

S·A·F·E

Stroke Alliance For Europe

THE STROKE PATIENT
VOICE IN EUROPE



SAFE ANNUAL REPORT 2018

THE STROKE ALLIANCE FOR EUROPE

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2018

STROKE ALLIANCE FOR EUROPE

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

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



OUR MISSION

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

OUR VISION

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

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

PRESIDENT'S MESSAGE

I am pleased to report that the last year has again been one of major success and progress.

During 2018, after months of hard work with the domain groups of experts convened by ESO, all of which included representation from SAFE, a consensus was achieved on a Stroke Action Plan for Europe.

A set of recommendations was jointly launched with ESO in the European Parliament in May. This autumn we released a lay version of the Stroke Action Plan with the scientific version being published in the European Journal of Stroke in October.

SAFE now has 33 member organisations for the first time in our history, and happily approximately 10 now employ staff, a sure sign of increasing professionalism.

We would like to express our grateful thanks to Bayer for supporting the working conference and the development of the Stroke Support Organisation Faculty Tool (SSOFT). Victoria Brewer has managed this huge project with great professionalism and we are thrilled to now have an educational and training tool to drive forward advocacy and the growth of stroke support organisations. Its success will, I believe, be measured by the number of countries impacted by the cadre of people mobilised by the tool. They will be enabled to advocate and campaign, build stroke support organisations and improve stroke care and support.

We would also like to thank the BMS/Pfizer Alliance for their additional support for the 2018 working conference.

This year we have again contracted Weber Shandwick to support our work within the EU. Through this collaboration we have continued to raise the profile of stroke within the European Parliament, and have initiated contact with the forthcoming Romanian Presidency and the Committee of the Regions. (The European Committee of the Regions (CoR) is the voice of regions and cities in the European Union (EU). It represents local and regional authorities across the European Union and advises on new laws that have an impact on regions and cities, which is 70% of all **EU** legislation).

We held successful regional conferences in June and July, in which member organisations had the opportunity to meet and discuss issues, challenges and progress.

These covered all countries in Europe, and we are grateful for the support of Boehringer Ingelheim whose sponsorship enables these events to occur. Alongside the working conference, the regional conferences have been of critical importance in enabling the setup and development of stroke support organisations.

We have delivered more stroke messaging to the public than ever before, and our presence on social media grows day by day. Jelena Misita, SAFE's Communications Manager, has done an outstanding job, as well as managing our work around stroke awareness, including sitting on the World Stroke Campaign working group, our website, and our creation and print work, of reports and literature, Jelena handles many meetings with outside partners.

This includes for example the work with the Angels project involving thousands of leaflets in 13 different languages being produced and distributed.

Our industry partners group, where commercial organisations get together with us to discuss how we can help move the agenda of stroke prevention, care and survivor support forward, has gone from strength to strength. I want to thank in particular all those individuals and their organisations who have played such a key role in enabling SAFE to perform and achieve at the highest level yet. Their contributions are very much appreciated, and absolutely essential for SAFE sustainability.

We are once again holding our working conference with an important national organisation, the German Stroke Foundation. This organisation deserves the highest praise for its continued support of SAFE, an involvement that stretches back to the earliest formation of our coalition.

2018 has been our busiest year to date, with ongoing and new projects such as Merz's spasticity website, the website on Prevention sponsored by Amgen, being developed and providing much needed information on the web.

Our Volunteer Gary Randall deserves our thanks for his support with regard to our contract with Oxford University to deliver a research report on the economic impact of stroke to be launched October 2019, and in managing a raft of EU research projects.

The SAFE board has worked harder than ever this year, and I as President would like to commend and thank them all for what they have given to help conquer stroke. We have made changes to our governance to ensure that we are able to manage an ever-growing coalition and range of financial and other obligations.

I would also like to particularly single out Sandra Jackson, who moved into a full time role with SAFE this year to provide the Secretariat, necessary given the growth of SAFE. Sandra as a consequence has been able to address some of our longstanding issues with regard to the installation of a management accounting system enabling us to better ensure the sustainability of SAFE into the future. Additionally Sandra has continued to ensure, with the Treasurer Grethe Lunde, effective cost control to ensure our money goes as far as it can to conquer stroke.

As the central activity of SAFE has raised its performance, so too we see more member organisations beginning to grow and employ staff, conduct campaigns, run services, and build their websites and social media activity.

It's been a great year, the future promises much - together we are stronger.



Jon Barrick
SAFE President



Photo by SAFE

SAFE IN 2018 THE STORY SO FAR

STROKE ACTION PLAN FOR EUROPE 2018 – 2030

Building on the preceding Helsingborg Declarations of 1995 and 2006, the Stroke Action Plan for Europe was written in close collaboration between SAFE and ESO.

70 experts, scientists, stroke survivors, medical professionals and stroke advocates worked in seven domain groups, covering the most important topics along the stroke care pathway, from prevention to life after stroke.

The domain groups addressed the following topics:

1. **PRIMARY PREVENTION**
2. **ORGANISATION OF STROKE SERVICES**
3. **MANAGEMENT FOR ACUTE STROKE**
4. **SECONDARY PREVENTION AND ORGANIZED FOLLOW-UP**
5. **REHABILITATION**
6. **EVALUATION OF STROKE OUTCOME AND QUALITY ASSESSMENT**
7. **LIFE AFTER STROKE**

The draft version was presented at a consensus meeting in Munich in March 2018. SAFE had a representative on each of the seven domain groups ensuring more attention was paid to the whole stroke care pathway. The draft documents were open to public comments and the final document was prepared after the Munich workshop. Patient organisation representatives were involved every step of the way.

The Stroke Action Plan for Europe 2018 – 2030 was officially launched at ESOC 2018 in Gothenburg, to a scientific audience, and then the published Recommendations were shared for the first time in the European Parliament

with a range of guests including MEPs and policymakers. The lay version of the Plan was also launched at the World Stroke Congress in Montreal, Canada in October 2018.



The Stroke Action Plan for Europe includes targets for each of the domains – primary prevention, organisation of stroke care, acute stroke care, secondary prevention, rehabilitation, evaluation of outcomes and life after stroke -

STROKE SUPPORT ORGANISATION FACULTY TOOL



In 2018, in partnership with the European Stroke Organisation (ESO), SAFE developed an innovative education platform on stroke advocacy for Stroke Support Organisations (SSOs) – the Stroke Support Organisation Faculty Tool (SSOFT).

The overarching objective of SSOFT is to achieve improved stroke care and enable SSOs, ESO members and their communities to strengthen their ability to advocate and impact on stroke prevention strategies, diagnosis and treatment and after care.

SSOFT provides knowledge and training on how to create effective advocacy activities and campaigns through six modules that provide information on:

WHAT ARE STROKE SUPPORT ORGANISATIONS (SSOS)

MAKING CHANGE HAPPEN

USE OF EVIDENCE

ROLE OF PATIENT VOICE;

HEALTH & CARE SYSTEM ADVOCACY

PUBLIC ADVOCACY

The modules combine both theory and practical information, as well as providing interactive content, videos and activities. The modules also include supporting materials to assist learners on how they can practically apply this information within their own context.

The modules are accessible via the SSOFT website (www.ssoft.info) through a simple registration process. Visitors to the website can also learn more about SSOFT, SAFE and ESO, find their nearest SAFE Stroke Support Organisation (SSO) as well as hear from SAFE members about their experiences.

SSOFT's development and execution was successfully led by Victoria Brewer, SAFE Project

Director with the involvement of experienced Content Writers; Sarah Belson, International Development Manager at the World Stroke Organisation; and Joe Korner, who worked as the Director of Communications at the Stroke Association UK for ten years. In addition, this project was made possible by the involvement of the many members of SAFE.

From the beginning of the development of SSOFT the needs of the members of SAFE have been central to the whole process. It was those needs that were the focus at the last SAFE Working Conference in Zagreb (December 2017) where half a day was dedicated to gaining insight and feedback from the numerous member who attended - *"For our members by our members"*



Photos By Shutterstock

SAFE members have also been actively involved in the development of the content by either testing the modules, providing cases studies or sharing their experience in interviews. These examples have brought much of the content to life by providing real world cases studies of how the knowledge contained in the modules can be applied.

SSOFT was completed in November 2018 and fittingly launched at the 2018 SAFE Working Conference in Berlin bringing the project full circle.

The Stroke Support Organisation Tool project was generously supported by Bayer. For more information, please email ssoft@safestroke.eu or visit www.ssoft.info

WE LAUNCHED A WEBSITE FOR STROKE PREVENTION

Reliable, easy to use information on ten modifiable stroke risk factors can now be found in one place on a website developed by SAFE www.strokeprevention.info.

The website was launched in September 2018 and contains all the relevant information on stroke risk factors in a simple format aimed at a range of audiences. All the information presented on this website is in a form appropriate for people with busy lifestyles, unable to digest too much detail at one time, as well as people with disabilities.

The idea for this project was based on findings from the INTERSTROKE study, which showed that ten modifiable risk factors are responsible for 90% of strokes. SAFE's goal with this website is to increase awareness and encourage behaviour change by creating an online resource that collates all relevant information on the most common risk factors:

hypertension, physical inactivity, unhealthy diet, obesity, smoking, cholesterol, heart disease, alcohol, stress and diabetes.

Prior to developing this website, our research showed that it was difficult to find consistent and coherent information about stroke prevention in one place online. In addition, a lot of the information was not in a format appropriate for people with disabilities.

The website includes educational information produced by professional medical writers, a series of infographics and short animated videos, enabling people to get correct, evidence-based material in bite-size pieces of selected content.

This website is developed and owned by SAFE and was made possible by an educational grant from Amgen. SAFE retains full editorial control over the content of the website.



SAFE ANGELS PROJECT: BRINGING THE PATIENT EXPERIENCE TO THE ANGELS INITIATIVE

The Angels Initiative was developed by Boehringer Ingelheim (BI) with the mission to increase the number of patients who can be treated in stroke-ready hospitals, and to optimise the quality of treatment in all existing stroke centres. In 2017, the Angels Initiative was endorsed by the European Stroke Organisation (ESO), the largest European organisation of stroke professionals. SAFE with members from twelve countries, partnered with BI to support this ambitious project by adding the important dimension of the patient perspective.

SAFE is proud to be part of the Angels Initiative, providing critical information to stroke patients when they most need it - in the stroke unit. The realisation of this project started simultaneously in selected hospitals in May 2018 in twelve European countries: Spain, Serbia, Poland, Czech Republic, Latvia, Croatia, Macedonia, Greece, Ukraine, Georgia, Hungary and Turkey.

Stroke patients and their families are now provided with information on stroke and

important next steps on their path to recovery. The patient-focused materials consist of five leaflets. Each leaflet includes details of national, regional and local stroke support organisations in each of the countries, so that patients and carers can access further support in the months and years to come. SAFE is immensely grateful to the UK Stroke Association for its help providing the information, which was then translated for each participating country.

This project will enable patients to be actively involved in their treatment, leading to informed communication between healthcare professionals and patients and better outcomes. An online survey in thirteen languages will collect patient's feedback about both the quality and quantity of information they received during their stay in the hospital. The results of the survey are expected to reveal the best performing hospital in terms of patient-doctor communication and provide insights into what needs to be improved in the future.



SAFE REGIONAL CONFERENCES 2018

During May and early June SAFE held Regional Conferences in Madrid, Dublin and Prague. These were extremely well attended, with c,70 delegates.

These conferences are held to keep SAFE members up-to-date on SAFE activities, enable members to use the resources that SAFE provides as well as providing the opportunity for people to learn, share ideas and get encouragement from more experienced members. This year members enjoyed presentations on the Stroke Action Plan for Europe and the Stroke Support Organisation Faculty Tool (SSOFT), plans for World Stroke Day and the next steps in the BI Angels Initiative. Organisations gave updates on activities in their own countries, and many new alliances were forged amongst members.

The Regional Conferences are extremely popular with members and new delegates alike, not least for the networking opportunities they provide.

“I really enjoyed all the updates on what SAFE was up to mostly on the Financial Burden & Stroke Action Plan.”

“To catch up with people from other SSO’s, and to find out what is happening at a European level.”

“Meeting other delegates - exchange of experience - ideas for new activities of SSOs”.

SAFE would like to thank Boehringer Ingelheim for its continued sponsorship of the regional conferences.

The **Economic Impact of Stroke Report** has been the subject of research activity by Oxford University throughout the year, and will be finalised in the summer of 2019, with the launch in the EU planned for October 2019.



SAFE'S INVOLVEMENT WITH EUROPEAN RESEARCH

SAFE continued to participate in the Horizon 2020 EU research funding programme throughout 2018 under the guidance of its Research Manager, Dr Gary Randall.

SAFE is now involved in five EU-funded research projects and contribute to the dissemination of information about each project:

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

PRESTIGE-AF and TENSION were both new in 2018 and SAFE members did a good job of translating press material, for which we thank them.

The following two projects finished this year: -



WAKE-UP, which used brain imaging to test if thrombolysis is safe in those who have a stroke while asleep, was a major success. A key speech was given at ESOC and the positive results were published in the New England Journal of Medicine. WAKE-UP will change clinical practise and will improve outcomes for thrombolysis patients because brain imaging was shown to be a reliable diagnostic tool for the first time.



EuroHYP-1, which used hypothermia to reduce the effects of acute stroke, finished this summer after running for almost six years. Unfortunately, recruitment and implementation of the treatment remained very difficult throughout. Some basic results about the safety of the procedure, but not necessarily its effectiveness, are expected in early 2019.





Designed by Pressfoto / Freepik

Going forward, we continue to support new proposals:

PINNACLES

is an enlarged version of a proposal we came very close to getting funded 3 years ago. Its focus is self-management, physical fitness and activity in the chronic stroke population. Gary Randall is heavily involved in advising on and writing parts of this proposal. We are asking for a large budget (approx. 20M euro) because the implementation will be in 12 EU countries.

Two further proposals deal with managing patients with multiple co-existing disease;

DECODE CM

looks at cognitive decline in the elderly, including stroke survivors

MICROBIOSsis

looks at the role of gut bacteria in depression, pain and cognitive performance.

All of these three are stage 1 proposals at the moment. If successful, there will be a further competitive round of stage 2 submissions in early 2019.

Finally, our funding model i.e. how we pay members for EU project work (which in turn allows some of you to pay SAFE membership fees) will continue to adapt as necessary. In some cases, the SAFE Advocacy Manager will centrally translate project results into all SAFE member languages and will co-ordinate distribution thereafter. In others, this work will be done directly by members themselves. The choice will depend on the timing and content we have from each project. SAFE's intention is that we again have a package of project information for distribution by members during late 2018, early 2019.

During 2017 SAFE paid €9,891 to members for dissemination of EU research projects. In 2018 this figure increased to €19,938.

SAFE GOVERNANCE AND MEMBERSHIP

BOARD

SAFE is governed by a board that can comprise no fewer than five and no more than eleven members. In 2018, the SAFE board consisted of ten members:

President:

Jon Barrick	UK
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Vice President:

Markus Wagner	Germany
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Secretary:

Monique Lindhout	Netherlands
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Treasurer:

Grethe Lunde	Norway
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Member

(East Europe): Ivan Milojević	Serbia
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Member

(Central Europe): Anita Arsovska	Macedonia
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Member

(South Europe): Pnina Rosensweig	Israel
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Member

(North Europe): Kolbrún Stefánsdóttir	Iceland (Resigned June 2018)
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Member

(West Cluster): Hariklia Proios	Greece
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STAFF

SAFE continues to be supported by Sandra Jackson as Secretariat and Lucinda Shaw as the SAFE Fundraising and Partnerships Manager.

Both are based at the Stroke Association offices in the UK, but report directly to the SAFE board on their activities. Our thanks to the Stroke Association for hosting these roles.

Gary Randall continues as the SAFE Research Manager on a pro-bono basis. Our grateful thanks go to Gary for continuing to generously support SAFE in this important role.

Jelena Misita continues as the SAFE Advocacy and Awareness Manager.

Victoria Brewer was employed by SAFE throughout the year on a self-employed basis as the Project Director for SSOFT.

SAFE MEMBERSHIP ORGANISATIONS IN 2018**

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

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

CONSOLIDATED STATEMENT OF FINANCIAL ACTIVITIES YEAR ENDED 31ST DECEMBER 2017

Income from:	Euro
Sponsorship Income**	€601,788.78
Membership fees	€25,100.00
European Research project funding contributions	€32,042.54
Jon Barrick Speaker fees	€1,668.38
Total Income	€660,599.70

Expenditure on:	Euro
Meetings (board meetings, industry partner meetings, etc.)	€23,404.31
Conferences (Working Conference, Regional Conferences and external conferences)	€169,711.86
Staff costs (Secretariat, Advocacy Manager, SSOFT Project Manager, Merz Project Manager)	€82,147.57
European Research Project dissemination to membership	€9,891.00
Project costs	€57,880.79
SAFE Report costs	€40,381.75
EU Lobbying agency costs	€40,704.00
Membership of other organisations	€922.73
Professional fees and bank charges (including set-up of new accounts system)	€14,289.25
Other costs	€75,277.67
Cash moved to create a reserve	€200,000.00
Funds accrued for expenses in 2018**	€300,000.00
Total Expenditure	€1,014,610.93

Reconciliation of funds:	Euro
Total funds brought forward at 1 January 2017	€418,120.51
Total funds carried forward at 31 December 2017	€64,109.28
**Note: Funds received for project costs in 2017 were spent in 2018	

Accountantskantoor
ACCOUNTING & TAX PARTNERS NV



Burgelijke vennootschap die
de rechtsvorm van een NV
heeft aangenomen



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, 2017.

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, 2017, and the result of the operations for the year then ended.

Leuven (Belgium)
October, 2018

Accounting & Tax Partners nv

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KREDBEBB

SUPPORT STROKE ALLIANCE FOR EUROPE

If you would like to support SAFE, please use following bank account details:

Bank Name:	KBC Bank
KBC's BIC:	KREDBEBB
IBAN: (International Account No.)	BE51 7350 1165 7162
Account Holder:	Stroke Alliance For Europe (SAFE)
Bank Address:	Havenlaan 2 1080 Brussels Belgium
Information number:	Tel: +32 2 533 7575
SAFE Secretariat:	Stroke Association House 240 City Road London EC1V 2PR United Kingdom
E-mail:	mail@safestroke.com



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SAFE would like to thank the following organisations
for their continued support during 2018

AMGEN



Daiichi-Sankyo

IPSEN
Innovation for patient care



 **Boehringer
Ingelheim**



Bristol-Myers Squibb

