



**Annual Report  
and Accounts 2013**



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## Foreword from the Chair

The year ending March 2013 saw many changes. At the beginning of the year, as a result of an initiative from the staff we moved to smaller offices within the same building resulting in a significant annual saving on our rent.

Last year we introduced **free membership** to all those who wanted to join Rett UK and also encouraged more people to donate by direct debit. I am pleased to say that membership has increased by 11% and more members are contributing by direct debit, but we would encourage more of you to follow suit. One of the many benefits of being a member is that you receive Rett News quarterly without charge. Over the last year this was sent to 1,200 addresses across the UK and other parts of the world. Rett News is also available online.

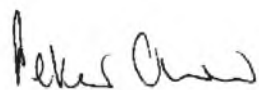
In the very near future members will receive copies of 2 new publications, *Rett Syndrome Best Practice - Management Care Guidelines* and *the Rett Syndrome Family Companion*. Funding for these was provided by Jeans for Genes and The Freemasons Grand Charity. Everyone involved is to be congratulated on a magnificent team effort and in particular the care team.

During May this year, Paul Chapman decided to stand down as Chair of Trustees for family and business reasons. As Vice Chair I was asked to take over and this explains why I have written this foreword. The Board have thanked Paul for all his hard work and for the substantial sums of money raised by the two memorable Gala Dinners that he ran. His drive and energy will be missed.

Our priority over the coming year is to focus on providing advice, help and information to the wider Rett community and in particular to newly diagnosed families through our Regional days, Clinics and our new publications.

We are indebted to our staff team and volunteers for their help throughout the year.

**Peter Oliver**  
Acting Chair of Trustees



Date: 5 October 2013



# Report of the Trustees for the Year Ended 31 March 2013

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 2013. 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 LU1 2NA

## Auditor

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

## Bankers

HSBC

## 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 550 families, given assistance to over 35 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

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
- to find a cure for Rett syndrome.

In line with our vision, Rett UK's strategic aims are to:

**DELIVER:** excellent support services that meet the long term needs of the Rett community, reducing isolation and exclusion, and improving quality of life, independence, confidence, health and wellbeing;

**PARTNER:** with relevant organisations and professionals to fund, raise awareness, resource and deliver key services, projects and campaigns, ensuring that the identified Rett community needs are achieved; and

**ENABLE:** the organisation to effectively grow and develop, for the long term benefit of the Rett community.

## Support Today

Rett UK's family support team has taken on a new team of staff this year. **Julie Benson** joined the organisation in July 2012 as Family Support Manager. Julie has 12 years' experience of working within an advocacy setting supporting people with learning disabilities, those experiencing mental ill health, drug and alcohol misuse, older people and family carers. Prior to this, she worked for 6 years in a special school as a teaching assistant working with children with profound and multiple learning disabilities, autism, challenging behaviour and sensory impairments. **Patrice Hosier**, Family Support Officer, joined the team in October 2012. Patrice also has a lot of 'hands on' experience of working with people with learning disabilities within a hospital setting and latterly as a Registered Care Manager of a residential home.

Between them they have over 20 years' experience of working within such areas as children's services, education and adult health and social care.

They currently offer a high level of support to all our families, particularly in responding to the numerous calls we receive on our Telephone Helpline. To date they have taken over 1,200 calls, supported over 550 families, including 35 families with a new diagnosis.





## What our families say about us...

### Karina Driscoll, Surrey:

*"Rett UK have been an amazing help for me and Melody this last couple of months. If it wasn't for you, Melody would still be very very poorly right now. The emotional support that Julie and Patrice have also provided has kept me sane. What you guys do isn't just about raising money it's about support and I think that is the most important thing. As a cure will still take years and support can be given now thank you so much from the bottom of my heart."*



The year 2012/13 saw the introduction of the Rett Community Regional Family Days, as a replacement for the Family Weekends, which have begun to be less well attended than previous years.

The Regional Days follow a similar format to that of the Family Weekends; however, they are held at several regions across the UK. Funded by the Jeans for Genes grants we are able to offer families the opportunity to meet with our professional medical advisors and therapists, listen to lectures and presentations, receive updates regarding latest treatments and research, and to trial state of the art 'Eye-Gaze' technology. The events provide families with the opportunity to meet other families within their local community to share experiences. Activities are provided for Rett children and siblings throughout the day, which allows other family members to attend lectures whilst knowing that their children are safe and being well-looked after by our professional staff and volunteers.



### Mike Bickerton, dad to Emily shares his thoughts about our regional day in the North East:

*"We have never met anyone with Rett syndrome before, other than our daughter, and it is an experience I will never forget. We were genuinely impressed with every aspect of the day; venue, food, changing facilities, lectures and friendliness of all the staff were outstanding."*

These events are proving extremely successful, with families supporting the days with enthusiasm and the feedback has been tremendous. To date we have been able to meet directly with over 400 family members including 74 people with Rett syndrome, many of whom had never attended previous events. By travelling across the country to the regions where people live, we have been able to engage with many more families than those attending the Family Weekend, which has been really great for us and very beneficial for them.

*Rett UK's Best Practice Guidelines are a great way to give doctors, who may never have treated a person with Rett syndrome before, a really good grounding in the management and care of the disease. I think it will quickly become a lifeline"*

**- Prof. Angus J Clarke, DM FRCO, Rett syndrome expert and clinician and Chief Medical Officer for Rett UK.**

We are planning to continue with the Regional Days during 2014/15, with draft dates circulated in Rett news, and we are looking forward very much to meeting even more people when we hit the road again.

We are also aware that many families would still like the opportunity of the Family Weekends, and with this in mind, we are now looking at the possibility of holding an event to celebrate our 30th birthday.

### Best Practice Management and Care Guidelines

People with Rett syndrome may require various diagnostic and screening tests, assessments, referrals and multi-disciplinary interventions at different stages of their lives. So although this been prepared for professionals, it will be of interest to parents/ carers of individuals living with Rett syndrome.

Funded by a grant from Jeans for Genes award, through Genetic Disorders UK, it has been nationally recognised as an excellent format for a best practice guide and promoted through their website.

Rett UK will also be attending the Rett Syndrome Europe conference in October, to launch the guidelines within the European Union.

### NHS Rett syndrome Clinics

Rett UK continue to support the specialist clinics. The family support team attend to support families who have received a recent diagnosis or those experience complex medical issues. The clinics provide the opportunity to meet with a multi-disciplinary team under one roof. Following the appointment, a comprehensive report with recommendations for treatments, assessments and interventions are sent to the local medical team. Our medical advisors are always happy to offer support to other clinicians who may have little or no previous experience of Rett syndrome.

### Family Companion

Our aim for 2013 will be to produce a complimentary document for families which we are calling our Family Companion. Fully funded by the Freemasons Grand Charity the companion is designed to give families lots of practical information and tips for management of symptoms. It will be written in



an Easy Read format for families and will contain information on all aspects of Rett syndrome from diagnosis and causes to therapeutic interventions, via education and common symptoms.

### Transition

2012 saw us being successful with our funding bid to Children in Need to support our continually improving Transition Service.

For many of our families Transition from Children's to Adult Social Care services is simple. However, for too many others it can be a difficult time for them and their child, this has been particularly evident over the past year with the current cuts to local government budgets and local spending cuts. The impact this has had on the individual and their families has at times been immense and meant that many have not been able to achieve places in the colleges, day services, residential placements or supported living schemes. Over the past year the team has provided advocacy support at multi-disciplinary meetings, 14+ reviews and educational tribunals and referred a number of families on for professional legal advice regarding Community Care Law.



## The Future

The coming year for the Family Support Team, we believe is going to see a number of families beginning to feel the impact of the Welfare Reforms, starting with the 'Bedroom Tax', the introduction of Universal Payments and Personal Independence Payments. Early 2014 will see the biggest change in legislation for over 30 years with the introduction of the 'Care and Support Bill' and the proposed changes to the Statement of Special Educational Needs process. In addition there will be the introduction of Personal Health Budgets and Direct Payments for health needs.

Our team are keeping up to date with all relevant changes to legislation so they can be as up to speed with changes that may impact on the families.

Finally, we are campaigning alongside the 'Changing Places' and Mencap to put pressure on more councils to provide accessible disabled toilets with hoisting facilities and changing tables.

Rett News, our free magazine, continues to garner praise from our members. Its handy A5 format helps to keep our distribution costs to a minimum and the efficient design means that we are still able to include all your favourite features. Our quarterly magazine is enriched through the wonderful contributions from our supporters and we would like to say 'thank you' for remembering to include us in your networks. Please do continue to send us your articles and photographs - Rett News will be all the better for them!

*"Thank you for the very readable Rett News and supplement. I do appreciate the handy size (more economical) and as usual I had to sit down straight away and read it through (though I must admit to always looking out for a word about my granddaughter Kerry and her hard working mum!)."*

- Audrey, Grandparent to Kerry



Of course Rett UK also supports the professionals who form the social, clinical and medical teams around people with Rett syndrome. Training about Rett syndrome was provided to care support teams, enhancing the staffs' knowledge about the disorder and ensuring care provision takes the many unique qualities of Rett syndrome into account.

*"I learned so much in the day's training session and I now have more of an understanding of Rett syndrome, the presentation was interesting and well delivered..."*

- Day Centre staff

During the course of the year Rett UK has utilised social networking to inform members of support issues and events, together with raising awareness of Rett syndrome with people who do not have a direct association with the condition. 2012/13 has seen our Facebook and Twitter followers grow to over 2,000 and 1,000 respectively and our daily Facebook snippets have proven very popular.

Have a look at [www.facebook.com/rettuk](http://www.facebook.com/rettuk) to see what you're missing.



## Thank you for your support

Like many charities, Rett UK receives no government funding and we rely upon donations from individuals, companies and trusts to fund our vital work. Without the hard work and commitment of our supporters Rett UK would not be able to continue supporting families (often for many years), providing information and training to professionals and running events, such as Regional Days and Clinics, across the UK, so thank you very much. We would like to thank each and every one of you who has donated to Rett UK. Unfortunately we cannot name everyone, but rest assured every penny donated helps to make a difference.

**Don't Delay, Donate Today!**



“We have never met anyone with Rett syndrome before, other than our daughter, and it is an experience I will never forget. We were genuinely impressed with every aspect of the day; venue, food, changing facilities, lectures and friendliness of all the staff were outstanding.”

– Mike Bickerton, dad to Emily.  
Rett UK’s North East Regional Day at  
Northern Counties School, Newcastle



## Corporate donors

Kuehne & Nagle: £10,000 Charity of the Year cheque plus a further £1,000 raised at a family day, thanks to the Marjerrison family and their daughter Gracie for recommending us.

Landsheriffs: £5,000 donated, and since 2008 the Landsheriffs have donated £25,000 to Rett UK, we thank them for their continued support.

Telford Homes: £1,000 donated, thank you to the Durant family and their daughter Claire.

Flextronics Global: £1,000 donated, thanks to Phil Barker who has a close friend with a daughter with Rett syndrome.

## Our sporting heroes

Each year many parents, brothers, sisters and friends undertake exciting challenges to raise funds for Rett UK. This year our London Marathon team raised an astonishing £6,500 and we thank them for all their training miles and for slogging it out on the day. The Great North and Great South run teams also raised over £2,000. Jill Spence and her sister Linda Smith raised nearly £3,000 by completing the Great Edinburgh Run. Jill is mum to Sophie who has Rett syndrome. Ronnie Jaffa, a former Trustee raised £4,000 by organising a Golf Day at Moor Park. Ronnie is married to Lorna and Jessica, their daughter has Rett syndrome.

Our biggest running event of the year was the British London 10k and in 2012 our team of 37 runners earned over £12,000. Each year we present our fastest man and fastest lady with celebration cups and congratulations to our 2012 winners; Heather Henderson - Kathy O'Brien Memorial Cup for the fastest woman and Nick Lawson - Ronnie Jaffa Cup for the Fastest Male.



The Cup Winners Celebrate Post-Race

## Other Events

**Scotty's Ball** – in memory of little Scott Lisle who passed away in 2009. Paul and Julie raised £4,000. **Gill Sanders** – £5,000 raised through events at Jardines Bistro, Wivenhoe. Gill is a friend of the Johnsson family whose daughter Hannah, 6, has Rett syndrome. **Jill Spence and her sister Linda Smith** raised nearly £3,000 by completing the Great Edinburgh Run. Jill is mum to Sophie, 8, who has Rett syndrome. **Robert Valentine**, a Trustee, raised £6,000 by organising a Go Kart evening. **Yvonne Oliver** has run the **300 Club** since 1996. Since then it has raised circa £20,000 and paid out £16,500 in prize monies. There are still places left so why not join?

If you have an idea to raise funds and have fun at the same time, give us a call on **01582 798910** or email **fundraising@rettuk.org** and we'll do all we can to help.



Applications to grant making trusts and foundations have risen considerably, making access to this source of funding ever more difficult. Rett UK was delighted to be awarded over £60,000 from the following:

- The Albert Hunt Trust
- The Austin & Hope Pilkington Trust
- The Bartle Family Trust
- BBC Children in Need
- BL Robinson's Charitable Trust
- The Casey Trust
- David Solomons Charitable Trust
- The Dixie Rose Findlay Charitable Trust
- Freemasons Grand Charity
- Genetic Disorders UK
- Waitrose (North London Support Group)
- The Wixamtree Trust

Other trusts supported the work of Rett UK but chose to remain anonymous.

Scotty's Ball

£4,000

Gill Sanders

£5,000

Jill Spence  
& Linda Smith

£3,000

## Hope for Tomorrow

Whilst supporting families living with Rett syndrome is our main purpose, Rett UK recognises the value of research into Rett syndrome – all research. We hope that the cure is in the not too distant future and we are proud to support, and have the support of, the many researchers working tirelessly for this. We at Rett UK also know that, as research progresses, the information held about people with Rett syndrome will be of fundamental importance in ensuring timely and relevant access to treatment and to aid recruitment into clinical trials.

That's why we chose to support the British Isles Rett Syndrome Survey over the course of the year. This important database has collated information about individuals with Rett syndrome for nearly 30 years. Rett UK's Chief Medical Advisor, Prof. Angus Clarke runs the project and is looking to develop it into a registry specifically aimed at furthering treatment and trials.



Prof. Angus Clarke

We hope that the cure is in the not too distant future. We are proud to support, and have the support of, the many researchers working tirelessly for this.

Robert Valentine

**£6,000**

Ronnie Jaffa

**£4,000**

Yvonne Oliver

**£20,000**

since 1996



Rett UK continued to support our PhD students by facilitating access to families and distributing research questionnaires to our members. Jo Belcher is a PhD student who is researching the usefulness (or otherwise!) of online support websites and email groups for UK-resident parents of people with Rett syndrome,

**Jo says:**

*"My research is funded by the South East Doctoral Training Centre (ESRC grant) and fuses online with offline methods (both quantitative and qualitative). It aims to explore the nature of online support spaces for parents of children with a rare syndrome (Rett syndrome). It involves the use of online methods including an online survey an online record completed after use of these sites (on PC or smartphone) and Skype and email interviews where synchronous or face-to-face methods are not feasible."*

More information about Jo's study can be found here:

[http://www.surrey.ac.uk/sociology/research/doctoralresearch/projects/jo\\_belcher.htm](http://www.surrey.ac.uk/sociology/research/doctoralresearch/projects/jo_belcher.htm)

In November 2012 the Rett Syndrome Europe general assembly took place in London, where Lorna Jaffa, representative from Rett UK and Minutes Secretary, welcomed the delegates to the meeting. 14 countries were represented that day and two researchers; Angus Clarke and Laurent Villard were also invited. Member countries each gave a brief report about their associations. October 2013 sees the 3rd European Rett Syndrome Conference "Research

Update and Preventive Management" and we very much look forward to seeing you all there. Every year we receive donations from individuals and companies alike that we are asked to restrict to research - it's simple to do, just let us know that you'd like your money to be spent on research and that's what we'll do. Tracey did just that, here's her story:

*Tracey has been a fervent supporter of Rett UK since first contacting us in 2006. Tracey's daughter Jasmine, was first diagnosed in Australia in 2006 and as many families will understand it took some time to lose the 'Developmental Delay' label and for Rett syndrome to be correctly identified.*

*Tracey's fundraising takes many forms from football to dinners, with many friends and local contacts supporting her and Jasmine, to balls and fun days. Tracey and her organising committee run an annual football tournament which sees teams from around the local area competing. It is such a wonderful event and is fast becoming quite an institution. In 2012 the day expanded into a Family Fun Day and has raised thousands of pounds.*

*Many of Tracey's friends and family also fundraise for Rett UK, over the years we have had contributions from several friends running the gruelling 10 miles of the Great South Run as well as many other events. Simply Health in Andover has also been generous on many occasions and continues to support Tracey and Rett UK.*

So a huge thank you to Tracey and all those who help organise and participate in such wonderful fundraising over the last 7 years - well done to you all.



Rett UK continued to support our PhD students by facilitating access to families and distributing research questionnaires to our members.

## 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.

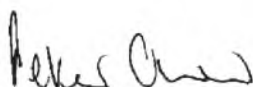
Rett UK will regularly monitor its reserve via the Treasurer and Chief Executive who will report the current reserve to each quarterly Finance Committee and Trustee meeting.

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.

#### Peter Oliver

Acting Chair of the Trustees



Date: 5 October 2013

## 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](http://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 three sub-committees, each with specific terms of reference and chaired by a member of the Board of Trustees:

**The Finance Committee:** discuss and agree 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.

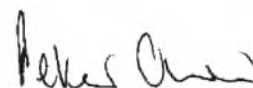
**The Management Committee:** is a committee convened by the Chair of the Board of Trustees when there is an issue of importance that requires consideration and/or decision before the next Board of Trustees meeting or another specific deadline.

**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

**Peter Oliver**



Date: 5 October 2013





“Rett UK has been an amazing help for me and Melody this last couple of months. If it wasn't for you Melody would still be very very poorly right now. The emotional support that Julie and Patrice have also provided has kept me sane.”

– Karina, mum of Melody

## 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 2013.

The past year has continued to be a difficult time for charities raising funds. I would like to thank the many supporters of Rett UK who have, along with staff and trustees, worked hard to raise funds. Costs have continued to be reviewed so that the funds are put to effective use helping those affected by Rett syndrome.

During the year to 31 March 2013 events such as a Jazzie Fun Day and Curry Quizzes have been held. Grants were received from the Freemasons, The Wixamtree Trust, BL Robinson's Charitable Trust and The Dixie Rose Findlay Charitable Trust among others.

Total funds of £292,736 were received, compared to £329,803 in the previous year, excluding funds transferred from Rett Syndrome Association UK (RSAUK) when Rett UK took on the assets and activities of RSAUK.

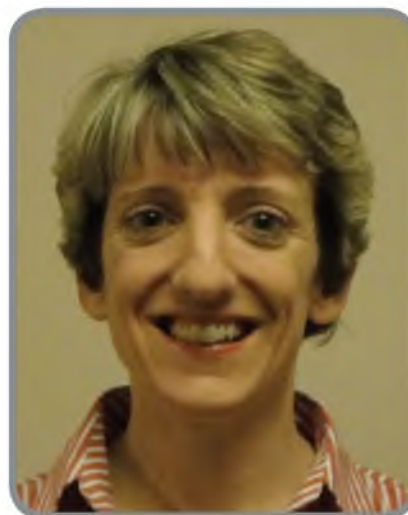
Rett UK decided to hold Regional Days rather than its annual Family Weekend in order to cost effectively provide a condensed support event for more families across the UK. The total expenditure for the year was £267,987.

At 31 March 2013 the reserves of Rett UK stood at £107,011.

**Lucy Duncan**  
Honorary Treasurer



Date: 5 October 2013





## 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 2013 on pages 20 to 25. 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 2013 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.

**David Grunberg** BA FCA  
(Senior Statutory Auditor)



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

Date: 7 October 2013

## Statement of Financial Activities for the Year Ended 31 March 2013

	Notes	General Funds 2013 £	Restricted Funds 2013 £	Total Funds 2013 £	Total Funds 2012 £
<b>Incoming Resources</b>					
Voluntary income	2	202,279	84,185	286,464	426,417
Activities for generating funds	2	5,686	10	5,696	9,723
Investment income		576	-	576	551
<b>Total incoming resources</b>		<b>208,541</b>	<b>84,195</b>	<b>292,736</b>	<b>436,691</b>
<b>Resources Expended</b>					
Charitable activities	3	108,513	61,329	169,842	191,923
Costs of generating funds	3	96,216	765	96,981	161,158
Governance costs	3	1,164	-	1,164	1,348
<b>Total Resources Expended</b>		<b>205,893</b>	<b>62,094</b>	<b>267,987</b>	<b>354,429</b>
<b>Net movement in funds</b>		<b>2,648</b>	<b>22,101</b>	<b>24,749</b>	<b>82,262</b>
<b>Reconciliation of Funds</b>					
Total funds brought forward		75,859	6,403	82,262	-
<b>Total funds carried forward</b>		<b>£78,507</b>	<b>£28,504</b>	<b>£107,011</b>	<b>£82,262</b>

The notes on pages 22 – 25 form part of these financial statements



## Balance Sheet as at 31 March 2013

	Notes	2013		2012	
		£	£	£	£
<b>Fixed assets</b>					
Tangible assets	5		13,955		19,792
<b>Current assets</b>					
Debtors		15,640		17,423	
Cash at bank and in hand	9	106,576		84,736	
		122,216		102,159	
<b>Creditors; amounts falling due within one year</b>	10	(29,160)		(39,689)	
<b>Net current assets</b>			93,056		62,470
<b>Total assets less current liabilities</b>			£107,011		£82,262
<b>Financed by:</b>					
General Fund			78,507		75,859
Restricted Fund			28,504		6,403
<b>Total Funds</b>	7		£107,011		£82,262

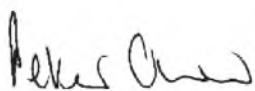
The notes on pages 23 – 25 form part of these financial statements

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 financial year in accordance with the requirements of Section 393 and which otherwise comply 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 5 October 2013 and were signed on its behalf by:



**Peter Oliver**

# Notes to the Financial Statements for the Year Ended 31 March 2013

## 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, 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 2013 £	Restricted Funds 2013 £	Total Funds 2013 £	Total Funds 2012 £
<b>Voluntary income</b>				
Income transferred from RSAUK	-	-	-	106,888
Grant income	7,600	54,110	61,710	19,249
Corporate income	17,850	-	17,850	26,430
Donations	176,829	30,075	206,904	273,850
	<b>£202,279</b>	<b>£84,185</b>	<b>£286,464</b>	<b>£426,417</b>
<b>Activities for generating funds</b>				
Sales	2,247	10	2,257	5,006
Unity Lottery and 300 Club	3,413	-	3,413	3,633
Other receipts	26	-	26	1,084
	<b>£5,686</b>	<b>£10</b>	<b>£5,696</b>	<b>£9,723</b>
<b>Investment income</b>				
Bank interest	£576	£-	£576	£551

### 3. RESOURCES EXPENDED

	Charitable Activities 2013 £	Costs of Generating Funds 2013 £	Governance Costs 2013 £	Total Funds 2013 £	Total Funds 2012 £
Clinics, research and support services	35,655	765	-	36,420	22,514
Purchases for resale	-	1	-	1	4,945
Magazine, booklet and information	5,235	3,729	-	8,964	12,229
Family weekend and Regional Day	4,512	-	-	4,512	28,394
Event operations	150	18,737	-	18,887	44,056
Insurance and professional indemnity	308	731	855	1,894	2,719
Legal, professional and accountancy <sup>1</sup>	2,691	1,794	-	4,485	4,846
Printing, postage and stationery	2,474	1,668	-	4,142	4,210
Rent and property expenses	6,289	4,193	-	10,482	23,268
Repairs and maintenance	5,399	3,638	-	9,037	7,337
Staff costs (note 4)	93,117	54,015	-	147,132	177,260
Staff recruitment	1,628	1,049	-	2,677	2,698
Telephone	3,535	1,994	-	5,529	5,438
IT	5,243	3,348	-	8,591	8,787
Travel	2,102	407	64	2,573	2,723
Bank and credit card charges	518	345	-	863	1,403
Trustee expenses	-	-	245	245	21
General expenses	986	567	-	1,553	1,581
	<b>£169,842</b>	<b>£96,981</b>	<b>£1,164</b>	<b>£267,987</b>	<b>£354,429</b>

<sup>1</sup> Included in legal, professional and accountancy is an audit fee of £4,485 (2012 – £4,750)

### 4. STAFF COSTS

	2013 £	2012 £
Wages and salaries	127,831	156,843
Social security	12,254	15,476
Other staff cost	140,085	172,319
	<b>7,048</b>	4,941
	<b>£147,133</b>	£177,260
The average number of people employed by the charity was:		
	No.	No.
Charitable activities	2.5	3.5
Costs of generating funds	2	2.5
Governance	-	-
	<b>4.5</b>	6

### 5. TANGIBLE FIXED ASSETS

	Office equipment £	Office furniture £	Computer Hardware/Software £	Total £
<b>Cost</b>				
At 1 April 2012	3,060	2,235	18,943	24,238
Additions	-	237	-	237
At 31 March 2013	<b>3,060</b>	<b>2,472</b>	<b>18,943</b>	<b>24,475</b>
<b>Depreciation</b>				
At 1 April 2012	765	414	3,267	4,446
Charge for year	765	573	4,736	6,074
At 31 March 2013	<b>1,530</b>	<b>987</b>	<b>8,003</b>	<b>10,520</b>
<b>Net book value</b>				
At 31 March 2013	<b>£1,530</b>	<b>£1,485</b>	<b>£10,940</b>	<b>£13,955</b>
At 31 March 2012	£2,295	£1,821	£15,676	£19,792



## 6. ANALYSIS OF NET ASSETS

	Unrestricted £	Restricted £	Total £
Tangible assets	13,955	-	13,955
Debtors	15,640	-	15,640
Cash at bank and in hand	63,292	43,284	106,576
Creditors	(14,380)	(14,780)	(29,160)
	<b>£78,507</b>	<b>£28,504</b>	<b>£107,011</b>

## 7. SUMMARY OF MOVEMENT OF FUNDS

	Balance at 31 March 2012 £	Transfers £	Income £	Expenses £	Balance at 31 March 2013 £
<b>General Fund</b>	£75,859	£-	£208,541	£(205,893)	£78,507
<b>Restricted Funds</b>					
Research Fund	-	-	14,226	(14,226)	-
Transition Project Fund	-	-	1,500	(1,500)	-
Music Therapy Fund	187	-	106	(187)	106
North London Support Group Fund	278	-	290	(190)	378
Regional Day Fund	2,250	-	-	(2,250)	-
TESS Fund	-	-	5,000	(5,000)	-
Family Guide Fund	-	-	22,000	-	22,000
Support Services Fund	-	-	16,320	(16,320)	-
Care Pathways Fund	-	-	9,000	(6,337)	2,663
CDKL5 Fund	3,688	-	11,396	(15,084)	-
MECP2 Fund	-	-	4,357	(1,000)	3,357
	<b>£6,403</b>	<b>£-</b>	<b>£84,195</b>	<b>£(62,094)</b>	<b>£28,504</b>

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.

### Transition Project Fund

The Fund is utilised for the provision of a support worker working specifically with people with Rett syndrome who are at the transitional stage between childhood and adulthood.

### 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 provide 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.

## CDKL5 Fund

The Fund is used for activities relating to this sub-group of Rett syndrome where the CDKL5 gene affects the making of a protein that is essential for normal brain development.

## 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 2013, nor for the year ended 31 March 2012.

During the year, expenses of £245 (2012 - £21) 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 (2012 - £926).

### 9. DEBTORS

	2013 £	2012 £
Other debtors	6,460	7,934
Prepayments	9,180	9,489
	<b>£15,640</b>	<b>£17,423</b>

### 10. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2013 £	2012 £
Accrued expenses	9,660	18,903
British Isles Rett Syndrome Survey	7,000	20,786
FOXG1	5,000	-
Roald Dahl's Marvellous Children's Charity	7,500	-
	<b>£29,160</b>	<b>£39,689</b>

### 11. OPERATING LEASE COMMITMENTS

At 31 March 2013 Rett UK had an annual commitment under a non-cancellable operating lease as follows:

	2013 £	2012 £
<b>Land and Buildings</b>		
Expiry date within one to five years	£7,200	£7,200

## Patrons, Staff and Professional Advisers

### Trustees

- Michael Britten
  - Paul Chapman, Honorary Chair
  - Wendy Daykin
  - Lucy Duncan, Honorary Treasurer
  - Rebecca Gordon
  - Lorna Jaffa
  - Robert McNamara
  - Ian Morse
  - Peter Oliver, Honorary Vice-Chair
  - Carol-Anne Partridge
  - Jonathon Petford
  - Hilary Truss
  - Robert Valentine
- Resigned 20 May 2013  
Resigned 8 December 2012  
Appointed 15 June 2013
- Appointed 8 December 2012
- Resigned 8 December 2012  
Resigned 8 December 2012
- Resigned 8 December 2012

### Honorary Patrons

- Ann Clwyd MP
  - Evelyn Glennie DBE
  - Gloria Hunniford
  - Jon Snow
  - Yvonne Milne MBE
- Honorary Life President

### Staff Team

- Suzanne Barlow
  - Julie Benson
  - Patrice Hosier
  - Sarah Kilcoyne
  - Debbie Main
- Executive Director  
Family Support Manager  
Family Support Officer  
Accountant  
Membership and Fundraising Manager

### Professional Advisers



**Chief Medical Adviser:**  
Prof A J Clarke, DM FRCP, Geneticist

- Dr Hayley Archer, Geneticist
- Dr Sarah Bernard MD, MB, ChB, FRCPsych, DRCOG, Consultant Psychiatrist of Learning Disabilities
- Prof. Adrian Bird, Ph.D
- Dr Hilary Cass, BSc MRCP FRCPCH, President, Royal College of Paediatrics and Child Health
- Prof Jill Clayton-Smith, Consultant Clinical Geneticist
- Helen Cockerill, Clinical Expert Speech & Language Therapist
- Sally-Ann Garrett, Speech & Language Therapist
- Mr David J Harrison B BS, BSc, FRCS, AKC, Consultant Spinal Surgeon (retired)
- Dr Alison M Kerr OBE FRCP FRCP&CH, Honorary Consultant in Paediatrics and Learning Disability (retired)
- Dr Bronwyn Kerr, Consultant Clinical Geneticist
- Prof Michael Kerr, Professor of Learning Disability Psychiatry & Epileptologist
- Gilly Martin, Specialist Physiotherapist
- Cindy-Jo Morrison, Music Therapist
- Dr Richard Morton, FRCP FRCPCH, Consultant Paediatrician



- Mr Kelvin Smith, International Society for Prosthetics and Orthotics and the British Association of Prosthetists and Orthotists
- Dr P Sutherland MA BM BCh FRCA, Anaesthetist
- Dr C Troake , Specialist Post Mortem Coordinator

## 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.



Search: Rett UK

## Keep Informed

2012/13 has seen our Facebook and Twitter followers grow to over 2,000 and 1,000 respectively.

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



Search: Rett UK



@ RettUK



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E **support@rettuk.org**

Registered Charity Number: 1137820  
Registered Company Number: 073395227

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**[www.rettuk.org](http://www.rettuk.org)**