Rett News

Support today, hope for tomorrow

www.rettuk.org
issue: two/2020

35 YEARS
1985 2020

Rett UK
Small charity. Huge impact

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RETT SYNDROME
AWARENESS MONTH
October 2020
RettUK.org

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Rett syndrome (RTT) is a rare neurological disorder and is the most common genetic cause of severe disability in females, yet very few people have ever heard of it. Although rare, males can have Rett syndrome too. It is present from conception and usually remains undetected until major regression occurs at around one year of age, when children may lose acquired skills and become withdrawn. Genetic but largely not inherited, Rett syndrome is usually caused by a fault on a gene called MECP2 which is found on the X chromosome. People with Rett syndrome have profound and multiple physical and communication disabilities and are totally reliant on others for support 24/7 throughout their lives.

Rett News Contents

Front cover image: Jude Drinkwater

Welcome to Our Summer Newsletter

RETT SYNDROME
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Here we are in August, still working from home and things are still quite tricky for our families I know. The recommendation for high risk groups is that they can ‘pause’ shielding now but just the word ‘pause’ makes us all nervous about what is around the corner.

For that reason, we are very much committed to continuing with our support online; new webinars, coffee & chats, wine & whinges are being added regularly to our calendar. Please keep an eye on our social media platforms, the website and your email inbox to make sure you don’t miss these support events. Just a note on emails – if you are not seeing them please check your spam inbox as we know some will end up there until you ‘whitelist’ the Rett UK email address.

In this *Rett News* we have an excellent article on breathing dysfunction written by Dr Ana Abdala and Dr Adrian Kendrick, a topic which is complex and misunderstood by general health professionals. We reproduce a really interesting interview with Dr Adrian Bird who recently won the prestigious Brain Prize alongside Dr Huda Zoghbi. Also in family support, we look at what council tax reductions you may be eligible for, we have our annual survey we would really appreciate you completing please and some fab updates from the communication team including the publication of the communication guidelines for individuals with Rett syndrome.

Back in April we launched our COVID-19 Survival Fund. Huge thanks to everyone who has donated, bought something in our online auction or raffle tickets! We have raised over £32,000 which significantly helped us in the first quarter of what is going to be a very tough year. We have had some grant successes too but are waiting to hear on a bigger one from the lottery as this goes to press. Fingers crossed! But be reassured we are very much still here for you and have every intention of continuing to be.

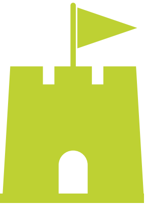
In fundraising we thank the amazing people who have continued to step up and support us. We are always bowled over by the lengths people go to! We bring you ideas about how you can get involved in if you would like to; October Awareness and The Big Give Christmas Challenge are still very much on the agenda despite the pandemic. This year our project for the Big Give is all about supporting our families’ mental health, well-being and relationships. We know how incredibly stressful this has been for our families and the toll it has taken on everyone. You can read more about this work on page 40.

We are still running our extended helpline hours so please do not struggle on alone and get in touch. This is your charity and we are here for you.

Stay well and stay safe. I hope you get a lot from your latest copy of your *Rett News*.

Best wishes,

Becky Jenner, CEO



Rett UK AGM 2020 and We are Recruiting New Trustees!

Save the date!

Rett UK Annual General Meeting

Saturday 26 September 2020

This year the Rett UK Annual General Meeting will be held on Saturday 26th September 2020 online using Zoom.

As usual we will send out the voting papers at least 21 days before the meeting. We shall do this around the 1st September. We will use email where we have email addresses but post for anyone who we do not currently hold an email address for or those that have expressed preference to receive our communications via the post. We will need these returned by Saturday 12th September.

You are very welcome to join us during the AGM which will be between 12.30pm and 1pm using the Zoom link which you will find on both the voting papers and the Agenda. You can also go to our website, 'About Us' page, where you will find digital versions of the forms, along with the accounts for the year ending 31st March 2020. You can then open the papers and click on the Zoom link to join the meeting. Alternatively, if you have a question you would like to put to the trustees you can call Becky Jenner on **07557 850 024** between 12.30pm and 1pm to speak to the board members.

Rett UK exists for your benefit. We very much value your input and welcome you to join us on 26th September so you can be involved.

Become a Rett UK Trustee

Perhaps you would like to become a trustee of Rett UK? We are currently recruiting new trustees who can bring a range of skills and experience to the board which oversees the business of the charity. You do not need to be a parent, any family member, friend or associate can be a trustee. Rett syndrome affects all ethnicities, cultures and backgrounds equally. We want our board to be representative of our members so we actively encourage diversity amongst board members. For an informal chat about the role please email **chairoftrustees@rettuk.org**. Then, if you would like to apply for the role we ask you to complete an application form, we will need to take up two references and complete a DBS check. We have a comprehensive induction pack and you would be assigned a buddy to help you get familiar with the role.

The trustee board normally meets four times a year on a Saturday for four hours. This may be in person or online using Zoom. If in person, the meetings are normally in London. Reasonable travel expenses are paid and lunch is provided.

Outside of the main board meetings you may meet with colleagues as part of a sub-committee; either finance, management, fundraising or policies and procedures. These are always held online, normally for about an hour.

Please get in touch if you would like to find out more about this interesting and rewarding role. We would love to hear from you!

Support During the COVID-19 Outbreak

by Julie Benson

Rett UK Support Services During the COVID-19 Outbreak

We will continue to keep you up to date with the coronavirus situation, the impact on our community, what people can do to help their loved ones, latest government advice etc.

We have pulled all the information in to one area of the website. **https://www.rettuk.org/covid19/**

Please look out for more information about how Rett UK is adapting to the COVID-19 crisis to provide the best possible support we can for our families. We are developing more web-based resources that families can access for free to support with communication and education during the school holidays as well as other useful resources and links that will help families through this period.

Rett UK is here to support you.

The Rett UK team will do everything we can to support our families through this very difficult period. Please do not struggle on alone if you need someone to talk things through with. Please do call us.

If you have any questions about any of these events, please call Julie on 01582 798 911 or email support@rettuk.org

Calibre audio

Calibre Audio is a national charity lending free audiobooks for anyone who is print disabled. Calibre Audio is free to join for everyone who has a print disability, they do all ages including children's books.

Their digital library service includes unlimited borrowing of over 11,500 unabridged audiobooks.

https://www.calibre.org.uk/

They add more than 700 new books each year.

- Over 3,000 audiobooks specifically for children and young people
- Calibre has the rights to record audiobooks that are not commercially available
- Available on streaming, download, memory stick and MP3 CD
- Free postage and no fines for late or lost audiobooks
- Manage your account online or by phone
- Regular podcasts, newsletters and reading suggestions
- A friendly, personal, quick service

UPDATE ON OUR COVID-19 SURVIVAL FUND AND THE FUTURE OF RETT UK

At the beginning of April we launched our COVID-19 Survival Fund to help fill some the holes in our income from lost community fundraising and our fundraising events we had planned for this, including the Spring Fair and In Conversation with Dame Evelyn Glennie.

You responded magnificently not only with very generous donations but lovely comments which really buoyed the team who were all feeling rather desperate about the prospect of not being here when our families needed us more than ever.

Here are just a few of your lovely comments:

> *“So important your services are maintained for the benefit my daughter and all Rett sufferers. Very best wishes.”*
>
> *“A vital lifeline and support for families with Rett daughters.”*
>
> *“Great little charity offering excellent help and advice.”*
>
> *“For mine and everyone else’s daughters. Without Rett UK my daughter wouldn’t have a voice, xx”*

We are delighted to say that at the end of June the appeal has raised over £31,000! This includes £2,000 raised from the auction. Many thanks to Vivianne Vayssieres, our Head of Fundraising who did such sterling work getting the auction prizes.

Thank you so much for your support; we are indebted to you.

Our online raffle is now live with some great prizes to be won. All proceeds will be added to the appeal.

So where does that leave Rett UK now?

At the moment we are holding our own and some successful grant applications from The Steel Charitable Trust and The Masonic Charitable Foundation have certainly helped that. We have at last been able to apply for some emergency government funding via The National Lottery Community Foundation. Many thanks to everyone who shared our open letter to Rishi Sunak, Chancellor of the Exchequer, engaging your local MPs to bring it to his attention that the small and medium size charities, like Rett UK, that were supporting the most vulnerable people in respect of Coronavirus were being overlooked and in real danger of folding unless some support is available for them. We have applied for £90,000 and should find out in July whether we have been successful or not. To say everything is crossed would be an understatement!

As part of our drive to keep going in these challenging times we have had to make some changes to the office team. At the beginning of April we furloughed two members of staff, Rob (Deputy CEO) and Donna (Office Manager) leaving Becky, Julie, Gill and Abigail to continue with the core family support services. Donna and Rob will be returning part-time in August and September, full-time again from October. We also had to say a very sad 'Au Revoir' to Viv our Head of Fundraising as her focus was the event fundraising which we have had to cancel for the foreseeable future. We did manage to secure a 50% rent reduction on the office for six months which has been helpful and we are very grateful to Jonathan Schuman, our landlord for agreeing this.

Due to the uncertainty around COVID-19 and the vulnerability of our families we have decided not to run any face to face family support or fundraising events until at least 21st April. We know this will come as a blow but we have to put safety first. Events also take time to plan and incur costs which are not always recoverable if cancelled.

So, we are continuing with our extended helpline hours, we will do more formal webinars and informal zoom sessions. The communication workshops we were going to deliver this year and some elements of the regional roadshows we are putting online. The results of the Family Support Evaluation Survey is also giving us some pointers as to the topics you would like covered but please complete the survey is you have not already done so: **https://www.surveymonkey.co.uk/r/SupportServicesJune20**

Paper copies can be requested by emailing **support@rettuk.org**

Perhaps you have other ideas about how Rett UK can support you and your family during these uncertain times. Please email **becky.jenner@rettuk.org** or call **01582 798 910** if you have, I would love to hear them!

Support Round Up

by Julie Benson

Improving knowledge and understanding of Rett syndrome

Well, what difficult times we have all been facing, with having to shield, self-isolate, social distance and work from home. All very significant changes to our lives, some for the better and others more challenging. Thank goodness for some good weather which I am sure has helped!

At Rett UK we are so disappointed that we have had to take the decision to cancel all our Regional Events for 2020 due to coronavirus (COVID-19).

As many of you who will have attended these events remember, they are a great opportunity to meet other families, listen to some expert presentations, by such dedicated professionals who give their time to these events and Rett UK freely, to ensure families have the most up to date information about conditions that may impact on their daughter/son's quality of life.

The opportunity to have a short one to one session with these professionals is also valued and appreciated by all those who choose this option.

The day is busy with lots of activities, including entertainment for people with Rett syndrome and their siblings, activities such as petting zoos, bubble artists and face painters. The end of the day is always marked by an activity for everyone, which brings the event to a nice close and with everyone together.

We are hoping to reschedule these events in the future, whilst taking on Government guidance on gatherings and protecting those who may be deemed 'extremely vulnerable'.

To ensure we stay connected and continue to support families through lockdown, we are turning to online events and webinars. These events have included discussions with professionals, family support and communication events. Many of these have been recorded so if you did miss them you will be able to view via the links on our website: **https://www.rettuk.org/webinars/**

We are also holding more informal zoom communication and support meetings, which you can find on our events page of the website and are posted regularly on our social media channels: **https://www.rettuk.org/how-we-can-support-you/events/** or **https://www.facebook.com/RettUK/**

We totally appreciate that this move to more online contact is not everyone's cup of tea, and we are looking at how we can engage more effectively with families who do not use technology to ensure they are not left feeling isolated and forgotten.

PLEASE COMPLETE OUR SURVEY

Rett UK is undertaking a short survey, which looks at how we can shape our services in the future to meet the needs of ALL of our families.

Please if you are able, complete this either online via the link **https://www.surveymonkey.co.uk/r/SupportServicesJune20** or fill in the paper survey included with your *Rett News.* More details on page 58.

Thank you.

Connecting families – reducing isolation

Support Groups

Rett syndrome is such a rare disorder it can leave you feeling terribly isolated. You may be desperate to be near someone who understands what's happening and who is experiencing the same roller coaster of emotions you're going through.

Our local support groups can help. They've been set up so parents like you can meet other parents who understand what you're dealing with. The groups are an empathetic space where you can share tips, strategies and support as well as organise informal social events.

We currently have support groups in Bristol, Essex, Kent and North London. If you'd like to set up your own local support group, we can help you get started.

For more information contact **support@rettuk.org**

Extended Rett UK Helpline Hours During the COVID-19 Outbreak

We know what a difficult and stressful time this is for our families.

We have always stressed we are here for you and you should not ever feel you are doing this alone. Whilst we cannot be there to help with practical issues, we can be contacted either by telephone, email and Facebook. Having someone to talk your concerns through with can be very helpful.

With immediate effect we are extending our helpline hours to seven days a week from 9am to 10pm.

Becky Jenner, CEO and parent to Rosie, age 25 who has Rett syndrome, and Julie Benson, Family Support Manager with over 7 years' experience at Rett UK, will be available during these hours.

For all your support questions and concerns, please call:

9am - 10pm

07557 850 025

- *Mondays*
- *Wednesdays*
- *Sundays*

9am - 10pm

07557 850 024

- *Tuesdays*
- *Thursdays*
- *Fridays*
- *Saturdays*

You can also email

support@rettuk.org

or send us a message through our Facebook page.

THE VOICES OF RETT

RETT SYNDROME BURDEN OF ILLNESS SURVEY

THANK YOU FOR LENDING US YOUR VOICE!

We hope this finds you and your family well during these trying times for everyone as we battle the coronavirus. We also recognise that learning the Sarizotan trial was terminated has been especially hard to hear.

We at Newron Pharmaceuticals want to take a moment to thank you for your participation in the Rett Syndrome Burden of Illness Survey. We received a very positive response from caregivers in the UK with 98 families participating. Please know that your participation and responses will be integrated together with nearly 750 participants from across the UK, Italy, Germany, U.S. and Australia. Your robust input to the survey will be your voice and will help deliver a critical family-centric perspective to be used in support of the Rett community. Please be assured that despite the clinical trial being terminated, Newron remains committed to ensuring that the valuable data from this survey is made available to the international Rett community.

The data will be used to raise awareness of Rett syndrome, underscoring the diversity of families across a spectrum of patient ages, and length of time since diagnosis. It covers a broad range of experiences with the management and treatment of Rett patients, and the physical, emotional, and social toll of Rett syndrome on families and caregivers.

This information will provide objective data to support accessing government financial services not presently available for this diagnosis. It provides a broad international picture of the social and economic impact of Rett syndrome that will enable regulators, payers and other decision makers to more fully understand the burden of the disease.

Once all of these data have been collected, they will be analysed and published. Thereafter, Rett organisations will help disseminate the results. The information you have provided supports the great unmet need for better treatments and services for our loved ones with Rett syndrome.

It is our sincere hope that you and your nearest and dearest are remaining safe and healthy during this challenging time.

Again, thank you for lending us your voice!

Newron Pharmaceuticals

Coping with Lockdown and Children with SEND

by Dee Cowburn

Dee Cowburn, mum to Tilly who was diagnosed with Rett Syndrome in 2018 shared her experience of the COVID-19 lockdown with News Week. Dee said she was left on the point of burnout and had found the lockdown 'traumatic' as the support for her three-year-old daughter, had suddenly stopped which left Dee feeling like she had 'fallen off a cliff edge' as lockdown measures were imposed.

Charities told MPs on the Education Select Committee that parents of children with SEND (special educational needs disabilities) felt 'utterly abandoned' due to the lack of support available, with some schools in England using COVID-19 risk assessments to prevent pupils from attending classes.

Dee says that the experience of her and her partner having to provide support for her daughter, who requires 24-hour care, has been relentless without any let-up and has left them worn out.

She said: "It's really challenging having a child who needs 24/7 care and you get on with it because it's your child and it's unconditional love and of course you do, but you don't have the respite in the form of when she goes to nursery. It gives you a sense of normality that you can keep, and you've got a really tight support team wrapped around you: an occupational therapist, speech therapist, physiotherapist, she would have a physio at nursery, she would have one-to-one three days a week at nursery, all of that suddenly stopped. Before the lockdown, Tilly would be given 30 hours of education at a nursery, where she would also receive one-to-one support, funded by the local council, giving her parents crucial respite while also allowing the more time with her five-year-old sister."

Dee describes an entire system of interventions involving several therapists and a physio that was so crucial to her daughter's care and development, which were suddenly stopped, leaving her and her partner on their own.

The full story can be read here: **https://www.newsweek.com/special-educational-needs-disabilities-send-lockdown-children-parents-1515875?fbclid=IwAR1SDH1MsZv5_**

Thank you to Dee for sharing her story and highlighting the difficulties of lockdown for parents who have a child with SEND.

Tilly and Dee

Our Experience of COVID-19 and Rett Syndrome

by Val and Rod Dawson

Val, Rod and Belinda

Our daughter, Belinda, is 37 years old and has Rett syndrome.

Belinda lived at home with us, mum, dad and older brother Jim, until she was 20. The transition from children's services to adult provision was tough but we secured a day placement at a local day centre that she'd been attending from school and began to look for a residential placement for her as her medical and physical needs grew. We were extremely lucky to find such a residential home about 17 miles from our home. Belinda had the best of both worlds. It was an extremely difficult decision to make but it was the right decision for all of us. To say she is happy is an understatement. Belinda thrived in her new environment, she was able to see all her friends from school at the day centre 3 days a week and lived in a fantastic home so close to us. They are both amazing and are totally committed to meeting her constantly changing needs and have done so over the last 17 years.

Then COVID-19 arrived in Belinda's home! After going into lockdown from early March it was devastating news for us as the staff had taken every precaution they could. Temperatures of every resident was taken every day to be able to identify anyone under the weather especially if they were not able to verbally say they felt unwell. From that moment we were only able to see her through the window, which was extremely hard on us and her and we were not able to take her out as we usually did.

The dreaded phone call came on 17th May to tell us Belinda had woken that morning with very sore eyes, and they thought she had started with Conjunctivitis and suspected she had a sore throat. Isolated immediately in her room, Belinda then had a COVID-19 test that came back 2 days later as positive. It was a very worrying time but at no time did Belinda have a high temperature or cough or any breathing problems. Staff told me how happy and chilled she was listening to music and watching TV in her room. She initially found it intriguing that people were coming into her room wearing full PPE that she just didn't seem to notice it at all they said. As time went on and still testing positive 2 weeks later, I think we were all feeling the strain. Staff were telling us she was fine but we were desperate to see her and Belinda was becoming withdrawn and not eating very much.

Finally, after getting the all clear 3 weeks after becoming unwell we were able to see her through the window again and we've been able to see her outside in a Marquee since the 9th July. She was so excited to see us laughing and bouncing around in her wheelchair. She's just fine now, eating well and putting some weight back on, she lost a few pounds, but at the end of the day she came through it having only suffered mild symptoms she was very lucky.

We can't thank all the staff enough as up to press 12 residents have had the virus and 15 staff. Everyone has made a full recovery with only 3 residents having to go to hospital for a few days. Many residents and staff testing positive were asymptomatic and that is one of the issues that we all face.

HAPPY BIRTHDAY CLARE MILNE!

Clare Milne recently celebrated her 40th birthday. Here, her close friend and massage therapist for 14 years, Emily Papirnik has written her a special birthday poem.

Dear Clare

Thank you for being you

Thank you for being the person who has taught me how to communicate

And how important nonverbal communication is

Thank you for being the person who brightens up my day, with that twinkle in your eyes

Thank you for being that person who has shown me how important it is to be the best of me in every moment

Thank you for being that person who has taught me how important it is how we treat each other

Thank you for being that person who has shown me how invaluable massage is and the comfort it can bring

Thank you for being that person who has taught me so much about being considerate to others

Thank you for being that person who has made me see how important it is to really value everyone for their individuality

Thank you for showing me how to notice what people are saying in their eyes rather than concentrating on what is coming out of their mouths

Thank you for being that person who has made me look within myself enabling me to learn so much about myself

Thank you for being my first regular client fourteen years ago

Thank you for giving me so much confidence

Thank you for being the wonderful you that you are!

Happy Birthday beautiful one!

NEW!

RETT NEWS

NOTICE BOARD

Rett News is read online and in print throughout the UK by some 3,500 people. We are now offering space for readers to advertise items for sale.

Please provide a good description of the item you are selling, photo, price, location, contact details, collection and delivery or postage cost. Payment by BACS, prior to printing deadline.

Advertising rates

Families: Half page: £10; Full page: £20

Businesses: Half page: £100; Full page: £200*

*If you would like us to typeset your advertisement, please contact Viv for details

Interested in advertising with us?

Email: **info@rettuk.org**

Tel: **01582 798 910**

For corporate advertising, please contact Viv

Tel: **07929 355 541**

Email: **viv@paulerochelle.co.uk**

Rett News Advertising Terms & Conditions

All contents of advertisements are subject to the Editor's approval.

Rett News shall not be liable for any aspect of postage or delivery including and without exclusion indirect, special or consequential loss or damages arising from any postage, or delivery.

Rett News shall not be liable for any incorrect or inaccurate description in the advertisement.

VeloPlus Wheelchair Transport Bike

FOR SALE

The nearly new (hardly used) VeloPlus Wheelchair Transport Bike (donated by David Cuming Ashfield Special Needs Technical Director) did not reach its reserve price at the auction so is now for sale with most of the proceeds to Rett UK.

Description: VeloPlus Wheelchair bike without power assistance. Preowned.

Website: www.ashfieldspecialneeds.co.uk

Donated by: Ashfield Special Needs Ltd

Unique feature: The VeloPlus is designed for transporting people by bike without them having to leave their own wheelchair. Suitable for any wheelchair up to 74cm in width. With tilting ramp.

Price: £1,500 **Value:** £2,500 preowned. New from £4,595

Transport/Collection: Location of bike: Cambridgeshire. Delivery and training by Ashfield Special Needs Ltd free of charge (depending on area), otherwise by courier – costs apply.

Interested? Please contact Viv on **07929 355 541** Email: **viv@paulerochelle.co.uk**

SIGN UP FOR OUR MONTHLY E-NEWSLETTER

Keep up-to-date with the latest research news from around the world

Subscribe free to our monthly E-Newsletter via our website and direct to your inbox when it is published.

Full of information on support, fundraising and events that might be of interest, we hope that the E-Newsletter will be a good way for you to remain up-to-date.

Information will have hypertext links through which you can find out more or read the full content.

As with all our services, we welcome feedback and any ideas you have for future issues.

Sign up at **www.rettuk.org**

Council Tax Reduction

Did You Know that... you could get a significant reduction in your Council Tax bill simply by the nature of how you use a room? And it is not means-tested?

Some of us are still in lockdown in our homes, staring at four walls. However, those four walls may entitle you to a chunk off your Council Tax bill!

It is not means-tested, so available to those who are prevented from claiming Council Tax support and is very sensitive to individual personal circumstances.

Disability reduction – what is it?

The Disability Reduction Scheme applies if:

- Someone (adult or child) has a 'permanent and substantial disability'

  and
- There is a room (not a bathroom, kitchen or toilet) which is predominantly used by the disabled person

  and
- The room is of essential or major importance to the disabled person in view of the nature and extent of her/his disability.

It must not be a bathroom, kitchen or toilet. These are covered by other routes to be mentioned in the next edition.

So, if there is a disabled adult or child who has a room that helps with their physical or mental wellbeing, this may be eligible. As is normal in ordinary homes, the room could be used by everyone else: it's not about the exclusive use by the disabled person but they use it mostly.

Some real examples include:

- Using a room as a study, allowing a disabled person to work at home
- A conservatory which brings the garden into the home of a 'housebound' person who loves gardening
- Using a small back room for physical therapy
- A small cupboard-size room to store equipment such as oxygen cylinders
- A box room used as a 'play' room for a 19-year-old person with a learning disability
- Adaptations to a kitchen for someone with sight impairment

There are lots of other examples, arising from individual needs.

If there has been an adaption, such as converting a garage to a sensory room, that clearly meets the definition – BUT the use of the room can be much less dramatic – nothing needs to have been knocked down or altered to pass the 'test'.

Each disabled person may have very individual requirements, and live in differently set-up homes, but if you can link the need for the room with the needs of the disabled adult or child, give it a go.

What do I get?

Your Council Tax bill will be charged at the Band below the one it is registered at. If you are already on Band A you will only be charged a percentage of that.

Note: If your council tax is already fully rebated, such as via a qualifying DWP benefit, there is no need to apply for this.

However, if you are not eligible to council tax support, for example if you have too much capital, this could be worth going for. Those on higher council tax bands will proportionately gain more.

How to claim

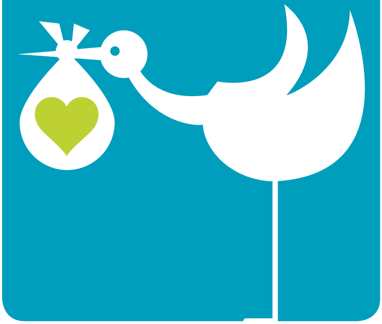
Each district, borough or city council will have their own application form – check their website. A visit to the property may be required.

And make sure you ask for it to be backdated – this is about the only bit of the benefit system where a claim can be backdated for as long as the rules are met!

Thank you to Stephen Watkins at the Benefit Boat for allowing us to share this information. **www.benefitboat.com**

IT'S A BOY!

Congratulations to Trustee Celia Carter and her husband Joe on the safe arrival of their beautiful baby boy, Laurie. Both mum and baby are doing well and Celia and Joe are already totally in love!



Information We Request About People with Rett Syndrome

Why does Rett UK ask for information about the person you support with Rett syndrome, such as their date of birth, diagnosis – clinical or genetic and other information considered personal?

Rett UK have, since it started 35 years ago, sent birthday cards to everyone with Rett syndrome, where we have known the date of birth. Making these special when there is a milestone birthday, such as 18, 21, and beyond, the oldest person we know is 72!

In addition, possibly more importantly, when we are approached by scientists/clinicians who are looking into the viability of undertaking any clinical trials, we are often given criteria by which people with Rett syndrome will be eligible to take part, this often includes age.

If your daughter/son does not receive birthday greetings from us, this is probably because we don't have their date of birth, please contact us on **01582 798 911** to update us with this information.

When speaking to you on the telephone we may ask you for your daughter/son's date of birth if we do not already have it, as part of ensuring the data we hold is accurate and up to date.

If you would prefer not to share this information, please just let us know – we will fully respect your decision.

Deputyship and The Court of Protection

Andy Riddle is the Managing Director of Professional Deputies – a specialist Court of Protection firm that focus primarily on managing the affairs of vulnerable adults.

Here he answers some of the more common questions that parents of a child with Rett syndrome may have.

What happens when my child turns 18?

The assumption of the Mental Capacity Act 2005 is that at the age of 18 everyone has the full capacity to run their own affairs and can make their own decisions. In situations where this is not the case, parents are able to seek a Deputyship Order. A Deputyship in the Court of Protection over both finances and health and welfare gives parents the same rights post-18 as they had (prior to the young person who does not have capacity) becoming 18 to manage their affairs.

How can I as a parent ensure I still have a say in decisions that affect my child's health and welfare?

Most of our work so far has focused on the health and welfare side of matters, where a number of parents have not been aware of the fact that once their child attains the age of 18, they no longer have the legal authority to make informed decisions when it comes to their child's health and welfare without a Health & Welfare deputyship order in place. This understandably comes as a major shock to parents who have raised their child since birth dealing with the daily difficulties of a child who may have Rett syndrome.

What is the Court of Protection and the role of a deputy?

The Court of Protection is a superior court of record created under the Mental Capacity Act 2005. It has jurisdiction over the property and financial affairs and health and welfare of people who lack mental capacity to make decisions for themselves.

The role of a Health & Welfare deputy may involve the deputy for example making decisions on some of the following aspects for the person who cannot make them for themself:

- With whom and where the person should reside
- Decisions on day-to-day care, including diet and dress
- Consenting to and refusing consent to medical and/or dental examination and treatment
- Making arrangement for the provision of care services
- Whether the person should take part in particular leisure or social activities
- Complaints about the person's care or treatment

When should I start to consider an application to the Court of Protection?

The process of applying for deputyship takes some months to work through the Court of Protection. An early application when the young person is nearing the age of 18 is therefore advisable before problems with Adult Social Care, the NHS, medical professionals or care settings may arise.

Andy possesses over twenty years of experience, working within the field around managing vulnerable client's affairs. Ten of those were spent advising numerous local authorities throughout the UK on these services, while 2011 saw him set up his own firm – Professional Deputies.

He is someone who has a healthy passion for the Adult Social Care sector, and who believes passionately in the rights of those who are suffering from some form of mental incapacity.

Professional Deputies have been working closely with Rett UK for some time now, assisting a number of families with applications to the Court of Protection where they are looking to become either the Health & Welfare Deputy, Property & Financial Affairs Deputy or both for their child.

In looking to continue our support of Rett UK (especially in the current climate) Professional Deputies will look to donate £200.00 (for each application) to the charity for every referral they receive from families associated with Rett UK.

Andy Riddle

For further information, contact Andy by phone **020 3011 5586**, email **andy@deputyship.co.uk**
www.deputyship.co.uk

HEALTH CHECKLIST

Many thanks to everyone who has contributed to this important document and to The Bolland Charitable Fund for their support.

Download your copy from:
www.rettuk.org/healthchecklist

Alternatively, we do have a limited number printed. Please call **01582 798 910** if you would like us to post a copy to you.

Rett Disorders Alliance UK
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Rett Disorders Alliance UK
RETT UK • REVERSE RETT • FOXG1 UK

Understanding Rett Disorder

by Dr Alison Kerr MBChB DCH MRCP FRCP MD OBE

Dr Alison Kerr

Looking back and looking ahead

Long after retirement, my husband's death and my move to Edinburgh, I'm happy to be asked to write for Rett families and helpers, recalling the past research and thinking ahead.

It was when Andreas Rett watched two mothers waiting together at his clinic with similar, pretty girls whose hands were being held still by their parents, that he turned to his clinic assistant 'we have seen other girls like this haven't we?' and his assistant produced a list.

Andreas investigated intensively and then presented what he had found at a European neurology conference, that included John Stephenson, senior paediatric neurologist at Glasgow Children's hospital, who had also seen such girls. When John knew that I was ready to begin a new research project, he suggested Rett syndrome and I invited a series of these children, one at a time, with the families to the hospital, recording their stories from the first days of life. Thus, with families directly involved, the complete sequence of events became clear.

Following the USA example, the Scottish and UK Rett Associations invited Andreas Rett to Glasgow, with the British Rett girls, families and paediatricians, to listen, look and discuss the disorder. This pattern developed world-wide, encouraged by the Associations, bringing the girls, families and a full range of medical specialists together, frequently planning such a Rett gathering linked to a routine international medical conference.

Thus, watching the girls with Rett disorder became the key to progress in solving the problems for these girls and their families, with the Associations inviting experts in every health and brain related field together, to watch and carefully consider what goes wrong in this brain, in which so much is normal. The genes had to be involved with girls so predominantly affected and the rare male case so distinctly different and indeed MECP2 on the X chromosome is centrally involved, but that leaves much to be understood to allow release of the potential intelligence.

In quiet observation of people with Rett disorder it is clear that much of the personality is intact and calls for expression. The most able are often the most frustrated, presenting challenges to the geneticist, neuro-chemist, musician, singer, artist… It is clear that the genetic faults should not be left to rule the brain.

The compactness of the UK population, coordinated road and rail transport and the generous provision of the National Health Service have make Britain a leader in understanding complex developmental disorders. It is my hope that the UK Rett Association will continue in their most valuable role, setting an example for solving the problems for developmental neurological childhood disorders that are among the most challenging to understand and remedy.

I do congratulate the Rett families and the UK Rett Association for this valiant and generous work continued through these most productive years, setting an example for solving the problems for developmental neurological childhood disorders that are among the most challenging to understand and remedy and providing invaluable support to help families deal with the significant challenges families face every day.

Nina Panda and her mum

Printable Mask Exemption Cards

The Government have made new rules about wearing face coverings on public transport and in shops (from 24th July).

Public transport includes buses and trains. Taxis are not public transport, but some taxis may ask you to wear a face covering.

The Government have said some people have a legitimate reason not to follow the face covering rule. This is called an exemption.

Some people can't wear a face mask or covering because of a disability or severe distress. Keep Safe have designed a selection of DIY cards to help deal with public situations that might happen, which can be printed or saved onto your phone as photos.

To find out more, visit:
keepsafe.org.uk/mask

Disability Travel Support

I am exempt because I have a learning disability and face masks cause me severe distress

SEN Travel Support

My child is exempt because they have a disability which means they cannot wear a face mask

Home Schooling and COVID-19

by Abigail Davison-Hoult

Still here....

I have had a break from writing this blog for a few weeks – after all, nothing had really changed apart from the weather. Our attempts at home schooling went down the pan and everyone lost any initial enthusiasm for arty creative sciency projects, baking, gardening and even Grandpa's version of Joe Wicks exercise classes. Screens of various sizes have turned my children into zombies and 'quality time' is something we have started to take for granted. Days have turned into weeks and then months, and I have found myself spending all the time keeping on top of the demands of work, feeding (I am so sick of cooking!), washing, cleaning, sourcing food, entertaining....

Then came the call from The Outside World – my husband was to return to work in just three days' time! All the worries I had shoved to the back of my mind came flooding back: What was the risk of him catching COVID-19? How would we keep ourselves safe? How would I manage work without him around? How would I entertain two children with very different needs? At the same time though, I was pleased for him. We have completed a lot of DIY/garden jobs in the past three months and now without a focus, he was finding life a bit aimless. He needed to get back to the structure of a working week.

Luckily for me, I was given school places for both children. My son is in school

Esme

Patrick and Esme

Tarka the puppy

Monday to Wednesday and my daughter Thursday and Friday till the end of term. They both desperately needed everything that school provides: the structure and routine, the social interaction, some teaching by teachers they prefer to the dud supply teacher they had at home-school. Whilst it is still a juggling act to get everything done, it is lovely to be able to spend 1-1 time with each child. One day a week I do a long day of work whilst my husband holds the fort. The weather is still good so we can spend lots of time outdoors and have all the windows open. After taking one child to school, the other child and I walk our new puppy and get some exercise. Then we do an hour or two of school type work.

We are cautiously seeing some select friends again – outdoors and observing social distancing. The difference in the children for being able to see their peers is remarkable. I think the lack of socialising has probably had the biggest impact on them over anything else. I feel in some ways relieved that the responsibility of educating my children does not now lie solely with me. It is also nice to know that they are being mentally stimulated some of the week. I trust that both schools have micromanaged their risk assessments and hygiene protocol. The risk of the children catching the virus is outweighed by the benefits of resuming some normality. I know we are fortunate that Esme is physically robust and in good general health and therefore the decision for her to stop shielding was not so difficult as it would be for some of our friends.

For now, things seem a little more organised. Just time to get used to it before the schools break up for the summer when we will have to change things again!

And as for September – who knows?

Family Stories – Susan Jennifer Gooding

by her mother, Jennifer Gooding

STORIES OF SUSAN

Finding out and walking

My amazing daughter Susan who, through no fault of her own, had Rett syndrome is a story worth writing. I have been trailing through my memories for anecdotes that will draw your interest.

Sue was a beautiful baby. Perfection personified with rosy cheeks, the loveliest round eyes and a head of dark hair. Within a few months of progression in the expected way I started to notice she was falling behind. Holding a cup with both hands disappeared into resting a cup on her forearm and holding with her other hand. From sitting up in her pram to rolling around like a bottom weighted toy without any balance at all. Our doctor said I was imagining things as it was our first baby, but I could not leave it alone and contacted the child specialist directly. He had no diagnosis but suggested putting her in a home and getting on with our lives. Well, we chose to start swimming through the enormity of Sue's slide into a fractious baby who could not sleep, eat solids and with the presenting symptoms of Rett syndrome – hands clenched into fists unable to hold onto me or anything else, unable to sleep more than three hours during the night and shouting on and off during the day. Sue and I perused the local streets on and off all day which was what seemed to calm her down. Hence my realisation that keeping her moving in some way helped her. I decided to teach her to walk. Back breaking for me but somehow right for Sue. We also bought her a tricycle which she loved to bits and I had to hide it and she used to roll around until she found it behind a chair. She never crawled and her limbs would not move as she wanted.

Sue obviously knew herself that movement helped her, and I started to tie her feet to the pedals of her tricycle and pull her up the road. She loved it. A member of the public gave me a lecture on cruelty for tying her feet to the pedals. Don't forget 55 years ago there was no knowledge in this country of Rett, so I decided that I was on my own as regards finding my daughter inside her body. My husband worked hard to support us, and I worked hard to understand Sue. Observation was the key word. Watch and put myself into her body and see what I would like to happen. Her eyes were the window into her mind, and I knew her intelligence was there and is still there today.

There were no disability benefits in the sixties and no knowledge about Sue's symptoms. In one way that was a good thing because I had no preconceived ideas and so observed and listened to my instincts.

Potty training

Having decided to treat Sue as someone who understood what was said to her, I went ahead to teach her to become potty trained. This was when she was about two and a half. I did not put pads on her during the day so when we went out somewhere I used to say to her, "Do not wet yourself until you are back inside the front door.” I then learnt that Sue took everything literally. She would immediately relieve herself on the front door mat. Well, as long as I acknowledged that she knew what I had asked and told her that a potty or her seat on the grown up toilet was where you did the business we had no more accidents. Another milestone reached. I am not saying it was easy, as night-time was a little difficult. The only sheets to put in her bed at night were a bit more primitive than what is available now. So Sue did not wear pads at night either. A very necessary thing learnt if not particularly something that you would write about in a book

Sue’s walking progressed and we used to walk everyday up and down the road. She could not balance herself by herself but loved to walk except if neighbours stopped to talk. Taking her on buses was also an experience as obviously she looked big enough to walk. Her eye contact with her family was quite good but I noticed her eyes connected to the glass windows but not to what was passing us by. However I just hoped this would improve with time which it did.

Susan’s 5K run

I must tell you about Susan’s journey into doing a run in the park in aid of cancer. It was Sue’s second year at having a go at participating in something way out of her normal activities. The first year she was barred because she was in a wheelchair and was bitterly disappointed. Sue’s lead carer, Lee, applied again in 2017 and did not disclose the fact that Sue would be pushed round a 5K course by Lee and Nicky (also a senior carer) in Mote Park, Maidstone. Sue wore her pink t-shirt which had her name on it, and the name of the agency who supplies her carers, with pride.

Above: Sue at Leeds Castle

For several weeks before the race she had been getting fit in the hydro pool when she had the hydro pool to herself once a week. With carers holding her hands she walked the widths of the pool in ever increasing numbers until she reached 65 widths. She was so determined to do it which would enable her to cope with the hills and rough ground of Mote Park. We also let her know that we would let Richard know how many widths she had done each week and he would have to increase his exercises accordingly. I feel they would have been quite competitive if Sue had been able without her Rett syndrome preventing her from doing physical normal things.

Lots of people cheered Sue on and her carers were exhausted when they crossed the line but were over the moon to see Sue receive her medal and later on a thank you for the money raised by family and friends.

A good day for everyone involved but especially for Sue as it gave her a sense of achievement. Needless to say, Sue wasn’t silly and her widths in the hydro pool dropped by half as there were no more races to work for until next year!

We’d love to hear more of your stories.

Please share your daughter or son’s good news stories or achievements with us here at Rett UK.

An Interview with Brain Prize Winner Sir Adrian Bird

by Ruairi J Mackenzie,
Science Writer for Technology Networks

Sir Adrian Bird

The annual announcement of the Lundbeck Foundation's Brain Prize represents the largest yearly award for brain research. Laureates, who share a €1 million ($1.13 million) sum, are recognised for their outstanding contribution to neuroscience.

This year's laureates are two geneticists, University of Edinburgh professor Sir Adrian Bird and Baylor College of Medicine professor Huda Zoghbi. They are recognised for their work towards understanding the inherited brain disorder Rett syndrome.

Bird's lab made the first identification of a gene, MECP2, mutations in which were later determined to be causative in Rett syndrome by Zoghbi's clinical lab years later.

Their work, conducted independently, has led research to the brink of clinical trials for the syndrome and may have resonance far beyond this rare condition. Technology Networks recently spoke to Sir Adrian to discuss his lab's contribution towards decoding the origins of Rett syndrome.

Ruairi Mackenzie (RM): What is Rett syndrome?

Adrian Bird (AB): Rett syndrome is a profound neurological disorder that is caused by mutations, in nearly all cases, in the MECP2 gene. It's characterised by a period of normal development, followed by, at the age of 18 months or so, a crisis, when the child obviously becomes distressed. At this point, skills such as walking and speech, which may have been learned prior to this point, are lost and they never return. In addition, the children can't walk, and they grow into adults who are wheelchair-bound.

There are breathing difficulties in the sense that the children have apneas – that is they hold their breath quite often for a distressingly long time.

There are other issues, such as tendency to scoliosis, seizures and sleep irregularity. It's a serious disorder for which there is absolutely no cure.

Rett syndrome affects girls predominantly. The reason for that is that the MECP2 gene is on the X chromosome. Mutations on the X chromosome are not less severe in males than in females; they are more severe. In Rett syndrome, they're so severe that males generally do not survive with these mutations. There is no common Rett syndrome in males. There are a few cases, but the vast majority of cases affect girls who have one mutated copy of the gene, and one unmutated copy of the gene and it's this combination that allows them to survive, but at the price of Rett syndrome.

RM: What's the prevalence of Rett syndrome?

AB: Roughly one in 10,000 births. I'm not sure how that translates into numbers in the world, but it's neither exceptionally rare nor highly frequent.

RM: Could you tell us about your research into the MECP2 gene?

AB: My lab was a basic, blue skies lab that was and still is interested in how gene expression is regulated – how different genes can be switched on and off to make the different cell types in the body.

One of the mechanisms that was of interest at that time was DNA methylation, whereby a small methyl group is attached to cytosine residues in the DNA. We were involved in studying that from quite an early time. The question was, "What is it good for? Is it a signal that can be read?" To answer that question, we looked for proteins that might be able to recognise methylated DNA and distinguish it from unmethylated DNA.

That's how we came across MECP2, because this protein binds preferentially to DNA that has these methyl groups attached and so that was a potentially a reader, if you like, of the DNA methylation signal. We got interested in it as a way of trying to understand what DNA methylation did. We thought that by finding the proteins that read it, we could then ask what they do. And that would tell us about what DNA methylation does as well.

RM: How has your field of research changed in the three decades since the MECP2 publication?

AB: It has changed dramatically, because of all sorts of technologies; not only DNA sequencing, but also techniques in microscopy and mass spectrometry. The armory that we have available to address questions now bears no comparison with the way it used to be. We, for example, had to purify the MECP2 protein. For that we used classical protein purification methods, which are still sometimes used. Once we got the protein, we had to break it up with enzymes and then determine the amino acid sequence at the very tips of those broken fragments. We then worked backwards to work out what the DNA must have been that encoded the fragments. That allowed us to purify a copy of the mRNA and that allowed us to subsequently go and find the bit of the genome that encoded the mRNA. Many, many steps that today would be virtually instant because the whole genome is sequenced and you can PCR every bit of it in a day, if not one or two days. So yes, it's totally transformed.

RM: You shared the prize with Dr. Huda Zoghbi from Baylor College of Medicine. It seems to me to be a great example of collaboration between basic and translational science. Does it seem to you like these kinds of collaborations have become more common in recent years as opposed to back in the 90s?

AB: Huda is a clinician who sees patients with Rett syndrome. She was interested in it as a disorder, whereas we came from the opposite direction; we were interested in proteins, DNA methylation and gene regulation. The protein we found happened to be the protein that is involved in Rett syndrome. It was the Zoghbi lab that actually made that connection. We had no idea we were working on something clinically relevant. As to whether or not that kind of collaboration is more common, I think it definitely is. Biology used to be much more siloed – molecular biologists or structural biologists or geneticists or microscopists operating with a relatively small number of techniques within a community that all did more or less the same thing. The new technologies have really broken down those barriers. And importantly, they've broken down the barriers with medical science. Medicine is now accessible much more quickly and directly than it ever was before. Biology has become one huge canvas rather than a small number of vignettes.

RM: Your 2007 paper in Science establishes a critical principle of your research, which is the possibility that the symptoms of Rett syndrome could be reversed. Could you outline how you achieved that reversal of symptoms in mice?

AB: We wanted the mice to grow up without any MECP2 and then we wanted to put it back, to see whether or not the defects that arose as a result of not having it could be fixed if you made it available later on.

The way we did this was to "knock-in", to manipulate the natural gene. We didn't add an extra gene; we simply manipulated the gene that was already there. We inserted what's called a stop cassette, a piece of DNA that stops a gene from being expressed while it's present. On either side of that stop cassette, we had sites that would allow it to be cut out when we wanted it to be cut out.

We injected these mice with tamoxifen, because tamoxifen triggered the activation of a system, derived from bacteria, that would chop out the stop cassette whenever we wanted. This worked brilliantly. It's the sort of experiment that you scribble on an envelope, and you think, "But there are five steps there. And we need them all to work perfectly. And life very often isn't like that." But in fact, in this case, every single step worked very well. We were able to create mice that had no MECP2, because their MECP2 gene was stopped. Then, after the tamoxifen injection, their gene was activated and then they got better. That's really how we did it.

RM: That's a really exciting finding. But the great challenge is trying to apply that animal-based finding to human patients. Could you summarise the advances the field has made in the last 13 years?

AB: Of course, it's frustratingly slow. I should make the point that the animal model of Rett syndrome developed in mice is an extremely good mimic of the human disorder. With many diseases of this kind, the mouse and the human are not necessarily very equivalent. There are differences; mice are not people. It's very important in this case that what MECP2 does in mice, it also does in people. The fact that we could get it to reverse in this way really strongly suggested that it was going to be curable in humans. But in mice, we use genetic tricks, which I previously described, and you can't do those genetic tricks in humans.

You need to somehow add a functional gene into the brain. And this is not trivial. But the most important thing I just want to say is that no one expected any brain disorder that arose during development, as this one does, to be reversible. The assumption was that all such disorders were irrevocable, and you would never be able to do anything about them. That's really the notion that the 2007 paper overturned. It had this dramatic effect of attracting people to the possible ways, and there are several, of fixing this mutation.

One of the most obvious and sort of, in a sense, the most crude way is to do gene therapy, whereby you go in with a virus that you've hijacked. In place of its own genome, you've inserted the MECP2 gene. The problem with this is you can't really regulate how much goes into individual cells. You need a virus that goes to quite a large number of neurons. You can't do that with the current viruses that we have available, though that is a little bit controversial. Some people disagree with that.

The second problem is that you do not want to put too much MECP2 in, because there is another disorder called MECP2 duplication syndrome, which as the name suggests, is where there are two copies of the gene where you should have only one. This is at least as bad as Rett syndrome. So that tells you that too much MECP2 is toxic and too little is toxic, so you need to put in the right amount and with gene therapy that's not easy to manage.

That sounds hopeless. But, in fact, experiments in mice have suggested that it works remarkably well. Putting back some MECP2 protein is hugely beneficial in a way that no drug has ever approached. So there is leeway, a window of opportunity if you'd like, to put in a safe amount that stays low and doesn't ever go high. And the situation now is that clinical trials are being planned, but they have not yet been started. So we're waiting with bated breath to see what happens with the first clinical trials. There is a plethora of private and academic labs that are trying to find different ways of curing Rett syndrome. One would like to be 10 years down the line when hopefully some of them will have managed to do that.

RM: Do you think the etiology of Rett syndrome means that it's likely to be among the first of the autism spectrum disorders that we are able to cure? How do the genetics of Rett disorder compare to these other disorders?

AB: The first point I should make is that not everyone agrees it's an autism spectrum disorder. People get quite excited about names and words. In the latest edition of the DSM [DSM-V, released in 2013] it is not classed as an autism spectrum disorder. But autism is so incredibly broad that it's very difficult to define where the edges are. It's now pretty clear from the genetics, that autism isn't one disorder, it isn't even ten disorders, it's probably hundreds of disorders, all differing depending on the root cause.

As to whether or not Rett syndrome will be among the first of these disorders that we cure – I would like it to be among the first tried. But if other disorders of this kind are the first cured, I wouldn't really feel as though any meaningful race had been lost.

As for the genetics of other disorders – I think with the explosion of exome sequencing and, more recently, whole genome sequencing, there are lots of single gene disorders that are turning up that people didn't realise were caused by single gene. But the question is, to what extent is the reversibility of Rett syndrome a peculiarity of this disorder? And to what extent is it actually the thin end of a wedge that will include large numbers of autism spectrum disorders? I'd like to think that lots of them will be reversible. But you've got to do the experiments. It's actually taken quite a while for people to look, but it looks as if it's turning out that some are reversible. Only a handful have been looked at properly. Some are reversible and some don't seem to be. The data isn't always utterly convincing, but some of it is.

Predicting the future and how things will go is not always a useful thing to do. But I can't believe that there won't be lessons to be learned from Rett syndrome that won't be of relevance for other neurological disorders as well.

Professor Sir Adrian Bird was speaking to Ruairi J Mackenzie, Science Writer for Technology Networks. Interview has been edited for length and clarity.

Breathing Dysfunction

by Dr Ana Abdala Sheikh and Dr Adrian Kendrick

Increasing knowledge and understanding of Rett syndrome

Overview

Breathing dysfunction is a common condition in people with Rett syndrome. It can have a big impact on quality of life and increases the risk of developing certain conditions.

Different types of breathing dysfunction can occur in Rett syndrome:

- During wakefulness, central apnoeas are common. They happen when the effort to breath is reduced or absent, causing an interruption in breathing. They are often interspaced with periods of rapid and/or forceful breathing (hyperventilation). Central apnoeas can also happen during sleep but are usually less frequent than in wakefulness.
- During sleep, obstructive apnoeas and hypopneas are most common. Obstructive apnoeas occur when muscles and soft tissues in the throat relax and collapse causing a blockage of the airway. If the blockade is partial and only reduces the flow of air by half, it is called a hypopnea. Occasional sleep apnoeas/hypopneas are very common in healthy people (everyone experiences them). However, if they last longer than 10 seconds each, and more than 5 occur in an hour, clinical intervention may be required.

Symptoms

The signs of breathing dysfunction can sometimes be easily spotted by a family member or carer. They can include one or more of the signs below:

- Breath holding
- Forceful air blowing or air swallowing
- Noisy, laboured or fast breathing
- Repeated short periods where breathing is interrupted by gasping or snorting
- During sleep – snoring frequently followed by pauses then snorts

The above may be accompanied by:

- Frequent nigh time awakenings
- Daytime sleepiness, lethargy and irritability
- Muscle spasms that may resemble seizures
- Blue skin or lips

How common is it?

The RTT Natural History Study [1] identified that nearly all participants with classic or severe atypical Rett experienced breathing dysfunction at some point in their life. Whereas those with mild atypical Rett were less likely to experience breathing disturbance (6-7 out of 10). Breathing issues have a relapsing-remitting nature, meaning they could appear, become worse or improve, disappear or reappear at any stage of life. Obstructive sleep apnoeas are more common in people with Rett syndrome than in the general population but do not affect every person with Rett.

Causes of breathing irregularities

The breathing dysfunction experienced during wakefulness is caused by abnormal development of the brainstem (the region of the brain the controls breathing muscles). This also contributes to the breathing dysfunction during sleep. Obstructive sleep apnoeas can also be caused by various factors not necessarily related to Rett syndrome.

Common risk factors for obstructive apnoeas are:

- Having a narrow airway – such as large tonsils, adenoids or tongue, nasal congestion or a small lower jaw
- Being overweight or having too much fat around the neck
- Taking medicines with a sedative effect – such as sleeping tablets, anti-anxiety or some anti-epilepsy medications
- Having severe scoliosis
- Being older (40 years of age or more)

The breathing dysfunction in Rett syndrome is entirely involuntary (out of the person's control) although anxiety and pain are known to make it worse.

When to seek medical advice

It is advisable to have a baseline assessment of breathing as soon as first symptoms are noted. You will need a referral from your GP, see section 2 below. Reassessment is also recommended if symptoms change or become worse or reappear after a period of remission. For instance, the nature of breathing dysfunction can often change around puberty and in mid-life.

If lips, tongue, face or skin suddenly turn blue/grey (or gums and round the eyes in people with darker skin) call 999 or go to A&E.

If fingers, toes, hands or feet gradually turn blue and cold (with normal lip coloration), this could be the sign of poor blood circulation. This does not constitute a medical emergency and you can see your GP for advice.

Complications of breathing irregularities

If left unmanaged, breathing dysfunction can have a significant negative impact on quality of life. It may further impair motor coordination, concentration, memory, mood and cause poor sleep.

Severe breathing dysfunction may also increase the risk of abnormal heart rhythms which have been linked to sudden death.

Abnormal blood gases can cause muscle spasms that may be confounded with seizures. They can also trigger actual seizures.

Diagnosis

Seeing your GP

Your GP will usually ask a few questions about the symptoms, it may be helpful to bring home videos showing the symptoms you are describing.

Your GP can provide a referral to specialist clinics that assess people with sleep breathing disorders. The specialists will then arrange for an overnight assessment, either by taking some equipment home with you, which they can then analyse at the clinic, or by spending the night at the clinic.

Testing at home

The specialists will teach you how to use portable equipment. Let them know if your loved one will not tolerate devices attached to their finger and hand. In this case the device can almost always be placed on a toe or ear lobe.

The equipment to take home may include:

- A sensor to monitor heartbeat and blood oxygen
- A band that is placed around the chest to measure breathing movements

Testing at the sleep clinic

If a more detailed investigation is required, a test called polysomnography will be carried out at the sleep clinic. This may be necessary particularly if the patient has seizures that are frequent at night or are resistant to treatment.

Various sensors will be placed around the body:

- Electroencephalography (EEG) – to measure quality of sleep and detect seizures
- Electromyography (EMG) – to detect muscle movements including breathing muscles
- Plethysmography bands – to measure movements of the chest and abdomen
- Airflow probes – to measure how much air moves through the airways
- Pulse oximetry – to measure heart rate and blood oxygen
- Electrocardiography (ECG) – to detect abnormal heart beats
- Sound and video recording may be used

Treatments

The sleep breathing dysfunction may be easier to manage than the breathing disturbances experienced during wakefulness.

Lifestyle changes

If the patient is obese, weight loss may help improve obstructive sleep apnoeas and hypopneas. As mentioned above, anxiety and pain are known to aggravate daytime breathing dysfunction, therefore removing or treating the causes of anxiety or pain may well help.

Breathing aids

The first line treatment for sleep breathing disorder involves the use of a tight-fitting mask around the nose and mouth connected to a device that aids breathing. Depending on the nature of the breathing dysfunction different types of device may be prescribed including continuous positive airway pressure (CPAP) or non-invasive assisted ventilation (NIV). These may be prescribed for daytime or nigh time use.

If blood gases are abnormal during wakefulness, other devices may be prescribed to correct them, included compressed gases and rebreathing masks.

Surgery

If upper airway narrowing or severe scoliosis are present, surgical interventions to correct them may help improve breathing particularly during sleep.

Drug treatments

So far, no drugs are specifically licensed to treat breathing dysfunction in Rett syndrome, although several clinical trials are ongoing. Various small studies showed that some drugs commonly prescribed to treat anxiety or epilepsy improved breathing dysfunction in some individuals. A neurologist consultant may prescribe those drugs at their discretion. However, some drugs are contraindicated in people who have long QT interval, which is a type of abnormal heart rhythm that is common in Rett. In this case, joint assessment by a cardiologist consultant may be required.

References

1 Tarquinio, D. C., W. Hou, J. L. Neul, G. K. Berkmen, J. Drummond, E. Aronoff, J. Harris, J. B. Lane, W. E. Kaufmann, K. J. Motil, D. G. Glaze, S. A. Skinner, and A. K. Percy. "The Course of Awake Breathing Disturbances across the Lifespan in Rett Syndrome." Brain Dev 40, no. 7 (Aug 2018): 515-29. https://dx.doi.org/10.1016/j.braindev.2018.03.010.

Communication Guidelines for Individuals with Rett Syndrome

by Dr Gill Townend

What is Rett Syndrome?

Rett syndrome is a neurodevelopmental disorder affecting around 1 in 10,000 females. It occurs more rarely in males. It is characterised by severe physical and communication disabilities. In most cases, it is caused by a mutation in the methyl-CPG-binding protein 2 (MECP2) gene.

Why did we create the guidelines?

Severe disruption in communication skills has a profound impact on quality of life. While literature on best practices in communication assessment and intervention is growing, many caregivers and communication professionals struggle to access appropriate and timely information, training and support to build their knowledge and expertise. These guidelines were developed to help support the communication development of individuals with Rett syndrome.

- 650 people in 43 countries participated in the project
- 490 caregivers and 120 communication professionals completed the surveys
- 36 professionals and parents formed our expert panel

How did we create the guidelines?

The project team reviewed research literature and conducted surveys with parents and professionals to identify best practices in assessment, intervention and long term management of communication. An expert panel reviewed draft statements and recommendations developed from the literature review and survey responses. Using statements and recommendations that reached a consensus of more than 70%, the guidelines are based on available evidence from research and practice combined with expert opinion.

What do the communication guidelines include?

268 statements and recommendations, relating to:

- Rights of the individual
- Beliefs and attitudes of communication partners
- Professional knowledge and teamwork
- Features of Rett syndrome that impact communication
- Strategies to optimise engagement
- Assessment
- Intervention (targets and goals, strategies, techniques) including use of Augmentative and Alternative Communication (AAC)

How will the guidelines help individuals with Rett Syndrome?

These guidelines provide information that will help families, therapists and educators to enable any individual with Rett syndrome to meet their full communication potential. They aim to improve assessment, intervention and long term management of communication, to stimulate training and implementation of best practice across the globe and to promote research to fill the gaps in the currently-limited evidence-base.

Project Team

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This project was funded by Rettsyndrome.org and coordinated by the Rett Expertise Centre Netherlands-GKC

RETT SYNDROME Communication Guidelines:

A handbook for therapists, educators, and families

Guiding Principles

Professional Practice

Features of Rett Syndrome and Coexisting Conditions

Strategies to Optimise Engagement

General Communication Assessment

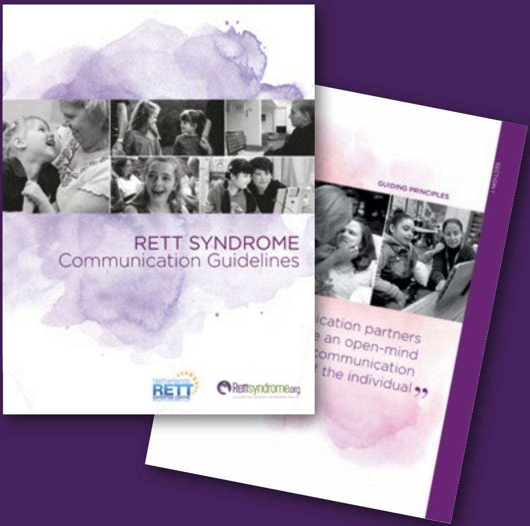
AAC Assessment

Assessment of AAC System/Device

Intervention

Download your copy of the guidelines here:

https://cris.maastrichtuniversity.nl/en/publications/rett-syndrome-communication-guidelines-a-handbook-for-therapists-



Rett UK Communication and Education Support Update – Summer 2020

by Dr Gill Townend

Maximising the communication potential of people with Rett syndrome

What an unexpected few months it has been for everyone, including those of us on the Communication and Education Team. We had just celebrated the first successful round of our new-style regional workshops in January and were busy planning dates and venues for our 'out and about' communication groups in March and April, and round two of the workshops in June, when along came lockdown.

Since then we have moved everything online and have been very pleased to see our Regional Communication Champions (RCCs) embracing the opportunity to offer communication support to families through regular online 'coffee & chat' and 'wine & whinge' sessions. We have also been delighted by the positive feedback we have received in response to the communication-related webinars led by Gill and Abigail. Zoom and GoToWebinar have become our new best friends (!) and we can see the benefits of continuing to offer more online activities alongside face-to-face events once we are able to resume those safely.

Look out for further 'coffee & chat' and 'wine & whinge' sessions and other online communication activities in the upcoming weeks and months.




Here are a few snapshots from our last regional workshops in January

Rett UK Network for Communication Professionals

Sharing good practice

At the end of 2019, the Network for Speech and Language Therapists was opened up to include other members of communication teams who work with individuals with Rett syndrome, such as teachers and teaching assistants, as well as SLTs and SLT assistants.

The Network recently enjoyed an intense mini-series of webinars focusing on literacy. This was offered in conjunction with the Dutch Network for Speech and Language Therapists working with people with Rett syndrome, with all webinars presented in English.

The webinars were well attended by members of both Networks and gave plenty of food for thought.

The webinars were:

FEBRUARY 2020
Why is literacy critical in AAC?
Featuring a recording of Dr. Karen Erickson's keynote address from the 2019 Communication Matters conference

MARCH 2020
Comprehensive literacy instruction for emergent learners
With Maureen Donnelly

APRIL 2020
Comprehensive literacy instruction for beginning conventional learners
With Maureen Donnelly

APRIL 2020
Reading Avenue
With Tina Voizey

At the moment we are busy developing a Communication Professionals section on the Rett UK website, where the webinar recordings will be housed along with research news and updates, and other relevant information for communication professionals. This area will be open to members of the Network.

If you are a communication professional and would like to join the Network, get in touch with Gill Townend by sending an email to **gill.townend@rettuk.org**

Rett Syndrome Communication Guidelines Webinar

If you would like to know more about the Communication Guidelines, why not take a look at a recording of the webinar we held on 17th July.

During the webinar, Gill walked through the Handbook, demonstrating how the Guidelines set a baseline of good practice for developing the communication skills of people with Rett syndrome and how they offer a starting point for assessment, intervention and long-term management of communication.

This webinar, just like the Guidelines, was aimed at parents, carers, therapists and educators.

The recording can be found on our website at:
www.rettuk.org/webinars

STOP PRESS...
Rett Education 2020

Communicate, Educate, Advocate! Virtual Conference

Due to the ongoing COVID-19 situation, the conference we were planning for November will now be held online.

Look out for more news with the programme and dates coming shortly.

Upcoming online support events

To register, visit our website using the links below to reserve your place.

Wednesday 5th August, 2-3pm
Family Support Coffee & Chat
Challenging Behaviour
www.rettuk.org/FamSupportBehaviour

Thursday 13th August, 2-3pm
Communication Support Coffee & Chat
Families of over 35s
www.rettuk.org/CommsSupportover35

Friday 21st August, 8-9pm
Family Support Wine & Whinge
Over 18s Adult Living Options
www.rettuk.org/FamSupportOver18Living

Wednesday 26th August, 2-3pm
Joint Family and Communication Support Coffee & Chat
Back to School
www.rettuk.org/CommsSupportSchool

DON'T FORGET!

Notify us if you move home, change your phone number or email address.

Email:
donna.tinch@rettuk.org

Thank you!

OCTOBER IS...

Rett Syndrome Awareness Month

October is Global Rett Awareness Month

A great chance for us to make a lot of noise about Rett syndrome, sharing stories that inform, educate and engage people who can help us improve the lives of people living with Rett syndrome and their families. And to raise some much needed funds for Rett UK.

How can you get involved this year?

Cake, cake, cake...

Purple is the name of the game! We will have purple food dye, recipe cards and Rett UK logo cake toppers for the baking enthusiasts amongst you. Perhaps a school or work cake sale, an afternoon tea with friends?

Street parties

What better way to celebrate the lifting of lockdown and getting back to some normality than holding a street party with friends and neighbours? We can provide you with bunting, balloons, food dye, cake toppers and suggestions about how to make your street party a resounding success without a lot of work! Half term week (and some late autumn sunshine!) would be a great time to hold your street party!

Purple pumpkins

As you head towards the end of October you also have Halloween of course! Purple Pumpkins can look amazing and are great fun to do. If you are a Facebook user, why not share a photo of your Purple Pumpkin, with a few lines about why support for Rett UK is so important to you? Or hold a Purple Pumpkin competition as part of your street party or as a stand alone event?

For a whole month, we have the opportunity to stimulate recognition via Public Relations and encourage fundraising through donations.

RETT
SYNDROME
AWARENESS
MONTH
October 2020
RettUK.org

Something more active?

If you are looking for something more active to do then choose one of our three **Key Number** events.

1,500 - is the number of people with Rett syndrome we estimate there would be in the UK if they were all diagnosed.

10,000 - the prevalence of Rett syndrome in females is around 1;10,000

40,000 - the prevalence of Rett syndrome in males is around 1:40,000

You can run, walk, cycle, swim or push (if doing with a wheelchair user) any of these distances. Steps, miles or kilometres, do it on your own, or involve friends, family or work colleagues – the choice is yours! We will provide challenge packs with t-shirts, flyers and branded promotional items to help with your fundraising. If you regularly run, cycle, swim etc. then log your challenge on your preferred App and send us a screenshot of your completed challenge to receive your unique Rett UK medal and certificate. Interested? Email **fundraising@rettuk.org**

If you have an idea you want to discuss with us please get in touch with one of the team **01582 798 910** or email **fundraising@rettuk.org**

Let's make some noise about Rett syndrome this October!

We would love to see some photos and hear how it went for future issues of *Rett News*. Please share with **donna.tinch@rettuk.org**

#LivingWithRettSyndrome #RettSyndromeAwareness #RettUK

The Big Give Christmas Challenge 2020

Our pledges could be doubled or even quadrupled by The Big Give!

STAGE ONE NOW OPEN!

WE ARE COLLECTING PLEDGES – DEADLINE 28TH AUGUST AT 5PM

The minimum pledge is £100. Pledges are not collected until after the online donation stage close in December.

To make a pledge, visit: **www.rettuk.org/biggive2020** but you can also find the link on our website home page

THE GIFT OF SUPPORT & WELL-BEING THIS CHRISTMAS

The UK's biggest match funding campaign, The Big Give Christmas Challenge, returns in 2020!

Yes, sorry to mention Christmas in the middle of the summer but the campaign essentially starts now as we submit our project proposal and we have to collect pledges in support of that project by 28th August at 5pm!

The next stage is getting match to a Champion Funder before the online donations open on 1st December at 12pm and close on 8th December at 12pm.

The target to raise this year is £20,000.

How does it work?

25% has to be raised in pledges by 28th August 2020

25% comes from a Champion Funder

50% has to be raised in online donations (01/12/2020 to 08/12/2020)

theBigGive
CHRISTMAS CHALLENGE 2020

The project this year

Rebuilding Family Life Post COVID-19

The impact of COVID-19 has taken its toll on families in many ways. The difficulties the families have faced and continue to face, covers a breadth of issues.

Continuous and often rapidly changing guidance about self isolation, shielding and social distancing, juggling being a carer, a therapist, a teacher and play provider! Then worrying about the financial impact, longer term job situation and dealing with a prolonged period of isolation has put a huge strain on the emotional, physical health and well-being of all family members. In many cases relationships are strained. Siblings too are feeling the stress and anxiety.

This year's project will aim to support all family members to give them a variety of platforms in which to access support in groups and individually. The aim is to teach the families tools to enable them to navigate these circumstances in a way that helps them build resilience and maintain a reasonable level of physical and mental health for the whole family.

This support will be delivered through webinars, informal Zoom meetings, 1:1 online coaching. We will also be doing presentations and workshops at our Regional events during 2021/22 which will include dedicated sibling workshops.

More information in the next issue of *Rett News* but also on our website and social media feeds.

Can You Help?

What difference do we make?

Rett UK receives no direct government funding and relies entirely on the generosity of our families, their friends and colleagues in order to help us continue to provide the much needed and valued Family Support Service.

We do also regularly receive funding from grants and trusts but increasingly they are asking us to tell them about the difference we make to the lives of people with Rett syndrome and their families.

We would like your help to provide this information to funders in order to evidence the value and the impact of the professional support and information we provide to our families.

If you have a story of support to share, please email **becky.jenner@rettuk.org** or call **01582 798 910.**

Thank you!

MEMORIES – THE STORY OF OUR SON, JUDE DRINKWATER

by Claire & Phil

Jude was born on 25th January 2018. From day one we knew Jude was going to be a fighter. He struggled feeding, had low muscle tone and, every now and again, jerky limb movements. As he got older, we saw delays with development of speech, mobility issues and lack of interest in toys. Despite all of this he was the happiest, strongest and most resilient little boy.

We were in and out of hospital most of his life but with every scan, blood test, injection, operation or intubation, he took it like a trooper, and it became our 'normal'.

Every test that Jude had had in his short life to try and determine what was causing his differences came back clear – brain scans, muscle biopsy, blood tests, hormone test.

Not knowing what was causing his differences was torture, but thanks to the incredible work of genetics teams across the UK, on 20th December 2019 we were told they had found something, and we finally had an answer.

Jude had a very rare condition called Rett Syndrome.

Looking back, they were all obvious signs of Rett. The thing is that we had no idea what Rett was and even if we had, apparently boys don't get it...

As you're all aware, Rett usually only affects girls. There are very few cases of it affecting boys – where a male child may have it, the child is usually miscarried. The fact that Jude had been with us at all had defied all odds and expectations and we were so thankful that we'd had this time with him. We found both comfort and relief in finally knowing what it was that Jude had been living with. He was a fighter from the beginning until the very end.

He peacefully passed away on 1st January 2020.

We often try and picture what the future would be like with him still here. But it's hard.

Would we rather he hadn't had Rett? Of course – he'd still be here. But he wouldn't have been the Jude we fell so hopelessly in love with.

Would we do it all again? Over and over. We'd do it in a heartbeat because we had him, and he was our Jude. We lost him, but we had him. For that we are forever grateful.

He was perfect. We will love him for a lifetime.

Fundraising Round Up
THANK YOU

DRIVEWAY CHALLENGE

Giorgio Rigali, uncle to Freya, has pledged to raise £50,000 for Rett UK in loving memory of his mum Jill. During lockdown he challenged himself to run 40 miles on his driveway – and on his 30th birthday! Giorgio reported:

"I set out at 4:50am with the aim of running 64K without leaving my driveway before the day ended. I never in my wildest dreams expected what happened throughout the day.

The support online and face to face was phenomenal! The messages and donations just flooded in, from close friends, family, old friends and people I have never met before.

The second half of the run was brutal, but I really wanted to get to 64km in memory of mum, who would've turned 64 on 11th June. I can honestly say that I would not have made it without the support of everyone.

I am still incredibly overwhelmed by all of the support I received. These charities are incredibly close to the hearts of my family and I. Rightly so, our magnificent NHS has been at the forefront of fundraising, so I was gobsmacked when the donations for these two smaller charities continuously came in.

I finally finished around 8.30pm with a handful of supporters surprising me to push me over the finish line.

Together, we raised over £2,000 in one day. I am just an idiot who ran around his driveway for a day – you are the amazing people who have made vital donations to two charities that have seen a significant reduction in their incomes due to coronavirus.

I will be forever grateful for all of the support I received. You are all superheroes!

I'd like to particularly give a shout out to all my family, especially my amazing wife Claire Rigali who spent the day managing a two year old and a five week old, so I had the time and space to complete this challenge. She had a lot harder job than me!

I have raised £4,279.82 so far. If anyone would still like to donate, you can do so via the link below: **https://uk.virginmoneygiving.com/GiorgioRigali**

This challenge has taken a lot out of me, so a rest from challenges is in order, but no doubt I'll be back to it with my next stupid idea soon! Stay safe. Giorgio."

Giorgio Rigali

A SOCIALLY DISTANCED VE DAY CELEBRATION

The wonderful residents of Follyfield Road held a quiz to celebrate VE Day and chose to support Rett UK in honour of neighbour Sarah Shaw who celebrated her birthday during lockdown. Here, resident Jane Skelt reports on their fundraising efforts:

"Follyfield Road in Banstead, Surrey is a cul-de-sac of just 22 houses. On Saturday 18th April 2020 the residents held a socially distanced pop quiz. One of our residents, Sarah Shaw, lives with Rett syndrome and is supported by your charity. It was agreed, by all who took part in the quiz, that we would donate some money to the Rett UK charity.

Plans were already underway to celebrate VE Day on Friday 8th May. The road was decorated with flags and bunting and some residents dressed in outfits from the era. We held a socially distanced front drive party with bingo, quizzes and music, again turning it into a fundraising event for Rett UK. The weather was glorious with the sun shining brightly. Every household donated prizes and we had a good old sing song with flag waving.

Chris Carter, our MC, and his wife Linda, our main organisers, kept everything running smoothly, and worked incredibly hard calling the bingo, running the quiz, and playing music.

The day started at 11am with 2 minutes silence followed by the last post. Chris made an emotional speech and throughout the day we heard music from the war years, listened to Churchill's speech and heard music that residents had requested. The day ended with everyone singing Land of Hope & Glory and waving our flags.

Everyone was so very generous supporting Sarah and in the end the final total raised, from both events, was a wonderful £1,310.

We all remember, with fondness, a glorious day, not only remembering those who died and suffered to give us our freedom but also because we raised money to support a very worthy cause, 'Sarah's charity', Rett UK."

Residents of Follyfield Road;
Top left: Sarah Shaw;
Top right: Chris and Linda Carter

MY LOCKDOWN FUNDRAISER

by Charlotte Truss

Charlotte Truss

During the first couple of weeks during lockdown it was very easy to think of all the things I was unable to do as opposed to the things I could not.

I have always enjoyed watching the news, in fact I watch it every morning whilst eating breakfast. However, throughout the beginning of the lockdown period it wasn't the news I was used to. I became quite concerned and communicated with my support staff via my eye gaze about what I had seen on the news and how it would affect me. COVID-19 became a threat to me and they became a high risk of catching the virus due to health reasons. I was unable to continue activities I would normally carry out on a weekly basis and I was confined to my flat in Portishead. Everything seemed very negative.

Each day I was able to stretch my legs and get some fresh air on the piazza. This was the only other place I was able to go other than inside my flat.

After around three and half weeks I started hearing a lot about Captain Tom on the news. It was one of the first positive things I had heard in a while. I decided that I wanted a challenge too. I was very motivated. Rather than a couple of laps around the piazza I wanted to push myself and set a goal that I didn't even know would be possible until I tried. So, I took to Facebook to set up a fundraiser. With the help from mum, dad and lots of friends and family my goal was been shared around 100 times. I was going to walk 70 laps in 7 days to raise money for a charity I am very close to – Rett UK.

Each day I would head out on the piazza in all weather conditions with my two members of support staff to complete as many laps as possible. The goal each day was 10 laps sometimes I exceeded it and others I was under but at the end of the week I had completed all 70 laps!

I was so proud of myself and I know everyone around me was proud too. Altogether I managed to raise £1,271.00 for Rett UK.

Now that lockdown rules are starting to lift, I have continued walking every day and I've become very strong and enjoy taking different routes, seeing different areas and the sun shine.

Charlotte's support worker, Kirsty Hart told us: "I would just like to take this opportunity to say, Charlotte is a fantastic lady and very inspirational, Charlotte's 'will do' attitude continues to amaze the whole staff team in everything she achieves."

Thank you Charlotte and for also raising £140 through your birthday fundraiser.

DESIGN4RETAIL

Thank you to Design4Retail Ltd for choosing Rett UK as Charity of the Year!

During the year the wonderful staff have raised £406.92 undertaking bake sales, raffles, walks, fun runs, car washes and lunches! The team also completed the DFlycra cycling/running challenge.

Three members of staff (Dan, Poppy and Vanessa) were due to complete the London Marathon and Manchester Marathon which have been postponed. Dan, Poppy and Vanessa decided to complete the 2.6 challenge instead, sharing the 26.2 miles between them (running 8.73 miles each) and raised £350.06. Design4Retail supported Rett UK in honour of someone special whose family member is an employee.

Dan, Emily and David

Tim and Steve

THOMAS' 2.6 CHALLENGE

Leann de Belder, Thomas' mum reported: "Since lockdown Thomas has missed some of his weekly activities – swimming, Gymboree – but we've kept exercising in the home, our garden and then locally. Thomas is just 2 years old but much like his auntie Tamsin was at a similar age has bounds of energy! With his parents, he set out to run/walk/move forward for 26 non-stop minutes as part of the 2.6 challenge on 26th April, the date that should have been the London Marathon 2020.

A fine morning and despite a slow start, Thomas got into some rhythm, pumping his arms furiously for maybe 5 minutes and then noticed a car (or was it a dog?). "Come on, Thomas!" his support crew (parents) urged. Thomas kept going and even ignored a field filled with sheep and lambs on his path forward. 26 minutes and 1.5K later we had a happy boy content with his wiggly worm snack reward.

Through his endeavours, Thomas raised £329.78 for Rett UK, and wishes the very best for his auntie Tamsin, others with Rett syndrome, their carers and those scientists searching its cure."

Thomas with his mum and dad

THANK YOU TO YOU, AND YOU AND YOU...


Lottie Townend


Lottie and her family


Jude Drinkwater

The very talented **Lottie Townend** challenged herself to learn a new dance every day throughout lockdown in May and uploaded a video of herself performing it onto Instagram and Facebook. Lottie raised a whole lot of awareness and £293.75 in donations. On day 31 her mum Gill, dad David and sister Alice all joined Lottie's grand finale dance, having spent much time practising! Lottie told us: "During May I decided to challenge myself to learn a new dance each day and film myself performing them to upload on my social media accounts! These dances were a mix of styles including K-pop covers and having fun with my own choreography! I even managed to persuade my family to join in so make sure to look out for a familiar face in my last video! For each dance, I donated and fundraised money for four different charities – The Trussell Trust, Refuge, HARP Southend, and of course Rett UK! I was amazed that I was able to raise a total of £800, of which £293.75 was donated to Rett UK! Thank you so much to everyone who donated!"
You can check out all the videos on Lottie's Instagram **@lottietownend**.

Donations totalling £1,300 received in loving memory of **Jude Drinkwater #JudetheDude**.

Hannah Spink raised £166.24 in support of her planned marathon inspired by lots of special children.

Dominic Taylor-Jones, a long standing supporting of Rett UK, ran 3,650 miles for Rett UK and raised £92.50, in honour of someone special.

Lauren Barcroft raised the roof for Rett syndrome during lockdown with quizzes and dancing in honour of her dear sister, Carly and raised £352.50.

Stacey Weeden was due to undertake the Bristol 10k which was cancelled. Not to be deterred, Stacey decided to run her own 10k during lockdown and raised £631.25 in honour of her sister Hayley.

Staines Congregational Church held a Charity Coffee Morning and raised £138.

Elisha Clarke

Alfie Sammon

Esme Davison-Hoult

Sincere and heartfelt thanks to all our supporters!

Romford Mail Centre donated £500 in honour of Olivia Coster.

Congratulations to **Eileen and Allen Aitchison** on their Golden Wedding Anniversary and thank you for donations totalling £150 in honour of their granddaughter, Elisha Clarke. We hope you can have your celebrations soon.

The Tuesday Club at the Holy Navity Church, Mixenden for their donation and continued support in honour of Elisha Clarke.

Alfie Sammon allowed his mum to shave his head in lockdown and donated £50!

Laian Najjar raised £400.09 whilst raising awareness in memory of her nephew Kai.

Marie Maitland knitted a scarecrow and raised £80.

Donations from **Mrs Chris Barned** in lieu of birthday gifts, in honour of her great-niece Emily Slugocki.

Janice Dawes requested donations in lieu of birthday gifts and raised £237.50 in honour of her granddaughter Maisie. Happy birthday and we hope your celebrations can go ahead soon.

Anna Brassington raised £37.50 with her skipping challenge in honour of her daughter Emma.

Easby Chapel donated £500 in honour of Esme Davison-Hoult

Donations in lieu of birthday gifts for **Esme Davison-Hoult** totalling £100. Happy birthday wishes Esme!

Mendip Lodge raised £1,043 in honour of Phoebe.

Kay Beadle has been very busy during lockdown creating unique and very beautiful pieces of jewellery from fused glass. Kay has generously donated all profits, totalling £375 to Rett UK in honour of her daughter, Katie.

Donations received in loving memory of:

Mrs Jean Truss
Bruce Heath
Charlotte Jones
Pauline Budd
John Smeeth
Eileen Middleton

To Our Wonderful Fundraisers…

GOOD LUCK

Our London Marathon 2020 runners taking part in the rescheduled event on Sunday 4th October:

Katy Cox
Running for her daughter, Freya.
https://uk.virginmoneygiving.com/KatyCox5

Tom Gander
Running for his niece, Hana.
https://www.justgiving.com/fundraising/Tom-Gander1

Louise Stevens
Running for her daughter, Savannah.
https://uk.virginmoneygiving.com/LouiseStevens15

Mario Barbosa
Running for his colleagues' niece.
https://www.justgiving.com/fundraising/mario-barbosa

Peter Duncalfe
Running for his niece, Rosalie.
https://uk.virginmoneygiving.com/PeterDuncalfe

Team Brighton Marathon 2020:

Ed Louttit
https://www.justgiving.com/Edward-Louttit

Darren Barnes

David Mash

Lauren Barcroft

Andy Barcroft

Team BM Ride 2020:

Christopher Collins
https://www.justgiving.com/fundraising/Christopher-CollinsBrightoncyclemarathon

Clive Hayward
https://www.justgiving.com/fundraising/clivehayward318

Pete Davies

Tim Bowry

Thank you to our Facebook fundraisers:

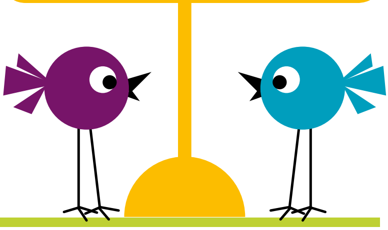
Kay Beadle
Stewart Catt
Rebecca Day
Claudia Emma
Abigail Jones
Sarah Jones
Gary Queen
Charlotte Truss
Terry Turton
Claire Wasp
Jessica Williams

If you would like to donate to us via Facebook, please visit **donations.fb.com** for details

facebook

DIRECT DEBIT DONATIONS

Thank you to everyone who has either set up or increased their direct debit donation.



COULD YOU BE A RETT UK CHAMPION?

There are many ways you can help:

OCTOBER AWARENESS 2020

October is Rett Syndrome Awareness Month. See pages 38 & 39 for fabulous ideas on how you can help.

BIG GIVE 2020

The Big Give Christmas Challenge is back! See page 40 for details.

VIRTUAL EVENTS AND FUNDRAISING PLATFORMS

There are lots of ways you, your friends and your families can fundraise during the coming months. See opposite pages for easy (and fun!) fundraising ideas you can do from home.

We love to hear about our supporters and any events you are planning. Please let us know about your event so that we can support you every step of the way.

FUNDRAISE FROM OUTBREAK..

The outbreak of coronavirus is affecting all our lives in lots of different ways. If your fundraising plans have been postponed or cancelled, we've put together a selection of ideas for virtual fundraising that you can do from home instead. There are lots of ways you, your friends and your families can fundraise during this period. **https://www.rettuk.org/fundraising-for-rett-uk-during-covid-19-outbreak/**

Here are some ideas:

Amazon Smile

Amazon donates 0.5% of the net purchase price of eligible purchases to Rett UK. Support us by starting your shopping at Amazon Smile. **https://smile.amazon.co.uk/**

Easyfundraising

Raise donations for Rett UK whenever you shop online. **https://www.easyfundraising.org.uk/causes/rettuk/**

Ziffit & VirginMoney Giving

Turn unwanted goods into donations for charity. **https://uk.virginmoneygiving.com/giving/worldofbooks/charities/**

amazonsmile

easyfundraising feel good shopping

Virgin moneygiving

ziffit.com

HOME DURING THE COVID-19

Virtual Events

All the major fundraising platforms (Virgin and Just Giving) are allowing any kind of virtual event to help charities raise lost income from cancelled events.

If you're stuck for ideas you could you...

- Take on a family challenge to see who can run up the most flights of stairs
- Tackle an indoor assault course
- Create a colouring competition
- Host an online charity quiz for friends and family – Houseparty has some excellent games that everyone can play on voice chat
- Set yourself a new challenge to complete every day
- Learn something new or improve a skill
- Donate the money you've saved from not buying your morning coffee on the way into work or from not buying as much fuel for the car

The ideas are endless... please share yours!

Auction or Sell Unwanted Items

Now is a great time to declutter, and working through your possessions is a chance to remember memories associated with them. Sell your clutter on eBay, or go to a website like Music Magpie, which will give you cash in return for your old CDs and DVDs. Donate the money you make to Rett UK.

Donate Your Commute or Other Expenses

Many of us are finding that we are working from home or cancelling activities outside of the house. This may mean that you find that we are saving money on travel or other expenses. If you are able, you could consider donating those savings to Rett UK.

Coronavirus Swear Jar

Put a donation into the jar whenever you or someone in the house uses the word 'coronavirus' and watch the money come flooding in.

Direct Donations

If you would like to make a donation, here are our other direct donation details:

Bank Account: **Metro Bank, 10-20 Castle Street, Luton LU1 3AJ**

Account name: **Rett UK**

Account No: **32450725**

Sort Code: **23-05-80**

Reference: **Please quote your name/ company**

PayPal payments: **info@rettuk.org**

To discuss your ideas or opportunities with a member of the team, please call **01582 798 910**.

Events for 2021 You Can Get Involved In...

BRIGHTON MARATHON RIDE 2021

6 CHARITY PLACES

Sunday 18th April 2021

Taking place on Sunday 18th April 2021 a few hours before the BM10K and Brighton Marathon, BM Ride will offer cyclists of all abilities the exclusive opportunity to enjoy the sights of Brighton city centre and the seafront on closed roads over a 50K distance.

Whether a keen cyclist who is heading out for a group ride, a family wanting to ride together or someone looking for a new challenge, BM Ride will have something for you.

BRIGHTON MARATHON 2021

5 CHARITY PLACES

Sunday 18th April 2021

Over 12,000 runners take part in the marathon each April, enjoying a course that starts in Preston Park at 9.45am, snakes its way through the city centre, along the glorious seafront and finishes at the iconic Madeira Drive in front of thousands of cheering spectators.

The course bests for the men and women are well under 2hrs 10min and 2:29, making it the second-fastest marathon in the UK. It is also the second-largest marathon in the UK and eighth-largest in Europe.

Since the first Brighton Marathon in 2010, the Brighton Marathon has grown dramatically to become the Brighton Marathon Weekend attracting larger numbers of runners and spectators each year to the city.

LONDON MARATHON 2021

3 CHARITY PLACES

Sunday 25th April 2021

We are delighted to have 3 places in the 2021 London Marathon. The route takes in the breath-taking views of the UK's famous capital while making your way around the 26-mile course of the London Marathon. If you would like further information or to enter our ballot please email **fundraising@rettuk.org**

If you are interested in taking part in any of these events, or if you have secured your own place and want to be part of #TeamRett, please email **fundraising@rettuk.org**

Time to get creative!

RETT UK CHRISTMAS CARD COMPETITION

This year we would like to add to our Christmas Card offer with a card designed by someone with Rett syndrome or a sibling. The competition is open to adults with Rett syndrome and children with a winner for each age group and an overall winner.

Age group winners will receive an Amazon voucher for £10 and the overall winner one for £30. We will print the overall winner's design and will have it for sale on our website. We will also feature the designs on our social media platforms.

The age groups are:

- Siblings 10 and under
- Child with Rett syndrome 10 and under
- Siblings 11-18 years
- Young Person with Rett syndrome 11-18 years
- 18+ (people with Rett syndrome, not siblings)

The designs can be done using any format or materials including eye gaze drawings, ideally on an A4 size piece of paper.

Please send your entries to:
Rett UK, Victory House, Chobham Street, Luton LU1 3BS no later than **31st August 2020**.

Please do not fold your designs and ensure you include the person's name, age, address and plus a telephone number for a parent or carer.

The winners will be chosen by the Rett UK trustees and staff team at their AGM on 26th September 2020. Winners will be contacted by telephone, a certificate and the voucher will be sent to them and winning designs shared on our social media platforms.

Any queries please contact **info@rettuk.org**

We look forward to seeing your designs!

CHRISTMAS CARDS

Our Christmas cards are available to purchase on our website and can also be ordered directly from the office. Your support is very much appreciated as every purchase helps fund Rett UK.

For prices and to place your order, please visit **www.rettuk.org/shop** or contact the office by email **info@rettuk.org** or call **01582 798 910**.

We will also have an order form available in the next issue of *Rett News*.

MEMBERSHIP

BECOME A MEMBER OF RETT UK

FAMILY COMPANION – HAVE YOU RECEIVED IT?

If you have not received a copy of this useful resource, which is packed with information, it might be that you have not yet subscribed to be a member of Rett UK.

Membership is free and it's really simple to join. Please complete our membership form via our website or contact us on **01582 798 910**.

It only takes a few minutes of your time and ensures that you receive free copies of our newsletter, invitations to our regional and national events AND your free copy of the Family Companion.

MEMBERSHIP FOR ADULTS WITH RETT SYNDROME

We have been reviewing the information currently received by our members and have recognised that it is very valuable for support staff and paid carers, particularly those living within residential care or supported living environment and not just our family/carers.

To ensure that information is shared with these workers and anyone else who may find the information useful, we have introduced a membership for adults with Rett syndrome.

This new membership will ensure that individuals will receive copies of *Rett News* on a quarterly basis and their own copy of the Family Companion, which will be available for their support staff to read.

If your daughter/son has recently moved into either a residential care home or support living service, please contact us so that we can activate their membership.

If you would wish to have further information regarding the membership, please contact a member of the Family Support Team, who will be able to help.

Email **support@rettuk.org**
or call **01582 798 911**.

When your work is done, ours can still continue... if you create a legacy

We exist to offer support, information and practical advice needed to help families deal with the challenges that Rett syndrome presents. We're here not just for the person with Rett syndrome but for the family as a whole. A diagnosis of Rett syndrome impacts everyone and we are here when we are needed, both now and in the future.

Bequeathing Rett UK as little as 1% of your assets in a will can be straightforward. Please act now!

By doing this, you are ensuring that help and support from Rett UK is always available for the person for whom you care and have love.

For more information, please contact **becky.jenner@rettuk.org**

Collection Tins

We have updated our collection tins with our new address details. If you have a collection tin, please contact us so that we can provide you with a new collection tin label.

Please contact **donna.tinch@rettuk.org** or telephone **01582 798 910.**

DON'T FORGET!

Notify us if you move home, change your phone number or email address.

Email:
donna.tinch@rettuk.org

Specialist Post Mortem Examinations

Research into Rett syndrome can greatly benefit from a specialist post-mortem from brain donation.

Information packs are available from our office.

If you wish to give consent for donation, please contact Dr Claire Troakes or Sashika Selvackadunco on **020 7848 0290**. If it is out of usual working hours, please leave a message and a member of the team will contact you as soon as possible.

Post-mortem examinations can take place up to 72 hours after the person's death.

RETT UK 300 CLUB

JOIN NOW!

Think of this as a lucky chance for you and an opportunity to raise funds for Rett UK.

We still have some numbers left so if you would like to buy some numbers and be in the monthly draw please contact our 300 Club organiser, Yvonne Oliver at **yvonne.oliver17@gmail.com**

Yvonne will send you the necessary details and a registration form.

THANK YOU TO ALL OUR DONORS!

Huge thanks to all those who have supported us throughout 2020 by paying a donation either monthly or annually.

Thank you to those donating via direct debit, whether its £2 or £10 a month, it all counts.

If you would like to make a donation to Rett UK please fill in the form on page 59 of this issue of *Rett News* or email **info@rettuk.org** or call us on **01582 798 910**.

Thank you.

300 Club Results

Well done to all those whose numbers were pulled out of the velvet bag!

The winners are:

MARCH 2020

Prize	Amount	No.	Winner
1ST PRIZE	£30	No: 90	Andrew Slugocki
2ND PRIZE	£20	No: 166	Dieter Teubler
3RD PRIZE	£10	No: 239	Elizabeth Antonakopoulos

APRIL 2020

Prize	Amount	No.	Winner
1ST PRIZE	£30	No: 234	Kim Spencer
2ND PRIZE	£20	No: 11	Peter Mather
3RD PRIZE	£10	No: 216	Ann Luntley

MAY 2020

Prize	Amount	No.	Winner
1ST PRIZE	£30	No: 99	Gwenda Dimmock
2ND PRIZE	£20	No: 21	Deborah Sykes
3RD PRIZE	£10	No: 86	Paul & Faith Tutton

JUNE 2020

Prize	Amount	No.	Winner
1ST PRIZE	£30	No: 141	Joan Langdown
2ND PRIZE	£20	No: 137	Mr & Mrs Graeme Forrester
3RD PRIZE	£10	No: 242	Gwenda Dimmock

theBigGive
CHRISTMAS CHALLENGE 2020

THE GIFT OF SUPPORT & WELL-BEING THIS CHRISTMAS

Please see page 40 for details about how you can double or even quadruple your donations.

STAGE ONE NOW OPEN!

WE ARE COLLECTING PLEDGES – DEADLINE 28TH AUGUST AT 5PM

OUR BANK DETAILS

For direct debits and to pay cash or cheques into our account, our account details are:

Bank: **Metro Bank**

Account Number: **32450725**

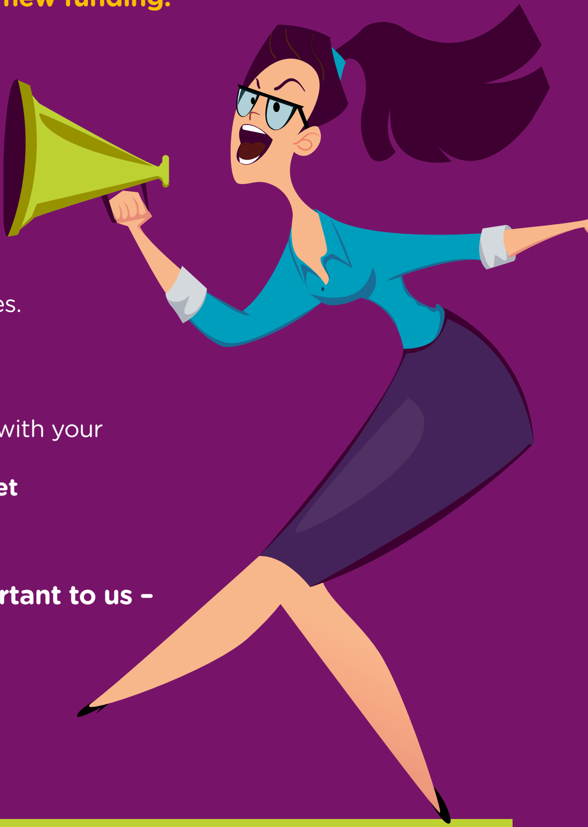
Sort Code: **23-05-80**

Account Name: **Rett UK**

Your feedback please!

RETT UK FAMILY SUPPORT SERVICES EVALUATION JUNE 2020

Your feedback is VITAL so that we understand what is working and where there is room for improvement, as well as being able to report back to our funders who need to understand the impact of the work they are supporting and to attract essential new funding.



Please spare a few minutes to answer these questions which cover the last 12 months. You do not have to complete your name or provide contact details unless you would like one of the team to contact you with regard to your responses.

Online it only takes on average 8 minutes. Please use the link: **https://www.surveymonkey.co.uk/r/SupportServicesJune20**

or complete the paper survey included with your *Rett News* and return to:
Rett UK, Victory House, Chobham Street
Luton LU1 3BS

Thank you! Your voice is very important to us –

This is your charity

I'd Like to Make a Donation to Rett UK

Instruction to your Bank or Building Society to pay by Direct Debit

Please fill in the whole form using a ballpoint pen and send it to:

Rett UK Ltd, Victory House, Chobham Street, Luton, Bedfordshire LU1 3BS

Name(s) of Account Holder(s)

Bank/Building Society Number

Bank/Building Society Sort Code

Name and full address of Bank/Building Society

To the Manager of:

Address:

Postcode:

Please pay BPS Re Rett UK Ltd Direct Debits from the account detailed in this Instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this Instruction may remain with BPS Re Rett UK Ltd and, if so, details will be passed electronically to my bank/building society.

Service User Number

2	7	4	3	4	5

Reference No (office use only)

Banks and Building Societies may not accept Direct Debit Instructions for some types of account.

Signature

Date

I would like to make a regular monthly donation of:

☐ £2 ☐ £5 ☐ £10 ☐ Other amount (please specify) per month

Surname __________ Forename(s) __________

Address __________

__________ Postcode __________

Telephone __________ Email __________

Rett UK would like to send you information about our work, events and merchandise. Please tick here if you don't want this information ☐

Gift Aid Declaration Add 25% to your gift without paying a penny more. Tick the Gift Aid box and for every £1 you give, we can claim 25p back from HM Revenue and Customs.

☐ YES I want all donations I've made over the past 4 years and all future donations to be treated as Gift Aid until I notify you otherwise.

To qualify for Gift Aid you must pay UK income tax or capital gains tax at least equal to the amount Rett UK will reclaim in the tax year. Please let us know if you change your name, address or tax status by calling 01582 798 910.

The Direct Debit Guarantee

THIS GUARANTEE SHOULD BE DETACHED AND RETAINED BY THE PAYEE

- This Guarantee is offered by all banks and building societies that accept instructions to pay Direct Debits.
- If there are any changes to the amount, date or frequency of your Direct Debit BPS Re Rett UK Ltd will notify you 10 working days in advance of your account being debited or as otherwise agreed. If you request BPS Re Rett UK Ltd to collect a payment, confirmation of the amount and date will be given to you at the time of the request.
- If an error is made in the payment of your Direct Debit, by BPS Re Rett UK Ltd or your bank or building society you are entitled to a full and immediate refund of the amount paid from your bank or building society – If you receive a refund you are not entitled to, you must pay it back when BPS Re Rett UK Ltd asks you to.
- You can cancel a Direct Debit at any time by simply contacting your bank or building society. Written confirmation may be required. Please also notify us.

theBigGive
CHRISTMAS CHALLENGE 2020

STAGE ONE NOW OPEN!

WE ARE COLLECTING PLEDGES – DEADLINE 28TH AUGUST AT 5PM

THE GIFT OF SUPPORT & WELL-BEING THIS CHRISTMAS

Our target to raise for this year is £20,000

For more information, please see page 40

35
YEARS
1985 2020

Rett UK
Support today, hope for tomorrow

RETT UK LTD, VICTORY HOUSE, CHOBHAM STREET, LUTON, BEDFORDSHIRE LU1 3BS
GENERAL ENQUIRIES: 01582 798 910 / info@rettuk.org • www.rettuk.org