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Sent: 31 August 2009 17:04
Subject: August eBulletin

LTCAS E-Bulletin

August 2009



LTCAS News

- **LTCAS Annual conference - change of date**

LTCAS will be holding its Annual Conference and AGM on **Tuesday 23 February 2010** (not on Wednesday 24th February) at **Perth Concert Hall**. Please put the new date in your diaries!

- **Bi-monthly Members' Networking Events**

A big thank you to Epilepsy Connections for delivering a workshop at our first members networking event, there were around 16 members in attendance and the session was well received by all members one member commented:

"fab event, took away some really useful learning for my own organisation!"

LTCAS is pleased to announce that Action for Sick Children and Care Co-ordination Network UK will be delivering our second interactive networking event:

'Family centred support and approach to enhance self management for children and young people?'

This event will take place on **Thursday 22 October** at 10.30am and will be followed by a networking lunch. To sign up for the session and network with other LTCAS members, please email event@lucas.org.uk

These events aim to showcase some of the good work of our member organisations, help members to share good practice and to network with each other. The date for the final event of 2009 is Thursday 3 December (pm) - members please put this date in your diary!

- **Training and capacity building service for members**

LTCAS will shortly be starting to work together with a consultant to look at requirements from our members/associates and other stakeholders in relation to training and capacity building, and in relation to specific support for Self Management. We are aware that a need exists, but more detailed work needs to be done to pinpoint what the priorities are, what already exists, and where the gaps are. In addition to asking about your requirements, we will also be asking you about training, information or support that you may be able to provide to others.

We will initially be sending out a questionnaire to find out about your requirements. We will also be organising a series of focus group meetings, in order to gather more detailed information. You will be hearing more from us about this soon.? In the meantime, if you have any enquiries, please contact Veronica Harper, Head of Corporate Services, email veronica.harper@lucas.org.uk

- **Self Management Fund update**

The first round of the Self Management Fund attracted a huge interest, and LTCAS will be proudly announcing the successful organisations and projects in a series of press releases, and on our own website, shortly. Our Grant Allocation panel had some hard decisions to make but we are sure the successful projects from this round will make a huge difference to people's self management in Scotland.

We are busy now supporting applications for the **next round of the fund, which closes on 29th October 2009.**

The Self Management Fund is open to voluntary organisations and community groups supporting those affected by a long term condition in Scotland. The fund is available to projects specifically focused on self management issues which will enable people to learn more about the management of their condition, and to become active partners in their own care. Further details, including an application form and guidance notes, can be downloaded from our website www.ltcas.org.uk

If you have a good idea and want to discuss it with us, please contact our Grants Officer, Jen McCole at jen.mccole@ltcas.org.uk or 0141 404 0231.

We are also holding **ideas/drafts surgeries**, an opportunity for you to discuss your ideas in one to one sessions with our Director of Self Management and Grants Officer. These sessions are planned for Glasgow and Edinburgh on the following dates

Edinburgh, 1 September
Glasgow, 22 September
Edinburgh, 7 October

To book your session please contact Jen on the details above. If you are unable to make those dates, please do let us know and we can arrange an alternative.

- **LTCAS HUB - Free trial of meeting rooms extended!**

We are extending our offer of a free one day trial of our meeting room facilities to the end of September. This offer is for **members and associates who have not used the meeting rooms yet.**

We have several meeting rooms available, from small rooms suitable for one-to-one meetings and small groups, to larger rooms suitable for up to 66 people.

Many of our members and associates are already using these facilities for events such as training days, interviews, team meetings and therapy sessions. Use of the meeting rooms includes free tea, coffee and water. We also have a laptop, data projector, DVD player and microphones available for hire. You need to book your meeting room by the end of September 2009 in order to take advantage of this offer.

Not a member yet? Join up now to take advantage of this free trial!

News from LTCAS Network

- **Lupus UK - new member of LTCAS**

Lupus UK are the only national charity for Lupus sufferers and their families and aims to raise awareness of the illness amongst the public and the medical profession, provide funding for research into the illness, its causes and its management and hopefully its eventual cure.

The Strathclyde Lupus Group is the local branch of Lupus UK and we continue its work at a local level. We have contacts in Oban, Lanarkshire, Glasgow, Renfrewshire, Ayrshire and Dumfries & Galloway.

All our contacts are themselves Lupus sufferers and are available to listen, give support and provide information to those who need it. We run informal contact meetings throughout the area where people can come together, chat and meet with fellow sufferers.

Our monthly Glasgow meeting from the **4th of September** will now be held in the LTCAS premises and we are looking forward to moving to this new venue where we will be able to meet in a relaxed setting and have the option of changing the format of some of the meeting and possibly invite speakers along, discussions or whatever the members decide. For more information contact group chair, **Karen Allan Tel: 01294 604869.**

- **Launch of Scottish Recovery Network (SRN)'s new website**

We are delighted to officially announce the re-launch the SRN website. We have worked to ensure it is now easier to access information, stories and resources found on the site.

We would welcome any initial comments or thoughts.

To view the new site visit www.scottishrecovery.net

- **World Arthritis Day 2009 is on Monday 12 October, and the theme is Let's Work Together?.** The campaign considers the challenges of work, be it paid employment, voluntary work or work at home supporting a family, and embraces people with rheumatic diseases, healthcare professionals and employers.

In preparation for World Arthritis Day, Arthritis Care would like people with arthritis to complete our work survey so that we can find out what they need from their employer so that they are able to work well without this having a negative impact on their health. Find out more, and complete our survey at <http://edit.arthritiscare.org.uk/InyourArea/Scotland/Newsandevents/WorldArthritisDay>

- **Tell the world what you're up to during Mental Health Awareness Week!**

www.samh.org.uk

It's now less than two months to Scottish Mental Health Awareness Week, 4-10 October. Remember, if you or your organisation is planning an event, we'd like to list it on the SAMH website as part of the calendar of events for the week.

Just tell us:

The name of your event:

The date and time:

Brief details of what's involved:

Whether it's open to the public:

Who to contact for more information:

Send your listings for Mental Health Awareness Week to Anne Mathie, Information Officer at anne.mathie@samh.org.uk, or call? 0141 568 7032.

- **Leonard Cheshire Disability - seeking Trustee for Scotland**

A major charity supporting disabled people, Leonard Cheshire Disability has a vital role to play in providing support services, campaigning for change and providing innovative projects that give disabled people the opportunity to have an improved quality of life.

Right now, we are embarking on a strategic transformation programme to ensure our organisation is fit for purpose and ready to meet the challenges of the future and you can have a vital input into our aims and work in Scotland.

In this voluntary role, you have the ability to act as a passionate and persuasive ambassador for our organisation and vision. Contributing significantly at Board level, you will ideally have strategic experience either at Board or Trustee/Non-Executive Director level within a major organisation.

To ensure our Board has the right balance of skills and experience, you will either be a disabled person who has played a leading role regionally/nationally in challenging the barriers to disabled people or have strong financial and commercial skills. In addition, you will have an understanding of how things operate in Scotland and especially the work of the devolved parliament.

This is a voluntary role with a time commitment of 2-3 days a month

Full details can be seen at www.harveynash.com/lcd

- **For Scotland's Disabled Children**

For Scotland's Disabled Children (FSDC) has launched a Scotland wide coalition campaigning for rights and justice for disabled children and young people. FSDC want families with a disabled child to enjoy the same quality of life as other families. Over the last ten years a range of policy and legislative frameworks have been developed to enable families with a disabled child to enjoy better lives but too many families still complain that they cannot access the appropriate services.

Over 30 organisations have already joined the coalition and more are being urged to sign up. The coalition focuses on improving services and provision to families with a disabled child around the areas of short breaks, transition support, childcare and education.

To help support their campaign and for more information please contact Donna Tomlin at donna.tomlin@cafamily.org.uk or telephone her on 0131 659 2939.

- **Survey to find out parents' views of ASN framework in Scotland**

The Additional Support Needs (ASN) framework has been in place in Scottish education since 2004 but how well is it working for Scotland's Disabled Children (fSDC) wants to know parents' views and experiences of the framework and its processes. Most importantly, we want to know if disabled children and young people are getting the support they need and if that is making a difference to their experience at school. To take part in this online survey please go to

http://www.scotinform.co.uk/Onlinesurveys/ForScotlandsDisabledChildren/for_scotland_s_disabled_children.htm

If you require a paper copy or other format of

the survey please contact Donna Tomlin at donna.tomlin@cafamily.org.uk or on 0131 659 2939. The findings will be published and also submitted to the Scottish Government to influence its review of how the framework is working in practice.

- **Harry Potter themed workshop** for children aged 7-11 with a condition affecting their appearance.

Changing Faces will be holding this workshop in Edinburgh on Saturday 3 October 2009, and there are a few places still available. The day will involve:

- Lots of fun games and activities
- Ideas for dealing with other people's questions and comments about their appearance
- Tips for making friends

A folder full of tools and activities to remind children about the day.
The workshop is free of charge.

For further details, flyers and booking forms, please contact Gareth Jenkins on 0845 4500 640 or email scotland@changingfaces.org.uk

The final **deadline for bookings is 9th September.**

- **Independent Living Scotland 2009**

9th-10 September 2009, SECC, Glasgow

Independent Living Scotland is the leading event for disabled people and healthcare professionals in Scotland & the North of England. Key organisations & associations are taking a stand at the show to raise their profile and get their message across. For more information please and to register for this free event please go to the website www.independentlivingscotland.co.uk

- **Bipolar Fellowship Scotland Conference "Be all you can be"**

19 September 2009, Perth

The Bipolar Fellowship Scotland Conference & AGM will take place on Saturday 19th September

For more information about the programme and booking details download the flyer below or [click here](#)

[Download flyer](#)

- **Voluntary Health Scotland (VHS) Survey**

VHS has been in operation for nine years now and we believe that it is now time to assess its perceived role and the value of the services which it offers.

The purpose of this survey is to gain an understanding of how VHS is perceived by its members and stakeholders in the voluntary sector and beyond, in order to judge the extent to which it is providing the kind of services and support which the third sector and other stakeholders need and to determine any future

direction which VHS might take.

The questionnaire is very simple to complete and should only take a few minutes of your time. All your answers will remain confidential and the results will enable us to enhance or change our services where required, for your benefit.

The survey will run until the 11th September can be accessed at the following link:

http://www.surveymonkey.com/s.aspx?sm=G12Km8igGaEj9IuE11dnhO_3d_3d

- **The Involvement of Disabled Parents in their Children's Education**

Children do better at school when parents are involved in their education. Across the UK, legislation and policy has been introduced to strengthen parental participation.

This seminar is being held on Thursday 1st October and is for educational professionals, policy makers and voluntary sector staff interested in parental involvement and how barriers faced by disabled parents can be removed. The seminar will enable attendees to engage with the research findings, provide an opportunity for reflection on professional and institutional practice, and enable discussion of the issues the study raises.

To book your place or require more information please e-mail richard.brunner@strath.ac.uk.

- **Twestival!**

The newly-formed **West of Scotland charity No Strings Attached** has been announced as the official charity for the September festival.

Twestival will be held at the **Living Room, St Vincent Street, Glasgow, on September 10**.

More than 8500 people voted for their favourite charity and 2868 chose No Strings Attached. It came in just ahead of CHAS, with Quarriers coming in third place.

Fiona Garrett, spokeswoman for the charity, said: "This is fantastic news. It has been a long two weeks for us watching the votes come in."

No Strings Attached is an independent charity that develops opportunities for children with asthma through music and the arts. It is working in association with the Royal Scottish Academy of Music and Drama to help develop children's confidence to participate in music and arts.

- **Disability Information Greater Glasgow (DIGG)**

DIGG provides information, help and ongoing support for disabled people and their families, particularly those with a physical disability including brain injury, visual impairment and neurological conditions. The employees each live with a long term disability, and their experience contributes greatly to the effectiveness of the service. We also have a useful website (www.digg.org.uk), with links to a self-assessment facility and (under development) to a site providing information and advice about choosing a care home.

DIGG also develops and presents self management programmes and materials to help individuals to understand and play an active role in managing their problems. The courses include confidence building, communication with professionals, access to information, managing symptoms, self-assessment, goal planning and pacing oneself.

For more information or to book a course telephone 0141 945 5036, or e-mail us at info@digg.org.uk. Or visit us (Tuesdays to Fridays) at Unit 18, Chapel Street, Maryhill, Glasgow G20 9BD to the rear of Macdonalds, just before the canal.

- **Epilepsy Connections**

- Events for children and young people (open to young people with epilepsy, their brothers, sisters and friends).
 - 20th September, Indoor Climbing at the Glasgow Climbing Centre (Ages 7 upwards)
 - 5th October, Cinema Ice Age 3 at Glasgow Film Theatre (All ages part of the autism friendly programme)
 - 14th October, Memory Workshop (for pupils attending Secondary School)
 - 13th December, Workshop carried out on theatre stage, followed by a performance of the pantomime

Aladdin (all ages)

Contact the office on 0141 248 4125 for details or to reserve a place.

- Epilepsy Support Groups in Forth Valley

- 8th September, 20th October and 1st December, 2.30 - 4.00pm, The Almond Tree, 7 Melrose Place, Dundee Court, beside Williamson Street car park, Falkirk
- 24th September, 5th November and 17th December 2.30 - 4.00pm, Claremont Lodge Hotel, Kellie Place, Alloa
- 6th October and 17th November 2.30 - 4.00pm, Golden Lion Hotel, Kellie Place, Stirling

You don't need to reserve a place, just turn up.

- Confidence-Building Course

Course content: Getting motivated, taking the next step towards your goals, building on your strengths and working on overcoming your current difficulties.

13th and 15th October, 10.00am - 4.30pm at Epilepsy Connections office, 100 Wellington Street, Glasgow

Contact the office on 0141 248 4125 for details or to reserve a place.

- Art and Drama Classes for adults with epilepsy

Art classes will be starting on 4th September and will run for a period of 8 weeks in Glasgow.

Drama classes will be starting on 1st October and will run for a period of 8 weeks in Glasgow.

Contact the office on 0141 248 4125 for details or to reserve a place.

- Mainstreaming Project

This project offers adults with epilepsy the chance to access education, training, voluntary and paid employment. The next group starts in October in Glasgow.

If you are interested in joining the group, or finding out more about this course, then contact Anna Rossi at the office on 0141 248 4125

- **TouchBase @ Sense Scotland**

TouchBase is Sense Scotland's Glasgow resource offering a range of fully accessible facilities for disabled people, business, charities, community and the public. Located just two miles from the city centre and with excellent road and public transport links, TouchBase is an ideal venue for business meetings, training events, arts activities, exhibitions and private functions. With 7 meeting rooms, a cafe open to the public, arts suites and a courtyard venue TouchBase has a lot to offer. Visit www.sensescotland.org.uk/touchbase for more details or drop in to the cafe. Sense Scotland are also participating in Doors Open Day on Saturday 19th September from 10am-4pm join us for tours, musical performances, family arts and crafts and lunch in the cafe. www.glasgowdoorsopenday.com

- **SAMH Forum - Let's Get Physical**

9 October 2009, Edinburgh

For Mental Health Awareness Week 2009, SAMH wants you to Get Active! Why not join us to discuss the link between physical and mental health at the SAMH Forum in Edinburgh.

We'll be discussing the barriers that people with mental health problems may encounter as they become more active and the links between lifestyle and mental health. We'll ask why people with mental health problems can experience poorer physical health than others and hear from people who have taken steps to become more active.

[For more information about the event please click here](#)

- **Scottish Mental Health Awareness Week** runs from 4-10 October. We know that every year, organisations and individuals up and down the country put a huge amount of effort into organising events during the week,

and this year, SAMH wants to provide a place where you can publicise your events.

So if you are planning something for this year's Mental Health Awareness Week, whether it be big or small, please let us know about it. All events will be listed on the SAMH website at www.samh.org.uk and if we receive your response before 21 August, may be included in the next edition of The Point magazine.

- **The College of Occupational Therapists at the Independent Living Exhibition**, SECC Glasgow, 9th and 10th of Sept

COT is the professional body for Occupational Therapists, their assistants and OT students in the UK with around 3,000 members in Scotland. Please come and meet Elizabeth MacDonald, the Scotland policy officer, at our stand to find out more about what occupational therapy can offer people with Long Term Conditions, and COT influencing activity e.g. Government agendas such as the Dementia strategy, Mental Health Delivery refresh, equipment and adaptations.

- **Climb Annual Conference** featuring Amino Acid and Urea Cycle Disorders will take place Saturday 10th October, 2009 in Dudley, West Midlands at the Cophthorne Hotel. Amazing speakers will cover diagnosis, treatment, caring issues, diet and cover PKU, Tyrosinaemia, OTC and other conditions.

For more details please contact ClimbFamily Services on 0800 652 3181.
From Climb, National Information Centre for Metabolic Diseases.

- **PAMIS - Petition for fully accessible changing places**

If you have not already done so PAMIS is asking you to please sign the petition that is asking for fully accessible changing places to be available for everyone.

The petition can be signed if you go to the PAMIS website <http://www.dundee.ac.uk/pamis/> and click sign petition which is under the news heading Toilets for Everyone.

- **National Rheumatoid Arthritis Society (NRAS) Extends Health Professional Membership**

One of our core activities and goals is to work as closely as possible with Health Professionals to assist them in any way we can to improve patient information and education.

We are therefore pleased to now be able to offer free membership of NRAS to all Health Professionals in rheumatology units:

Free membership includes:

- NRAS membership (normally £17.50 per annum)
- NRAS resource folder with copies of key resources from the NRAS web site, nras publications and information on the help and services NRAS can provide to display in your unit- (one free copy per hospital only)
- NRAS magazine which includes updates on new developments, patient stories and a spotlight on a rheumatology unit
- Bi-monthly enews with information on latest developments
- NRAS support network, information on local groups and volunteer activity plus general leaflets in quantity for your patients. Posters to display in clinic
- Copies of NRAS surveys and publications, including booklets on 'How to claim Disability Living Allowance?', 'a guide to Benefits', 'Your Next Steps for newly diagnosed patients plus 'Managing well' for patients with established RA, plus booklets on working with RA for both employers and employees
- Access to NRAS team, helpline, network of volunteers
- All other membership benefits (see NRAS leaflet)

Please pass this on to any health professionals that this might be of interest to, and ask them to contact NRAS at: enquiries@rheumatoid.org.uk or on 0845 458 3969 with their full contact details, including job title and work email address.

West Fife NRAS group meeting in Dunfermline.

Monday 14th September is the new date for the very first West Fife NRAS Group meeting to be held in the annexe room at Carnegie Hall Dunfermline from 2pm to 4.30pm. This meeting was postponed from 2nd September. For more details call 0845 458 3969

Tayside & Perth NRAS Launch meeting in Perth Royal Infirmary

Monday 14th September 6.30 to 8pm. Final details to be confirmed. Please register to attend by calling NRAS on 0845 458 3969

Greenock NRAS Group

Next meeting Tuesday 15th September at 6pm at the James Watt College, Finnart Campus all welcome for a talk on the role of Occupational Therapy in treating Rheumatoid Arthritis for more information contact NRAS on 0845 458 3969

• Headway - the brain injury association Carers Seminar

The Scotland Development Office (SDO) is keen to arrange a seminar for those caring for people with brain injury. Initially we had hoped it would take place over the summer however now summer is nearly over this seems unrealistic.

When considering the Programme for the seminar, the Scotland Development Manager Pauline consulted with a number of members from different Headway groups to discuss the content.

The day would cover many different aspects of brain injury including information on the anatomy of the brain, memory and social relationships.

The seminar design would be interactive so that it would not feel as if carers were being talked to and overwhelmed with lots of complex information. There would also be quizzes and simulation exercises so that it was fully interactive. I am hoping that carers will warm to this innovative way of finding out more about how to cope with loved ones who have a brain injury by attending this seminar.

The day is most likely to run between 10am - 3pm and be held in Glasgow - all expenses for attendance will be reimbursed and lunch will be provided on the day.

Ideally, anyone interested in attending this seminar should contact the Scotland Development Office. Our details are Pauline and/or Liz on 0131 537 9481 email: headway.scotland@lineone.net

• Supporting Scotland's Carers - From Recognition to Rights

16 September 2009, Edinburgh Conference Centre

Carers play an integral role in Scottish society, saving the nation an estimated £7.6 billion per year. But this vital workforce is often invisible, under-represented in decision-making and lacking the support mechanisms to meet their needs and those for whom they care.

Delegates hear about the particular challenges faced by young carers focusing on educational attainment, mental health, social development and supporting young carers moving on from their caring responsibilities. Other key issues will include how we can support carers to improve the care they provide through early identification and support as well as providing respite care and medical support services.

While we are pulling together the final agenda for this event, please register your interest above. Alternatively you can take advantage of our early bird discount by booking your place now.

If you have any questions please email carers@holyrood.com or call Holyrood conferences on 0131 272 2133.

• Brain Injury Rehabilitation Trust - Innovations: Models and Management of Brain Injury Rehabilitation

23-24 September 2009

The Brain Injury Rehabilitation Trust is convening its third major international conference at The Burlington Hotel in Birmingham. This is aimed at clinicians, especially psychologists, and other professionals working in the field of brain injury. The conference will cover exciting new developments in neuroscience and rehabilitation practice. For full details see www.birt.co.uk/conference

• Chartered Society of Physiotherapy consultation

At the Chartered Society of Physiotherapy (CSP) Quite we have embarked on a very significant project called Charting the Future, with the purpose of preparing the physiotherapy profession for the challenges and

opportunities that lie ahead. Key to this work will be the involvement of our service users to ensure that the project - and therefore the physiotherapy profession of the future - is completely focused on their needs and expectations.

The CSP is looking to arrange a meeting of a group of physiotherapy service users on **Tues 8th September in London**, to explore with them their experiences and expectations of physiotherapy, whether in the NHS or via some other source. The meeting will take place from 1pm to 4pm, with a sandwich lunch provided on arrival.

If you would be interested in attending please contact Elaine Venables venablese@csp.org.uk for more details.

Information about the project is available at www.csp.org.uk/uploads/documents/csp_charting_the_future.pdf

• **Allied Health Professions Consensus Conference- panel member wanted**

NHS Education for Scotland are developing an Allied Health Professions strategy this year and have chosen to use a consensus methodology adopted from the Royal College of Physicians Edinburgh(RCPE) which involves a consensus conference. This conference is planned for 12 and 13 November 2009.

NES are in the process of approaching key people, including patients, carers and service users to be on the panel. They are hoping to find a person with a long term condition or a carer from the LTCAS network who would be interested in being part of the panel.

Being a panel member is quite a time commitment, but NES would welcome involvement from LTCAS member organisations. A pre-conference meeting will be held on Wednesday 11 November and the actual conference will take place at Murrayfield. Accommodation and dinner will be provided at the Edinburgh Marriott.

For further details about the role and a briefing paper for panel members please contact Grier McGhee at Grier.McGhee@aaaht.scot.nhs.uk or phone 01292 513138/ 07825227856.

Long Term Conditions - National Update

• **Priority groups for flu vaccine announced**

[For the most up-to-date advice and information about swine flu please click here](#)

Health Secretary Nicola Sturgeon has announced the priority groups who will be first to receive the vaccine against H1N1.

The following groups have been prioritised and will be vaccinated in this order:

- People aged over six months and up to 65 years in current seasonal flu vaccine clinical at-risk groups. (about 640,700 people)
- All pregnant women, subject to licensing considerations (about 60,000 people)
- Household contacts of people with compromised immune systems e.g. people in regular close contact with patients on treatment for cancer (about 53,000 people)
- People aged 65 and over in the current seasonal flu vaccine clinical at-risk groups (about 428,250 people). This does not include otherwise healthy over 65s, since they appear to have some natural immunity to the virus
- Frontline health and social care workers (approx 250,000 people) will begin to be vaccinated at the same time as the first priority group

The Government also highlighted groups at greater risk of seasonal flu including those with a variety of long term conditions. [For full details please click here.](#)

• **Scottish Government self directed support event - 29th September 2009**

The Scottish Government is dedicated to increasing the use of direct payments in Scotland. Research evidence shows that many people who purchase their own support through direct payments enjoy a better quality of life. The Scottish Government is firmly committed to involving people who use services and family carers, through

developing its strategy for self-directed support.

This event will provide up to date information on recent self-directed support developments in Scotland and delegates will hear directly from direct payment recipients. Service users and professionals will have the opportunity to share their views on the next steps to making self directed support a reality.

To register please visit www.shsceventsbookings.co.uk and choose "Directing your own support: A self directed support event" from the list of options. You will then be asked to fill in your details and requirements for the day.

- **STV series on emotional well-being and stress**

STV is producing a brand new television series which aims to look at the issues that affect people's emotional well-being and stress levels. This will be a very supportive and constructive series and is being produced in conjunction with the Scottish Government.

The producers are looking for people who would like to take part in a programme which would involve people who think they should be getting more out of their lives taking on constructive challenges and receiving special one-to-one expert advice.

If you or someone you know would be interested in taking part in this programme, or would just like to know more about the project, then please call 0800 959 6688 or e-mail feelbetter@stv.tv

- **Living and Dying Well, A Chance to Share Progress
3 December, Edinburgh**

This event aims to provide delegates the opportunity to:

- reflect on the significant progress since the publication of Living and Dying
- share and learn from their experiences
- hear updates and outputs from the Living and Dying Well working groups
- be involved in future developmental work through workshops

The event is aimed at: anyone involved in Health and social care within the NHS, voluntary or independent sector, patients and carers with an interest in the improvement of palliative and end of life services in Scotland.

[For full details please click here to download the event flier](#)

- **[Independent Living in Scotland event 2009 9th & 10th September, SECC, Glasgow - click here for full details](#)**

- **Chronic Obstructive Pulmonary Disease (COPD) Draft Clinical Standards - Open consultation meeting
6 October, Edinburgh**

NHS Quality Improvement Scotland is currently developing national clinical standards for COPD services. This open meeting is part of the consultation programme to gather feedback, including from people who use services, family members, carers and representatives from voluntary organisations.

To register for the event please contact: Margaret McAlees on 0141 225 6881 (text phone 0141 241 6316) or qis.sdu@nhs.net

- **GMC case studies - Good Medical Practice in Action**

The GMC has launched a new series of online tutorials that tackle ethically challenging scenarios. The tutorials, which include cases involving child protection, whistle blowing and addiction have been added to those already featured on GMP in Action, the GMC's interactive learning website. This popular online resource explores common real-life medical and ethical dilemmas and explains how doctors should tackle the issues using the core GMC guidance, Good Medical Practice (GMP). To access GMP in Action go to www.gmc-uk.org/gmpinaction

- **Council for Healthcare Regulatory Excellence (CHRE) - Promoting Improvement in Regulation Public Discussions**

The opinions of patients and the public on health professional regulation and our work really matters to us which is why we are inviting your organisations and those that you represent to take part in our public discussions.

Our main aim is to promote the health, safety and well-being of patients and other members of the public. Our four public meetings will take place across the UK and focus on the following three areas:

- To update you on the work we are doing to engage with patients and the public in our work.
- To present to you our performance review report of the nine health professional regulators. To ask for your views on our findings and approach to the performance review.
- To report on our project to ensure that regulators' registers work for the public and to ask for your views on the presentation and content of the regulators' registers. The register is a published list of health care professionals which meet the standards set by the regulator.

We want to hear the thoughts of your organisations and those you represent on the above issues which are key to health professional regulation where you live.

Details of the **Scotland event** are:

Date: 21 September 2009

Location: Surgeon's Hall, Nicholson Street, Edinburgh, EH8 9DW

Time: 1pm - 4.15pm

If you want a place, please contact Dan Scott at CHRE (by email dan.scott@chre.org.uk or telephone 020 7389 8030) to register your interest.

- [Please click here for an update on the National Review of Managed Clinical Networks](#)

- **Publications**

[An Essential Guide to Independent Living in Scotland](#)

[Ready for Action: What disabled people want for independent living in Scotland \(easy read\)](#)

['see me' National Plan to 2011](#)

New Scottish Government publications are available at <http://www.scotland.gov.uk/Publications/Recent>. These include:

- Service Commissioning and Procurement Survey (7.8.09)
- Limited Review of the Mental Health (Care and Treatment) (Scotland) Act 2003: Report (7.8.09)
- Pandemic Flu: Guidance on Health Workforce Issues for NHSScotland Boards (11.8.09)
- Reviewing Care and Repair in Scotland 2009 (12.8.09)
- Review of Care and Repair Projects (17.8.09)
- Preparing for a Changing Climate: Consultation Responses (18.8.09)
- Cancer Waiting Times January-March 2009 (18.8.09)
- Social Work Inspection Agency: Annual Report and Accounts 2008-09 (21.8.09)
- Waiting Times and Waiting Lists - Quarter Ending 30 June 09 (25.8.09)
- Scotland's People Annual Report: Results from 2007/08 Scottish Household Survey (26.8.09)
- Scottish Household Survey 2009 Quarter 1 Data Release (21.8.09)

- **Consultations**

[Shaping the Future of Care Together](#) - UK Government Green Paper (closes 13 Nov 09) - this consultation is about proposed changes to the way social care is delivered in England. However it contains proposals to "consider integrating some elements of disability benefits, for example Attendance Allowance" which would apply in Scotland. Tavish Scott has asked two questions (click [here](#) and [here](#) for details) in the Scottish Parliament about how the potential impact on people in Scotland is being considered.

- [UK Equality Bill - Specific Public Sector Duties to Promote Equality and Socio-economic Duty](#) (closes 26 October)
- [Consultation on the review of the Mental Health \(Care and Treatment\) \(Scotland\) Act 2003](#) (closes 6 November 09)

- [The Care and Treatment of People with Mental Disorder and Learning Disability \(Scrutiny, Quality Improvement and Protection\) Mental Welfare Commission for Scotland: Future Structure](#) (closes 25 September 09)
- [The Role of the Registered Social Worker in Contributing to Better Outcomes for Scotland: Guidance for Local Authorities](#) (closes 25 September 09)
- [Scottish Labour Party policy consultation](#) (see specifically 'Health and Housing' paper that asks how support should be provided to people with long term conditions) Consultation closes 2 October
- [Right to Control](#) (Office for Disability Issues, UK Government) Consultation closes 30 September

Scottish Parliament News

Upcoming Parliamentary Business

- Scottish Government will announce their **legislative programme for the next session** on Thursday (3 Sept) around 9.30am
- 3 September - Ministerial Statement: Influenza (H1N1)
- 3 September - Members Debate: Insulin Pump Therapy
- 1 September - Education, Lifelong Learning and Culture Committee will take evidence at Stage 1 of the Public Services Reform (Scotland) Bill
- 1 September - Local Government and Communities Committee will take evidence on Local Government Finance Inquiry
- 1 September - Health and Sport Committee will consider its approach to scrutiny of Scottish Government's Draft Budget 2010-11
- 9 September - Health and Sport Committee is expected to take evidence on the Public Services Reform (Scotland) Bill

Recent Parliamentary Business

Parliament has been on recess.

Parliamentary Questions - answered

Written questions:

- [Bill Butler \(Glasgow Anniesland\) \(Lab\)](#): [To ask the Scottish Executive whether it plans to issue guidelines to NHS boards in respect of ending charges for inpatient telephone use and, if so, when.](#)
- [Marlyn Glen \(North East Scotland\) \(Lab\)](#): [To ask the Scottish Executive whether the decision by NHS Tayside to continue with the community health nurse pilot will result in additional funding being provided.](#)
- [John Wilson \(Central Scotland\) \(SNP\)](#): [To ask the Scottish Executive what guidelines are given to local authorities regarding the information held on disabled people residing in the local authority area.](#)
- [Rhona Brankin \(Midlothian\) \(Lab\)](#): [To ask the Scottish Executive whether it will review provision for young people with speech and language and communication impairments in Scotland in order to tackle unequal provision between areas.](#)
- [Hugh O'Donnell \(Central Scotland\) \(LD\)](#): [series of questions on funding of the voluntary and community sector](#)
- [Jim Tolson \(Dunfermline West\) \(LD\)](#): [To ask the Scottish Executive how many and which railway stations do not conform to disability access standards under the Disability Discrimination Act 1995, broken down by region.](#)
- [Hugh O'Donnell \(Central Scotland\) \(LD\)](#): [To ask the Scottish Executive who will administer funding for individual projects under the Single Interface Programme for community and voluntary groups.](#)
- [Karen Whitefield \(Airdrie and Shotts\) \(Lab\)](#): [To ask the Scottish Executive how the needs and rights of](#)

children with disabilities are being taken into account in the work of the National Child Protection Guidance Working Group.

- **Mary Scanlon (Highlands and Islands) (Con):** To ask the Scottish Executive whether people with haemophilia who have regularly received blood products are at risk of (a) contracting or (b) carrying variant Creutzfeldt-Jakob Disease (vCJD).
- **Jackie Baillie (Dumbarton) (Lab):** various questions on Mental Health Tribunal for Scotland
- **Dr Richard Simpson (Mid Scotland and Fife) (Lab):** To ask the Scottish Executive how many (a) doctors, (b) GPs, (c) hospital consultants, (d) junior doctors, (e) nurses, (f) allied health professionals, (g) hospital pharmacists and (h) managers there were in (i) 1997 and (ii) 2007
- **George Foulkes (Lothians) (Lab):** To ask the Scottish Executive whether it has corresponded with people with medical conditions affected by the use of compact fluorescent or low-energy light bulbs in relation to the phasing out of incandescent light bulbs.
- **Dr Richard Simpson (Mid Scotland and Fife) (Lab):** To ask the Scottish Executive how many (a) doctors, (b) GPs, (c) hospital consultants, (d) junior doctors, (e) nurses, (f) allied health professionals and (g) hospital pharmacists there are expected to be in 2011

Oral questions:

There have been no recent oral questions due to Parliamentary recess.

Current Motions (added since last e-bulletin)

(where the text of a motion is lengthy only the title is included. For full text and full list of current motions please see [Scottish Parliament website](#))

- **S3M-4695 Patricia Ferguson: Revive MS Support - 25 Years of Service** That the Parliament congratulates the workers, volunteers and users of Revive MS Support as they celebrate 25 years of service to those affected by Multiple Sclerosis; notes that every year over 2,500 people benefit from the therapies, information and support provided by the charity; recognises the strong emphasis on partnership working which is at the heart of the organisation, and commends all those involved in both the centre in Maryhill and at the outreach clinics operated across Scotland.
- **S3M-4693 Mike Pringle: Cash Boost for Telecare Services** That the Parliament welcomes the City of Edinburgh Council's massive £1 million home care boost to increase funding for its Telecare programme now being extended across Edinburgh, which will allow vulnerable and older people to remain independent in their own homes, reduce the need for long-term care or hospital admission and save an estimated 3,000 hospital bed days and 3,000 care home days per year, while also expanding the Telecare programme to offer increased support to domestic abuse sufferers and disability groups.
- **S3M-4692 Jackson Carlaw: European Men's Health Forum's Prostate Health Project** That the Parliament welcomes the prostate health project being run by the European Men's Health Forum (EMHF), which aims to gather information from men across Europe on their experiences of developing problems involving the prostate as they seek support, diagnosis and treatment and also on the responses that they have had from health service providers regarding these issues with a view to using this information to inform health professionals and policy makers in dealing with men's prostate-related healthcare; notes that the EMHF is establishing a website to provide men with information on the issues of prostate health, which will go live on 14 August 2009, and encourages men to share their experiences of suffering from problems with the prostate in their respective countries through this web-based facility.
- **S3M-4690 Duncan McNeil: 30 Years of Headway** That the Parliament congratulates Headway on reaching its 30th anniversary; notes that for three decades its dedicated and hard-working team has been providing vital and much-needed support and advice to brain injury survivors and their families; acknowledges that it has grown from humble beginnings to set up more than 100 groups and branches across the United Kingdom, including 13 in Scotland; welcomes its efforts to challenge the discrimination suffered by people with brain injuries, and offers the brain injury charity its support and best wishes for the future.
- **S3M-4688 Kenneth Gibson: Launch of Lifelong Carers Service** That the Parliament warmly commends ENABLE Scotland on the successful launch of its Lifelong Carers service for south-west Scotland; notes that this service, covering North Ayrshire, South Ayrshire and Dumfries and Galloway, is supported by the Big Lottery Fund and will support family carers who are over 50 and care for adult relatives with learning disabilities; is aware that there are 465 people in North Ayrshire alone with learning disabilities, almost half of whom live at home; recognises that many people who have cared for their loved ones, often their children, are understandably anxious about their future, and acknowledges that the Lifelong Carers service will help older

carers and the people they care for create an emergency plan for any eventuality, ensuring that they have the right information to make decisions for the future.

- **S3M-4677 Christina McKelvie: The Euan MacDonald Centre for Motor Neurone Disease Research?** That the Parliament welcomes the opening of The Euan MacDonald Centre for Motor Neurone Disease Research and the arrival of Siddharthan Chandran as Professor of Neurology at the University of Edinburgh and director of the centre; considers that Professor Chandran's appointment and the pooling of international expertise at the centre offers an excellent chance of advancing the knowledge of degenerative diseases and the practice of regenerative medicine, and looks forward to the centre producing novel interventions to improve the quality of life for patients suffering from degenerative diseases and to extend the time during which patients can enjoy that improved quality of life.
- **S3M-4676 David McLetchie: Waterwalks for Leonard Cheshire Disability?** That the Parliament welcomes Leonard Cheshire Disability's sponsored Waterwalks from Colinton Village to Edinburgh Quay on 13 September 2009, which are not only a healthy way of raising money for charity but also encourage people to discover Edinburgh's beautiful hidden gem, the Union Canal, and wishes all participants an enjoyable and successful day out.
- **S3M-4673 Robin Harper: Same as You, Scottish Consortium for Learning Disability** That the Parliament notes the contents of the research published by the Scottish Consortium for Learning Disability, *Adults with Learning Disabilities Implementation of "The Same As You?"*, published on 10 August 2009; notes in particular that adults with learning disabilities now have access to a wider range of day opportunities, that full-time attendance at a day centre has declined from 37% in 2003 to 12% in 2008, that 16% has used a Local Area Co-ordinator to help them become more involved in their community but that only 18% are in paid employment and that one in five aged 35 and over still live with a family carer; congratulates, however, local authorities on the progress that they have made so far, while noting that it is essential that efforts continue to ensure that people with learning disabilities benefit from government policies to promote independent living, and calls on the Government to continue to support and assist in the extension of the scope of support presently in place for those with learning disabilities.
- **S3M-4618 George Foulkes: Banned Campaign Goes Nationwide** That the Parliament congratulates the Banned campaign, led by Mark Cooper, which seeks to improve the accessibility for disabled people of licensed premises across Edinburgh and now Scotland; recognises that the campaign has been adopted by Capability Scotland; looks forward to the campaign's development and future successes, and believes that no one should be barred from accessing a pub or club or receive a poorer standard of service because of a perceived disability.
- **S3M-4480 John Wilson: Jobcentre Plus Failing Job Seekers** That the Parliament calls on the UK Government to address the disturbing conclusions of the Institute for Public Policy Research (IPPR) report, *Now It's Personal: Personal advisors and the new public sector workforce*, which highlights significant inadequacies in the role of personal advisors and asserts that an upskilling of the advisor workforce is needed to increase service effectiveness; is concerned that soaring levels of unemployment have resulted in more people receiving back-to-work support from personal advisors at Jobcentre Plus than at any point since its creation in 2002; worries that major gaps exist in specialist training, including in relation to childcare, homelessness, drug and alcohol misuse and mental health problems, and that the needs of the most vulnerable groups in society are not being adequately addressed by personal advisors, and is concerned that, despite a £1.7 billion allocation to the Department of Work and Pensions to increase the personal advisor network, evidence continues to suggest that low pay among Jobcentre Plus staff is resulting in a loss of skilled advisors and high levels of staff turnover, which means a lack of continuity in support for job seekers.

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An estimated 2 million people in Scotland live with one or more long term condition. A long-term health condition is one of prolonged duration, generally longer than a year that may affect any aspect of the persons life. Symptoms may come and go. Usually there is no cure but there are often things that can be done to maintain and improve quality of life.