RS News
Rett Syndrome Association Scotland

WINTER 2014 EDITION

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Shelagh Joss • Badaguish • YPI Report • Christmas Fayre Report
Accounts • Rock The Rovers

Mary, Joan, Alice and Jacqui at the
Glasgow Charities Christmas Fayre 2013
Our research enterprise has had a big boost recently – we, along with others, have been awarded project grant funding worth more than £500,000 for projects in the Rett gene therapy area. This funding is a clear sign of the current interest in trying to develop this type of approach for ameliorating Rett syndrome in patients.

The team at University of Glasgow working on Rett syndrome is going to become quite substantial for at least a couple of years – two postdoctoral scientists, two or more PhD students, a technician, and several postgraduate and undergraduate project students. The team hope to be able to attend part of the Family Weekend this coming summer and meet some of the families.

The research that we shall do with the project grant funding builds on previous work, supported in part by a series of grants from RSA Scotland. In that research we found that if the protein lacking in Rett syndrome patients, MeCP2, can be provided to the cells of mice lacking the MeCP2 gene (a good genetic model for Rett syndrome) using viral vectors, the cells can begin to function normally. Furthermore, we were able to show that the mice themselves develop a considerably less severe disease condition after this treatment. The new project grant funding will be used to optimise the design of the viral vector for delivery of the MECP2 gene in the mouse model, as well to test out the best route for delivery and a number of other parameters that will influence how we should be designing what is needed for human gene therapy trials.

A cause for optimism is the fact that human gene therapy trials for other genetic disorders are showing increasingly promising signs of being successful, and we very much hope that this will also turn out to be the case in RTT – but we know, as do parents and families of Rett patients, that it is likely to be a long road.

We would like to acknowledge the funding that RSAS has made available to us so far, which played no small part in enabling the work that has led to the recent funding success, and we hope that RSAS continues to fund, in whatever way it can, the kinds of innovative and risky projects that can lead to bigger things.
From deep in retirement I'd like to say how much I enjoy reading your newsletter and following the impressive progress that has been made towards a full understanding of the Rett syndrome and I've been most happy to see how the Association is continuing to help in that work.

Mark Bailey and Adrian Bird are some of the key players in the quest for understanding the routes by which effective treatment can be provided for people with the disorder and I am quite certain that your interest and commitment as well as your grants for projects really boost their motivation.

For scientists who work in laboratories, being aware of the relevance of their research to people's lives is truly a great motivator.

It may seem surprising how busy one can be in retirement but that's how it is for me. The care of my sister's large artistic output was one task that helped to fix the date of my retirement and just recently we have had a great breakthrough in having the paintings seen and enjoyed outside Art galleries. The large new NHS hospital at Larbert has invited paintings to be placed in several departments and in the main corridor.

At the same time a project to which we have given a number of paintings (Art in Health Care) expects some of them to be displayed in NHS premises across central region. So, if you are in hospitals, do look out for paintings by Marjorie I. Campbell!

Retirement has also given me welcome time to improve my cello playing with the local orchestra and several chamber groups, to spend time with our young families, look after our rather large garden and recently to learn the art of wood carving.

We are lucky that Tom and I are both still in good health and can enjoy a lot of walking and a fair amount of travelling. Of course I still enjoy hearing from Rett families and colleagues when they want to get in touch.

I look back on the years spent in Rett service with very much pleasure - there are so many good memories to dwell upon!

A Brief Note for the Membership from Alison Kerr

Then and Now 1982-2014

By Dr Alison Kerr, February 2014

I've been asked to share my thoughts on how the work for people with Rett has changed through the years since I became involved.

Compared to almost every other disorder affecting people, progress on understanding the Rett disorder has been impressive. That is due to new technologies, allowing examination of the brain and the genes that build it, but equally, to the commitment of so many families and scientists to solve the problems.

In 1982 John Stevenson, senior neurologist at Glasgow's Royal Hospital for Sick Children asked me to find out how common the disease was. He had only just heard it described by Bengt Hagberg but realised that he had seen and been puzzled by these children.

From that and Rett's 1960s description we traced 19 girls and estimated the prevalence of the disorder. Support quickly came from the newly formed Rett Associations in the USA, Scotland and England. Joint international conferences allowed scientists, therapists and families to meet around the girls to discuss their difficulties. Advice clinics throughout Britain (1990) made possible the longitudinal British Isles health Survey, recording information from repeated clinical examinations and health questionnaires, with families providing permission to share that data among researchers. This resource allowed us to understand the problems and directed the research. We learned about the early signs before regression, the regression event, the irregular breathing, vacant spells, epilepsy, movement, growth, posture and nutrition problems and the long term outcomes.

From the outset, an X-chromosome mutation seemed likely but such a fault is hard to find when only one in a family has the disease. Carolyn Schanen's team investigated a special family with several recurrences and that led in 1999 to Huda Zogbi's Texas department discovering the mutation in the gene MECP2, newly described by Adrian Bird's Edinburgh team. They then developed mice with the same defect and comparable problems. This was a huge advance in understanding how the genetic fault affects the brain and heralded development through further animal research, to understanding the chemistry, physiology and genetics of the disorder, with the promise of designing effective treatment.

Thus research on the Rett disorder has progressed steadily due to the commitment of families and scientists, through roughly decade-long, periods following Rett's original observations.

1980s Increased recognition of the prevalence and clinical problems
1990s the anatomy and physiology became better understood
2000s the genetic fault and its effects on the brain were elucidated.

Now the 2010s carry possibilities for cure and prevention

So, a lot has changed since 'Then' and underlying it all has been the steady, combined support of both families and scientists.

PROFESSOR SIR ADRIAN BIRD
Rett Syndrome Association Scotland would like to congratulate Professor Bird on his recent knighthood in recognition of his services to science.

Professor Bird was instrumental in the discovery that by using a mouse model, Rett-like symptoms in the mice can be readily reversed by restoration of a functional MeCP2 gene, raising the prospect that Rett Syndrome itself might be curable.

Drs Mark Bailey and Stuart Cobb also work in collaboration with Professor Bird.
RSAS still holds some copies of the above DVD, which Alison made just before she retired, sharing some of the wealth of experience gleaned from her years of Rett clinic work. Copies can be obtained from the secretary and are for the information of professionals caring for people with Rett Syndrome. Alison recommends that families should share the DVD with their professional carers because it allows doctors, therapist and teachers to acquire a broader experience of the disorder at different ages and different levels of severity than they are likely to be able to gain from their everyday practice and that can improve the quality of care they can provide. The DVD may also be downloaded on a computer. Alison would be very pleased to receive feedback from families and professionals about how the film is being used and to what extent it achieves its purpose.

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**My Work with Rett Syndrome**  
**By Dr Shelagh Joss MBChB, MRCPCH, Med**

I am a Consultant Clinical Geneticist, now based in the new Laboratory Medicine Building at the Southern General Hospital in Glasgow. I see adult and paediatric patients and their families there and at clinics in the Fraser of Allander Paediatric Neurology Unit at Yorkhill, at Child Development Centres around Glasgow and Clyde and at outreach clinics in Hamilton and Dumfries. My colleagues in Glasgow and in the 3 other Genetics centres in Aberdeen, Dundee and Edinburgh provide outreach clinics in most parts of Scotland.

Most of my work involves assessing patients who have learning disability, trying to establish the cause and arranging appropriate testing. I have occasionally made a diagnosis of Rett syndrome but usually the diagnosis has been made by a paediatrician before the patients come to my clinic. I offer to see these families if they are considering having another child and want to know the chance of having another child with Rett syndrome. Sometimes adult siblings of an individual with Rett syndrome want to know if there is a chance that they could have an affected child.

If the diagnosis of Rett syndrome is confirmed by a genetic test and a mutation has been found in the MECP2 gene we can offer relatives a test to check that they do not carry a mutation even though they do not have features of the condition. This can occur but is rare. If a parent carries the mutation there would be a significant chance of having another affected child. In most cases parents' tests are negative and the chance of having another affected child is small and in the order of 1-2%. If parents are concerned about this chance we can discuss options available for testing in a future pregnancy. If another relative’s test is negative their chance of having a child with Rett syndrome is similar to the chance of anyone in the general population.

If a MECP2 gene fault has not been found in the affected patient I can consider if there are other tests we could arrange. Alterations in other genes can sometimes cause conditions very similar to Rett syndrome but with slightly different associated health problems. If a different diagnosis was made I would give the family information which is relevant to them. Like Rett syndrome, most of these other conditions are the result of a new mutation which has occurred in the affected child and has not been inherited from either parent. For these conditions, the chance of having a second affected child is small.

There are some rare autosomal recessive conditions which resemble Rett syndrome. Autosomal recessive means that the affected individual has an alteration (mutation) in both copies of a specific gene. This usually means both parents are not affected but are carriers and have one usual copy of the gene and one altered copy of the gene. When both parents are carriers of a genetic disorder like this there would be a 25% chance that each of their children will be affected.

If any members would like to ask about any of these issues they could ask their GP to refer them to me or to their local Genetics Service. Usually it would be possible to offer them an appointment in a clinic close to where they live.

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**RS MEDICAL ADVISOR IN CONCERT**

As well as his medical work Dr Mark Bailey is a member of the Lochwinnoch Choral Society (LCS), which is giving three performances. The first is an appearance at the City Halls, Glasgow on 8th March along with several other choirs and the Glasgow Orchestral Society. http://www.glasgowconcerthalls.com/events/commonwealth-celebration-concert-let-glasgow-flourish-2/

LCS are then teaming up again with Sirens of Titan to do two concerts - Glasgow Oran Mor on 31st March, and Lochwinnoch McKillop Hall on 30th March.

If you are interested in attending one of the performances tickets are now on sale.
Youth & Philanthropy Initiative

The Initiative is designed to support and develop individuals to become caring and contributing members of society by developing skills in teamwork, presentation, research, communication and decision making.

In October 2013 two groups of 6th year students at Largs Academy separately approached RSAS having decided that they wished to support the Association in this year’s YPI challenge (see photo, next page).

Both groups visited the Association “office” in West Kilbride and after discussion the groups chose to support the Family Weekend at Badaguish 2014 and Janette Montagues’ proposed RS YouTube video production (see page 8).

Having gathered information the groups would make a presentation and the winning group in their section would be awarded £3,000 for their chosen charity.

Having discussed various aspects of Rett Syndrome the students then collated the information and both groups made their presentations. Unfortunately neither group was successful in receiving the award but it was heartening that they supported RSAS and the Association is grateful to all of them for their time and effort.

Beth McQuillan
Intrepid Sky Diver

Beth is the sister of Rett girl Lorna and has decided that she would like to raise funds for RSAS, by doing a sponsored sky dive. It is hoped this will take place in May at Strathallan, but will be subject to weather conditions at the time.

Beth has set up a mobile phone fundraising page and if you would like to sponsor Beth please use the instructions below.

If you wish to give eg £10 then text the message: RSAS13 £10
To the number: 70070
You will receive an acknowledgement of your donation on your phone.

Please note that, because this is a free fundraising page we are unable to get messages along with the donation so will be unable to see who has sponsored Beth. Please make sure that, when you sponsor her, you let her know the details.
**Lorna McQuillan**

**Eye-Gaze Computer**

Lorna “SPLATS” a friend.

Lorna using the eye-pointer equipment.

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**Youth & Philanthropy Initiative**

Carly, Jill, Chloe and Caroline (seated) at the Largs Academy YPI recording session (Photo by Kirstie)

Tristan, Cameron, Euan, Rachael, Alexandra & Catriona Largs Academy YPI Group

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Gleaner Oils representatives, Jimmy Turnbull, Marion Wilson & Hannah Young receive the Certificate of Thanks from Jenna & Hazel Young.

Chairman, Graeme, hard at work networking at the RS Europe Conference.
Jenna prepares to descend the abseil tower…
Holly, Erica, Jenna and Hazel safely back on dry land.
Jenna & Raymond take to the water.
…nearly there.
Kate & Angela waiting for the barbecue to start.
Gordon, Ian, Harris, Holly and Erica enjoying their time on Loch Morlich.
Ian working hard in the back of the canoe.
Holly, Erica, Jenna and Hazel safely back on dry land.
Rhiannon, Kev, James, Lucie, Gordon and Holly get-together on site.
Jenna prepares to descend the abseil tower…
Raymond & Jenna, Erica & Holly and Gordon & Harris pause for a photo on the cycle path in Badaguish forest.
Raymond, Rhiannon and Kev relaxing at the barbecue whilst Angela watches a participant on the walkway.
Kate & Angela waiting for the barbecue to start.
Raymond, Rhiannon and Kev relaxing at the barbecue whilst Angela watches a participant on the walkway.
Hannah-Marie, Muriel and Anne enjoying themselves at the barbecue.
Graeme, Rhian, Muriel and Kate socialising at the barbecue.
Rett Music Therapy Booklet and Rett Music Project

The music therapy booklet is in the last stages of production and will be sent out shortly. Our grateful thanks go to Janette Montague who produced the booklet and also to Sarah Fernandez, Muriel Macleod and Vikki Cavanagh who appear in the booklet.

During the production of the booklet, Janette came up with an idea for another Rett project.

Janette says:
“I could compose a piece of music, based on the Rett girls sounds, so that their sounds were what the whole thing was based on, and they would be heard in the final piece, demonstrating brilliantly how in Music Therapy, the child/young Rett woman, should be at the very heart of things. I would enlist about six other Music Therapists in Scotland to perform the piece and we would have a brilliant film, showing footage of the Rett girls and their parents (if wanted) bits of talking taken from interviews I could conduct with parents etc, all encompassed in a specially written piece of music, with the Rett peoples’ sounds at the very heart of it. This would spread awareness of Rett Syndrome, show what Music Therapy is all about, and hopefully attract funds as we could show people how to donate at the end of it.

I think this would be so emotive, would have a big impact, would show more visually and in sound, and would be a live thing, which people could respond to emotionally as well as in other ways.

It would reach a worldwide audience if it was on say, YouTube as a video”.

Janette has just finished recording a piece for the Piobaireachd that can be watched on Youtube at: http://www.youtube.com/watch?v=RD_svm4fb5Y

The committee has discussed this new idea from Janette and will be making further enquiries about the production.

MUSIC THERAPY BOOKLET

Janette Montague

The music therapy booklet, produced by Janette Montague and sponsored by Beanfeast Charity for Children, Paisley, is now at the printers, Adprint and will soon be ready for issue to our members. Once you have received your free copy, if you would like any further copies please advise the secretary.

Eye-Gaze Computer

By Julie McManus (Lorna’s teacher at Aird Unit)

Lorna McQuillan, an S2 pupil at Stranraer Academy, has been making almost daily use of an eye-gaze computer since the 15th of January this year. Lorna works on this with 1:1 support, focussing initially on sensory activities, in an area where there are no distractions. The software she is using is called “Look to Learn”. This technology is on loan to the school from CALL Scotland, who support young people in Scotland with various communication difficulties.

It truly is a wonderful piece of equipment! Lorna uses her eye-pointing skills to splat familiar people with custard pies! This is one of her favourite activities! Lorna has also been selecting pieces of music to listen to, and it is wonderful that she is making these choices independently.

The staff that work with Lorna have been incorporating Lorna’s likes and daily activities, within the eye-gaze computer. For example, Lorna can select the snack that she wants to eat first for her mid-morning break e.g. grapes.

The member of staff working with Lorna can ask her to choose which activity she wants to do, and Lorna then selects using her eyes. Staff have recorded that Lorna is clearly making choices, and communicating her preferences via this technology.

In summary, Lorna is benefiting hugely from having access to this wonderful eye-gaze technology, and it will be lovely to share her success with it in the future.

RETT SYNDROME: THERAPEUTIC INTERVENTIONS

RSAS has now added two copies of the book to its library.

The book covers various aspects of RS including chapters on osteoporosis, mealtimes, digestion, communication and physiotherapy, as well as many other RS aspects of interest to us.

This book is free to borrow.

If you would like to borrow a copy please contact the secretary.
DONATIONS
As always our grateful thanks to all who have supported the RSAS by their fundraising and donations. Without your help we would not survive.

Hazel Mackay, Buckie
M. Chivers, Ledbury (in remembrance of Helen Griffiths)
Donna & Frank (c/o Tom & Martha Duncan)

David Nicholls, Ashkirk
Sheila Nicholls, Ashkirk
Dr Alison Kerr, Bridge of Allan

FUNDRAISING
Claire Andrew elected RSAS to receive matched funding from the Bank of Scotland Foundation for a fundraising event she participated in.
Audrey O’Brien took part in the 2013 Coast to Coast Rely for Rett, on a very wet and cold day, to raise funds for RSAS.
Richard McMahon took part in the 2013 Coast to Coast Ultra and covered the complete distance of 85 miles in one cold and wet day, to raise funds for RSAS.
Raith Rovers Supporters Club raised money for RSAS at their Rock the Rovers music concert.

Raith Rovers Football Club
As mentioned in the last issue of RS News, Rock the Rovers took place on Sunday August 25th 2013 at Kittys and Kandy in Kirkcaldy.
This annual music festival raises funds for various charities and prior to the Raith Rovers v Falkirk football match on September 25th cheques were presented to this year’s chosen charities, including Rett Syndrome Association Scotland.
Our grateful thanks go to Gavin Quinn and his team of organisers as well as to everyone who attended the music festival.
Tom Duncan, committee member, represented RSAS and the Association was very pleased to receive a cheque for £375.00.

Jenna Mackay
On the day of her birthday, Jenna Mackay visited the offices of Gleaner Oils Ltd in Elgin to present staff with a Certificate of Thanks, for the very generous donation they made to Rett Syndrome Association Scotland (see Centre Page photo).
Every year staff at the company choose a charity and this year RSAS was the chosen recipient of a very generous cheque. RSAS was nominated by Jimmy Turnbull, whose niece in Belfast has a Rett daughter.
Money is raised through donation of gifts etc by staff, for a raffle and proceeds from the sale of tickets are then matched by the company. Some staff members also take part in a weigh-in and pay a forfeit for every pound they put on over Christmas. This forfeit is then also matched by the company.
Many thanks to everyone who took part in the event and raised money for Rett Syndrome Association Scotland.

CHRISTMAS FAYRE
Donations were received at the Fayre from:
Frances Binnie, Prestwick
Alice Cleary, Neilston
Sharon (c/o Mary McNicol),
Mr J Cleary, Skelmorlie
Mary McNicol, Inchture

E Payne (c/o Joan Phillips)
E Reah (c/o Joan Phillips)
E McDade (c/o Joan Phillips)
Trish (c/o Joan Phillips)

Joan Phillips raised more money at a further sale of stock remaining from the Christmas Fayre.

COLLECTION BOXES
Joyce’s, Buckie has now made three donations so far this year from their collection can.

Congratulations!
Rhiannon Thompson and Kevin McDonald.
We are pleased to announce that RSAS supporters Rhiannon and Kevin have become engaged and we look forward to hearing details of their plans for their future together.

Grateful thanks to John and the boys at adprint for all their help.
## Accounts

The 2012 – 2013 Accounts have now been independently examined and passed to OSCR

Rett Syndrome Association Scotland
SC016645

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### Receipts and payments accounts

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### Section A Statement of receipts and payments

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**A1 Receipts**

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<td>Receipts from fundraising activities</td>
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*A1 Sub total* 8,487

**A2 Receipts from asset & investment sales**

| Proceeds from sale of fixed assets               |        |                    |                 |                           |                            |                           |                         |
| Proceeds from sale of investments               |        |                    |                 |                           |                            |                           |                         |

*A2 Sub total* -

**Total receipts** 8,487

**A3 Payments**

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*A3 Sub total* 16,172

**A4 Payments relating to asset and investment movements**

| Purchases of fixed assets                      |        |                    |                 |                           |                            |                           |                         |
| Purchase of investments                        |        |                    |                 |                           |                            |                           |                         |

*A4 Sub total* -

**Total payments** 16,172

**Net receipts / (payments)**

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**A5 Transfers to / from funds**

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**Surplus / (deficit) for year**

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<th>Amount</th>
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FORTHCOMING EVENTS

Coast to Coast Ultra for Rett 2014
It has been decided that this year, due to organization difficulties, the Coast to Coast Relay for Rett will not take place. However, for those of you super-fit people out there we intend to organize the Coast to Coast Ultra once again, to take place one day in May.

This event will follow the C-C route of previous years and entrants will either be able to cover one of the stages ie Largs to Glasgow (40 miles approx), Glasgow to the Falkirk Wheel (25 miles approx) or the Falkirk Wheel to South Queensferry (20 miles approx) or the whole distance of 85 miles.

If anyone is up for it we could also increase the distance to finish in Edinburgh and make a grand total of 100 miles.

If you think you, or someone you know, would like to take part or if you can offer your services to help organize the event please let the secretary know as soon as possible.

Badaguish Family Weekend 2014
This event is being organised for the weekend Friday 8th – Monday 11th August 2014
We hope that Dr Mark Bailey and some of the research team at Glasgow University may be able to join us to take part in the activities and also meet with the families. We also hope that Dr Shelagh Joss will be in attendance again this year.

We are planning the usual activities – cycling, canoeing, archery and abseiling and hopefully we will again have some musical entertainment in the evenings.

Once this issue of the newsletter is distributed letters will be sent out about this event, but meantime if you are interested in attending please contact the secretary.

RettUK Roadshow
RettUK have been in touch with us with regard to a Roadshow taking place in Scotland.

The event would be designed to encourage professionals to attend in order to learn more about RS and also to encourage someone to take a lead to hold specialist clinics in Scotland.

Unfortunately funding for this event has not yet been forthcoming but RettUK are continuing to work on this.

This year the RSE conference is being hosted by the Austrian Rett Association and will be held on 15th November in Vienna.

The main topic this year will focus on Rett centres or clinics in Europe, to give an idea of practices in each country.

Again, it is hoped that we will have a representative at the meeting and if you would like to attend on behalf of the Association please contact the secretary.
This year’s Christmas Fayre was a great success thanks to the support of the many members and their family and friends who turned up on the day to help. Jacqui, Alice and Mary are regular helpers at the event and it was lovely to once again see Frances Binnie, who for many years was treasurer and secretary of the Association.

It is always gratifying to see so many gifts donated to the stall and thanks to everyone who provided them this year.

Particular thanks should go to Joan Phillips, Rhian’s grandmother, who not only arrived early in the morning to help set up the stall and stayed until the bitter end to help dismantle the stall, but also provided many of the items on sale, which she had painstakingly made throughout the preceding year and which provided an eye catching and interesting display.

The Fayre is also turning into a social event where different charities come together and catch up with each other’s news.

Sale of goods and donations this year resulted in £450 being raised on the day and a further £55 was received when Joan hosted a sale of remaining stock the following month.