

**16th January 2015**

Reverse Rett and Rett UK have recently come together to establish new ways that the charities can work with and alongside each other in the best interests of individuals with Rett Syndrome and their families in the UK.

Rett Syndrome is a complex post natal neurological condition which first begins to show itself in previously healthy little girls some time before their second birthday. Girls typically lose the ability to speak and use their hands and over time, can lose the ability to walk as well. Many girls develop breathing difficulties and an array of eating and digestive problems. Seizures and orthopaedic problems requiring surgery are also common. The medical, educational and care complexities and the overall impact on the girl or woman who is affected and on everyone around her is immense.

Rett UK and Reverse Rett are the leading Rett charities in the UK. Rett UK primarily works to provide professional family support on a national level. Reverse Rett aggressively funds research to speed treatments and a cure for the condition. Whilst the work of each organisation is distinct, both organisations recognise that in the coming years, as improvements in management and potential new therapies and treatments emerge, there will be areas of mutual interest which could be addressed more effectively together, in order to best meet the needs of children and adults with Rett Syndrome in the UK.

Becky Jenner, CEO of Rett UK and Mum to Rosie age 19 who has the condition says:

*Rett UK very much welcomes the opportunity to work collaboratively with Reverse Rett to enhance the lives of those affected by Rett Syndrome in the UK and to give them hope for the future as new treatments and therapies emerge. I am confident families will welcome this initiative and the new opportunities that it may present.*

Rachael Bloom, Executive Director of Reverse Rett and mum to Amber age 19, who has the condition, says:

*We are moving into a new era of rett research; an era where we will see an increasing number of clinical trials and pilot studies of medications and procedures, which we hope will relieve symptoms in our children. Driving research from the lab into the homes and lives of our children is a gargantuan task. Reverse Rett welcomes the opportunity to collaborate with Rett UK on areas that will enable both organisations to help families get the treatment they need for the children they love.*

Rachael Bloom, Executive Director, Reverse Rett  
Becky Jenner, CEO, Rett UK



### About Reverse Rett

Reverse Rett works to speed treatments and a cure for Rett Syndrome and related *MECP2* disorders by funding research that will have a practical and positive impact on our children's lives, with a demonstrated track record, delivering over £2.5 million to research in the last five years. We fund research from basic science to clinical trials and work to facilitate the translation of this work into clinical applications for people with Rett Syndrome and related *MECP2* disorders.

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### About Rett UK

Founded in 1985, Rett UK provides professional support to families through a national helpline, including telephone and email support, co-ordinates Rett specialist clinics in conjunction with the NHS, organises support groups, regional family days and have a dedicated parental contact network. The recently launched Family Companion and Best Practice Guidelines for Professionals are seen as invaluable resources that bring together 30 years of experience in supporting people with Rett Syndrome.

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