

Tuberous Sclerosis Association

Scottish Newsletter

September 2010

www.tuberous-sclerosis.org



Scottish Get Together

Saturday 6th November 2010

Just a reminder to everyone that this year's Scottish Get Together is on Saturday 6th November. The event will be held again at the Long Term Conditions Alliance Hub, Bath Street, Glasgow.

Our Speaker's for the day will be; Elizabeth McBride, Project Officer (Transition) from PAMIS and Judith Paterson, Welfare Rights Co-ordinator, from Child Poverty Action Group. Hopefully everyone should have received the programme and booking form in September, if you haven't just let us know or would like some further information please contact Lynn on **07510 595 968** or email lynn.shields@tuberous.sclerosis.org and we'll be delighted to book your place.

Vicky Mason, our Scottish Volunteer Organiser, is kindly organising our tombola again this year, so if you have anything you would like to donate please bring it along on the day.

We look forward to welcoming you all on the 6th.

Appeal to Scottish Members

Clinic Trial Exist-2

We have been contact by a Clinical Research Organisation managing the EXIST-2 trial on behalf of it's sponsors.

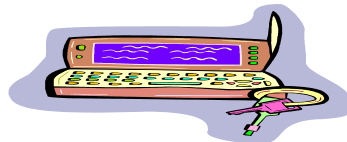
The Exist 2 clinic trial investigates whether a drug can shrink or slow the growth of kidney lesions in patients with Tuberous Sclerosis Complex or LAM.

This trial is still actively recruiting. To date 44 patients are enrolled on the trial, and a further 55 are needed by the end of November. UK sites so far are in Brighton, London, Cardiff, Nottingham and Northern Ireland.

The company are willing to pay all reasonable travel expenses.

So if you're over 18 years old, have an AML at least 3cm in longest diameter and want to find out more, please ring Jane Cox (TSA Deputy Head of Research) on **01273 696 955 extension 3541 or drop her an email jane.cox@bsuh.nhs.uk**

Tea Room - Scottish Epilepsy Initiative



The Teenage Epilepsy Agenda (TEA) Room is an innovative online forum for young people to interact with their peers, gain support and share their experiences of epilepsy in a safe and supportive environment.

They can provide IT equipment for young people age 13-19 who are undergoing diagnosis or who have been diagnosed to allow them to access the TEA Room. To apply to this fund download the application form and the "Information for Parents" document from the website www.scotishepilepsy.org under appeals at The TEA room or **Tel 0141 248 0072** for more information. To join the forum sign up at www.thetearoom.org.uk

Family Fund

The Family Fund has recently introduced a further change to its income eligibility criteria. From 16th August 2010, any family caring for a severely disabled child where household income is less than £28,000 will be eligible to apply for a grant. The income limit of £28,000 has now been set as the same for the whole UK. The limit has increased in Scotland so many more families will be eligible.

For further information visit the Family Fund website at www.familyfund.org.uk or call **0845 130 4542**

Paving the Way to Self Management



Genetic Alliance UK
Supporting. Campaigning. Uniting.

Douglas Caldwell has recently joined the Genetic Alliance UK to work on the "Paving the Way to Self Management" project.

The goal of the project is to create a series of 10 Vodcasts (online videos), that will be freely available on the Genetic Alliance UK website, featuring people with rare conditions from across Scotland describing how they have become knowledgeable at self-managing their condition.

It's hoped that these videos will become a valuable training resource for health professionals as well as helping to inspire people to become more pro-active in managing their own conditions and even give people a few ideas about where to get started.

The aim is to show the range of people that are involved in the management of a rare condition including family and carers as well as providing insight into the issues people encounter, and how they have endeavoured to overcome them. The videos will also show that people with rare conditions often become skilled in dealing with their condition and can be more knowledgeable about the condition than the healthcare professionals that they come into contact with.

Douglas is hoping to be able to add Tuberous Sclerosis Complex to the 10 featured conditions and is eager to hear from anyone, who either has the condition or cares for someone who does, feels they have a good grip on its management and would like to become involved. The project covers the whole of Scotland so you can get involved even if you live in the middle of nowhere!

Douglas can be reached on Tel [07854 197 091](tel:07854197091) or email douglas@geneticalliance.org.uk and he would also love to hear your thoughts on the project itself. Do you think a series of videos like this will be useful to people?

Please remember to look out for the videos next year on the Genetic Alliance UK website.

Curriculum for Excellence



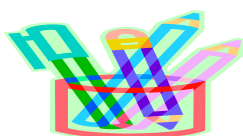
Learning and Teaching Scotland is the principal curriculum body for Scotland, supporting the delivery of Curriculum for Excellence, Assessment, Community and Lifelong learning.

Scotland's new curriculum is now being rolled out into Scotland's secondary schools.

Learning and Teaching Scotland (LTS) has created this handy website guide.

Visit Learning and Teaching Scotland website
www.ltscotland.org.uk

Support for Learning



Amendments to the Additional Support for Learning Act 2004 come into force in November. The legislation is about making sure all children receive the additional support they need.

Local authorities have duties and responsibilities under the act and must provide support for any child with additional support needs. They must also identify additional support needs, monitor the needs and support provided, and respond to requests for assessment from parents.

They must prepare a Co-ordinated Support Plan for children with the most extensive needs. The plan aims to co-ordinate provision between the local authority and other agencies. Children's views will be noted in the plan. When establishing additional support needs and developing a plan, local authorities must seek and listen to views, advice and information from other relevant agencies.

For more information visit www.scotland.gov.uk/Topics/Education/Schools/welfare/ASL or contact Lynn on Tel [07510 595 968](tel:07510595968)

New Carers Strategy

2010-2015

The long awaited new Carers Strategy has been published by the Scottish Government which will guide the priority areas for carers in Scotland for the next five years. The Strategy re-affirms that carers are equal partners in the planning and delivery of care and that without the valuable contribution of Scotland's carers, the health and social care system would not be sustained. The key actions of the strategy will be:

- the development of a Carers Rights Charter
- to improve the provision of information and advice to carers through workforce training and support from the one stop shop NHS Inform
- to produce information to carers on issues relating to stress and caring and to ensure carers aged between 40 and 64 have access to health checks
- to invest £281,000 in carer and workforce training in 2010-2011, focused on carers in the greatest need (subject to the outcome of the next Spending Review)
- to invest a further £1m to provide more innovative short breaks to be delivered by the voluntary sector

The Young Carers strategy, **Getting it Right for Young Carers** has been published as a separate strategy but with clear links across to the adult version.

The strategy emphasises that young carers deserve to be children and young people first and foremost, and lays out how services should respond to help achieve this.

For more information about the Carers Strategy, contact Lynn on 07510 595 968 or email lynn.shields@tuberous-sclerosis.org

New Health Information Service

A new online and telephone NHS information service for Scotland has recently been launched. The new service called NHS Inform will provide patient and carers with a one stop shop of quality-assured health information online at www.nhsinform.co.uk or by calling **0800 22 44 88 (8am-10pm)**. The site features elements such as an updated and expanded Health A-Z directory, common health questions and links to local health and support information across Scotland.

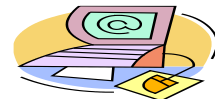
There are plans that the site will also include dedicated zones for:

- Mental health and well being
- Living a healthy lifestyle
- Carers information



If you have any questions about NHS inform, contact the team at nhs.inform@nhs24.scot.nhs.uk or call them on **0800 22 44 88**

Respite Directory Launched



Shared Care Scotland has re-launched it's online respite directory. The national directory of short break (respite) services provides information about respite services across Scotland.

To find out more, visit www.sharedcarescotland.com or call Leslie Gudgeon on **01383 622 462**.

Blue Badge Reform

A consultation on the reform of the Blue Badge Scheme in Scotland is currently underway. The consultation covers: eligibility, eligibility assessments, enforcement, badge design and security, administration, organisational badges and concessions. It will run until 8th October 2010. For details please visit: www.scotland.gov.uk/Publications/2010/07/12102032/0

Genetic Alliance UK

New Development Officer for Scotland



Genetic Alliance UK
Supporting. Campaigning. Uniting.

Genetic Alliance UK is the national charity of over 130 patient organisations, supporting all those affected by genetic conditions. Genetic Alliance UK aims to improve the lives of people affected by genetic conditions by ensuring that high quality services and information are available to all those who need them.

Natalie Frankish is the new Development Officer for Genetic Alliance UK in Scotland and will be representing the needs of families affected by genetic conditions through policy campaigns to influence MSPs, policymakers and the NHS. Genetic Alliance UK has developed a virtual patient panel in Scotland, a forum for patients and their families to raise awareness of their condition and share their views and experiences.

Natalie is very keen to hear from you if you have been affected by a rare disease or genetic condition and are interested in getting involved with the work of Genetic Alliance UK in Scotland.

Visit the Genetic Alliance UK in Scotland website at <http://www.geneticalliance.org.uk/scotland/index.html> or drop Natalie an email natalie@geneticalliance.org.uk

Alternatively call Natalie on **0131 651 4805**

Jobcentre Plus

Support for carers looking for work

A voluntary scheme called '**Work Focused Support for Carers**' is available to carers over the age of 18 who work less than 16 hours a week. It is also open to carers who are on Carers Allowance and also to those carers not receiving any benefits.

Very importantly for carers, the project will provide respite costs to allow carers to attend advice and training sessions! The responsibility for arranging the replacement care will lie with the individual and Jobcentre Plus cannot recommend any specific provider.

Support for Carers is available to carers who:

- do not work at all or who work less than 16 hours a week
- are aged 18 or over
- are not able to get help from any of the other

Jobcentre Plus employment support programmes such as **New Deal** or **Pathways to Work**.

To find out more, make an appointment (of up to an hour) at your local Job Centre Plus.

PAMIS

Changing Places Toilets

Changing Places toilets are specially designed for people with complex and multiple disabilities who require the help of one or two assistants.

PAMIS has details of 62 Changing Places toilets in Scotland. These Changing Places toilets were built before the new British Standard, BS 8300: 2009 was launched so they may not be as large as the standard recommends but they all have a height adjustable changing bench and a hoist. For further information please contact pamis@dundee.ac.uk Tel **01382 385 154**. As many of the Changing Places toilets listed are in resource centres and sports centres we would advise you to contact them to check availability and opening hours before you visit.



Many of the Changing Places toilets require a RADAR key to access them. These are available from www.radar.org.uk.

Useful Websites

www.careinfoscotland.co.uk

A website with a range of useful material about community care.

www.direct.gov.uk

The government website gives lots of information on many issues involving public services. There is lots of information on your rights in various situations including employment, education and disability.

www.scotland.gov.uk

The website of the Scottish Government, giving information on a whole range of Scottish topics including Health and Community Care.