

Tuberous Sclerosis Association



Scottish Newsletter

July 2009

www.tuberous-sclerosis.org

Welcome

Welcome to the 2nd edition of the Scottish Newsletter and thanks to everyone who responded via the feedback forms. We've had lots of positive comments and many useful suggestions. We hope to publish the newsletter on a quarterly basis in order to keep you informed of the latest legislative changes, developments training etc specific to Scotland. Any suggestions are very welcome, please contact Lynn on 07510-595968. In addition, our Scan magazine will continue to highlight our members personal experiences, letters, research information, Q & A section and all the additional information members throughout the UK continue to requested.



New Project

Launch of Nurse-led Single Gene Complex Needs Project (SGCN)

Recently families and professionals have worked together to better understand the challenges people face living with genetic conditions. Partly as a consequence of that effort, a new project has been funded to work in Scotland. **Initially with people who are 16 years or over, who have single gene conditions and who, as a consequence, have complex needs.** The project is called the Single Gene Complex Needs (SGCN) project. It is hoped that the SGCN project could work alongside organisations, including the TSA. They need to reach people who live with single gene conditions whose needs are not being met in the community or who perhaps are experiencing challenges with for e.g. the co-ordination of service provision.

The SGCN project plan has considered very carefully the significant changes to the way health and social care is delivered in Scotland but more importantly puts the interest and concerns of patients at the centre of all that the project does to build the capacity of local service providers.

This SGCN project marks a significant expansion of resources provided by our genetic centres in Scotland. Marie McGill, the project lead explained "the commitment to effectively manage a person's care and monitor activity and outcomes at every stage of a person's journey has been recognised by genetic services as an essential pre-requisite to maximise people's outcomes and improve the quality of service provision. The SGCN project will work in collaboration with our third sector, public and private sector partners towards this goal. Many people living with complex needs as a consequence of genetic change are faced with sizable challenges. Many people living with complex needs who want input from relevant disciplines tell us they face challenges with access to, and co-ordination of, services. Many professionals have little or no experience of working with families with complex needs as a consequence of genetic change. All require support to optimise Care Pathways and peoples outcomes.

Dr Mary Porteous has also acknowledged that "it is vitally important that advances in genetic technology are matched with improvements in the holistic care of individuals affected by complex genetic disease".

Working in collaboration with families and professionals they aim to improve families' quality of life. This might mean (and with the help of families) making it easier for services in the local community to understand needs better, help assess and plan individuals care and inform decision makers about the challenges families living with TSC/ single gene conditions face.

A referral form is available for any member (over 16) and for further information please contact TSC Adviser Lynn Shields on 07510-595-968 or Marie McGill Nurse Consultant and National Lead on 0131 537 1062.

Scottish Get-Together



This year, as a result of Halloween being on the last Saturday in October, we have postponed our Annual Get Together until **Saturday 7th November**. We are delighted that the event will be held in the new Long Term Conditions Alliance Hub, 349 Bath Street Glasgow (www.ltcas.org.uk). Our confirmed speakers to date are Tony Young from the Department of Work and Pensions, who will provide us all with lots of useful information on Disability Benefits and Dr Clare Cotterill, GIG, who will be providing us with an update on how our members/patients are assisting shaping our Scottish NHS. Full details and booking forms will be sent to members in due course.



Carer Pathway



Enclosed with this edition of the TSA Scottish Newsletter is a draft document aimed at helping those who care for people with TSC. The document has been prepared by The Princess Royal Trust for Carers, the UK's largest provider of support services for unpaid carers and young carers. Called the carer pathway, the document outlines the stages for a carer when the person they look after is first diagnosed with TSC. The carer pathway runs through what should happen step by step – from diagnosis of TSC to identification of the carer, and through to setting out what needs to be done if the carers themselves become ill.

Hopefully, the carer pathway will help carers find out about their entitlements (such as a carer's assessment) and where they can go to get further help and advice, in addition to the TSA and the TSC Advisers. This might include, for example, The Princess Royal Trust for Carers' network of independently managed carers' centres which provide support such as one-to-one advice, guidance about benefits, group meetings, alternative therapies and a chance to meet those in the same boat. Unpaid carers play a huge role in the lives of people with TSC. The carer pathway aims to ensure that their role is recognised and supported by the necessary agencies and that carers have a say in the services they receive.

The document is still in draft form and the TSA, its author, Ann Allcoat (who is the Trust's Development Manager for carers' centres in Scotland) are keen to know what carers of those with TSC think of it. It's hoped that it will reflect an "average" experience of caring but your comments can help us to make sure that it is as representative as possible.

If you would like to comment on the draft document, please contact either Lynn Shields, TSC Adviser on 0751 0595968 or email lynn.shields@tuberous.sclerosis.org or write to Lynn Shields, TSA Scotland, PO Box 8728, Airdrie ML6 8LP, or Ann Allcoat, 0141 285 7933, email aalcoat@carers.org, The Princess Royal Trust for Carers, Charles Oakley House, 125 West Regent Street, Glasgow G2 2SD. For further information on the work of The Princess Royal Trust for Carers, please see www.carers.org

Family Fund

From April this year the Family Fund can now award grants to severely disabled young people aged 17 or under in Scotland www.familyfund.org.uk
The Family Fund has also launched a free to join website Family Fund extra, which gives families of disabled children and young people online discounts from leading high street names such as Comet, Argos, Haven Holidays and Stone Computers
www.familyfundextra.org.uk

Message from the Ambulance Service



We all carry our mobile phones with names and numbers stored in its memory. However, if we were to be involved in an accident, or were taken ill, the people attending us would have our mobile phone but wouldn't know who to call in an emergency. For this reason the ICE (In Case of Emergency) Campaign is trying to encourage the widespread practice of storing the number of the person who should be contacted in an emergency under the name of ICE (also ICE2, ICE3 etc if appropriate) In an emergency situation, Emergency Service personnel and hospital staff would be able to contact the right person quickly



The SDGP offers golfing opportunities and training for anyone in Scotland with learning difficulties, sensory loss, amputees, and anyone with other, lesser known conditions, serious health issues or disabilities. They organise regular competitions and training with PGA Professionals, as well as fun golf events for members wishing to play 9 or 18 hole golf games.

Membership to the SDGP costs only £15 per year and on production of three score cards, played on a good standard golf course; we are able to calculate a golf handicap for any new members.

More Information about the SDGP is available by calling 07950 003 885 / www.sdgp.co.uk

Free Flu jab for Carers

Carers who care for a family member or friend who cannot manage on their own due to frailty, disability or illness are entitled to a free flu inoculation this winter.



Last year the Scottish Government extended free flu immunisation to include those who are the main carers for an elderly or disabled person, whose welfare may be at risk if the carer falls ill. The final decision on who is offered the flu jab rests with the patient's doctor who is familiar with the medical background and social circumstances. So if you are a carer please make sure that you ask your GP about the flu jab and remain a healthy carer.

Self Assessment Website

A pathway to help you do it your way

www.digg.org.uk

The purpose of this guide is to help disabled people live to their full potential: to live as normal a life as possible. In order to do so it is necessary to know what is available. For example: support; opportunities for leisure, recreation and learning; employment; benefits.



The guide is intended to be an information pathway, taking you in steps through the processes involved in getting the support you need so that you may be able to achieve your aims and aspirations. If you proceed along this pathway for the first time fairly quickly you will get a good general idea of what you should be thinking about. However, you should then repeat the process more slowly, pausing from time to time to explore some of the links to other websites. These links provide much more detail about various aspects of the processes involved in achieving your aims. What you want to do will change over time. As you begin to achieve your goals, your aims and aspirations will change and hopefully become more ambitious. The guide is written with this in mind.

Disabled Parking

Passed by Parliament



Drivers who abuse disabled parking bays will soon be fined £30 under a new law passed by MSP's this year.

The Disabled Persons' Parking Places (Scotland) Act 2009 was introduced by Jackie Baillie, MSP, and was passed unanimously by Holyrood.

Not only will it mean that disabled parking bays will be legally enforceable but local authorities will also be required to contact the owners and operators of private car parks, such as supermarkets and shopping centres, to come to an agreement to make disabled parking places in their car parks enforceable.

GIG

Virtual



Panel

The Genetic Interest Group (GIG) would like more members for their Virtual Panel in Scotland. I'm Claire, and I run the Panel, and am really keen to attract more representatives from the TS community.

The Scottish Government commissioned the panel in 2008 to get patients' experience on using the health service. Panel members have already influenced health policy in Scotland, including the addition of a new genetic test on to the Newborn Screening programme.

The virtual panel is an opt-in email group that gives you the opportunity to feed back your views, join committees and attend high-profile events, please see enclosed information leaflet. Your commitment can be as little as 5 minutes every few months, or more if a particular issue takes your interest.

TSC Adviser Lynn Shields says: "If more TS patients join this Panel, we'll have a much louder voice in the NHS in Scotland and at Holyrood.

If you would like to discuss any details about becoming involvement in the Virtual Panel please give me a call on 0131 651 4805

I look forward to welcoming you on board.

Claire

Hi Everyone,



Hope this edition of the TS Scottish newsletter finds you all well. The time will soon be upon us again when we hold our annual Get-Together and I would ask for your help with donations of any unwanted gifts, etc for the raffle which takes place during then. This has become a bit of a tradition that I hold a small raffle to raise some funds for the TSA.

Many of you have already been very generous with donating items that can be used in the raffle for prizes thus making it possible, and for that we are very grateful. So, if you do have any unwanted items gift-sets etc, which you think we could use, please bring them along with you when you are coming to the meeting, if you would like to talk with me beforehand please feel free to give me a ring on 0141 569 2067.

Thank you for your continued support.

Best Wishes

Vicky Mason (TS Volunteer Organiser)

Library

The PAMIS Library is a partner of the Scottish Consortium of Learning Disability (SCLD). The other organisations that make up the SCLD Library are Capability Scotland, Down's Syndrome Scotland and Enable.

The library contains a wide range of books, multi-sensory stories, videos, journals, cds, research material and reports which cover a variety of subjects that are relevant to families, carers and professionals caring for people with profound and multiple learning disabilities.



The main subject areas are: Law & Policy, Services & Welfare, Training, Therapies, Sensory Impairment, Health, Communication, Education and Research.

The library is open to parents, carers, service users, students and organisations in Scotland that have an interest in children or adults with profound and multiple learning disabilities. Up to 4 items can be borrowed at a time for up to 4 weeks. Multi-Sensory stories can be borrowed for 6 weeks. A catalogue of the library is online www.sclld.org.uk. Alternatively contact TSC adviser Lynn Shields on 07510 595 968 or email j.t.taylor@dundee.ac.uk
Tel 01382 384953

Intensive Interaction

An Intensive Interaction Network has recently started in Scotland. Intensive Interaction is a way of working with people with PLMD that gives both teacher and young person the freedom to be themselves, explore the means by which we can relate to each other and discover pathways of communication, the cornerstone of all learning. The organisers are looking to expand the network to include more parents.

Anyone interested, please contact:

Helen Beltran, beltran@renver-pct.scot.nhs.uk or

Fiona Tanner fionatanner@nhs.net

A New Network for Wheelchair

Users and Carers

Scottish Wheelchair Users' Voice (SWUV) is a new network bringing together representatives of organisations for children and adults who use wheelchairs and their families. It aims to: provide an independent national voice for wheelchair users, develop a strong working relationship with service providers enhance the public and political profile of the needs of wheelchair users, ensure that policy makers and providers take account of the role and needs of carers in supporting users to achieve full lives, work to ensure that the needs of wheelchair users are responded to.

SWUV will monitor the changes in wheelchair and seating services as the Action Plan is implemented and work to ensure that users and carers are regularly consulted. It will provide an information network for people who use wheelchairs, their families and staff. The SWUV committee includes representatives of: Quarriers; Capability Scotland; Spinal Injuries Scotland; the British Polio Fellowship; Glasgow Centre for Inclusive Living; Scottish Consortium for Learning Disability; Accessible Transport Forum; Learning Disability Alliance Scotland and PAMIS. Membership is free and open to all people who use wheelchairs, their carers and professional staff with an interest in wheelchair and seating issues. You are very welcome to join SWUV as either an individual or a representative of an organization.

Further information and membership forms from:

Jessie Roberts, Senior Co-ordinator PAMIS on 01382 385154

This newsletter attempts to report items of interest. We do not knowingly reproduce inaccurate or libellous material. We do not promote or recommend any treatments, therapy or institutions or professional systems. Individuals and organisations referred to by us do not necessarily endorse this reference.