



ANNUAL REPORT & ACCOUNTS 2022



Contents

SAFE - A powerful voice in Europe	3
Letter from the President	4
Highlights of our year	
Our new members	6
Our events	6
Awareness campaigns	8
Advocacy in Europe	9
Strengthening our governance & finance	11
Improving our profile and reach	11
Our key activities for 2023	12
Our governance	13
Our members	14
Our finances	15
Consolidated statement of financial activities	17
Accountants statement	19

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 37 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 to strengthen SSOs; to advocate at national and European levels; and to encourage research in order to enhance stroke prevention and to improve the quality of life of stroke survivors, their families and carers.

Our objectives

Education to raise awareness and understanding of stroke 1	Education initiatives on prevention 2	Identify those at risk 3	Improve access to appropriate treatment and care for persons affected by stroke 4	Improve the quality of life of people affected by stroke and their families and carers 5
Promote better access to accurate and clear information about stroke 6	Increase the priority given to stroke by policy and decision-makers, and by health-care providers 7	Promote research on stroke and related areas 8	Promote research on stroke and related areas 9	



Letter from the President

Dear Members and Supporters,

I am pleased to present the Stroke Alliance for Europe's annual report and accounts for 2022. This year has been a time of significant progress for our organisation, and I am proud of the many achievements we have made together.

First, I would like to say how wonderful it was seeing our members in person at our members meetings in Barcelona and Thessaloniki after so many years of webinars. And I am also delighted to welcome our three new member organisations Hjernesagen (Denmark), Vaincre l'AVC (France) and Chest Heart & Stroke (Northern Ireland). I am looking forward to seeing you and working with you all over the coming years.

One of our key achievements this year has been the European Life After Stroke Forum series of webinars. Through this exciting initiative, we have been able to provide a platform for stroke survivors, carers, stroke support organisations, healthcare professionals and policy makers to share their experiences and knowledge, and to promote best practices for stroke recovery and rehabilitation. The webinars have been very well received and have attracted a wide range of participants from across Europe and beyond. We are looking forward to continuing this initiative in 2023 with our first in-person meeting in Barcelona.

Another important milestone this year has been the prominent inclusion of stroke in the European Union's Non-Communicable Diseases (NCD) Initiative - Healthier Together. This initiative aims to reduce the burden of NCDs, including stroke, across Europe. Our advocacy efforts have helped to ensure that stroke and the Stroke Action Plan for Europe is recognised as a priority area. In 2023, we will work closely with policymakers and other stakeholders to develop effective strategies for prevention, treatment and life after stroke.

Despite these successes, we recognise that there are still significant challenges facing stroke patients and their families. During the year we have worked on the forthcoming report - Our 'A Life Saved Is A Life Worth Living' report, to be published in 2023. It shows that too many stroke survivors and carers have a wide range of needs in the longer term that are not being met. There is an urgent need for more research into the longer term needs of stroke survivors and, crucially, into what interventions are most effective for improving recovery and preventing other strokes

I would like to take this opportunity to express my sincere gratitude to all our members and sponsors for their continued support throughout the year. Your dedication to improving stroke prevention, treatment, rehabilitation and life after stroke across Europe has been instrumental in our collective success. Together, we are making a real difference in the lives of stroke patients and their families.

Looking ahead, we will continue to build on our achievements and work to address the challenges facing all those affected by stroke. We will continue to collaborate with stakeholders and policymakers to promote effective policies and practices, and to ensure that stroke remains a top priority on the European health agenda.

Once again, I would like to thank all our members and sponsors for their unwavering support in 2022. We look forward to continuing our work together in the years to come.

Sincerely,

Hariklia Proios

Hariklia Proios
President of SAFE

Highlights of our year

Our new members

We were delighted to welcome three new members:



Denmark



France



Northern Ireland

This brings our membership to 37 organisations from across Europe. We are looking forward to working with you in 2023.

Our events

Members' meetings

We held two face-to-face meetings this year for the first time since the pandemic. In June and October we met over 50 representatives from SSOs from 30 countries in Barcelona and Thessaloniki. In Barcelona we welcomed special guests representing local member, Fundació Ictus, celebrating their 15-year anniversary.

At our General Assembly, Chris Macey (Ireland) and Marina Charalambous (Cyprus) were re-elected to the SAFE Board and Jan Konig (Czech Republic), Dorina Dobрева (Bulgaria) and Marianne Tangen (Norway) were voted onto the Board. The board appointed two honorary members – Grethe Lunde and Jon Barrick, as a thank you to all the hard work and support they have given to SAFE during their time on the Board.



Chris Macey
Ireland



Marina Charalambous
Cyprus



Jan Konig
Czech Republic



Dorina Dobрева
Bulgaria



Marianne Tangen
Norway

Our events

European Life After Stroke Forum

We continued with the European Life After Stroke Forum (ELASF) webinar series we started in 2021. We ran five sessions:

- Be inspired and share control: the added value of self-management support
- Life after stroke: Communication in everyday life
- Getting back to work after stroke
- Fatigue after stroke: what can we do?
- Physical activity: getting active without sweat and lycra!

In total more than 1,100 people attended and we received very positive feedback:



Thank you very much for such fantastic presentations and inspiring stories ”

Thank you to all speakers today and to SAFE in general for a very useful and perspective changing day ”

All the webinars are available to view [here](#)

In 2023, we will host our first face-to-face Forum in Barcelona, Spain. We have an exciting line up of speakers, presentations, parallel sessions and poster exhibition. You can find more details about the programme on the [ELASF website](#).



Ruth Miller

Careers Advisor Professional

Webinar speaker: Fatigue after stroke: What can we do?

Awareness campaigns

Spreading the news about stroke research

We participated in Brain Awareness Week in March and International Clinical Trials Day in May to promote the work of our EU research partners. Thank you to all our members who helped to promote this research this year during Brain Awareness Week. This year we promoted five projects:

- The [Precious project](#) (PREvention of Complications to Improve OUtcome in elderly patients with acute Stroke).
- [Prestige-AF](#) (Prevention of Stroke in intracerebral hemorrhage survivor with Atrial Fibrillation)
- [Tension](#) (Efficacy and safety of ThrombEctomy iN Stroke with extended leSION and extended time window: a randomised, controlled trial) i
- The [Proof study](#) (PenumbraL Rescue by Normobaric O=O Administration in Patients With Ischaemic Stroke and Target Mismatch ProFile)
- [ANGIE](#) (MAGnetically steerable wireless Nanodevices for the tarGeted delivery of therapeutc agents in any vascular rEGion of the body)

We also became partners in four new EU research projects on 2022: CLASP (Co-designing Life After Stroke Support Pathways) and three which focus on Artificial Intelligence RES-Q+, TRUSTStroke and Validate.



Calling for people to check their blood pressure

We used European Stroke Awareness Day and on World Hypertension Day to highlight that high blood pressure is one of 10 modifiable risk factors of stroke. Many of our members joined us in our campaign.

1 in 5 Europeans have high blood pressure with the biggest numbers recorded in Croatia (37% of people aged 15 years and over), Latvia and Hungary (both 32%).



We have updated our website strokeprevention.info which is available in six languages English, French, Polish, Portuguese, Russian and Spanish.

Advocacy in Europe

Success for stroke at the European Commission.

In April, we submitted our response to the European Commission non-communicable disease (NCD) initiative, Healthier Together in partnership with the European Stroke Organisation. Many of our member helped us with information for our submission.

The Healthier Together Plan is a toolkit to guide Member States and EU policymakers towards a holistic and coordinated approach for health promotion, disease prevention, treatment and care for four disease groups: diabetes, cardiovascular diseases, chronic respiratory diseases and mental health and neurological disorders.

We were delighted that our work resulted in stroke having a significant presence throughout the initiative. Stroke is specifically drawn out as a priority area under mental health and neurological disorders. Priority is given to implementing the Stroke Action Plan for Europe (SAP-E) across the EU, increasing public awareness, and improving screening, encompassing the entire chain of care from primary prevention to life after stroke. In summary:

- Stroke is mentioned 92 times
- SAFE and ESO are referred to as key contributors
- The SAP-E is considered a best example of action to be considered by Member States
- In the mental health and neurological disorders chapters stroke and dementia are the only two neurological conditions that have specific priorities identified
- Stroke prevention is specifically drawn out in the CVD section.

This is good news, as stroke is at the top of Europe's NCD health policy agenda. And it is a great opportunity for more effective stakeholder participation and collaboration.

At the EU level there will be a drive for action focused on disease prevention, diagnosis, treatment and care that will both improve patient outcomes and protect healthcare system sustainability. The full report can be found [here](#).

Four stroke-specific projects were highlighted as best practice NCD initiatives and were amongst 15 projects presented to representatives of Member States Ministries of Health EU. We are delighted to let you know that FAST Heroes was one of five projects considered by the Member States as most relevant for further implementation in Europe. These projects will get 70% funding from the EU (the rest being funded by the country).

For more information about Best Practice projects and funding [click here](#).



Advocacy in Europe

Cardiovascular Disease Plan initiative launched

As a member of the European Alliance for Cardiovascular Health (EACH), we were pleased to be involved in the development of the Cardiovascular Disease Plan for Europe which was launched in May. EACH brings together patients, healthcare professionals, insurers, researchers and industry to tackle Europe's leading cause of death.



The proposed plan aims to reduce premature and preventable deaths in Europe by one third in 2030, improve access for all to high quality cardiovascular risk assessments, set multi-disciplinary care pathways and pave the way for greater quality of life, building on the EU Non-Communicable Diseases Initiative, Healthier Together.

It complements and strengthens the work that SAFE are doing on the SAP-E and ensures that stroke remains high on the European policy agenda. For more information about the plan see [here](#).

Stroke Action Plan for Europe successes this year

Working with the European Stroke Organisation, we began 2022 by launching the SAP-E Stroke Service Tracker (SST). Based on anonymous data collected from 48 countries, the SST will help us to monitor progress in the quality of stroke care and its outcome. It will also allow for comparisons between countries.

The [SAP-E status report](#) highlighted recent developments and achievements:

- inclusion of stroke as a priority in the EU NCD Initiative, Healthier Together
- the establishment of a strong and growing network of over 90 National Coordinators
- the publication of the Essentials of Stroke Care guidelines
- the development of the National Stroke Plan template.

Bulgaria, Croatia, Kosovo, North Macedonia, Slovakia and Spain in 2022 signed the [Declaration for action on stroke](#), committing to improving stroke services across the entire chain of care and taking a step towards the full implementation of the SAP-E. SAFE Board member, [Dorina Dobрева](#), shared insights on Bulgaria's path to signing the declaration and how tireless advocacy by National Coordinators and their team led Bulgaria towards this achievement.

We would also like to congratulate Ireland for launching their National Stroke Strategy 2022-2027, on World Stroke Day 29 October 2022.



Strengthening our governance and finances

In 2022, we held two virtual and two in-person board meetings to review our risk register, our financial situation, our policies and our current and future plans. We also held one in-person General Assembly with our members. We held regular one-to-one meetings with our industry partners keeping them up to date on specific projects, depending on what their interests are.

The board established a strategy group which met twice, and we held workshops at board members meetings to discuss our new organisational strategy which we will publish in 2023.

Improving our profile and reach

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.

Views to our website are approximately 12,500 per quarter. We publish weekly news for our 4,186 subscribers. We also have dedicated social media content that we put out on a weekly basis to our 4,459 twitter followers and 2,224 Facebook followers. In addition, we have been posting more focussed content on our YouTube channel and have 32 subscribers to our channel.



2,224
followers



4,459
followers



32
subscribers

Our key activities for 2023

1

Advocating for stroke – we will:

- Develop and implement our advocacy plan to increase the profile of stroke at the EU and national level
- Continue our work with the SAP-E implementation committee, ensuring that the work-plans remain focused on improving patient outcomes and cover the whole care pathway including rehabilitation and life after stroke

2

Strengthening stroke support organisations – we will:

- Hold one in-person members meeting
- Relaunch our advocacy support programme for members

3

Preventing stroke – we will:

- Review and update www.strokeprevention.info

4

Focusing on life after stroke – we will:

- Host our first in-person Life After Stroke Forum in Barcelona in March and begin planning for 2024
- Provide health information through the 'Surviving Stroke' Angels guides in 13 languages
- Launch our 'A Life Saved Is A Life Worth Living' report in March
- Raise awareness of the importance of life after stroke care and support on European Stroke Awareness Day in May

5

Supporting stroke research – we will:

- Share the facts, figures and exciting information about our EU research projects in March during Brain Awareness Week
- Support the development of new EU research projects

6

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
- Host a virtual General Assembly in June
- Launch the refresh of our brand providing consistency across all our projects

Our governance

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 officers, 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 four Officer positions: President, Vice President, Treasurer and Secretary.

The 2022 SAFE board

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

Members at large

Hrvoje Jurlina, Croatia
Jan Konig, Czech Republic
Pnina Rosenzweig, Israel
Marianne Tangen, Norway
Ivan Milojević, Serbia
Dorina Dobрева, Bulgaria
Rubina Ahmed, United Kingdom

The Board held four meetings in 2022, two virtual and two face-to-face. Its role is to monitor implementation of SAFE's strategic plan and provide policy and procedural direction, and to supervise the finances.

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 members

Our members are patient support or stroke support organisations throughout Europe dedicated to raising awareness of stroke issues in their country and providing long-term support and information to stroke survivors for as long as they need.

Belgium	Belgische Vereniging tegen cerebrovasculaire accidenten
Bulgaria	Association for Stroke and Aphasia
Catalonia	Fundacio Ictus
Catalonia	Federacio Ictus de Catalonia
Croatia	Croatian Stroke Society
Croatia	Mozdani Val
Cyprus	Cyprus Stroke Association
Czech Republic	Sdružení CMP
Czech Republic	CEREBRUM
Denmark	Hjernesagen – The Danish Stroke Association
Finland	Aivoliitto ry
France	Vaincre l'AVC (French Stroke Foundation)
Georgia	Medical Foundation "Mkurnali"
Germany	Stiftung Deutsche Schlaganfall-Hilfe
Greece	Hellenic Action / Alliance for Stroke
Hungary	Nemzeti Stroke Liga
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 Foundation
Portugal	Portugal AVC
Romania	ALIA – The Association for a Fight Against Stroke
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
United Kingdom	Chest Heart Stroke Northern Ireland
Ukraine	Ukrainian Association of Stroke Patients



Our finances

Message from the Treasurer

In 2022, income was €394,297 (€517,717 in 2021):

Membership income increased slightly to €50,617 (€47,024 in 2021) due to new organisations joining SAFE. There was no increase in membership fees in 2022.

Sponsorship of €316,760 (€398,800 in 2021) was received from BMS-Pfizer Alliance, Boehringer Ingelheim, Ipsen, Novartis and Merz Therapeutics. Unfortunately we lost AstraZeneca, Amgen and Bayer as partners as they no longer focus on patient organisation support.

€606 was received in delegate fees for ELASF 2023. SAFE received donations of €3,811 (€2,438 in 2021):

- €500 from Cittadinanzattiva APS due to Arlene Wilkie's participation in the Cardiovascular Protection Active Citizenship Network
- €1,435 from Novartis Pharma due to Jon Barrick's continued participation in the International Cardiovascular Council.
- €1,350 from Ipsen for Jon Barrick's participation on their patient's advisory board
- Further donations of €515.72 have been received via the SAFE website.

The €22,504 (€69,454 in 2021) received from partnerships with European research organisations shows SAFE's continuing importance to the consortium involved in these research projects. We received income from the new ANGIE project and continued involvement with the Tension project.

In addition, we carried forward income of €977,452 from 2021.

Our thanks go to all our supporters in 2022 for their continued support and recognition of the importance of the work SAFE does on behalf of its members and its partners, for stroke survivors in Europe.

In 2022, our expenditure was €580,757.15 (€258,611.80 in 2021). Our work is outlined in the 'Highlights of the year' section above and in summary we held two members meetings which we had been unable to do in previous years; we started our new work on the Surviving Stroke leaflets with the Angels Initiative; we continued our work on the 2022 ELASF webinars and started planning for the in person event in 2023, and we continued our work on the Stroke Action Plan for Europe.

Our planned expenditure for 2023 from our funds is €429,921. This is funds we have raised already and will spend on projects such as the EU research projects, ELASF, the Surviving Stroke literature, SAPE and the Life saved report.

As a result, we had an overall surplus of €359,277 of which €250,000 is our reserves (Note: the decision was taken by the board to increase the reserves from €200,000 to cover for 12 months of fixed costs and essential core costs).

Consolidated statement of financial activities year end 31 December 2022

	2022	2021	2020
Income	(Euro)	(Euro)	(Euro)
Membership fees	50,617	47,024	45,653
Industry	316,760	398,800	363,968
ELASF delegate fees	606	N/Aww	N/A
Donations	3,811	2,438	24,044
European research projects	22,504	69,454	21,889
Total income	394,298	517,716	455,554
Carried forward income	977,452	718,345	528,290
Expenditure			
Project costs	303,277	48,803	64,126
Staff costs	206,029	164,680	153,938
European research projects	16,794	9,729	16,790
Core costs	56,452	35,397	30,645
Total expenditure	582,552	258,609	265,499
Planned expenditure	429,921	616,676	412,687
Surplus/Deficit	359,273	360,776	305,658
Total carried forward	789,194	977,452	718,345

	2022	2021	2020
Assets	(Euro)	(Euro)	(Euro)
Cash at bank 31 December 2022	797,440	980,328	677,102
Accounts receivable	50,716	4,784	43327
Total assets	848,156	985,112	720,429
Deferred charges	0	1,786	
Current liabilities	58,962	5,874	2,084
Total funds carried forward	789,194	977,452	718,345

How the carried forward funds are allocated

Research funding carried forward (liability)	131,921	127,880	87,887
Project funding carried forward (liability)	298,000	488,796	324,800
Deferred charges	0	1,785	0
Profit/loss carried forward 2022 (equity)	359,273	358,991	305,658
Of the equity above, the agreed amount allocated to reserves is:	250,000	200,000	200,000

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 registered office in Belgium, Brussels, Washingtonstreet 40, for the accounting year ended December 31, 2022.

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, 2022, and the result of the operations for the year then ended.

Boechout (Belgium)
May, 2023

Peter Van Loock

SBB Gecertificeerde Accountants en Adviseurs BV

Stroke Alliance for Europe

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