Annual Review 2014/15

30th ANNIVERSARY

Rett UK

Celebrating 30 years 1985-2015

On average **30** girls born every year in the UK and **6** boys

Chairman's Foreword

Rett UK is 30 years old! Since the charity was founded in 1985 we have grown considerably as a self-help organisation. In the early days paediatricians diagnosed the little girls with this devastating disorder. Initially we ran clinics in people's houses. Support to desperate families, who saw their perfectly normal one year old girl deteriorate before their eyes, was given by our Founder, Yvonne Milne who has since been awarded an MBE for her work.

Gradually as numbers grew, peer to support was added and eventually a grant enabled us to launch regional groups providing essential mutual support within the communities where our families lived; a key component in breaking down the isolation experienced by families of such a rare and complex disorder. But families were also desperate to find a cure and a Research Fund was set up. In 1999 the cause of Rett syndrome was discovered and since then there has been hope of a finding a cure. We were delighted that in 2007 our funding was instrumental in supporting the work of Professor Adrian Bird at Edinburgh University showing the reversal of Rett syndrome in laboratory mice. We knew then that Rett syndrome (RTT) was potentially a reversible disorder.

We also knew that there were many undiagnosed people all over the country and great efforts were made to have RTT known throughout the medical profession. Our annual Family Weekend was a meeting place for families to share advice and meet the growing number of professionals who were interested in helping those with Rett syndrome.

27 Family Weekends

Over **300** clinics held

Thirty years on our core purpose remains the same but our organisation has developed. Our specialist Rett clinics are held in hospital settings and are run in four different centres across the country. This key partnership between the NHS and Rett UK has enabled us to develop important relationships with clinicians who are our medical advisors providing the specialist input so lacking amongst the general medical community.

Peer to peer support continues through our contact family network and families also get support from our professionally trained Family Support Team who are very knowledgeable about the condition. 'Regional Road Shows' are held all over the country, enabling families to meet together, to listen to doctors, therapists and other experts. In addition, there are one to one sessions with experts such as music therapists, physiotherapists, Eye-gaze

12 Regional Days

> *"Rett UK are a lifeline to us Rett Families. I don't know what I would have done without them. Following diagnosis they were there for us supporting and advising and helped greatly. Their ongoing support is so valuable. There is always a friendly, supportive, empathetic person at the end of the phone to listen and help no matter what you need. The regional days, family weekends and support groups help us to meet other families and would not happen without Rett UK. A huge thank you to you all."*
>
> Gwenda, Mum to Grace

Over **2,000** families supported

professionals giving further access to that specialist support which leads to better outcomes for the person with Rett syndrome and their family.

Technology has advanced the cause of both Rett UK and those with the disorder. We are now finding that although those with RTT have profound and multiple disabilities, they are increasingly able to use Eye-gaze Technology to help communication. This is an exciting development for the future. Facebook and Twitter have helped Rett UK to reach out to more people and keep them up to date with worldwide advances and research.

From the days when it was initially just girls who were thought to have Rett syndrome we now know that a very small number of boys are affected. As our children grow into adulthood we are very aware of different problems that they face. We are in a unique position of being able to share that experience and knowledge acquired over the last 30 years to help the significant number of people, both children and adults, who are yet to be diagnosed.

We were delighted this year to be able to share much of this experience in the Family Companion, a handy A5 size Filofax style file, which was funded by The Freemasons Grand Charity launched in October 2014.

> *"The best handbook... it has everything you need to know in there. If there is something you want to know and the info is not in there then you just have to email or call them and they will get it for you."*
>
> Parent of a Rett child

Cover images: Jessica Jaffa, Niamh Griffiths and Sarah Greenall; Top left Sienna Thomson, Christopher Dupree; Left: Lorna Jaffa; Right: Rosie McLoughlin; Overleaf: Becky Jenner

It contains a wealth of knowledge on all subjects related to RTT with articles written by doctors, therapists, researchers, teachers and other experts including our Family Support Team.

Other highlights this year have been our fundraising campaign 'To Know Her is To Love Her'. We were incredibly moved reading all the quotes from families and friends whose lives have been touched by knowing someone with Rett syndrome. We were very grateful to Coleen Rooney for sharing her thoughts about how her sister, Rosie, touched her life. Rosie sadly passed away in 2013 aged just 14. All of the quotes are testament to the endearing and captivating nature of those affected by the disorder – locking sufferers into a body that does not function properly but leaving them with the ability to light up a room with a smile or a look that says 'Hey I am here!'

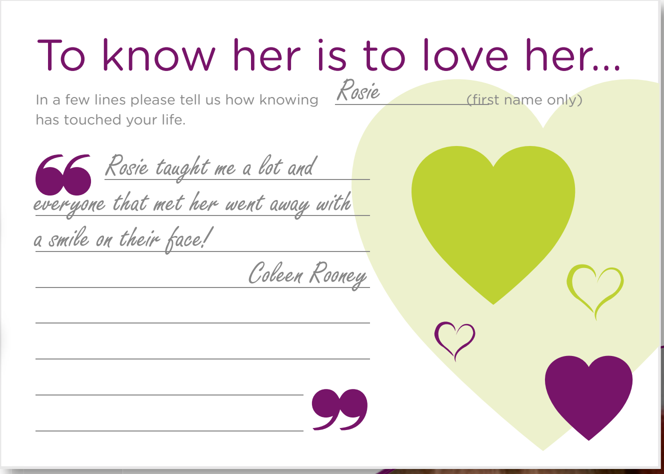
In addition, we were really pleased to announce an alliance with Reverse Rett in January 2015 outlining plans to work more collaboratively for the benefit of the Rett community. We look forward to making more strategic partnerships and alliances in the forthcoming year which strengthen our ability to further our aims and objectives and use valuable resources efficiently and effectively.

All of this work needs funding and we are enormously grateful to everyone whose incredible fundraising endeavours, in so many imaginative ways, progress our work. Our loyal supporters and community fundraisers who run, swim, jump and abseil and the Trusts, Grants and Companies who provide much needed funds for specific projects. We thank you all!

The future looks bright and we look forward with great enthusiasm!

Lorna

Lorna Jaffa



To know her is to love her...

In a few lines please tell us how knowing Rosie (first name only) has touched your life.

"Rosie taught me a lot and everyone that met her went away with a smile on their face!"

Coleen Rooney

2014/15 Annual Review

Over
500 families
and professionals who
are caring for someone
affected by
Rett syndrome
supported

Membership
rose to
1,385

"Exceptional support! I have phoned Rett UK numerous times and have always found the staff informative, professional, with the ability to empathise. I am always left with the feeling that I'm not alone in my struggle to secure the best for my daughter. Rett UK go above and beyond and I can't thank them enough!"

Joanna,
Mother of Keisha,
22 years old

Our TESS service (Telephone Electronic Support Services) delivered by our Family Support Team, remains the first port of call for those affected by this devastating disorder with more families making contact especially via social media in the first instance but then signing up to become members and accessing the full range of support services available. We have seen a significant increase in the demand for TESS, in the last year as a result of the changes in education, health and social care services, increased personalisation of support packages and cuts to local services. It is vital that we secure funding for this key element of our work as we look to the future.

Over
2,500
individual points of
contact with family
members via Tess –
An increase of **71%**
on the previous
year

These points of contact were through calls to our telephone helpline, via our support email, direct correspondence and increasingly via social media, such as Facebook and Twitter.

The intensity of the calls is varied from requests for information to seriously distressed families at point of new diagnosis or bereavement. Family Support Team members are highly skilled and trained to deal with any call they receive and are able to offer comfort, support, empathy, guidance, advice and information.

In addition, we have supported families through various different issues, concerns and problems including; challenging behaviour, bereavement, breathing irregularities, child protection, new diagnosis, health concerns, therapeutic interventions, nutrition, transitions, screaming & crying and scoliosis.

160
Professionals
trained, increase
of **213%** on
previous year

'So helpful, more so, reassuring . Of late I have spoken to these support workers many times and I don't think I would cope without them. Let's get lots of donations to keep these lovely ladies at the end of a phone.'

Susan, Mum to Lucy

12
families
supported
through
bereavement

I want to say a huge thank you to Rett UK for everything they have done for me this last month, I couldn't of got through it without you. I want to tell you how wonderful they are and I owe them everything!

Karina, Mother of Melody,
8 years old

19
families
supported
through new
diagnosis

385 people attended regional events

Complementing the work of TESS we went out to meet the families with 3 regional events during the year held in Leeds, Surrey and North London.

These are important opportunities for families to get together sharing mutual support as well as listening to high calibre presentations from our key advisors on specialist Rett areas which help in the care, management and understanding of this rare disorder.

Feedback from evaluations of these events shows their immense value.

83% of attendees say it enabled them to develop new friendships

88% experienced reduced feelings of isolation

88% increased their understanding of Rett syndrome

72% increased their confidence when it came to dealing with professionals

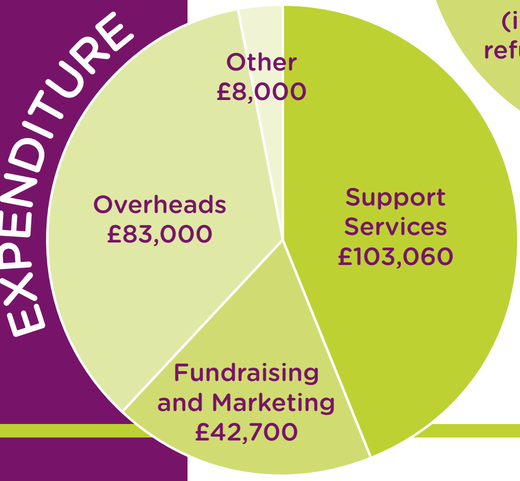
94% of attendees would want to attend future events

Total **EXPENDITURE** this year:

£236,760

(2013/14: £210,180)

This information is extracted from the full annual accounts which is available on our website **www.rettuk.org**



Looking to the Future

Rett UK now has a new CEO, Becky Jenner, who has over 12 years charity experience and she is also mum to Rosie, who has Rett syndrome bringing her personal experience to the role.

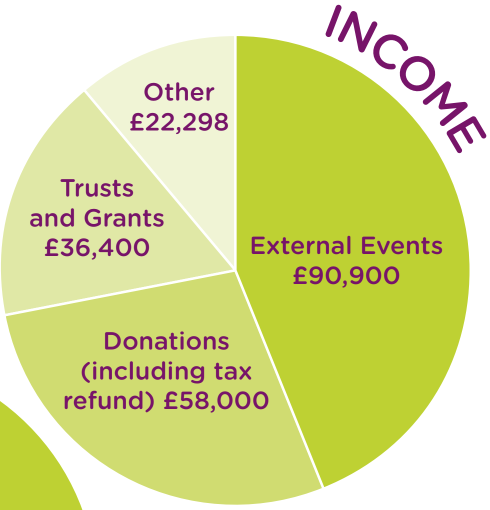
Becky joined in October 2014 and has been prioritising fundraising and whilst we finished the financial year on a deficit, every month since January 2014 we have shown a surplus so we look to the future with much more optimism.

Community fundraising is very strong following the February Appeal and we are applying to various trusts for grant funding to support our current work but also to enable us to develop some new areas highlighted in our business plan 2015/2018.

We were also delighted to be joined by a new office manager in July 2014, Donna Tinch, brings extensive office and business experience to the role. In 2015/16 we would like to recruit a part-time community fundraiser to strengthen the team still further.

Rett UK has exciting plans for 2015/18 including developing regional hubs engaging with local health, education and social services to improve local support for our families, introducing webinars hosted by our key advisors so we can reach more people in a cost effective way and in October 2015, we are celebrating 30 years of providing services to Rett families with our Family Weekend at the Hilton Hotel, Northampton.

Support today, hope for tomorrow.



Total **INCOME** this year:

£207,598

(2013/14: £197,153)

Our Supporters

Rett UK does not receive any government funding so relies heavily on our intrepid, creative and brave supporters who take on ever more challenging and arduous challenges to raise funds to help more families affected by Rett syndrome.

This year star fundraisers have who raised over £2,000 included:

- London Marathon Team 2014 – Lucy & Angela Duncan, Lyn Howie, Sharon Slade, Mark Taylor, Andrew Grigg, Fred Vasilev, Paul Grundy, Chris Lake, Judy Orme and Dominic Taylor-Jones
- P.J Livesey Group 3 Peaks Challenge
- Nadini Restaurant Curry Club organised by Jonathan Taylor
- Marshgate Mountaineers organised by Emma Alleyne
- Team Kathryn London 10K
- John and Lucy Wyatt's Golf Day
- David Crane
- Russell Moat & Detailing Addicts
- Philip Cuthbert
- David & Janine Durant
- Patricia & Adrian Orchard

Numerous people have supported Rett UK both individually and in teams. Thank you. Without you our work would not be possible and our families' calls for help would go unanswered.

Business Supporters

- Landsherriffs

Charitable Trusts

- BBC Children in Need
- St James Place Foundation
- The Bartle Family Trust
- Javon Charitable Trust
- Awards For All
- The Casey Trust
- David Solomon Charitable Trust

Above: Marshgate Mountaineers; Top right: P.J Livesey Group 3 Peaks Challenge

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