Registered number: 07278507 Charity number: 1136809

### **REVERSE RETT**

(A company limited by guarantee)

# TRUSTEES' REPORT AND FINANCIAL STATEMENTS FOR THE PERIOD ENDED 31 DECEMBER 2013

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### REFERENCE AND ADMINISTRATIVE DETAILS OF THE COMPANY, ITS TRUSTEES AND ADVISERS FOR THE PERIOD ENDED 31 DECEMBER 2013

### **Trustees**

Monica Coenraads
Rachael E Bloom
Andrew J Stevenson, Treasurer
Rita Ross (resigned 15 November 2012)
Kelly Phillips, Chair
Helen Simmonds
Thomas Carroll (appointed 15 March 2013)
Marc Souter (appointed 1 September 2012)
Catriona Moore (appointed 15 March 2013, resigned 10 February 2014)
John Sharpe (appointed 24 March 2014)

### Company registered number

07278507

### Charity registered number

1136809

### Registered office

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

### Independent auditor

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

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### TRUSTEES' REPORT FOR THE PERIOD ENDED 31 DECEMBER 2013

The Trustees (who are also directors of the charity for the purposes of the Companies Act) present their annual report together with the audited financial statements of Reverse Rett (the company) for the 18 month period ended 31 December 2013. The Trustees confirm that the Annual report and financial statements of the company comply with the current statutory requirements, the requirements of the company's governing document and the provisions of the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" issued in March 2005.

### Structure, governance and management

### a. CONSTITUTION

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

Reverse Rett (formerly Rett Syndrome Research Trust UK) is a National Charity which exists solely to accelerate treatments and cures for Rett Syndrome and related *MECP2* Disorders. The charity operates in England, Wales, Scotland and Northern Ireland. The Charity's objectives are:

To relieve sickness and to preserve health for the public benefit by developing treatments and cures for Rett Syndrome and related *MECP2* disorders, in particular but not exclusively by:

- funding research projects;
- organising and sponsoring scientific workshops;
- collating information from experts in the field and providing access to it; and
- increasing general public awareness and knowledge of Rett Syndrome and related MECP2 disorders.

The change of name for the charity from Rett Syndrome Research Trust UK to Reverse Rett was agreed at a meeting of the Board of Trustees on 12th July 2013. This name change was formally adopted by Companies House on 5th September 2013.

### **b. METHOD OF APPOINTMENT OR ELECTION OF TRUSTEES**

The management of the company is the responsibility of the Trustees who are elected and co-opted under the terms of the Articles of Association. The Trustees of the Charity who served during the year ended December 31st 2013 are shown on page 1.

The first Trustees are those persons notified to Companies House as the first directors of the Charity. The Charity may by ordinary resolution, appoint a person who is willing to act as a Director and determine the length of rotation in which any additional directors are to retire. The first four Trustees were involved in the founding of the Charity and the remaining three are directly involved in the continued work of the charity. To ensure best practice, all Trustees have worked through the NCVO publication, 'The Good Trustee Guide' and have been encouraged to read the Charity Commission publication, 'The Essential Trustee.'

The Reverse Rett Conflict of Interest Policy has been recently updated and signed by all Trustees.

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

Trustees are informed of their responsibilities through the Essential Trustee publication from the Charity Commission and the NCVO publication, the Good Trustee Guide.

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### TRUSTEES' REPORT (continued) FOR THE PERIOD ENDED 31 DECEMBER 2013

### d. ORGANISATIONAL STRUCTURE AND DECISION MAKING

Rachael Bloom, Founding Trustee and Executive Director of Reverse Rett maintains operational control of the organisation. Since the inception of the Charity, Rachael has had responsibility for implementing the charity's strategic priorities and for the day-to-day running of the organisation, including communications, fundraising and administration. Rachael became a formal employee of the Charity from 1 April 2012 and now reports to the Board of Trustees.

There are two additional full time members of staff who report directly to the Executive Director.

Andrew Stevenson was offered the position of Community Fundraising Manager on September 1st 2012 and continues his work in this role to date.

After working for the organisation on a voluntary and then hourly basis for a number of months, Thomas Johnston was offered the position of Resource Development Officer on January 10th 2014 with a commencement date of February 1st 2014 and continues his work in this role to date.

Both the Community Fundraising Manager and the Resource Development Officer report directly to the Executive Director. The staff members also have regular and open communication with the Chair of Trustees.

As a Founding Trustee of the charity, Andrew Stevenson was recused from any meetings to discuss his potential employment at Reverse Rett. Employment of Directors of the Charity is permitted by article 6.4.2 of the Memorandum and Articles of Association of the charity which provides that Directors of the charity may be employed providing that the majority of Directors do not benefit in this way.

### e. RISK MANAGEMENT

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

### **Objectives and Activities**

### a. PUBLIC BENEFIT

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

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

Rett Syndrome is a severe and complex brain disorder caused by sporadic mutations of the X-linked gene, *MECP2*. Rett Syndrome attacks little girls almost exclusively. Most girls with Rett Syndrome seem healthy and typical at birth but within a year or two begin to manifest symptoms of neurological damage. Loss of previously acquired skills and speech are accompanied by movement and autonomic disorders. Functional hand use is replaced by constant handwringing or other stereotypies. Autonomic nervous system imbalances impact normal cardiac and breathing rhythms, digestive and circulatory functions, and often seem to keep the children in a constant physiological state of stress, the fight-or-flight response. Many children suffer extreme anxiety, tremors, seizures, and orthopaedic problems such as scoliosis, kyphosis and abnormal bone mineralization. While some are able to walk, at least half become wheel-chair users from early childhood. All are at increased risk of sudden and unexplained death. Many girls with Rett Syndrome survive well into adulthood, requiring total, 24 hour a day care for their entire lives. The cost, both financial and in terms of human suffering, is enormous.

### TRUSTEES' REPORT (continued) FOR THE PERIOD ENDED 31 DECEMBER 2013

In February of 2007, a dramatic and unexpected result was achieved in the laboratory of a researcher at the University of Edinburgh. Rett Syndrome, previously considered incurable, was completely reversed in a mouse model of the disorder. These results were reported in the journal Science (Guy J, Gan J, Selfridge J, Cobb S, Bird A. Reversal of neurological defects in a mouse model of Rett syndrome. Science. 2007 Feb 23; 315(5815):1143-7). The laboratory of Prof. Adrian Bird, who first identified *MECP2*, was able to accomplish this remarkable transformation even in cases of disease so advanced that the animals were days away from death. Within a matter of weeks, these animals were indistinguishable from their normal, healthy counterparts. We believe that these recent advances in Rett research suggest a new paradigm for addressing serious neurological disorders, and that within the upcoming decades the eradication of the crippling array of symptoms caused by Rett will be achieved.

Since the inception of Reverse Rett in 2010, there have been a number of further developments in Rett Syndrome research. Recent data from a number of labs suggests that there may be many ways to improve Rett symptoms pharmacologically in mice. The next few years will require clinical trials and pilot studies of existing medications and procedures to explore whether applied individually or in combination, they can relieve symptoms in humans.

Work towards a reversal or cure for Rett Syndrome is also moving forward. This will likely require addressing the underlying genetic problem; repairing the *MECP2* mutation via gene correction/therapy or protein replacement, activating the silent healthy copy of the gene on the inactive X, or finding a way, perhaps through modifier genes, to bypass *MECP2* altogether.

Reverse Rett works to accelerate treatments and ultimately a cure for Rett Syndrome and related *MECP2* disorders.

The organisation has three identified priorities which will enable us to move quickly towards that goal:

- Funding international Rett Syndrome research focused on basic science, treatment and reversal.
- Capacity building/facilitating treatment within the UK medical community.
- Ensuring the sustainability of the organisation so that we can ensure we see our vision all the way to its ultimate conclusion.

### Achievements and performance

### a. REVIEW OF ACTIVITIES

### Funding research:

We aggressively fund research focused on treatment, reversal and better understanding the basic science underlying this complex condition.

The projects we support can be broken down into the following categories:

- **Treatment** We fund labs who are targeting symptoms which result from *MECP2* mutations via drugs and/or procedures. This is largely a symptom-by-symptom approach to relieving some of Rett Syndrome's many manifestations and improving quality of life.
- **Reversal** We fund approaches that work to fix the underlying cause of Rett, aberrations in *MECP2*, in efforts to actualize the 2007 pre-clinical reversal for human clinical application. Included are gene therapy; activation of the silent *MECP2* gene on the inactive X; identification and deployment of modifier genes.
- Basic science –We invest in rigorous science to develop an accurate, detailed knowledge base of the neurobiology of Rett as a direct conduit to the creation of new strategies to overcome it.

### TRUSTEES' REPORT (continued) FOR THE PERIOD ENDED 31 DECEMBER 2013

Between July 1st 2012 and December 31st 2013, Reverse Rett funded 17 labs with a total of £1,075,536.

The Trustees would like to record their heartfelt appreciation to the fundraisers, donors and supporters whose time, energy and commitment make the work of Reverse Rett possible.

### Rett syndrome research: think local, act global

Reverse Rett works in partnership with the Rett Syndrome Research Trust (US) to fund the international research program focused on these three approaches. The shared use of a common Scientific Advisory Board enables us to ensure a coordinated, concerted and consistent effort in terms of the identification, monitoring and review of appropriate research projects.

Reverse Rett is prudently run and research funding is only approved by the Trustees if funds are already held. International research funding is allocated to specific projects on a quarterly basis. Payments for international projects are sent to the Reverse Rett account in the USA and subsequently distributed directly to the research projects we support.

- Reverse Rett has seen rapid growth in the past three years during which we have tripled our income and subsequent research commitment.
- We have a solid track record of consistently funding research. This year alone, we have seen four key research publications from four research projects which we have significantly contributed to.

### The MECP2 Duplication Fund at Reverse Rett

• The MECP2 Duplication Fund at Reverse Rett was established in spring 2013. The fund exclusively supports projects devoted to the study and means of treatment of MECP2 Duplication/ Triplication Syndrome. 100% of funds raised and contributed by families of children with MECP2 Duplication Syndrome and their supporters are committed to MECP2 specific projects via the US based RSRT.

### (ii) Capacity building/Facilitating treatment in the UK:

Avenues to the development of potential treatment pathways in the UK are being vigorously explored. The infrastructure required to ensure that people with Rett Syndrome and related MECP2 disorders in the UK have access to treatment and or clinical trials continues to be a priority for this organisation.

Reverse Rett is working closely with relevant organisations, academic institutions and individual clinicians and researchers to further this objective.

Reverse Rett continues to work closely on national issues pertaining to the development of treatment pathways with key groups and patient organisations including Orphanet, Eurodis, Rett Syndrome Europe, Rare Disease UK, Genetic Alliance UK, British Society for Gene and Cell Therapy and others.

Reverse Rett has initiated the development of an up to date registry of individuals with Rett Syndrome and related MECP2 disorders in the UK. This registry can be completed on line on the charity website: <a href="http://www.reverserett.org.uk/what-we-do/research/register-your-child/">http://www.reverserett.org.uk/what-we-do/research/register-your-child/</a>

In the period between July 2012 and December 2013, Reverse Rett also sponsored and participated in two European scientific workshops; the British Society of Gene and Cell Therapy Conference and the 3rd European Rett Syndrome Conference "Research Update and Preventive Management" held in Maastricht.

The sponsorship of these two conferences promotes and nurtures interest in Rett Syndrome amongst the medical and scientific community in Europe and facilitates collaboration between various individuals, groups and organisations working towards a common goal.

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### TRUSTEES' REPORT (continued) FOR THE PERIOD ENDED 31 DECEMBER 2013

### (iii) Ensuring the sustainability of the organisation so that we can ensure we see our vision all the way to its ultimate conclusion.

At Reverse Rett, we work to ensure sustainability of the organisation broadly in four key ways:

- 1. Increasing general public awareness and knowledge of Rett and related MECP2 Disorders.
- 2. Engaging families of children with Rett Syndrome/MECP2 disorders and their wider communities to raise funds and nurture connections to drive the science forward.
- 3. Working to access additional funding streams to support the continuing work of the organisation in the longer term.
- Strengthening organisational infrastructure and internal processes.

### 1. Increasing general public awareness and knowledge of Rett and related MECP2 Disorders.

Increased public awareness and knowledge of Rett and related *MECP2* disorders can help grow our support base and ultimately increase our research commitment. Here is how we've been working to increase public awareness:

- This year we have completely redeveloped our website with the generous pro bono support of Wiltshire based web-design company Symphony-Online who have made the new website, responsive, engaging and much more user-friendly so that the Reverse Rett team are able to update and utilize the website more easily to better communicate with and inform our supporters and the general public.
- We use our social media capability to support and enhance the information we share through the website in Plain English.
- We write articles and participate in interviews with TV, radio, magazines and newspapers whenever possible.
- We hold events or attend events through which we share information about Rett and the potential for treatment through video, presentations, displays and other literature.
- We engage with other organisations and companies who can help increase awareness of Rett Syndrome and the vital work we are doing.
- We've won two national awards in recognition of our work:

Best New Charity Award in the Charity Times Awards 2011

Best New Charity Award in the Just Giving Awards 2012

### As of the present day we have:

- Facebook page: 3176 Likes
- Twitter: 1509 Followers
- 472 Just Giving pages set up from July 2012-Dec 2013
- Average 2470 visitors a month to our website

### In addition:

- More than 350 people attended the third and fourth Reverse Rett London events respectively.
- 2. Engaging families of daughters with Rett Syndrome to raise funds and nurture connections to drive the science forward.

Reverse Rett was founded and is run by parents of children with Rett Syndrome. Families continue to be the lifeblood of our work at Reverse Rett. It is only through the commitment, passion and involvement of families that we are able to bring the work of Reverse Rett before the general public and inspire them to support us.

We work with families to support their on the ground fundraising, both on an individual and community level.

In 2012-2013, the charity identified the need to nurture the commitment and continued involvement of existing

### TRUSTEES' REPORT (continued) FOR THE PERIOD ENDED 31 DECEMBER 2013

family fundraisers and to provide an increased level of resources for newly diagnosed families, both in terms of information/resources and facilitated connections with each other.

We developed two projects to meet these needs:

### **Changemakers (The Lifeline Project)**

The Changemakers project focused on empowering parents to impact a better future for their child through active participation in the work of the charity.

Grants to the organisation made in 2012-2013 enabled Reverse Rett to run three Changemakers workshops involving thirty parents and caregivers of children with Rett and related *MECP2* disorders in London, Leeds and Glasgow.

Families who have participated in the workshops remain actively involved in the work of the charity and connected to each other via a national Changemakers Facebook Forum run by the charity.

Through the Changemakers workshops and the generous support of the Gannochy Trust, the Rayne Foundation and The Big Lottery Fund: Awards for All, a comprehensive action pack for parents was also developed, printed and distributed to more than 500 families across the UK.

The Trustees of Reverse Rett would like to thank the following trusts and foundations who have generously supported this work; Awards for All-The Big Lottery Fund, The Gannochy Trust, The Rayne Foundation, The Goldsmith's Company, The Hasluck Charitable Trust, The Margaret Murdoch Charitable Trust, The Liz and Terry Bramall Charitable Trust and the Manchester Guardian Society Charitable Trust.

### Reverse Rett Parent 2 Parent

Reverse Rett Parent 2 Parent is a new project facilitating structured connections between trained volunteer mentor parents and newly diagnosed parents seeking information, resources, guidance and support from another parent who has walked in their shoes.

This project is funded through a generous grant from Roald Dahl's Marvellous Children's Charity.

The Trustees of Reverse Rett would like to thank Roald Dahl's Marvellous Children's Charity for their kind support, without which, this critical work would not be possible.

Both the Changemakers and Parent 2 Parent projects will continue to enable the charity to engage more effectively with families of children with Rett Syndrome and related *MECP2* disorders; helping us to grow our support base and enhance the overall impact of the organisation as we work towards our ultimate goal.

### 3. Working to access additional funding streams to support the continuing work of the organisation in the longer term.

Both of the aforementioned projects were funded through grants from Trusts and Foundations, through which the organisation has started to access alternate funding streams to support our ongoing work.

In 2012-2013, income from Trusts and Foundations totalled: £37,375

Further work to increase the level of support from Trusts and Foundations continues to date.

### 4. Strengthening organisational infrastructure and internal processes

In Spring 2013, Reverse Rett officially launched our Professional Advisory Board, comprising of individuals from

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### TRUSTEES' REPORT (continued) FOR THE PERIOD ENDED 31 DECEMBER 2013

a variety of backgrounds and professions, who have a long term demonstrated commitment to our work and the experience, skill and resolve to help the organisation grow.

Work to ensure that the PAB and the Board of Trustees work more cohesively continues to date.

The Board of Trustees is also working to improve the function of the Board and its oversight of both the day to day activities and long-term vision and strategy of the organisation.

The organisation has recently been working in collaboration with Symphony-Online to develop and implement a new CRM/Database which will enable further streamlining of internal processes and improve supporter care and communications across the board.

### **b. FINANCIAL REVIEW**

#### a. Direct costs

Direct costs refer to expenditure by the charity. Total direct costs were £1,131,494

### £38,405 included day to day running costs.

Day to day running costs include: Postage, printing, hourly admin costs, bookkeeping, office rental and more. These day to day running costs represent 3.4% of the charity's direct costs.

### Reinvestment in the organisation:

### £173 included brand redevelopment

This brand redevelopment was to ensure that materials were redesigned to incorporate the organisation's name change from Rett Syndrome Research Trust UK to Reverse Rett.

These brand redevelopment costs represent 0.015% of the charity's direct costs.

### £9174 included the development of action packs for supporters and families

These action pack development costs represent 0.8% of the charity's direct costs.

Special thanks to the Big Lottery Fund, the Gannochy Trust and the Dorothy Pamela Smith Trust whose generous support covered all costs associated with the development and production of these action packs.

### Sponsoring scientific workshops and conferences:

£8206 included the sponsorship of and participation in the Rett Syndrome Europe Conference in Maastricht and the British Society of Gene and Cell Therapy Conference in the UK

These conference sponsorship and participation costs represent 0.7% of the charity's direct costs.

Special thanks to the Jomati Foundation for providing a generous grant to cover the costs of the organisation's sponsorship of and participation in these conferences.

### Research funding:

£1,075,536 included payment to the Rett Syndrome Research Trust USA for subsequent distribution to the international research projects we support.

This research funding represents 95% of the charity's direct costs.

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### TRUSTEES' REPORT (continued) FOR THE PERIOD ENDED 31 DECEMBER 2013

#### b. Trustee's renumeration

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

Reimbursement of Trustee's expenses on P.19 refers to reimbursement of day to day working expenses incurred by these Trustees as employees of the organisation. These costs include travel to meetings, conferences and workshops, postage and the purchase of items which are difficult to purchase by cheque or direct bank transfer, such as online transactions for items required by the charity.

### Financial review

### a. RESERVES POLICY

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

### Plans for the future

#### a. FUTURE DEVELOPMENTS

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

### Over the next five years, from 2013 to 2018, we want to:

- Grow our income from £500,000 in 2012 to £1.25 million by 2017, enabling us to triple our annual research commitment.
- Work with the UK medical community to ensure that potential treatments and therapies can be implemented within the UK.
- Promote early identification and intervention in Rett Syndrome in the UK.

### To achieve these aims we know that we need to meet two organisational challenges:

- We need to make sure that our admin and finance systems provide the infrastructure we need as the organisation grows.
- We need to make sure that we can make the impact of a larger organisation without losing efficiency or compromising our mission and vision.

### TRUSTEES' RESPONSIBILITIES STATEMENT

The Trustees (who are also directors of Reverse Rett for the purposes of company law) are responsible for preparing the Trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare financial statements for each financial year. Under company law the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgments and accounting estimates that are reasonable and prudent;

## TRUSTEES' REPORT (continued) FOR THE PERIOD ENDED 31 DECEMBER 2013

 prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in operation.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company's transactions and disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

### DISCLOSURE OF INFORMATION TO AUDITOR

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

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

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

This report was approved by the Trustees on

Kelly Phillips, Chair

and signed on their behalf by:

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

We have audited the financial statements of Reverse Rett for the period ended 31 December 2013 set out on pages 13 to 21. 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 section 145 of the Charities Act 2011 and regulations made under section 154 of that Act. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an Auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and its members, as a body, for our audit work, for this report, or for the opinion we have formed.

### RESPECTIVE RESPONSIBILITIES OF TRUSTEES AND AUDITOR

As explained more fully in the Trustees' responsibilities statement, the Trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view.

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

### SCOPE OF THE AUDIT OF THE FINANCIAL STATEMENTS

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

### **OPINION ON FINANCIAL STATEMENTS**

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2013 and of its incoming resources and application of resources, including its income and expenditure, for the period then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice applicable to Smaller Entities; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

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

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

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

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

**Hillier Hopkins LLP** 

Chartered Accountants Statutory Auditor

Hillier Hophins Lel

Radius House 51 Clarendon Road Watford Herts WD17 1HP

Date: 7 JULY 2014

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

## STATEMENT OF FINANCIAL ACTIVITIES (Incorporating Income and Expenditure Account) FOR THE PERIOD ENDED 31 DECEMBER 2013

	Note	Restricted funds 2013	Unrestricted funds 2013	Total funds 2013 £	Total funds 2012 £
INCOMING RESOURCES	Note	L	£	ž.	£
Incoming resources from generated funds: Voluntary income	2	_	975,664	975,664	253,522
Incoming resources from charitable activities	3	95,414	445,589	541,003	255,829
TOTAL INCOMING RESOURCES		95,414	1,421,253	1,516,667	509,351
RESOURCES EXPENDED		<u> </u>			
Costs of generating funds: Fundraising expenses and other costs		_	125,622	125,622	36,650
Charitable activities		76,714	1,054,780	1,131,494	448,282
Governance costs	4	4,625	72,921	77,546	15,699
TOTAL RESOURCES EXPENDED	6	81,339	1,253,323	1,334,662	500,631
MOVEMENT IN TOTAL FUNDS FOR THE YEAR - NET INCOME FOR THE YEAR		14,075	167,930	182,005	8,720
Total funds at 1 July 2012		-	27,739	27,739	19,019
TOTAL FUNDS AT 31 DECEMBER 2013		14,075	195,669	209,744	27,739

The notes on pages 15 to 21 form part of these financial statements.

(A company limited by guarantee) REGISTERED NUMBER: 07278507

### BALANCE SHEET AS AT 31 DECEMBER 2013

		3	1 December 2013		30 June
	Note	£	2013 £	£	2012 £
CURRENT ASSETS					
Debtors	10	35,156		761	
Cash at bank		179,388		31,178	
	•	214,544	•	31,939	
CREDITORS: amounts falling due within one year	11	(4,800)		(4,200)	
NET CURRENT ASSETS	-	<del> </del>	209,744		27,739
NET ASSETS			209,744	-	27,739
CHARITY FUNDS				=	
Restricted funds	12		14,075		_
Unrestricted funds	12		195,669		27,739
TOTAL FUNDS		·	209,744	-	27,739
		:		=	۷۱,۱۰

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

The Trustees acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and for preparing financial statements which give a true and fair view of the state of affairs of the company as at 31 December 2013 and of its net incoming resources for the period in accordance with the requirements of sections 394 and 395 of the Act and which otherwise comply with the requirements of the Act relating to financial statements, so far as applicable to the company.

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

The financial statements were approved by the Trustees on behalf, by:

Rachael E Bloom

The notes on pages 15 to 21 form part of these financial statements.

25th June 2014 and signed on their

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### NOTES TO THE FINANCIAL STATEMENTS FOR THE PERIOD ENDED 31 DECEMBER 2013

### 1. ACCOUNTING POLICIES

### 1.1 Basis of preparation of financial statements

The financial statements have been prepared under the historical cost convention, with the exception of investments which are included at market value, and in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008). The financial statements have been prepared in accordance with the Statement of Recommended Practice (SORP), 'Accounting and Reporting by Charities' published in March 2005, applicable accounting standards and the Companies Act 2006.

### 1.2 Company status

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

### 1.3 Fund accounting

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

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

### 1.4 Incoming resources

All incoming resources are included in the Statement of financial activities when the company has entitlement to the funds, certainty of receipt and the amount can be measured with sufficient reliability.

Donated services or facilities, which comprise donated services, are included in income at a valuation which is an estimate of the financial cost borne by the donor where such a cost is quantifiable and measurable. No income is recognised where there is no financial cost borne by a third party.

Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

### 1.5 Resources expended

All expenditure is accounted for on an accruals basis and has been included under expense categories that aggregate all costs for allocation to activities. Where costs cannot be directly attributed to particular activities they have been allocated on a basis consistent with the use of the resources.

Fundraising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of the charitable activities. Governance costs are those incurred in connection with administration of the company and compliance with constitutional and statutory requirements.

### NOTES TO THE FINANCIAL STATEMENTS FOR THE PERIOD ENDED 31 DECEMBER 2013

		Damk-!-41		<b>T</b> _4_1	<b>T-1</b> -1
		funds	Unrestricted funds	Total funds	Total funds
		2013	2013	2013	2012
		£	£	£	£
	Donations		975,664	975,664	253,522
3.	INCOMING RESOURCES FROM CHARITA	ABLE ACTIVIT	TIES		
		Restricted	Unrestricted	Total	Total
		funds	funds	funds	funds
		2013	2013	2013	2012
		£	£	£	£
	London Event 2012	-	130,084	130,084	202,616
	The Big Give	-	184,636	184,636	53,213
	London Event 2013	-	130,869	130,869	-
	Lifeline Project	14,650	-	14,650	-
	Gene Therapy Workshop	10,000	=	10,000	-
	Use in Farringdon	200	•	200	-
	MECP2 Fund	58,039	•	58,039	-
	Action Packs	7,900	-	7,900	-
	Roald Dahl	4,625		4,625	
		95,414	445,589	541,003	255,829
<b>4</b> .	GOVERNANCE COSTS				
		Restricted	Unrestricted	Total	Total
		funds	funds	funds	funds
		2013	2013	2013	2012
		£	£	£	£
	Auditors' remuneration	_	4,800	4,800	4,200
	Independent Examination fees	•	-	•	1,800
	Bank charges	-	737	737	-
	Professional fees	-	13,835	13,835	-
	Governance expense - wages & salaries	4,625	47,875	52,500	8,750
	Governance expense - NI	-	5,674	5,674	949

## NOTES TO THE FINANCIAL STATEMENTS FOR THE PERIOD ENDED 31 DECEMBER 2013

### 5. DIRECT COSTS

	Basis of Allocation	Project funding £	London Event 2013 £	Lifeline Project £	Gene Therapy Workshop £
Misc expenditure	Actual	4,752	•	-	-
Telephone	Actual	1,728	-	-	•
Postage	Actual	7,241	-	228	-
Running vests	Actual	-	-	-	-
Administration cost	Actual	3,566	-	-	-
Transfer to Rett Syndrome					
Research Trust USA	Actual	1,017,897	-	-	-
Travel and accomodation	Actual	7,421	-	1,467	-
Brand redevelopment	Actual	173	-	-	-
Office rental costs	Actual	10,495	1,507	-	-
Workshop and conference					
expenses	Actual	-	-	2,031	6,175
Action packs design and supply	Actual	-	-	1,274	-
		1,053,273	1,507	5,000	6,175
		Me2CP2	Action	Total	Total
		Fund	Packs	2013	2012
		£	£	£	£
Mice expenditure		_	_	4,752	_
Misc expenditure		-	-	4,732 1,728	- 175
Telephone		-	•	7,469	894
Postage Running vests		-	•	7,409	4,575
Administration cost		_	_	3,566	7,801
Transfer to Rett Syndrome Res	oarch Trust	-	-	3,300	7,001
USA	earch trust	57,639	_	1,075,536	424,446
Travel and accomodation		57,039	_	8,888	1,394
Brand redevelopment		_	_	173	6,600
Office rental costs		_	_	12,002	2,397
	00000	- -	_	8,206	2,091
Workshop and conference exp		-	7,900	9,174	-
Action packs design and supply	,	-	7,900	3,114	_
		57,639	7,900	1,131,494	448,282

## NOTES TO THE FINANCIAL STATEMENTS FOR THE PERIOD ENDED 31 DECEMBER 2013

		Staff costs	Other costs	Total	Total
		2013	2013	2013	2012
		£	£	£	£
	Fundraising expenses	35,435	90,187	125,622	32,522
	Costs of generating funds	35,435	90,187	125,622	32,522
	Project funding	-	1,053,273	1,053,273	452,410
	London Event 2013	-	1,507	1,507	, <u> </u>
	Lifeline Project	-	5,000	5,000	-
	Gene Therapy Workshop	-	6,175	6,175	_
	MECP2 Fund	•	57,639	57,639	-
	Action Packs	-	7,900	7,900	-
	Charitable activities	-	1,131,494	1,131,494	452,410
	Governance	58,174	19,372	77,546	15,699
		93,609	1,241,053	1,334,662	500,631
	ANALYSIS OF RESOURCES EXP		e		
7.	ANALISIS OF RESOURCES EXT	ENDED BY ACTIVITIES	3		
7.	ANALISIS OF RESOURCES EAT	Activities			
7.	ANALISIS OF RESOURCES EAT.	Activities undertaken	Support	Total	Total
7.	ANALISIS OF RESOURCES EAT.	Activities undertaken directly	Support costs	Total	Total 2012
7.	ANALISIS OF RESOURCES EAT.	Activities undertaken	Support	Total 2013 £	
7.		Activities undertaken directly 2013 £	Support costs 2013	2013	2012
7.	Project funding	Activities undertaken directly 2013	Support costs 2013	2013 £	2012 £
7.	Project funding London Event 2013	Activities undertaken directly 2013 £ 1,053,273	Support costs 2013	2013 £ 1,053,273	2012 £
7.	Project funding London Event 2013 Lifeline Project	Activities undertaken directly 2013 £ 1,053,273 1,507	Support costs 2013	2013 £ 1,053,273 1,507 5,000 6,175	2012 £
7.	Project funding London Event 2013	Activities undertaken directly 2013 £ 1,053,273 1,507 5,000	Support costs 2013	2013 £ 1,053,273 1,507 5,000 6,175 57,639	2012 £
7.	Project funding London Event 2013 Lifeline Project Gene Therapy Workshop	Activities undertaken directly 2013 £ 1,053,273 1,507 5,000 6,175	Support costs 2013	2013 £ 1,053,273 1,507 5,000 6,175	2012 £

(A company limited by guarantee)

### NOTES TO THE FINANCIAL STATEMENTS FOR THE PERIOD ENDED 31 DECEMBER 2013

8.	NET INCOME		
	This is stated after charging:		
		2013	2012
		£	£
	Auditor's remuneration	4,800	4,200
	During the period, 2 Trustees received remuneration of £84,792 (2 During the period, no Trustees received any benefits in kind (2012 During the period, 2 Trustees received reimbursement of expenses	- £NIL).	12 - £1,444).
9.	STAFF COSTS		
	Staff costs were as follows:		
		2013 £	2012 £
	Wages and salaries	84,792	8,750
	Social security costs	8,817	949
		93,609	9,699
	The average monthly number of employees during the period was	as follows:	
		2013	2012
		No.	No.
			1
	No employee received remuneration amounting to more than £60,	000 in either year.	
10.	DEBTORS		
10.		31 December 2013	30 June 2012 £
10.	DEBTORS	2013 £	2012 £
10.		2013	2012

### NOTES TO THE FINANCIAL STATEMENTS FOR THE PERIOD ENDED 31 DECEMBER 2013

11.	CREDITORS: Amounts falling due within one year				
			31 De	cember 2013 £	30 June 2012 £
	Accruals and deferred income			4,800 ————————	4,200
12.	STATEMENT OF FUNDS				
		Brought Forward £	Incoming resources	Resources Expended £	Carried Forward £
	Unrestricted funds				
	General Funds - all funds	27,739	1,421,253	(1,253,323)	195,669
	Restricted funds				
	Gene Therapy Workshop	-	10,000	(6,175)	3,825
	Lifeline Project	-	14,650	(5,000)	9,650
	MECP2 Duplication Fund	-	58,039	(57,639)	400
	Action packs Roald Dahl	-	7,900 4,625	(7,900) (4,625)	-
	Use in Farringdon	-	200	-	200
		-	95,414	(81,339)	14,075
	Total of funds	27,739	1,516,667	(1,334,662)	209,744
	SUMMARY OF FUNDS				
		Brought	Incoming	Resources	Carried Forward
		Forward £	resources £	Expended £	Forward £
	General funds	27,739	1,421,253	(1,253,323)	195,669
	Restricted funds		95,414	(81,339)	14,075
		27,739	1,516,667	(1,334,662)	209,744

### NOTES TO THE FINANCIAL STATEMENTS FOR THE PERIOD ENDED 31 DECEMBER 2013

### 13. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Restricted	Unrestricted	Total	Total
	funds	funds	funds	funds
	2013	2013	2013	2012
	£	£	£	£
Current assets	14,075	200,469	214,544	31,939
Creditors due within one year	-	(4,800)	(4,800)	(4,200)
	14,075	195,669	209,744	27,739

### 14. OPERATING LEASE COMMITMENTS

At 31 December 2013 the company had annual commitments under non-cancellable operating leases as follows:

	31 December 2013	30 June 2012
	£	£
Expiry date:		
Within 1 year	2,417	-
•		