

Tuberous Sclerosis Association

Scottish Newsletter

July 2011

www.tuberous-sclerosis.org



TSC Clinic

Glasgow

The next TSC Clinic in the west of Scotland will be on Monday 29th August at Yorkhill Hospital Glasgow.

The Clinic is coordinated by Dr Shelagh Joss, with input from Dr Ihab Shaheen, Consultant Paediatric Nephrologist, and Dr Judith McKie, Psychiatrist.



If you feel attending the Clinic would be helpful please ask your GP or other medical professional to refer you, alternatively, and for further information, please contact TSC Adviser **Lynn Shields on 01236 608257 or email lynn.shields@tuberous-sclerosis.org**

Scottish Get Together

Saturday 27th August 2011

Just to remind everyone that the next Scottish Get Together is planned for Saturday 27th August at the Long Term Condition Alliance Hub (LTCAS), Bath Street Glasgow 10.30am—4.00pm.

Our apologies to all as there was an unavoidable delay with sending out the Programme and Booking Forms.

The LTCAS Hub is fully accessible and entrance on the day is via the stairs to the left of the building, alternatively there is a lift beside the main entrance.

Our confirmed speakers for this event are:

- Staff from the Scottish Health Research Register www.sspc.ac.uk
- Mig Coupe from Mindroom www.mindroom.org
- Universal Comedy www.universalcomedy.co.uk

Some places are still available so please do contact us if you would like to come along:

Chris Johnson, Membership & Support Services Coordinator, PO Box 8001, Derby DE1 0YA email:

chris.johnson@tuberous-sclerosis.org - Tel: **01332 - 290734**

Autism Friendly Screenings



Dimensions and ODEON have teamed up to host an autism friendly screening of 'Mr. Popper's Penguins' in cinemas across the country at 11 a.m. on Thursday the 11th August. Screenings in Scotland include:

Edinburgh, Dundee, Glasgow, Kilmarnock.

Screenings are termed autism friendly because the lights will be on low; the volume will be turned down; you'll be able to take your own food and drinks; you'll be able to move around the cinema if you like.

Tickets can be bought as normal from the cinema in your area or online through the ODEON website www.odeon.co.uk – support workers/carers can attend for free with a CEA card.

To find out more about this and how to get a card please go to www.ceacard.co.uk

If enough people attend on the 11th August ODEON hope to continue to provide this service each month.

Scottish Get Together

Hi Everyone,

Hope this edition of the 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 I organise during the event. 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/tombola for prizes thus making it possible, and for that we are very grateful. So, if you do have any un-wanted 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

Q4S

Q4S is a new free-to-use web resource which has been completed as part of an EU Leonardo da Vinci part funded project. The fully accessible resource provides practical advice and guidance to help disabled learners enhance their understanding about the reasonable adjustments that can be made to accommodate their disability in the learning context; advice about what they might expect of their teachers in terms of adjustments to practice; a skills 'self check'; advice about disclosure and confidentiality; links to a range of multi format case studies; and links to additional online resources.

Users can browse the resource by disability and/or skill, and information on autism spectrum disorders (ASD) is included. For further information please see <http://www.q4s.eu/GB/>

Autism (Scotland) Bill

Helps to build consensus among political parties at Holyrood.



As a direct result of the National Autistic Societies (NAS) campaigning, the Autism (Scotland) Bill gained enough support to reach Stage 1 of the Parliamentary process. Although the Bill didn't pass its Stage 1 vote, it has had a significant impact on national policy. When the Bill was first brought to the Scottish Parliament, there was no Government strategy to tackle the needs of people with autism in Scotland.

Thanks to the Bill, there is now a renewed government commitment. Ministers have finally accepted that a national autism strategy is urgently needed and must be implemented. They have also guaranteed that the strategy will be monitored and scrutinised for successful outcomes. The Autism (Scotland) Bill was proposed by Hugh O'Donnell, MSP for Central Scotland, and aimed to place a legal obligation on the Scottish Government to produce a strategy for autism services throughout the country. As a result of the Stage 1 debate, a cross-party consensus emerged that the autism strategy would need to be resourced. Ministers have now announced a £10 million allocation for autism support in Scotland, to be rolled out over three years.

Shona Robertson MSP, Minister for Health and Sport, said: *"A great deal has been achieved in Scotland, but we agree that the time is right for a national strategy for autism, and I acknowledge Hugh O'Donnell's role in bringing that about."*

At present, of the 50,000 Scottish people with autism, only 7,500 are known to local authorities. The hidden cost of not meeting the needs of people with autism in Scotland currently amounts to £2.3 billion each year, according to the National Audit Office. The NAS are urging the Scottish Government to actively engage with people who have direct experience of autism, so it can better understand their support needs and ensure the new autism strategy is as effective as possible and will continue to work with our supporters to ensure a better future for people with autism.

For further information please see www.scotland.gov.uk

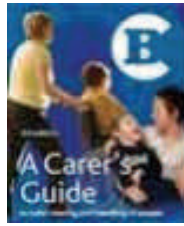
Guide For Employers

Skills Development Scotland – Scotland's skills body and NAS Scotland – have teamed up to produce a handbook that provides information on supporting people with autism into employment and realising their potential once they are in a role.

It also gives them advice on how to recognise when an employee may have autism. It can be downloaded from www.autism.org.uk

A Carer's Guide:

Safer Moving and Handling of People



The Carer's Guide 3rd edition, has been extensively revised by Fife Moving & Handling for Family Carers Project Group, consisting of representatives from PAMIS, Fife Princess Royal Trust Carers Centre, Fife Council and NHS Fife in consultation with nine family carers and Backcare.

The contents include basic information on core stability and posture, and national guidance on safer moving and handling. Also included is a room by room guide providing tips on adaptations to environment and useful equipment.

This guide is **Free to carers** (£6 for professionals) and is available from Backcare. To order a copy please see www.backcare.org.uk or call **020 8977 5474**

Enable Scotland

& Online Petition

We believe that compulsory training on learning disability and autistic spectrum disorders for all teachers and support staff is essential. And yet, most training is offered only as an option.

This must change. An online petition has been started by ENABLE Scotland to help make it happen - and we're right behind it.

Please sign-up today and help ensure that children and young people with learning disabilities and ASD are given the right support in schools, so that they can achieve their full potential.

Sign up to the online petition: www.enable.co.uk or for further information please contact Linda Noble, ENABLE Scotland **0131 663 9427**
Linda.noble@enable.org.uk

Holiday Resource List



Just to remind everyone Enable have produced a Holiday resource list packed full of useful information on a wide variety of holidays, including: holidays with support, holidays in Scotland, Northern Ireland, Wales and England. There is also information on holiday resources abroad.

To download a copy please visit <http://www.enable.org.uk/publications.php> or call **0141 226 4541**

Self-directed Support:

National Strategy for Scotland



The Scottish Government has launched its 10 year Self-directed Support Strategy. It aims to have as many people possible taking control of how they receive social support care. Self-directed Support, which encompasses direct payments, provides individual budgets for people to buy or arrange their own support packages. Currently, 3,500 people already use Self-directed support - this number will hopefully increase with the strategy set out by the Scottish Government and COSLA. Self-directed Support should be available to everyone, but not imposed.

Download the full report and read more on at:

www.selfdirectedsupportscotland.org.uk or call **Lynn Shields on 01236 608257**

Disability Grants



Charities and Trusts provide funding towards the high cost of disability equipment, holidays, housing, wheelchairs, days out, in fact anything above and beyond the normal cost of everyday living.

Searching for extra funds takes time in between work, caring, hospital appointments..... www.disability-grants.org could save you lots of time finding Disability Grants which could potentially assist with the resources and equipment you need.

As always, if you don't have access to the internet or would like some assistance or further information please call **Lynn Shields** on **01236 608257**

Speyside Trust Badaguish

Badaguish is a place where you can explore and develop new and exciting skills in safety, amidst the superb forest and mountain scenery of the Caringorms National Park in the Scottish Highlands. It is committed to Access for All and to programmes and facilities which offer equal opportunities in an integrated setting.

Accommodation is available in many combinations to suit, and a wide range of outdoor activities are available led by qualified instructors. For further information please see www.badaguish.org or call **01479 861285**

A new regulator for Scotland:

Social Care and Social Work Improvement Scotland

From 1 April 2011 a new public body will begin operating in Scotland: Social Care and Social Work Improvement Scotland. This body has been created by the Public Service Reform (Scotland) Act 2010. Social Care and Social Work Improvement Scotland, or SCSWIS for short, will be an independent organisation with its own Board responsible for its governance. It will be funded by the registration and continuation fees it charges and by Scottish Government. It will operate independently to scrutinise and improve care, social work and child protection. For further information please see www.scswis.com or call **0845 600 9527**

Changes affecting Housing Benefit for those receiving care

From 1 April 2011 anyone who receives care and is a private tenant may be entitled to additional Housing Benefit to help pay their rent if the following applies: overnight care is provided to the Housing Benefit claimant or their partner by a carer who does not live with them, and they have a spare bedroom which is used by the carer for overnight stays. If you know of someone or care for someone who meets the above criteria, they or their representative should visit www.dwp.gov.uk or call the Benefit Enquiry line **0800 88 22 00**.

PAMIS

(Promoting a More Inclusive Society)



PAMIS library stocks a range of books and publications that can be borrowed. The library contains over 1,500 resources on a variety of subjects that are relevant to families, carers, professionals caring for people with profound and multiple learning disabilities. These include books, multi-sensory stories, videos, journals, DVDs, research material and reports. Anyone living in Scotland can borrow from the **PAMIS library**, you just need to fill in a membership form.

PAMIS will post the resources out to you free of charge but you will need to pay for the postage of the resources back to PAMIS. For further information please call **01382 385 153** or email j.t.taylor@dundee.ac.uk