

Tuberous Sclerosis Association

Scottish Newsletter

April 2009



Welcome

Welcome to the first edition of the new Scottish Newsletter. We at the TSA hope to keep you informed of the latest developments, news and events in Scotland throughout the year. Our aim to produce this newsletter on a regular basis, and will be in addition to our, 3 times yearly, Scan magazine.

We hope you enjoy the first edition and find it informative, and we look forward to receiving your input and comments.



Free Information Day

Saturday 20th June 09
St Stephens Church
Bath Street Glasgow
10.30am—4pm

In partnership with the TSA the National Autistic Society's (NAS) Advocacy for Education Service and *help!* programme are pleased to offer a FREE Information Day on education rights and entitlements, benefits and approaching behaviour difficulties.

The National Autistic Society Scotland is part of the UK's leading charity for people affected by autism. They were founded in 1962 by a group of parents who were passionate about ensuring a better future for their children.

Booking forms have been sent to members but if you haven't already booked a place and would like to come along please call **Diane on 0121-445-6970 or Lynn on 07510-595-968**. Carla and Barrie from NAS and Lynn look forward to welcoming you on the day.

NAS also provide the following:

- Information, advice, advocacy, training and support for individuals and their families
- Information and training for health, education and other professionals working with people with autism and their families
- Specialist residential, supported living, outreach and day services for adults
- Specialist schools and education outreach services for children
- Out-of-school services for children and young people
- Employment training and support and social programmes for adults with autism.

For more information on their services please call 0141 221 8090 or visit www.autism.org.uk. In addition, their Autism Helpline provides impartial, confidential information, advice and support for people with autism spectrum disorders, their families, professionals, researchers and students.

Telephone 0845 070 4004 or email autismhelpline@nas.org.uk

Half a Million Scots Carers Seek Greater Help

National Care Organisations launched a campaign on January 22nd to raise awareness of the work done by unpaid carers in Scotland. They are seeking to persuade local authorities and NHS Boards to engage productively with carer organisations to improve support for carers. This follows the shift in responsibility for funding carer services from the Scottish Government to local authorities and NHS Boards under the 2007 Concordat. The campaign will be rolled out around The Country.

They need carers throughout the country to become actively involved in the campaign through letter writing to local councilors, MP's and MSP's.

A template letter is available for anyone who wishes to support the campaign. Contact Lynn on 07510-595-968

Outlook Weekend

Glasgow

24th-26th April 09

The Outlook Group are meeting in Glasgow this year and many of our members have already booked. The Event is being held in the Ramada Hotel Ingram St Glasgow and not the Central as previously advertised. If you haven't already booked and would like some further information on this action packed and fun weekend please contact Diane on 0121-445-6970

Insurance

Ben Francis, from the GIG Team in London,



is working with people affected by genetic conditions to improve insurance services.

From the extensive feedback they have been receiving from members, GIG made the decision to undertake a research initiative assessing the experiences of people affected by pre-existing medical conditions and insurance. This project builds upon earlier investigations that resulted in the creation of a series of underwriting templates designed to ensure that Life Assurance companies are presented with all of the *relevant* information at point of application, thus making it faster, easier and more transparent for all. The templates have proved to be successful in initial trials and they are now expanding their work to look at the possibility of using them within different insurance products like travel insurance or mortgage protection insurance. They would really like to get better understanding of the real problems and inconveniences people face when trying to source insurance cover. They will then be able to work with industry representatives to effect change within application practices. Ben has also arranged to travel to Glasgow in April to talk with the TSA Outlook Group.

GIG have an online questionnaire and a web-link <http://tinyurl.com/genetics-insurance>

For further information please contact: **Benjamin Francis**

Project Officer – Insurance Templates

Genetic Interest Group Telephone 0207 7043141 or 07929035590 (mobile)

In addition the TSA have an insurance fact sheet available to download from the web site alternatively call Lynn on 07510-595-968

Patients Help

The General Medical Council have a new website to let patients and carers know who to contact when they have a concern about a doctor. The website has online complaint forms and details of the local support available in Scotland.

Visit: http://www.gmcuk.org/complaints/flash/index_en.html

Education Law Unit



The Education Law Unit is Scotland's expert legal resource in the field of School Education, with a particular focus on the rights of disabled pupils and pupils with additional support needs. The Education Law Unit works in partnership with schools, education authorities, parents' groups and charities to make pupils' rights in education a reality.

If you have an enquiry about education in law in Scotland, you can contact the Law Unit with your questions by e-mail on advice@edlaw.org.uk, by telephone or minicom on 0141-445-1955.

The Education Law Unit is funded by the Scottish Executive and BBC Children in Need www.edlaw.org.uk

Travel Options

46 Trongate Glasgow G1 5ES

Travel Options is a travel agency based in Glasgow which offers a full range of holiday opportunities plus optional specialised support for disabled travellers. They offer flights, accommodation, package holidays, car hire, ferries, ski and snowboarding, business travel, UK breaks, travel insurance, cruises, long haul, attraction tickets, low cost airlines and touring holidays



As a social enterprise they also provide training for people with disabilities, and service the travel needs of the voluntary and statutory sectors. They are part of an inter-church organisation and registered charity founded in 1989 and committed to promoting the ability of people for full cultural, social and economic inclusion with their community.

Email—info@travel-optionsltd.co.uk

Tel 0141-559-5500

Carers in Crisis



Copies of Carers UK's new research into the extreme hardship amongst the nations carers is available from their website www.carersuk.org

The main recommendations of the report are that the government must review and overhaul Carer's Allowance and other benefits for carers. Also to ensure that the National Carers Strategy promise becomes a reality, that no carer falls into financial hardship because of their caring role.

Copies of the Government's new Carers Strategy are available to download from www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Carers/NewDealforCarers/index.htm

Alternatively call Lynn on 07510-595-968 and arrange for a copy to be sent to you.

Government lead on respite



The Scottish Government, jointly with COSLA, the umbrella organisation for local authorities, has published new **Guidance on Short Breaks (Respite) service development.**

Its main purpose is to improve respite provision through better planning, a shift to preventative support, and by personalising support to improve outcomes for carers and those with care needs.

The new guidance supports the government's commitment 'to progress towards delivering 10,000 extra respite weeks per year' for which Ministers made available an additional £4 million from April 2009.

The government is also working towards a manifesto commitment that 'by 2011 carers in the greatest need will have a guaranteed annual entitlement to breaks from caring.'

For a copy of the full guidance visit

www.scotland.gov.uk/News/Releases/2008/07/17111930

Alternatively call Lynn who will be happy to arrange for a copy to be sent to you.

Bookcase



The Care Commission produces a range of publications available free of charge, to explain the role of the organisation and its work to improve the quality of care throughout Scotland.



These publications provide useful information for people who currently use, or are preparing to use, care services as well as their families, relatives and carers. The publications include information about the National Care Standards, the level of care people should expect to receive and what to do if they need to make a complaint.



If this is the first time you have seen information /details about *Care News* and you would be interested in receiving a copy in the future, please contact the Care Commission Communications Team on 01382 207100 and give them your contact details.

In December 08 our Scottish TSA Adviser attended the launch of Genetic Interest Group (GIG) and Gengage in Edinburgh and participated in the Consultation Event on the creation of a Scottish Patients Rights Bill.

GIG is a network of 140 patient groups and medical charities that support children, families and individuals affected by genetic conditions. One of their roles is to inform the Scottish Government about what patients and families really need from the NHS.

We at the TSA and GIG would like to support people to get involved in the development of their NHS. The Scottish Government's "Patient Focus, Public Involvement" policy states that patients should have a say in how health services are regulated, designed, and delivered.

Thanks to everyone who have already contributed and submitted their views. For further information and a copy of the detailed report please contact Claire Cotterill on 0131-651-4805.

Detailed information can also be viewed at www.gig.org.uk

Training

In addition to the training we have already provided and hope to provide in the future there are many organisations from the Borders to the Islands who provide courses in First Aid, Moving and Handling, Direct Payments Workshops, and Stress Management. If you would like any further information on the courses available in your area please contact Lynn on 07510-595-968

Turn2us

Is a new charity providing an online service to help people access information on all Benefits and Grants available to them from both statutory and voluntary organizations in the UK. In many cases, applications for support can be made directly from the website and people can be kept informed by email or by text to their mobile phone.

You can access the service at

www.turn2us.org.uk

For further information on grants please contact Lynn on 07510 595-968



Accessible Holiday Accommodation

This holiday apartment is in a beautiful and peaceful area in the Sidlaw Hills, near Pitroddie. The proximity of both Perth and Dundee, mean there are plenty of activities at hand, such as swimming, disabled horse riding and duet bikes. The flat sleeps up to four and includes a hoist. Tel: 01738 860748

OSBIS

Online Short Break Information Service (shortened to OSBIS) is a new service which provides easy access to information on all forms of short break and respite care services including:

- home based and residential breaks,
- family placements,
- befriending projects,
- supported holiday breaks,
- guest houses and hotels.

This directory of information is nation-wide and can be accessed at: www.carebreaksscotland.org

Speech Therapy

Cerebra - is a charity set up to help improve the lives of children with brain related conditions. Cerebra is offering vouchers up to £500 to use on speech therapy for children. The requirements are that the child must be school age, have a Co-ordinated Support Plan and the child should not have received one-to-one speech therapy in the last 6 months. If you have any questions please call Alex on 0800 328 1159 or e-mail alex@cerebra.org.uk. Cerebra, also offers grants to buy equipment or resources. www.cerebra.org.uk.