

SAFE Regional Meeting Athens 2016

SAFE's first regional conference for 2016 was in **Athens, Greece**, where our host organisation Hellenic Action for Stroke welcomed delegates from Israel, Catalonia, Italy, UK, France, Spain and Portugal, and Malta, plus Miquel Gallofré, Stroke Programme Director from Catalonia and SAFE's representative in ESO.



Our Greek hosts emphasized the importance that information plays for stroke care professionals. For stroke survivors, peer support groups have more benefits as the patients relearn to socialize. When it comes to support groups, stroke survivors in Greece prefer online groups because they are more flexible. The key issues and challenges are „the Greek factor“ – lack of history with group support, and challenges in unitary healthcare. But Greece's strengths are that it has a great network of highly educated professionals, whose role should be to organise those patient support groups and achieve active participation.

Israel has a very impressive history of well organised Stroke Clubs. As Pnina from Israel stated „there are 16 clubs for survivors and their spouses in Israel, with 600

members. The problem that they have come across is that there are different age generations in the same groups, which is something that is universal for all support groups across Europe, so they are considering making different groups based on different interests.

In Catalonia, the situation is very different. As Eli from Catalonia, a stroke survivor and founder of ICTUS foundation said, the main issue for stroke survivors is what to do with their lives after the stroke. ICTUS now acts as an umbrella providing national campaigns and supporting research, and it gives each local association concrete support. It offers a wide range of services and activities, such as rehabilitation, counseling and leisure activities. It also developed a telethon as a very significant source of funding. Apart from their field work, they also use the internet and Facebook for reaching out to stroke survivors, but in her opinion it is not an ideal platform for reaching patients, especially the ones in the acute stage.

In Italy the focus has shifted from stroke survivors to stroke carers, since, as the representatives of Italian Stroke organisation Nicoletta and Fancesca stated, over 3 million people in Italy are stroke caregivers, among which half are children, a third are the spouse, and 169,000 carers are teenagers 14-15 years old. So the organisation is now advocating for the rights of the carers. Aside from developing online courses for paid stroke carers, a Family Carer Act has been achieved to support the role, recognition, empowerment, rights, value of carer and their interaction with the government, health services as well as the civil society.

In 2014 the UK stroke association launched „My Stroke Guide“ a key resource in providing information and help for stroke survivors and carers. Stroke survivors can also find a digital self-management tool at www.mystrokeguide.com, which focuses on secondary prevention. Each guide contains an overview, and 250 videos on essential guides for stroke survivors, constantly adding new content which includes a survivor/carer and a HCP. Since 2015, the guide has been available in 17 different areas of the UK as an NHS Commissioned service. The plan for future development is to make it a free access digital tool for all stroke survivors by 2017.