

Tuberous Sclerosis Association

Scottish Newsletter

February 2010



Welcome

Welcome to the 3rd edition of the new Scottish Newsletter. Our sincere thanks to you all for your continued support and suggestions for our newsletter, please keep them coming.

All TSA Trustees and Staff would also like to take this opportunity to wish you all a very Happy, Healthy and Prosperous 2010.

Carers Pathway



Our sincere thanks to Ann Allcoat, Development Manager Scotland, Princess Royal Trust for Carers, and to all our members who have made some very valuable suggestions to the draft TSC Carer Pathway document.

The final document will clearly highlight what anyone who provides care for someone affected by TSC (that includes all you mums, dads, brothers and sisters) should expect from all Social and Health Care practitioners. We hope this will enable members to work with, and be a valued member of the team providing care. A copy of the final Carer Pathway will be included with the next issue of the Scottish Newsletter.

There is also lots of work going on in Scotland in relation to a generic Young Carers Pathway. Louise Morgan, PRT Young Carers Scottish Development Manager has been working with the Young Carers Strategy Group. The Pathway is based around the Getting it Right for Every Child agenda. We hope to have further information on this project soon and will update you all in the next edition

If in the future you require further copies, to give to Social Workers, Health Care staff etc please contact

TSC Adviser Lynn Shields on **07510 595968**

or email lynn.shields@tuberous-sclerosis.org

Energy Assistance

The Energy Assistance Package, is a comprehensive package of support for people at risk of fuel poverty in Scotland and Funded by the Scottish Government.

The package aims to help households maximise incomes, reduce fuel bills and improve the energy efficiency of their homes.

Families of disabled children in receipt of benefits are particularly encouraged to call the free advice line.



The Energy Assistance Package is open to everyone in Scotland and offers different levels of advice and support depending on householders' circumstances such as grants for heating systems and free insulation for eligible people.

Call the free advice line on **0800 512 012** or visit www.energyassistancepackage.com to find out how you can benefit.

Holiday Inn

Free and Discounted Rooms

No need to register in order to take advantage of this offer.

All you need to do is ring the Holiday Inn central booking line on **0845 124 9973** and say you want to book a room for a disabled person and an interconnecting room for their carer/support worker.

Furthermore, if the person has a disabled person railcard you can also get up to 35% off the cost of their room.



Free Epilepsy Alarms

Muir Maxwell Trust Edinburgh

When you are looking after a child with severe epilepsy, families can be consumed with the anticipation of a seizure. Many parents check on their children throughout the night and the loss of sleep and the stress for the whole family is immense.

Parents can apply directly to the Muir Maxwell Trust for an epilepsy alarm, or go through their health visitor, community nurse, epilepsy nurse, GP or consultant. They will receive a voucher from the Trust, which requires to be countersigned by a medical professional who can confirm the diagnosis of epilepsy. The voucher is then sent directly to the manufacturer and the alarm will be delivered in approximately two weeks.



To request your epilepsy alarm voucher, please email Family Liaison Manager Ann-Marie Nelson at info@muirmaxwelltrust.com with the following information:

1. Your child's name and date of birth
2. Your name, full postal address and contact telephone number
3. A short description of how your child's seizures manifest themselves

Call the Trust Office on 0131 273 5256 Alternatively contact TSC Adviser, Lynn Shields on 07510 595968

The Trust does not means test for movement alarms, but donations are gratefully received.

Free telephone counselling service for disabled people



'Your Call' is a free telephone counselling service which is open to disabled people from all over Scotland. The 'Your Call' counsellors are all disabled people themselves, providing them with an understanding of what it means to live as a disabled person in Scotland. The counsellors work as volunteers and are trained to a professional standard in counselling. The service will now take calls from Monday-Thursday 11am-3pm. Evening sessions will also be available from December.

The 'Your Call' number is **08088 01 03 62** and the service is open to all disabled people in Scotland over the age of 16 and their immediate family members.

Epilepsy Medication

The Scottish Government accepts there are certain drugs where a switch to a generic equivalent in 2010 may not be clinically appropriate for all patients.

This includes some drugs prescribed for use by those with epilepsy. It appears that people will be assessed on an individual basis. Patients who are being prescribed those drugs will continue to receive the same proprietary drug that they currently receive, where their prescriber (clinician) decides this is the right course for the patient.

The Scottish Government will be working with clinicians and patient groups like Epilepsy Scotland to ensure that these new arrangements are introduced sensitively. This will help improve the effectiveness of prescribing while safeguarding the interests of patients.

If this issue is important to you, please contact your MP and your MSPs and share your views.

Epilepsy Scotland also welcomes your feedback at enquiries@epilepsyscotland.org.uk

ALISS Project



Your help wanted in co-creating a web-based information service!

The ALISS project (Access to Local Information to Support Self Management) is about addressing the challenge of finding information to support people when they have a long term condition.

The project team want to meet and involve people with long-term conditions so they can work together to develop a community-driven electronic service.

The ALISS team would especially like to contact people with long term conditions and unpaid carers. **(Please see enclosed flyer)**

If you have any questions about ALISS, please don't hesitate to ask. In the first instance, please contact:

Jenny Dowswell on **0131 244 2774**
or email

jennifer.dowswell@scotland.gsi.gov.uk .

MWC launches national survey

The Mental Welfare Commission (MWC) is launching its first national survey of service users' and carers' views in January 2010. The survey will gather the views of people who have used services offered by the MWC so that it can review its practice.



The Scottish Development Centre for Mental Health has been asked to run the new survey to ensure that it is independent. Individual responses are confidential and are not shared with the Mental Welfare Commission.

A web version of the questionnaire will be available from 5 January 2010 on the Mental Welfare Commission website www.mwcscot.org.uk

To request more information, please contact Hannah Biggs at the Scottish Development Centre for Mental Health on 0131 555 5959 or email hannah@sdcmh.org.uk

National Managed Clinical Network (NMCH)

The NMCN for Children with Exceptional Healthcare Needs (CEN) is a new network which has been set up for Scotland. It aims to strengthen and develop specialist services for children with complex needs. The group of children and young people the network will focus on is defined by their complex health needs rather than what they have been diagnosed with. To find out more or to get involved, please visit

<http://www.cen.scot.nhs.uk>

National Autistic Society (NAS Scotland)

launches "We Exist" campaign for a Scottish Autism Bill

NAS Scotland together with over 100 organisations and key people from across Scotland, has launched a new report entitled "We Exist". The report asks the Scottish Government to implement a national strategy, backed with legislative power through a Scottish Autism Bill, to meet the needs of people living with autism.

At present England, Wales and Northern Ireland have Autism Strategies. The Scottish Government has been urged to recognise that people with autism in Scotland should not be disadvantaged in any way and support the NAS Campaign.

NAS Scotland is asking the Scottish Government for:

- A duty to identify and record the numbers of children and adults with autism
- People with autism to be able to get an appropriate assessment of their needs
- Each local area to plan for services that meet the needs of people with autism
- Appropriate training of staff to deliver high quality services
- Local areas to establish cross-agency leadership arrangements to develop joint working
- A duty to engage with and consult people who have autism

If you would like further information on this campaign please contact NAS Scotland on 0141-221-8090

Highlights of 2009

Hope this issue finds you all well. By the time this goes to print all the Christmas & New Year festivities will be long gone so from myself, Vicky Mason, a very happy- be it belated- 2010 to you all. It's usually at this time when we also look back over the previous year in Scotland in relation to TSA events in 2009. We had our first Scottish visit in a long time from the Outlook Group in April, which I really enjoyed. In June we held a very successful Autism Awareness Day with The National Autistic Society. Lastly but by no means least we had our annual Scottish Get-Together in November. We had 3 speakers at this event, Dr Claire Cotterill from GIG Scotland, Nancy Grieg from the Long Term Conditions Alliance and Tony Young from the Department Of Work & Pensions. Claire came along with Gillian Scott to speak about the work GIG (Genetic Interest Group) in Scotland does. Claire ran workshops and asked our members for suggestions as to what kind of services are needed for people in Scotland. Nancy from Long Term Conditions Alliance Scotland (LTCAS) discussed their work, and also via workshops asked our members for their comments and suggestions in relation to the Scottish Long Term Conditions Manifesto.

Copies of comments from all 3 focus groups are now available, (if you would like a copy or any further information please call Lynn Shields on 07510 595968 or email lynn.shields@tuberous-sclerosis.org. Everyone at the TSA is delighted that our members had the opportunity to participate and hopefully influence positive change in Scotland, via GIG's Rare Disease strategy, and the LTCAS Manifesto workshops.

**Many of our members also joined Rare Disease UK and I would urge you all to join
([please see enclosed Rare Disease UK leaflet](#))**

Tony Young came along and gave everyone some very useful information on disability benefits and it was interesting to know that there are benefits people are entitled to that are never claimed, because of sometimes the rigmarole and quagmire of paperwork that's involved. There is the website though for that www.dwp.gov.uk where you can find out more. Everyone again we think went away benefitting from something (excuse the pun) and feedback has been very positive. Instead of holding a raffle this year, I decided to try something different and held a tombola instead and to my amazement I raised £70.00 for TS funds, no doubt this will have helped pay for something towards the cost of the event. We also raised £8.20 for the sale of TS goods which were also on sale which is a wee extra bonus. Hilda also sold the TSA's Christmas cards. Sincere thanks to our Speakers, Claire, Nancy and Tony and thanks also to everyone who came along and contributed and supported the event.

We look forward to seeing you at future events in Scotland during 2010.

With Best Wishes Vicky Mason (Scottish Volunteer Organiser)

Travel Insurance

The Genetic Interest Group (GIG) has been working closely with many organisations including the TSA and has produced a new Travel Insurance guide. Sincere thanks to GIG and our members, particularly our Outlook members, who contributed to this useful guide during their visit to Glasgow in April 09. We have included a copy for your information.

Join the debate

Have you ever wondered how your personal health records are stored and who has access to them? Do you want to know more about how things might change as the NHS shifts to a system of electronic records?

Now is your chance to learn what the NHS plans to do with your personal information, and to let the government know what you think. Patients, carers, health workers and members of the public are being invited to find out more and have their say through a six-month national consultation, organised by the New Economics Foundation, from September 2009 to February 2010. The project organisers are inviting the TSA to take part, by ordering a free copy of the specially design 'discussion game', playing the game at one of their meetings and sending back the results.

To find out more, visit the project website: www.whoseeswhat.org.uk. You'll find details of how to get hold of the game and more information about the issues involved, alternatively call **Annie Quick on 020-7820-6384**

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