The Fund is utilised to produce and distribute our new Rett syndrome Best Practice Guidelines.

MECP2 Fund

The Fund is used for activities relating to this sub-group of Rett syndrome where the syndrome is due to duplication of the MECP2 gene.

8. TRUSTEES' REMUNERATION AND BENEFITS

No trustees were remunerated or received other benefits for the year ended 31 March 2014, nor for the year ended 31 March 2013.

During the year, expenses of £122 (2013 - £245) incurred on behalf of the charity were reimbursed to one of the trustees. During the year Rett UK, purchased trustee and officers' liability insurance at a cost of £855 (2013 - £855).

9. DEBTORS

| | 2014 | 2013 |
|---------------|---------|---------|
| | £ | £ |
| Other debtors | 4,192 | 6,460 |
| Prepayments | 24,558 | 9,180 |
| | £28,750 | £15,640 |

10. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

| | 2014 | 2013 |
|--|---------|---------|
| | £ | £ |
| Accrued expenses | 9,848 | 9,660 |
| British Isles Rett Syndrome Survey | 2,372 | 7,000 |
| FOXG1 | 5,000 | 5,000 |
| Roald Dahl's Marvellous Children's Charity | - | 7,500 |
| | £17,220 | £29,160 |

11. OPERATING LEASE COMMITMENTS

At 31 March 2014 Rett UK had an annual commitment under a non-cancellable operating lease as follows:

| | 2014 | 2013 |
|--------------------------------------|--------|--------|
| | £ | £ |
| Land and Buildings | | |
| Expiry date within one to five years | £8,260 | £7,200 |

Patrons, Staff and Professional Advisors

Trustees

| ppointed 5 October 2013 |
|---|
| |
| esigned 20 May 2013 |
| ppointed 15 June 2013 |
| onorary Treasurer |
| esigned 23 September 201 |
| onorary Chair |
| 5 |
| opointed 5 October 2013 |
| |
| onorary Vice-Chair |
| 5 |
| ppointed 5 October 2013 esigned 23 February 2014 |
| |

Honorary Patrons

Yvonne Milne MBE

Honorary Life President

Ann Clwyd MP **Evelyn Glennie DBE Gloria Hunniford Jon Snow**

Staff Team

Suzanne Barlow:

Chief Executive Officer (retired November 2013) Julie Benson: Family Support Manager **Patrice Hosier:** Family Support Officer Sarah Kilcoyne Accountant Debbie Main Office Manager

Professional Advisors

Chief Medical Adviser: Prof A J Clarke DM FRCP; Geneticist

Ana Paula Abdala Sheikh PhD; Research Fellow, University of Bristol Dr Hayley Archer; Geneticist Learning Disabilities Prof. Adrian Bird PhD Child Health Prof Jill Clayton-Smith; Consultant Clinical Geneticist Helen Cockerill; Clinical Expert Speech & Language Therapist Sally-Ann Garrett; Speech & Language Therapist Mr Alex Gibson BSc MB BS FRCS; Consultant Spinal Surgeon Learning Disability (retired) Dr Bronwyn Kerr; Consultant Clinical Geneticist **Gilly Martin;** Specialist Physiotherapist Cindy-Jo Morrison; Music Therapist Dr Richard Morton FRCP FRCPCH; Consultant Paediatrician British Association of Prosthetists and Orthotists Dr P Sutherland MA BM BCh FRCA; Anaesthetist Dr C Troake; Specialist Post Mortem Coordinator

ed 23 September 2013



Dr Sarah Bernard MD MB ChB FRCPsych DRCOG; Consultant Psychiatrist of

Dr Hilary Cass BSc MRCP FRCPCH; President, Royal College of Paediatrics and

- Mr David J Harrison B BS BSc FRCS AKC; Consultant Spinal Surgeon (retired) Dr Alison M Kerr OBE FRCP FRCPCH; Honorary Consultant in Paediatrics and
- Prof Michael Kerr; Professor of Learning Disability Psychiatry & Epileptologist
- Mr Kelvin Smith; International Society for Prosthetics and Orthotics and the
- Dr Jane Williams MB BS DCH MRCP FRCPCH; Consultant Paediatrician





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E support@rettuk.org

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www.rettuk.org

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Don't Delay, Donate Today!

Every penny donated helps to make a difference. All donations help fund our strategy to diagnose, treat, support and work towards a cure for Rett syndrome.



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Keep Informed

2013/14 has seen our Facebook and Twitter followers grow to over 2,450 and 1,300 respectively.

So consider following us, if you're not already, to help keep our social media networks growing.



