
S·A·F·E

Stroke Alliance For Europe

**THE STROKE PATIENT
VOICE IN EUROPE**



2021

ANNUAL

REPORT



The Stroke Alliance for Europe

is registered in Belgium (ASBL 0661.651.450) with registered office at

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Stroke Alliance for Europe – a powerful voice in Europe

The Stroke Alliance for Europe (SAFE) is a non-profit-making organisation that represents a range of stroke support organisations (SSOs) across Europe. We were established in 2004 in Brussels with a membership of eight European SSOs. Since then we have grown to 34 members.

Our mission

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.

Increasingly we are focusing on co-morbidities, recognising the importance of the link between stroke and conditions such as heart disease, dementia and diabetes.

Our objectives

- education to raise awareness and understanding of stroke
- education initiatives on prevention
- identify those at risk
- 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 clear 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
- coordinate the efforts of national stroke patient groups in Europe

Message from SAFE's President

2021 continued to be a challenging year for our members and all those affected by stroke. The ongoing pandemic and the war in Ukraine placed huge pressures on our healthcare systems. In my first year as president, I have been so impressed by the exceptional work our European stroke support organisations have done in response to this through awareness raising, service provision and advocacy to ensure that all affected by stroke receive the vital support, care and information they need.

These issues, along with the predicted increase in the numbers of people living with stroke, mean that prevention of stroke, effective treatment and life after stroke support and care is even more important now than ever. To respond to these circumstances, stroke must become a greater priority for health and social care across Europe.

To this end, our work as co-chair of the Stroke Action Plan for Europe (SAPE) implementation committee with the European Stroke Organisation, is more essential than ever. Over 90 national coordinators throughout Europe have taken on the task of implementing the SAPE in their countries. All the work they do is voluntary, and I am so pleased to see that many of the national coordinators are our members. Significant strides are being made towards our goal of every country having a stroke action plan – with countries signing up to a Declaration in support of the SAPE and many others moving on with developing new stroke plans in their country.

As you know, life after stroke is a key focus in the SAPE, ensuring that life after stroke care and support is given an equal status with hospital and rehabilitation care in the stroke pathway. Raising awareness of life after stroke continues to be a priority for us and to support this we have continued with our European Life After Stroke webinar events. Over the last two years we held five webinars, attracting over 2,000 participants with the vast majority saying they were satisfied with the webinar content. This has allowed us to keep the momentum and interest going in this vital but neglected area of care and research. We aim to build the life after stroke healthcare, research and patient community, stimulate debate and build interest in our first face-to-face conference in March 2023.

In addition to the work, we have achieved this year – which you will read more about in this annual report – I have also been working with the SAFE board on developing our new five-year strategy which I will share with you at the beginning of 2022.

I am very proud of all we have collectively achieved this year and I would like to thank all our members and our sponsors for all their support in 2021. I am very much looking forward to seeing everyone in person again and face those stroke challenges head on, together.



Hariklia Proios, President

SAFE 2021

Our key activities

Advocating for stroke

1. Supporting the development and implementation of national stroke plans through the Stroke Action Plan for Europe (SAPE)



In 2021, as co-chair of the SAPE implementation committee with the European Stroke Organisation (ESO), our aim was to strengthen and develop national coordinators in each European country to develop country specific stroke action plans using the principles of the SAPE as a foundation. Out of 52 countries, we have 49 countries that have signed up to work on the SAPE on a national level, with 89 named Coordinators leading the implementation. 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.

In 2022, we will continue our work with the SAPE implementation committee. This role ensures the work plans 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 and we will highlight the SAPE work with ESO at our stand at the ESO conference in May, in Lyon France.

In addition, we will focus on life after stroke services, holding meetings with key stakeholders to develop a set of life after stroke recommendations that countries can use in the national stroke plans.

This work will be supported by the launch of 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/guidelines of possible long term unmet needs.

2. European and International policy work

We joined the European Alliance for Cardiovascular Health early in 2021. We worked to ensure that stroke was an equal partner to heart in the collaboration. We contributed to the original joint launch statement in June and in September we were speakers at the launch event on World Heart Day. This, plus the work of many others, has led to the European Commission Healthier Together Non-Communicable Diseases Initiative launch at the end of 2021.



In 2022, to ensure that we effectively raise the profile of stroke in key European and Global health policy initiatives, we will contribute to both the Healthier Together initiative and the World Health Organisation declaration on "Epilepsy and other neurological conditions".

3. Formation of the stroke interest group at the European Parliament

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.

In addition, we secured the support from ESO 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.

In 2022 we will continue our work to develop a Stroke Interest Group. This group will include the support of the organisations listed above and the strategic outreach to MEPs. We will organise regular meetings, undertake promotion of SAFE's advocacy activities and achieve strong representation of stroke in all relevant health policy initiatives of the EU.

Strengthening stroke support organisations

1. Member's meetings

We brought our members together for several virtual meetings in 2021. We covered topics including providing emotional and psychological support online during the pandemic and implementing the SAPE.

However, nothing matches the power of in-person members meetings and networking. We will hold our first in person meeting in June 2022 in Barcelona and will hold a second meeting in the autumn of 2022.

2. Stroke Survivor Organisation Faculty Tool (SSOFT)



In 2021, we carried out a strategic review of our advocacy e-learning tool SSOFT. SSOFT is used internationally resulting in over 1,900 registrations and over 1,600 certificates being given across all modules. The review involved users of SSOFT and demonstrated that it is an excellent training tool, building people's knowledge to enable them to advocate for change.

In 2022, we will review and update the content of all the modules, and we will relaunch SSOFT and seek funding to reach and engage a wide community of stroke advocates. In addition, we will work closely with a select number of advocates, providing peer-to-peer support and the opportunity to make suggestions to improve the tool based on their user experience.

3. Stroke Media & Advocacy Resource Training (SMART)



In 2021, to support the eLearning tool SSOFT, we launched the SMART programme, which provided a series of advocacy training events for SSOs and SAPE national coordinators. The topics included 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 and we will soon be launching the sessions in the form of campaigning documents.

In 2022, we will continue with our virtual educational advocacy meetings with our members, 1:1 mentoring and production of relevant training and support material.

Preventing stroke



Our stroke prevention information site www.strokeprevention.info, available in six languages (English, French, Polish, Portuguese, Russian and Spanish), was launched in 2018, has 30 easily understandable articles of information and advice on the 10 modifiable risk factors for stroke. In 2021, we reviewed and updated all the articles and the supporting research references. The site receives around 900 hits every month.

In 2022, we will translate the new content into five languages and will re-launch the site on European Stroke Awareness Day.

Focusing on life after stroke



In 2021 we launched our European Life After Stroke webinar series, to raise the profile of life after stroke as an issue, 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 caregiver. We had a global audience and over 1,500 attended.

The series was endorsed by the European Brain Council, the European Federation of Neurological Associations, the European Stroke Organisation and the World Stroke Organization

In 2022, we will continue this series and host five webinars over two days. The topics covered are: Self-management, Communication, Meaningful activity, Getting back to work and fatigue

In addition to this, we will plan of our first in person Life After Stroke meeting in 2023 in Barcelona. To promote this, we will be hosting a stand at the ESO Conference in Lyon, France in May 2022.

Providing information on life after stroke



We aim to provide health information to those affected by stroke. In partnership with the Angels initiative, we produce the 'Surviving Stroke' brochures to help those affected understand more about the condition, be more actively involved in their treatment decisions and learn more about the important next steps to recovery. The brochures should positively influence communication between healthcare professionals and patients.

In 2021, we worked with SSOs in Croatia, Cyprus, Czech Republic, Georgia, Greece, Hungary, North Macedonia, Poland, Serbia, Slovakia, Spain, Turkey and Ukraine to update the brochures and have new translations available in stroke units in their countries. The brochures also include national, regional and local SSOs contact details, so that those affected can access further support in the months and years following their stroke.

In 2022, these new documents will be made available in printed and digital versions and shared within stroke units and online in the countries that have taken part. In addition, we hope to work with at least one new SSO and have the brochures available in one new language.

Supporting stroke research

Our role in supporting research, is to, along with our members, disseminate information and results of the EU research projects.



In 2021, we focused on patient involvement in research and interviewed patients from the Precious (looking at using everyday drugs to treat stroke complications and save lives) and SVDS Targets trials (developing targets for intervention for the prevention of stroke and dementia). In addition, we supported the launch of the new ANGIE project (developing targeted treatment using microbots) on European Stroke Awareness Day. 20 of our members supported this, translating the information, and sharing it through newsletters, websites and social media throughout Europe.

In addition, we supported the development of eight trials who applied for both Horizon Europe 2021 funding and Erasmus calls. We were delighted to hear that two of these grants were successful: Res-Q (developing a European wide data collection tool) and Validate (using AI to determine individual treatment options)

Strengthening our governance and finances

In 2021, we held four virtual board meetings where on a quarterly basis we review our risk register, our financial situation, our policies and our current and future plans. We also held one virtual General Assembly with our members. We held regular 1:1 meetings with our industry partners and held one virtual group meeting to update them on our 2021 work and 2022 plans. In addition, we keep different partners up to date on specific projects depending on what their interests are.

In 2022, we will work with the board and members and publish our new organisational strategy for 2023-2027.

Improving our profile and reach

In 2021 we continued to work to improve our communications profile and our reach to current and new supporters. This is important to ensure that our members, key stakeholders and new individuals and organisations learn about our work and use our products and take part in our events.

We refreshed the content on our main website, safestroke.eu, and restructured our home page to make it clearer in what we do, and to make it more mobile friendly. Our views to the website are approximately 14,000 per quarter. We publish weekly news for those that have signed up to our general newsletter as we have seen an increase from 2,634 to 3,803 in subscribers from 2020. We also have dedicated social media content that we put out on a weekly basis and have seen our Twitter following increase from 3,220 to 3,871 from 2020. And for Facebook we have seen an increase of 1,869 to 2,014 from 2020. In addition, we have been posting more

focussed content on our YouTube channel and have 30 subscribers to our channel. We have focused on embracing the visual aspect of our digital communications and ensure that we have good digital images to support all our communications.

In 2022, we will continue to communicate through all our regular channels. In addition, we will undertake a review of our brand and identity, in line with our new strategy.

SAFE 2022 Priorities

Advocating for stroke – we will:

- continue our work with the SAPE implementation committee and ensure the work-plans remain focused on improving patient outcomes and cover the whole care pathway including rehabilitation and life after stroke
- 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
- 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

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
- 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:

- relaunch the www.strokeprevention.info website, in six languages, 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
- Provide health information including through the 'Surviving Stroke' Angels guides in 12 languages

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

Sustainable and effective organisation – we will:

- Launch our new strategy 2023-2027
- Build our network of funders through developing relationships with stroke support organisations and industry partners
- Review and implement all our governing policies and procedures
- Refresh our brand to provide consistency across all our projects and achieve better profile of our work

SAFE governance 2021

SAFE has functioned as a legally registered, non-profit-making association in Belgium (ASBL) 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 2021 SAFE board:

Hariklia Proios	Greece	(President)
Anita Arsovska	North Macedonia	(Vice President)
Marina Charalambous	Cyprus	(Secretary)
Chris Macey	Ireland	(Treasurer)

Members:

Hrvoje Jurlina	Croatia
Pnina Rosenzweig	Israel
Grethe Lunde	Norway
Ivan Milojević	Serbia
Dymtro Gulyayey	Ukraine
Rubina Ahmed	UK

Jana Bara-Dobrkovska, Czech Republic (elected June 2021, resigned December 2021)

The Board held four virtual meetings in 2021. Its role is to monitor implementation of SAFE's strategic plan and provide policy and procedural direction, and to supervise the finances.

In addition, Jon Barrick remains involved with SAFE as an honorary member. We thank him for all his support in 2021, in particular for his support with our Stroke Action Plan for Europe and Needs and Wants projects.

Staff

We have a team of five to coordinate our work:

Arlene Wilkie (Director General)

Sandra Jackson (Secretariat)

Caroline Moye (Communications Manager)

Lora Ivanova and Megha Kaira (Advocacy and campaigns)

Our grateful thanks go to our volunteer, Gary Randall who left SAFE in 2021, for all the support and guidance he gave to SAFE on our EU research projects.

Our members in 2021

Our members are organisations either dedicated stroke patient/survivor support organisations, or organisations where work for and with patients/survivors makes up an important part of their activities

Belgium	Belgische Vereniging tegen cerebrovasculaire accidenten
Bulgaria	Association for Stroke and Aphasia
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)
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	Freno al Ictus Fundacion
Sweden	STROKE-Riksförbundet
Turkey	Turkish Cerebrovascular Diseases Society
United Kingdom	Different Strokes
United Kingdom	Stroke Association
Ukraine	Ukrainian Association of Stroke Patients
Ukraine	Ukrainian Anti-Stroke Organisation

SAFE finances 2021

Message from the Treasurer



In 2021, income was €517,716.89 (€455,555.50 in 2020).

- Sponsorship of €398,800 (€363,968 in 2020) was received from Amgen, AstraZeneca, Bayer, BMS-Pfizer Alliance, Boehringer Ingelheim, Ipsen and Merz.
- Membership income increased slightly to €47,024.20 (€45,543.60 in 2020) due to new organisations joining SAFE. There was no increase in membership fees in 2021.

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

- The €69,454.73 (€21,889.81 in 2020) received from partnerships with European research organisations shows SAFE's continuing importance to the consortium involved in these research projects. The increase in income was partly due to SAFE becoming involved in the new ANGIE project, and continued involvement with five other projects.
- SAFE received a donation of €500 from Cittadinanzattiva APS due to Arlene Wilkie's participation in the Cardiovascular Protection Active Citizenship Network, and €1,750 from Novartis Pharma due to Jon Barrick's continued participation in the International Cardiovascular Council. Further small donations of €188.16 have been received via the SAFE website, making the total donations €2,438.16

Our thanks go to all our supporters in 2021 for their continued support and recognition of the importance of the voice of the stroke survivor.

In 2021, our expenditure was €258,611.80 (€265,501.79 in 2020). This expenditure was low compared to the years preceding the pandemic largely as we were unable to spend our funds on face to face meetings.

As a result, we had an overall surplus of €259,105.09 (€190,053.71 in 2020). This, plus our brought forward figure from 2020 of €718,344.43, results in €977,449.52 carried forward to 2021.

We intend to spend this as follows:

EU Research funding	€127,880.32
Project funding	€488,796.00
Deferred charges	€1,785.92
New strategic projects 2023-2027	€158,987.28
Reserves	€200,000.00

Consolidated statement of financial activities year ended 31st December 2021

	2021	2020	2019
Income	(Euro)	(Euro)	(Euro)
Sponsorship Income	398,800.00	363,968.00	523,947.00
Membership fees	47,024.20	45,653.60	47,448.00
European research project funding contributions	69,454.73	21,889.81	43,609.12
Miscellaneous income	2,438.16	24,044.09	738.95
Total Income	517,716.89	455,555.50	615,743.07
Expenditure			
Conferences (working, regional and external)	634.80	11,783.56	163,789.24
Staff costs	164,680.55	153,938.21	160,460.35
European research project dissemination to membership	9,729.60	16,790.40	17,929.51
Project costs*	48,169.67	21,566.20	100,537.45
SAFE report costs	0.00	30,777.88	49,487.48
EU lobbying agency costs	0.00	0.00	69,654.85
Core costs	35,397.18	30,645.54	45,334.78
Total Expenditure	258,611.80	265,501.79	607,193.66
Surplus/Deficit	259,105.09	190,053.71	8,549.41

*Note: Projects are Prevention website, ELASF 2021, SSOFT, SAPE

Reconciliation of funds

Total funds brought forward	518,344.43	328,290.62	317,262.51
Reserves	200,000.00	200,000.00	200,000.00
Total funds carried forward	977,449.52	718,344.43	528,290.62

Cash at bank and in hand 31 December 2021	980,328.08	677,102	611,793
Accounts receivable	1,210.00	39.750	
Total assets	981,538.08		
Deferred charges	1,785.92	3,577	
Current liabilities (liability)	5,874.48	2,084	83,503
Total funds carried forward	977,449.52	528,290	

Total funds carried forward	977,449.52
Research funding carried forward (liability)	127,880.32
Project funding carried forward (liability)	488,796.00
Deferred charges	1,785.92
Reserves (equity)	200,000
Profit/loss carried forward 2022 (equity)	158,987.28

ACCOUNTANTS STATEMENT

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

Scope

We have reviewed the financial accounts of the Association “Stroke Alliance for Europe”, abbreviated “SAFE”, with registrated office in Belgium, Brussels, Washingtonstreet 40, for the accounting year ended December 31, 2021.

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, 2021, and the result of the operations for the year then ended.

Boechout (Belgium)
March, 2022

Peter Van Loock

SBB Gecertificeerde Accountants en Adviseurs BV

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