

SAFE ANNUAL REPORT 2019

The Stroke Alliance for Europe

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Stroke Alliance for Europe

Every 20 seconds someone in Europe has a stroke. A stroke does not discriminate. It can happen to anyone at any time in their life. Strokes are sudden and their consequences can be devastating.

The Stroke Alliance for Europe is the leading European patient organisation solely concerned with helping everyone affected by stroke in Europe.

Our mission

We work towards all patients in Europe with stroke having rights of access to a continuum of care. From prevention and risk identification, through emergency response to organised stroke units in acute phase, to appropriate rehabilitation and secondary prevention measures.

Our vision

SAFE's vision is to work towards greatly decreasing the number of strokes in Europe and that all who are touched by stroke get the help and support they need.

SAFE therefore engages in activities such as campaigning, education and encouraging research, which contribute to the advancement of stroke prevention and the improvement of the quality of life of stroke survivors, their families and carers.

President's message



This has been a busy and exciting year for our organisation, especially in terms of advocating on pan-European level. We have continued work around the Stroke Action Plan for Europe, forming an implementation committee with the European Stroke Organisation. We held a seminal event at the EU parliament raising the profile of stroke more than ever before, engaging with the Deputy Director General of the EU's DG Sante and the EU Committee of the Regions. Through our funding of Oxford University's project on the economic impact of stroke, we have produced up to date and compelling evidence about the cost of stroke in Europe. With all this accomplished, we continue to press ahead, as we have now completed the third and final year of the research which will provide us with vital European and country specific data on the future economic impact of stroke and power of interventions. The Economic Impact of Stroke in Europe report will be launched in full at the Joint World Stroke Organisation/European Stroke Organisation conference in Vienna in May 2020.

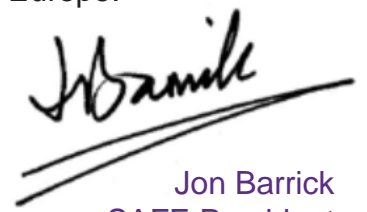
We have continued with the Angels project to produce vital information booklets on stroke to distribute to patients and families while in hospital. We have provided this information in 15 different languages to ensure that more people across Europe can use our materials to improve the lives of stroke survivors.

We continue our educational work with those who wish to understand stroke support organisations and become advocates for better care through our online teaching and learning tool SSOFT, and our regional and working conferences.

A particular highlight for me in 2019 was the concrete evidence of the value of our partnership orientation, our Industry partners have been very supportive again, our outreach to ESO has been reciprocated, and we continue to see the number of SSO's grow, and then become members of SAFE. Yet again we go into a new year with record membership which bodes well for the future.

As SAFE goes from strength to strength in activities to reduce the number and effects of strokes, the Board must also ensure the long-term sustainability of SAFE. The Board has achieved much of its work through dedicated voluntary time but has recognised that this needs to be added to by full time paid staff. The Board agreed that SAFE required more permanent leadership to drive forward and to achieve our goals. I am delighted to let you know that we recruited our first Director General this year and I know you will all join me in welcoming Arlene Wilkie into the SAFE family.

In 2019, we have been able to deliver many significant achievements because of our close working community. I would like to thank those that have worked with and for SAFE this year, and to the members and sponsors who have supported us practically and financially. This next year is my last as President and I am looking forward to ensuring we have a solid 2020 of achievement to strengthen the long-term sustainability of all stroke support organisations in Europe.



Jon Barrick
SAFE President

SAFE 2019

Our 2017-2021 strategy sets out seven priorities that we work towards to achieve our mission and vision:



Prevention of strokes

Stroke has now climbed to become the second biggest cause of death in the world, and the number one cause of severe long-term adult disability. SAFE does not have the resources to combat the disparate cause of ill health across Europe, but we can play a part in more focussed campaigns to ensure that where warning signs appear, or can easily be diagnosed, then action takes place to prevent a stroke.

SAFE's website on stroke prevention: available in five more languages

In 2018 SAFE created the website www.strokeprevention.info, providing key information about 10 modifiable stroke risk factors in a lay-friendly format. We were motivated to do this because, despite compelling evidence that it is a largely preventable condition, around 17 million strokes occur worldwide each year. Stroke shares risk factors with other cardiovascular diseases and with many other non-infectious, or non-communicable diseases.



The aim of this website is to inform and inspire people to take individual steps, such as giving up smoking or taking better control over their blood pressure, and to take an active role in preventing stroke.

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In 2019:

To increase greater accessibility of its content for millions of people who speak these languages, the website was translated to Polish, Spanish, Portuguese, Russian and French and relaunched in autumn 2019.
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Support stroke patients to receive better access to specialist care and rehabilitation

Stroke treatment and care is not a priority in many countries. Provision is unequal across Europe and within member countries. SAFE will put the experiences of people who have had a stroke and their families at the centre of all our discussions, campaigning and lobbying, acting as an advocate at a European level and supporting local level member campaigns.

Angels Initiative and SAFE: improving patient – doctor communication

The Angels Initiative is a unique healthcare initiative launched by Boehringer Ingelheim in partnership with the European Stroke Organisation (ESO), the World Stroke Organisation (WSO) and SAFE.

The Angels Initiative project aims to improve stroke outcomes, save lives and reduce long-term disability. It achieves this by providing information brochures in stroke units to patients and their carers to help them understand more about their condition, and how to actively be involved in their treatment decisions. The SAFE Angels brochures are contributing by positively influencing communication between healthcare professionals and patients. SAFE raises the profile of the Angels Initiative through our stroke support organisations, direct contacts with patients and carers and social media channels.

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In 2019, we have:

1. Provided the SAFE Angels brochures to more European countries

In 2018 the Angels information was made available in the languages of twelve European countries and thirteen languages: Spain, Serbia, Poland, Czech Republic, Latvia, Croatia, North Macedonia, Greece, Ukraine, Georgia, Hungary and Turkey. In 2019, this project expanded to include Slovakia, Cyprus and France.

2. Updated the SAFE Angels brochures based on feedback from patients and medics

SAFE made changes in the format, producing a collection of all five brochures in one specially designed folder. The overarching title is 'Surviving Stroke'. The core texts for all brochures were provided by the Stroke Association UK.

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“ We didn't have similar patient materials in the past. Now that we do, patients often take all five different brochures and even try to take more copies, for relatives and neighbours. ”

Mikheil Shavgulidze, Georgian stroke organisation Mkurnali Foundation

Influencing and campaigning

Stroke is a preventable, treatable and beatable condition, and as a European alliance support organisation we are in a strong position to campaign and lobby effectively at EU level for more resources and awareness of stroke, and to support members to operate at country level.

Translation of the Stroke Action Plan for Europe: reaching wider audiences

The Stroke Action Plan for Europe 2018-2030 (the Plan) is a result of collaborative work between SAFE and ESO, building on the Helsingborg Declarations of 1995 and 2006, and includes two new domains: primary prevention and life after stroke. The final report was published in 2018 after 18 months work involving over 70 experts in stroke prevention, treatment, rehabilitation and aftercare, as well as stroke advocacy.

In 2019 SAFE:

1. Translated the Plan to increase accessibility to more European countries

To ensure that the Plan is used by as many countries as possible, SAFE translated it to French, Portuguese, Russian, Polish, Spanish, Ukrainian, Finnish, Turkish, Norwegian and Greek.

2. Promoted the Plan to encourage its implementation

The first of these activities was at the ESO conference in Milan, when we had the printed versions available at our stand. The Plan was also promoted at SAFE's regional conferences. The pdf version of the Plan was promoted through SAFE's website and social media in each of the ten languages, together with the English version.

The Economic Impact of Stroke in Europe Report: How much does stroke really cost in Europe?

Following the successful cooperation with King's College London and the launch of the Burden of Stroke in Europe report in 2017, SAFE commissioned its next key piece of research: the economic impact of stroke in Europe.

The goal of this study, carried out by a health economics team from the University of Oxford in England, is to increase the priority given to stroke, and reinforce and underpin the influencing of European and country-level policy work already underway as a result of the Burden of Stroke in Europe report.

Recent modest improvements in acute care mean that more people are surviving stroke, but with impairment. The consequence being that we have a major health economic and social burden catastrophe waiting to happen. This will severely impact all European countries, but especially those where inequalities in stroke healthcare are already known.

The research has been divided into three parts: the current cost assessment; future costs projections in case of business as usual; and the impact of interventions on future costs, both on pan-European and country by country level. The findings will be used by SAFE and partner organisations to build a case for investment in different areas of the stroke care pathway.

The first part of the research, the current costs, was published in 2019. It provided a breakdown of the analysis for each country into direct healthcare, direct non-medical and indirect costs, covering the costs in social care services, and the wider societal and family and carer, such as days of income lost due to disability, payments in day care, welfare and nursing home costs.

SAFE presented this data to its members at the annual working conference end of November 2019, continuing after that to promote the findings through SAFE social media channels, as well as through SAFE member organisations' networks.

SAFE will present the latter two parts of the research at the joint WSO/ESO conference in May 2020 in Vienna, creating a synergy of multi-organisation joint efforts and maximising the impact of the report's key findings. The launch will raise the profile of the issue that stroke costs and the implications of not doing anything. It will bring the issue to the forefront across a wider audience, including government and policy-makers.

Joint event with Romanian Presidency of the Council of the European Union

The event 'Joining forces to prevent and control non-communicable diseases: The role of policy in tackling stroke' took place in Brussels, at the Committee of the Regions. The event, held under the patronage the Romanian Presidency of the Council of the EU, was organised by SAFE in collaboration with ESO and the Romanian National Association of Stroke.

The event brought together European, national and local policy stakeholders to foster discussions on the need for policy action in the area of stroke. In particular, as identified by SAFE's Burden of Stroke in Europe report, the disparities between and within European countries across the stroke care pathway, from primary prevention to life after stroke, was addressed as a priority. The event also looked into the role policy and policy stakeholders play in achieving the targets of the Stroke Action Plan for Europe 2018-2030. We hope that the discussions will feed into the Romanian and upcoming Finnish and Croatian presidencies' health priorities, as well as current and future EU action for preventing and controlling non-communicable diseases.

SAFE and ESO are following-up with key speakers and participants to move forward the identified opportunities. Joining forces with EU policy-makers to address the burden of stroke that stroke survivors, their families and the overall society are currently facing is essential



Photo: SAFE

Grow and support stroke support organisations

We want to increase the number of organisations, and the groups of stroke survivors and carers associated with them, across Europe, and help our members to share good practice, experiences and learning and enable sustainability and growth.

Stroke Support Organisation Faculty Tool: online training for our members

SAFE, in partnership with the European Stroke Organisation (ESO), identified a need to support members to become strong and positive advocates, so that they can campaign for improved prevention strategies, diagnosis and treatment for stroke, as well as aftercare of survivors and their families. To this end, an online eLearning tool, the Stroke Support Organisation Faculty Tool (SSOFT), was co-created with SAFE members to educate people on the principles of stroke advocacy.



Stroke Support Organisation Faculty Tool

In 2019:

This project was successfully launched in 2018 and consists of six modules: what is a stroke support organisation, what is advocacy and how is it done, the use of evidence, the role of the patient voice, health systems advocacy and public advocacy

Its implementation started in 2019, by promotion through SAFE's social media channels, and SAFE organised meetings with member organisations. To date, around 350 people from across Europe have used this training course to learn more about stroke advocacy.

“ The SSOFT learning tool gave me all the knowledge and information about stroke and other speech and language disorders. I really like helping those in need. When you offer help without propriety, without expecting a reward, it gives you a feeling of satisfaction and completeness. SSOFT helped me understand and obtain all the necessary information I needed. ”

Maria Karadimou, teacher.

SAFE regional and working conferences: bringing our members together

SAFE has organised a working conference each year since forming in 2004 – as well as regional conferences for the last five years. Delegates come together to share best practice, skills and experience, and the conferences have played a key part in nurturing and encouraging the growth of stroke patient organisations across Europe. The conferences also provide an opportunity for SAFE to update its members on progress against strategy, with updates on specific key projects, and policy and influencing work. We use the conferences to guide members on how to use resources produced for their advocacy work, to best effect change and raise awareness of all the issues in their own countries.

“ As always the conference provided delegates with nothing but the best. Actual topics, interesting workshops, igniting many ideas for next year, getting useful information. It was all excellent. ”

In 2019:

SAFE brought together 30 European countries from member organisations gathered within their clusters in Paris, Krakow and Stockholm for our regional conferences. At these meetings SAFE updated members on its strategy, its projects including SSOFT, the prevention website and the economic impact of stroke research, its policy work including the Stroke Action Plan for Europe and the Romanian Presidency event in the EU.



Research

Research evidence has led to the development of real improvements in stroke prevention, treatment, rehabilitation and care. SAFE has a unique role to play as a stroke support organisation being a visible, pro-active member and advisor to project consortia, disseminating information about research projects through our members.

SAFE's profile amongst the clinical research community in Europe is now higher than it has ever been. This is evidenced by the fact that we had a record number of approaches this year to support research proposals in various ways. These range from simple letters of support, or patient surveys that provide opinion on a research topic, through to full-blown participation by SAFE in a research consortium.

In 2019:

1. We supported 13 research proposals in the following three categories:

Full research and innovation projects

CELLSTROKE – stem cells and acute stroke

EVERBRAIN - extracellular vesicles and brain regeneration post-ischaemic stroke

MICROBIOSsIS – the role of the gut microbiome in post-stroke comorbidity

ACIST – N-Acetylcysteine and intravenous thrombolysis in ischaemic stroke

AURORAS - uric acid and reperfusion in acute stroke

ANGIE – micro-robots to treat thrombolysis

PhD student training networks

ENTRAIN – neuroinflammation and stroke

ADVANCE – image analysis and prediction modelling of stroke outcome

CRANIA – neuroimaging analysis of stroke in the elderly

PRONEST – personalised robots and stroke rehabilitation

European Commission funding for Small and medium-sized enterprises programs

STROKEWATCH – new wearables to detect Atrial Fibrillation

DEEPSTROKE – intelligent image analysis for fast, accurate triage in stroke

GONDOLA – novel foot stimulation and walking rehabilitation

2. SAFE was involved as a paid beneficiary of the following five EU Horizon 2020 research projects and contributes to the dissemination of information about each of them:

PRESTIGE-AF – how do atrial fibrillation drugs affect stroke?

TENSION – is thrombectomy effective up to 12 hours post-stroke?

PROOF – high-dose oxygen therapy in acute stroke

PRECIOUS – common complications and acute stroke

SVDs@Target – small vessel disease and its role in stroke

Governance and resources

To deliver our strategy we will generate the resources required to sustain and develop SAFE. We will maintain partnerships that help to deliver our strategy.

At our 2018 General Assembly, held after the working conference in Berlin, the following key decisions were made:

- Three board members were elected: Grethe Lunde from Norway (Norsk forening for slagrammede (NFS) as the North Cluster Representative, Chris Macey from Ireland (Irish Heart Foundation) as Treasurer and Marina Charalambous from Cyprus (Cyprus Stroke Organisation) as board member at large.
- Two new organisations were ratified and became full SAFE members: Porážka.sk from Slovakia and CEREBRUM from Czech Republic.
- In addition, SAFE awarded grants to the following SSOs in: Catalonia, Croatia, Cyprus, Iceland, Portugal, Serbia and Turkey for their work in fighting stroke, supporting survivors and their families, and building the patient voice during 2018.

SAFE 2020

In 2020, we will:

- Launch the Economic Impact of Stroke in Europe report
- Host the Life After Stroke forum
- Actively participate in the implementation of the Stroke Action Plan for Europe
- Lobby within the EU to make stroke a European health priority
- Host three regional conferences
- Scope a stroke survivor wants and needs survey
- Promote SSOFIT
- Work with the Angels Initiative
- Promote strokeprevention.info
- Represent, communicate and work with our members and supporters
- Fully review our governance, policies and procedures

SAFE governance 2019

SAFE has functioned as a legally registered, nonprofit-making association in Belgium (AISBL) since 2004. The principles which govern SAFE are outlined in our constitution.

General Assembly

The General Assembly is comprised of all the ordinary member organisations of SAFE and its principal responsibilities include electing the board and its president, approving the admission of new member organisations, approving budgets and annual accounts.

Board

SAFE is governed by a board that can comprise no fewer than five and no more than eleven members. The board has four key positions: President, Vice President, Treasurer and Secretary. The 2019 SAFE board:

President

Jon Barrick, UK

Vice president

Markus Wagner, Germany

Secretary

Monique Lindhout, Netherlands
(resigned June 2019)

Marina Charalambous, Cyprus
(co-opted as Secretary June 2019)

Treasurer

Grethe Lunde, Norway
(resigned as Treasurer November 2018)
Chris Macey, Ireland
(appointed November 2018)

Members

(East Europe), Ivan Milojević, Serbia
(Central Europe), Anita Arsovska, North Macedonia
(South Europe), Pnina Rosensweig, Israel
(North Europe), Grethe Lunde, Norway
(appointed November 2018)
(West Europe), Hariklia Proios, Greece

The Board met four times in 2019. Its role is to monitor implementation of SAFE's strategic plan and provide policy and procedural direction, and to supervise the finances.

Staff

SAFE has a team of five people to coordinate its work:

Secretariat

Sandra Jackson

Fundraising and Partnerships Manager

Lucinda Shaw

Research Manager

Gary Randall

Advocacy and Awareness Manager

Jelena Misita

Director General

Arlene Wilke (appointed September 2019)

Sandra and Lucinda are based at the Stroke Association offices in the UK, but report directly to the SAFE board on their activities. Our thanks to the Stroke Association for hosting these roles. Our grateful thanks go to Gary for continuing to generously support SAFE in this important role on a pro bono basis.

SAFE members in 2019 **

Austria	Schlaganfall-Hilfe Österreich
Belgium	Belgische Vereniging tegen cerebrovasculaire accidenten
Catalonia	Fundacio Ictus
Croatia	Croatian Stroke Society
Cyprus	Cyprus Stroke Association
Czech Republic	Sdružení pro rehabilitaci osob po cévní mozkové příhodě
Czech Republic	CEREBRUM
Finland	Aivoliitto ry
France	France AVC
Georgia	Medical Foundation “Mkurnali”
Germany	Stiftung Deutsche Schlaganfall-Hilfe
Greece	Hellenic Action / Alliance for Stroke
Hungary	National Stroke (Prevention and Rehabilitation) League
Iceland	HEILAHEILL
Ireland (Republic of)	Irish Heart Foundation
Israel	Neeman Association for Stroke Survivors
Italy	Associazione Lotta Ictus Cerebrale (ALICe)
Latvia	Parsirdi.lv
Luxembourg	BLËTZ, asbl
Macedonia	STROKE Ohrid
Netherlands	Hersenletsel.nl
Norway	Norsk forening for slagrammede
Poland	Stroke Foundation
Portugal	Portugal AVC
Serbia	Udruženje Moždaniudar
Slovakia	Porážka.sk
Slovenia	Združenje bolnikov s cerebrovaskularno boleznijo
Spain	Federacion Espanola de Ictus
Sweden	STROKE-Riksförbundet
Turkey	Beyinder
United Kingdom	Stroke Association
United Kingdom	Different Strokes
Ukraine	School for Stroke Survivors (SSS) “Victory over the stroke”

** these member organisations are either dedicated stroke patient organisations or organisations where work for and with patients makes up an important part of their activities

SAFE finances 2019

Message from the Treasurer

In 2019, income was €615,743.07 (€825,931.61 in 2018)
This decrease was due to sponsorship received in 2018 for 2019 projects (€300,000 was accrued in the 2017 and 2018 accounts).

- Membership income grew to €47,448.00 (€40,770.00 in 2018) due to a slight increase in membership fees and in the number of members.
- Sponsorship grants were received from Amgen, Angels, Bayer, BMS-Pfizer Alliance, Boehringer Ingelheim, Ipsen and Allm. Our continued sponsorship from these organisations reflects a number of important initiatives for which we successfully secured funding. We hope to continue our relationships with these organisations, whilst always looking for new ones.
- The €43,609.12 (€55,955.82 in 2018) received from partnerships with European research organisations shows SAFE's continuing importance to the consortium involved in these research projects. The decrease in income was due to no new projects starting in 2019.
- Our thanks go to all our supporters in 2019 for their continued support and recognition of the importance of the voice of the stroke survivor.



Expenditure was €607,193.66 (€872,778.38 in 2018). This decrease was mainly due to large projects such as the Stroke Support Organisation Faculty Tool development, the Burden of Stroke Report and the Romanian Presidency event in the EU, that were undertaken in 2017 and 2018.

Consolidated statement of financial activities year ended 31st December 2019

	2019 (Euro)	2018 (Euro)	2017 (Euro)
Income			
Sponsorship Income	523,947.00	729,116.00	601,788.78
Membership fees	47,448.00	40,770.00	25,100.00
European research project funding contributions	43,609.12	55,955.82	32,042.54
Miscellaneous income	738.95	89.79	1,668.38
Total Income	615,743.07	825,931.61	660,599.70
Expenditure			
Meetings (board, industry and other)	20,576.86	24,676.54	23,404.31
Conferences (working, regional and external)	163,789.24	177,313.64	169,711.86
Staff costs	160,460.35	125,103.32	82,147.57
European research project dissemination to membership	17,929.51	26,686.94	9,891.00
Project costs	100,537.45	346,341.67	57,880.79
SAFE report costs	49,487.48	128,590.45	40,381.75
EU lobbying agency costs	69,654.85	18,407.13	40,704.00
Membership of other organisations	0.00	808.98	808.98
Professional fees and bank charges	2,639.31	4,951.96	14,289.25
Core costs	22,118.61	19,897.75	75,277.67
Cash moved to create a reserve	-	-	200,000.00
Funds accrued		-	300,000.00
Total Expenditure	607,193.66	872,778.38	1,014,610.93
Surplus/Deficit	8,549.41	-46,846.77	-345,044.23
Reconciliation of funds			
Total funds brought forward	317,262.51	*364,109.28	418,120.51
Reserves	200,000.00	200,000.00	-
Total funds carried forward	528,290.62	517,262.51	64,109.28
Cash at bank 31 December 2019	611,793		
Current liabilities	83,503		-
Total funds carried forward	528,290		

*Note: Includes €300,000 accrued in 2017 for 2018 and 2019 expenditure

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Stroke Alliance For Europe

**THE STROKE PATIENT
VOICE IN EUROPE**



SAFE is a non-governmental, non-profit organisation

ASBL No. 0661.651.450