

## Membership information pack

### Why is the Stroke Alliance for Europe needed?

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>. They all deserve support and a voice in decision making.

### What does the Stroke Alliance for Europe do?

SAFE is the voice of stroke survivors in Europe. Our overall objectives are to:

- promote awareness and understanding of stroke
- promote prevention of strokes
- identify those at risk of stroke
- improve access to appropriate treatment and care for persons affected by stroke
- improve the quality of life of people affected by stroke and their families and carers
- promote better access to accurate and understandable information about stroke
- increase the priority given to stroke by policy and decision-makers and by healthcare providers
- promote research on stroke and related areas
- co-ordinate the efforts of national stroke patient groups in Europe
- support the growth of stroke organisations reflecting the views of stroke survivors and their supporters.

Our vision is to greatly reduce the number of strokes in Europe and ensure all those touched by stroke get the support they need, including advocating for improvement in stroke care.

We engage in activities such as education, supporting national stroke support organisations (SSOs), campaigning 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. Increasingly we are focusing on co-morbidities, recognising the importance of the link between stroke and conditions such as heart disease, dementia, and diabetes.

SAFE is a non-profit-making organisation, representing a range of SSOs across Europe. SAFE was formed in October 2004 in Brussels with a membership of eight European SSOs. Since then, we have grown to 36 members in more than 30 European countries.

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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/)

## **What has SAFE achieved?**

In 2017, we consolidated our position as the voice of stroke patients, survivors and carers in Europe by signing a memorandum of understanding with the European Stroke Organisation (ESO). We are committed to working together to improve outcomes for stroke patients, survivors and carers, in particular through the implementation of the 2018 Stroke Action Plan for Europe (SAPE). This has involved developing a series of tools including a declaration for ministries of health, a set of SAPE KPIs and basics of stroke care manual all covering the full pathway of stroke care. We've held meetings with representatives from national scientific societies and SSOs from across Europe where we have shared the tools and how to involve patients, survivors and carers and politicians in their advocacy work.

In addition to supporting the growth of SSOs and our membership through holding annual and regional conferences, we successfully collaborate and work at the EU level to raise awareness of stroke, through membership of the EU Health policy forum, holding meetings with MEP's and Commission staff, and by lobbying for improvement in stroke provision and care.

To enhance our policy work, we have produced key European data including the Burden of Stroke in Europe in 2017 and the Economic Impact of Stroke in Europe in 2020. This latest research showed that the number of people living with stroke is set to rise and the cost of stroke is projected to increase by 44% to €80 billion by 2040. However, the research also showed that this burden can be reduced – by using interventions such as prevention treatments for atrial fibrillation, mechanical thrombectomy and community rehabilitation – and that these interventions increase outcomes, tend to generate cost savings and are generally good value for money. Therefore, stroke is an increasing cause for concern but it is a viable investment proposition.

Our Stroke Support Organisation Faculty Tool (SSOFT) is an education and training programme created to support SSOs to strengthen their ability to advocate and influence prevention strategies, diagnosis, treatment and aftercare. Since launch, over 1,000 registrations and over 1,300 certificates have been given across all modules.

The SAFE Angels initiative ensured that selected hospitals in Croatia, Cyprus, Czech Republic, France, Georgia, Greece, Hungary, Latvia, North Macedonia, Poland, Serbia, Slovakia, Spain, Turkey and Ukraine are now able to provide information, in their language, on stroke and important next steps on the path to recovery to stroke patients and their carers. The patient-focused materials on a range of subjects include national, regional and local SSOs contact details, so that patients, survivors and carers can access further support in the months and years following their stroke.

We have been delighted that we have retained all our members and added one more from Spain in 2020. We have also retained all our industry partners and have added two more to the group. SAFE will continue to work on securing its long-term sustainability and look for more partnerships. SAFE is in a strong and confident position for 2021 and beyond.

## **Future priorities**

Looking forward, our new initiatives fall into three arms of work - building a powerful patient voice, raising expectations in stroke care and advocacy.

We will continue our policy work to further the SAPE implementation and will launch a series of advocacy training webinars for our members as well as increasing our activity at the EU level. We will also host a series of short, topic-specific webinars throughout 2021 to build momentum and engagement for our 1<sup>st</sup> European Life After Stroke Forum in March 2022. We will continue to raise the importance of stroke prevention. We hope to bring our members back together again towards the end of 2021 - face-to-face meetings are vital for our membership, and the 2020 pandemic has largely prevented this. We will continue to promote the use of SSOF and the Angels patient information brochures.

In addition, we believe it is necessary to campaign for stroke as a non-communicable disease to be given appropriate attention, and to find sponsors for independent research into the met and unmet needs of stroke survivors and their loved ones during their life after stroke, which will complete the series of four key policy reports on stroke, all of which covered each country of Europe. We also believe it is crucial to support member organisations to recover from COVID-19 and enable sustainability and regrowth.

## **Why join SAFE?**

A key priority for SAFE is the support of its member SSOs, and to ensure their concerns are given a voice at EU level, and in research and awareness programmes, policy, campaigning, and development initiatives.

In 2020, we carried out a member's survey to help us focus our work on patient and member needs. It showed that 80% of respondents were either satisfied or very satisfied with their membership, 92% agreed or completely agreed that SAFE is an effective voice for the stroke community in Europe and 84% agreed or completely agreed that SAFE provides networking opportunities for its members.

## **As a member of SAFE:**

- You will access a range of benefits to help support your work and growth
- You will help build a network across Europe that will strengthen the collective voice of stroke support organisations
- You will be able to use the SAFE logo (after approval) on your materials as appropriate, to demonstrate your engagement with this EU-recognised NGO
- You will enhance our ability to drive change on stroke across Europe. Your logo and membership will be recognised on the SAFE website and appropriately in our materials as necessary
- Your membership ensures that the voice of stroke survivors and carers is more likely to be heard in the crucial discussions about policy and stroke resources, at both EU and national level
- Your membership ensures greater credibility for SAFE and therefore improves SAFE and our members standing with funders and the media.

## What are the benefits of joining SAFE?

- 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 the online learning materials on the SAFE platform, the Stroke Support Organisation Faculty Tool (SSOFT)
- Patient information/Angels literature translation into the language of your country
- Access to finance such as research dissemination funding, and potentially grants to smaller SSOs to enable growth
- 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
- Free access to SAFE webinars (for member meetings, our new advocacy training series, and the European Life After Stroke Forum 2021 webinar series)
- One free place and one discounted place at the 1<sup>st</sup> European Life After Stroke Forum 2022
- One free place at regional meetings
- Opportunities to present at regional meetings
- Networking with your peers through member meetings and subgroups
- 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?

SAFE membership creates a community with like-minded organisations. Our membership is open to civil society organisations from Europe engaged in supporting stroke survivors. SAFE 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 SSOFT 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 Organisation) 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 2021*	Fee 2020
< €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 General Assembly, it was agreed, that because of the pandemic. The membership fees for 2021 would not be increased. The 2021 fees remain at the same level as the 2020.

### 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)