Rett News

Support today, hope for tomorrow

www.rettuk.org
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RETT SYNDROME
GLOBAL AWARENESS MONTH
October 2021
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undetected until major regression occurs at around one year of age, when children may lose acquired skills and become withdrawn.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: Rachel, Mick, Grace and George

CEO Welcome

by Robert Adamek

Can I start by saying thank you once again to all those that helped us reach our 2021 Big Give pledge amount for our Rett UK Advocacy, Achieving the Best Outcomes campaign (pages 7-9). The project is very important to us as it tackles a growing and fundamental need for the people that we support from ensuring Social Care and NHS Continuing Health Care funding is being assessed and awarded correctly to ensuring the most appropriate settings with Education, Health and Care Plans that are fit for purpose.

Last year's project, 'Rebuilding family life post Covid-19', is still live and the last two webinars are being recorded and will be published shortly. If you haven't had a chance, please look over the carefully created resources that are there to help you building resilience, self-esteem and confidence to deal with the challenges you are facing.
www.rettuk.org/rebuilding2021

I think that if the last 18 months has taught us anything it's the realisation of just how important our friends, neighbours and people that we care about are. Striving to build better links and working together with various organisations for the benefit of the Rett community is very important to us and we are currently committed to doing that through a variety of ways:

- Regular meetings with the Rett Syndrome Associations world leader's forum where we share best practice, latest's resources and ideas.
- Close partnership work through the Rett Disorders Alliance covering our Health checklist and joint events. **www.rettuk.org/healthchecklist**
- Launching our professional communication network – The Network is supported by Rett UK's Communication and Education Project and is intended for all those who work with people with Rett syndrome, in any setting, with any age group and at any level of experience, in any region of the UK. **www.rettuk.org/CPN**

Something that has been difficult has been the cancellation of major fundraising events and a low uptake on what would normally be sell-out events. I realise running events are not everyone's cup of tea, so we have quite a few ways to get involved with some cool fundraising ideas for this October's Awareness Month (see page 4).

This year the Rett UK Annual General Meeting will be held on Saturday 18th September 2021, online using Zoom. If you have a question you would like to put to the trustees you can call me on **07812 998 110** 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.

None of what Rett UK do would be possible without the amazing team we have, and I am immensely proud of them and their achievements. Our work is vitally important, and we continue to strive to bring positive change and improvement for the people we support and their families.

Hope to see you soon.

Robert Adamek

Robert Adamek, CEO

OCTOBER IS…

Rett Syndrome Global Awareness Month

October is Global Rett Syndrome 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.

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 or an afternoon tea with friends?

Street parties

What better way to raise awareness 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 we head towards the end of October we also have Halloween! 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 why not hold a purple pumpkin competition as part of your street party or as a stand-alone event?

Make

Are you feeling crafty? Maybe you've been wanting to try out something new for a while. Or maybe you have been crafting for as long as you can remember, and it just makes you happy! Either way, set yourself a challenge linked to your hobby through October.

Colours for Rett

October is Rett Syndrome Awareness Month

Rett syndrome is a neurological disorder affecting mainly girls with profound and multiple physical and communication disabilities

Those with Rett Syndrome are totally reliant on others throughout their lives

During October, wear something purple and/or green rather than your uniform & donate a minimum of £1 to help give a non-verbal child the gift of communication. A two day training event for families costs £1500

Support Rett Syndrome Awareness Month
www.rettuk.org/octoberawareness

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

RETT SYNDROME GLOBAL AWARENESS MONTH *October 2021*
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**

#LivingWithRettSyndrome
#RettSyndromeAwareness
#RettUK

Matched Giving

Don't forget to enquire about Matched Giving with your employer – whether you're raising money in the office or outside of work, ask your employer about matched giving. Lots of our fundraisers have doubled the amount raised by their employer so don't be afraid to ask.

Want some advice on your idea that is not listed above? Email **info@rettuk.org** or call **01582 798 910** and we can help you with your plans!

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**

Rett UK AGM 2021

Save the date!

Rett UK Annual General Meeting

Saturday 18th September 2021

This year the Rett UK Annual General Meeting will be held on Saturday 18th September 2021 at Resource for London, 356 Holloway Road, London N7 6PA and will be available for our members to attend online using Zoom.

As usual we will send out the voting papers at least 21 days before the meeting. We shall do this prior to 29th August. 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 4th September.

You are very welcome to join us during the AGM which will be between 12.30pm and 1pm using the Zoom link **www.rettuk.org/agmmeeting2021** which you will also 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 2021. 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 our CEO, Robert Adamek, on **07812 998 110** 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 18th September so you can be involved.

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**

Thank you!

theBigGive
CHRISTMAS CHALLENGE 2021

Advocating for better outcomes for people with Rett syndrome

The Big Give CHRISTMAS CHALLENGE is back!

For the sixth year, Rett UK is applying to take part in the Big Give Christmas Challenge; the UK's biggest online match funding campaign where donations can be doubled and even quadrupled!

Last year, thanks to your amazing support, we raised £20,326 for our project 'Rebuilding Family Life Post COVID-19' which has enabled us to provide dedicated webinars and facilitated group discussions focusing on dealing with the emotional toll that COVID-19 has wrought on our families. We were also delighted to be able to provide more intensive 1-1 support for families with the most complex issues.

This year we are hoping to raise £25,000 to help support part of our core service which is providing advocacy for people with Rett syndrome and their parent carers. Rett UK Advocacy, Achieving the Best Outcomes is advocating for better outcomes for people with Rett syndrome in health, social care and education. It is fundamental to what we do. Families are exhausted by fighting a system that was already massively under-resourced, hard to navigate. COVID-19 has hugely exacerbated the issues and added to the crisis.

Rett UK Advocacy, Achieving the Best Outcomes

The aims of this work are that:

- Children/young people with Rett syndrome are supported to achieve their best possible educational and developmental outcomes in the most appropriate setting with an Education, Health and Care Plan that it's fit for purpose.
- People with Rett syndrome are able to achieve optimal health and well-being, with access to health services and social care services that provide appropriate treatment, therapies, equipment. Ensuring Social Care and NHS Continuing Health Care funding is being assessed and awarded correctly, and that the support provided is meeting needs.
- Parent Carers feel supported in navigating the maze of health and social care services. They are getting the best out of what is available, and it meets the social, educational and health needs of their daughter/son.

We are aiming to raise a total of £12,500 in online donations between midday on #GivingTuesday the 30th November 2021 and midday on Tuesday 7th December 2021. Donations can be any amount up to £5,000 but you must not donate online during this period if you have already made a pledge to support the project back in July/August 2021.

Your support for the Big Give in the past has been amazing so we hope we can call on you again to help us with this crucial work.

One donation, twice the impact!

Thank you.

What is the Christmas Challenge?

The Christmas Challenge (the UK's biggest online match-funding campaign) helps UK-registered charities to raise funds for their projects by doubling donations when the campaign goes live at midday (12pm) on Tuesday 30th November 2021. For example, a £100 online donation made to a participating charity during the Christmas Challenge can be doubled to become £200. With Gift Aid where eligible that becomes £225!

The match funds

The matching pots used to double donations for charities taking part in the Christmas Challenge are made up of a combination of funds. These are funds sourced by the charity ('Pledges') and funds sourced by the Big Give ('Champions') which are available if we are successfully selected by a Champion. We can still take part in the Christmas Challenge even

if we are not selected by a Champion. Pledge funds and Champion funds (if selected by one) combine to form the matching pot and are used to double donations. Donations are matched by our Pledge funds until these are exhausted and then donations are doubled by Champion funds. You can watch a short video explaining how it works at: **https://www.thebiggive.org.uk/s/christmas-challenge**

How would it work for you?

As a Pledger, you commit a Pledge promise to our matching pot. Your funds will be used to match online donations when the campaign goes live. Research shows that 84% of donors are more likely to give in a match funding campaign and that donations are on average 2.5 times bigger. By committing a Pledge promise you will help us to inspire donors to support Rett UK.

If we are selected for Champion funding, your Pledge promise could be worth up to four times its initial value once it's added to the Champion funds and online donations. This makes the Christmas Challenge one of the most attractive times to make a contribution to Rett UK.

Additional information

- In December, we will let you know the outcome of the Christmas Challenge and ask you to fulfil your Pledge promise. The timeline for fulfilling the pledge (i.e. transferring the funds to us) is between 7th December 2021 12pm - 14th January 2022 at 5pm.
- Please note that if you pledge to Rett UK you will not be able to make an online donation to us as part of this campaign because your pledge will be used to match these donations. You can find full details of the Christmas Challenge 2021, and how your pledge will enable us to be part of the UK's largest Matched Funding Challenge, at: **https://www.thebiggive.org.uk/**

Thank you for your support and please don't hesitate to ask if you have questions about the Christmas Challenge and what being a Pledger could mean to Rett UK.

Warmest wishes,

Robert Adamek, CEO

robert.adamek@rettuk.org

Support Round Up

by Julie Benson

Improving knowledge and understanding of Rett syndrome

Online Family Get-Together

Our online events are taking a break during the summer holidays, we will be back in September with new events, starting with an Online Family Get-Together in Scotland and Northern Ireland. As with the Online Regional Events, the aim is to link local families together, in an informal way as we would do with our face-to-face regional events, whilst primarily they are for people living in the regions, people from all over the UK are welcome to join these online events.

We are all looking forward to when we will be able to recommence our face-to-face regional events and we are tentatively planning for these popular events to start again in 2022.

Coaching

Janie Beaumont is a qualified Life coach and naturopath nutrition practitioner. Her life coaching skills enable her to practice a holistic approach to her work. She is also mum to twins, Olive and Tilda. Olive has Rett syndrome, so Janie knows first-hand the challenges families face every day.

These are coaching sessions not counselling; identifying goals and supporting you to develop strategies to help you achieve them. Please note that we have limited spaces and consideration will be prioritised based on the needs of the families.

The 1:1 coaching sessions are proving very popular with families and we have had several already sign up to the programme. We do still have limited spaces so if you feel this is something you may wish to consider now or in the near future, please do get in touch with us by contacting Julie on **01582 798 911** *or* **julie.benson@rettuk.org**.

Noodles

What are noodles you may ask? Noodles are a set of short videos that may help with the incredible overwhelm of daily life for those affected by Rett syndrome

These Noodles are on the Rett UK website and are a great resource for when you are feeling a little frazzled and overwhelmed: **https://www.rettuk.org/noodles/**

Beer & Banter

We have many regulars now joining us for the Beer & Banter sessions, which are a great opportunity for dads to get together too! These sessions are an opportunity to speak to other dads, share what it's like being a dad with a daughter/son with Rett syndrome, to share experiences and knowledge, or just to chat.

Don't be put off by the title, Beer is not compulsory, you can enjoy a cuppa, non-alcoholic drink, or an alternative tipple, whichever you would prefer.

If you would like to join us, the next event is on 13th September at 8.00pm. To join the groups, go to: **https://forms.gle/dk18moPQvha2QRJF7** and register, you will be sent an email with the link to join the group.

Future Planning

We are taking a long hard look at our Support Services, evaluating what we are currently doing against what we would like to do in the future, and we have some exciting ideas, which we think you will like. However, what we really would appreciate is as much feedback from you as possible. I can hear the sighs from here... not another survey! We really do want to hear from you about your experiences of using the Family Support Services and how you think we could improve what we currently do, and to let us know what we do well and what else you think we could do to help and support you as a whole family. We would love to hear from parent/carers, siblings, grandparents, aunts and uncles and friends too, who may have used our services previously or who may wish to use us in the future.

We will be making the survey available online shortly and we can also arrange for a paper copy to be posted to you if you prefer. We may also be giving some of you a call too, we really want you to have every opportunity to shape the future of Rett UK.

Your opinions really do matter to us, and we want to ensure that the services you receive from Rett UK are the very best!

Your feedback please!

RETT UK FAMILY SUPPORT SERVICES EVALUATION

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.

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.rettuk.org/survey2021** or you can fill in a paper survey. Contact Julie on **01582 798 911** or email **julie.benson@rettuk.org**

Thank you! Your voice is very important to us –

This is your charity

Maintaining Good Respiratory Health

As parents and carers, you will possibly have experienced in your child, young person or adult, chest or respiratory infections. These can be quite common and, in some cases, recurring, particularly during winter months.

Whilst in the young, there may be issues around safe eating and drinking, and a Gastrostomy may improve matters and reduce the number of recurrent chest or respiratory infections, people may still be susceptible to aspirations of saliva or vomit, even when no food or water is given orally.

We begin to understand the importance of good and robust respiratory health, and there are several things we can do to reduce risks of aspiration and of subsequent chest or respiratory infections and keep the chest as healthy as possible.

One of the first starting points for assessment is to establish if the person has any breathing difficulties such as breath holding or hyperventilation. We can also establish whether the person is a feeble or forceful breather too, as this can also impact on their ability to cough effectively and clear secretions.

Once we have established breathing patterns, we can then look to see whether the person has a good swallow action,

whether they are clearing their saliva or are drooling significantly or if the saliva is pooling in the pockets within the mouth.

We then need to look at their cough reflex. Is this strong and productive and enabling the person to clear any mucus that may be trapped in the throat or is this just sitting in the throat and not being effectively coughed up.

So, let's look at how we can address some of the potential issues above:

Drooling

Drooling is a symptom of impaired swallow, known as dysphagia. The oral and pharyngeal phases of swallowing are disrupted by various conditions, including Rett syndrome. Although we may see lots of saliva from someone with Rett syndrome there is no reason the believe that they produce any more than usual.

Drooled saliva is not helpful and makes the skin around the mouth moist and sore, and if the hands go to the mouth, they may also become wet and sore and require regular use of barrier creams to prevent skin breakdown and to prevent odour. Saliva that is left around will produce an unpleasant odour.

Pooling in the mouth and nose

Pooling is the term used for saliva that pools in the mouth, often with food residue from those who eat orally or may have small tastes of food. Pooling is saliva that is trapped in the pockets of the mouth or pharynx and is a sign that swallowing is limited or absent and the individual may have failed to clear the mouth and the throat.

Secretions collect in the gulley's between the gums and lips, the gulley's in cheeks, and under the tongue.

When tongues are used proficiently it ensures that saliva is moved around and swallowed, and not allowed to pool.

Saliva collected in the mouth with a gaping mouth increases the risk of bacteria entering the mouth and causing infections. To ensure this does not happen it is doubly important to have good oral health and hygiene, to prevent infections.

There is always a risk that pooled saliva may be inhaled, and depending on posture and position of head, there is also a risk that saliva may just run back and down into the airway, tilting the head back will increase these risks.

Detecting and facilitating swallowing

It is important to detect and facilitate swallowing throughout the day and that means looking at what is happening in all positions.

Remember that pooled saliva will be disturbed by movement. Ideally before someone is moved, turned over, or transferred it is essential that any pooled saliva is removed from the mouth. This could be with suction, preferably by helping them to allow the saliva to pour out of the mouth and wiping it away or helping them to swallow.

Having undertaken all the above people may still be having recurrent chest or respiratory infections so we should look at other interventions that will help with respiratory health, such as chest physiotherapy.

Exercise for people with Rett syndrome

People with limited mobility should still be encouraged, supported and facilitated to undertake physical exercises appropriate to their abilities to prevent ill-health.

Where possible, it is important that people are given opportunities to stand, either independently, or supported and where necessary with the use of a standing frame.

Standing or sitting upright will make someone take deeper breaths, and lungs work harder.

Positioning

Positioning and posture are extremely important for people with Rett syndrome. All equipment should be regularly re-assessed to ensure the posture is optimised. Aim to maintain tolerance of alternate side lying and supine (lying on back as opposed to lying on side) for as long as possible.

Suction

For people with little or no cough, there may be the need to use suction to remove secretions. Whenever suction is used then everyone would require their own assessment and protocol in place and staff trained to undertake suctioning with a recording process for how often it is used.

Chest physiotherapy

Percussion, vibrations and shakes are hands-on techniques performed to the chest to unstick and mobilise the mucus and aim to promote a better cough and drag secretions from the lungs. For someone who requires lots of manual techniques, you may find the need for equipment to take over the role of a member of staff. The techniques should not be performed without the assessment of a physiotherapist, to rule out any dangers and risks to the individual and to ensure families are taught correctly.

Prophylactic antibiotics

Prophylactic antibiotics are lower doses of antibiotics given to people regularly as a preventative measure to reduce the risk of respiratory infections. These can be very successful in people with Rett syndrome and may be something you wish to discuss with a consultant or GP if a person is having repeated infections. Prophylactic antibiotics, which will require some blood tests prior to be prescribed, are often used throughout winter months when there are increases in coughs, colds and flu.

More information about establishing and maintaining good chest health is available from Rett UK in partnership with Kay Coombes from ARCOS and Sian Midwinter from Midwinter Physiotherapy, who have helped to produce two new factsheets for our Family Companion and who both gave their time to be part of the Online Family Conference with their remarkably interesting and informative talks. All talks are still available to watch by visiting: **https://rett-uk-online-family-roadshow-2021.heysummit.com/**

Rett UK teamed up with our colleagues at Reverse Rett, to deliver a bitesize session around the importance of respiratory health for people with Rett syndrome. We had some very experienced parent panellists, Yvonne Milne, MBE, Sam Lacey and Melise Davison.

Their shared knowledge and experience were really helpful to other parents and highlighted the importance of preventative and supportive practices that can help to reduce some of risk of chest infections by good delivery a good respiratory protocol.

We appreciate this can be a big issue for families and people with Rett syndrome and we will be working on producing some good information and clear guidance around building and maintaining good respiratory health.

If you missed the live event, the session is available to watch here: **https://www.youtube.com/watch?v=PR6WBR4pVXA&t=2813s**

DON’T FORGET!

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

Email: **donna.tinch@rettuk.org**

Thank you!

Top 10 Tips for DLA and PIP Forms

Do you find completing DLA (Disability Living Allowance) and PIP (Personal Independence Payments) Forms overwhelming?

Applying for any benefits can feel, and often is, quite daunting. We hope that these simple tips will be helpful, however please bear in mind that we can also support you to complete the forms.

We can also support you with challenging the decision, if you feel it is not a reflection of daily life.

1. Not sure if you are entitled or not? Apply, you have nothing to lose.
2. Write EVERYTHING down about your child, no matter how small, this could make the difference to the success of your claim and the rate you are awarded.
3. Keep a diary of any care you are providing for a week before you complete the form, you may be surprised how much care is really needed.
4. Take your time completing the form, it may be worth completing and leaving for a couple of days, then re-reading it through.
5. It can be stressful, and you may feel you are repeating the same information over and over again, so do allow yourself breaks, if needed.
6. Don't be afraid to ask for support or help in completing the form, you don't want to make mistakes and delay your entitlements.
7. There is a lot of information that Rett UK can provide you with, so give us a call. Cerebra also have a very comprehensive guide that you may find helpful too: **https://cerebra.org.uk/wp-content/uploads/2021/07/DLA-cerebra-dla-guide-jun21.pdf**
8. Include as much supporting evidence as you can, letters, reports etc. Rett UK can also provide you with a supporting statement too.
9. Try to find a friend to talk to as it can be really difficult having to think about all the challenges your child has in such depth.
10. Take a photocopy of your completed form before you send it and remember to send recorded/signed-for delivery.

If you have any questions about completing you DLA or PIP forms, please do give us a call on **01582 798 911**. We are more than happy to help.

DO YOU HAVE QUESTIONS ABOUT BENEFITS?

Disability Living Allowance and Personal Independence Payment

DLA

PIP

Wednesday 29th September
10.15am to 11.15am

Join us for a general parent to parent Q & A/support session.

11.30am to 1pm

If have questions about Disability Living Allowance (DLA) or Personal Independence Payment (PIP) please join us for an expert led session.

Lizzie Batten, DLA advisor for Brighton based charity Amaze will be sharing her tips and insights into how to present the best case to ensure you are awarded the benefit at the right level and how to challenge decisions if you think they are wrong. Please check our website and Facebook page nearer the time for the link to join the Zoom session.

Universal Credit

UC

Tuesday 9th November
10am to 1.30pm

We have Jayne Knights, benefits expert with Renaissance Legal, online to talk to you, from 10am to 12pm, about Universal Credit (UC), including how to claim if your young person is still in full-time education.

There will be a 30 minute break followed by a one hour parent to parent Q & A/ support session.

Both sessions are delivered as part of our ongoing collaboration with Demelza Hospice and Battens Disease Family Association.

Christmas CARDS

Our Christmas cards are available to purchase on our website **www.rettuk.org/shop** and can also be ordered by filling in the order form on page 49.

Your support is very much appreciated as every purchase helps fund Rett UK.

Act Now! Scrap Care Charging and Introduce Free Home Care

Time to end the social care charging scandal

Social Care is unfair and a post code lottery. It is time for FREE home care. Thousands of disabled and older people throughout the Covid pandemic have experienced social care cuts and increases in care charging. Families and carers are struggling to make ends meet and pay the week's shopping bill. Others are being pushed into debt.

It really is a choice for some people between heating their home or eating or paying the care charges. As Sue explains: "Out of the blue in August, my son got a bill for £4,500. He's nineteen, profoundly disabled. He lives in a care home. I have no idea how we can pay for it. It would clear out most of his account, leaving him with as little as £100 a month to live his life for the rest of his life. We've yet to receive an explanation or how they expect us to pay, and I'm worried this is just the start."

Unlike the NHS, social care support is not free, and even people with a meagre income, including those on means-tested benefits, have to pay towards social care. Good social care support helps Disabled and older people to live fulfilling lives with choice, control and dignity to have meaningful relationships, and take part in community life.

Campaigners are, therefore, calling on the government to abolish social care charging and introduce free home care. In the interim, we are urging the government to ensure disabled and older people are not forced to pay for social care out of their benefits.

Take action and write to your MP, today:

1. Submit the form on the link below. It will find your MP: **https://actionnetwork.org/letters/introduce-free-home-care-and-scrap-care-charging?source=direct_link& Act Now – Scrap care**

2. Edit the template letter as much or as little as you want on.

3. Send it and share this action on social media!

MY HEALTH PASSPORT

Don't forget to make use of the Rett UK Health Passport which enables you to record and easily update everything that someone involved in your daughter's/son's care should know in one place.

Download the Health Passport here: **www.rettuk.org/healthpassport**

Charlotte in the kitchen of her new house; Below: Charlotte and Anneke's home

Charlotte's New Home

by Hilary Truss

A couple of years ago Charlotte and her supported living flat mate Anneke did some work with their care provider on what they wanted out of life.

This Life Plan was addressed for several reasons, primarily because it had become increasingly obvious that they had outgrown their current first floor flat which they rented from Golden Lane Housing (part of Mencap) and needed to move on; also, the facilities for the support team were less than ideal.

It turned out that they wished to continue living together in Portishead, North Somerset and Charlotte wanted a bathroom with a proper bath, something she has missed for the last 15 years or so!

Unfortunately, no housing association would consider providing a larger property to Charlotte and Anneke, as house prices in Portishead had increased considerably and it was not financially viable to do so. This was a challenge as Portishead provides a relatively level and accessible access to its high street, cafes and other facilities as well as being where the two ladies wish to continue living.

Sadly, Charlotte's Grandma passed away during lockdown and left enough money for my husband and I to put down a substantial deposit for a house; so, knowing this was the only way Charlotte and Anneke were going to get a bigger property in Portishead we went for it!

We managed to find a house on the level in the centre of town with a bedroom and wet room extension, small back garden and a drive big enough for two cars. We couldn't believe our luck and put in a cheeky offer in between lockdowns when the stamp duty holiday had just started which was accepted. The 1970s house used to belong to an elderly man who had died about a year before and the family were keen to sell by July 2020, when we purchased it.

The house required quite a bit of work to it to bring it up to standard as a supported living home and I felt I just had enough knowledge to project manage the renovation. Our first stroke of luck was finding a house with an extension, all be it one that needed some work to make it habitable. Our second stroke of luck was to find a father and son local builder who just happened to be available to do the renovation in the not too distant future.

The renovation began in October and the work we had to do included enlarging the downstairs wet room to make it a bathroom big enough for a bath and hoist for Charlotte, a new bathroom for Anneke, plus installing a completely new central heating system, the original being condemned! That gave me the opportunity to put a little extra heating in Charlotte's bedroom and bathroom as she feels the cold so much. Add new fire doors throughout and smoke detectors in all the rooms.

We were advised by the local authority that it would be easier if we involved a housing association who could let the house to the ladies and the ladies would then receive Housing Benefit plus Council Tax exemption. So, my husband and I are the super landlords and the housing association let it to Charlotte and Anneke. Housing Benefit pay the housing association the rent they have set, then they pay us a fair rent for the property.

Charlotte and Anneke moved in on 16th March. Because of Covid this in itself was a real challenge. They are exceptionally happy; I haven't seen Charlotte smile quite so much for a long time. She loves having a garden to sit in and adores having a bath. Anneke has a bedroom and bathroom upstairs as well as a bedroom for the member of staff who is sleeping over. Charlotte's room, downstairs has a sliding door straight out into the small back garden, which has been really lovely for the spring and summer. They just have a lot more space which means they are not on top of each other all the time.

Apart from the odd snagging problem – mainly blocked drains which are now resolved – everything has gone really smoothly! If you are thinking of doing something similar, I'd love to tell you in more detail how to go about it. If you contact Rett UK, they can put you in touch with me.

CHC Funding

by Laura Hall

Charlie Hall celebrates her birthday

At the beginning of 2019 we began the final part of transitioning from children's services to adult services.

We met with the local transition nurse who believed Charlie's care package should be paid for by the NHS and not social care due to her high care needs.

We arranged a meeting along with someone from our local 0-25 team to complete a checklist which was the first part of the Continuing Healthcare (CHC) process. We also had to complete a Best Interest Decision and Assessment of Capacity form for Charlie.

In July 2019 we completed the 2nd part of the process and had to fill in a Decision Support Tool (DST) form. This was made up of several descriptors which assessed whether Charlie would be eligible for Continuing Healthcare funding. This meeting was long and stressful as I was required to provide evidence for each of the following descriptors: breathing, nutrition (food and drink), continence, skin (including wounds and ulcers), mobility, communication, psychological and emotional needs, cognition (understanding), behaviour, drug therapies and medicine, altered states of consciousness, other significant care needs and each need was given a "score" of "priority", "severe", "high", "moderate", "low" or "no needs". If you have at least 1 priority need, or severe needs in at least 2 areas, you can usually expect to be eligible for NHS Continuing Healthcare.

The outcome of Charlie's original DST saw her scoring 1 severe, 3 high, 5 moderate and 3 low.

I pulled together all the evidence I had for each of Charlie's medical issues from her breathing issue requiring BIPAP through to clinic letters from various consultants, dieticians, and other "professionals".

Prior to this meeting, the transition nurse told me it wasn't a big deal, it was just about who paid for Charlie's care package, so it was made out to be a real formality and not of massive importance to Charlie or myself particularly! Boy was that wrong!

Charlie was given 50:50 funding meaning social care and the NHS/CCG paid for Charlie's care package, but after talking to Becky Jenner at Rett UK, she agreed to help us appeal the decision based on her believing Charlie's health needs should qualify her for full CHC funding.

In April 2021 after a long appeal process partly due to Covid, Charlie was awarded full Continuing Healthcare funding. This meant we were no longer required to contribute towards Charlie's care package, which under social care rules in adult care is expected. Once a review of her care needs was carried out Charlie would get a much better care package.

We were asked what sort of care we were looking for, I told them I wanted to keep our current carers who I have employed for many years now through Direct Payments and requested 6-8 hours of care a day, every day. This was a really strange thing as under Social Services we were given hours and made to feel grateful for getting those.

I also told them I wanted 4 nights respite a month with one of Charlies current carers.

We had to have a care plan review which was then sent off to someone to price up so as to give Charlie her budget for the year.

We chose to take Charlie's budget as this managed Personal Health Budget. These means I can employ my own carers and have a Company looking after the stressful payroll, DBS and admin tasks.

CHC funding, once it's all settled and we have the carers trained and in place, will allow Charlie to continue living at home with us, but will give me the break from caring for her at the same time, which currently normally involves 19 hours days and very little sleep!

Charlie has gone from having 35 hours a week with social care funding, and having to make sure I didn't use all those hours each week, saving some for respite, to having 8 hours care a day, 7 days a week, with 4 nights 24 hours care respite once a month as well, now having 6 carers as part of her care team instead of just 3. Using her budget we have also been given a substantial amount of money for activities and trips, as well as having money for all the admin, training, payroll etc.

The only negative so far is because I'm managing and training the carers rather than using an agency it's a bit more stress and work load at the start but hopefully in a couple of weeks it will settle but because I am managing the carers myself we have greater flexibility. There were also issues changing from social care over to the CHC, but we have persevered and I think we are nearly where everything should be!

If your person with Rett has significant health needs I would definitely look into CHC funding as it can make a huge difference to the support given and contact Rett UK who can provide advocacy support to help guide you through the process which is incredibly stressful!

Becky Jenner who provided advocacy support to Laura and her family reported: "It was a pleasure to be able to support Laura and Charlie through this process and we are delighted that it got the outcome which was the right one. It's shameful that the family had to wait so long to get this support which should have been there from the off."

If you feel you are not getting the support, please do get in touch with one of the team at Rett UK. We are here to help fight your corner as well as bringing a lot of experience and knowledge to the table.

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.

GET YOUR COPY NOW!

UK and Ireland edition of the Rett Syndrome COMMUNICATION GUIDELINES

Have you got your copy of the Guidelines yet?

Would you like to pass on copies to other members of your family and/or the professionals who work with your daughter/son/sibling with Rett syndrome?

Would you like to share the Guidelines with colleagues?

The Guidelines are available as a digital download and in printed book format. Whilst retaining all of the same information as the original guidelines that were published through the IRSF (Rettsyndrome.org) and Maastricht University in 2020, this edition now uses British rather than American English and includes an extra section in Appendix 5 with links to UK and Ireland-centric AAC suppliers and organisations.

To get your free digital copy now, go to:
https://www.rettuk.org/communicationguidelines

If you are a parent/carer/family member of someone with Rett syndrome and you are a member of Rett UK, you can request a free printed copy.

If you are a professional paid to work with people with Rett syndrome, why not sign up to our Communication Professionals Network and you will receive a printed copy of the Guidelines (included within the one-off CPN joining fee) as well as accessing all of the other benefits of membership.

To request your copy or to find out more, contact Gill Townend: **gill.townend@rettuk.org**.

Rett UK Communication and Education Support

by Tracey Campbell, Abigail Davison-Hoult and Gill Townend

Maximising the communication potential of people with Rett syndrome

EVENTS AND ACTIVITIES

Rett Education: Communicate, Educate, Advocate – LIVE Discussion Groups in 2021

These monthly Discussion Groups are an informal follow-up to last year's Rett Education conference. They are held live over Zoom and are open to anyone who has watched the designated talks for each month's chosen topic. The sessions are interactive, and attendees are expected to turn on their camera and microphone to participate – this is your chance to give feedback on the Rett Ed talks, to ask your questions, and to share your experiences and top tips with like-minded others. The discussions will not be recorded and will not be available to watch later.

The remaining groups for 2021 are:

Thursday 23rd September 8-9pm
Why and How to Develop Literacy
Focus on Rett Education 2020 talks by Karen Erickson, David Koppenhaver and Jane Farrall.

Thursday 21st October 8-9pm
Rett Education 2020 – What has it changed for you?
A chance for you to reflect on and share with others what you have learned from the talks and what you are doing differently now.

Information about each Discussion Group will be made available on the conference website 3 weeks in advance of the session. To find out more, go to: **https://rett-uk.heysummit.com/discussion-groups/**

We look forward to seeing you there!

Rett UK Communication Professionals Network (CPN)

We are delighted to announce the launch of our new website designed exclusively for the Rett UK Communication Professionals Network (CPN).

With the launch of the new CPN website we are inviting all interested Communication Professionals* to register for or renew their existing membership of the Network. To take a look and find out more about the benefits of becoming a CPN member, go to:
https://rettuk.org/cpn

Please note, you will have access to limited areas of the website before you register.

If you have any queries or would like to know more about the CPN, please contact Dr. Gill Townend at **cpn@rettuk.org**.

**By "Communication Professional" we mean anyone working in a specialist capacity with a focus on communication. For example, Speech and Language Therapist/SLT assistant, teacher/teaching assistant, and anyone else in a paid professional role supporting communication skills.*

Rett UK
Communication
Professionals Network

Pilot Friendship Group

What is the most fun you can have at 10:30 on a Saturday morning for 6 weeks? Turns out it's to be part of the Friendship Group pilot! Rebecca Day and Tracey Campbell ran the project for a group of adults with Rett syndrome, over Zoom, in July and August. Tracey tells us how it went:

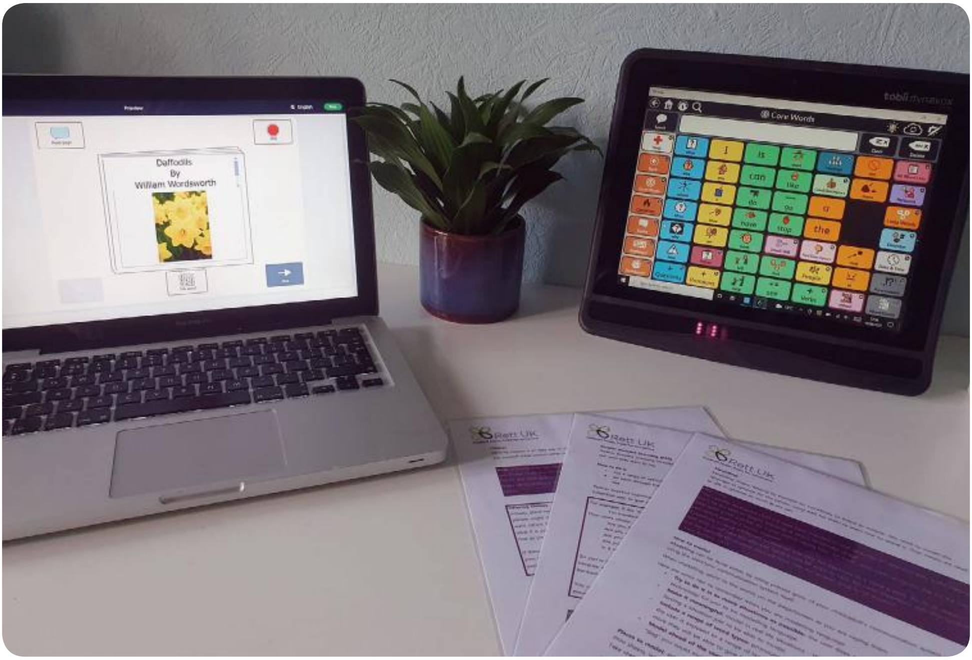
The idea for the friendship groups came after listening to Jaquie Mills talk during the Rett UK Communicate, Educate, Advocate conference. We know that people with Rett syndrome can be isolated, and that the pandemic has not helped with that. We asked people to fill out a questionnaire on behalf of the person they knew with Rett syndrome who would be interested in joining the group. The largest response we had was from people over the age of 19 and so we decided to trial this group for six weeks. Each week had a different theme planned, although regardless of the topic for reasons unknown the subject often came back to men, cake, alcohol, and underwear, especially pants. Usually, laughing at me was part of the session, Rebecca's favourite moment was when one of the women referred to me as 'easy'. It was also one of my favourite moments because I loved the fact the women were so comfortable in the group. It was deliberately very informal, in fact one day we didn't even get around to using the theme! Whilst we did discuss the Olympics, you can imagine where that conversation ended, especially when discussing diving.

When we did use the theme, it was based on a song, book, or poem which we listened to together. We had pre-prepared topics of discussion and provided AAC system navigation pathways to useful pages that may be useful. However, you don't need to have a full AAC system to join in. We had two faulty devices on separate occasions, and we used Partner Assisted Scanning (PAS) to ensure full participation. For people who are not sure what PAS is check out the Yes/No Game webinar, or the bitesize webinar when it's released. As always please don't hesitate to get in touch with the Communication and Education team.

As these sessions were a trial, so we can hopefully have groups suitable for all age groups in the future, we tried out different themes and formats before rolling it out to other groups. The first week was a 'Getting to Know You' week. Next up, we had 'The Queen's Knickers' by Nicholas Allan, Rebecca's favourite on account of the highbrow content. The following week we gave into the fact that the woman liked to discuss men, so the theme was The Buffalo, it's a parody of The Gruffalo that I wrote last year. There is a girl who is wandering through the neighbourhood chatting to boys. With each of the themes we do probe gently into more serious topics - with this one we discussed how we need to be as kind to ourselves as we are to others. The ethos behind the groups is to help establish relationships and friendships so they are fun not serious. However, I am pleased to report that all the women chose a nice man over a rich one when we played 'Would You Rather?'. The next session was due to be 'Daffodils' by William Wordsworth, but we ditched it to have a good old natter instead. As we had been off the previous week, there was a bit of catching up to do. The penultimate week we were delighted to have new participants, so we used the 'Daffodils' theme from the week before. On the last week, we read an excerpt of 'The Boy, the Mole, the Fox, and the Horse' by Charlie Macksey. Shamelessly, we also used the last week to rate our group, nonetheless, decision making is an important life-skill, so we didn't feel too badly about it.

Feedback from the participants was incredibly positive, adjectives used included *excellent*, *funny*, *calm*, *great*, *gentle*, *fantastic*, and *wonderful*! The participants felt relaxed during the sessions, as we all should when just meeting up with friends to chat, this then had a positive impact on the participants using their devices. Perhaps as there was no pressure for anyone to answer and no right or wrong answers. It was noted by one of the parents involved that her daughter didn't have many opportunities to meet with friends in the way other woman her age would. She felt the group was a good opportunity to experience the camaraderie found in a group just meeting for fun to talk. An experience that many of us take for granted yet so often missing from the lives of those with complex communication needs. In terms of the themes of the group and different formats that we used, there was no preference, people enjoyed the variety. The ladies on the last session produced a variety of themes that they would like to talk about in future. A suggestion that participants take it in turn to be the facilitator of the group is something we will explore in the forthcoming groups. It wasn't all positive feedback however, 10.30am on a Saturday is too early for adults. We have taken this onboard and will move the time to later in the day. That decision has almost nothing to do with the suggestion from one of the participants that we could drink cocktails (or prosecco) and eat cake (or pasta) later in the day!

As the trial has helped the participants to have fun, communicate and feel like part of a group we will be delighted to offer the same experience to other members of Rett UK. Well not exactly the same, we will keep it age-appropriate! If you know someone with Rett syndrome who would like to join please email me at **tracey.campbell@rettuk.org.uk**. Fun guaranteed! Although, we will refrain from drinking alcohol for participants younger than eighteen, apologies teenagers!



TEAM NEWS

Communication and Education Support - Team News

As you will have seen in the last edition of *Rett News*, life is never quiet in the Communication and Education Support team, and in July we were thrilled to double in number the Regional Communication Champions (RCCs) in the team. Over the coming months the new "trainee" RCCs will be shadowing our more experienced RCCs in the work they are doing to support families through the loan scheme and other (online) communication activities. We are delighted to be able to draw on the experiences and skillsets of a widening group of people, and to be covering more of the UK, helping us prepare for a time when we can also resume in-person regional events and activities. So, let's set the spotlight on our wonderful network of RCCs and introduce them to you.

Gill Townend

Communication and Education Support Project Lead

Abigail Davison-Hoult

Communication and Education Support Coordinator

Tracey Campbell

Communication and Education Support, and Regional Communication Champion (see page 28)

Meet our Regional Communication Champions

Judith Worrall

My name is Judith. I live in the West Midlands with my husband, daughter and two young people that we have looked after since they were little. My daughter is 37 and has Rett syndrome. She is my pride and joy. I have been involved with Rett UK since Pauline was 4 but only semi-recently become involved in the Communication Project which I am passionate about. Three years ago we loaned an AAC device from Rett UK. I immediately realised the importance of communication for the people we love and care for. I am honoured to be an RCC and I am committed to helping other people with their communication journey. It has been amazing for us.

Kelly Dimmick

I am Kelly Dimmick, originally from Norfolk but now living in Stourbridge, West Midlands. I am a mother of 2 children with different abilities. My son is 10 and has Asperger's, my daughter 8 has Rett syndrome. I have a background in NHS finance, and have been "retired" since my daughter was 1. I started on this amazing path of communication with my daughter when she was diagnosed as I had come across Rett UK, and they were very helpful and positive. I found it not only helped Amy but helped me to accept what was happening and to plough myself into something positive. She attends mainstream school and I have continued to attend literacy events with her. I have found I enjoy working with her and want to pass on the positivity and possibilities to others.

Anna Knight

Hi, I'm Anna, I have been an RCC since Rett UK started developing communication support. I have a sister with Angelman syndrome who started my interest in AAC from information learnt at the AngelmanUK conferences. I then introduced AAC to our family; it has been a bit of a rollercoaster with systems but currently she uses PODD in both low and high tech formats. I then decided to take the leap and train as a Speech and Language Therapist, currently working in schools. Through being an RCC I have learnt different vocabularies and enjoy trying to think of interesting ways to model in everyday situations.

Callie Ward

Hi, I'm Callie. I am a qualified teacher. I previously worked in both a mainstream and SEN school but after my niece was diagnosed with Rett syndrome in 2015 I focused on supporting her to develop communication abilities. Through this I met Susan Norwell and had the amazing opportunity to train and learn with her. Alongside Abigail, I launched the Rett UK Communication and Education Project in 2017; running training events and the loan device scheme to help people get started with AAC as well as out and about communication groups using AAC in a range of environments. Last year I moved to working independently, teaching children and adults with complex needs to communicate, read and write in regular individual and group classes, but have continued my association with Rett UK as an RCC.

Rebecca Day

Hi! I'm Rebecca, and I have been a Regional Communication Champion since June 2019. I am based in North Wales and, when I am not working for Rett UK, I am researching bilingualism in Rett syndrome as part of my PhD at Bangor University. I have a personal link to Rett syndrome as someone close to me was diagnosed with Rett syndrome when I was 10 years old so I have grown up understanding the needs and potential of individuals with the disorder. I feel so privileged to work with Rett UK offering communication support and resources to families.

Brett Martin

I'm dad to my awe inspiring 34-year-old Rett daughter. I became seriously interested in communication just 4 years ago after a paradigm-shifting Rett UK day's training session – also life changing for my daughter! Charlotte continually inspires me to focus on communication. Knowing how hard it is for her to communicate gives me the reason to work hard too. I am based in South East Kent and Charlotte lives in an amazing care home just a few miles away. I am also lucky enough to chair the Beer and Banter sessions for male relatives of those with Rett syndrome.

Joanna Campobello

My name is Joanna Campobello and I have a degree in Pedagogy and Social Care. In the UK I was practicing as a social worker, supporting children and young people with disabilities. I have two daughters, one husband and one white cat. I speak three languages and when my 8-year-old was diagnosed with Rett syndrome I started learning the 4th one – AAC. I understood I needed help and Rett UK sent a lifeboat to rescue me. If you feel lost or just need a bit of assistance there is a bunch of lovely people called RCCs working for Rett UK. All people with Rett syndrome have an ability to communicate, using a method that best suits them. We are here to help find the right path for you and the person you are supporting. I am based in Berkshire and I'm looking forward to hearing from you.

Tracey Campbell

I live near Glasgow with my husband and three children. My 15-year-old daughter has Angelman syndrome. I gained my first understanding into best practice for communication at an AngelmanUK conference in 2014. I realised that many people were not getting a chance to become competent communicators and immediately wanted to change that. I started supporting some of my daughter's friends, one of whom has Rett syndrome. I became an RCC in 2019 and I love it. I love supporting the families and seeing their development, the friendship group pilot was tremendous fun and a brilliant team to work with.

And now for our new recruits! Please join us in welcoming them to the Communication and Education Team

Jeniffer De Almeida

Hi, my name is Jeniffer! 17 years ago, whilst working as a teaching assistant in London, I met two young ladies diagnosed with Rett syndrome; one of those young ladies is still a dear friend today and my main motivation to expand my knowledge and continue my support as a Regional Communication Champion with Rett UK. This earlier experience led me to further my education within child development and a job within Tobii Dynavox, where I gained further skills and understanding in the implementation of Augmentative and Alternative Communication (AAC) and Assistive Technology (AT).

Robert West

Hello, my name is Rob West and I live in Leeds with my partner Dee and our wonderful daughters Thea (6 years old) and Tilly (almost 5 years old). Tilly was diagnosed with Rett syndrome in 2018. Like her sister, she is a star, and we are very proud parents! She is a very chatty and strong-willed little girl who loves communicating in all ways. We have worked really hard on Tilly's communication and learned a great deal, and I am excited to help other families in my role as a RCC.

Alysia Martindale

My name is Alysia Martindale. I currently work full-time as an Assistive Technology Specialist for Communication and Environmental Control at Norwood. I am also completing my Master by Research, focused on AAC. I was introduced to Rett syndrome in 2016 when I met Frankie Ross, then worked as her private carer supporting her eye gaze device which was new to us both and was where my AAC journey started. I am hoping with my role as RCC I will be able to share my experience in family homes and residential homes as well as supporting families to set up environmental control as who wouldn't want to be able turn the TV off independently when dad or brothers watching the football!

Victoria Fusco

My name is Victoria Fusco and I am mum to 3 children, Alexander, Matilda and Harriet. My youngest daughter Harriet is 8 and has Rett syndrome. I live in Whitby, North Yorkshire and have been a Primary School teacher for the last 16 years. Rett UK have helped us as a family with communication support and I feel confident to share the skills and knowledge I have learned with other families to help give their children a voice.

Rachel Ashton

Hi I'm Rachel, mum to Ava-Mae who is 6 years old and diagnosed with Rett syndrome and step-mum to Kai, 9 years old. We live in Hazel Grove in the North West. I was in Payroll and Customer Services for 22 years. When my daughter was diagnosed with Rett syndrome 3 years ago it devastated me, but I had to be strong and the best I could be for myself and Ava-Mae. In 2020 we loaned an eye gaze device from Rett UK to provide my daughter with the opportunity to communicate. Loaning the device and watching webinars taught me a lot about communication and it made me very passionate to learn much more. This has led me to my new opportunity as an RCC which I am delighted about. I am excited to be part of the team and having the opportunity to give back by supporting others.

Lisa Green

Hi, I'm Lisa from North Nottinghamshire. I have a daughter, Katie, with Rett syndrome who was diagnosed last year. Rett UK has been our source of ongoing communication support which has been amazing. I feel we have been on a huge communication journey this last year that has led our daughter to now using low and high tech AAC.
I wanted to become an RCC to support others through their communication journeys and to also support the work carried out by Rett UK. I am really excited to take on this new role and am looking forward to getting started.

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

Carly Hynes

My name is Carly Hynes. I am a teacher in a small SEN school in Liverpool. I have been involved in the AAC community since May 2015, when our first young person transitioned with an electronic device. At that point I knew I needed to upskill myself to be able to support her the best way I could. Since then, we have supported 17 young people and their families to use AAC to express themselves. I also support wider families and colleagues through my role with the Liverpool CAAT team. Outside of work I have an allotment, hand rear orphaned baby hedgehogs and keep bees.

Luisa Perez-Milne

Hi, I'm Luisa. Originally from Colombia I am an engineer, mother of 3 girls. Isabella 14, Luana 7 and Alanah 10 months. Isabella was diagnosed with Rett syndrome at the age of 18 months, and she has been using Tobii Dynavox devices since before her third birthday. I have been passionately supporting Isabella to succeed in her communication journey and along the way I became her programmer, communication partner and advocate. Over the last 10 years or so I have also supported and helped other families to acquire the device then teach people how to use it. My family has now relocated from Texas to Orkney, Scotland, and I am looking forward to sharing and expanding my knowledge and experience through Rett UK as an RCC.

Watch this space – there are more RCCs in the pipeline!

Fundraising Round Up

THANK YOU

by Donna Tinch

WALKING FOR RETT UK

by Donna Graham

Rebecca Robinson, Faye Kenton, Jack Morley-Brown, Mandy Lloyd, Donna Graham, Beth Baillie, Beverley Thompson and Lyndsey Thompson

Jaycie Breingan, Pat Elliott and Julie Graham who supported us on the day on the walk

On 29th May 2021, members of my family and friends joined me in walking 10 miles around Lincoln to raise money and awareness for Rett UK.

My second cousin, Grace was diagnosed with Rett syndrome at 4 months old and I know that Rett UK have supported Grace and her family. My Uncle Mick spoke to me earlier this year and asked me to become involved in raising money and awareness for Rett UK, alongside the 'Grace's Day' event that he had organised in honour of Grace, his great-niece. It was then I decided to organise a sponsored walk of 10 miles in Lincoln.

We started our 10 mile walk from the Lincolnshire Poacher and it took us about 4 hours to complete. We were very grateful to Pat Elliott (Grace's nanny), Julie Graham (Grace's great-auntie) and Jaycie Breingan (Grace's second cousin) for the water they provided during our walk as it was extremely hot!

Alongside the walk, I organised a charity Raffle with the help of my mum, Julie Graham. We spent many weekends speaking to local businesses to ask for donations for the raffle whilst raising awareness for Rett UK. We were astonished by the generosity of local business in Lincoln and ended up with 35 prizes in the raffle!

From the walk and the raffle, we raised over £2,757. It was an absolute pleasure to raise money and awareness for Rett UK, so that the charity can continue to support families across the UK, just like they have supported my cousin and his family.

I would like to say a huge thankyou to: Beverley Thompson (Grace's great-auntie), Lyndsey Thompson (Grace's second cousin) and my friends: Mandy Lloyd, Rebecca Robinson, Faye Kenton, Beth Baillie and Jack Morley-Brown, who walked with me and raised money and awareness for this amazing charity.

GRACE'S DAY

by Mick Dunn

Earlier this year we were thrilled to receive a call from Mick Dunn sharing his plans to undertake a 100km walk within 20 hours!

Mick planned to undertake the beast of a walk around the beautiful grounds of Blenheim Palace in honour of his great niece, Grace, and aptly named the challenge 'Grace's Day'.

Here Mick, who is certainly no stranger to a challenge, talks us through Grace's Day which raised over £6,750 for Rett UK!

So, after many weeks of planning, training and fundraising Grace's Day was finally here! 08:00 pm came around very quickly on Saturday 5th June. My wife Shelly and I kicked it all off and with the support of the family we headed out into the evening sun.

20 hours was the target but I wanted to do it quicker so I had a pace in mind, a 15-minute mile pace was the aim until at least halfway, and then we would see. One lap was 9.1km so I had to do 11 and a little bit extra to get to 100km. After 3 hours I developed a problem on my left foot, which I tried to sort out but it was too late the damage was done, I put that down to bad preparation.

Shelly had done a great job in setting the pace, but it was time for her to swap with my good friend Gary a teammate of many previous challenges. We wouldn't see Shelly again until the morning and she vowed to return with bacon butties, ready to do her second stint.

Lap 3, Gary and I ploughed on through the darkness after watching the day fade. We carried on at a fast pace clocking up the kilometers in good time. At around 01:00 am we were joined out of the darkness by another surprise teammate, Jessie, who again Gary and myself have undertaken many challenges with. We were all in good spirits but at around 04:00 am, just as the day was breaking, I realised my foot was in a bad way and we had to take a couple of minutes to try and sort it out. The thing was no matter how much pain I was in there was no way I could stop, there was too much at stake here.

Below: Rachel, Mick, George and Grace with family and friends and Nick Mason, watch manager, and colleagues from Woodstock Fire Station
Inset: Grace and Rachel

The day broke to a wonderful sunrise, which instantly made everything better. We went full steam ahead as we had to meet my next companion whom I had called in advance to be ready for around 05:30 am. Step up Adrian who was raring to go by the time we made it round to the Flagstaff entrance.

Gary and Jessie had got me through the night and by 05:30 am we had completed over 60km. After a quick bite to eat I had to get off, so I bid them both an emotional farewell.

Lap 7 and Adrian was ready for this and we set off at a good pace. After about an hour we were interrupted by BBC radio Oxford, whom I had totally forgot about. They wanted to see how I was doing via a live broadcast and Adrian was mortified when I handed him my phone to tell them all about it! BBC Oxford allowed me to do a few live interviews in the run up to Grace's Day, which enabled me to raise awareness about Rett, which was fantastic, and for which I was very grateful.

Adrian and I had word that Shelly had returned to Blenheim with food so we made our way hastily to the changeover point, where both Shelly and Grace's granddad George were waiting.

Lap 8 and after a quick hello and bite to eat Adrian, George and I set off again. Every time I stopped it was really hard to get going again as everything was starting to get uncomfortable. Around the back half our lap we were joined by another surprise guest, Steve, who had cycled 8 miles to walk for Rett UK. Steve joined us for a couple of miles then had to get off, but it was great to see him.

Lap 9 saw the arrival of Amy and Chris and the departure of Adrian and George who had kept the pace steady. By now my left foot was giving me tremendous pain and no matter how many Ibuprofens I took there was no respite, anyway there was still 16 miles to go so it had to wait for attention. This was a hard lap and I really had to dig deep to get through it. Amy and Chris did a great job keeping me occupied to forget about the pain.

Lap 10 saw the arrival of my wife Shelly and my very good friend Sam. Grace's dad George also made it. They were just what I needed to keep me pushing on and the girls didn't let me slow down!

Mick Dunn

Mick being congratulated by Winston Churchill (lookalike) and Pat Elliott, chief cheerleader

Raising awareness at Blenheim Palace

The promise of a cold can of Guinness when I finished was enough. By now there was a strong showing from Grace's family and a group from Rett UK had set up in the gazebo provided by Blenheim Palace.

Lap 11 was very emotional, with everyone gathering at the start/finish line I was determined to get this done in 18 hours so after a quick chat with my sister Pat who was chief cheerleader, we set off again, this time with a large group. We received a call asking how long we would be as Sir Winston Churchill was waiting... and I thought 'he is dead, does that mean I am'!

At the back end of the course I was struggling and after stopping for the call of nature I struggled to catch the group, Graces dad stayed with me and eventually we caught up. The final straight to the finish was long overdue and by now there were members of the public everywhere. Gary and Adrian had returned along with Sir Winston Churchill (lookalike) and when I saw him I thought I'd lost my marbles!

A finish line was set up and after a rousing speech by Grace's dad we all crossed the line and at that point I was honored to push little Grace over the line in her pushchair.

JOB DONE 100KM IN 18 HOURS.

The whole Grace's Day event had been fantastic from day one, with great support from friends and family, as well as Donna from Rett UK.

Was it worthwhile? Absolutely! Was it painful? Absolutely! Would I do it again? Absolutely!

A special thanks to Shelly, Gary, Jessie, Adrian, Sam, George Snr and George Jnr, Amy and Chris for walking with me. I always said this was a family thing and they all played their part. Rett UK were awesome in their support and advice. Thank you to Blenheim Palace for allowing us to stage Grace's Day.

Robert Adamek from Rett UK reported: "We are delighted for the support from Mick and all and the wider family and friends in honour of Grace. I was lucky enough to be in attendance on the day and had the pleasure of meeting a lot very supportive family members and friends. What you have done has been phenomenal. Mick, you are definitely built different! No sooner had you finished this gargantuan challenge you were on to planning the next one. So watch this space for a possible future mega challenge!"

Gary, Winston Churchill (lookalike) and Adrian

Mick, together with his family, approaches the finish line

Images © Katie Streather Photography

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

Welbourn Church of England Primary School

Barry Woodward

Welbourn Church of England Primary School held a cake sale and non-uniform day in support of Mick Dunn and Donna Graham's fundraising events. Headteacher Tracy Boulter reported: "The children were challenged to run or walk 100 laps per class in honour of Grace and I am delighted to tell you they exceeded their target and ran/walked over 1,000 laps as a school, raising over £300 for Rett UK."

At the end of July, school teacher **Barry Woodward** undertook The Pedders Way Challenge and raised £2,266.84. Barry told us: "We lost my mum to Motor Neurone Disease two years ago and one of our family, Sophie, battles Rett syndrome, so I wanted to raise awareness and funds for both charities." Barry chose the first weekend of the summer holidays for his challenge and reported afterwards: "Saturday went brilliantly! It was warm but the beautiful scenery helped me along the way together with a great support crew including my wife and children. I'm really pleased with the money raised and all the awareness of Rett syndrome from the multiple mini assemblies I did with my classes at school."

Ffion Roberts walked 200 miles during the month of June and raised £195. Ffion undertook the challenge to raise awareness of Rett syndrome in honour of her cousin Alaw and awareness of cystic fibrosis in honour of her son Gethin.

Tracie Twohigg raised £187 in honour of her daughter Cassie.

Jadie Ford undertook 100 squats a day during the month of May and raised £300 in honour of her step-daughter, Nancy.

Janet Theedom and **Emma Gudge** kindly donated £100 in memory of Carolyn Chadwick.

Michelle Lygo

Clive Hayward

Robert Killick with his wife Laura

Clare Cruz

In memory of Michelle Lygo, **Sarah Christie** (sister) and their dad **Alan Lygo** raised £160 in celebration of their summer birthdays.

Clive Hayward was due to undertake the Brighton Marathon Ride which has now been postponed to 2022. Clive, who has no connection to Rett syndrome, raised a lot of awareness during his months of training and smashed his target raising £425! Clive hopes to support the charity again in 2022.

Congratulations to **Sarah and Chris Wilcox** who recently celebrated their 25th Wedding Anniversary! The couple asked family and friends for donations in lieu of gifts, and raised over £400 in memory of their daughter, Daisy May.

Robert Killick undertook the Yorkshire Challenge, walking 50km on one of the hottest days this year! Rob raised over £370 and his motivation and inspiration to complete the challenge was his god daughter, Penny.

Donations in celebration of the life of **Clare Cruz** raised over £1,500.

Donations in loving memory of **Rebecca Leigh** raised £200.

Thank you to our Facebook fundraisers:

Lauren Barcroft • Melissa Beevis
Claire Bowen • Laura Brady • Becky Chapman
Pat Drinkwater • Angela Ginn • Aimee Grace
Anne Green • Becky Hayward
Tara Hemingway • Becky Jenner • Toni Marsh
Kerry McCabe • Sam Medley
Lesley Richardson • Robyn Roberts
Adam Russell • Katie Page Samson
Katie Speedy Smith • Rochelle Stringer
Matt Sutton • Hilary Truss
Shannon Twohigg • Tracie Twohigg
Jules Ola Walker • Emily Wright

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

facebook®

DONATIONS RECEIVED IN LOVING MEMORY OF:

Patricia Allen
Rosie Baggs
Mrs Valerie Chadwick
Mrs Shelia Chapman
Emma Edwards
Joyce Kibble
Mrs Linda Maude
Rachel Wolsoncroft

Lydia and Lisa Allen
Below: Patricia, Lisa and Lydia Allen back in the day

Rebecca Leigh

Rebecca Leigh

"Our beautiful angel Rebecca now has her wings, a week shy of her 39th Birthday. Whilst our hearts are utterly broken, we feel blessed that we were chosen to be her family. All who knew her loved her, she did not speak but had eyes and a smile that conveyed so much more than words ever could. Fly high my little sister, I love you Bec ❤."

Clare Cruz

"As a family we were very touched by the amount that was raised in Clare's memory as it was a real expression of the impact that Mum herself had had in many people's lives. After having her own children Clare set up a playgroup with other parents in North London in the sixties which eventually led to her taking on a role in social work relating to daycare for the under-fives. She was always involved in different ways in supporting families and so donating to Rett UK, a charity that has been so helpful to her own granddaughter, seemed the most appropriate way to mark her memory. Thank you Rett UK for all you do".

Clare Cruz and grandaughter, Pippa

To Our Wonderful Fundraisers...

GOOD LUCK

Good Luck to all our supporters!

Declan Findlay who is going to jump out of a fully functional plane at 13,000 ft and fall to Earth at 120mph! If that isn't enough, in the evening of that same day, he will be taking a ride up the tallest abseil tower in the World, Northampton Lift Tower, and abseiling 418ft down!
https://uk.virginmoneygiving.com/DeclanFindlay

LONDON MARATHON

Hazel Adamek
https://uk.virginmoneygiving.com/HazelAdamek

Karen Anderson
https://uk.virginmoneygiving.com/19924_8568991_48386

Jenny Collier
https://uk.virginmoneygiving.com/19966_9684175_42257

Dominic Dahmen
https://uk.virginmoneygiving.com/DominicDahmen

Peter Duncalfe in honour of his niece Rosalie
https://uk.virginmoneygiving.com/PeterDuncalfe

Angela Duncan in honour of her granddaughter, Emma
https://uk.virginmoneygiving.com/19966_8879145_64550

Julie Hyne and her daughter **Emma Hyne** in honour of their daughter/sister, Annie
https://uk.virginmoneygiving.com/EmmaandJulie

Julie Liggett
https://uk.virginmoneygiving.com/19966_8888159_49489

Ajit Panda in honour of his daughter
https://uk.virginmoneygiving.com/Ajit_Panda

Marie Peters in honour of her granddaughters, Amelia and Ruby
https://uk.virginmoneygiving.com/MariePeters1

Peter Samson in honour of her twin daughters, Amelia and Ruby
https://uk.virginmoneygiving.com/PeterSamson3

Team Barcroft (aka Lauren, Sam and Barney) in honour of Carly
http://www.justgiving.com/Team-Barcroft

GREAT NORTH RUN

Joanne Lewis
http://www.justgiving.com/joanne-lewis32

Eva Hodgson
http://www.justgiving.com/Lysbethrettuk

Mark Taylor
www.justgiving.com/fundraising/mark-taylor222

Mike Howie
http://www.justgiving.com/Mike-Howie5

Bianca McConnell
http://www.justgiving.com/Bianca-McConnell

Matthew McAteer
http://www.justgiving.com/Matthew-McAteer2

Ash Bakawala
https://uk.virginmoneygiving.com/AshBakawala

We have places in the 2022 London Marathon! To register your interest please email **donna.tinch@rettuk.org**.

BECOME A RETT UK CHAMPION!

If you are inspired by our fabulous Rett Champions and want to help, please have a look at our events on pages 4, 5, 41 and 43. You might also refer to our events page, which we are continuously updating, on our website **https://www.rettuk.org/events/?events-type=fundraising**

If you don't see anything that appeals to you but perhaps have an idea in mind, please speak to us.

We shall provide support with your fundraising ideas, give you social media promotion as well as a t-shirt or running vest, flyers, etc. to help promote your event.

Please call Donna on **01582 798 910** to discuss your ideas.

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.

Make Some Noise About Rett Syndrome This October!

RETT SYNDROME
GLOBAL AWARENESS MONTH
October 2021
RettUK.org

October is Rett Syndrome Global Awareness Month

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

If you have any ideas about how you can fundraise for Rett UK during the month of October that aren't listed on pages 4-5 and would like to chat them through with us, please email us at **info@rettuk.org** or call **01582 798 910**. We'd love to help and have Fundraising packs that we can send out to you. These are packed full of good ideas and contain useful infomation about Rett syndrome and how to maximise donations.

So, what are you waiting for? Let's get creative!

Get creative!

RAISING FUNDS FOR RETT UK

FUNDRAISING PACK

Be a Rett Hero!

Rett UK
Support today, hope for tomorrow

www.rettuk.org

RAISING FUNDS FOR RETT UK

ONLINE FUNDRAISING
in 6 easy steps...

1. **DECIDE ON YOUR CHALLENGE**
See our fundraising ideas page or our website

2. **CREATE A FUNDRAISING PAGE**
Rett UK is registered with the following fundraising websites (Just Giving charges slightly less):
www.justgiving.co.uk
www.virginmoneygiving.com

3. **VISIT YOUR CHOSEN SITE**
Follow the instructions for setting up your own personalised page.
Here are some tips on how to make it more appealing:
Add your own photograph Make sure you have permission if you are using a photograph of someone else
Make your text personal Include why you have chosen Rett UK as your charity
Ensure your target is achievable
Ask a family member or friend to make the first donation Make it as large as possible. It's quite daunting to go to an empty page and people often follow the lead of the first donor
Personalise your 'thank you' message

4. **SPREAD THE WORD!**
Ask people to pass on your challenge details to their friends, families, colleagues, etc...

5. **KEEP YOUR PAGE UPDATED**
Provide updates with progress reports of training.

6. **PROVE YOUR ACHIEVEMENT!**
Well done! Now put up a photograph to show that you completed your challenge.

I'm going to wear something purple every day for a year to raise funds for Rett UK

RAISING FUNDS FOR RETT UK

Fundraising **IDEAS!**

FANTASY FOOTBALL
Do you think you know all there is to know about football? Well, why not start your own fantasy football league with friends or colleagues. Charge £5 per entry and the winning team gets a small trophy.

QUIZ NIGHT
A fun way for all you clever clogs to raise money. Charge an entry fee, and choose your subject: Sporting Heroes, 70's Pop Music, Food & Drink, TV / Film or you could do your own version of Who Wants to be a Millionaire.

SPOT THE BABY
Gather together childhood and baby photos. Charge £1 per guess and have fun guessing who's who.

GAMES EVENING
Skittles, Tiddly Winks, Cards, Draughts, Shove Ha'penny. Get teams together for a night of traditional games, charging an entry fee.

BOTTLE TOMBOLA
Get bottles donated, get a table and book of raffle tickets and this popular event is sure to raise cash.

SPONSORED HEAD SHAVE
A fun way to raise cash for Rett UK! Get friends and colleagues to sponsor you having your head shaved, or alternatively get sponsored for having your hair dyed a funky colour.

SPONSORED SILENCE
Give Mum and Dad (or your work colleagues!) some peace and quiet, and raise money at the same time. Decide to keep silent for one hour or more, and get sponsored for doing so. Get a group of friends to do the sponsored silence with you, and together raise lots of money.

NAME THE TEDDY BEAR
Choose a name for your teddy. Write it down, and keep in a safe place. Then ask your friends and family to pay 50p each to guess the name of your teddy.

A FLUTTER AT THE RACES
Hire a room, book a horse race evening package and have an evening at the races. You could even have a Day at Ascot theme – picnic hampers and ladies in large hats!

We've plenty more fundraising ideas on our website, download our 100 ways to raise £100 from www.rettuk.org

Once you've decided on your event you need to tell everyone! Included in your pack are some hints and tips on how to publicise your fundraising.

Rett UK
Support today, hope for tomorrow

Rett UK Ltd, Victory House, Chobham Street
Luton, Bedfordshire LU1 3BS
General Enquiries: 01582 798 910
Email: fundraising@rettuk.org • www.rettuk.org

Registered as a charity in England and Wales No. 1137820 and in Scotland No. SC047369
Registered Company in England and Wales Company No. 07339522 • © Rett UK 2017

Events for 2022 You Can Get Involved In...

RUN THE VIRGIN MONEY LONDON MARATHON FOR RETT UK!

Saturday 2nd October 2022

The Virgin Money London Marathon is an iconic event that's high on everybody's bucket list! We will have places in the London event and virtual event and we'd love to have you on our team!

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.

BRIGHTON MARATHON RIDE 2022

Sunday 10th April 2022 (TBC)

Taking place 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.

GREAT NORTH RUN 2022

(TBC)

The Great North Run is the biggest half marathon in the World. Experience iconic landmarks and an electric atmosphere as you run 13.1 miles through the streets of Newcastle upon Tyne and South Shields.

Join over 55,000 other runners taking on the world-famous route. You'll make your way through an unforgettable course which takes in the iconic Tyne Bridge and finishes in the coastal town of South Shields, before enjoying a well-deserved rest in the finish village.

If you're lucky enough to have your own place in any of these events, we'd love to have you on our team.

To register your interest in these upcoming events or for further information, please contact **donna.tinch@rettuk.org**

GIVEAWAY

BILLY FOOTWEAR

A mum in our community has been in touch. She purchased two pairs of these 'Billy Shoes' in a toddler size 9.

Her daughter has outgrown the shoes which retail at £120 per pair! As there is still plenty of life left in the shoes, Laura would love to pass them on to another child who could use them, free of charge.

The website states:

Our innovative FlipTop Technology changes the footwear game. Smashing fashion with function, the zipper shoes of BILLY Footwear revolutionizes how footwear is put on and taken off.

For more information on the shoes please visit: **https://billyfootwear.com/**

Please get in touch with **donna.tinch@rettuk.org** or for more enquries, call **01582 798 910**.

Recycle4Charity

https://www.recycle4charity.co.uk/

Cash for your ink cartridges

Ink cartridges – we all seem to go through so many of them!

Recycle4Charity is a free, easy to use ink recycling programme and also a simple way to help the environment whilst raising funds for Rett UK.

Free Postage Labels are now available to print on the website here **http://www.recycle4charity.co.uk/Register/C2193**

Stick the Label onto any envelope or small box then post back via any Royal Mail letterbox or post office... it's all free of charge!

If you have any questions, send us an email **donna.tinch@rettuk.org**

Easyfundraising

Turn your everyday online shopping into FREE donations for Rett UK!

easyfundraising® is the UK's biggest charity shopping fundraising site.

It's simple to use and it's free. Since we joined Rett UK has received £1,863 simply by our supporters shopping online.

For further information and to sign up, visit **https://www.easyfundraising.org.uk/causes/rettuk/**

easyfundraising
feel good shopping

Are you up for a challenge?

TAKE PART IN A CHALLENGE OF A LIFE TIME!

Skydiving gives you an unbelievable and exhilarating rush like no other and with no experience required it's your opportunity to reach for the skies – it's the closest feeling you can get to flying!

Sign up today to jump for Rett UK, a national charity dedicated to supporting and empowering people with Rett syndrome and their families.

For more details, contact Donna on **01582 798 910** or email **fundraising@rettuk.org**

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**

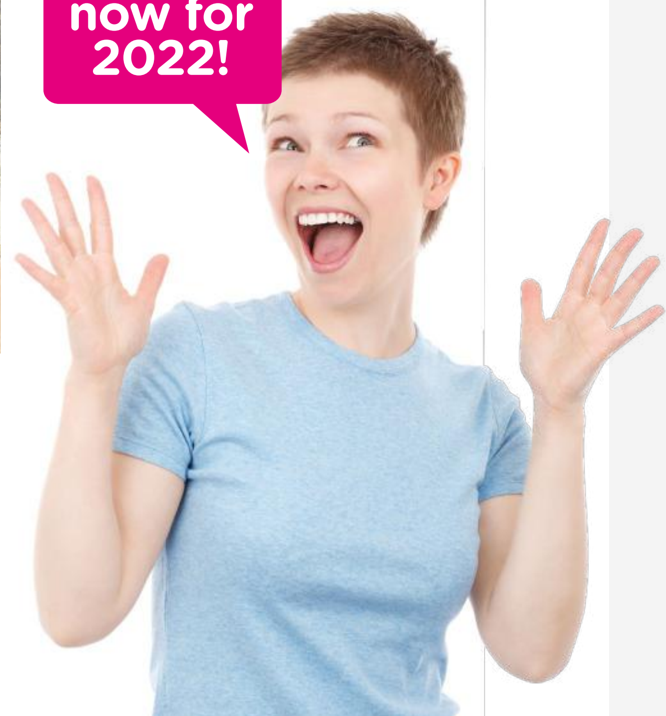
RETT UK 300 Club

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.

Join now for 2022!



RESULTS

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

The winners are:

MARCH 2021

1st	£30	No: 122	Clive & Kay Beadle
2nd	£20	No: 79	Peter Truss
3rd	£10	No: 258	Peter Mather

APRIL 2021

1st	£30	No: 93	Lorna Jaffa
2nd	£20	No: 154	Don & Helen Gardner
3rd	£10	No: 220	Nathan Oliver-James

MAY 2021

1st	£30	No: 259	Lucy Duncan
2nd	£20	No: 273	Wendy McWhirr
3rd	£10	No: 109	Deborah Sykes

JUNE 2021

1st	£30	No: 279	Rita Hyland
2nd	£20	No: 49	Caron Lawson
3rd	£10	No: 291	Sarah Teubler

MEMBERSHIP

BECOME A MEMBER OF RETT UK

FAMILY COMPANION – HAVE YOU RECEIVED YOURS?

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 supported 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**.

I'd Like to Make a Donation to Rett UK

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

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.

giftaid it

☐ 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

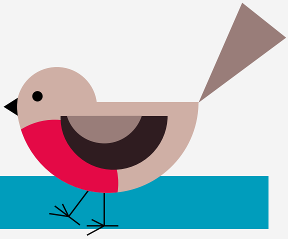
THIS GUARANTEE SHOULD BE DETACHED AND RETAINED BY THE PAYEE

DIRECT Debit

- 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.

Christmas

Cards and Gifts



Yes, it is time to start thinking about Christmas! Your support is very much appreciated as every purchase helps fund Rett UK.

To place your order, just complete the order form overleaf and send it to us with your payment (cheques made payable to Rett UK) or you can place your order over the phone by calling 01582 798 910 or via our website **www.rettuk.org/shop**.

Payment by cheque (made payable to Rett UK), via Paypal (to **info@rettuk.org**) or by Bank Transfer (Account Number: **81486829** Sort Code **40-03-01**).

◀ **PIN BADGES**

Epoxy and stainless steel
3cm wide

▼ **CYCLE SHIRTS**

Various sizes (Enquire at **fundraising@rettuk.org**)

▼ **SILICONE WRISTBANDS**

Purple/green with white lettering

◀ **KEY RINGS**

Epoxy and stainless steel
3cm wide

▼ **CHRISTMAS CARDS**

Merry Christmas and a Happy New Year

NEW

15cm x 15cm

10cm x 21cm

10cm x 10cm

9.8cm x 13cm

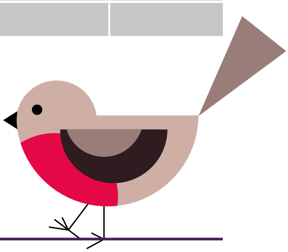
Look out for some fantastic eCards on our Facebook page and website

Order Form

GIFTS	Price Each	No.	Total
Pin Badge	£2.00		
Key Ring	£2.00		
Wrist Band (Purple)	£1.00		
Wrist Band (Green)	£1.00		
Cycle Shirt	£80.00		
CARDS (10 per pack)	**Price/Pack**	**No.**	**Total**
Kissing Robins (B)	£2.99		
NEW – Angel White Holly (A)	£4.50		
LIMITED STOCK – Penguins (Time Together) (B)	£2.99		
LIMITED STOCK – Peace, Hope and Joy (A)	£4.50		
SUB-TOTAL			
Postage & packing**			
Additional voluntary donation			
TOTAL TO PAY			

POSTAGE & PACKING COSTS**

Cards (A): 1 pack add £2.50; 2-6 packs add £4.30; 7-12 packs add £4.80
Cards (B): 1-2 packs add £2.50; 3-10 packs add £4.80
Wristbands: Up to 3 add £2.50
Pin Badges/Key Rings: up to 10 add £2.50; up to 20 add £4.00
Cycle Shirts: please enquire. Additional quantities, price on request



Forename(s) ____________________ Surname ____________________

Address ____

________________________________ Postcode ______________

Telephone ____________________ Email ____________________

Yes! I would like to make a donation to the Rett UK Christmas Appeal: £ ______

Payment can be made by cheque (made payable to Rett UK), via Paypal (to info@rettuk.org) or by Bank Transfer (Bank: Metro Bank Account Number: 32450725 Sort Code 23-05-80). Please quote your name as a reference.

Gift Aid Declaration

Please make every pound you give worth an extra 25% more to Rett UK by ticking this Gift Aid declaration. ☐ 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.

Name of taxpayer ____

Signed ________________________________ Date ______________

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 798910.

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.

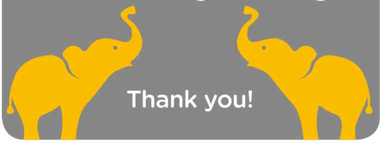
If you wish to give consent for donation, please contact Dr Claire Troakes or Sashika Selvackadunco on **020 7848 0290**. If it is out of usual working hours, please leave a message and a member of the team will contact you as soon as possible.

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

DON'T FORGET!

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

Email:
donna.tinch@rettuk.org



DIRECT DEBIT DONATIONS

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

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**

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.**

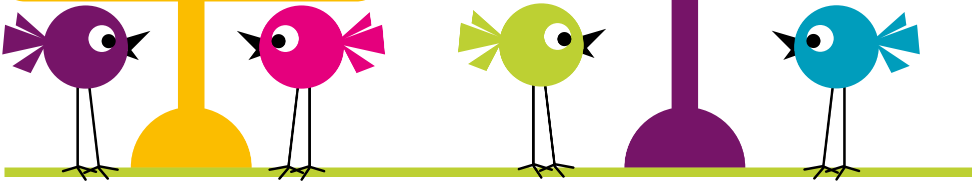
THANK YOU TO ALL OUR DONORS!

Huge thanks to all those who have supported us throughout 2021 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.



HAVE YOU OPTED IN?

IMPORTANT!

Update your details NOW!
Dont' miss out on future issues of *Rett News*!

Changes to data protection regulations require you to **OPT IN** in order to continue to receive our information. We also need to ensure that you have specified **HOW** you would like to receive that information.

Thank you to everyone who has returned their forms or completed online. For those who haven't yet responded, we urge you to do so as soon as possible.

If you require a copy of the form, please contact Donna Tinch on **01582 798 910** or email **donna.tinch@rettuk.org**

Alternatively, you may complete the ONLINE form at **www.rettuk.org/gdpr**

Thank you for your support.

Holiday in the Countryside

We have a 24-year-old daughter with Rett syndrome and have struggled to take any holidays with her because of her different needs. When she was young we her camping, or staying with friends or family, or even rented holiday accommodation, because we could carry her and she didn't have so much equipment etc.

We are fortunate in having a huge old Rectory with a large garden in the country which was ideal for our own children and many foster children, but now we are retired and don't foster we would like to offer accommodation for other families who have a child with Rett syndrome, and struggle to find/or afford to get away for a break.

We have spare bedrooms, a lift, wide doorways and ramps and hoists where needed. Large sitting rooms and kitchen etc – all wheelchair friendly and a hydrotherapy pool with hoist. There is a field if you want to camp, and plenty of parking space. No fixed charge but affordable donations would be welcome.

Please contact us if you interested on **01454 261 221**.

Wendy & Michael Britten

theBigGive
CHRISTMAS CHALLENGE 2021

Advocating for better outcomes for people with Rett syndrome

THE GIFT OF ACHIEVING THE BEST OUTCOMES THIS CHRISTMAS

Our target to raise for this year is £25,000

For more information, please see pages 7-9

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