

RETT SYNDROME ASSOCIATION SCOTLAND

Scottish Registered Charity: number SC 016645

News Sheet November 2015

My apologies that you haven't received a Newsletter this year. Unfortunately our printer retired at very short notice and I have been struggling to find a replacement. Hopefully I have now accessed someone and I will soon be back in business. Our very grateful thanks go to John, Robert and David at Adprint, Prestwick who have given us such good service over the years and have helped sponsor the production of the Newsletter.

As it is unlikely that I will be able to get a newsletter professionally printed this year I thought I would issue this News Sheet to keep you up-to-date with the Association news.

With best wishes for a very happy Christmas and New Year,

Kind regards,

Caroline Groves
Secretary / Treasurer / Editor

Stylus / Pens

I have taken delivery of 200 stylus pens engraved with "Rett Syndrome Association Scotland 01294 829100". They are a 2 in 1 product with a silicon nib for use as a stylus on tablets and smart phones and a press top which extends a nib for writing in black ink. They come in assorted barrel colours.

At £1 each they make an ideal stocking filler and will also be good publicity for us. Postage for up to 10 pens costs £1.26.

The pens are very stylish and sold well at the Christmas Fayre, with repeat orders.

If you would like to buy some pens, please contact me.

Accounts

The Accounts for the financial year 2014 – 2015 were submitted to the Office of the Charity Regulator (OSCR) and accepted by them. They are available to view on our website and I will include them in the next official newsletter. Meantime if you want to see them beforehand and don't have online access please let me know and I will post you a copy.

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AGM

The AGM took place in Glasgow in June and the committee was re-elected. However, we are desperately looking for new blood and new ideas to enable the Association to continue. Will you be brave enough to volunteer to help? Don't wait to be asked, get in touch.

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YPI (Youth and Philanthropy Initiative)

This year we had two groups from the 6th form at Largs Academy representing RSAS in the hope of winning £3,000 for us. Unfortunately neither group got through to the final but it is wonderful that the students give up their time and are so enthusiastic in their efforts to win support for us.

Coast to Coast 2015

Unfortunately, despite our best efforts, this event had to be cancelled due to lack of entrants (not surprising when participants are required to cycle 100 miles). We hope to resurrect the event in 2016, so if you know of anyone who is up for the challenge please get in touch.

Our special thanks go to Allan Bell. Allan took part in the very successful 2014 event and has been enthusiastic all through this year about taking part again. Hopefully he will be available next year.

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Rett Music Project

After Janette Montague had suggested a follow up to her Music Therapy Booklet in the form of a piece of music especially written for Rett Syndrome Association Scotland and including sounds and rhythms provided by our Rett people we were awarded a second donation by Bean Feast, Paisley. Bean Feast had previously funded the production of the booklet.

This donation has gone a long way towards the cost of the recording, the first phase of which took place at the end of March.

With video footage of the sounds and rhythms of the Rett people on tape Janette then worked on composing her music and the second recording took place on Sunday 15th November.

Janette is still searching for a title for the music, so if you have any ideas please let me know.

Janette and guitar player, David, have given their time and effort free of charge and we are extremely grateful to them.

I would also like to thank Bean Feast, Paisley for their very generous donations making the production of the music possible.

We are waiting with bated breath for the final piece to appear on YouTube & Vimeo, which should happen before Christmas.

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Condolences

We were very sad to learn of the death of Jane Lees in a tragic accident in June.

Jane was a long term, active member of RSAS and took part in many of the fundraising events and get-togethers held by the Association. Jane will be greatly missed and our condolences go to her family, carers and friends.

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Fundraising

Following the demise of The Dove Trust where we had an online fundraising page, we are now in the throes of registering with Virgin Money Giving. We have already completed the registration form with HMRC for Gift Aid and we have been accepted by them. The next stage is to register with Virgin (more forms to be completed), but once this is done we will be ready to receive all your fundraising money! Meantime, if you are planning a fundraising event please contact me.

The amount of money in the RSAS coffers continues to diminish so members are asked to come up with funding sources. If you know of a source of funding source please contact me.

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Essential Life Plan

By Isabel Allan MBE Dip Couns.
Mother & Carer

Isobel our founder and mother of a Rett person, has produced three information manuals; Essential Life Plan, Special Needs & Toothcare and Person Centred Planning & Outcome April 2013.

Consideration is being given to the production of these manuals for distribution to our Family members. Meanwhile, if you would like a copy please contact me.

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Family Weekends 2015 & 2016

Our Family Weekend took place again this year at Badaguish, despite a long delay in planning the event due to problems with booking the lodges on suitable dates.

We were pleased that this year 10 Rett families were able to attend and canoeing, cycling, archery and abseiling were again on offer.

This year we were lucky to have a demonstration of eye-gaze technology at the Weekend and we were all given the opportunity to try it for ourselves. Many thanks to Julie McManus, Additional Support for Learning Teacher, who brought along the equipment and supervised us. Julie has also offered to give information to anyone with an interest in this technology, so please let me know if you would like to get in touch with her.

As in previous years we had a barbecue one evening and a ceilidh on another and it is wonderful to see all the children (and adults) having such an enjoyable time.

A provisional booking has been made for a similar event to take place 5th – 8th August 2016 and if you are interested in joining us please let me know, although details and information will be sent to all our families as soon as possible.

Eye Care Provision

For many years we have advised new members that eye care provision for their Rett people can be accessed under the auspices of Dr Daphne McCulloch at the Glasgow Caledonian University Eye Clinic.

Dr McCulloch has now left the Clinic and we send her our best wishes for the future.

However, I am very pleased to say that her place has been taken by Dr Gael Gordon, Optometrist and parent of a Rett girl.

Gael is keen to promote good eye care in people with Rett Syndrome.

If you wish to make an appointment please ring Glasgow Caledonian University Eye Clinic, 0141 331 3378 and ask for a special needs appointment.

Young people should be seen annually and adults biennially (or any time if there appears to be a problem).

Since eyesight is generally good in people with Rett but they cannot say if their vision becomes blurred it is important for families to remember to arrange for vision checks to make sure that spectacles are obtained if and when they are needed.

Road Show and Clinic

Rett Syndrome Association Scotland and Rett UK are joining forces to host a Road Show in Scotland in an attempt to inspire professionals to take an interest in Rett Syndrome, with a view to being able to stage clinics on a regular basis.

RSAS and Rett UK will be jointly funding this event, as well as pooling our resources and Becky Jenner, Rett UK and I are in contact with each other to discuss matters.

We are hoping to holding the event in the central belt of Scotland, perhaps at the end of March or the beginning of April.

If you have any suggestions for a suitable venue please let us know and we would also like to know your three priorities in terms of topics for the event.

You can let us know by contacting us in any of the following ways:

rettsyndrome@btconnect.com

RSAS, Blackthorn, 12 Ailsa View, West Kilbride KA23 9GA

01294 829 100

or by contacting Rett UK using the following links:

<http://www.rettuk.org/how-we-can-support-you/rett-uk-regional-days/>

<https://www.facebook.com/RettUK>

becky.jenner@rettuk.org

Donations & Fundraising

Rett Syndrome Association Scotland is always grateful for the support given to us by the many people who make donations and raise funds for us.

Donations

M Chivers, Porth, in memory of her granddaughter, Helen Griffiths (Two donations)

D R Nicholls, Ashkirk (Two donations)

Beanfeast for Children, Paisley

Donna & Frank

Alison Guthrie on behalf of F Binnie, Prestwick

J Berrington,

D Connan

G Loffler

M Shooter

K Whitehead

S Fernandez

B Davis

Jacqui Cleary, Neilston (Three donations)

M McNicoll

John Cleary

T Kane
E & A Griffiths
A Neil
J Patience
K Yule
A Shanks,
A Darling
T & M Duncan
M Liu
H Mackay, Buckie

M McGregor
M Simpson
A Warnock
K McMahon, Newtonmore
A McLeod,
C Johnston
S Murray & Faye
G Dallachy
L & I Sloan
Dr A Kerr

Fundraising

Christmas Fayre, Milngavie 2014

Joan Phillips ran a Christmas Fayre in the Fraser Centre and £95 was raised.

Fundraiser

Hazel Mackay, Nigel & Linda Ross, Emma, Morag and Fiona, Charity Therapies & Craft raised £500.

Coast to Coast 2012

Further donation payments of £111.94 were received from online sponsorship of Audrey O'Brien.

Kilt Walk

Julie Forsyth took part in the Kilt Walk and raised £280.00

Coast to Coast 2014

Chris Park, who took part in the 2014 Coast to Coast event received double-matched funding of online sponsorship from the Robertson Trust and Edrington Giving More and £1,924 was received. In total over £3,000 was raised.

Collecting Boxes

Hazel Mackay & Joyces, Buckie collected a further £21.50 + £36.50

Sky Dive

Lynn Wilkinson, together with her friend, Lesley Mason, did a sponsored sky dive to raise money to buy a beach wheelchair for her Rett sister, Angela. The excess money she raised was matched by the Bank of Scotland Foundation and a total of £480 was donated to RSAS.

Glasgow Charities Christmas Fayre 2015

This event took place at the Glasgow City Chambers and thanks to the hard work of Joan Phillips, Alice Cleary, Jacqui Cleary, Mary McNicoll and Caroline Groves, who all manned the stall, a total of £326 was raised. Thanks also go to those who made money donations and / or donations of goods to the stall.

Raffle

Lisa Boyle, daughter of committee member, Tom Duncan, works for Slater Hogg & Howison and to celebrate 40 years in business the Burnside office held a raffle with gifts donated by local businesses. RSAS was the Burnside's chosen charity and £425 was raised for the Association

Give as you Earn

We are receiving regular payments from an anonymous donor.

Dress Down Day / Quilt Sale

Catriona Stirling and colleagues at the Lloyds Banking Group, Sighthill North, held a Dress Down Day and quilt sale (made by her friend, A Darling) and with matched funding from BoS Foundation £940 was raised.

British Neurological Association Festival of Neuroscience

The BNA held this event in Edinburgh in April and RSAS was delighted to support Mark Bailey and his research team to provide a symposium "Gene Therapy for CNS disorders". As RSAS was a sponsor of this symposium I was able to attend as the Association representative and although I thought that much of what was being presented would be beyond my understanding I found the speakers were very interesting and I was amazed at the scope of the research taking place around the world. I would estimate there were over 100 delegates attending this symposium, which in itself shows the interest being given to neurological conditions and it was very exciting to learn of the way research is going forward. Speakers at this symposium were:

Dr Stuart Cobb, University of Glasgow, UK – **Gene therapy in developmental / intellectual disability disorder – Rett Syndrome**

Dr Steven Gray, University of North Carolina, Chapel Hill, USA – **CNS gene therapy in neuropathy – from basic science to clinical trials**

Professor Mimoun Azzouz, University of Sheffield, UK – **Gene therapy in neurodegenerative disorders**

Dr Stephanie Schorge, University College London, UK – **Gene therapy in epilepsy**
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Dr Mark Bailey, University of Glasgow, UK – **Genome / mRNA editing and mutation correction in CNS disorders**

In total about 1,600 delegates registered for the Festival and as well as those from the UK about 100 other national locations from the EU and around the world were represented.

A full report of the Festival can be accessed at
<https://www.bna.org.uk/static/BNA2015%20meeting%20report.pdf>

Research

RSAS continues to support research and the committee is maintaining contact with Mark Bailey and his research team to consider the most effective ways of continuing to do this.

If you need to contact me regarding any of the above articles or for further information please get in touch:

rettsyndrome@btconnect.com

RSAS, Blackthorn, 12 Ailsa View, West Kilbride KA23 9GA

01294 829 100

About RSAS

Founder / Honorary President

Mrs Isobel Allan MBE
15 Tanziacknow Drive
Glasgow G72 8RG

Chairman

Mr Graeme Dallachy
Stable Cottage
Garchell Farm
Balfron Station
Glasgow G63 0QY

Secretary / Treasurer

Mrs Caroline Groves
Blackthorn
12 Ailsa View
West Kilbride
KA23 9GA
Email: rettsyndrome@btconnect.com
www.rettsyndromescotland.co.uk

Committee Members

Jan Hunter
Anne MacLeod
David Jackson
Kate McMahan
Tom Duncan
Pauline McQuillan