



*Welcome to the SIGN  
patient network update*

## SIGN goes public

In the last edition I mentioned that we were trying to raise our profile among the general public. Many of you were very keen to help us by disseminating our general information leaflet to members of your organisation. I would like to thank those of you who helped to do this - every leaflet distributed means another person hears about us!

### **SIGN targeting book worms!**

We are currently working with local authority libraries to create awareness among service users. We've asked the libraries to hold copies of patient versions of clinical guidelines in their reference section and excitingly, to host displays about SIGN and the guidelines.

Throughout November and December the SIGN stand has been on show in six libraries in East Dunbartonshire. This has allowed members of the public to find out about us and pick up copies of our patient versions of clinical guidelines. The exhibition will visit libraries within Stirling Council between January and April.

If you live or work in this area and wish to highlight this to any groups you are involved with, please get in touch for precise dates and locations. We will be visiting various other local authority libraries throughout 2008 and we will keep you posted on this.

### **Shop your way to involvement**

Members of the SIGN team will be visiting Eastgate shopping centre, Inverness on 11<sup>th</sup> January 2008 and Almondvale shopping centre, Livingston on 31<sup>st</sup> January 2008 with the patient involvement stand. This is to create awareness of our organisation and to encourage members of the public to become involved in our work.

If you are in any of these areas on these dates, why not pop in and say hello. Perhaps you could tell people from your organisation that we will be visiting these areas to encourage them to come and visit the stand?

## British sign language versions of patient guidelines now available

We now have British sign language (BSL) versions of the following patient guidelines on DVD:

- Acute coronary syndromes
- Arrhythmias
- Chronic heart failure
- Dementia
- Epilepsy in children and young people
- Lung cancer
- Stable angina
- Prevention of cardiovascular disease

If you work with people who are affected by any of the conditions and would like to order copies of the DVDs please get in touch with me. If you would simply like to tell members of the deaf community about SIGN and our work, we also have a general information DVD available.



## Gathering service users' views on Chlamydia

As with all SIGN guidelines, the updated guideline on Chlamydia will contain a chapter which focuses on the information needs of patients and carers. In November, we visited a sexual health project in Glasgow to speak to some service users about the information they need and how it should be delivered. We found this visit very worthwhile. The types of things people wanted information on included:

- choice of tests and treatments;
- why it's important to tell partners;
- how they will know if it is cleared up; and
- what the effects are if left untreated.

Eighteen people spoke to us and we will be able to use the information collected to advise clinicians on what they should be discussing with patients who have Chlamydia.

The guideline is due to be published in autumn 2008 but you can read more about our findings sooner by acting as a lay reviewer for this guideline. Please let me know if you would be interested in doing this.

## Discussion day at SIGN with Santa's little helpers!

Patient and carer representatives on SIGN guideline development groups are invited along to a Christmas themed discussion day on 17<sup>th</sup> December to have some input into patient involvement activities that we plan to carry out in 2008. For example, we would like to revamp the patient section of our website and plan to carry out further awareness raising initiatives such as poster campaigns.

We want to hear your ideas and perhaps you are willing to volunteer to help us? The day will consist of round table discussions in the morning followed by a Christmas buffet lunch. If you are a patient or carer representative on one of our groups and would like to come along to this informal event, please let me know and I can give you further details.

## We need your help!

### Interested in working with the SIGN bosses?

To ensure the views of patients, carers and members of the public are taken into consideration at all levels of SIGN's work, we wish to recruit a lay representative for SIGN Council.

Members of SIGN Council (the policy making body for SIGN) determine the overall direction of SIGN's development and play a key role in shaping the SIGN guideline programme. As a lay member of SIGN Council you would be asked to contribute the patient/public perspective at a strategic level. The types of things you would be involved in would be selection of topics for guideline development and the recruitment of lay representatives to guideline development groups. If you would be interested in taking on this role, please get in touch with me and I will send you further details.

We are relying on you to help make a difference!



Karen Graham, Patient Involvement Officer ☎ 0131 718 5108 @ email [karen.graham2@nhs.net](mailto:karen.graham2@nhs.net)

## Become a guideline development group member

SIGN will begin to review the following guidelines next year:

- Prophylaxis of venous thromboembolism and antithrombotic therapy (prevention and treatment of blood clots). These two guidelines will be combined to produce a new guideline on investigation and management of venous thromboembolism.
- Management of sore throat and indications for tonsillectomy
- The care of patients with chronic leg ulcer

We are also beginning to develop a new guideline on management of atopic dermatitis in primary care.

We are now recruiting patient/lay representatives for these groups. We are keen to hear from people who have been affected by any of these conditions. Perhaps you or your child is always suffering from a sore throat? Do you know someone who has been affected by blood clots in their leg veins or do you perhaps have an interest in this? Do you have experience of living with atopic dermatitis or eczema?

Membership of a guideline development group provides an opportunity for patients' and carers' voices to be heard so please help us to get people involved. If you, or anyone you know might be interested in participating as a patient/lay representative, please contact me and I will send out further information and nomination forms.

Perhaps you work with people who have experience of these conditions and could help us to identify the issues that are important to patients and carers? We are also keen to hold focus groups or interviews with patients and carers for more of our guidelines, perhaps you can identify people who could take part?

If you think you could help us involve patients and carers in any way, please get in touch.

## Could you review one of our guidelines?

Have you or someone you know been affected by:

- Headaches; or
- Hip fracture

SIGN is currently reviewing clinical guidelines in these areas. The guidelines are due to go out for consultation in January/February and we are putting together a list of people who could review the draft guideline. If you have been affected by any of these conditions, or you know someone who has we would be delighted if you could act as a lay reviewer for these guidelines.

If you would be interested in doing this, please let me know.

## What did SIGN do in 2006/07?

I always update you on progress with patient/public involvement activities but perhaps you would be interested in hearing about other aspects of SIGN's work too? Our annual report from 2006-07 has recently been published and is available for download from our website or you can request a hard copy from me. Highlights include a report from our coronary heart disease launch in February, progress of our European cancer guidelines project and much much more. The main highlight is of course the photograph of me!



# Scottish Government wants to hear from you!

The Scottish Government is planning on making changes to existing neuroscience services. Neuroscience deals with disorders of the nervous system, including Parkinson's disease and motor neurone disease. Services need to be carefully organised at all levels to make sure that the right care and treatment is available when people need it. Work is currently underway, looking at a wide range of issues, to help decide how best to provide these services to the people of Scotland, now and in the future.

The Scottish Government would like to hear your views on this. You can make your voice heard by completing an on-line questionnaire at [www.scotland.gov.uk/Topics/Health/NHS-Scotland/Neuroscience/Getinvolved](http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/Neuroscience/Getinvolved) or you can request hard copies of the proposal and send your comments in by post to Ashbrook Research and Consultancy, 1 Woodside Terrace, Glasgow, G3 7UY.

## Standards of food and cleanliness in English NHS hospitals

Patient Environment Action Teams (PEAT) were set up in 2000 to assess NHS hospitals. These teams are responsible for assessing English hospitals and do not exist in Scotland. Under the programme, every inpatient healthcare facility in England with more than 10 beds is assessed annually and given a rating of excellent, good, acceptable, poor or unacceptable.

The PEATs consist of NHS staff, patient representatives and members of the public who look at the standards of cleanliness and food available to patients. The results show that both these areas have improved this year.

The results of the 2007 assessment are now available by clicking on the following link [www.msnpsa.nhs.uk/peat/](http://www.msnpsa.nhs.uk/peat/) or you can request a hard copy by phoning the National Patients Safety Agency on 020 7927 9500.

## Events organised by other people

The following events are not run by SIGN but are listed to share information and raise awareness. If you would like to attend one of these events, please contact the organisers directly.

### **Community Health Partnerships three years on: productive partnerships with the third sector** **20<sup>th</sup> February, Edinburgh Airport Hilton Hotel, Edinburgh**

This is a joint event organised by Voluntary Health Scotland (VHS) and the Councils for Voluntary Service (CVS) which will have four main themes:

- Health Improvement in CHPs - the contribution of the voluntary and community sector (VCS)
- Achieving greater public involvement in CHPs through the engagement of the VCS
- CVS - their role in CHPs
- Showcasing success - stories from the field

For more information visit [www.vhscotland.org.uk/events/conf/vhs\\_flyer\\_feb\\_08.pdf](http://www.vhscotland.org.uk/events/conf/vhs_flyer_feb_08.pdf) or phone 0131 557 6845.



**Keep Well Conference**  
**5<sup>th</sup> - 6<sup>th</sup> March, Beardmore Hotel, Clyebank**

This conference will aim to increase the level of awareness, understanding and ownership of the current heart health, health inequalities and anticipatory care agenda in Scotland.

It will also include learning from Have a Heart Paisley. A detailed programme will be available later in the year, but the event will involve a mix of plenary and parallel sessions with opportunities for networking and finding out more about local practice via a marketplace.

If you would like to register your interest in the conference and receive further details as soon as they are available, please email [keepwell@health.scot.nhs.uk](mailto:keepwell@health.scot.nhs.uk)

**Health Awareness**

**World Braille Day**  
**4<sup>th</sup> January**

The World Blind Union (WBU) is the voice of blind and partially sighted round the world. WBU represents about 162 million people from 158 countries. If you would like to read more about World Braille Day you can visit [www.worldblindunion.org/](http://www.worldblindunion.org/)

Do you work with people who are visually impaired or blind? Did you know that SIGN has large print editions of patient versions of clinical guidelines and can have these translated into Braille on request? Please let me know if you think any of our information would help someone you know!

**Eat a breakfast - save a life day**  
**26<sup>th</sup> February 2008**

Breakfast is the most important meal of the day yet if you are anything like me, you will find having to eat breakfast an inconvenience! We are lucky to have the choice - so many children in the world do not have the choice of breakfast.

To help raise money for needy children across the world, a breakfast party will be organised for SIGN staff on or around 26th February. Staff will be charged for the food they eat and will be asked to donate £1 to Feed the Children. I will let you know how our breakfast party goes in the next edition!

Can you perhaps organise a breakfast fundraising event within your organisation? To find out more about this day visit [www.feedthechildren.org.uk/pages/eat\\_a\\_breakfast.shtml](http://www.feedthechildren.org.uk/pages/eat_a_breakfast.shtml) or phone 0118 932 0095.

**Hypoparathyroidism Awareness Day**  
**5<sup>th</sup> January**

Hypoparathyroidism (HPTH) is a rare condition which occurs where there are inadequate or ineffective levels of parathyroid hormone and may be due either to a congenital disorder or as a direct result of thyroid surgery.

Hypoparathyroidism UK is run for people with HPTH by people with HPTH, with advice and guidance from interested professionals. It hopes to raise awareness and understanding about HPTH and to campaign for a better level of care and treatment for people living with this condition.

To find out more about this day and to find out how you can help visit [www.hypoparathyroidism.org.uk/](http://www.hypoparathyroidism.org.uk/) or write to EJ Glenister, 6 The Meads, East Grinstead, West Sussex, RH19 4DF

This will be the last newsletter of 2007 and once again I would like to thank you on behalf of the SIGN team for your contribution to our work throughout the year. I feel we have achieved a lot this year in the area of patient/public involvement and a lot of that is down to the commitment and enthusiasm of our patient network members. I hope you have a lovely Christmas and I look forward to working with you in 2008!

Best wishes

*Karen Graham*

