

## SAFE Regional Meeting in Oslo

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**16th June 2016, Oslo, Norway-** The meeting was again dedicated to stroke self-management, stroke clubs and usage of Internet to raise awareness of stroke. Grethe Lunde, a stroke survivor of 22 years, has just left the board of the Norwegian association, and was introduced as the SAFE board's Treasurer which will be the focus of her energy now.



Finnish Brain Association gave inspiring presentation on the self-management of stroke. The colleague from Finland was talking about the usage of Internet to raise awareness and gain support for SSO's activities. Their website became an important source of information, with people sharing their stories on stroke, asking for help and information.

Jon Barrick said a recently conducted needs survey for peer to peer groups showed that the main things people need are medical information, instructions on how to do things (e.g. use of arm), on who can help them, but also about equipment, relationships, and help with decision-making and their rights (financial, employment, pension etc). He also presented a list of what's important to stroke survivors in terms of quality of life – relating to society, family and personal considerations. The organisation also has a publications area, and WSO has a 'patient education repository', that has no copyright so any member organisation can easily use it. The COPE Technique manual should be created, since it can then be published everywhere.

### **Presentation on stroke clubs**

The Netherlands has over 100 regional groups, all run by volunteers, which focuses on exercise, language training, art painting, music but also organizes excursions and day trips, said Lineke from Netherlands. A major issue for the stroke survivors there is aphasia. But through national and annual activities the organisation is trying to change people's perspective and make them realize that it is important to be aware that you can look normal on the outside but that there could be a lot going on inside in terms of how coping with the impact of stroke.

Peer groups are immensely important, but also that the people coming there are not miserable individuals sitting in a circle, but positive people who are there to give each other support and mutual understanding.

The main activity in Norway now is to establish more stroke clubs, as they are the most important part of the organisation, said Arne from Norsk Forening for Slagrammede. They are prepared to give new organisers administrative assistance in the registration process, the access of funding and are willing to provide some seed funding. As for the reaching out, Norway has provided three publications concerning Stroke – a leaflet for the European Stroke Day, brochures from stroke survivors and a new website.

When it comes to the outreach, the Swedish Stroke Association has 79 member organisations with over 9 thousand members, including stroke units and staff, said Kjell, the general manager of STROKE-Riksförbundet . The only people that are not in the organisation are the patients still in the acute phase, so the plan is to visit the rehab and healthcare units and meet stroke survivors when they need help the most. For the National Stroke Day, it plans to organise events, concerts and meetings with stroke survivors.

## **Supporting Supporters and Volunteers**

The main issue in Latvia, as Inese from ParSirdi.lv, stated, is that untreated atrial fibrillation causes 40% of all strokes, and that the patients are being treated with old medicines, if they get treated at all. The main purpose of the organisation now is fighting for access to new medicines for AF and to raising awareness of AF. They are organising different events in order to talk to patients about new treatment alternatives. Apart from holding educational events for National Stroke Day and World Stroke day, the organisation is quite active on social media, with FB being used primarily for patients and Twitter for influencers. The plan is to publish different articles in various Medias about patients' experiences and emphasize that „Untreated atrial fibrillation is just like a Russian roulette“.

Finland held a successful stroke awareness campaign where the main objectives were to raise awareness of hypertension as the most common risk factor for stroke, urge people to get regular blood pressure tests, change their lifestyle. During the campaign they measured over 10 thousand people's blood pressures via 100 measurement points, which exceeded all targets by 20%. The campaign won World Stroke Organisation's award for the Best campaign in a high income country in 2015. This year they are aiming higher and hope to have an even better campaign, by using social media add-ons and the website as a hub, and by upping the broadcast media channel activities.