



# **STROKE ALLIANCE FOR EUROPE**

## **Membership Information Pack 2022**

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## About SAFE

Stroke is the leading cause of adult disability and one of the biggest killers across Europe. It is predicted that by 2040, there will be 12 million people living with stroke in Europe - an increase of 35% on the current figure of nine million stroke survivors<sup>1</sup>.

SAFE's vision is to greatly reduce the number of strokes in Europe and ensure all those touched by stroke get the support they need.

We engage in activities such as strengthening our SSOs, advocate at the European and national country level, and encouraging research, all of which contribute to the advancement of stroke prevention and the improvement of the quality of life of stroke survivors, their families and carers.

We are a non-profit-making organisation, representing a range of SSOs across Europe. Formed in 2004 in Brussels with a membership of eight European SSOs, we now have 36 members in more than 30 European countries.

## What have we achieved?

### Advocating for stroke

Our first strategic priority is to raise the profile of stroke and advocate for change at the European and national level. We do this through:

- Identifying issues and taking action
  - In 2018 we published the Burden of Stroke in Europe and in 2020 we published the Economic of Stroke in Europe
  - In 2018, in collaboration with the European Stroke Organisation, we published the Stroke Action Plan for Europe (SAPE). In 2021, as co-chair of the SAPE implementation committee with the European Stroke Organisation, our aim is to develop country specific stroke action plans using SAPE as a foundation. To date there are 48 SAPE national coordinators in 52 countries. The committee also launched the Declaration to implement the SAPE, the National Stroke Plan template, the Essentials of Stroke Care, the Services Stroke Tracker and the SAPE website.

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<sup>1</sup> A What Cost, the Economic Impact of Stroke in Europe, 2020, [www.safestroke.eu/economic-impact-of-stroke/](http://www.safestroke.eu/economic-impact-of-stroke/)

- Raising the profile of stroke at the EU level - we joined the European Alliance for Cardiovascular Health in 2021 and worked to ensure that stroke was an equal partner to the heart in the collaboration in the build up to the launch event on World Heart Day. This, plus the work of many others, led to the EU Healthier Together Non-Communicable Diseases Initiative launch at the end of 2021.
- Working with key stakeholders at the European level - in 2021 we researched and identified key MEPs with an interest in health and stroke. We also created an education briefing document to send to them with our introduction email. We secured the support from the European Stroke Organisation for our work, plus the support of the following allied health professional organisations: Council for Occupational Therapists for European Countries, Europe Region World Physiotherapy, European Federation of Nurses Associations, European Speech and Language Therapy Association and the International Council of Nurses.

### **Strengthening stroke support organisations (SSO)**

Our second strategic aim is to strengthen stroke support organisations throughout Europe. We do this through:

- Holding member's meetings – in pre-COVID times we held two to three in-person meetings each year throughout Europe, and during the pandemic we have continued this with virtual meetings. These provide networking and knowledge sharing between established and fledging SSOs. These meetings have resulted in many new SSO's being set up across Europe.
- Providing advocacy tools - to ensure our members are equipped to be stroke advocates throughout Europe. We have done this through:
  - Our advocacy e-learning tool Stroke Support Organisation Faculty Tool (SSOFT) launched in 2018. It contains six training modules covering how to set up and grow an organisation, how to use research, the importance of the patient voice, through to advocacy in both the public health care system and public facing media. SSOFT has been used internationally resulting in over 1,900 registrations and over 1,600 certificates being given across all modules.
  - In 2021, to support SSOFT, we launched the SMART programme, which provided a series of advocacy training events for SSOs and SAPE-E national coordinators. The topics including how to write an advocacy strategy and how to work with policy makers and the media. The training sessions are available on our YouTube channel.

## **Raising awareness of preventing stroke**

90% of strokes can be prevented, therefore our third strategic priority is to raise awareness of stroke prevention. In 2018 we launched [www.strokeprevention.info](http://www.strokeprevention.info) a dedicated stroke prevention website available in six languages, containing easily understandable information and advice on the 10 modifiable risk factors for stroke.

## **Focusing on life after stroke**

Raising awareness of the urgent need to improve life after stroke care and support is our fourth strategic priority.

To address this, in 2021, we launched our European Life After Stroke series, to raise the profile of life after stroke, to discuss research and best practice, and hear the stroke survivor view. We held three webinars: Priorities, challenges and ways forward, Intimacy and sex; and Caring for the care-giver. We had a global audience and over 1,500 attended. The series was endorsed by the European Brain Council, European Federation of Neurological Associations, the European Stroke Organisation and the World Stroke Organization.

In 2022 the series was accredited by the European Accreditation Council for Continuing Medical Education (EACCME®).

In addition, we aim to provide health information to those affected by stroke. In partnership with the Angels initiative, we produced the 'Surviving Stroke' brochures to help patients understand more about their condition, be more actively involved in their treatment decisions and learn more about the important next steps to recovery. The brochures are also positively influencing communication between healthcare professionals and patients. These are available in 15 different languages across Europe.

## **Supporting stroke research across Europe**

Our final strategic priority is to support stroke research throughout Europe. Since 2011, we have been involved in eight large EU trials. These trials have received funding from the EU Seventh Framework Programme and the EU Horizon 2020 research and innovation programme. Our role, along with our members, is to disseminate information and results from these projects. In 2021, 20 of our members supported this, translating the information, and sharing it through newsletters, websites and social media throughout Europe.

## 2022 priorities

### **Advocating for stroke – we will:**

- continue our work with the SAPE implementation committee and ensure the workplans remain focused on improving patient outcomes and cover the whole care pathway including rehabilitation and life after stroke. We will continue to support national coordinators in their role to achieve a national stroke plan in each country.
- launch our ‘A life worth living’ Needs and Wants report by Kings College London, which sets out an inventory of needs of those affected by stroke. This could help to inform checklists and guidelines of possible long term unmet needs.
- raise the profile of stroke in key European and Global health policy initiatives: the EU plan “Healthier Together – an EU Non-Communicable Diseases Initiative” and the World Health Organisation declaration on "Epilepsy and other neurological conditions".
- form the Stroke Interest Group at the European Parliament. This group will include medical and allied health professional organisations, stroke survivors and MEPs. The group will promote our advocacy activities and achieve strong representation of stroke in all relevant health policy initiatives of the EU.

### **Strengthening stroke support organisations – we will:**

- resume in-person members meetings starting in Barcelona in June and a second meeting to be planned for the autumn
- finalise our review of SSOFT which we will relaunch, and engage a wide community of stroke advocates. We will work closely with a select number of advocates, providing peer-to-peer support.
- continue our virtual SMART educational advocacy meetings with our members, 1:1 mentoring and production of relevant training and support material.

### **Preventing stroke – we will:**

- finalise the review of the [www.strokeprevention.info](http://www.strokeprevention.info) and translate the new information into the five languages and re-launch on European Stroke Awareness Day.

### **Focusing on life after stroke – we will:**

- continue the European Life After Stroke series, and host five new webinars covering Self-management, Communication, Meaningful activity, Getting back to work and Fatigue
- start the planning of our 1st in-person Life After Stroke meeting in 2023 in Barcelona.
- review, update and translate the ‘Surviving Stroke’ guides into 12 languages and ensure their distribution to the supporting countries

## **Supporting stroke research – we will:**

- continue to support the dissemination of the six Horizon 2020 projects we are involved in.
- support the launch of three newly funded grants from the EU Horizon 2021 and the Erasmus programmes.
- support the development of new EU research trials throughout 2022.

## **Why join us?**

A key priority for us is the support of our member SSOs, and to ensure their concerns are given a voice in advocacy, in research and awareness programmes, policy, campaigning, and development initiatives.

Our latest member's survey showed that 80% of respondents were either satisfied or very satisfied with their membership of SAFE, 92% agreed or completely agreed that we are an effective voice for the stroke community in Europe and 84% agreed or completely agreed that we provide networking opportunities for our members.

## **As our member, you will:**

- access a range of benefits to help support your work and growth
- help build a network across Europe and strengthen the collective voice of SSOs
- use our logo (after approval) on your materials as appropriate
- enhance our ability to drive change on stroke across Europe. Your logo and membership will be recognised on our website and appropriately in our materials.
- ensure that the voice of stroke survivors and carers is heard in the discussions about policy and stroke resources at both EU and national level

## **What are the benefits of joining us?**

- Access to information, templates and pre-produced campaign and awareness materials and to European level data such as the Burden of Stroke and the Economic Impact of Stroke
- Access to advocacy training such as the online learning the Stroke Support Organisation Faculty Tool (SSOFT) and virtual training meetings
- Patient information translated into the language of your country
- Access to SAFE webinars (for member meetings, our new advocacy training series, and the European Life After Stroke Forum webinar series)
- One free place and one discounted place at the 1<sup>st</sup> in-person European Life After Stroke Forum meeting in March 2023
- At least one free place at regional members meetings
- Opportunities to present at regional members meetings
- Networking with your peers through member meetings and subgroups
- Potential access to finance such as research dissemination funding

- Invitation to SAFE General Assembly meetings
- Board and officer election voting rights
- Eligible to stand for board and officer election
- Access to SAFE member-only online area
- Listing in the SAFE online membership directory
- Right to use 'member of SAFE' logo on corporate materials (upon approval)
- Opportunity to submit conferences and educational activities for SAFE endorsement
- Letters of support from SAFE for national advocacy on key stroke issues
- Regular members only newsletters
- Showcase your work on a European level on our communication platforms such as our website, social media, networks and newsletter.

### **Who can join?**

Our membership creates a community with like-minded organisations. Membership is open to civil society organisations from Europe engaged in supporting stroke survivors. Membership is available via three categories ordinary members, associate members and honorary members.

**Ordinary membership** confers voting rights and full ability to engage in all initiatives and consultations, and to access SAFE streams of funding if appropriate, and support to templates, press releases, the SSOFIT training modules and all other material produced to support members to pursue their goals as SSOs.

Membership of SAFE will confer recognition of the organisation as a supporter of SAFE and the support of the voice of stroke survivors and carers in the stroke world, European (as defined by the World Health Organization) national organisations constituted according to the laws and customs of their country of origin, which represent the voice of stroke survivors and their families, support those at risk of and affected by stroke, and operate with a priority concern for life after stroke.

They will be non-profit, non-governmental organisations. The organisation will be able to demonstrate their involvement with stroke survivors and their families in the community, and that the aims of your organisation are guided by stroke survivor and family priorities.

**Associate membership** is available to organisations, constituted according to the laws and customs of their country of origin, which support those at risk of and affected by stroke, and who do not fulfil the criteria for ordinary membership.

They may be organisations or societies concerned with representing or driving forward the interests of medical professionals or researchers, or health professionals working in stroke related nursing, therapy, research and development. These will often be commercial organisations concerned with the development of treatments, aids, drugs, services, or research.



Associate membership does not confer voting rights and full access to all the benefits of ordinary membership, but may confer access to many benefits such as SSOFT training modules, information and campaign resources, invitations to events and participation in appropriate consultation initiatives, and gatherings. It also confers recognition of the organisation as a supporter of SAFE and the support of the voice of stroke survivors and carers in the stroke world.

**Honorary members** are individuals or organisations, constituted according to the law and customs of their country of origin, which have provided outstanding support to SAFE in furtherance of its objectives. It does not confer automatic voting rights or automatic usage of logo.

### What are the subscription fees?

Annual turnover		Fee 2022*	Fee 2021
< €200,000	=	€ 530.40	€ 530.40
€ 200,000	to € 500,000 =	€ 795.60	€ 795.60
€ 500,000	to € 1,000,000 =	€ 1,081.60	€ 1,081.60
€ 1,000,000	to € 2,000,000 =	€ 2,163.20	€ 2,163.20
€ 2,000,000	to € 3,000,000 =	€ 3,328.50	€ 3,328.50
€ 3,000,000	to € 4,000,000 =	€ 4,328.50	€ 4,328.50
€ 4,000,000	to € 5,000,000 =	€ 5,510.00	€ 5,510.00
€ 5,000,000	to € 6,000,000 =	€ 6,491.60	€ 6,491.60
€ 6,000,000	to € 7,000,000 =	€ 7,574.30	€ 7,574.30
€ 7,000,000	to € 8,000,000 =	€ 8,656.00	€ 8,656.00
€ 8,000,000	to € 9,000,000 =	€ 9,738.50	€ 9,738.50
> €9,000,000	=	€ 10,820.00	€ 10,820.00

### ***Associates – only pay the minimum fee***

\*At the December 2021 SAFE Board meeting, it was agreed, that because of the ongoing pandemic, membership fees for 2022 remain at the same level as the 2021.

### **Join us**

- To become a member, please complete this application form: <https://www.safestroke.eu/membership/>
- For more information, please contact [info@safestroke.eu](mailto:info@safestroke.eu)