

# Annual report and accounts 2024

The Stroke Alliance for Europe is registered in Belgium (ASBL 0661.651.450) with registered office at Rue Washington 40, Brussels 1050, Belgium. Email: <u>info@safestroke.eu</u> Website: <u>www.safestroke.eu</u>

# Welcome letter from our President

Dear Friends and Colleagues,

As President of SAFE, I am honoured to reflect on another inspiring and impactful year in our shared mission to improve the lives of people affected by stroke across Europe.

In 2025, we have strengthened our voice and our reach - from launching vital advocacy tools to expanding our prevention efforts through a refreshed, multilingual website that brings evidence-based information to communities in their own language. We have also deepened our commitment to research and innovation through our participation in EU-funded projects, helping to ensure the lived experience voice is at the heart of European health and care priorities. The European Life After Stroke Forum (ELASF) continues to grow and evolve, bringing together stroke survivors, carers, researchers, medical professionals and support organisations. Our 2024 ELASF in Dublin was our most successful yet. I extend my sincere thanks to everyone involved whose support makes this work possible.

Our members remain the driving force behind everything we do. Their dedication, creativity and compassion continue to inspire us all. From peer support and advocacy to education and prevention, their work delivers real impact for people with lived experience. Thank you for all that you do.

None of this would be possible without our sponsors. Your continued support empowers us to do more, reach further and advocate louder. On behalf of the SAFE Board, I offer heartfelt thanks.

Looking ahead, I am excited for 2025. We anticipate the publication of the updated Stroke Action Plan for Europe and the development of the EU European Cardiovascular Health Plan – both key opportunities to further embed stroke as a health and policy priority. We will host our flagship event, the ELASF, in Prague. We will also establish the new SAFE European Life After Stroke Task Force, ensuring that we shape care, research and policy in life after stroke.

Let us carry this momentum forward - together.

With warm regards,

Professor Hariklia Proios President, Stroke Alliance for Europe

## The first year of our new strategy – 'United against stroke'

#### Our vision

We want a Europe where preventable stroke is eliminated, death and disability is minimised and every person affected by stroke lives their best life possible

#### Our mission

Over the next five years and beyond, our mission is to reduce the incidence and impact of stroke in Europe, by bringing together and empower SSOs to deliver campaigns, advocacy, education, research and raise awareness.

#### Our goals

- 1. That everyone affected by stroke is supported by a national stroke support organisation
- 2. A substantial reduction in preventable stroke through acting on risk factors and symptoms
- 3. Making stroke a European health, care, social and research priority
- 4. Equality of stroke care in each European country through implementation of comprehensive national stroke strategies
- 5. Maximise our effectiveness by being a professional, ethical, financially stable and sustainable organisation

2024 was a productive and impactful year for SAFE. We strengthened our life after stroke profile, expanded our advocacy collaborations and grew our reach through key initiatives such as the European Life After Stroke Forum (ELASF) in Dublin, the launch of the lived experience abstract category for ELASF in Prague, our European advocacy work with members and the European Alliance for Cardiovascular Health (EACH), and the launch of our updated and redesigned prevention website.

As we move into 2025, our focus will be on driving awareness and implementation of the new Stroke Action Plan for Europe (SAPE) once published, supporting the EU Cardiovascular Health (CVH) Plan and preparing for ELASF 2026, while ensuring continued financial stability and member engagement.

Goal 1: That everyone affected by stroke is supported by a national stroke support organisation

**Our role:** we will build capacity in European stroke support organisations by producing tools, training, information and by providing members meeting opportunities.

#### **Members' meetings**

We met with over 50 representatives from 30 member organisations in Dublin. Each member shared how they support stroke-affected individuals in their country, discussed ideas for European Life After Stroke Forum (ELASF) 2025 and received an update on SAFE's 2025 workplan.

Together with the World Stroke Organization and the Canadian March of Dimes, we continued our work on the *Collaborative Space*, bringing stroke organisations together globally to share knowledge on topics such as peer support, volunteering, mental health and prevention.

#### Post-stroke spasticity: mapping the patient experience

To address critical knowledge gaps, 13 of our members partnered with Ipsen to develop maps of the post-stroke spasticity care pathway, covering medical, social, emotional and caregiver perspectives. Validated by the working group, these maps offer a holistic, evidence-based picture of patient journeys and highlight areas for improvement.

Next steps include adapting the maps into multiple languages and formats to support members' advocacy on post-stroke care. The project was launched at ELASF in Prague, will be presented at the European Stroke Organisation (ESO) and other events and has been submitted to several journals.

# Goal 2: A substantial reduction in preventable stroke through acting on risk factors and symptoms

**Our role:** we will raise awareness of signs and symptoms of stroke and provide upto-date information on the importance of primary and secondary stroke prevention.

We relaunched our stroke prevention website, <u>www.strokeprevention.info</u>, with a new design, logo and expanded, referenced content - reviewed and approved by two neurologists. A built-in translation tool now allows access in multiple languages. The site launched on World Stroke Day and was presented at the World Stroke Congress. Hariklia Proios also showcased it at the Asian Conference on Aging and Gerontology in, Tokyo, Japan. To date, nearly 3,000 new visitors have accessed the site.

**Goal 3: Making stroke a European health, care and research priority Our role:** we will ensure that stroke and the stroke survivor voice is clearly represented in the work of relevant European/EU bodies (such as European Parliament, European Commission, Council of Ministries, Presidencies of the European Union and in Horizon Europe stroke projects) and World/WHO groups.

#### Advocacy

We launched *Prevent, Treat and Support: A Manifesto for Stroke Survivors* to raise the profile of stroke during the European Parliament elections. We supported members and SAPE national coordinators to engage newly elected MEPs.

In partnership with the European Alliance for Cardiovascular Health, we represented stroke at a high-level CVH event in Budapest and at meetings with health attachés and MEPs in Brussels. SAFE member involvement in EU policy work grew from five in 2023 to 19 organisations.

This work contributed to Council of Ministries conclusions on CVH and the EU Health Commissioner's commitment to develop a CVH Plan.

We were also accepted as a strategic partner in the Brain Health Mission, which advocates for national brain strategies to improve care for neurological and mental health conditions across Europe.

#### European Life After Stroke Forum

Our second ELASF took place in Dublin, covering topics such as mental health, vision, secondary prevention and stroke in women. We increased attendance to 316 delegates (from 175 in Barcelona) and abstract submissions to 131 (from 41 in Barcelona). Feedback was overwhelmingly positive, with 98% satisfaction.

The event was generously supported by Bayer, BMS-Pfizer, Boehringer Ingelheim, Ipsen, Novo Nordisk and Merz, and endorsed by key European and international stroke and rehabilitation bodies. Special thanks to Professor Avril Drummond, Chair of the Scientific Committee, and Seren Events, our conference organiser partner.

"What an incredible 2 days at the European #lifeafterstroke conference....so many take homes and areas for improvement but for me, the unmet mental health needs of our stroke survivors were the most striking. We can and must do better at recognising and treating. #ELASF2024"

"What a way to close this conference #lifeafterstroke which has moved me to tears and reenergised my passion & commitment to prevent stroke and support people surviving stroke"

For 2025, we welcomed our new Scientific Committee Chairs: Associate Professor Nicola Hancock (UK) and Professor Anita Arsovska (North Macedonia). The third ELASF took place in Prague in March 2025 - more details are on the ELASF website (www.elasf.org). Looking ahead, ELASF in 2026 will be held in Stockholm.

#### Promoting EU-funded stroke research

We took part in Brain Awareness Week and World Stroke Day to spotlight EU research projects, with member support. We also featured the *Prestige AF* project as an Escape Room at ELASF. Projects included:

- **<u>ANGIE</u>** Nanodevices for targeted treatment in the vascular system
- <u>Prestige AF</u> Stroke prevention in survivors of intracerebral haemorrhage with atrial fibrillation
- <u>TENSION</u> A trial exploring thrombectomy for patients with extended lesions and time windows
- **VALIDATE** Using AI to improve stroke outcomes

Goal 4: Equality of stroke care in each European country through implementation of comprehensive national stroke strategies Our role: we will work in partnership with the European Stroke Organisation to mobilise key stakeholders to work with their governments to deliver a comprehensive stroke plan in each country.

#### SAPE Stroke Services Tracker launch

On European Stroke Awareness Day, we launched the new SAPE Services Tracker data with ESO, our members and SAPE national coordinators. The findings expose ongoing inequalities in stroke care across Europe, despite encouraging improvements in acute treatments and service organisation.

Data from 43 countries show some nations - such as Moldova, Bulgaria, Czech Republic, Estonia, Norway, Portugal, Romania, Sweden and Wales - are making strong progress. However, many still face serious gaps in access to stroke unit care, follow-up and life after stroke support.

This data reinforces the urgent need for targeted action to ensure equitable care for all stroke-affected individuals.

#### International conferences

At the ESO Conference in Munich, we hosted a stand and promoted our work on the Stroke Action Plan for Europe, ELASF and our *Life Saved is a Life Worth Living* report.

We also attended the World Stroke Congress in Toronto, participating in sessions on rehabilitation and life after stroke, meeting with global stroke support groups and strengthening our partnership with the Canadian March of Dimes

### Key activities for 2025

#### SSO capacity building

We will continue to support our members by planning a workshop to shape future member activities at the ELASF and through ongoing Collaborative Space meetings

#### Advocacy and the SAPE

In collaboration with ESO, we will launch the 2023 Stroke Services Tracker data and publish the updated SAPE. Two new advocacy resources will be released to support national-level action, and we will host a stroke event in Brussels to engage MEPs and key stakeholders.

#### **EU CVH Advocacy**

We will ensure stroke priorities are included in the EACH CVH plan and maintain our presence at MEP CVH group meetings. A communications plan will be developed in partnership with members to increase participation and visibility.

#### **Brain Health Mission**

Our involvement in this initiative is to be confirmed, subject to further clarification and definition of SAFE's role.

#### ELASF

We will host ELASF in Prague, focusing on expanding European and international participation, increasing engagement from people with lived experience and ensuring high-quality content. Planning for ELASF 2026 in Stockholm will begin and we will explore new funding streams to strengthen the event's sustainability.

#### European Life After Stroke Task Force

We plan to establish a task force to address post-stroke priorities, with two meetings scheduled and formal plans due for approval by year-end.

#### Lived experience network

We aim to launch a new network for stroke survivors, drawing on those already involved. This will include two online meetings, co-developing an ambassador programme and designing a tailored training offer.

#### Prevention

We will continue to expand our online prevention resources with new videos, case studies and tools, alongside a promotional campaign to boost visibility and usage.

#### Post-stroke spasticity (lpsen)

We will launch the Patient Experience Map at ELASF, with translations made available based on demand from member countries.

#### Secondary prevention (Bayer)

We will complete Delphi research and launch a White Paper to inform future strategies in secondary stroke prevention.

# Goal 5: Maximise our effectiveness by being a professional, ethical, financially stable and sustainable organisation

Our role: we will ensure that we are an effective organisation by having a committed and engaged board and 'staff', good governance and the financial recourses in place to support our work.

#### 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 2024 SAFE board:

Officers:

- Hariklia Proios, Greece, President (elected for a second term at the General Assembly)
- Hrvoje Jurlina, Vice President, Croatia (elected at the General Assembly)
- Marina Charalambous, Cyprus, Secretary
- Chris Macey, Ireland, Treasurer

#### Members at large:

Dorina Dobreva, Bulgaria, Hrvoje Jurlina, Croatia (until June 2024), Yago Bundgaard, Denmark. Maja Bozinovska, North Macedonia. Marianne Tangen, Norway, Liliana Curea, Romania, Sarah Belson, United Kingdom

The Board held four meetings in 2024, two virtual and two face-to-face in Dublin and Larnaca. Its role is to monitor implementation of SAFE's strategic plan and provide policy and procedural direction, and to supervise the finances.

#### Staff

Our team coordinate our work - Arlene Wilkie, Director General, Sandra Jackson, Secretariat and Anna Scott, Communications Manager

Fleishmann Hillard has proved advocacy strategic and operational support. Joe Korner has proved support for our advocacy tools

#### 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 Verenigingtegen cerebrovasculaire accidenten			
Bulgaria	Association for Stroke and Aphasia			
Bulgaria	Heart to Heart Foundation			
Catalonia	Federacio Ictus de Catalonia			
Catalonia	Fundacio Ictus			
Croatia	Croatian Stroke Society			
Croatia	Mozdani Val			
Cyprus	Cyprus Stroke Association			
Czech Republic	Sdružení CMP			
Czech Republic	CEREBRUM			
Denmark	Hjernesagen – The Danish Stroke Association			
Estonia	Estonian Stroke Patients Society			
Finland	Aivoliitto ry			
France	Vaincre I'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			
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

#### Income

In 2024, income was €531,959 (€648,117 in 2023, €394,297 in 2022, €517,716 in 2021):

- Membership income increased to €54,762 (€54,940 in 2023, €50,617 in 2022, €47,024 in 2021) due to new organisations joining SAFE and we increased the membership fees in 2024 by 3 per cent
- Sponsorship of €368,091 (€441,226 in 2023, €316,760 in 2022, €398,800 in 2021) was received from Bayer, BMS-Pfizer Alliance, Boehringer Ingelheim, Ipsen, Merz Therapeutics, Novartis and NovoNordisk.
- €47,912 was received in for the European Life After Stroke Forum including for fees and subvention (€10,432 in 2023)
- Donations and consultation income received was €1,832 (€1,715 in 2023, €3,811 in 2022, €2,438 in 2021)
- €59,362 (€139,804 in 2023, €22,504 in 2022, €69,454 in 2021) was received from partnerships with European research organisations shows SAFE's continuing importance to the consortium involved in these research projects.

In addition, we carried forward €872,358 from 2023 (€789,194 from 2022 €977,452 from 2021 and €718,345 from 2020).

Our thanks go to all our supporters in 2024 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.

#### Expenditure

In 2024, our expenditure was €560,115 (€564,953 in 2023, €582,552 in 2022, €258,609. in 2021).

- Project costs €252,117 (€343,599 in 2023, €303,281 in 2022, €48,803 in 2021). Our work is outlined in the 'Highlights of the year' section above and in summary expenses for work on the European Life After Stroke Forum, our advocacy work on the Stroke Action Plan for Europe and the relaunch of strokeprevention.info.
- Staff costs €190,071 (€175,337 in 2023, €206,029 in 2022, €164,680 in 2021)
- EU research projects €82,467 (€17,373 in 2023, €16,794 in 2022, €9,729 in €2021). We have increased our work here communication about research in both Brain Awareness Week and World Stroke Day.
- Core costs €35,460 (€28,643 in 2023, €56,452 in 2022, €35,397 in 2021)

#### Surplus and our plans

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As a result, we had a surplus of €844,201 (€872,358 in 2023, €789,194 in 2022, €977,452 in 2021).

From these funds we hold €250,000 in reserves. Our planned expenditure in 2025 from these funds is €504,930 which we have raised to spend on projects such as the European Life After Stroke Forum, the Stroke Action Plan for Europe and the European Task Force. Also included is funds we have received from the EU research projects that we will spend over the next five years.

	2024	2023	2022	2021
Income	(Euro)	(Euro)	(Euro)	(Euro)
Membership fees	54,762	54,940	50,617	47,024
Industry	368,091	441,226	316,760	398,800
ELASF fees and subvention	47,912	10,432	606	N/A
Donations and consultancy	1,832	1,715	3,811	2,438
European research projects	59,362	139,804	22,504	69,454
Total income	531,959	648,117	394,298	517,716
Carried forward	872,358	789,194	977,452	718,345
Expenditure				
Project costs	252,117	343,599	303,281	48,803
Staff costs	190,071	175,337	206,029	164,680
European research projects	82,467	17,373	16,794	9,729
Core costs	35,460	28,643	56,452	35,397
Total expenditure	560,115	564,953	582,556	258,609
Total funds carried forward	844,201	872,358	789,194	977,452
Acceta				
<b>Assets</b> Cash at bank 31 Dec 2024	834,358 <sup>1</sup>	803,019	797,440	980,328
Accounts receivable	35,000 <sup>2</sup>	93,024	50,716	980,328 4,784
Total assets	<b>869,358</b> <sup>3</sup>	896,043	848,156	985,112
	,	,	,	,
Deferred charges		-	0	1,786
Current liabilities	25,157 <sup>4</sup>		58,962	5,874
Total funds carried forward	844,201	872,358	789,194	977,452
Carried forward funds allocation				
Research (liability)	211,301	238,921	131,921	127,880
Projects (liability)	293,629	276,852	298,000	488,796
Deferred charges	0	0	0	1,785
Profit/loss carried forward (equity)	<b>339,271</b> ⁵	356,585	359,273	358,991
	050.000	050.000	050.000	
The reserves allocation is	250,000	250,000	250,000	200,000
Unrestricted/ allocated to ELASF emergency fund	89,271			

# Consolidated statement of financial activities year end 31st December 2024