



NEWSLETTER

Spring 2011



As the recession makes life hard across Europe, stroke survivors in many countries will find their lives that bit more difficult. Many countries will look to reduce social welfare, and access to health services, so stroke patient organisations are more important now than ever before.

In this issue of the newsletter we profile an opportunity for us all to make a real difference, a chance to get €100,000 for SAFE and at last enable the set up of an office in Brussels to fight for our cause. If you do only one thing in the next three months, it must be to vote every day and to get your contacts to also vote every day for SAFE. At the time of writing we are fourth in the vote, but surely we can get enough people to vote for SAFE? It's in your hands.

Every year we have to have a board meeting in Brussels, and this newsletter is being sent after our recent meeting in the city of SAFE's registration. The Board meeting was a very important one, with new board members Esteban Pont, Tina Viljanen and Kjetil Gaarder joining for their first face to face meeting. Topics included current Stroke research going on at European level, and future possibilities, more detail elsewhere in this newsletter, and big discussions about how to follow up from last years Eastern European working conference.

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We also set about organising the Working Conference and General Assembly for later this year. They will be held in Budapest over the 9th 10th and 11th November, so put these dates in your diary.

We will need to elect at least one new board member and a new vice chairman at these meetings so please consider whether someone from your organisation should stand.

Money of course remains an issue for SAFE, but the board meeting discussed our on-going fundraising and the question of fees. There are a number of organisations who have not paid their fees, and persistent offenders will be expelled. At the time of writing this newsletter a letter is going to one organisation to expel them. Please, if you owe fees, pay them up, the fees are not large but are very essential to the survival of SAFE.

Enjoy the newsletter, get your votes in for SAFE, and see you all in November in Budapest.

€100,000 available for SAFE, all you have to do is get lots of people to vote for it... One mission, one million

SAFE has been shortlisted to receive €100,000 from the One Mission One Million campaign, but we can **only** win this money by getting as many votes as possible.

Please enter this link and vote!

<https://www.heartofstroke.com/actfastonaf>

And you can do it every day – so please... keep voting!

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If SAFE wins this money we will support a campaign across Europe on the link between Atrial Fibrillation and stroke, and it will establish an office in Brussels so we can lobby the EU on Stroke matters.

Only you can make this happen so tell all your contacts and get them voting every day.



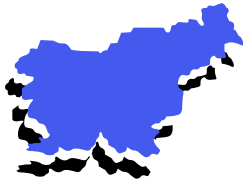


SAFE EUROPEAN STROKE AWARENESS DAY 2011 (ESAD) May 10

At the board meeting we heard of the plans of many organisations across Europe to raise awareness of Stroke.

Ideas include;

- Holding public meetings,
- Approaching radio stations to get interviewed and talk about stroke, its prevention and life after stroke,
- Holding walks where stroke survivors and their supporters walk a route, have pictures taken and then articles are put in the local paper. Some organisations ask friends, relatives and workmates to sponsor the walkers to complete the route and therefore it's used to raise money
- Putting on a cultural event such as a concert of music or a comedy show to raise money and to raise awareness
- Putting material on your website to say it's stroke awareness day and asking supporters to write in how they are planning to let others know about stroke
- Making badges with "I support stroke awareness day" on them and selling them and asking people to wear them throughout the week to get people talking about stroke
- Doing a newsletter and giving it away about stroke awareness day
- Asking the local paper to give you space to write about stroke awareness day
- Preparing information literature and placing it in hospital stroke units and in your local doctors waiting room
- Asking the local companies to check their workers knowledge of stroke and their blood pressure on stroke awareness day
- Please do send us your ideas and we can share them with others through this newsletter and the website



SUMMARY OF SAFE WORKING CONFERENCE IN LJUBLJANA, NOVEMBER 2010

Background:

Realising the high incidence of stroke within Eastern Europe and low level of medical and supportive services for stroke survivors and their caregivers, the last annual Working Conference (WC) of SAFE was geared towards providing content and materials to assist in developing stroke support organisations (SSO) in such areas. It also initiated invitations for participants from new SSO being developed in other parts of Europe, such as Poland and Iceland.

The three day annual meeting included a one day conference on Atrial Fibrillation, the one day Working Conference and SAFE's Annual General Assembly.

Content of the conference included addresses by representatives of the Slovenian Government; attaining the vision of SAFE in Europe - defining strategic plan, roles, SMART objectives; building and strengthening organisations (including how to set up a new patient organisation, funding and recruitment and maintenance of volunteers); building a reputation, including examples from European Parkinson's Association, and presentations of SSO from Catalonia, Italy, Slovenia and Poland. There were opportunities for formal group discussions following the frontal lectures, in addition to several informal social activities during the three day meeting.

Participants:

A total of 41 participants attended the one day WC – 23 for the first time and a further 18 veterans of previous WC (table I). The vast majority of new participants from countries with no existing SSO were medicos – some senior and some less so – concerned about and willing to invest efforts in improving the situation of stroke survivors in their countries via the creation of SSO (table II). Attendance of

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the novices was encouraged by outside sponsorship of most of the travel and other participation costs for up to two representatives from each country.

Feedback responses:

The overall impression was one of success in attaining the conference objectives of providing a practical workshop on developing SSO. 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 novices. The veterans were more selective in their enthusiasm. It would seem advisable in the future to clarify in advance to the veterans the aim of their being expected to share their experiences as stroke support volunteers and having this objective built even more into the program.

Alternatively, 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 and encouraged the recent decision for the UK Stroke Association to supervise the collation of materials on guidelines for the development of SSO.

If you would like to receive full details of the feedback, please email the Secretariat at mail@safestroke.org



Working Conference and General Assembly 2011 November 9, 10, 11 in Budapest

We are holding the conference in Budapest to enable easy travel from the East of Europe to this years gathering. We expect a good attendance and interested attendees should get in touch with Sandra Jackson to ensure we can send you details and joining instructions.

We are looking at the content, and would like organisations or individuals to contact Sandra with details of presentations they could make, or of the presentations they would like to hear. If you would prefer a workshop on a particular issue, let us know. We can't guarantee that all presentations will be accepted, as we have limited time.



Volunteers

This year 2011 is European year of the Volunteer.

2011 has been designated the European Year of Volunteering (EYV) in order to draw public attention to volunteering. The importance of volunteering has long been acknowledged by the EU and now the EYV 2011 aims to inform the general public about the benefits of volunteering. The year will foster an understanding for the importance of volunteering in creating a more democratic, caring and responsible society. Its main aims (and benefits) are:

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- promoting volunteering amongst European citizens
- supporting and reinforcing European volunteering organisations
- improving the recognition of voluntary work and the challenges it is facing
- celebrating the commitment of millions of European volunteers, who devote themselves to supporting people, causes or communities, both within the EU and abroad

At the Board meeting we agreed that SAFE organisations should be encouraged to make the most of this European year of Volunteering and these suggestions were made;

- A message from your organisation should go to all volunteers within your organisations celebrating and thanking volunteers for their contribution to people affected by stroke, and to say that in this EYV you are very appreciative of all they do.
- Each organisation to create and submit a message on the www.safestroke.org website and individual member sites celebrating volunteers' contribution to support those affected by stroke. This could also include examples of those volunteering in fundraising and philanthropy, and those in position of trusteeship or governance. Tell the world what your volunteers do!!
- SAFE members to organise appropriate recognition to celebrate their own volunteers, give awards, get volunteer's pictures and stories in the local newspaper and local radio. Run localised recognition events for localised volunteering activity.
- Over time SAFE members could work together and share volunteer training packs, and the various regulations that we as member organisations have around volunteering. As volunteering becomes at the fore front of civil society in Europe it would be useful for us to share these across the Alliance.



WHY lobbying at EU level is critical for stroke.

The EU has identified a number of areas of health and food policy that can be legislated at a supra-national European level. Many of these areas such as smoking, nutrition and food policy are important stroke policies in regard to prevention.

The EU contains the framework project, currently FP7, which funds research and development throughout the union and worldwide. As well as having funding for stroke-based research, FP7 can be used for funding of conferences and public awareness campaigns.

Mark Layward, an Intern at The Stroke Association UK with 3 years experience of working at the EU, presented a paper at the SAFE board meeting on the The EU and Health. This contained important information on:

- **Legislation**
 - Health
 - Salt
 - Food Labelling guidelines
 - Tobacco
 - Disability, working rights

- **Campaigns**
 - Milk
 - Europe against cancer
 - World days

- **Research**
 - FP7
 - Community research

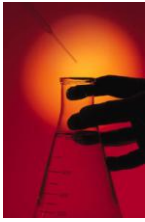
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- **Opportunities for Stroke in the EU**
 - Stroke Interested Parties
 - Mechanisms for affecting change
 - Written questions
 - Meeting MEPs
 - Receptions
 - Intergroup
 - Written declarations

- **The European Commission**
 - DG SANCO
 - Other parties
 - The European Stroke Organisation
 - The European Stroke Conference.
 - European Brain Council
 - Anticoagulation Europe
 - European Heart Rhythm Association
 - European Primary care Cardiovascular Society

- **A Stroke Setup for the EU**
 - Offices
 - Office Set Up

Unfortunately this document is too long to reproduce in this newsletter. If you would like to receive a copy of this document, please email the Secretariat at mail@safestroke.org



Research

Ongoing research projects

ESN – European Stroke Network:

- The project is going into its second phase now. In the first phase SAFE has given advice and support with respect to producing a brochure for the professional target group medical experts and the EU-Commission. The brochure can be downloaded under the following website: <http://www.europeanstrokenetwork.eu/>
- SAFE also supported the participation of the ESN at the World Health Summit in Berlin in October 2010.
- Together with coordinators and work package leaders the main deliverable for SAFE in the second phase is to produce a second brochure elucidating and showing practical examples of basic and translational stroke research in Europe for patients and the public. Interested SAFE members are welcome to support the task. Further information about the structure and content of the brochure and activities of the consortium will be available during the next weeks.

Potential new projects:

Investigator driven studies:

SAFE cooperates within the call FP7-HEALTH-2011 with two consortia.

Both proposals have been submitted by the researchers on the 10th February 2011. Submission is a two-stage process and both consortia have passed the first stage in October 2010:

1. First European Investigator-driven Clinical Trial Investigating the Benefits of Hypothermia in Ischaemic Stroke Patients (EUROHYP)
2. Efficacy and safety of MRI-based thrombolysis in wake-up stroke: a randomized, double-blind, placebo-controlled trial (WAKE UP)
 - The role of SAFE would be to some degree research on user involvement, but mainly communication and dissemination of purpose and results to the patients and the public.
 - The decision of EU-Commission if the proposals will be supported is expected in May 2011. Both projects would start in 2012 and have a timeline of 5 years.

Background

EUROHYP:

The aim is to focus scientists' work towards the most promising research and harness resources in an EU wide effort for a trial to bring concrete hypothermia treatments to stroke patients in the shortest time frame.

TRIAL PROJECT:

The number of hospitals participating in the proposed trial project is expected to be around 80 in total, from 21 countries in Europe

WAKE UP:

The consortium consists also of renowned European stroke researchers and centres and is coordinated by the University Medical Centre Dept. of Neurology Hamburg-Eppendorf, Germany.

Background: Up to 20% of strokes are estimated to occur during sleep and this large group of patients is a priori excluded from thrombolysis. However, carefully performed clinical and imaging observations suggest that in a large number of these patients strokes may have occurred in the early morning hours so that they might still be eligible for thrombolysis. The results of WAKE-UP will be incorporated into European and national guidelines for acute stroke treatment and are expected to change clinical practice immediately.

Small or medium-scale focused research project (STREP)

SAFE is cooperating with the ROKETS consortium. The Board members Jelka, Pavel and Markus with the assistance of Antje have worked on the proposal. The consortium consists of 9 experienced and renowned partners from Slovenia, Spain, Poland, Belgium, Germany, and Greece and is coordinated by the University of Jyväskylä, Finland.

ROKETS background:

The content of the proposal is to research and develop a 4-closed-loop-feedback ICT Personal Health System (PHS) that offers the ramp to launch the rehabilitation of stroke conditions to a new dimension. The proposal aims to empower the patient (P) to gain more healthy life years through personalised quality care. It will contribute to develop more sustainable health systems and to reduce disparities across regions in the delivery of rehabilitation care. ROKETS-PHS will integrate sensors and multi-parametric data collection components worn by the patient and embedded in the home or away.

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Summary:

The EU Commission is now very aware of SAFE and as already discussed in Ljubljana it is on the one hand a great achievement and opportunity to embark on such projects to build up reputation and a financial background for SAFE.

On the other hand we have to be clear about the fact that the deliverables and tasks of the projects are not trivial and need a clear structure and a lot of expertise to be fulfilled properly.

The SAFE Board will be discussing these challenges at its future meetings.



SAFE Website

If someone wanted to know about the things that were going on in your country and organisation, the SAFE website would be a place they look at.

Please email material that you want to put on the website about your organisation and countries stroke services to mail@safestroke.org

It is your website; make sure you put some information on it.



European Neurological Review – Volume 5 Issue 2

In this latest issue, Jean-Marc Burgunder, MD, and colleagues provide a comprehensive overview of the new European Federation of Neurological Societies' Guidelines on molecular diagnosis of neurological disorders, while Anastasios Chatzikonstantinou, MD, and Michael G Hennerici, MD, ask Is There an Optimal Management Regimen for Transient Ischaemic Attack Patients to Best Prevent Stroke? Elsewhere, in their article, Neural Transplantation for the Treatment of Huntington's Disease, Roger A Barker, MD and Rachel A Swain, MD, provide a comprehensive review of current practice, but note that although advances in this field are hampered by the need for more complete knowledge of the disease itself, the future of neural transplantation holds great potential.

Directed by an Editorial Board comprising internationally respected physicians, European Neurological Review's peer-reviewed articles endeavour to provide a concise and timely update on the latest opinion and advances spanning the breadth of neurological practice.

SAFE members can access the current edition, in full and for free in eBook format.
[<http://www.touchbriefings.com/ebooks/A1q7g6/euneurovol5iss2req/>]

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.

