

Charity Collection Submission – Reverse Rett

Dear Sir/Madam,

I am writing in response to your appeal for applications from charities for next season, in order to put forward our charity, Reverse Rett, registration no. 1136809.

We are a small charity working to fund scientific research to speed treatments and a cure for Rett Syndrome, a condition which affects 1 in 10,000 girls and combines the symptoms of autism, epilepsy, Cerebral Palsy, Parkinson's and anxiety disorders, all in one child.

In brief, Rett Syndrome is caused by a spontaneous mutation which occurs before birth, but the symptoms generally do not become apparent until the child reaches around 18 months of age. At this stage, development slows down and a period of regression begins, where the child will lose the skills she has already acquired. This will include losing speech, mobility and purposeful hand function.

As time goes on, children with Rett will develop further symptoms including respiratory difficulties, swallowing and feeding difficulties, anxiety issues, behavioural problems, sleep disturbance, scoliosis and seizures. Skills continue to be lost so that most girls with Rett lose all mobility, all speech, all hand function, and are entirely dependent on others for all their basic needs throughout their lives.

When my own daughter, Hannah, was diagnosed with Rett Syndrome in 2010, there was no hope of treatments or a cure and her future looked bleak. But we discovered that in 2007, Rett Syndrome had in fact been reversed in the lab, and shortly after Hannah's diagnosis, Reverse Rett was founded, with the aim of working to speed treatments and a cure, and to translate that breakthrough reversal from animals to humans.

Since then, we have delivered over \$5 million to research and have significantly impacted the scientific landscape so that treatments and a cure are now on the horizon for our girls. Last year, we funded the first ever clinical trial in the UK which is currently running to help alleviate girls' respiratory difficulties (the leading cause of fatalities in girls with Rett), and a gene therapy clinical trial is on the horizon for 2019, representing our best hope for a full reversal. We fund research internationally and have created collaboration between labs across the world so that findings are shared and progress is faster.

In addition, we provide support to newly diagnosed families through our Parent to Parent mentoring scheme, which aims to help and guide parents of newly diagnosed girls through the challenging, lonely and terrifying early days following that diagnosis.

We are based in Manchester but I personally work in Sutton and cover our events and fundraising in the south. We are only a 4 person team (three of whom have children with Rett) and all the money we raise comes from dedicated families and friends of girls with Rett who are committed to changing their futures.

We welcome every opportunity to raise both awareness and funding - Rett Syndrome is the leading cause of profound disability amongst females and can happen to any family, and yet is very little known about. Reaching a new audience and community is invaluable to us and we will take on any challenge presented if it enables us to do this.

For further information about Rett Syndrome or the work we do please do visit our website at www.reverserett.org.uk or feel free to contact me either at this email address or on 07758219673.

Many thanks for your time, I very much hope to hear from you within the future.