Rett News

Support today, hope for tomorrow

www.rettuk.org
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Rett UK
Victory House, Chobham Street, Luton,
Bedfordshire LU1 3BS
General Enquiries: 01582 798 910
Support Line: 01582 798 911
Email: info@rettuk.org
fundraising@rettuk.org
Website: www.rettuk.org
Facebook: Rett UK • Twitter: @RettUK
Just Giving: www.justgiving.com/rettsyndrome

HONORARY POSTS – PATRONS
Zlufqar Ahmed, Lee Allen, Neal Astbury,
Ann Clwyd MP, Andy Collins, Dame Evelyn Glennie,
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Trusts and Foundations Officer: Becky Jenner
Family Support Manager: Julie Benson
Office Manager: Donna Tinch
Editor: Donna Tinch
Volunteer Administrator: Angela Duncan
Communication & Education Support Team:
Dr Gill Townend, Tracey Campbell,
Abigail Davison-Hoult (Coordinator)
Bookkeeper: Becca Prince

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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undetected until major regression occurs at around one year of age, when children may lose acquired skills and become withdrawn.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: Lara at our Regional Day, Belfast

CEO Welcome

by Robert Adamek

Hello and welcome to another great edition issue of *Rett News*!

Now that summer is in full swing, and the weather is warming up nicely why not check out our list of accessible holidays on pages 13-14 for some inspiration on your next break.

In May the team were in Belfast for our communication focused regional day and our first in person event in over 2 years. It was so heart-warming to hear the feedback from the families present and a parent who attended the day told me:

"The approach and information I learned from the sessions will be life changing for my family. I wasn't sure if it was too late for us to start using communications devices and I was told... It's never too late."

We are currently in the planning stages of our next regional event in Scotland. We are hoping for an October date and will keep you posted!

There is no escaping the fact that the current economic situation has been putting a strain on people's budgets and while it doesn't show much in the way of easing up, we have complied some helpful information about benefits for carers on pages 15-16.

One of the biggest single issues we are contacted for help with on a regular basis, are EHCP's. They apply to people aged up to 25 who need more support than is available through special education needs support. In response we are delighted to launch our Ask Julie sessions with Victoria Federico, Senior Associate – Court of Protection Department with Penningtons, Manches, Cooper LLP. For a full list of the sessions please see the programme on page 10.

The Rett UK communication team have been hard at work creating some absolutely fantastic webinars and programmes. If you haven't had a chance to watch the numeracy webinars or join one of our friendship groups head over to pages 31-32 and follow the links. Also don't forget our communication partner training starting in June.

The Big Give is back so please 'save the date' for the online donation stage in December – one donation but double the impact! If you are saving pennies in a jar or would rather donate than send Christmas cards – please make your donation on the Big Give.

Huge thanks to all our amazing fundraisers and those taking part in future events (pages 34-37). This year's sign-up to events has been record breaking and the sheer volume of activity is immense. Without this support Rett UK cannot continue. If you fancy getting involved head over to:

www.rettuk.org/runforrett2022

My final ask is that you fill in our family support services evaluation survey. This is really important to us and helps us report back to those that fund our work:

www.rettuk.org/survey

Best wishes,

Robert Adamek

Robert Adamek, CEO

Support Round Up

by Julie Benson

Improving knowledge and understanding of Rett syndrome

Ask Julie

We are currently developing a series of webinars called 'Ask Julie'. We have already got a monthly webinar running, looking at all aspects of Education, Health & Care Plans (EHCPs) – see page 9 for details – and hope to add more in the future. If you have a topic that you would like us to include, please do get in touch, by telephone **01582 798 911** or email **julie.benson@rettuk.org**.

Beer & Banter

Our Beer and Banter sessions continue this year and welcome all adult male relatives, young or more seasoned. These are proving to be really valuable but relaxed sessions. A great exchange of knowledge, experience and for those new to Rett syndrome a chance to share those first daunting thoughts amongst a group of peers providing a measure of reassurance that there is an exciting future ahead. Don't be put off by the title, beer is not compulsory! If you haven't yet attended, why not check it out? Brett Martin and Steve Nangrave, who run the sessions, are really friendly and welcome newcomers.

Join us for a chat, share experiences and anecdotes about this journey we are on as dad's of a child with Rett syndrome.

The sessions are a live event and will not be recorded. Anything you say during the sessions will be held in strictest confidence.

The next meet-ups are on Thursday 4th August at 8.00pm. To register visit: **https://forms.office.com/r/kKgqiLjxgc** and Thursday 22nd August at 8.00pm. To register visit: **https://forms.office.com/r/8xJMATtJKA**

Regional Event

We are delighted to have finally held our first face-to-face event, since the Pandemic, in Belfast, Northern Ireland.

It was well attended by almost 30 families, who all had a great time and were able to listen to presentations by Daniella Tropea who shared information regarding DataRett, Racheal Stevenson who gave us an update on the latest gene therapy developments and drugs trial and Gill Townend who introduced us to the Rett Syndrome Communication Guidelines.

The theme of the day was communication. There were opportunities to learn more and understand about establishing a yes/no, partner-assisted scanning, what impacts the ability to communicate, being a good communication partner, and an opportunity for 1:1 communication consultations.

We were pleased also to welcome representatives from Tobii Dynavox and Smartbox, who were there to give demonstrations of eye-gaze equipment, and a representative from the Family Fund, who was able to share information about the funding they offered.

There were plenty of things for siblings to do too, some exotics and some scary reptiles joined us for the morning, including an 8-foot python, a cuddly chinchilla, a bearded dragon, and some rather creepy insects too.

We would like to extend our sincere thanks to all the staff at the Dunsilly Hotel, Antrim, who went above and beyond to ensure that the event went smoothly and our stay was uneventful. Thank you all.

BELFAST REGIONAL EVENT

We will be sharing all the information about the Regional day via email so you wont miss out if you were unable to attend. This will include presentations, information, and access to additional resources through our website.

If you know someone who may not regularly receive our e-newsletter or magazine, please let them know they can contact **julie.benson@rettuk.org** to sign up for the circulation list.

THE BIG GIVE CHRISTMAS CHALLENGE IS BACK!

For the seventh 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!

For more details, see back page.

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/survey** 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

CHANGING PLACES

We're delighted to share the news that everyone has been eagerly awaiting – the results of applications for a share of the funding from the Department of Levelling Up, Housing, and Communities have been announced!

£23.5m worth of funding has been allocated across 191 councils and will see 513 new Changing Places toilets installed across England, meaning toilet accessibility for those who need Changing Places toilets will be vastly improved in these areas.

The remaining £6.5m of the fund will be allocated to local councils in a further round later this year and will focus on areas where there is little or no Changing Places toilet provision.

Full List Of Awardees

See if your area benefits:
http://tiny.cc/pifsuz

NICE Guideline on Disabled Children and Young People up to 25 with Severe Complex Needs

Integrated service delivery and organisation across health, social care, and education

This final guideline has now been published on the NICE website **https://www.nice.org.uk/guidance/ng213.**

It is a lengthy document that we are not recommending you read! But it does contain some useful information should you need to challenge a health or social care provider, who you feel may not be meeting their responsibilities.

You can find some helpful tools and resources here:
https://www.nice.org.uk/guidance/ng213/resources

To support the guideline, they have also produced an equality impact assessment:
https://www.nice.org.uk/guidance/ng213/history

The recommendations are certainly worth reading as these are the standards that service providers should be working to.
https://www.nice.org.uk/guidance/ng213/chapter/Recommendations-on-support-for-all-disabled-children-and-young-people-with-severe-complex-needs

What is an Education, Health & Care Plan (EHCP) and Why is it Important?

An Education, Health and Care Plan (EHCP) is for children and young people aged up to 25 who need more support than is available through special educational needs support.

An EHCP identifies the education, health, and social needs of the child or young person, and sets out the support (provision) to meet those needs.

An EHCP is a legal document describing the child/young person's special educational needs, detailing the additional special educational provision and an appropriate placement.

The EHCP is a contract between the Local Authority and the parents of the child named in the plan.

Parents, the nursery/school placement, professionals, and therapists will all have the opportunity to contribute to the plan before it is agreed upon and signed off by the local authority.

The EHCP is a lengthy document and should cover all aspects of the child's health, education, and social needs that may impact on their educational experience and learning.

The plan is made up of 11 separate sections, each containing details of the child's needs. Below is the list of the different sections. Whilst all sections are important in identifying the child's needs, those highlighted in green will set out the need, with Section F being the most important as this is which sets the support the child will need clearly and is legally binding.

Section A

The views, interests, and aspirations of the child and parents or the young person;

Section B

The child or young person's special educational needs ("SEN");

Section C

Health care needs that relate to their SEN;

Section D

Social care needs that relate to their SEN or a disability;

Section E

The outcomes sought for the child or young person;

Section F

The special educational provision required to meet their SEN;

Section G

Any health care provision reasonably required by the learning difficulties or disabilities which result in the child or young person having SEN;

Section H

Any social care provision required from social services under the Chronically Sick and Disabled Persons Act 1970, and/or reasonably required by the learning difficulties or disabilities which result in the child or young person having SEN;

Section I

The name of the school or other institution to be attended by the child or young person, and the type of that institution (or just the type if no specific institution is named);

Section J

Details of any direct payment which will be made;

Section K

Copies of all of the advice and information obtained as part of the EHC needs assessment.

It is important that the wording is appropriate and that the targets are SMART, Specific, Measurable, Achievable, Realist, and Time-specific.

Rett UK recognises the importance of an EHCP. To help parents to understand the complexities of requesting, producing, and completing an EHCP, we are, as part of the 'Ask Julie' series in partnership with Victoria Federico, Senior Associate, with Pennington Law, will be offering some short webinars. During the sessions we will be looking at all aspects of the EHCP process, from what is an EHCP, the review process, how to challenge if you feel it is not working and how it can work for the over 18's.

13th July 2022 10.00-11.00am
LA legal duties around EHCP's
https://forms.office.com/r/6Br1xQWgTT

28th September 2022 10.00-11.00am
Annual Review of EHCP
https://forms.office.com/r/7SPuzZDBAA

25th October 2022 10.00-11.00am
EHCPs for 19-25 year olds
https://forms.office.com/r/2xz6mxHxe1

24th November 2022 10.00-11.00am
Challenging an EHCP – including appealing to the SEND Tribunal
https://forms.office.com/r/M4LsyYPsBF

If you have missed any of the past events, please don't worry, they will be available via our website, shortly after each event.

For more information or if you have any questions please call the office on **01582 798911** or email **julie.benson@rettuk.org**

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**

Rett UK
ASK JULIE

INFORMATION SESSIONS

We are delighted to have Victoria Federico, Senior Associate – Court of Protection Department with Penningtons, Manches, Cooper LLP, joining us for these sessions looking at all aspects of Education, Health & Care Plans.

Throughout the events, Victoria will be sharing short webinars and explaining to us what an Education, Health & Care Plan is:

- Why they should be in place
- Parent responsibilities
- Why it is so important to get the contents right
- The legal duties of the local authority
- Reviewing the document
- How it applies to young adults 19-25 years of age and
- How to challenge the document if you don't think it is right for your child or young person.

All the events will incorporate a short webinar, before a question and answer session. *These events will NOT be recorded, to protect individuals' confidentially.* We do plan to have the webinars available as a resource on our website after the events.

Please see the dates, information and links to the sessions on page 10.

☆ ☆ ☆ ☆

High Court Calls Time on Council Delays for Children with Special Needs and Disabilities

In a landmark judgment issued on 8th March 2022, the High Court has made it clear that every local council must keep to fixed legal time limits when reviewing the needs of children and young people with special educational needs.

Read the full judgement here: **https://www.watkinssolicitors.co.uk/site/blog/watkins-news/high-court-calls-time-on-council-send-delays**

DON'T FORGET!

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

Email: donna.tinch@rettuk.org

The Difference That Rett UK Makes

Staying in education, thanks to Rett UK

by Val McGurk

We are so grateful to have received such fantastic support from Rett UK over the past 20 years.

Rett UK once again came to our rescue recently, when our Local Authority refused to allow my daughter, Beth aged 22, to repeat a year at college.

Julie and Abigail, from Rett UK, helped us to prepare an appeal.

Our appeal focussed on the fact that, through no fault of her own due to COVID shielding, Beth had not been able to achieve specific learning outcomes around eye gaze communication at college. Rett UK provided a powerful advocacy statement that focussed on why this aspect of learning is so crucial for students with Rett syndrome to maximise their potential.

As a result, we won the appeal and were absolutely delighted. However, the support from Rett UK didn't end there. Abigail has kindly volunteered to meet with us and the College to sharpen Beth's targets and provide expert advice.

The College has also ensured Beth now has a dedicated communication partner and that her eye gaze has been made permanently accessible via a new mounting system. Instead of the utter frustration of being confined to body language as her only means of communication, Beth is beginning to express her needs through eye gaze and make purposeful choices. This way of learning and communicating is opening up a whole new world for Beth and it transcends all aspects of her health and social and emotional well-being.

In addition, following advice and encouragement from Julie, we have decided to challenge our Local Authority to extend Beth's college placement further until she is 25 years old. This provision is offered to all students in theory but seldom happens in practice, due to lack of publicity and the challenges involved in providing evidence of learning progression in young people with Rett syndrome.

A few years extra in education will provide a lasting legacy, not just for transition, but for the rest of Beth's life and we remain indebted to Rett UK for striving to make this a reality.

We'd love to hear more about how Rett UK makes a difference to you.

Please share your views with us here at Rett UK.

Accessible Holidays

Holiday suggestions

For many families travelling with a child/adult with disabilities can be difficult, but we are pleased to say more and more people are now offering adapted accommodation for people with disabilities.

We are compiling a list for families based on their recommendations.

Below are some of the places already suggested, but if you find a little gem, which is suitable for people with disabilities, please do let us know so we can add to the list and share it with other families. You can email **julie.benson@rettuk.org**

Brickhouse Cottages, Hambleton, Nr Blackpool
https://www.brickhousecottages.co.uk/

Center Parcs
https://www.centerparcs.co.uk/discover-center-parcs/lodge-holidays/accommodation-type/adapted-lodges.html

Laughan Barns Lsandudernum
https://www.laugharnebarns.co.uk/

Marsham Court Hotel in Bournemouth
https://marshamcourthotel.co.uk/

Ellwood cottages in Dorset
https://www.ellwoodcottages.co.uk/

Disabled Holidays
https://www.disabledholidays.com/

Limitless Travel
https://www.limitlesstravel.org/disabled-holidays/holidays-with-hoists/

Euan's Guide
https://www.euansguide.com/news/holiday-cottages-with-hoists/

Our Bench in the New Forest
http://www.ourbench.co.uk/

Nutley Edge
https://www.nutleyedge.org.uk/categories/accessible-cottages/

Flat Spaces in Alton Hampshire
This is right on the steam railway line. You can sit in the garden and watch the trains going up and down as well as of course going on them!
http://www.flatspaces.co.uk/flatspaceshampshire.html

Trevassack Holidays
https://trevassackholidays.com/

Adapted caravans

There are some independently owned adapted caravans. Below are a few sites:

https://www.shorefield.co.uk/holidays/accommodation/wheelchair-accessible

https://www.awayresorts.co.uk/

https://www.breansandscaravans.com/brean-sands/accessible-holidays.asp

Facebook groups

Accessible, Adapted or Disabled Holiday Lets
https://www.facebook.com/groups/Accessible.hols.places.days

Accessible, Adapted or Disabled Foreign Holidays & Travel Info (UK based)
https://www.facebook.com/groups/504986963256563

Days out and longer stays

You may also find the guide below helpful for days out and longer stays.

https://www.motability.co.uk/news/rough-guide-to-accessible-britain/

So above are just a few suggestions that we have so far. So if you manage to get a break away this year or in the future, please remember to send us your recommendations.

Happy holidays!

Benefits for Carers

Every day we hear more and more about how people are struggling with their bills, and the additional resources someone with disabilities may need.

This may be because they need to use more water due to having to bathe more often, or they may require the house to be heated to a higher temperature to keep them warm.

With the increasing cost of living and the prices of everyday necessities going up fast, it's good to know where you may be able to go to get some additional help, and access to some additional resources.

Water Bills

WaterSure is a scheme that helps some people with their water bills. If you get help through the WaterSure scheme, your water bill will be capped. This means you will not pay any more than the average metered bill for the area your water company deals with.

One Rett parent commented: "So just got ours added and our bill will be capped at £38/month instead of £73!"
https://www.citizensadvice.org.uk/consumer/water/water-supply/problems-with-paying-your-water-bill/watersure-scheme-help-with-paying-water-bills/

Energy Bills

Energy costs can really add up. This can be especially true if you are at home a lot of the time or need to keep particularly warm. It is therefore common for carers to worry about how they or the person they care for will afford their gas and electricity bills.

There are some simple changes you can make to keep your bills as low as possible, as well as lots of different forms of financial support available.
https://www.carersfirst.org.uk/help-and-advice/topics/help-with-your-energy-bills-as-a-carer/

Council Tax

You may be eligible for a reduction in your council tax bill if you have someone in your household with a physical or learning disability.

The schemes are based on whether you have to live in a larger property than you would if you didn't have a disabled person in the house or if someone you live with has a learning disability.

You can check if you are eligible for a discount below.
https://www.gov.uk/council-tax/discounts-for-disabled-people

Transport

If the person you live with receives the higher level of DLA you may be eligible for a Motability vehicle. To find cars that will be available through the Motability Scheme.
https://www.motability.co.uk/

Motability may also be able to help with a Motability Grant to offer financial support for things such as driving lessons, help with the deposit for a vehicle.
https://www.motability.org.uk/?ssSourceSiteId=motability

If you need to use public transport then many providers will also let a carer travel for free on most buses and trains, to check if you are eligible please visit the website below, there is also information about discounted Road Tax:
https://www.turn2us.org.uk/Benefit-guides/Travel-costs-People-with-disabilities-and-carers/Bus

Leisure

There are many discounted activities available to disabled people and their carer.

You can apply for a CEA card, which gives free entry for carers into cinemas, you can apply for one here:
https://www.ceacard.co.uk/

Carers first also have lots of ideas and information for carers to get discounted offers and access to venues, more details are available on their website:
https://www.carersfirst.org.uk/help-and-advice/topics/discounts-for-carers/

Changes to Benefits in Scotland

Thank you to Contact Scotland for making us aware of the changes to benefits in Scotland.

A new benefit for disabled adults aged between 16 and pension credit qualifying age has now launched in Scotland. This new benefit – called Adult Disability Payment – will replace Personal Independence Payment (PIP) in Scotland.

The new benefit will initially pilot in certain specific council areas before rolling out to the rest of Scotland on 29th August 2022.

When can I make a new claim for Adult Disability Payment?

Initially, the Adult Disability Payment is only replacing new claims for PIP.

The date you can make a new claim for Adult Disability Payment will depend on where in Scotland you live:

- From 21st March 2022, it will replace new claims in the areas of Dundee City, Perth and Kinross and the Western Isles. If you live in one of these areas, you will not be able to make a new claim for PIP from 21st March, and instead, you will need to complete a claim for the new Adult Disability Payment with Social Security Scotland.
- From 20th June, it will extend to Angus, North Lanarkshire, and South Lanarkshire.
- From 25th July, it will further extend to Fife, Aberdeen City, Aberdeenshire, Moray, North Ayrshire, East Ayrshire, and South Ayrshire.
- And from 29th August, it will be rolled out to the rest of Scotland.

You can make an application for the new benefit online at **mygov.scot** or by calling free on **0800 182 2222**. British Sign Language users can use video relay via the contact Scotland BSL app.

What happens to existing PIP or DLA claimants?

Adults in Scotland who are already getting PIP or Disability Living Allowance (DLA) for adults won't transfer onto the new Adult Disability Payment until later in the summer. This process is expected to happen in stages.

Once existing claimants start to transfer, this will happen automatically without the need for existing claimants to make an application for the new benefit.

How does Adult Disability Payment differ from PIP?

The new benefit's eligibility criteria are very similar to PIP. But the way the benefit is assessed is expected to be different from PIP. Social Security Scotland plans to have much fewer face-to-face assessments. Social Security Scotland may still ask you to attend an assessment if it believes this is the only practical way to get the information it needs. But that assessment won't be carried out by a private company.

Adult Disability Payment awards are also likely to be for longer periods. The Scottish Government recently confirmed that disabled people on the highest rates of the benefit, who have conditions unlikely to change, will receive indefinite awards of Adult Disability Payment. This means their award will not be subject to regular reviews.

https://www.linkedin.com/shareArticle?mini=true&url=https://contact.org.uk/?p=14618&title=&summary=&source=

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!

TRUE COLOURS TRUST FUNDED SESSIONS AT ALL-ABOARD WATERSPORTS

Free, fully accessible, and adaptive water sports sessions in Bristol Harbour for Rett families.

All-Aboard have received funding from the True Colours Trust enabling them to offer a number of fully funded watersports sessions to children with disabilities or life limiting conditions, and their families. True Colours is also mindful of the difficulties faced by siblings of a very unwell child, so it is possible to offer these sessions solely to siblings with parents/ carers if the patient is too poorly to access them.

They can offer the following activities:

- **Paddling** – canoeing, kayaking, stand-up paddleboarding. Kayaking includes the use of katakanus, a stable 4 person canoe that has a central “trampoline” that is often more comfortable than the traditional seat for participants with certain disabilities.
- **Sailing** – in stable access dinghies that can be sailed from one position
- **Boat trips** – around Bristol harbour on their wheelchair accessible motor boats.

How does it work?

Sessions are a maximum of 2.5 hours, for up to 8 participants. They provide fully trained, qualified and experienced instructors, and where possible and beneficial they will also provide an experienced and trained volunteer to assist with the session.

They will offer participants a range of date and time slots so that they can chose one that suits them. Certain dates and time slots may have restricted choices of activity, depending on other sessions being run by the Centre at that time.

Unfortunately they are unable to provide activities for children under the age of 3 years, and those aged 3-7 years will only be able to go on the boat trips.

Are the activities accessible?

They have hoists to facilitate transfer from wheelchair to watercraft if required, and other adaptive equipment. Buoyancy aids are provided for all participants and wetsuits or waterproofs etc. if required. The Centre is fully accessible (although may be limited in use due to Covid).

There is a car park next to the Centre that is free for up to 4 hours, with accessible parking spaces available.

https://www.truecolourstrust.org.uk/

https://www.allaboardwatersports.co.uk/

How do I book?

Interested participants should contact: **fundedactivities@allaboardwatersports.co.uk** to make a booking.

Initially they will need to restrict the offer to one session per family.

What happens after my session?

If you enjoy your session with them there's plenty on offer at All-Aboard for the future! Their friendly team can advise you which other sessions will suit your needs.

Participants will be sent an email following their session asking for feedback that they may have. Any feedback is greatly appreciated in order for them to demonstrate the benefit of their sessions to strengthen any future grant funding applications and support further projects in the future.

TAYSHA RETT PROGRAM UPDATE

Taysha Gene Therapies recently announced that they have received Clinical Trial Application (CTA) approval from Health Canada for the phase 1/2 clinical trial of their investigational gene therapy for adult females with Rett syndrome.

You can find a link to the investor press release here.: **https://ir.tayshagtx.com/newsreleases/news-release-details/taysha-gene-therapies-announcesinitiation-clinical-0**

‘Uptime’ - activities in standing and walking

115 parent caregivers and **49** therapists from **28** countries gave us their top tips for how to support ‘uptime’ in Rett syndrome. See what they told us.

SUPPORT FOR THE PERSON

Fitness and function – building physical capacity

- Embed ‘uptime’ in everyday routines
- Allow time for activities to start and then be completed
- Look for signs that activities are manageable and enjoyable
- Include breaks within the activity to achieve more activity without fatigue
- Create breaks for movement within long periods of sitting

Fun activities – individual interests

- Explore opportunities for enjoyment, social engagement and learning
- Consider activities that offer responsibility (e.g., household chores, grocery shopping)
- Work towards self-chosen activities that are motivating
- Give praise for achievements and rewards according to individual preferences

Family and friends – a rich social environment

Create a supportive team of helpers

- Plan together with the individual, families and helpers
- Combine ‘uptime’ and social activities with family, classmates and within community environments
- Focus on the activity rather than performance

Opportunities in the physical environment

- Be active in different environments - in indoor and outdoor settings, at home, at school and in the community
- Explore natural environments
- Use adaptive equipment where appropriate at home and school
- Consider adjustments to furniture, e.g., standing stations in the house

SUPPORTIVE ENVIRONMENTS

‘Uptime’ is important for health and wellbeing. We hope you enjoy designing new routines and activities to increase ‘uptime’ for individuals with Rett syndrome.

For further information, please contact Associate Professor Jenny Downs at jenny.downs@telethonkids.org.au

TELETHON KIDS INSTITUTE
Discover. Prevent. Cure.

REGION H Rigshospitalet

ARIEL UNIVERSITY

אוניברסיטת חיפה
University of Haifa
جامعة حيفا

International Rett Syndrome Foundation
www.rettsyndrome.org

Research Into Music Use in Daily Life by People with Rett Syndrome and Their Parents and Primary Caregivers

My name is Jennifer Bullock and I'm a final year student on the Music Therapy Master's course at the University of the West of England in Bristol. In my first year I was privileged to be able to work with a young woman with Rett syndrome and became very interested in the condition, something I'd not come across prior to training. Alas, our work was cut short by the onset of COVID-19, but I have continued to be interested, and have thought about the challenges families of those with Rett syndrome may have encountered during the pandemic – I take my hat off to you all!

Music is such a powerful way of both communicating with and improving the well-being and functioning of those with the condition, and there is much literature about music therapy and Rett syndrome. However, I recognise that whilst only trained music therapists can deliver music therapy itself, parents, carers and families can be hugely involved in musical activities in everyday life, and this seems to have been less studied. For my dissertation research project, I've chosen to look into the experiences of parents and primary caregivers of people with Rett syndrome in using music with them, and I would very much value hearing about your musical activities. My hope is that the project will give parents and primary caregivers a voice, valuing their experiences and enabling them to share them with others, and potentially informing music therapists and feeding into the creation of musical resources for use at home.

I've created an online survey with questions which I hope will enable you to share your experiences in as much detail as you would like. Participation is anonymous and I'd love to hear from many people to gain a broad picture of how music is used by those with Rett syndrome and their parents or primary caregivers, and in due course, I hope to be able to share my findings with you and the Rett syndrome community.

Please do click on the link below to access the survey, and feel free to email me directly with any questions you might have: **jennifer3.bullock@live.uwe.ac.uk**. I'd be grateful if survey responses could be submitted by Sunday 26th June in order to give me time to analyse the results.

With huge thanks in advance – looking forward to hearing from you!

Link to access the survey:
http://tiny.cc/bjfsuz

UWE Bristol University of the West of England

This research has been approved by the Psychology Ethics Committee, UWE

Voting in the Local Elections 2022

by Tracey Campbell

Have you ever considered how to help adults with Rett syndrome to vote?

ENABLE Scotland's #ENABLEtheVote campaign has been running for a few years. Here is a link to their campaign: **https://www.enable.org.uk/get-support-information/membership/campaigns/our-campaigns/enablethevote/local-council-elections-2022/**

The ENABLE information explains the process for voting including the complicated voting process in Scotland. It's called Single Transferable Votes and it means that you rank your favourites rather than just choosing one candidate. Find out more about the process here: **https://www.enable.org.uk/wp-content/uploads/2022/04/Easy-Read_-May-22-Scotland-Voter-Guide-Web-Accessible-1.pdf**

Some people may be keen to vote in person, as is their right, this should be a straightforward process whereby you fill in a form on arrival, that allows a scribe in a booth. You may be asked how the officials would know the vote is the person with Rett syndrome's choice.

So do prepare the person that you are supporting that they may have to demonstrate their yes or no response. Take any symbols that you have used or other choice making equipment such as E-tran frames. If you think there is a possibility that the person you are supporting may not be able to demonstrate their communication skills in this type of scenario it may be worth videoing at home and taking that to the polling station.

If the person you are supporting requires further information about why they should vote and what they are voting for you may find this explanation useful – either on this pdf:
https://drive.google.com/file/d/1o95Hq2HjB5oz_G8m_3n8lzu22_Q66fx6/view
or on this video:
https://www.youtube.com/watch?v=9Ab52XUoRFs
When you have read the information you may want to use this form to gather information about what the person you are supporting is interested in.

The next step in the process is to find out what your local candidates are interested in and what they stand for. Sadly, there is a lack of easily accessible, easy read information available.

You can usually contact candidates via social media or email their party office if they are affiliated with a political party. Here is an example letter: **https://www.rettuk.org/exampleletter** Please copy or write your own based on this.

Please do let Rett UK know how you have got on voting.

Thanks to ENABLE Scotland for campaigning to raise the number of disabled people participating in elections.

For more information or to look out for updates, please find the info on Tracey's blog here: **https://www.traceycampbellact.com/post/voting-in-local-elections-2022**

Happy voting!

Tracey Campbell
Achieving Communication Together

MOVEMENT FOR GOOD

MOVEMENT FOR GOOD NOMINATIONS

If you have a minute to spare please can you nominate us for a chance to win £1,000. Thank you!

Our charity number is 1137820

https://movementforgood.com/

Aisha Purvis of Sensmart

Drawing on her professional experience in healthcare, along with her personal experience as a carer, Aisha Purvis founded Sensmart to address malnutrition, dehydration, and food waste in care settings.

She shares her big aspirations for the future of this brand new start-up and her hopes to effect wide-reaching change.

Read the full interview here: **https://rarerevolutionmagazine.com/peopleofrare/aisha-purvis-of-sensmart/**

For more information visit: **https://sensmart.co.uk/**

Sensmart
It makes sense

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.

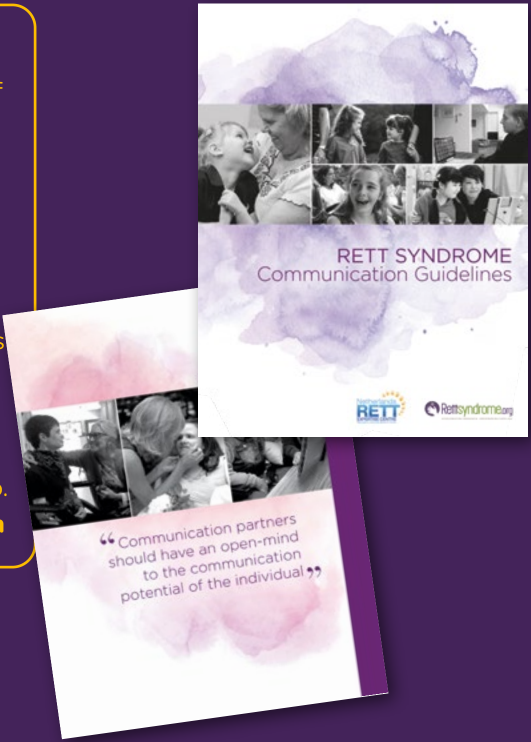
To get your free digital copy now, go to:
https://www.rettuk.org/communicationguidelines

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.

Contact Gill Townend:
gill.townend@rettuk.org.

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.

Sign up here: **https://rettuk.org/cpn**



Communication and Education Team Update

Maximising the communication potential of people with Rett syndrome

Communication Partner Training

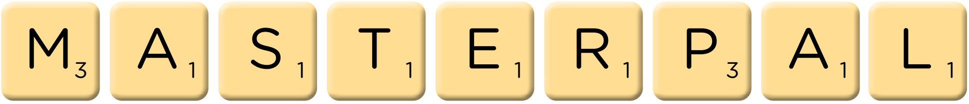
by Tracey Campbell

At Rett UK, we are always looking for ways to improve our services and ensure that they lead to the best outcomes possible for people with Rett syndrome. The Communication and Education Team are no different. Communication Partner Training is the latest addition to our service. Three of our Regional Communication Champions (RCCs) recently ran a course for the participants of the current loan program. Rett UK made the change because during the pandemic families have not had the same opportunities to practice with low tech resources. Also, they are unlikely to have experienced being in an environment where people are modelling the use of AAC around them.

Of course, when we make decisions, we like them to be available for our families as soon as possible. Therefore, rather than developing a whole programme in-house, we based the training sessions on the freely available Model as a MASTER PAL programme designed by Tabi Jones-Wohleber. Model as a MASTER PAL covers the following topics:

- Modelling
- **M** otivation
- **A** ccepting multiple modalities
- **S** tatements more than questions
- **T** ime (wait time, and time for growth)
- **E** ngaging naturally
- **R** esponse not required
- **P** resuming potential
- **A** ppropriate prompting
- **L** etting the child lead

Rett UK added in training about Yes/No responses and Partner Assisted Scanning. We wanted to run the first course as closely as possible to the pre-made materials. This allowed us to compare the course to the training we had previously delivered. The materials on Model as a MASTER PAL are extremely easy to use and well explained. However, as Rett UK are specifically delivering training for communication partners of people with Rett syndrome, we are going to adapt the training slightly. The training is certainly a good basis for any professionals reading the article.



> *The training of communication partners is vital to ensure the loan of the AAC device is successful. This is a new concept for most people and can be a scary one. Our role is to stand alongside, supporting those who are within the individual with Rett syndrome's "inner circle". The best way of doing that is coaching how to: model, let the child lead, and make statements/comments, rather than questions. This will set those communication partners up for success and hopefully be the beginning stage of a long and autonomous communication journey for the individual with Rett syndrome.*
>
> **Carly, one of the RCCs who ran the training with Tracey**

Our plan is to run more communication partner training courses and make them available to everyone, not just those on the loan programme. We recognise that people with Rett syndrome will have new communication partners often and that, sometimes, even an experienced partner needs a refresher, motivator or to update their skills. The sessions took place over four 2-hour sessions. We are still experimenting with the amount of time to spend doing the training and the number and length of sessions. I am sure many of you will be pleased to know that the time is likely to reduce and not increase!

> *The training has really improved our communication with our daughter.*
>
> *We are more aware of her natural cues and how to build on that with the low tech/high tech methods.*
>
> *The training has developed my confidence so I felt ready for the eye gaze device and knew I would be supported throughout the loan period.*
>
> **Amanda, mum to Hannah aged 6, who attended the recent Communication Partner training sessions for loan program families**

Completing the communication partner training is likely to become a condition of entry to the loan programme. Not because we want to make things harder for parents, we just want everyone to be able to maximise the time they have with the device. This is especially important for those looking for funding for a personal device. It can still sometimes be a difficult and drawn-out process. So, the earlier in the loan period families feel confident the better.

Overall, the Communication Partner Training has been successful and is likely to become part of the services the Rett UK Communication and Education Team offer, if future funding allows.

See page 33 for the dates of the next planned sessions and the link to the booking form.

Friendship Groups

By Tracey Campbell

The Rett UK Communicate, Educate, Advocate 2020 Conference inspired the friendship groups. I must confess that I do love running the friendship groups. They are relaxed and fun. Like any friendship group, they are full of laughter and people you want to be around. We do recognise that it is not a true replication of friendships, as all the attendees require a communication partner. However, whilst the RCCs who facilitate the groups will have prepared resources and topics, we take the lead of the conversation from the attendees. And like any good get-together, those conversations can stray far from the original topic!

> *It is a pleasure to meet great friendly faces over Saturday Zoom. The girls show their personalities and if someone needs to leave early that's fine. Some girls are tired and need more time to respond and that's fine too. The meeting is very relaxed and although we plan activities, these are never set in stone, our aim is to be led by the girls themselves.*
>
> **Joanna, one of our RCCs**

The RCCs never demand anyone must communicate and all forms of communication are accepted, just as they should be when we are hanging out with friends. Some people contribute only by facial expressions and gestures, they enjoy the experience just the same. The communication partners of the people with eye-gaze devices or other forms of communication often report that the person with Rett syndrome communicates more during the group.

> *Rosie is really enjoying the friendship group! She's not using her eye gaze as too busy watching the people but is very responsive with her yes, no, and smiles! Now associates the sessions as prosecco time and her favourite subject matter of course... men!*
>
> **Rosie's communication partner about their experience in the adults' group**

The groups cover a wide range of topics, including current affairs and different interests that the participants have. For example, in the adults group we have covered, climate change, the Olympics, and the upcoming elections. In this group, we do, however, always tend to come back to the favoured conversations of alcohol and men. It is fair to say that last week was the least engaged the adults have ever been as we discussed the elections! So, we kept the serious stuff brief and moved on to more pressing topics such as Olly Murs and Channing Tatum, as well as all the many social engagements everyone had to look forward to. In the younger groups, we have had discussions around books such as “Fantastically Great Woman Who Changed the World” and sometimes we play games, for example, Bingo. The youngest group has only met once.
We played songs from YouTube to help prompt discussion about getting to know one another a little better. Pedro the Parrot puppet seemed to be a hit.
He dances to the music and can also do some Partner Assisted Scanning using his Yes/No response. After each session, we review what has worked well and what we could do better in the next one. We are always looking to adapt and keep interest levels up.

For those of you who are unsure, just come along and give it a try. Although please don't expect it to be like a formal lesson. Esmé describes her group as "chaotic" and Polly says hers is "silly". They are both in agreement, however, that the best part of their groups is meeting their friends.

The groups run either the third or fourth week of the month. See page 31 for the dates of the next planned sessions and the link to the booking form.

Loan Program

By Abigail Davison-Hoult

Since 2018, Rett UK has been in a position to loan eyegaze devices to families, offering full support for the duration of the loan period. Initially, the loan was for 6-8 weeks but we quickly realised that this wasn't long enough to get to grips with using it in combination with other methods of AAC eg; Yes and No, Partner Assisted Scanning, and low tech paper based methods.

Dani Hunt using her loan device

With the onset of the pandemic, we took our services online and took the opportunity to reshape the loan program. The introduction to using AAC that had previously been delivered in person now had to be conducted via virtual means, and the devices were deployed to families for an initial 8-week period with the option to then extend the loan for a further 4 months if desired. During this time, as with the previous version of the loan program, families committed to sending weekly video footage of communication interactions between the person with Rett syndrome and either family members, carers, or friends. Each family was linked to a dedicated RCC who was responsible for providing emailed feedback for the videos and guiding the family through the process.

Using virtual means to run the program and offer a high level of support worked surprisingly well and had the added benefit of there being no geographical constraints when pairing RCCs and families. After running 4 blocks of the loan program this way, however, it became apparent that the six-month loan period was too long for families to keep up the momentum.

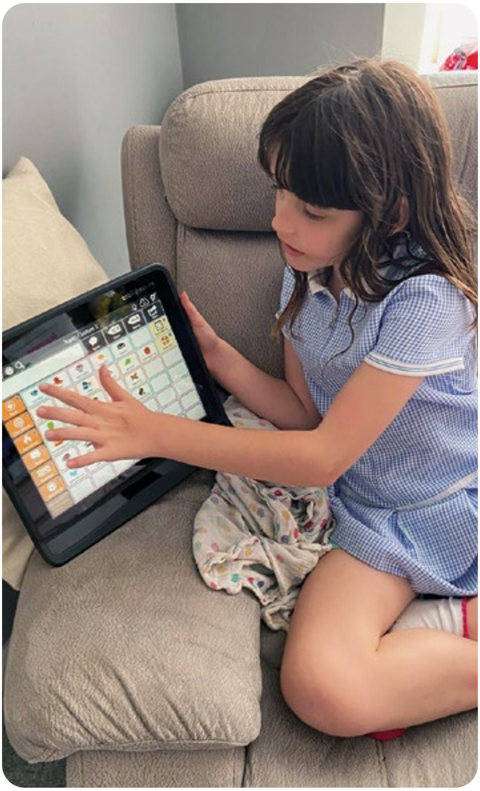
The third iteration of the loan program has been introduced for the current block of families. Before receiving the device, families are required to attend an online training program that introduces methods using AAC concepts that underpin all communication. Submission of the weekly videos starts at this point. After completing the How to be an effective communication partner training, families receive their device and are paired with their RCC. They have the device for an initial 8 weeks with the option to extend for a further 8 weeks. We hope that this length of time will be just right!

The video footage is a crucial part of the program. The program is structured in a way that aims to meet some of the criteria required by funding bodies to accept an application. By supporting families through the different scenarios, we hope that they can demonstrate that they have the necessary level of commitment required to integrate AAC into their daily lives.

We can loan out a maximum of 9 devices (Tobii Dynavox, Smartbox, and EyeTech machines) within a block and all the RCCs who support loan families have a wealth of experience. If you are interested in loaning a device, please contact Abigail at **abigail.davison-hoult@rettuk.org** to be added to the list.

Here is Sarah's experience of the loan program:

> “*My daughter Betsy was displaying signs of Rett syndrome when she was 5yrs old, by which point she had lost all spoken language and some purposeful hand use.*
>
> *Due to this Betsy's anxiety escalated and it was extremely sad to see her struggle so much.*
>
> *I was put in touch with Rett UK and they changed our lives for the better. I was able to loan an eye gaze device through the loan programe and Betsy was keen to use it straight away, asking for all her favourite things! Before Betsy would put her head in her hands when she could not say something and now she has the biggest smile when the device asks for her!*
>
> *We had fantastic support during this trial, being taught how to use it and right through to applying for and being successful in receiving funding for Betsy's own device.*
>
> *We were helped through each stage and when Betsy received her own she continued to grow on her journey to communicate.*
>
> *We rely on the device daily, Betsy will point for this to be switched on, it goes to school with her, she absolutely loves to use this to request things and we know she will eventually communicate her feelings to us. Having the device opened up a whole world of opportunities for Betsy to communicate after what can only be described as a traumatic period of regression and such sadness at the skills she lost.*
>
> *Now Betsy is able to learn new skills, skills that make her and us as a family smile, skills that will help her develop into the amazing individual that she is, and to be able to communicate with those who don't know her so well as she grows into an adult.*
>
> *Rett UK and the Sequel Trust gave Betsy the gift of communication and for that, we and Betsy will always be truly grateful.*”



Betsy Pickett with her loan device

Supported Loan Programme

Why do we offer a supported loan program?

- To build knowledge and skills in using Augmentative and Alternative Communication (AAC) strategies to support and enhance communication between the person with Rett syndrome and their communication partners (e.g. parents, carers, therapists, teachers);
- To provide an opportunity to trial use of an eye gaze device; and,
- To gather evidence to support an application for funding so that the person with Rett syndrome may be provided with a device of their own in the future (if agreed to be the appropriate next step).

Who is the program for?

Anyone with Rett syndrome of any age (from toddler to adult), no one is too old or too young, and their primary carers.

Usually we would expect a close family member (parent, adult sibling) to be the main contact and person who takes the lead responsibility for getting involved in the programme. However, key workers in residential settings and, less frequently, education staff may be the main contact and take lead responsibility.

How does the program work?

The program is in two parts:

Part One: Communication Partner Training

A short series of small group sessions that may run over two – four weeks (sessions will be around 2-3 hours long). Attendance is required at all sessions.

Part Two: Eye Gaze Device Loan/Trial Period

Initially for 8 weeks, with an option to extend for a further 8 weeks. During this time each person/family will be supported by a designated Rett UK Regional Communication Champion (RCC). The family will send weekly videos for feedback from the RCC and attend fortnightly small group sessions with their RCC, where tips and activity ideas will be shared.

What is required from participants?

- Attendance at all Communication Partner training sessions.
- Attendance at all fortnightly sessions with RCC during loan/trial period.
- Sending in short weekly videos for feedback from supporting RCC (each video only needs to be 1-2 minutes long).
- Filling in a Case History form, Pre-loan Evaluation Questionnaire and Loan Agreement before the start of the program and repeating the Loan Evaluation Questionnaires after 8 weeks and 16 weeks.
- Using the eye gaze device as much as possible, in different situations throughout the day, and in different settings, during the loan period.

The loan program runs in blocks 2-3 times a year. Communication partner training sessions may also run independently from the loan program. If you are interested and would like to join the waiting list for a future loan block, please send an email to abigail davison-hoult, Rett UK loan program coordinator:
abigail.davison-hoult@rettuk.org

Friendship Groups for Children and Adults with Rett Syndrome

Do you know someone with Rett syndrome who would like to meet with their peers and join in social communication activities online?

Our Regional Communication Champions run monthly Friendship groups online for all ages. Activities vary, according to the interests of the group members. Whether it's sharing music and stories, telling jokes, talking about world events, or just having a chat, why not come along, make new friends and catch up with old ones? Widen your social circle and practice your communication skills while having fun.

These groups are for children and adults with Rett syndrome who use any form of communication. If the person uses an eye gaze device or symbol boards, great – make sure they are on hand to use in the group. If they don't have any formal system in place yet that's also ok, we'll all be developing our communication and interaction skills along the way. We expect a parent or carer to accompany each person with Rett syndrome during the session.

If you are interested and would like to join the next session in June, just click on the link for the appropriate age group to complete the registration form. We will then send you details on how to join the session.

Monday, 20th June 7.30-8.30pm
Friendship group 13-18 yrs
https://forms.office.com/r/X2jxx0isEf

Thursday, 23rd June 7.30-8.30pm
Friendship group 19+ yrs
https://forms.office.com/r/0mxS0AtK8H

Saturday, 25th June 10.00-11.00am
Friendship group <6 yrs
https://forms.office.com/r/EQbAYwpZBH

Saturday, 25th June 11.00am-12.00pm
Friendship group 6-12 yrs
https://forms.office.com/r/yY8K1mm9Zt

Please note: We will publish links to register for each session a few weeks in advance. However, you can also add the July dates to your diary now:

Mondays, July 18th 7.30-8.30pm
Friendship group for teenagers (13-18s)

Thursdays, July 21st 7.30-8.30pm
Friendship group for adults (19+)

Saturdays, July 23rd 10.00-11.00am
Friendship group for under 6s

Saturdays, July 23rd 11.00am-12.00pm
Friendship group for 6-12s

DO YOU HAVE A STORY THAT YOU WOULD LIKE TO SHARE WITH US?

Please share your daughter or son's good news stories or achievements with us here at Rett UK. We love to hear them! Email:donna.tinch@rettuk.org

NEW

Introduction to Numeracy for All Ages

Are you unsure about how to support and develop the numeracy skills of someone with Rett syndrome? Are you stuck and looking for helpful tips and ideas? Are you wondering why numeracy skills might even be relevant? Then these sessions are for you!

In two recent webinars Luisa Perez Milne and Rob West, two of our Regional Communication Champions, shared lots of practical ideas and suggestions for introducing numeracy and helping with understanding of numerical (and everyday) concepts. They offered quick and easy to implement ideas, and activities that make use of things around the home and can be adapted in the classroom. This information is suitable for parents and carers of people with Rett syndrome of all ages, from toddler to adult, and also for teachers and TAs supporting the curriculum in schools.

To watch the recordings and download the handouts, just click on these links:

Introduction to Numeracy Part 1
www.rettuk.org/numeracypt1

Introduction to Numeracy Part 2
www.rettuk.org/numeracypt2

We hope that Rob and Luisa will present more webinars on numeracy in the autumn.

NEW

How to be an Effective Communication Partner

Did you know that effective communication isn't all about how the person with Rett syndrome (or other complex communication needs) communicates? It isn't all about eye gaze technology either. It's about how you as a Communication Partner think and act, and the things you can do without any technology. If you're feeling stuck and want to know what you can do to communicate more effectively, while supporting the person in your life with Rett syndrome, then sign up for our Communication Partner training.

Over two sessions, two of our Regional Communication Champions will take you through ideas and activities for developing your own skills in things like modelling and partner-assisted scanning. These sessions are suitable for parents and carers of people with Rett syndrome of all ages, from toddler to adult, and are a pre-requisite for any family thinking about joining our device loan program in the future.

If you would like to join the next sessions in June and July, click on the link to complete the registration form. We will then send you details on how to join. Attendance at both sessions is required.

Dates and times:

Part 1
Saturday 18th June 9.00am-12.30pm

Part 2
Saturday 2nd July 9.00am-12.30pm

To register:
https://forms.office.com/r/8nygnnuV6D

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

To Our Wonderful Fundraisers...
GOOD LUCK

Team Three Peaks 2022

In celebration of his 21st birthday, **Llewellyn Forward** has set himself the Three Peaks challenge! On 30th June, together with **James Carter**, **Tim Hurst**, and **Charles Forward** will climb the highest mountains in Scotland, England and Wales, in honour of Gwen.
https://gofund.me/a8eb942c

Team London Marathon 2022

Introducing our 7 wonderful supporters taking on the London Marathon this year. We wish them good luck and all the best with the months of training ahead.

Alice Dolan
https://www.justgiving.com/fundraising/alice-niamh2

Simon Lane
https://www.justgiving.com/fundraising/simon-lane12

Stacey Mills
Running in honour of Sofia


Emma Stevens and Nicki O'Mahony

Emma Stevens and Nicki O'Mahony
https://www.justgiving.com/fundraising/emma-stevens47

Eleanor Wellesly and Gustav Holst Stuge
http://www.justgiving.com/Eleanor-Wellesley1

Team Great North Run 2022

We are thrilled to have a team of 19 at this year's Great North Run. Thank you and good luck to:

Ash Bakawala
https://greatnorthrun.enthuse.com/pf/ashraf-bakawala

Ashlea Dixon
http://www.justgiving.com/Ashlea-Dixon5

Marleen Goulty
http://www.justgiving.com/Marlen-Slinning

Ronan Holloran
https://www.justgiving.com/fundraising/ronan-holloran

Tim Horwood
https://www.justgiving.com/fundraising/timh-gnr

Clare Nicholson
http://www.justgiving.com/Clare-Nicholson8

Neil Nicholson
https://greatnorthrun.enthuse.com/pf/neil-nicholson

John Rumney
http://www.justgiving.com/fundraising/J-Rumney

Jordan Ramsey
http://www.justgiving.com/Running-for-Rett

David Hannant • Eva Hodgson
Mark James • Julie Jordan • Angela Long
Dav Masaon • Emma Mellor
Live Milligan • Richard Thompson

If you're lucky enough to have your own place in any of these events, we'd love to have you on our team. Please contact **donna.tinch@rettuk.org**

Fundraising Round Up

THANK YOU

by Donna Tinch

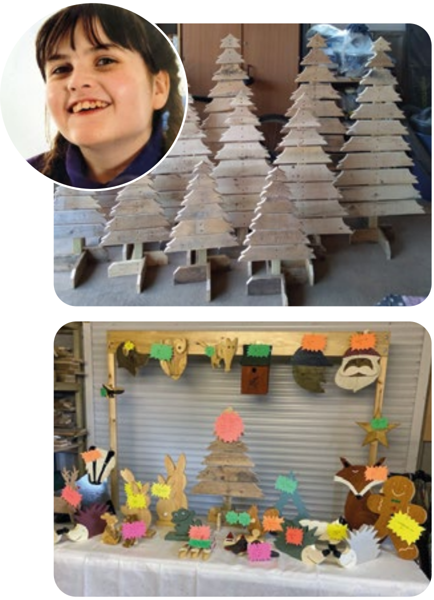
JOG2LE

Dennis Tailor undertook John O'Groates to Lands' End challenge in October for Rett UK and Friends of CME.

Dennis's passion to help charities started in 1992 when he raised funds for a local Women's refuge, and he has been fundraising ever since! To date, he has raised over £580,000 for a number of charities!

Dennis, a retired great granddad told us: "Thanks go to all the lovely generous people who donate to my causes each year! The biggest buzz is that I can do something and that something makes a huge difference. I have a great time and love what I do." He got the bike he named 'Doris' 20 years ago and takes her out every few years to do a big event. This year's challenge covered 1,200 miles in sun, rain, and wind and took 20 days to complete! This was the fourth time Dennis has completed the solo 1,200-mile challenge, which takes him into the nooks and crannies of beautiful parts of England. Rett UK is delighted to receive £1,998.94 from Dennis' fundraising. Robert Adamek, CEO said: "While Dennis was doing his challenge I would look forward to his calls into the office to update us on his progress with such happiness and positivity in his voice. Dennis' passion for his fundraising is unmatched and the will power needed to complete 1,200 miles solo in 20 days is something I wish I had! Thank you Dennis."

THANK YOU TO YOU, AND YOU AND YOU…



Tony Sutton's wooden creations; Inset: Chloe Nicholson

Glenis and Ashleigh Wilson

Rett Team RWBHC

Sophie and Pete Gilbert took on the Route 66 challenge throughout 2021. Sophie ran, whilst Pete cycled, and the couple (and puppy Millie!) covered an impressive 2278 miles and completed the challenge with 5 days left of 2021! A fantastic achievement that raised £1,540 and a huge amount of awareness in honour of Gwen.

Donations in honour of **Clare Little** and **Jennie Harwood**.

Tony Sutton makes and sells hand-crafted wooden items, and puts aside half of the proceeds raised during the year. Tony has donated £1200 from his creations crafted throughout 2021, in memory of his granddaughter, Chloe.

Apple Tree Day Nursery – staff, parents, and children undertook a sponsored walk and raised £633.75.

Addington School held a 'wearing purple day' for October Awareness and raised £59.

All Saints Academy held a Christmas non-uniform school day and raised £1,574.86 in honour of someone special.

John Scott recently celebrated his 70th birthday and asked for donations to support the work of Rett UK and the MS Society.

Ashleigh Wilson's Gran, **Glenis Wilson**, celebrated her 90th birthday in December 2021 and her friends generously donated a total sum of £212 in lieu of gifts.

Lucy Brandon ran the Vienna Half Marathon in honour of her niece Hana and raised £1260.

Huge thank you to the fabulous Rett Team RWBHC – **Tracy Fieldsend**, **Hannah Smith**, **Amber Vater**, **Suzanne Coles**, **Pete Sammon**, **Ellie Hayward**, **Claire Robinson**, **Butch**, **Martha Hayward, Elizabeth McLaughlan**, and **Rebecca and Steve Williams** who smashed the muddy and wet Calne Smartt Smasher 10k, raising over £2,000 in honour of Freya.

Ann Russell with Grace

Lawrence Watt with Rosie

Sincere and heartfelt thanks to all our supporters!

Ann Russell held several cake sales and raised £113 for Rett UK in honour of her great-granddaughter Grace.

Congratulations to **Lawrence Watt**, who cycled 100 miles in the glorious sunshine from Leicester to Skegness, in honour of his niece Rosie. Thank you for your awesome support, Lawrence, and for raising over £2,000.

DONATIONS RECEIVED IN LOVING MEMORY OF:

Wendy Daykin • Steve Rogers
Amrik Singh Edwin 'Pym' Spencer
John Spriggs • Lindsey Catherine Flowers
Olive & Ted Flowers • Colin Foster
Stacey Jane Mullen • Rev. Noel Gibbard
Natalia Mora Eisler • Margo Hunt
In memory of our lovely friend Jan
Mark Woffinden (SNR) • Kenneth Smith
Barry Westmoreland • Alexandra Cosby

Amrik Singh with granddaughter, Simran

Kenneth Smith

Jenna Smith

Thank you to our Facebook fundraisers:

Glenn Boyes
Shauna Boyle
Jenna Clements
Sarah Hanson
Aubrey Hayes
Elyse Hocking
Paul Jenner
Abigail Jones
Dawn Jones
Vivienne Marshall
Nathan Milne
Zoë Reed
Hilary Truss

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

facebook.

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 38-42. You might also refer to our events page, which we are continuously updating, on our website **https://www.rettuk.org/runforrett2022**

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.

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.
https://www.rettuk.org/skydive

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

RUN FOR RETT 2022

We're delighted to partner with RunForCharity to access over 350 local events.

Visit: **www.rettuk.org/runforrett2022** and choose your region to find an event near you. From half and full marathons to obstacle races and fun runs – we have the event for you!

Most popular events:

- Amsterdam Marathon
- Brighton Marathon
- Bungee Jump
- Cardiff Half
- Chase the Sun Tatton 10K
- Edinburgh Marathon
- Hackney Half
- Hampton Court Palace Half
- Leeds Half
- London 10K
- Manchester Marathon
- Oxford Half
- Royal Parks Half
- Spartan Race

Need help or more information? Contact Donna on **01582 798 910**.

www.rettuk.org/runforrett2022

RUN FOR CHARITY

Other Ways to Help...

Easyfundraising

Raise donations for Rett UK whenever you shop online

Turn your everyday online shopping into FREE donations. When you use easyfundraising to shop with any of the 4,000 retailers, the retailer makes a small donation to say thank you and sends those free funds to Rett UK!.

Since we joined Rett UK has received £2,132.84 simply by our supporters shopping online!

Add the Donation Reminder (for your laptop or PC) which makes sure you never miss a donation. It is a helpful way to remind you when any store offers a donation. If you add the Donation Reminder during the next 30 days and shop, they'll donate £1 to Rett UK. Refer any friends and family to easyfundraising so they can raise whenever they shop online too. When they raise their first £5, easyfundraising will match it and give £5 to Rett UK. Refer as many friends and family as you like – it's unlimited! For further information and to sign up, visit **https://www.rettuk.org/shopping**

Auction or Sell Unwanted Items

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

Direct Donations

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

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

Account name:
Rett UK

Account No:
32450725

Sort Code:
23-05-80

Reference:
Please quote your name/company

PayPal payments:
info@rettuk.org

Make Some Noise About Rett Syndrome This October!

RETT SYNDROME
GLOBAL AWARENESS MONTH
October 2022
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 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.

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

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Registered Company in England and Wales Company No. 07339522 • © Rett UK 2017

CARTRIDGE RECYCLING

Every year, millions of printer cartridges are thrown out of homes and offices needlessly wasting precious natural resources. By recycling your old printer cartridges through our partners, Recycle4Charity, you are helping to raise vital funds for Rett UK, as well as protecting the environment whilst raising awareness and the profile of Rett syndrome. So far, £1,787.78 has been raised since we joined the scheme!

Donations are generated from both Original and Remanufactured Ink Cartridges listed. Ink cartridges not on the list do not generate a donation but can still be recycled if sent together with cartridges eligible for a donation. Toner and laser cartridges are not accepted as part of the programme.

Supporter Cathy set up a collection box in her local church, and within a month was able to send off a full box which raised £56.25 for Rett UK! Cathy told us: “Another box has already been collected and dispatched and boxes introduced into a village shop, and two more rural churches. In small rural communities, there is a lot of community spirit, and once people were aware of the facility to recycle they were happy to join the recycling. This is an excellent scheme and it’s simple to do, it counts towards the church eco award, helps the environment as well as the charity!”.

Perhaps your local church, shop, dentist, doctors’ surgery, workplace, or sports club would be happy to have a box? Please visit **https://www.rettuk.org/recycle** to sign up.

If you have any queries, please contact Donna **01582 798 910**.

Recycle4Charity

www.recycle4charity.co.uk

Nectar Donate

It's now even easier to help us raise funds as Rett UK has been approved for Nectar Donate.

This means you can now use your Nectar points to support us. If you haven't used your Nectar card for a long time, why not dust it off now, check your account balance and donate those points to us!

The best thing about Nectar Donate is that it won't cost you or us anything. Crowdfunder has generously waived platform fees for anyone donating their points.

To find out more head to our profile page
https://www.rettuk.org/nectar

Donate your Nectar points

Your Nectar points can now be used to support our charity

Rett UK

nectar Donate | powered by Crowdfunder

RETT UK 300 Club

RESULTS

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

The winners are:

JANUARY 2022

1st	£30	No: 87	Rita Hyland
2nd	£20	No: 222	Peter Truss
3rd	£10	No: 48	Don & Helen Gardner

FEBRUARY 2022

1st	£30	No: 245	Colette Mcloughlin
2nd	£20	No: 74	James Mcwhirr
3rd	£10	No: 92	Tony Edward

ITEMS FOR SALE & FOR FREE

Note: Rett UK accept's no responsibility for items advertised.

FOR SALE

Adapted Trike

Description: 20" wheels, fixed cog (so pedals turn automatically) when assisted with the parent pull handle. The parent pull handle can be removed and the bike pedalled independently if capable.

Includes foot sandals with straps and leg calipers for improved ankle support with straps.

Adjustable thorasic trunk support for hips and waist. Chest strap and waist safety strap for extra security.

Height adjustable swivel seat to assist balance and transfers.

Pair of active hands mini grips which assist with the young person keeping their hands on the handlebars, tightly and securely. Size small in black (optional)

Price: £400

Collection: From Doncaster only

Interested? Call **01582 798 910**

FOR SALE

Tobii Eye Gaze with Dell Latitude 10 tablet

Description: Programmes included:

Sensory FX • Look to Learn • Tobii Communicator

I also have the Look to Learn workbook (plus extra photocopies) so progress can be documented and monitored. I also have an eye pointing classification scale to judge skill level. Full factory reset completed on device.

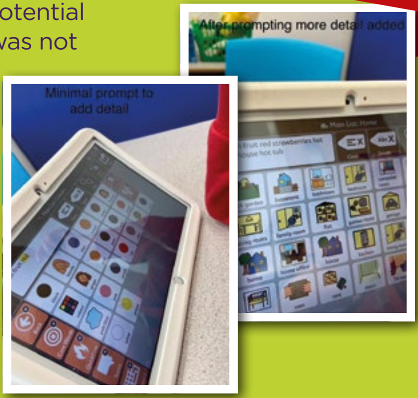
Price: £2,500 plus postage. Originally cost £4,500

Interested? Call **01582 798 910**

FOR SALE

AAC Device

Description: My son finds it tricky to use words, and we knew more was possible and his potential for more was there. Sometimes Makaton was not enough. After years of fighting with the NHS, school took his voice away from school in 2019 as he was not ready to use an AAC, and as a parent I let that happen. Struggling in lockdown with no speech therapy we bought a Tobii Dynavox, AAC device. When speech is modelled and you can categorise buttons, everyone started to believe in our son, what we saw at home. And this has opened up opportunities, and a big smile of ‘I can do this’.



You don’t need to use words to achieve your potential and we would love this Device to go to a family to reduce communication frustrations and open up new doors for their child. How amazing would it be if you can press a button and ask Alexa for your favourite song?

It’s a INDI FEATURING SNAP + CORE FIRST device for sale with a durable case too. We still have half a day of training worth £225 for teachers and parents to access and the device still has one year warranty to April 2023.

Our son has moved to a new model with his new school and more communication support now. We can do a factory reset to take off any personal details.

Price: £333

Interested? Email **traceyliot@gmail.com**

GIVEAWAY

Quest rollator walker

Description: A member of the community is giving this rollator walker for free.

More information: https://quest88.com/products/rollator

Interested? Email **donna.tinch@rettuk.org**

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.

Rett Disorders Alliance UK

RETT UK • REVERSE RETT • FOXG1 UK

Health Checklist

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

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

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

Your feedback please!

Help Us Review The Checklist

Please can you help us with this important review of the Rett Disorders Health Checklist. It takes around 5 minutes. We want to make sure the checklist is as useful to you as it can be. We are also reviewing it with the healthcare professionals that helped write it to make sure it still reflects best practice in each area but your views are equally important.

https://www.rettuk.org/Reviewhc

Your feedback is invaluable. Thank you.

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

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

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

Name(s) of Account Holder(s)

Bank/Building Society Number

Bank/Building Society Sort Code

Name and full address of Bank/Building Society

To the Manager of:

Address:

Postcode:

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

Service User Number

2 7 4 3 4 5

Reference No (office use only)

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

Signature

Date

I would like to make a regular monthly donation of:

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

Surname ______________ Forename(s) ______________

Address ______________

______________ Postcode ______________

Telephone ______________ Email ______________

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

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

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

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

The Direct Debit Guarantee

THIS GUARANTEE SHOULD BE DETACHED AND RETAINED BY THE PAYEE

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

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**

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

Thank you!

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

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**.

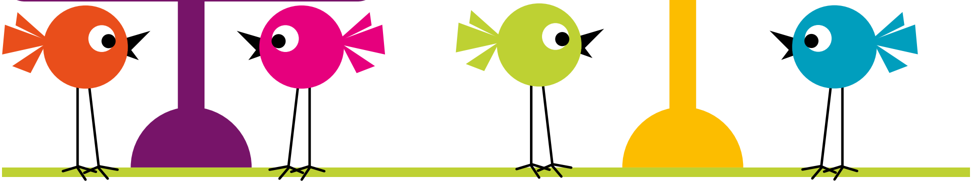
THANK YOU TO ALL OUR DONORS!

Huge thanks to all those who support Rett UK throughout the year.

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 49 of this issue of *Rett News* or email **info@rettuk.org** or call us on **01582 798 910**.

Thank you.



THE BIG GIVE CHRISTMAS CHALLENGE IS BACK!

For the seventh 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 £25,826 for our project 'Rett UK Advocacy, Achieving the Best Outcomes!'.

Advocating for better outcomes for people with Rett syndrome in health, social care and education is fundamental to what we do. Families are exhausted by fighting a system that was already massively under resourced and hard to navigate. COVID-19 has hugely exacerbated the issues and added to the crisis. With your help we can continue to provide this vital element of our support to everyone who needs it.

This year we are hoping to raise £35,000 to further develop our communication and education project. We are introducing numeracy and literacy training, using our carefully chosen books that encourage engagement, questions and discussion for people with Rett syndrome. We also have dedicated communication partner training and online friendship groups for people of all ages to meet and practise their communication skills in a fun, relaxed way with their peers.

Please look out for more information about the project. We look forward to bringing you regular updates through our social media platforms, monthly E-Newsletter and *Rett News*.

Rett UK
Support today, hope for tomorrow

RETT UK LTD, VICTORY HOUSE, CHOBHAM STREET, LUTON, BEDFORDSHIRE LU1 3BS
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