
S·A·F·E

Stroke Alliance For Europe

**THE STROKE PATIENT
VOICE IN EUROPE**



2020

ANNUAL

REPORT

The Stroke Alliance for Europe

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Stroke Alliance for Europe

There are nine million people living with stroke in Europe. It does not discriminate. A brain attack can happen to anyone at any time in their life. A stroke can be sudden and life-changing and the long-term consequences devastating.

The Stroke Alliance for Europe is the stroke patient voice in Europe, representing a range of European stroke support organisations.

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 greatly reduce the number of strokes in Europe and ensure that all those touched by stroke get the help and support they need.

SAFE 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.

Message from SAFE's Presidents

With more than nine million people living in Europe with the devastating effects of stroke and with numbers expected to increase, we must continue to shout, even in the midst of a pandemic, that stroke still matters and must be a priority for health and social care across the continent.

COVID-19 has affected every aspect of our lives, putting healthcare systems under tremendous strain, diverting attention from pressing health issues such as stroke. Stroke support organisations throughout Europe have reported a reluctance of people to report their stroke symptoms or to attend hospital; stroke units were used to treat other patients at the height of the pandemic; stroke patients were discharged early without the appropriate support, and outpatient visits and much rehabilitation were halted.

Our members told us of the devastating affect the pandemic has had on the ability to deliver services and raise funds to remain sustainable. At SAFE, we have been amazed and inspired by how stroke survivors and their families, stroke support organisations, medics, nurses, therapists and researchers have adapted and coped during this time.

SAFE has also had to adapt and change as a result of the pandemic, but we have had a solid year of achievement to strengthen the long-term sustainability of stroke support organisations across Europe. I know we will all have to work doubly hard in the next few years to keep SAFE and SSO's sustainable.

I have been involved in SAFE for 12 years, the last six as President and I have always believed that SAFE could make a difference to the quality of life of stroke survivors, and to improve the possibilities of surviving a stroke, and that change for the better can be achieved. I have met some truly inspirational people through and in SAFE and it has been so rewarding to support the growth of stroke support organisations throughout Europe.

In this my last year as President, 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.

To be President of SAFE is a privilege given to few. As I handover to Harriet, I wish SAFE a fruitful and successful future in the years ahead.



Jon Barrick, President to November 2020

I would like to thank Jon for his immense fantastic contribution to SAFE over the years. During my tenure as President, SAFE will continue leading a number of important projects, the successful completion of which will be of top priority in the next couple of years. These projects include the Stroke Action Plan (2018-2030) and the European Life After Stroke Forum.

SAFE will continue to promote the Economic Burden of Stroke to member countries and to advocate on complex stroke issues including regional inequalities, diversity and gaps in stroke care.

We realise that we have a big role in instituting knowledge and education by raising expectations of what quality of stroke care should be. My ambition is to embrace all our members' interests and together continue to increase public awareness about stroke as a strategic priority across Europe.



Hariklia Proios, President from November 2020

SAFE 2020

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



Prevention of strokes

Stroke is the second leading cause of death globally and in Europe the number-one cause of severe long-term adult disability. SAFE raises awareness to ensure that when warning signs appear, or can easily be diagnosed, stroke can be prevented.

In 2018, SAFE created the website www.strokeprevention.info providing key information about 10 modifiable stroke risk factors in a lay-friendly format. Stroke is a largely preventable condition, but there are around 1.5 million strokes each year in Europe. Stroke shares risk factors with other cardiovascular diseases and many other non-infectious, or non-communicable diseases.

The aim of the 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. The website is now available in French, Polish, Portuguese, Russian and Spanish.

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In 2020:

The pandemic has worsened the stroke burden, having a major impact on all aspects of health service delivery across the stroke care pathway as well as stroke prevention. Fewer people are accessing timely stroke care and those at risk of stroke have a poorer outcome if they contract COVID-19. A stroke means you are at greater risk of getting complications like pneumonia if you have had the infection and evidence has shown that COVID-19 patients are at higher risk of having a stroke.

These are all important messages to be communicated, and since spring, we have been raising awareness of the issues around COVID-19 and stroke prevention, through our own channels and to our members.

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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 puts the experiences of stroke survivors and their families at the centre of all our discussions, campaigning, acting as an advocate at a European level and supporting local level member campaigns.

Giving stroke patients a voice

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

The project provides five patient-focused brochures on a range of topics at stroke units in their language to help them understand more about the condition and how to be actively involved in treatment decisions as well as support effective communication between the patient and their healthcare professional. The aim is to improve stroke outcomes, save lives and reduce long-term disability

SAFE raises the profile of the Angels Initiative through our stroke support organisations, direct contacts with patients and carers and social media channels. We have translated the Angels information in 16 languages. The Stroke Association in the UK provides the content for the patient information.

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In 2020:

We ensured that selected hospitals in Croatia, Cyprus, Czech Republic, France, Georgia, Greece, Hungary, Latvia, 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 five brochures include national, regional and local stroke support organisations' contact details, so that patients and carers can access further support in the months and years following their stroke.

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Influencing and campaigning

As the voice of the stroke patient in Europe, SAFE campaigns at the EU level for more resources and awareness of stroke. We also support members with their advocacy work, operating at a country level.

Making stroke a priority across Europe

The Stroke Action Plan for Europe 2018-2030 (SAPE) is a result of collaborative work between SAFE and ESO, building on the Helsingborg Declarations of 1995 and 2006. 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. To ensure SAPE is used by as many countries as possible, SAFE translated the plan into Finnish, French, Greek, Norwegian, Polish, Portuguese, Russian, Spanish, and Turkish and printed versions were promoted at the ESO conference, SAFE's meetings, our website, social media and other channels.

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In 2020:

We worked on the SAPE as part of the ESO-SAFE implementation committee. This involved developing a series of tools including a Declaration for ministries of health, a set of SAPE KPIs and Basics of Stroke Care Manual covering the full pathway of stroke care. We also held meetings with representatives from European national scientific societies and stroke support organisations where we have shared the tools and presented on how to involve patients and politicians in their advocacy work.

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A life saved is a life worth living

Survivors of stroke discharged from a largely medicalised pathway enter a world where support is usually unclearly defined, often fragmented or non-existent. People in their new post-stroke life face problems caused by stroke-related disabilities, often complicated by co-morbidities, and a broad range of additional issues. These challenges are compounded by the current situation whereby little research is directed to these areas and the voice of people surviving stroke is not heard. Life after stroke is a key priority within SAFE's overall strategy.

There is a need to promote research into all aspects of life after stroke, and to build support around the needs and wants of stroke survivors and their families. However, currently few opportunities exist regarding conferences, workshops, and shared networking events for advocates and researchers in this neglected, but vital area of care. SAFE has committed to organising an annual European Life After Stroke Forum to create a broad network of stakeholders involved in professionally researching, advocating and providing evidence for improved life after stroke care.

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In 2020:

Due to the pandemic, we had to postpone the 1st European Life After Stroke Forum planned for 2020 in Barcelona and reconfigure as a series of virtual webinar events in 2021. These life after stroke events are an ideal opportunity to build the life after stroke healthcare, research and patient community, stimulate debate and ultimately improve life after stroke care and build interest for our 1st European Life After Stroke Forum in 2022.

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The Economic Impact of Stroke in Europe

SAFE commissioned the health economics team at the University of Oxford, England to undertake research on the economic impact of stroke in Europe. The aim is to provide evidence to support our campaign for more investment in the stroke care pathway and underpin our influencing activity at the European and country-level.

The research looks at the current costs; 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 first part of the research - the current costs - was published in November 2019. It is the first research to show the full economic burden of stroke and includes healthcare, social care, informal unpaid care and societal costs (such as days of income lost due to death and disability).

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In 2020:

We launched the Economic Impact of Stroke in Europe report at the virtual ESO/WSO congress in November. The research showed that if things stay as they are, the number of people living with stroke will increase 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 generally good value for money for all countries involved in the research.

Stroke is an increasing cause for concern but it is a viable investment proposition. Our call to action is that policymakers and health planners need to act now to improve outcomes and reduce the burden of stroke in Europe.

Grow and support stroke support organisations

We want to increase the number of organisations and 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.

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. 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.

This online learning tool was 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

In 2020:

We have encouraged the stroke community to use SSOFT. Since its launch, it has been used across the world – resulting in over 1,000 registrations and over 1,300 certificates being given across all modules. Comparing 2020 vs 2019 there has been a 25% increase across all web metrics (visits and page views).

SAFE 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 six years. Delegates come together to share best practice, skills and experience and play a key part in nurturing and encouraging the growth of stroke patient organisations across Europe. The meetings also provide an opportunity for SAFE to update its members on progress against strategy, 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 the issues in their own countries.

In 2020:

Due to the 2020 pandemic, our Board made the decision not to hold its face-to-face regional conferences in 2020. We held two virtual meetings in June and November attended by over 100 people. Themes for the events were the impact of COVID-19 on stroke support organisations and stroke survivors, and life after stroke respectively.

In addition:

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.

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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 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. 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.

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

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In 2020:

We provided support in developing a funding proposal for the EU H2020 research and innovation programme. The ANGIE research project (FETPROACT-EIC-05-2019) aims to develop micro-robots to treat thrombolysis.

We undertook interviews with a prominent project researcher for each of the five research projects. The interviews were translated into 20 native languages and disseminated across 19 member countries (Croatia, Cyprus, Czech Republic, Germany, Georgia, Greece, Hungary, Italy, Macedonia, Netherlands, Norway, Portugal, Ukraine, Serbia Slovakia, Slovenia, Spain, Turkey and UK) as well as SAFE's own channels.

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Governance and resources

The pandemic has had an impact on how we deliver our strategic objectives. All our face-to-face work with the board and members stopped, and we had to replan 100% of our activities. It allowed us to focus, recharge and strengthen the work we are doing. We are more determined than ever before to achieve our aims and objectives, and do more for stroke survivors.

In our COVID-19 survey of our SSOs this summer, we heard that 75% are concerned about their future sustainability. SAFE must continue to support the growth and development of its SSOs.

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. We have been delighted that we have increased our membership by one this year.

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.

At our virtual 2020 General Assembly, the following key decisions were made:

- Two board members were elected: Rubina Ahmed (Stroke Association, UK) and Hariklia Proios (Hellenic Alliance/Action for Stroke)
- The Articles of Association were amended
- SAFE's 2020 budget was approved

Finally, we were also said a fond goodbye to Jon Barrick after six years on the SAFE board and welcomed Hariklia Proios as our new President at the General Assembly in November. Dr Proios is an Associate Professor of Neurocognitive Disorders and Rehabilitation Department of Educational and Social Policy at the University of Macedonia in Thessaloniki Greece. She has a particular interest in aphasia and communications after stroke. She is also the Vice Chair of the Hellenic Alliance/Action for Stroke.

To strengthen the SAFE team, we recruited two experts to boost our advocacy and policy work.

SAFE 2021

In 2021:

Looking forward, our new initiatives fall into three arms of work:

1. Building a powerful patient voice
2. Raising expectations in stroke care and advocacy
3. Building stronger stroke support organisations.

We will:

- Continue our advocacy work to further the SAPE implementation at both the EU and country level
- Develop and run a European Life After Stroke webinar series: Shining the Spotlight on Life After Stroke during 2021
- Start the planning for our 1st European Life After Stroke Forum in 2022
- Start the project to enable us to gather the patient experience data from across Europe.
- Continue to raise the importance of stroke prevention
- Bring our members back together at two separate meetings across Europe. Should we be unable to hold these meetings face-to-face, we would still intend to hold these meetings virtually
- Promote the use of SSOFIT and the Angels brochures
- Represent, communicate and work with our members and supporters
- Fully review our governance, policies and procedures.

SAFE governance 2020

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 budgets and annual accounts.

Board

SAFE is governed by a board that can comprise no fewer than five and no more than 11 members. The board has five key positions: President, President Elect, Vice President, Treasurer and Secretary. The 2020 SAFE board:

President

Jon Barrick, UK (retired November 2020)

Hariklia Proios, Greece (elected November 2020)

Vice president

Anita Arsovska, North Macedonia

Secretary

Marina Charalambous, Cyprus

Treasurer

Chris Macey, Ireland

Members

Hrvoje Jurlina, Croatia

Pnina Rosenzweig, Israel

Grethe Lunde, Norway

Ivan Milojević, Serbia

Derya Uluduz, Turkey (resigned September 2020)

Dymtro Gulyayey, Ukraine

Rubina Ahmed, UK

The Board met four times in 2020. Although, due to the pandemic, it only had one face-to-face meeting at the beginning of the year. 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 small team of five to coordinate its work:

Director General:	Arlene Wilkie
Secretariat:	Sandra Jackson
Communications Manager:	Caroline Moye
Advocacy Manager:	Lora Ivanova
Research Manager:	Gary Randall

Our grateful thanks go to Gary for continuing to generously support SAFE in this important role on a pro bono basis.

SAFE members in 2020 **

Belgium	Belgische Vereniging tegen cerebrovasculaire accidenten
Catalonia	Fundacio Ictus
Croatia	Croatian Stroke Society
Croatia	Mozdani Val
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
Netherlands	Hersenletsel.nl
North Macedonia	STROKE Ohrid
Norway	Norsk forening for slagrammede
Poland	Stroke Fundation
Portugal	Portugal AVC
Serbia	Udruženje Moždaniudar

Slovakia	Porážka.sk
Slovenia	Združenje bolnikov s cerebrovaskularno boleznijo
Spain	Federacion Espanola de Ictus
Spain	Freno al Ictus Fundacion
Sweden	STROKE-Riksförbundet
Turkey	Beyinder
Turkey	Turkish Cerebrovascular Diseases Society
United Kingdom	Different Strokes
United Kingdom	Stroke Association
Ukraine	School for Stroke Survivors (SSS) "Victory over the stroke"
Ukraine	Ukrainian Anti-Stroke Organisation

** 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 2020

Message from the Treasurer

In 2020, income was €455,555.50 (€615,743.07 2019). This decrease was expected and budgeted for and is explained below:



- Membership income decreased to €45,543.60 (€47,448.00 in 2019) due to some organisations having a lower income therefore paid less fees to us.
- Sponsorship of €363,968 (€523,947 in 2019) was received from Amgen, AstraZeneca, Bayer, BMS-Pfizer Alliance, Boehringer Ingelheim, Ipsen and Merz. This decrease was expected and budgeted for. In 2019, we received approximately €200,000 for our Economic Impact Report and for the Angels project, which we did not approach, companies for in 2020. Our continued sponsorship from these organisations reflects the 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.

We also showed an increase in income on two budget lines:

- The €21,889.81 (€43,609.12 in 2019) 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 2020.
- SAFE received a donation of USD20,000 from the BMS Foundation as part of their support of patient organisations during the pandemic.

Our thanks go to all our supporters in 2020 for their continued support and recognition of the importance of the voice of the stroke survivor.

Expenditure was €265,501.79 (€607,193.66 in 2019). This decrease was mainly due to projects such as the European Life After Stroke Forum, regional conferences and other meetings not happening in 2020 due to the global pandemic.

As a result we had an overall surplus of €190,053.71 (€8,549.41 in 2019). This, plus our brought forward figure from 2019 of €528,290.62, results in €718,344.43 carried forward to 2021.

Consolidated statement of financial activities year ended 31st December 2020

	2020	2019	2018
Income	(Euro)	(Euro)	(Euro)
Sponsorship Income	363,968.00	523,947.00	729,116.00
Membership fees	45,653.60	47,448.00	40,770.00
European research project funding contributions	21,889.81	43,609.12	55,955.82
Miscellaneous income	24,044.09	738.95	89.79
Total Income	455,555.50	615,743.07	825,931.61
Expenditure			
Meetings (board, industry and other)	7,076.11	20,576.86	24,676.54
Conferences (working, regional and external)	11,783.56	163,789.24	177,313.64
Staff costs	153,938.21	160,460.35	125,103.32
European research project dissemination to membership	16,790.40	17,929.51	26,686.94
Project costs	21,566.20	100,537.45	346,341.67
SAFE report costs	30,777.88	49,487.48	128,590.45
EU lobbying agency costs	0.00	69,654.85	18,407.13
Membership of other organisations	(included in core costs)	0.00	808.98
Professional fees and bank charges	(included in core costs)	2,639.31	4,951.96
Core costs	23,569.43	22,118.61	19,897.75
Total Expenditure	265,501.79	607,193.66	872,778.38
Surplus/Deficit	190,053.71	8,549.41	-46,846.77

Reconciliation of funds

Total funds brought forward	328,290.62	317,262.51	*364,109.28
Reserves	200,000.00	200,000.00	200,000.00
Total funds carried forward	718,344.43	528,290.62	517,262.51

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

Cash at bank 31 December 2020	677,102	611,793	
Accounts receivable	39,750		
Deferred charges	3,577		-
Current liabilities	2,084	83,503	-
Total funds carried forward	718,345	528,290	

ACCOUNTANTS STATEMENT

To the members and the Board of Directors of SAFE ASBL:

We have reviewed the financial accounts of the Association "Stroke Alliance for Europe", abbreviated "SAFE", with registered office in Belgium, Brussels, Washington street 40, for the accounting year ended December 31, 2020.

We have performed a limited review of the transactions and situation of the financial accounts. Our limited review was made in accordance with generally accepted accounting standards in Belgium. We have not performed a full audit and, accordingly, we do not express an audit opinion.

Statement

In our opinion, the financial statements referred to above present fairly the financial position of SAFE association as of December 31, 2020, and the result of the operations for the year then ended.

Boechout (Belgium)
May, 2021

Digitaal ondertekend
door Peter Van Loock
(Signature)
Datum: 20/05/2021
17:09:22

SBB Gecertificeerde Accountants en Adviseurs BV