Rett News
Support today, hope for tomorrow

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Our Rett UK Champions

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Rett syndrome is a rare neurological disorder affecting mainly females and very few males. 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undetected until major regression occurs at around one year of age, when children may lose acquired skills and become withdrawn.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.

Welcome from the CEO

Spring is fast-approaching and Christmas seems a long time ago now but many thanks to everyone who took part in our photo competition and shared/liked the photos. You can see the winning photos on page 19. Well done to our winners! Justin Kelly's photograph of Catherine will be appearing on one of our Christmas cards next time round.

Thoughts may be turning now to holidays, always something of a challenge when you have various needs to meet. We have information on page 8 that is worth perusing, notably that one of our readers has an adapted caravan for hire. Another idea might be to hire an adapted property. In Tenby, Wales, The Harriet Davis Trust has four properties adapted to various levels and over the Christmas holidays I was lucky enough to be able to take my daughter Rosie to one which has everything that one might possibly need by way of equipment. It's all in various sizes, together with an indoor pool and hoist! Read more about it on page 8. Please also keep looking at our Facebook page as we often share information there about holidays.

Thanks to some fantastic fundraising in 2015 by many people, we can now start working on our regional events for the next few years, the first being in Scotland at Hazelwood School on 22nd-23rd April. We are also near to confirming an event in Exeter and then another in Leeds. We are developing the Regional Hubs to make sure that we engage with the providers of the services which you use locally and the people who are directly involved in supporting Rett families. Alongside this we want to ensure that each area has a local support group and a parent-to-parent contact network so that families are connected, can share experience and provide mutual support. Look out for more information on the website, Facebook and in the e-newsletter.

Another development in the Rett community, which some may have seen via social media, is of the closure of the charity, Cure Rett. A full announcement is on the home page of its website. We would like to thank Kori and the team for their contribution over the last few years and in particular for their funding towards a UK Clinical Delivery Fund, which will be held by Reverse Rett and also for their contribution to the work of the Rett Disorders Alliance.

The Rett Disorders Alliance is hosting a meeting on 10th March in London, at which key people working in the Rett medical community are coming together with the hope of forming a working group to develop comprehensive best practice guidelines and a more cohesive and effective clinical provision for Rett syndrome in the UK. We are extremely excited about this work and the potential that it has to improve support for all our families in many areas. We will keep you up-to-date as the work progresses.

We hope you enjoy your Rett News!

Best wishes,

Becky Jenner

Support Round Up

By Julie Benson

Transitions

We are pleased to announce that we have been successful in receiving further funding from BBC Children in Need to continue in turn to fund the Transition Project. This will allow us to go on providing support to children and families during this time; we have been able to extend this support additionally to siblings.

At present we have 33 young people whom we are actively supporting during this time of change. The changes in question include the transfer of care from children to adult social care services, from paediatric health services to adult services; care management is led by the GP at this point. There may be alterations to financial benefits which young people receive; they may be examining their options for when they leave school or considering a move into supported living or residential care. All of this can be unsettling for young people, their parents and siblings. This is an area in which we can offer assistance to everyone.

We work with the whole family, keeping it informed about the timeline for change, working closely with young people and their parents to help them through this time and being attentive to siblings who may also be concerned about their sister's/brother's future.

Transition planning is key to a successful and stress-free process and we are available to help. Ideally, the process should start at the time of the 14+ school review. This is when the young person, parents, social worker and other key people involved in helping them can start to plan for the future. This planning process would look at some of the issues outlined above, such as choosing further education options and/or considering other daytime activities. We can assist by examining the local services offered by the local authority in its 'Local Offer'. We can try to identify which services can meet specific needs or give direction towards other providers if there is nothing suitable locally.

We can offer advice on how to choose an adult living option, where to start in this search and where to find information to help the young person and her family make that decision.

We shall be offering all young people within the transition age range 14 – 19 and their families the opportunity to be part of this project. There will be a short questionnaire to complete when they sign up and we are currently producing resources that will help young people to plan for their futures.

We will be contacting people shortly to tell them more about the project. However, if you would like to know more now, please contact Patrice, who will be able to help. Telephone 01582 798 911 or email patrice.hosier@rettuk.org.

Regional Hubs

Another busy year for the support services at Rett UK has begun.

Following directly on the tremendously successful 30th Anniversary Family Weekend, we are now engaged in the planning of our regional events for 2016/2017.

Currently we have two dates booked for this year and a third tentatively in the diary. They are:

• 22nd - 23rd April 2016	**Glasgow, Hazelwood School. Yes, we are finally heading to Scotland!**
• 8th – 9th July 2016	**Exeter, Ellen Tinkham School.**
• 14th – 15th October 2016	**Manchester/Liverpool area; venue to be confirmed**

For 2017, we are planning our first-ever event in Northern Ireland and two further events in England. As soon as we have dates and venues we shall publicise them.

As part of our future planning process, we are examining ideas for collaborating with local service providers including those in health, education and social provision to create a greater legacy from these events. We know that our families need to be better supported by the people who provide these regional services.

As part of this initiative we also want to ensure each region has at least one local support group and strengthen the parent to parent contact network. We also have roles for Regional Ambassadors who would be happy to represent Rett UK locally. You can read a Regional Ambassador's story on page 22.

Specialist Clinic Information

Many readers will know that we work in partnership with the NHS in supporting the Rett Specialist Clinics. The clinics all offer a range of experiences and information. We thought, however, that it would be useful to share with readers what information that we have currently and also about how we shall be working with our clinics to bring people the best possible experience when they attend.

At present there are four clinics, each of which is held at various times throughout the year in Cardiff, London, Manchester and Nottingham. London has clinics every 2nd and 4th week of the month; Cardiff, Nottingham and Manchester usually meet two to three times per year.

The overall management of the clinics sits with the NHS, which organises referrals, agrees funding and generates appointment lists. Rett UK can follow up and enquire about a referral and seek to discover whether or not it has been received and is being processed.

We can also talk to the clinic administration to find out if we can speed up an appointment, particularly if we know that someone is having a difficult time. However, the final decisions and content of the appointment list remain with the NHS.

We are not generally made aware by the administration teams as to who is attending, as this would breach patient confidentiality, unless of course a pre-appointment questionnaire has been completed. Some clinics issue these, in order to seek consent from those attending and thereby allowing the clinic to advise us of their attendance.

When you do receive an appointment at one of the clinics and you would like more information about what to expect on the day, what you might need to take and perhaps even concerning places to stay or how to get there, then we are here to help; give us a call on 01582 798 911.

We also provide a 'follow-up' to this clinic, whereby we contact you a couple of weeks after you have attended and talk about how you judge the appointment to have gone and we can then offer you further support if you need it.

Useful Information

London Clinic – Team

Dr. Hilary Cass, neurodisability consultant, supported by occupational, physio, speech and language therapists.

Directions and Parking information: **www.evelinalondon.nhs.uk/parents-and-visitors/getting-here/directions.aspx**

Manchester Clinic – Team

Professor Jill Clayton-Smith, clinical genetics consultant and Dr. Bronwyn Kerr, clinical genetics consultant, supported by physiotherapy experts.

Directions and Parking information: **www.cmft.nhs.uk/information-for-patients-visitors-and-carers/getting-to-hospital/central-site**

Nottingham Clinic – Team

Dr. Jane Williams, paediatrician, supported by visiting professionals.

Directions and Parking information: **www.nuh.nhs.uk/getting-here/city-hospital**

Cardiff Clinic – Team

Professor Angus Clarke, clinical genetics expert, Dr. Frances Gibbon, consultant paediatric neurologist, Professor Mike Kerr, neurosciences expert, supported by physio, speech and language and music therapists; Tobii Eye-Gaze.

Directions and Parking information: **www.cardiffandvaleuhb.wales.nhs.uk/st-david-s-hospital**

If you are travelling to any of the hospitals that may require that you stay overnight, there are a couple of good websites that will help you to choose an accessible hotel:
www.disabledgo.com
www.chuc.org.uk

Additional Information

If you need any further information, please contact Julie or Patrice at the Rett UK office on 01582 798 911.

Employment and Support Allowance (ESA)

Claiming at 16 and beyond

By Jayne Knights

Managing family finances when you have a disabled young person in the family can be tricky, especially as the 16th birthday approaches. If a young person will soon be 16 then, in theory, they, or their appointee, can choose whether to claim certain social security benefits in their own right or continue to be claimed for as a dependent young person within the family.

For further information on benefits for disabled young people and especially on the issue of deciding between an independent claim or staying with the family benefits, then please have a look at the excellent factsheet prepared by Hertfordshire County Council Money Advice Unit. To read the factsheet, see: **www.hertsdirect.org/docs/pdf/b/dyp.pdf**.

I also recommend the exceptionally useful benefits calculator which can be found at **www.turn2us.org.uk**. This enables you to calculate the impact on your benefits if your young person claims independently.

So, assuming that your young person is proceeding with an independent claim for ESA, I would like to explain the ESA claiming process. It is vital to be well-prepared and familiar with the terminology of ESA, which can appear to be very jargon-packed and bureaucratic. Often it will also be necessary to educate decision-makers and/or health professionals about Rett syndrome as they may not have heard of it before.

My aim here is to equip readers with the basics of the ESA process, so that the information will be familiar from the beginning. It is directed at the claiming person or their appointee/carer and so uses the term ‘you’.

Getting started

ESA is for people who are at least 16 and who are not able to work because of illness or disability. You can still claim ESA if you are studying full-time (this means over 12 hours a week) up to A-level standard at school or college but only if you are also receiving DLA or PIP (any rate or component). If you do not receive DLA or PIP, then usually you cannot receive ESA if you are in education.

You begin your claim by phoning 0800 055 6688 or you can print form ESA1 from the DWP website. Your form must be submitted with a medical certificate from your GP. You can claim ESA from three months before your 16th birthday but it cannot be paid until you are 16.

BEGIN YOUR CLAIM BY PHONING

0800 055 6688

Being assessed

When your ESA starts, you will receive £57.90 a week during the initial 'assessment phase'. This 'phase' is only supposed to last for 13 weeks but in reality it can last much longer. During the assessment phase, you will have to complete an ESA50 questionnaire about your disabilities and return it together with any supporting medical or other evidence which you have. Many people also have to attend a face-to-face medical assessment with a healthcare professional from Maximus.

The assessment process is known as the 'work capability assessment' (WCA). Most people have to show that they score at least 15 points from a range of activities covering physical activities such as 'mobilising', 'standing', 'reaching' in addition to cognitive ones such as 'communicating' and 'learning simple or complex tasks'.

Each activity is broken down into 'descriptors', each of which carry a certain number of points and you are viewed as unable to work if your combined score from all the activities reaches 15 or more. You score once from each activity heading which applies to you, from a range extending from zero to 15. Being awarded 15+ points means that you are at that point viewed as someone who has 'limited capability for work' (LCW).

The next phase

For people with a substantial level of disability, reaching 15 points is relatively straightforward and means entry at minimum to the Work Related Activity Group, at which point your ESA should rise to £73.10 plus an additional £29.05, which is known as the work-related activity component.

However, people with Rett Syndrome should really be aiming, if possible, for the Support Group of ESA and the decision that they have Limited Capability for Work-Related Activity (LCWRA) (yes, the jargon is exhausting). The Support Group should be a high priority for several reasons:

- Being in the Support Group brings a support component of £36.20 instead of £29.05
- There may be an additional enhanced disability premium paid in addition if you are receiving the income-related version of ESA. This is an extra £15.75 a week (which might also be available to you during the assessment phase if you are entitled to the highest rate of DLA care or enhanced rate daily living PIP)
- Entry to the Support Group means that you will be 'left alone' until your next assessment and you will not be required to do any work-related activity unless you so wish
- The Government plans to remove the work-related activity component in 2017 but Support Group members will not be affected

Admission to the Support Group using the descriptors

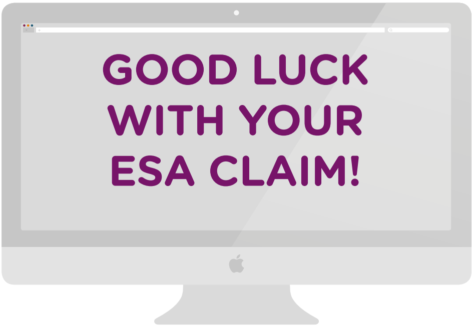
Some people are awarded a high number of points from the scoring system but are still not admitted into the Support Group. To access the SG you must demonstrate an 'extra layer' of substantial disability from a separate list of LCWRA descriptors, for example not being able to mobilise yourself more than 50 metres in a manual wheelchair or not being able to eat or drink without help from another person.

It is essential to refer to the descriptors when you are completing the ESA50 questionnaire. If you can show that you are likely to score substantially more than 15 points and you also fulfil one of the 'extra layer' LCWRA descriptors, then you may be able to avoid the need to attend a face-to-face medical assessment.

This factsheet from Disability Rights UK is a comprehensive guide to the descriptors and to the route into the Support Group using the exceptional circumstances rules, which I do not have space to discuss here!
www.disabilityrightsuk.org/work-capability-assessment

Ensure that your medical evidence is detailed and specific to you and relates throughout to the points system. Please avoid 'to whom it may concern' general statements; decision-makers hate them!

In conclusion, you can see that claiming ESA at whatever age needs planning, research, good evidence and tenacity; and don't forget all the internet resources that should help.



Other useful internet sites:
www.gov.uk/employment-support-allowance/overview
www.benefitsandwork.co.uk

For the ESA claim form:
www.gov.uk/government/publications/employment-and-support-allowance-claim-form

For Jayne's website:
www.jayneknights.co.uk

Membership

BECOME A MEMBER OF RETT UK

Have you received your Family Companion?

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 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.

Thinking about a holiday?

Here are a couple of ideas for you if you need somewhere fully adapted.

Camber Sands

Nancy Richards, who has a daughter Bianca, who has Rett syndrome, recently brought a chalet in Park Resorts Camber Sands, Rye and has made it disabled-friendly. The chalet is available to rent and if you would like more information please visit www.ukcaravans4hire.com and search for advert number 1398. Alternatively, Nancy can be contacted on 07951 111 985.

The Harriet Davis Trust

Rosie on Tenby Beach

Set up by parents of a young woman with complex needs, the trust has four properties in Tenby, Wales which are all adapted to meet the needs of children and young people with disabilities. Over the Christmas holidays our CEO, Becky Jenner was lucky enough to be able to take her daughter Rosie to one of the properties.

Becky reported that she was amazed by how large and well-equipped the property was. The family stayed at The Wheelabout, which sleeps ten and has an inside pool (not hydro but very warm!). There were several sizes and types of toilet chairs, shower chairs, a pool hoist, wet and dry area changing facilities and a through-floor lift. The adapted bedroom was on the first floor and had ceiling tracking which went through to the en suite bathroom which had a Kingcraft bath. In the bedroom was a profiling bed, with another single bed for a sibling or carer.

The views from the first floor across the fields to Tenby and the coast are most impressive. However, it is in an exposed position on top of a ridge; the wind was forceful!

Tenby beach is stunning and the town has some pleasant restaurants and shops. The properties do become booked-up quickly in school holidays; you will have more luck during term-time. The trust will prioritise children and young people under the age of 21 during school holidays but otherwise adults can use the houses too.

They are also very reasonably-priced as the trust does not charge commercial rates but only running costs.

In particular, Becky would highly recommend The Wheelabout.

www.harriet-davis-trust.org.uk

Fundraising

Thank you to all our fundraisers for choosing to support Rett UK

by Donna Tinch

With your help Rett UK makes the lives of those affected by this devastating disorder more bearable and gives them hope for the future. By fundraising on our behalf, you are helping us continue our life-enhancing work, and for that we cannot thank you enough.

John and Lucy Wyatt – Annual Charity Golf Day

For the past six years, John and Lucy Wyatt have organised an auction and annual charity golf day in memory of John's daughter Jade, who sadly passed away in 2009. To date, Lucy and John have raised £22,329.53 for Rett UK and we are truly grateful for their continued support. Thank you so much, John and Lucy, for your wonderful efforts and to your friends and family, who participate in your event every year. Here they say:

"Jade was a beautiful girl who always wore a smile on her face. She was incredibly brave and strong, coping with so many obstacles. She taught us to look beyond the surface, no matter how difficult life can be and understand that if you adjust your outlook in life, you can overcome anything.

Even though our hearts are broken, Jade has left us with a purpose in life, which is to strive on and make a difference by helping others. For the past five years, we have focused on raising money and awareness for this worthwhile charity by setting up an annual golf day with a raffle and evening auction.

We feel extremely lucky to have the support of our friends and family and are ever-grateful for their contributions and kindness. We have some incredibly helpful friends, Robert and Linda Arthey, who have helped us create this magical day. They have been both a source of enormous strength to the pair of us and have helped us raise as much money as we have done so far. Every year we feel overwhelmed by everyone's kindness and continued contributions; it helps to take a moment to reflect on Jade and to remind ourselves of how pleased we are to be able to give comfort to families directly and indirectly affected by Rett syndrome."

Anyone wanting to participate in next years annual Golf day is fully welcome. All details are available upon request via the Rett UK office at info@rettuk.org.

Jade Wyatt at Lucy and John's wedding

Bobby Arthy and John Wyatt

The Stony Stratford Tuesday Night

CHARITY CURRY CLUB QUIZ

Launched in April 2008, the Stony Stratford Tuesday Night Charity Curry Club Quiz has raised over £13,000 for Rett UK. The monthly quiz was founded by Jonathan Taylor, following his daughter Lily's diagnosis, as a way of regularly raising funds for Rett UK. The quiz night takes over The Naidni Restaurant, a local curry house in Stony Stratford with teams of four competing in the fun general knowledge quiz that's accompanied by great food and lots of laughs.

Jonathan says, "I wanted to raise money and awareness of Rett syndrome while creating a fun evening that everyone would enjoy. The proceeds benefit two charities, Rett UK and Willen Hospice, a local hospice that cared for my mum during her fight with cancer. It's a great evening, with excellent food and lots of banter and we have regulars that wouldn't miss it for the world!"

The quiz takes place at 8pm on the second Tuesday of each month at the Naidni Restaurant, Wolverton Road, Stony Stratford, Milton Keynes. Teams of four pay £15 per head which includes the quiz and a two-course meal with side dishes. There is an active Facebook group with 174 members through which quizzers can book tables and the winners' and runners'-up photos are posted: **www.facebook.com/groups/StonyStratfordTuesdayNightCharityCurryClubQuiz**

Lily is now 15 and suffers with the usual epilepsy and hyperventilation but unusually for a Rett girl also has the daily management of type 1 diabetes and coeliac disease, all of which makes schooling and respite care a real challenge.

Over the years Jonathan has also organised and competed in many sporting challenges to raise money for Rett UK, including entering four teams in the London Triathlon and running the London 10K. Jonathan has signed up to run the 2016 London Marathon for Rett UK; a challenge that he says he'd swap for a microphone and room full of people any day! You can sponsor him here: **www.justgiving.com/JTsLondonMarathonRunForRettUK**

Our sincere thanks to Jonathan, The Naidni Restaurant and all the supporters of the monthly quiz night.

Naidni Restaurant staff with Jonathan Taylor far right

Lily Taylor

Bend it like Beckham...

Regular donors the Land Sheriffs, held a football fundraising event in aid of Rett UK. They reported, "We recently held a charity football match to raise money for our long-term charity backing to Rett UK, the only UK charity providing professional support which does so much for people living with Rett syndrome. It was a great match, with MTR Crossrail taking the early lead but ultimately the quality of our side shone through and we won the inaugural SelectaDNA Cup. We would like to thank MTR Crossrail and all our generous donors and sponsors, who helped raise £1,088. The Land Sheriffs have supported Rett UK since 2008, donating around £30,000 in all.

Thank you to Andrew and Angela Slugocki, parents to Emma, for attending the evening as Rett UK Ambassador's!

Ryan Ricketts (General Manager, Land Sheriffs), Steve Murphy (Managing Director, MTR Crossrail), Tyler LeMay (Director, Land Sheriffs), Steve LeMay (Managing Director, Land Sheriffs), Andrew and Angela Slugocki

Jenny, Phil and Phoebe Collier

Milton Keynes Winter Half Marathon

Jenny and Phil Collier together with nine friends, Jenny, Phil, Jenny's brother Ian Higgins, brother-in-law Graham Gambles and friends Sean Hunt, Dave Attwood, Sally Murray, Celia Dashfield and Marie-Claire Parson, took part in the Milton Keynes Winter Half Marathon in honour of Jenny and Phil's daughter Phoebe and smashed their £2,000 target, raising £5,651.00 plus Gift Aid.

Jenny said, "Last summer our beautiful little girl Phoebe was diagnosed with Rett syndrome. We wanted to raise funds for Rett UK, which serves to support families from diagnosis into adulthood. We were delighted that everyone finished with all limbs intact! It was a great course, if a little wet and muddy at times. There were a few achy legs the next day but what a tremendous effort it was from everyone! Thank you to our amazing friends and family who ran with us (or in front of us) and helped to raise money for Rett UK. The total just kept on rising and went beyond what we ever thought we could raise."

Fundraising Round Up *by Donna Tinch*

THANK YOU

Thank you all for flexing your fundraising muscles for Rett UK

Helen Brown, Mal Hill, Mike Wells, Ollie and Cat Hopkins, Lee Campbell, Neil Bonnington, Charlie St. Ruth, Dee Synnott, Rob Clarke and John Kelly, a.k.a. The Bed Hot Chili Peppers took part in Knaresborough's 50th Bed Race in honour of Nell, the daughter of a friend of John; they smashed their target-raising £935.

Lacey

Lacey's Voice Charity Night – **Megan Ellis**, whose daughter Lacey has Rett syndrome, together with their dedicated family and friends, raised an impressive £3,129.95 at the fundraising night which they held in honour of Lacey. Megan reported, "The shops in the village rallied behind us and the sports centre let us use the venue at no charge. The singer performed at half-price; there was a disco and photo booth; wonderful auction prizes included a Toyota car donated for the weekend, among a whole range of others. I was so grateful for everyone's generosity and for doing so much for Lacey, and me and supporting our efforts."

Penny and Mick Taberner and friends from the **White Stone pub**, Meadowside, in Nuneaton went on a 'pub crawl' around the Black Country and raised £304 in honour of Penny's and Mick's daughter, Sally Jayne. Derek Ashton organised the trip, which was on an old green bus, driven by part-owner Kelvin. The friends visited six pubs, enjoying the real ale along the way. Monies were raised by a raffle and 'guess the number of sweets in the jar', with prizes being donated by event participants, the landlord of the White Stone and other pubs which were visited.

David Ball organised a carol-singing evening on 22nd December at his workplace, Middleton Lodge and raised £135. Thank you, Brian Rendell, for topping the donations up to £150.

Nell

Emily Bare, Jordan Ramsey and Paul McCulloch together raised £1,900 in honour of Emily and Jordan's niece, Nell. Paul recalls, "The skydive was so exciting, certainly after the first couple of seconds of shock! It was completely different to anything I've ever done. I'm so happy that we reached and passed our goal for this important cause and it's good to know that we have helped. Thanks so much to all our family, friends and colleagues who supported us."

Jordan takes the plunge

A thumbs up from Paul

Sarah Thomas and Leah raised £348 running the Cardiff Half-Marathon on 4th October in support of Rett UK. They have had the opportunity during the year to know a little girl with Rett syndrome. Sarah remarked, "We have been struck by the lack of awareness and knowledge surrounding this condition; we hope that by running the race we can raise more understanding and some well-deserved cash for an invaluable charity."

Lyn and Amy

Martin Tonks completed the Manchester 10k last summer, raising £125 in memory of his niece, Kimberley.

Lyn Howie and her sister **Amy Tyler** completed the Glasgow Half-Marathon, raising £470. Lyn commented, "Unfortunately it was only my sister Amy and I who were able to run on the day. This was due to sickness and injuries in others. Unfortunately, these things can't be helped but still we had fun."

Alvaro Hernández Trapote, for the second year-running, completed the Royal Parks Foundation Half-Marathon and raised a further £150.

Louisa Smart, together with her mother **Sue Smith** and friend **Clare Booth** completed the Morrisons Great Birmingham Run, raising £595 in honour of Louisa's daughter Annie. Louisa told us, "Rett UK gave us a great deal of support during the months following Annie's diagnosis. I wanted to raise as much money as possible to help Rett UK change lives and give a brighter future to those affected by Rett syndrome."

Sarah Brown and Craig Brown completed the Castle to Castle 10k in honour of Olivia, their friend's grand-daughter and raised £423.

Freya and Giorgio

Giorgio Rigali is dedicating the whole year to fundraising and raising awareness for Rett UK here is what he said. "Throughout 2016 I have set myself the ambitious challenge of completing 16 sport/fitness related events. These will include half marathons, marathons, ultra-marathons, triathlons, duathlons, rowing and the three peaks. All of my fundraising will be split between Rett UK and MNDA. My inspiration for completing these challenges is my 4 year old niece Freya. Unfortunately Freya has Rett syndrome, however her everlasting smile and love of life is enough to brighten up anyone's day. Freya receives fantastic support from her mum Katy and dad Neil, but not everyone suffering with Rett will receive the support that Freya does. My mission for the year (and beyond) is to raise as much awareness for RS and Rett UK as possible.

We are very grateful to **Clive and Kay Beadle** who kindly offered the opportunity for two people to join them at Adele Live in Birmingham raising £535 for Rett UK.

Last year, Lauren Slade's friend **Luca Bays**, aged 11, came up with an idea for a school project. He decided to raise money for Rett UK with a campaign called 'A Lolly for Lolly'. He developed the idea and designed the whole project, approaching friends, family and local businesses and asking if they would buy lollypops for 50p each. Lauren's mother, Sharon reported, "We also set up a Just Giving page called 'Luca's Lollypops for Lolly' and raised a further £80. In total, he raised £570.46! Luca is a truly impressive young man, we are all extremely proud of him."

Virgin London Marathon 2016

Team Rett UK

Debbie, Jodie and Lauren each secured a Rett UK charity place in this year's Virgin London Marathon. Here they tell us why they are running for Rett UK:

Grace, Olivia and Debbie

Debbie Coster is running for Rett UK in honour of her daughter Olivia. Debbie wants to raise as much money as she can for Rett UK as well as much-needed awareness, as so little is known about Rett syndrome.

She told us, "On 8th January 2015 our beautiful little girl Olivia was diagnosed with Rett Syndrome. With it not being a widely-known condition, when we learnt of the symptoms and the effect it would have on our little princess we were absolutely devastated. My heart was broken and I felt completely numb on being told our daughter's life would change forever. Running is a passion of mine and has been for many years. It would mean so much to me if I could help and be able to promote awareness for this amazing charity." **www.justgiving.com/debbiecoster**

Jodie Sharp is running for Rett UK in memory of Alison, for whom she was a carer for four years. Regrettably, Alison passed away in November 2015. Jodie recalled, "As a carer, I have been lucky enough to spend a great deal of time with and be a friend of a lady of whom I grew very fond. She had lived with Rett syndrome and was profoundly disabled. The night that I heard the sad news, I contacted Rett UK to find out if I could run the London Marathon for them. I wanted also to run for Alison, to raise awareness of the condition with which she lived, to raise vital funds for the charity and ultimately to celebrate my friend's life."
www.justgiving.com/Jodie-Sharp

Jodie and Alison

Carly and Lauren

Lauren Barcroft is running for Rett UK in honour of her sister Carly. She explained, "I'm running because I want to make my sister proud. I am very lucky to be aware of what Rett syndrome is and to have an older sister. Carly has grown into a beautiful woman, even though my mum was told that, because of the condition, she may not make it past her teens. Unfortunately, not everyone is aware of Rett syndrome and misdiagnosis can lead to people not receiving the right care and treatment. I know that when my sister first starting regressing, the advice and help available to my mum was limited. I want to make sure that anyone affected by Rett has

the same treatment and help as does my sister now and can access all those resources that are now available. This is is where Rett UK comes in, so I am very proud to be able to run the London Marathon for them."
www.justgiving.com/Lauren-Barcroft4

London Marathon own places

Many thanks to these Rett Champions who, while choosing to run for Rett UK, have secured their own places in the London Virgin Marathon. They are:

Andreas Forster www.justgiving.com/AndreasForster

Chris Lake previously ran the London Marathon for Rett UK in 2014 and is running again this year in honour of his sister Deborah.
www.justgiving.com/christopher-lake4


Lily and Jonathan

Jonathan Taylor is running in honour of his daughter Lily. Jonathan has been a consistent supporter of Rett UK for some years. You can read more about Jonathan and his fundraising efforts on page 10.
www.justgiving.com/JTsLondonMarathonRunForRettUK

Lizzie Spencer www.justgiving.com/tony-lizzie-spencer

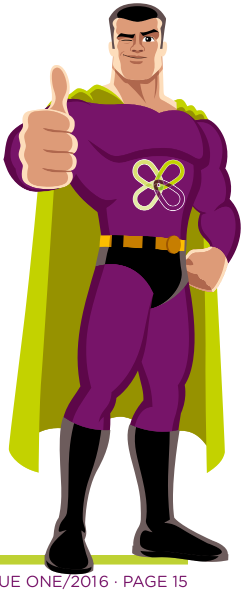
Sharon Slade, Lauren's mum said, "In London, on the 24th of April, I shall be running my third marathon to raise money for Rett UK. I have been fundraising for this truly dedicated charity since we received Lauren's RS diagnosis in February 2005, when she was four years old. A call to Rett UK was one of the first things I did all those years ago and from that day on the support we have received from the team has been fantastic. I am one of those strange people who enjoys running and so my way of giving something back to Rett UK is to set myself a running challenge each year and use it to fundraise as much as possible."
www.justgiving.com/Sharon-Slade6


Lauren and Sharon

Gary Worsley is supporting Rett UK in honour of his sister's best friend's daughter, Olivia Wasp. Gary has run the London Marathon for the past several years and his best time so far has been 2 hours 56 minutes.

Angela Duncan is a running veteran, having completed many London Marathons, as well as many other races! Her grand-daughter Emma (16), has a-typical Rett syndrome and Angela plays an important part in looking after Emma as well as supporting the rest of her family. Angela also volunteers as fundraising assistant in the office and is invaluable to the team.

We wish you all the best for the remainder of your training and for the Marathon itself. Thank you so much for supporting Rett UK.



RETT UK NEEDS YOU!

Rett UK Fundraising Challenge 2016

Saturday 14th May

Are you looking for a new, exciting challenge?

Join the intrepid band of white water rafters on the Olympic course at the Lee Valley White Water Centre in Hertfordshire.

The Centre was specially-built to host the 2012 Summer Olympic Games where Team GB won Gold and Silver.

The cost to take part is £35 per person and the suggested fundraising target is £200.

For more details, contact the Rett UK office on 01582 798 910 or email donna.tinch@rettuk.org

Come and join the team for a great day out!

Good luck!

Good luck and sincere thanks to our fundraising supporters, for events coming up over the next few weeks:

Cassie Booth and Toby: The Suffering Race on 12th March in honour of Annie Smart.
www.justgiving.com/cassieandtoby

Adam Gee, Francesca Brieley, Jaique Booth and Joshua Booth: Adidas Silverstone Half-Marathon on 13th March in honour of Chloe Miller.
www.adidashalfmarathon.com

Michael Patterson: North London Vitality Half-Marathon on 20th March and the Vitality Run Hackney on 8th May in honour of his niece.
www.justgiving.com/michael-patterson2016

Sarah Fattal: North London Vitality Half-Marathon on 20th March, in honour of her god-sister, Jessica.
www.justgiving.com/Sarah-Fattal1

Colin Downton: The London 2 Cambridge Challenge – 2nd – 3rd July 2016, in honour of his cousin, Leanne.
www.justgiving.com/Colin-Downton1

Vicky Evans: The Colour Run on 12th June in honour of her niece.
www.justgiving.com/Vicky-Evans9

Let us Know!

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

Might YOU be a RETT UK Champion?

If you are feeling motivated to support Rett UK, why not contact the office. Contact **fundraising@rettuk.org** for more information or phone **01582 798 910**. As well as these running and cycling events we also have tough mudders, skydiving and other challenge events.

To stay up to date with fundraising events and activities please keep an eye on our Facebook page **www.facebook.com/rettuk**.

2016 Running and Cycling Events

Paris Half Marathon
6th March 2016
www.semideparis.com/us/homepage

Plymouth Half Marathon
17th April 2016
www.rettuk.org/event/plymouth-half-marathon

ASICS Greater Manchester Marathon
10th April 2016
www.greatermanchestermarathon.com

Milton Keynes Marathon
2nd May 2016
www.mkmarathon.com/mk-marathon-2

Vitality Run Hackney
8th May 2016
www.rettuk.org/event/vitality-run-hackney

Capital to Coast Challenge
26th June 2016
www.capitaltocoast.org.uk/pages

The Country Wide Great Tour
4th-6th July 2016
www.rettuk.org/event/the-country-wide-great-tour

Colour Vibe Bristol
9th July 2016
www.rettuk.org/event/colour-vibe-bristol

Colour Vibe Edinburgh
17th July 2016
www.rettuk.org/event/colour-vibe-edinburgh

Parallel London
4th-5th September 2016
www.rettuk.org/event/parallel-london

Morrisons Great North Run
11th September 2016
www.rettuk.org/event/morrisons-great-north-run

Run to the Beat – London
13th September 2016
www.runtothebeat.co.uk/Event

Chester Marathon
4th October 2016
www.activeleisureevents.co.uk/marathon

Parallel London

New inclusive event for our families to tie in with the Paralympics

On Sunday, 4th September 2016, London will play host to Parallel London, a fully-inclusive large-scale mass participation run created to erase barriers and enable independence.

Staged in the Queen Elizabeth Olympic Park, this will be a national event seeking to attract 10,000 enthusiasts in this, the first year. Parallel London is a new disability-led event that has been specifically designed for anyone to join, regardless of age, disability, impairment or health condition.

The run will be split into a number of set distances (from 100m to 10km) to cater for every age and ability. The ethos is all about 'shared experience', with everyone involved in the run together at the same time. Parallel London is not just about racing against the clock but celebrating the spirit of togetherness and everyone crossing the finishing line.

The vision is for Parallel London to grow over time into a major annual fixture in the national events calendar. While also providing a tangible legacy from the London 2012 Olympics and Paralympics, Parallel London will be an exciting precursor to the International Paralympic Committee World Championships 2017.

The event will also host a range of exciting, interactive and fun environments, designed to bring to life a world without barriers and keep both participants and spectators entertained for the day.

These environments will include: charity village, sponsor activities, food & drink, fitness & active lifestyles, family and quiet spaces, culture, art and literature, technology – disability related assistive technology.

Initially, Rett UK is buying ten charity bonds places for this event and will be seeking a suggested fundraising target of £300. We can buy more if the demand emerges.

- A bond place can be used for entry by one adult (aged 17 and over) or two children (under 16)
- A child under 5 years of age can participate at no charge when entering alongside an adult.
- Free able-bodied carers' places will be available for those who will need someone to help them take part.

If you are interested in joining us for this event, please contact Donna.Tinch@rettuk.org, as soon as possible in order to secure a place.

We are also looking for sponsorship of the places. We already have two places kindly sponsored by Lorna Jaffa and Peter Oliver; thank you both.

If you are aware of a business or someone who would be willing to sponsor places for £100 each, please let us know.

Seasonal Scene Photo Competition

Congratulations to the winners of our Seasonal Scene photo completion! The winners were:

1st place **Justin Kelly** with his photo of Catherine
2nd place **Lorna Jaffa** with her cupcake photo
3rd place **Michelle Prendergast** with the sand 'Snowman'

Justin has donated £100 of his prize back to Rett UK and Catherine will be receiving a new DVD player. Lorna is going to sponsor a place at a new event with which we are involved this year, called Parallel London; read more about this on our fundraising events on page 18. Michelle has donated her £50 back to Rett UK.

Thank you, you lovely people.

Look out for Justin's winning photo on one of our 2016 Christmas cards.

Many thanks to everyone who took part and who liked/shared the Facebook posts.

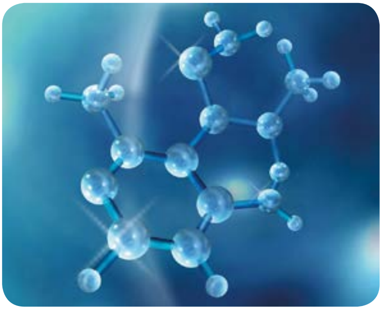
Research

Here we aim to bring you the latest research news from around the world.

Who? **Gong Chen, Pennsylvania State University**

What? **Restoring KCC2, an important molecule in normal nerve cell function and brain development might lead to a new treatment for Rett syndrome and autistic spectrum disorders**

When? **Published January 2016**



Researchers at Pennsylvania University report on finding KCC2, an important molecule to normal nerve cell function and brain development lacking in nerve cells of people with Rett syndrome. 'KCC2 controls the function of the neurotransmitter, GABA, at a critical time during early development'. When KCC2 was restored, the GABA function returned to normal. So increasing levels of KCC2 function might be a potential treatment for Rett syndrome. This correlates with a small study of children with Rett syndrome, funded by rettsyndrome.org in 2014, using IGF1 (insulin growth factor 1), which showed that 1GF1 was safe and well-tolerated. This has now gone to phase 2 clinical trials to examine how well it works.

You can read more about their study here:

http://www.news-medical.net/news/20160111/Research-could-lead-to-new-treatment-for-Rett-Syndrome-other-forms-of-autism.aspx

We note here their reference to autism spectrum disorders. It is not generally thought now, however, that Rett syndrome is an autistic disorder. In fact, it was removed from that classification in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition, updated in 2013, an authority used by clinicians and researchers to diagnose and classify disorders.

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 (Coordinator) or Richard Hudspith (Administrator) during working hours on 020 7848 0169/0290. If out of working hours, phone 020 7848 0002 (Institute of Psychiatry) and ask for Brain Bank staff to be contacted. Please remember that although a post mortem is of most value within 24 hours of the person's death, it is still of considerable benefit if it takes place within 72 hours.

Gall Bladder Disease in People with Rett syndrome

In this article we refer to the paper published in Developmental Medicine and Child Neurology, 2014. The authors include Jenny Downs and Helen Leonard from Interrett in Australia, whose names will be familiar. They have produced the Gastro and Intestinal Guidelines that are available on our website at:
www.rettuk.org/wp-content/uploads/2015/03/guidelines_gastro_intestinal.pdf

We thought it might be helpful to draw attention to a particular work, 'Prevalence, clinical investigation, and management of gallbladder disease in Rett syndrome'. Over the last few months we have had several support calls to discuss the question of gallbladder disease or gallstones being the cause of pain and distress to people with Rett syndrome.

The difficulties are in diagnosing the source of the pain, sometimes combined with lack of knowledge and experience of consultants in Rett syndrome, who are not looking beyond the Rett syndrome diagnosis to find the causes of the problems.

This research showed that gallbladder disease is more prevalent in people with Rett syndrome than in the general population. This would appear to be true both for children and adults although we can add only anecdotally that the cases of which we are notified involve older people with Rett syndrome.

It is quite well-recognised that people with Rett syndrome do have problems with reflux, movement of food through the gut and constipation. Inadequate intake of quantities of food and fluids, poor mobility, infections and medications can all contribute to poor contraction and emptying of the gallbladder.

This can lead to swelling/inflammation (cholecystitis) and gallstones. Repeated episodes of cholecystitis can cause scarring of the gallbladder and further loss of gallbladder function. Cholecystitis can be accompanied by other symptoms such as fever, jaundice and vomiting.

Gallstones by themselves do not generally cause abdominal pain until the point at which they are passed. However, abdominal pain is the main symptom of gallbladder disease, usually occurring in intense and recurrent attacks. It can become less severe and intermittent with time.

The communication difficulties of many people with Rett syndrome and their higher pain thresholds can make diagnosing something like this very difficult. However, parents and carers tend to be know when something is not right and what is not normal behaviour for those for whom they care.

If abdominal pain is suspected and other possibilities have been ruled out, we would advise speaking to a consultant about gallbladder disease. We can share the paper with consultants and put them in touch with a specialist who can further advise on the best course of action.

An Ambassador’s Story

By Kate Da Cruz

Philippa, Tinho and Kate

Rett UK asked me to attend a local fundraising evening. It was a music-based event in a club in Liverpool and a local venue to me. It was a superb evening, with a number of excellent bands and singers performing into the small hours of the morning. The singer of the lead band has a family member with Rett. Other fund raising activities included:

- A raffle with wonderful prizes, all donated by local businesses
- Home-made cup-cakes for sale
- Paying to shave off part of the lead guitarist’s hair (which he had been growing for 3 years and had dyed red for the occasion)
- Paying to wax a strip of leg hair from two of the lead band’s musicians

Music was the main focus of the night. It was great to get out to a club for the night as my daughter has Rett syndrome and has been in hospital a great deal during last year, so I have been light on social events. On arrival, I was made most welcome by the organisers. Then I busied myself talking to people, answering questions which they had about Rett syndrome and listening to their stories. I know that the evening as a whole not only raised a significant amount of money for Rett UK but also enabled people to learn more about its work. Rett UK was well advertised by means of literature on tables, T-shirts and balloons but to have an actual person introduced as representing Rett UK elevated the charity’s profile throughout the evening.

I was somewhat anxious about going as I did not know quite what to expect. I had been living in the critical care environment of our local children’s hospital for many weeks and had lost some of my confidence in going out and about. However, the whole evening was so relaxed and positive that I thoroughly enjoyed myself and believed that I had done something useful. The evening put to use the knowledge that I have gained through having a daughter with Rett syndrome in order to help others through Rett UK. If anyone thinks that they could help Rett UK in a similar way then it would very much hope to hear from you. Contact the office on 01582 798 910 or email info@rettuk.org.

Might you be a Regional Ambassador for Rett UK?

To support our goal of increasing the reach and scale of our work, we wish to establish a stronger regional presence. This will include developing our regional days, local support groups and regional ambassadors, who may be parents/family members/carers or friends of someone with Rett syndrome.

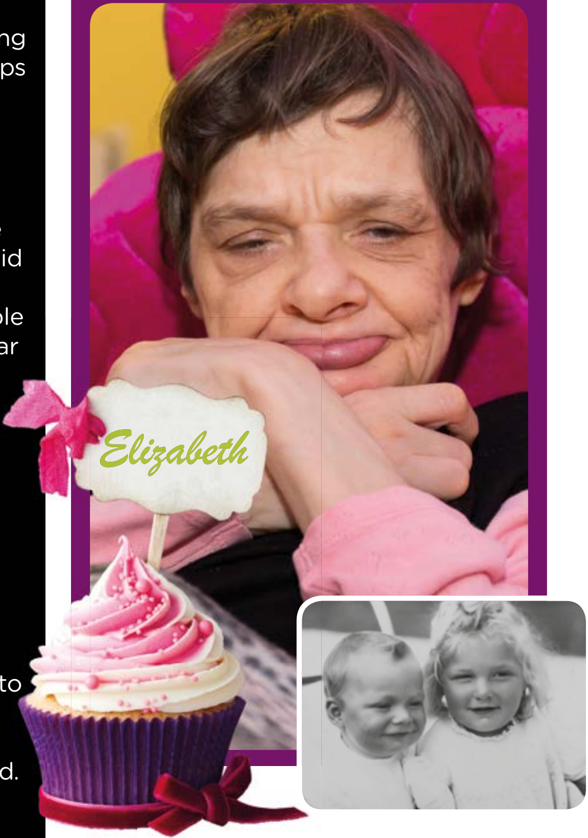
The Regional Ambassador roles are flexible volunteer positions, with paid expenses. There is an expectation that each Ambassador would be able to attend up to three events per year on behalf of Rett UK, which may involve talking about our work. There is not an expectation on the Ambassador to organise the event but just to be able to attend and speak, if required, about Rett syndrome and the difference that Rett UK makes.

Sometimes Regional Ambassadors may be asked to speak to the local press and TV and use social media to help raise awareness, spread campaign/appeal messages and encourage others to become involved.

If you think that is something in which you might be interested, please call Becky at the office, on 01582 798 910, for an informal chat.

Birthday Wishes

Happy Birthday wishes to Elizabeth Drewett, who celebrated her 68th birthday in December. Many thanks to Elizabeth's sister Cereta for sharing photos.



Top: Elizabeth on her birthday; Below: Elizabeth and younger bother, Peter as children

KEEP UP-TO-DATE

Sign up for our monthly E-Newsletter at www.rettuk.org

300 Club Results

Well done to everyone whose numbers were pulled out of the velvet bag this time

October 2015

1st prize...£350...Lorna Jaffa
2nd prize...£250...Rita Hyland
3rd prize...£150...Pat Fuller Worthing Lions

November 2015

1st Prize...£30...Mrs. V. Hooper
2nd Prize...£20...Vicky De Leval
3rd Prize...£10...Vicky De Leval

December 2015

1st Prize...£30...Sarah Teubler
2nd Prize...£20...Gillian Cheyney
3rd Prize...£10...Mrs. M. Garnett

If you'd like to join our 300 Club and receive the full benefit of our 12 monthly draws, please contact our draw organiser, Yvonne Oliver, yvonne.oliver17@gmail.com, who will send you all the details and a registration form.

Thank You

Thank you to everyone who has supported Rett UK over the past year. Like many charities we receive no government or NHS funding to carry out our services and rely entirely on donations

Front cover images: Skydive – Emily Bare.
Bottom: Left – Land Sheriffs Charity Football Match;
Centre – Team Phoebe Collier;
Right – Giorgio Rigali and Freya Cox

Farewell, Sarah

Sadly, this month we say goodbye to Sarah Kilcoyne, who leaves us after 7 years as accountant in our Luton office. Sarah joined us soon after we relocated from Friern Barnet and quickly became a key member of the staff team. Sarah used her experience as a qualified accountant to overhaul the internal accounting and reporting systems and we were very fortunate to have in the team someone of her ability.

Lucy Duncan commented, "I have very much enjoyed working with Sarah. Her helpful, clear and efficient reporting has made my job as treasurer easier. My fellow trustees have also found her work to be of enormous value in providing up-to-date analysis on our financial position. I speak on behalf of all of the trustees in thanking Sarah for all her hard work and dedication and wish her success in her new job."

Don't Forget!

If you have or are planning to move home, don't forget to let the office know you new contact details, as you may miss out on copies of Rett News and other important information.

Memories – Victoria Benning

By her parents, Elaine and Nigel Benning

Our brave and strong-willed daughter

We lost our beautiful, precious daughter Victoria on the 13th of December 2014. She had been in hospital several times over the previous three years but had always managed to pull through, so when she was admitted to Pinderfields Hospital in that December we hoped and prayed that she would do the same. Unfortunately, this was not to be and she no longer had the strength to fight the chest infection.

Victoria was a very brave and strong-willed young lady who enjoyed her short life and took everything in her stride. She was born on the 2nd of August 1994 and lived at home with her family until 2011 when she moved into Hollybank Trust in Mirfield, West Yorkshire. Victoria blossomed at Hollybank and loved to be with all her friends and amazing carers. She had a very busy social life there, always out and about, including a week-long trip to London, days out to Blackpool, speed boat and sailing trips, theatre and cinema outings, restaurants and shopping days out and even wheelchair ice-skating.

Her dad and I visited her every Sunday and he often popped in on a week night to see her on his way home from work. She loved food, men and chocolate and was quite vocal in making her needs and wishes understood! The carers at Hollybank really understood her and knew that sometimes she could be a ‘girly princess’; all sweetness and light and other times she could be a real ‘diva’ being very demanding! But as always she had the most beautiful cheeky smile and could giggle until she cried.

She had started using her Tobii Eye Gaze to communicate and this was amazing as we discovered that she had a real sense of humour which she showed us on many occasions. We took Victoria’s ashes back to Hollybank on Sunday, 2nd August 2015 to their memorial garden and as this would have been her 21st birthday we had a balloon release followed by a party to remember and celebrate her life.It is hard to believe we have now had two Christmases without our beautiful daughter. She will be forever in our hearts and memories and she now rests in Hollybank’s very special memorial garden near to her friends and the place she was most happy and content.

We will never forget this beautiful brave young lady who touched so many lives and was loved by all who knew her.

I'd Like to Make a Donation to Rett UK

Rett UK
Support today, hope for tomorrow

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, Langham House West, Mill Street, Luton, Bedfordshire LU1 2NA

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 FCC 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 FCC 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.

giftaid it

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.

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- 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 FCC Re Rett UK Ltd will notify you 10 working days in advance of your account being debited or as otherwise agreed. If you request FCC 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 FCC 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 FCC 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.

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