

## There are lots of ways you can help

Please contact us if you are interested in becoming a member or maybe you would like to be a Rett Champion. Our website gives details of fundraising events held throughout the year.

- With £5 you could help distribute our National Best Practice guidelines
- With £10 you help a parent access that vital telephone support
- With £20 you can buy one hour of support for a newly diagnosed family

*“When we had our diagnosis within about a week I picked up the telephone and spoke to one of the Family Support Workers. Even though it was a very distressing call to make, it was pivotal in helping us come to terms with everything. It's great to know someone is there to help.”*

Fundraising packs are available from the office please give us a call or email us to request one.

### Contact information

Enquiries – 01582 798910 – [info@rettuk.org](mailto:info@rettuk.org)

Follow us on Twitter - @RettUK

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## Rett Syndrome

- What is it?
- What it means for families
- How you can help



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Imagine being told your toddler you thought was healthy but perhaps slow to progress, in fact had a rare and devastating disability called Rett syndrome. A disability so complex it would leave them needing lifelong 24/7 care. These are the families Rett UK supports and where your donation is life changing.



Rett children appear to be born perfectly normal but by 18 months they start to regress.

They lose hand function, can no longer hold toys or feed themselves. By age three they could start having seizures, stop talking, walking and steadily their spine could start to curve.



Rett syndrome is the most common genetic cause of severe disability in females and less commonly in males, yet very few people have ever heard of it.

People with Rett syndrome have profound and multiple physical and learning disabilities and are totally reliant on others for support throughout their lives.

## How Rett UK helps

- Established in 1985, Rett UK is a parent led charity dedicated to making a real, positive and lasting difference to people living with Rett syndrome. We provide professional support services for families, carers and professionals.
- Our aims are:
  - To support families and carers and ensure that all people with Rett syndrome have access to best practice in diagnosis, treatment and care.
  - To promote, support and encourage research into the genetic, therapeutic and social aspects of Rett syndrome – and towards an eventual cure.
  - To increase the awareness of Rett syndrome and the issues facing all people with Rett syndrome, their families and their carers.



## Making a difference

The intensity of the calls that come in to the office is quite incredible and our family support team have a wealth of knowledge, experience and empathy which is put to good use daily.

This quote from a mum is typical of the feedback we get:

***“I would like to state that without the help of Rett UK I would have been left without a voice, without support, without a friendly ear to listen and understand how desperately worried I am about my daughter. I simply cannot express how invaluable the help and advice is ....helping my daughter and I in the here and now. Without their input we would be lost and very alone on a road that was cold, harsh and very frightening.”***

With your help Rett UK makes the lives of those affected by this devastating disorder more bearable and gives them hope for the future. A cure is a possibility but for over 3,000 families in the UK affected by Rett Syndrome the daily challenges are a reality. Access to the right information, therapies and treatments is not just helpful, but in the case of Rett syndrome it can be a life saver.