



SAFE Newsletter

Spring 2012



General Assembly and Working Conference for 2012

The General Assembly and Working Conference for 2012 is being held in Barcelona on 8th and 9th of November, with delegates arriving on 7th November. The venue is the [Husa Oriente Hotel](#) situated on Las Ramblas in the centre of Barcelona.

This year we are asking ALL delegates to use the knowledge we have given them over the last couple of years to try to obtain sponsorship for their travel costs, and also delegate costs of €500 if possible.

Those delegates unable to obtain local sponsorship can apply for a bursary from SAFE for the delegate fee and travel costs for one person from each organisation.

For each additional delegate who wishes to attend there will be a fee of €500.

This delegate fee of €500 includes accommodation for two nights, lunches during the conference, and an evening meal on 8th November.

Further details to follow – but start looking for sponsorship as soon as possible!



World Stroke Congress 2012

The 8th World Stroke Congress is being held in Brazil from October 10th to 13th. Already some of our members have sponsorship to allow them to attend.

This congress is very special for SAFE and stroke support organisations as the WSO will be launching the SSO Toolkit that SAFE have developed to assist in the creation of stroke support organisations across the world.

As per the previous two congresses, the WSO have kindly given SAFE and SSO's a free stand, and this year we would like to use the stand to show what SSO's have achieved in Europe.

We will produce a leaflet, in English, giving details of each of our member organisations. Please therefore send details of your organisation to the SAFE Secretariat at mail@safestroke.com

We would like therefore to have some leaflets from each member organisation to show on the stand.

Please send these to:

Sandra Jackson
SAFE Secretariat
Stroke Association House
240 City Road
London
EC1V 2PR
England



SLAGFORENINGER I NORDEN
Stroke Associations in the Nordic Countries



Nordic conference

The Nordic stroke organisations arranged a conference on stroke prevention and atrial fibrillation at Gardermoen, Norway, February 25.-26. 2012

The stroke organisations of Finland, Sweden, Denmark, Faroe Island, Iceland and Norway participated.

The first day included the following presentations:

- Prevention of stroke – Albert Pall Sigurdsson MD; Iceland
- Atrial Fibrillation – Professor Hans Ibsen, Denmark
- How to prevent AF to lead to stroke – Professor David Russell, Norway
- Screening of AF – Professor Mårten Rosenquist
- What is important to the patient and the family – Kjetil Gaarder, Norway and Chatarina Lindgren, Sweden.

After the presentations we discussed and finalised the final document which states what the Nordic stroke organisations ask the governments to do to reduce the number of strokes and the number of AF related strokes.

The second day of the conference included presentations of all organisations and a discussion on how to continue the cooperation between the stroke organisations.

A discussion forum in connection with SAFE's annual conference was suggested.



The working group for the Nordic conference.



United Kingdom



The Stroke Association

We've come so far in our fight against stroke, but we all know that there is still so much more to do. Our focus now must be to build on our collective successes to get stroke the attention we know it requires as one of the major health challenges we face today.

As the UK's stroke charity, we need to work with you, the people throughout Europe who share our commitment. Our goal is to build even greater support for the stroke community and build a powerful stroke movement that can be a force for change. On 1 May, we launched our new 'Life After Stroke' campaign and the first of what will be an annual Action on Stroke Month. And we have changed how we look. The success of our launch surprised even us. We secured over 600 items of media coverage for stroke and our Life After Stroke campaign, including our national papers, TV and radio. We are already seeing many new and influential relationships forming as a result of this unprecedented profile and endorsements of support.

This is a special year for the Stroke Association. But more importantly this is a big year for everyone connected with the cause of stroke. In our anniversary year, we want to show the world how our work improves the lives of stroke survivors, every step of the way on their road to recovery. We want more people to be aware of stroke, be able to spot the signs of stroke and know who to turn to for help.

Throughout the year we'll be telling more people about stroke and what they can do to prevent stroke. We'll be showing what impact 20 years of our funded research has had. We'll also be putting on events and activities to get more people than ever before supporting us so they can make a difference to the lives of people touched by stroke. We believe that together we can change the world for people affected by stroke.

Stroke survivor's stories

Two employees of the Stroke Association made some short films in conjunction with the BBC on stroke survivor's stories.

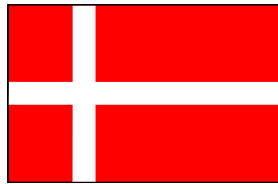
These were seen in many parts of Europe and they were invited to submit the films for viewing at the "Health Happening" film festival in the Czech Republic in May.

The films can be viewed at:

http://www.youtube.com/watch?feature=player_embedded&v=JwpooJmmvx4

http://www.youtube.com/watch?feature=player_embedded&v=DBwiMr7tsJ4

http://www.youtube.com/watch?v=ofAiHZ8bDts&feature=player_embedded



Denmark

In dialogue with citizens and politician about prevention

The Danish Stroke Association, HjerneSagen, will in May and June arrange two major prevention events. During the European Stroke Day in May HjerneSagen's local organizations will offer free blood pressure measurement in about 30 cities across the Country. They will try to make contact with citizens on the city's popular sites or shopping centres. Here they also distribute the new brochures on prevention:

- Stroke – are you at risk
- Beware of blood pressure – don't use to much salt
- Protect your brain – know your blood pressure

In addition the Stroke Association has produced a TV spot in cartoon style with a focus on risk factors for stroke. On www.hjernesagen.dk you can read more about the prevention of stroke and watch the TV spot.



Få målt dit blodtryk

Ca. 1 mio danskere har forhøjet blodtryk. Er du en af dem? Et forhøjet blodtryk øger din risiko for at blive ramt af blødning eller blodprop i hjernen. Læs mere på www.hjernesagen.dk.



HjerneSagen
blodprop@hjernen.dk

This is an advertisement HjerneSagen used in relation to the European Stroke Day

Hot debate on holiday island

From June 14. – 18. HjerneSagen has secured a place at the annual People's Meeting in 2012 on the popular holiday island Bornholm in the Baltic Sea. Here you can meet Prime Minister Helle Thorning with representatives from the government and the rest of parliament. Also representatives from industry, the Danish press and a number of interest and grassroots organizations will be at this meeting.

The purpose of HjerneSagens presence is to bring the discussion of prevention on the political agenda. In one of the events, we have set up a meeting with some of the key players in the Danish health policy. Here we will focus on HjerneSagens desire that all adult citizens are offered a preventive health check – a wish that has been parked on a siding in the political priorities. HjerneSagen will also use the Peoples meeting to enter into dialogue with the population and the tourists on the island by offering blood pressure measurement and information about how to prevent the risk of stroke.



Our work - Belarus

Natallia Usava and Natallia Halinouskaya have attended the SAFE Working Conference for the last 2 years, with the aim of being able to set up a stroke support organisation in Belarus. Here the two Natallia's give details of their progress so far.

We have decided to begin the work of our organisation by carrying out educational seminars for patients and their relatives, and also people with risk factors of a stroke. Training has been in the first days of each month in the Gomels Hospital. Our educational program is called "Today and tomorrow".

The themes of the seminars were as follows:

- On February, 1st - Prevention of strokes
- On March, 1st - Life after a stroke
- On April, 2nd - The help to patients with disturb of speech

During the seminars we answered questions from patients on diet, a way of life, features of therapy of a hypertension.

The results of the seminars and the materials on the topics placed will be placed on our website <https://sites.google.com/site/segodnyaizavtra/>

We will also have information on future seminars. .





The Global Atrial Fibrillation Patient Charter

In 2011, a steering committee of six patient organisations along with 39 other patient organisation representatives from 20 countries came together to develop a global charter for people living with atrial fibrillation (AF). [The Global AF Patient Charter](#) was created to bring a worldwide, unified voice to improving the care and treatment of individuals living with AF and AF-related stroke.

The Global AF Patient Charter is just the first step. We must now take forward the call-to-action recommendations and use them to put AF and AF-related stroke prevention at the top of national healthcare agendas.

Together we can make a difference!

The goal of Sign Against Stroke is to gather 1.7 million signatures in support of the Charter – one for each of the estimated number of grandparents, mothers, fathers, aunts and uncles killed or disabled by AF strokes every year. — and provide those signatures to healthcare decision makers in countries across the world. Demonstrating strong support behind the Charter recommendations will help put AF and AF-related stroke prevention at the forefront of national health agendas.

Sign the Charter now!

<http://www.signagainststroke.com/charter.html>



SAFE NEWS



Summary of verbal responses to feedback questionnaire from SAFE 2011 WC

The summary is based on questionnaires from 11 first time attendees and 20 “veterans”

Some of the key learnings from the programme were:

First time attendees:

- Good to have collaboration. Evidence base for what needs to be done very strong indeed. Sharing of practice is a great help.
- See what hosting organisation is doing.
- Need to work across boundaries whether locally, nationally, internationally.
- Good news – can reduce mortality and disability as well as stop strokes happening.
- Range of activities delivered by Safe members.
- Energy and vitality of SAFE as a movement. Potential of Safe to influence change.
- How to get some money for regional organisations.
- Mass media experience.
- Small patient groups are heart and soul of organisation. Involve stroke patients more into organisation.
- Well organised associations can achieve more benefits for stroke patients.

Veterans:

- **Sharing and collaboration:** Friendship between people. Importance of sharing. Meeting colleagues and good networking. Experiences from other countries. More working together with other countries sharing ideas. Learning to know other associations.
- **Knowledge** required of stroke activity glossary. Define education programs regarding the risk factor and stroke prevalence. How to inform people about stroke. Facts and figures re stroke across the world.
- Importance of **evaluation process** for materials, information, campaigns.
- Potential **funding** from corporations. Fundraising is always “in”. How to find money. The same problem for all – no money to act.
- Campaigns
- **Research** ESN. New investigations in stroke.
- Exciting use of cartoons, media.
- Inspiration. UN, ESN. WSO activities (UN high level and so on). Need to learn more.
- How to work with stroke patients’ family.
- Define program of patient rehabilitation.

In conclusion, the overall impression was one of success in attaining the conference objectives of providing a practical workshop on developing SSO’s. Even after a one day session positive, optimistic attitude changes on the possibility of influencing different areas of stroke care through stroke support organisations were apparent for the first timers. The veterans were more selective in their enthusiasm. In future, more “advanced” content could be presented to the veterans, parallel to the presentation of beginning skills for beginners.

We are proud to be able to impart that SAFE’s initiative in sharing this experience with the World Stroke Organisation has been positively received. As a result, SAFE is being turned to for guidelines to develop similar projects throughout the world. The WSO asked SAFE and the UK Stroke Association to supervise the collection of materials on guidelines for the development of SSO’s. This toolkit will be launched at the World Stroke Congress in Brazil in October 2012.



Some items from the minutes of the last board meeting

- **Finance/Banking Issues/Membership fees**
 - Proposal at next WC to increase minimum membership fee.
 - A €50,000 limit was agreed for the 2012 WC.
- **SAFE Agreements with the Stroke Association**
 - The agreement for the secretariat was passed and signed
 - The Memorandum of understanding for research covers all member organisations who may have an individual who works on behalf of research projects for SAFE. The SAFE board will agree in advance who is able to make a claim.
 - The Memorandum of Agreement was approved by the board
- **World Stroke Organisation**
 - Jelka Jansa was nominated to be the SAFE representative on the board of the WSO

The research update is attached separately to the newsletter.



We strongly recommend you distribute the newsletter to your members by mail, or provide us with their contact details to enable us to do so.