



SAFE Regional Conferences

May and June 2019



Our last year's achievements, and challenges going forward

Achievements

- Now 34 member organisations as members, and still growing
- Extending partnerships, working with EFNA, WSO , ESO and EPF
- 3rd year of retaining a lobbying company in Brussels, Weber Shandwick
- Launched the Stroke Support Organisations Faculty tool (SSOFT)
- Secured funding for regional conferences, and other projects
- Worked in partnership with ESO on Stroke Action Plan for Europe. This was published in full in October 2018. We published the lay version and working on translations. We had major policy push in EU in March securing the support of the EU Presidency
- Achieved major breakthrough possibilities with EU on stroke
- Industry Partners meeting continues to develop – next meeting July 10th in London

Challenges

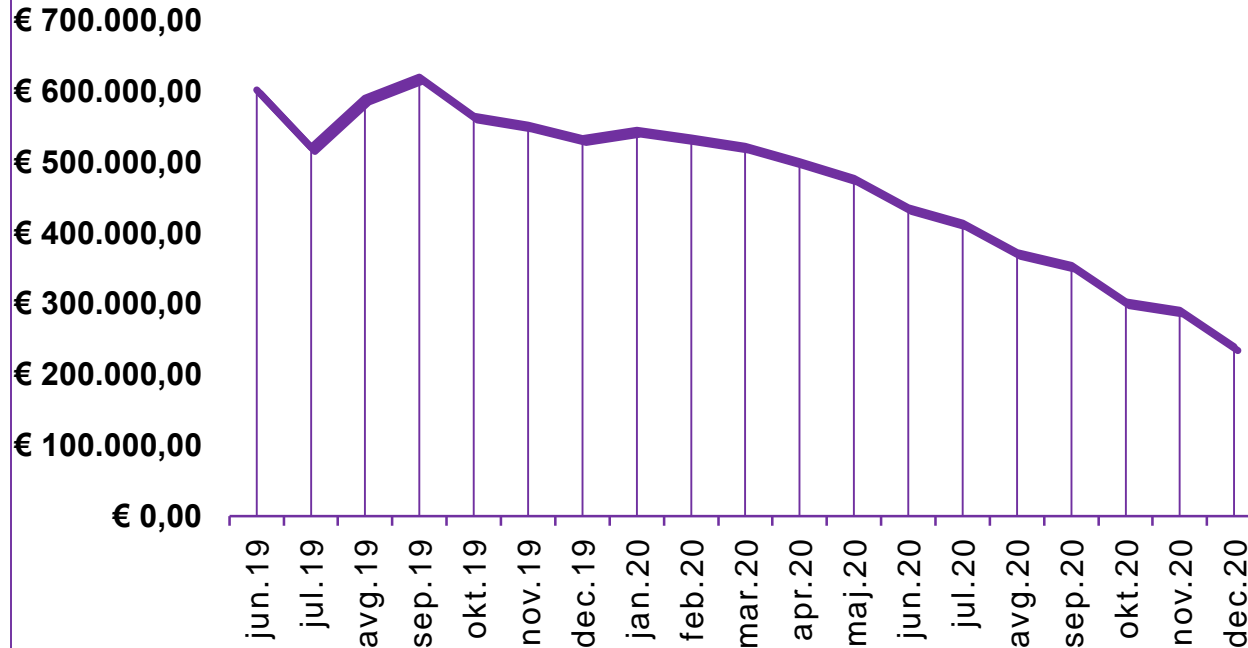
- A time of change as SAFE continues to grow membership, with limited resources
- A time of change with Board leaders moving to retirement, need new leaders
- A time of opportunity, policy breakthroughs and potential new projects on the horizon. Do we have the capacity and capability to seize the opportunities?
- A time of opportunity with diplomacy required to manage partners and members, for growing more projects. We need more engagement with them.
- A time of external challenges, with regard to others trying to take on our intellectual capital, trade marks, and subject areas.
- No funds available for Stroke Survivor Wants and Needs Survey
- It is a time of review, we have more demands with regard to our purpose and how we pursue it. We have future strategy and sustainability challenges

Finances, an ongoing struggle

- 2019 has continued to be a struggle as far as finances are concerned, with some sponsors having to cut back on funding
- We have outgoings we have to meet every month, salaries, hosting costs for websites, phone bills etc.
- Outgoings increasing
- Need more from membership fees
- Have to generate cash from activities, but how?
- Have built up some savings but these are rapidly being eroded

Cash flow forecast to end 2020

SAFE PREDICTED CASHFLOW TO END 2020



Strategy Review

- Board met in February
- Need to look at the situation because of the opportunities, challenges and cash flow situation
- Things have to be done in short term and some longer term issues
- Came up with specific issues and considered solutions

Conference/meeting funding

- At the moment we have not received full funding for the 2019 Working Conference and General Assembly in Porto in November. We need to cut the budget by approx. €40,000
- We therefore have two options currently available to us:
 1. Reduce the number of delegates funded to attend by SAFE from two to one from each organisation
 2. No longer have two SAFE conference dinners (with delegates providing for themselves in the evening instead) and cutting other costs such as gifts to delegates
- SAFE's preferred option is No. 2, but we would like the views of this conference on this.

Constitution Review to meet modern rules

- SAFE's Constitution has remained almost the same since being founded in 2004.
- We are currently in discussion with pro bono lawyers in Brussels to review the Constitution to ensure that it meets fully with up-to-date rules and regulations regarding NGO's registered in Belgium.
- SAFE's aim is to form a small committee to review the Constitution, and maybe change to having a Constitution and By-Laws. The Committee will work with the lawyers during 2019 and 2020 to produce recommendations to put to the General Assembly in 2020.
- We will be asking all members to review the Constitution for any suggestions/comments they may have.

President Elect Constitution Amendment

- Jon Barrick will retire as SAFE President at the GA in 2020, having served two terms on the SAFE board.
- To ensure the smooth transition to the next SAFE Presidency, the board would like to propose that a new position of President Elect be added to the current board structure.
- We would ask for proposals for this post at the GA in November this year, so that the President Elect could work alongside Jon for one year.
- We also need candidates for the board to step forward. All expenses are generally covered, in return for your voluntary work and expertise

European Level Life After Stroke Forum

- Need to consider new ways of holding conference that are financially viable
- At the moment we are dependent on sponsorship
- Need to be more self-financing to avoid uncertainty
- Life after stroke section in Action Plan does not have a conference for discussion of topics
- Can we fill this gap in the conference market. We would want to add delegates fees and exhibitors income to our revenue.
- Would start small in November 2020, General Assembly would be included in programme
- Would need a scientific committee to seek out speakers and help with marketing
- Chair of Life After Stroke domain group in the Stroke Action Plan is set to discuss this with us
- Could continue to sponsor at least one delegate from member organisations to attend if we receive sponsorship

Life After Stroke Forum topics

- The topics to be considered by the scientific committee would include...
 - Stroke self-management
 - Therapy from a patient perspective
 - The economics of stroke
 - Stroke and social care and support
 - Peer support and stroke
 - Enabling equipment for stroke survivors
 - IT and software
 - Smart housing and the amelioration of stroke
 - Education, Information and Training content and issues around stroke knowledge and awareness
 - Robotics and stroke
 - Workforce licensing and stroke
 - Secondary prevention and the stroke survivor and their families
 - Wants and needs from a patient perspective after stroke
 - Stroke and mental health
 - Relationship issues after stroke
 - Multiple morbidity after stroke.

New role within SAFE: Director

- New post needed to handle management of SAFE as it has grown, and to ensure new programmes of work are delivered
- Closing date was May 29th
- Interview date June 17th
- Recruitment agency sorted through applications and produced a long list
- Role will be self-employed and home-based so anyone in Europe could apply
- Together with fundraiser, role will be essential to secure future of SAFE
- Link to advert was sent to members asking them to advertise on their websites, Facebook pages, etc.

**Watch this space
for an announcement
very soon!**

So a lot to do to enable SAFE to continue

- Ultimately SAFE is dependent on its member organisations
- We need SSO's to thrive and grow
- Scenario 1 - The future may look like this: Paid staff, covering stakeholder engagement, communications, policy, fundraising, more commercial type conference, more income from membership fees, with a sustainable stream of income as a result

Or this

- Scenario 2 - Having to trim down staff numbers, go year to year dependent on gifts to support outgoings, reduced support for advocacy and SSO's as SSO's have failed to grow and membership fees remain static, maybe eventually go bankrupt unless we can make scenario 1 work.



Stroke Action Plan for Europe EU Summit What next?

Whats happening with the Stroke Action Plan?

- Have published lay version
- Now commencing with translations into other languages
- Aim in March was to hold meeting in EU to start policy work before May European Parliament elections
- Our lobbyists Weber Shandwick invited key speakers from within EU presidency units, (Romania, Finland, Croatia) and from DG Sante, Committee of Regions, and Chrodus PLUS. Was very successful
- Romanian President of EU has endorsed the Stroke Action Plan for Europe
- NOTE all this very expensive €70,000



Delivered in the EU



Thursday, 28 March 2019

European Committee of the Regions

Joining Forces to Prevent and Control
Non-Communicable Diseases:
The Role of Policy in Tackling Stroke

Putting the Stroke Action Plan for Europe
2018-2030 in the spotlight

The EU Meeting

Joining forces to prevent and control non-communicable diseases: The role of policy in tackling stroke



The EU event

- Event was live streamed
- Recorded to provide material for our website and social media work
- Weber Shandwick wrote report of proceedings and listed follow up activity
- Report has been widely circulated via email as a pdf
- Printed report will be available from our stand at ESO conference, and available to you today
- Follow up meetings already underway

Conference Report

CONFERENCE REPORT



**Joining forces to prevent and control
non-communicable diseases:**

The role of policy in tackling stroke

Putting the Stroke Action Plan for Europe
2018-2030 in the spotlight

28 March 2019

European Committee of the Regions



Proposals for action

Martin Seychell and Rokas Navickas proposed leveraging existing platforms facilitated by the EU - namely the CHRODIS + Joint Action, the Steering Group on Health Promotion, Disease Prevention and Management of NCD, and the Health Policy Platform - for future action on stroke.

Martin Seychell offered to facilitate discussions on the Stroke Action Plan for Europe within the Steering Group on Health Promotion, Disease Prevention and Management of NCDs, as well as to assist Member States in identifying priority actions, transferring best practices and assessing areas where the EU can add value through existing EU platforms.

Rokas Navickas proposed collaboration between SAFE, ESO and the CHRODIS + Joint Action, including the preparation of a potential future project on stroke. The Joint Action could contribute by helping identify stroke best practices currently implemented across Europe and supporting the development and implementation of a strategy for the transfer of those to different countries.

Martin Seychell also invited patient groups and medical societies to join the Health Policy Platform, to interact with other key policy stakeholders, help raise the profile of stroke at EU level and drive community consensus on stroke specific policy issues.

Further options for future work were raised by Mikel Irujo Amezaga, namely a European Committee of the Regions own-initiative report, which he offered to support with, or an EP resolution. If issued, these could be leveraged by local patient groups and medical societies when engaging with national policy-makers to call for the implementation of the Stroke Action Plan for Europe's recommendations.

Next Steps:

- As a follow-up to the meeting, SAFE & ESO propose a number of policy actions that different EU policy-makers could take to assist EU Member States in decreasing the burden of stroke. SAFE and ESO call on:

***Steering Group on
Health Promotion,
Disease Prevention and
Management of NCDs***

DG SANTE to facilitate discussions within the Steering Group on the implementation of the Action Plan as well the exchange of stroke best practices, in addition to the provision of support where Member States see the EU can be of added value.

***DG SANTE Best
Practices Portal***

DG SANTE to open a new call for best practices in public health so that the Stroke Action Plan can be submitted for evaluation.

CHRODIS + Joint Action

CHRODIS + Joint Action to support SAFE and ESO with the planning and implementation of a pilot project for the transfer of best practices outlined in the Stroke Action Plan for Europe across different EU Countries.

Next Steps:

Smart Specialisation Thematic Platforms

Interreg Europe to create a Thematic Platform that enables interregional cooperation on stroke in the area of research & innovation to fill current knowledge gaps.

Knowledge Exchange Platforms

CoR to adopt stroke as a priority area for interregional cooperation in 2020 and form a Knowledge Exchange Platform on stroke to foster policy discussions at EU level on stroke.

CoR own-initiative opinion

CoR to adopt an own-initiative opinion, highlighting the need for action to tackle the stroke burden, including through the implementation of the Action Plan at national and local levels.

EP Resolution

Members of the EP to adopt a resolution, potentially building on the CoR own-initiative report, calling on Member States to implement the recommendations of the Action Plan and on EU Institutions to leverage existing platforms, to put stroke more prominently on the agenda and truly facilitate the exchange of best practice.

EP Pilot Project

EP and the EC to consider supporting and approving a pilot project for reducing the societal and economic burden of stroke in Europe.

Our relationship with ESO

- Changing
- Have received €35,000 to help with SAPE costs
- From Vice President to observer on their committee
- Have set up a joint implementation group



How did we do in Social Media?

*The performance of the digital strategy rolled-out for the event
'Joining forces to prevent and control non-communicable
diseases: The role of policy in tackling stroke'*

Goals & Objectives of the Digital Strategy

Social Media Goals

Primary Key Performance Indicators

- To build on the burden of stroke and disseminate the aims and targets of the Stroke Stroke Action Plan for Europe 2018-2030.



- Impressions and engagements and URL/Link clicks

- To generate interest on the event, build noise around its importance and promote attendance



- Registrations, livestream views and URL/Link clicks

Executive summary

What has been done?

In Feb - March a Digital Strategy was rolled out at several levels, with these two as main pillars for the social media campaign:

- ✓ **SAFE Website:** an event webpage was created and continuously updated until the day of the event.
- ✓ **Social Media channels:** a social media strategy was set and implemented on Facebook and Twitter for a period of 6 weeks (from 20 February to 29 March).

Strategy implementation: Key overall findings



Registrations

89 people registered to the event and around **60 people attended it**



Live streaming

45 people registered to receive the link and **40 people accessed it**



Website

The event webpage was the **fourth and third most visited page** of the website in **February and March**, respectively.



Targeted emails

The targeted emails generated a total of **775 URL clicks**, of which 37% to open the registration form, 19% to open the live streaming form, 19% to visit the event webpage and 11% to open the Stroke Action Plan for Europe.



Facebook

Through 27 organic posts, the Facebook campaign led to a total of **18,851 impressions**, **1,384 engagements**, and **101 URL clicks**.



Twitter

Through 58 organic tweets, the Twitter campaign led to a total of **65,079 impressions**, **1,078 engagements**, and **409 URL clicks**.



EU Media

Dods and Politico shared the event with their community, which led to **82 clicks** overall.

Key learnings



Registrations

- ✓ The number of people registering to the event was higher than usual. Having a structured digital campaign contributed to generating more interest around the event.



Live streaming

- ✓ Even if not hundreds of people have seen it, live streaming the event allowed people across Europe to follow it on the day but also to have access to the recordings later on.



Website

- ✓ Having a webpage dedicated to the event is a way of driving traffic to SAFE's website and having a place where all information will permanently live.



Targeted emails

- ✓ When it comes to driving stakeholders' interest to the event, targeted emails were the most successful stream of the strategy. This was the platform that by far generated the most number of clicks and that led to the highest number of registrations (measured through clicks)



Facebook & Twitter

- ✓ Both Facebook and Twitter are good platforms for SAFE to roll-out a digital campaign and they should be complementary. While Facebook generated more engagements, Twitter led to more impressions and URL clicks. Next time we would recommend considering a more structured paid media campaign to ensure optimal results.



EU Media

- ✓ Although it is great to share news through EU media we have verified that the inclusion in the PoliticoPro Events calendar and the Dods alert did not generate much interest (measured through number of clicks). As free tools, they should nevertheless continue being used.

Website: key findings

The screenshot displays the SAFE website's header with navigation links: HOME, ABOUT SAFE, POLICY EVENTS, STROKE ADVOCACY, SSOFT, MEDIA, SUPPORT SAFE, ANNUAL REPORTS, CONTACT, and LOGIN. The main content area features a banner for the '2019 Joint event with Romanian Presidency of the Council of the European Union'. Below this, logos for SAFE, romania2019.eu, ESO, ANRS, and the European Committee of the Regions are shown. A text block describes the event's focus on preventing and controlling non-communicable diseases. A sidebar on the right includes a search bar and a vertical banner for the event on Thursday, 28 March 2019, from 9am to 12pm. At the bottom, there is a 'SAFE & angels - SURVEY -' banner and a list of sponsors including Amgen, angels, Bristol-Myers Squibb, and others.

From 1 February to 31 March:

- ✓ There were **677 distinct individuals visiting the event webpage at least once**. 147 were repeated visits from those 677 individuals.
- ✓ On average, **visitors spent around 21 minutes going through the webpage** which is 60% more than the website average.
- ✓ **70.75% of people that checked the event webpage exited SAFE website through the same page.**

The event page was the fourth and third most visited page of the website in February and March, respectively.

Social media: key findings



- ✓ When considering impressions and engagements:
 - ✓ **Content posted on the day of the event was in general more successful** than prior to the event.
 - ✓ **Video posts were generally the most successful** and **photo posts were in general more effective than text posts.**
- ✓ **Users engaged more with Facebook than Twitter content.** Content posted on Facebook generated more engagements (1,384) than Twitter (1,078) even though the campaign comprised only 24 Facebook Posts vs. 58 Tweets.
- ✓ **Twitter originated 3,5 more impressions than Facebook:** 65,079 v.s. 18,850
- ✓ **Facebook and Twitter users have clicked over 500 times on URL links.** On Facebook top 3 most clicked links redirected people to the event webpage, live streaming and the registration form. On Twitter the 3 most clicked links referred users to the Burden of Stroke Report, the Stroke Action Plan and the event webpage.

High Performing Facebook Posts



1351 people reached
2150 organic impressions
401 engagements



1048 people reached
1283 organic impressions
89 engagements

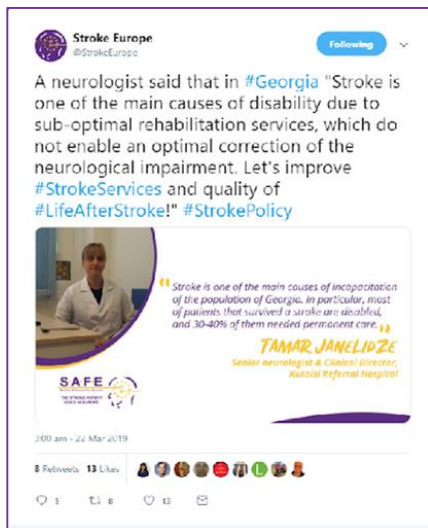


1005 people reached
1398 organic impressions
72 engagements



873 people reached
1398 organic impressions
70 engagements

High Performing Tweets



4280 impressions
97 engagements



3850 impressions
68 engagements



3346 impressions
51 engagements



3581 impressions
27 engagements



Translation of the stroke Action Plan for Europe 2018 - 2030

Translation of the Stroke Action Plan for Europe 2018 - 2030



Stroke Action Plan For Europe

FOREWORD

This year, around 630,000 people in the European Union will have a stroke, and, although the figures are patchy, at least 170,000 people in non-EU European countries will have one. That is more than one stroke a minute. Their stroke could be devastating - leading to death or life-long disability, shattering their lives and those of their loved ones. Those who survive their stroke will join the millions of stroke survivors across Europe who live with the health, social and financial impacts.

780,000 / YEAR
>1 / MINUTE

In 2017, the Stroke Alliance for Europe (SAFE) with the European Stroke Organisation (ESO), launched a comprehensive overview of stroke and stroke care in Europe. The Burden of Stroke in Europe Report revealed shocking disparities between and within countries along the entire stroke care pathway, with post-stroke support being neglected by all countries.

The report showed that between 2018 and 2035 the number of strokes is expected to rise by 34% due to an ageing population and across Europe the number of people living with stroke is set to increase by one million, reaching 4,631,050 survivors. The total healthcare and non-healthcare related cost of stroke in the EU - an estimated 45 billion Euros in 2015 is set to rise.

2

That is why, in May 2017, after many years of co-operation, SAFE and ESO formally agreed to work in concert to combat stroke.

This Stroke Action Plan for Europe is a joint project resulting from the collaboration. It follows and builds on the two previous "Helsingborg Declarations" which provided a vital platform for improving stroke care across Europe. ESO and SAFE are honoured to have Professor Bo Norrving as the coordinator of the Stroke Action Plan for Europe, who was also involved with the previous Helsingborg Declarations.

70 experts, working in groups assessing all aspects of the stroke care pathway, created the Stroke Action Plan for Europe. Their task was to review the evidence for best practice, and, taking into account the current state of stroke provision, to outline the key targets all countries and health systems should be aiming to achieve by 2030.

Especially important for stroke survivors and their carers, the Stroke Action Plan tackles the challenges people face in living life after stroke for the first time.

The Plan is both an aspirational framework and a call to action. SAFE calls on all decision-makers to use it to drive health policy change, lead research priorities, improve local stroke management and patient-focused care and to address the unmet needs unveiled by the Burden of Stroke in Europe Report.

The burden of stroke falls upon us all, but especially on the millions of stroke survivors and their loved ones, living with its consequences every day. Let us all pursue the targets set out in the Stroke Action Plan for Europe to reduce and minimise the impacts of that burden.

Jon Barrick, SAFE President,
Bart van der Worp, ESO President
Valeria Caso, ESO Past
President (2016-2018)

Beyond SAFE, the language barrier inevitably limits the opportunity to engage and influence others who otherwise might respond to the communication.

The popular version of the Stroke Action Plan for Europe, initially generously supported by BI, Ipsen and BMS Pfizer Alliance, is a vital document that outlines key recommendations from seven domains covering the stroke care pathway from Prevention to Life After Stroke.

STROKE ACTION PLAN FOR EUROPE 2018-2030



The original Stroke Action Plan is in English, and translating it to five additional languages - French, Polish, Portuguese, Russian and Spanish - would significantly increase its reach throughout Europe.

The translated versions will be available on SAFE website as PDF documents as of mid- May 2019 for download, with a limited circulation in each language printed before the end of 2019.

Acknowledgements

- The translation of the Stroke Action Plan for Europe to five European languages is supported by Boehringer Ingelheim.





Economic Impact of Stroke Report and World Stroke Day 2019



The Economic Impact of Stroke in Europe: now and in the future, with recommendations on how to affect a reduction in the cost burden by investment

Initial Project Objectives

- **Work package 1:** The first objective of this work is to provide an up-to date (for the year 2017) estimate of the economic costs of stroke for all 28 countries of the European Union, by including direct health and social care costs, informal care costs (i.e. the unpaid care provided by relatives and friends of people with stroke) and productivity losses.
- **Work package 2:** Based on our projections of the cost of stroke in Europe for the year 2017, we will develop projections of these stroke costs for the next 10 and 20 years, i.e. we will provide estimates of the cost of stroke for the 28 countries in the EU and for the EU as a whole for the years 2027 and 2037.
- **Work package 3:** Finally, in our last objective, we will assess how improvements in stroke care can cost-effectively improve stroke outcomes across Europe by investing in: pioneering new interventions such as thrombectomy; better rehabilitative care for stroke survivors; and better stroke prevention strategies such as primary prevention of stroke in patients with atrial fibrillation.

Progress Work Package 1

- Initially, the study on the economic costs of stroke was to focus only on the 28 Member States of the European Union. However, after discussion, it was agreed that the project would include a further 4 countries: Iceland, Israel, Norway and Switzerland.
- **Methodology summary:** In order to provide estimates of the total economic costs of stroke, a three-stage process is necessary. Firstly, data inputs need to be sourced, extracted and formatted; secondly, country-specific, analytic models need to be constructed based on data sourced as well as extrapolation where necessary; and thirdly estimation of the total costs and reporting of the findings will be undertaken. Total costs will be estimated using a top-down approach i.e. using national expenditure data for each country, and reported in Euros for each country and as a total.

Progress Work Package 2

- As part of work package 2, we plan to explore the potential predictors and reasons for variation in stroke-related health and social care costs. For this, we will undertake regression analyses using: national income, total population, population-based incidence estimates (i.e. numbers of people experiencing a stroke), population-based prevalence estimates (i.e. total number of stroke survivors), life expectancy, standardized CVD mortality rates, physician density, and hospital beds per 10,000 population as independent variables.
- We have now obtained all these estimates for all 32 countries under study. In particular, we have obtained age- and gender- stratified estimates of stroke incidence and prevalence from the 2016 Global Burden of Disease Project.

Progress Work Package 2 (cont)

- Using these regressions, we will be able to assess the association of each explanatory variable on health social care costs. For example, it will allow us to assess what the impact on the costs of stroke will be, both in the EU, and in each individual country, of an increase in stroke incidence or prevalence. This will help us assess what the likely health and social care costs of stroke will be in 2027 and 2037 (i.e. 10 and 20 years from now). We have now also obtained, for the 32 countries under study, the age- and gender-stratified population estimates.
- To these projected costs of health and social care costs we will add the projected costs of informal care and productivity losses due to mortality and inability to work due to illness. So that these cost projections can then be compared to current estimates of the burden of stroke, all future costs will be valued in 2017 prices.

Progress Work Package 3

- In this work package we will estimate how stroke outcomes can improve and how the economic burden of stroke currently, and in 2027 and 2037, might change through increased investments in stroke care and research. In particular we will assess the impact on population-wide costs and outcomes, of investing in a number of priority areas in stroke care, including:
 1. better stroke prevention strategies such as primary prevention of stroke in patients with atrial fibrillation (AF);
 2. pioneering new interventions such as thrombectomy; and
 3. better rehabilitative care for stroke survivors.
- Much of the work is to inform the Markov model required to assess the effect of these interventions on outcomes and costs.

Milestones

- **Work package 1:** We planned to have finalised all the work necessary for Work package 1 by 31 October 2018. We will be using the same methodology as used in previous costing exercises of stroke to evaluate the costs of informal care, so we do not envisage any problems in evaluating these costs. We envisage that obtaining unit costs for nursing/residential home care for the 32 countries under study will be the most time consuming exercise of the remaining work in work package 1.
- **Work package 2:** Given that when Work package 1 is finalised we will have all of the data required for work package 2, we envisaged the analyses required for this work package to be finished by early December 2018. We then envisaged the work to have been finalised by end of December 2018.



World Stroke Day 2019

From Prevention to Life After Stroke

SAFE's Communication Theme for 2019-2020



This year's main theme for SAFE's campaigning work remains Life After Stroke, the issues around it and how stroke survivors and their families are coping with it. The campaign will cover this year's European Stroke Awareness Day in May and will culminate on October 29, for the World Stroke Day, when SAFE will present the Economic Burden of Stroke in Europe Report.

The World Stroke Organisation's campaign this year is dedicated to Prevention. More information and campaign resources on stroke prevention will be available on the WSO website over the summer period.

Challenges

- After SAFE President stepped down from the WSC Chairman position, WSO radically changed course of communication, switching topics from Life After Stroke to Prevention
- This means that the resources they would produce would be still available for free, but about prevention.
- SAFE is strategically set in the direction of continuing with the Life After Stroke topic, because of past investments and because it needs it for building up towards the 1st European Life After Stroke Forum in 2020

SAFE's official political statement and motto is that the whole stroke care pathway equally matters, broadening communication in this year to all three major sections of the stroke care pathway (prevention/ treatment/ after stroke) would mean losing focus.

Life After Stroke topic underused in 2019



- Life After Stroke is a “blue ocean” at the moment, the medical and industrial community are traditionally focused on treatment and, to a slightly smaller degree, to prevention.
- Life After Stroke topics are central to the work of SSO’s.
- Our SSOs are either run by stroke survivors or by their carers- stroke is a trigger for organising scattered individual struggles into making an SSO and advocating for change

Upsetting numbers play in our favour: 34% increase in number of strokes until 2035- ageing Europe will face rising needs of those who will survive 1 Mio of strokes, a challenge no one is quite prepared for now.

Building awareness takes years to achieve, we have to be dedicated to it.

Grethe Lunde: A living inspiration

1. **Stroke survivor is a person.**
2. **A life saved must also be lived.**



Campaign Strategy

- Rely on SAFE resources- our SSOs
- Using empathy but not presenting stroke survivors as victims to invoke pity; lean on human rights and Stroke Bill of Rights; keep reminding about the rights to access to treatment and rehabilitation; return to work; etc.
- Interlink campaign's narrative with SAFE's political activities in 2019
- Reinforce the Stroke Action Plan for Europe Life after Stroke section in particular.

Campaign tactics

WHAT?

- Each week one interview with a SAFE SSO leader
- Using hashtag #LifeAfterStroke

WHY?

- To engage SSOs and amplify their voices
- To get more credibility for SAFE, using the strength of its members
- To build up the rationale and prepare audience for the 1st European Life After Stroke Forum

HOW?

- 3-4 questions about a Life After Stroke issue in their country (Back to work, rehabilitation access and costs, accessibility, financial support by the government,...)
- The last interview- the closing of the campaign in 2019- the interview with Jon Barrick, recapitulating on three-year achievements and looking forward to the future- announcing the 1st Life After Stroke Forum in 2020
- Use the most interesting sentences from these interviews throughout the year for social media campaign as quotes for advocating- feed the social media campaign with fresh multinational perspectives on Life After Stroke issues in 30 European countries

Implementation

1. **The communication campaign around Life After Stroke issues**, country by country, **started** with publishing interviews from the **beginning of April 2019** and is planned to be finished after 29th October (Economic Burden of Stroke launch date)
2. The materials from the SSOs' interviews are a resource for feeding the social media campaign, by using interesting quotes, photos, etc. and **it would be critical for all SAFE SSOs to take active part in this campaign, by sharing these social media messages through their channels** as well
3. There will be a **centrally prepared press release template** and an infographic with the key findings of the Economic Burden of Stroke Report- this will be sent to all SSOs early in September so it could be **translated and locally adapted**. These materials will be under a strict embargo for publishing, until 29th October
4. Past the Economic Burden of Stroke launch, **SAFE would need SSOs to disseminate key information in form of a short article**, in your language, in any media available and SAFE will support by picking up and re-sharing and re-posting the original SSOs' content*

*There is no budget for paying for this dissemination, as this is SAFE's project not the EU funded one.



Campaign's start: April 2019

Stroke survivors' needs in North Macedonia: Lack of multidisciplinary teams in after stroke care

Apr 12, 2019



A A A

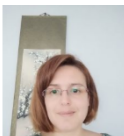
As announced earlier, SAFE will open conversation with our member organisations' leaders, in the attempt of shedding light on life after stroke issues across Europe.

This week we are talking with **Dr Maja Bozinovska Smiceska**, President of Association for a fight against stroke "Stroke" in North Macedonia.

SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?

MBS: Every stroke is different, and so is the recovery that follows. Patients suffer not just physical problems like weakness and impaired gait, but also difficulties with language, memory, cognition and emotional problems. Patients everyday life changes and become full of obstacles and frustration.

One aspect regarding rehabilitation in their recovery is intensive work with multidisciplinary team. So, the first problem in our country is deficiency of such team in most of our cities or inequality in specialized stroke



Stroke survivors' needs in Georgia: Swallowing problems after stroke not addressed properly lead to lung infection

Apr 19, 2019



A A A

"There is no stroke rehabilitation center in Kutaisi, Georgia, and after their hospital treatment, patients are discharged to go home. Unfortunately, patients' carers do not have enough information on how to take care of them once their loved ones are back home. Due to swallowing problems, many of stroke survivors return to the hospital very soon after their discharge, this time not because of stroke, but because of aspiration pneumonia-a type of lung infection that is due to a relatively large amount of material from the stomach or mouth entering the lungs" says Tamar Janelidze, MD, neurologist, co-founder and board member of Georgian stroke support organization, Medical Foundation Mikuruli.

SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?

TJ: In Georgia, there is an observed growth trend in cerebrovascular diseases. For last years, at the national health sector level, special attention is paid to acute strokes. In general, stroke is one of the main

Stroke survivors' needs in Portugal: Rehabilitation must be possible and accessible to everyone

Apr 25, 2019



A A A

"Currently, in Portugal, when a stroke occurs, the first phase of treatment, the acute phase, happens in similar conditions to the ones of the best practices in Europe. The first rehabilitation, still within a hospital circle, is already implemented with great differences across our country, and, on average, isn't as satisfactory. After... when the real life after stroke begins, the survivors and care givers, generally, feel alone, helpless! It's mostly in that moment, when the biggest problems start (including the psychological, socioeconomic, life reorganization, etc. ones), that, in most cases, there are flaws. Not only in the continuity of the strictly therapeutic recovery, but also in the social and psychological support, among

Search

SAFE
Stroke Alliance For Europe
THE STROKE PATIENT
VOICE IN EUROPE

Thursday
28 March 2019
9am-12pm

Joining forces to
prevent and control
non-communicable
diseases:
The role of policy in
facing stroke

Putting the Stroke Action Plan for
Europe 2018-2030 in the spotlight

ESU
EUROPEAN
STROKE
UNION

SAFE & angel

- SURVEY -

SAFE Annual Report
2018



SSOFT

Stroke Support Organisation Faculty Tool

SSOFT RECAP



SSOFT is an innovative online eLearning advocacy tool being developed by Stroke Alliance for Europe (SAFE), in partnership with the European Stroke Organisation (ESO).

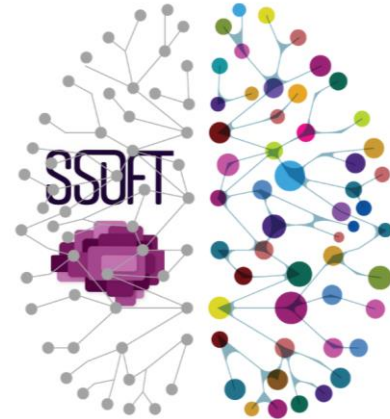
Through six modules, SSOFT provides knowledge and training on how to create effective advocacy activities and campaigns

- Module 1: Stroke Support Organisations (SSOs)
- Module 2: Making Change Happen
- Module 3: Use of Evidence
- Module 4: Role of Patient Voice
- Module 5: Health System Advocacy
- Module 6: Public Advocacy

The modules and learning environment are available free of charge and accessible via the SSOFT website through a simple registration process.

SSOFT PROJECT AIMS

- Generate more understanding and sustainability in creation and development of Stroke Support Organisations (SSOs);
- Increase the capacity and capabilities of Stroke Support Organisations (SSOs) to advocate for better prevention strategies, diagnosis and treatment as well as aftercare at a local and national level.



Stroke Support Organisation Faculty Tool

- Provide online training on stroke advocacy which can be utilised by SSOs, stroke survivors, family and careers of stroke survivors as well as professionals who are involved in stroke treatment and/or care pathway across Europe, with the potential to expand worldwide.

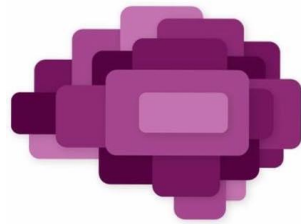
SSOFT IMMEDIATE GOALS

- Increase social media presence for SSOFT
- Create social media accounts e.g. Facebook, Twitter, YouTube Channel, LinkedIn and build online community (likes/shares)
- Make SSOFT related material e.g. news articles, blogs etc., available online e.g. SlideShare
- SSOFT links on SAFE member websites
- Sign posting of SSOFT from other stroke/patient organisations e.g. websites, newsletters, articles.
- Increase number of individuals from SAFE member SSOs engaging with the tool

ONLINE TOOL CALLS FOR ONLINE PROMOTION

- Increasing social media presence for SSOFT begun in the second half of February.
- A specialised social media agency is creating and regularly posting social media assets (content) on Facebook and Twitter.
- All assets can be stored in one [repository](#) and SAFE would appreciate all SSOs using these assets to help in SSOFT promotion.





SSOFT

Stroke Support Organisation Faculty Tool

**KEY SOCIAL MEDIA
STATISTICS
March - April 2019**

GROWTH IN NUMBER OF FOLLOWERS: MAY 2019

SSOFT - Facebook

31. May – 134 followers
(23 followers gained, 0 lost)



SSOFT - Twitter

31. May – 139 followers
(9 followers gained, 0 lost)



SSOFT FACEBOOK – May

Total reach – 8.572, Organic reach – 7.557, paid 1022
Total of 23 posts

1. Post with the highest organic reach - 1.161

SSOFT
Published by Amina Mešić [?] · May 10 at 5:00 PM · [Like Page](#) ***

Studies show that physical activity is key when it comes to reducing the risk of health problems, such as high blood pressure, diabetes, obesity, depression and #Stroke.
Here's why exercise is so important when it comes to reducing stroke risk
<http://bit.ly/2Hkr1MU>

SSOFT
Stroke Support Organization Quality Tool

✓ **Get More Likes, Comments and Shares**
Boost this post for \$30 to reach up to 8,700 people.

1,161 People Reached **61** Engagements [Boost Post](#)

[Lisa Koiwula](#), [Hariklia Prolos](#) and [Αντωνόπουλος Αρτυνιά](#) 6 Shares

Performance for Your Post

1,161 People Reached

36 Reactions, Comments & Shares

26 Like	3 On Post	23 On Shares
1 Haha	0 On Post	1 On Shares
0 Comments	0 On Post	0 On Shares
9 Shares	6 On Post	3 On Shares

25 Post Clicks

2 Photo Views	3 Link Clicks	20 Other Clicks
----------------------	----------------------	------------------------

NEGATIVE FEEDBACK

0 Hide Post	0 Hide All Posts
0 Report as Spam	0 Unlike Page

Reported stats may be delayed from what appears on posts

Post with the highest organic reach - 1.147

SSOFT
Published by Amina Mešić [?] · May 4 at 3:00 PM · [Like Page](#) ***

Depression is classed as a modifiable risk factor for #Stroke which means that, with the right support and rehabilitation, it can be improved, altering outcomes for patients before and after stroke.
#StrokePrevention
Read more <http://bit.ly/2TleAJL>

✓ **Get More Likes, Comments and Shares**
Boost this post for \$30 to reach up to 8,700 people.

1,147 People Reached **58** Engagements [Boost Post](#)

[Natalia Hallinouskaya](#), [Hariklia Prolos](#) and 2 others 7 Shares

Performance for Your Post

1,147 People Reached

29 Reactions, Comments & Shares

20 Like	4 On Post	16 On Shares
1 Love	0 On Post	1 On Shares
1 Sad	0 On Post	1 On Shares
0 Comments	0 On Post	0 On Shares
7 Shares	7 On Post	0 On Shares

29 Post Clicks

1 Photo Views	7 Link Clicks	21 Other Clicks
----------------------	----------------------	------------------------

NEGATIVE FEEDBACK

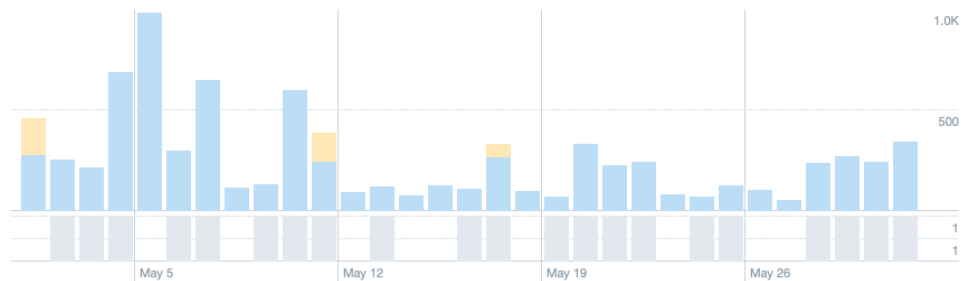
0 Hide Post	0 Hide All Posts
0 Report as Spam	0 Unlike Page

Reported stats may be delayed from what appears on posts

SSOFT Twitter – May

8.101 impressions, 384 paid

Your Tweets earned **8.1K impressions** over this **31 day** period



MAY 2019 SUMMARY

Tweets

22

Tweet Impressions

8,101

Profile visits

32

Mentions

3

New followers

9

Engagements

Showing 31 days with daily frequency

Engagement rate

0.8%



Link clicks

10



On average, you earned **0 link clicks** per day

Retweets

6



On average, you earned **0 Retweets** per day

Likes

19



On average, you earned **1 likes** per day

Replies

0

May 31
0 replies

On average, you earned **0 replies** per day

1. Tweets with the highest reach





SSOFT @SSOFT11
Depression is classed as a modifiable risk factor for **#Stroke** which means that, with the right support and rehabilitation, it can be improved, altering outcomes for patients before and after stroke. **#StrokePrevention**

Read more  <http://bit.ly/2TleAjL>
pic.twitter.com/4jpM2H0ecB

Impressions	1,660
Total engagements	9
Likes	4
Media engagements	3
Retweets	2

2. Tweets with the highest reach



SSOFT @SSOFT11
This is Antonia, a 29 year old Special Education teacher. She believes that **#SSOFT** can give a voice to stroke patients, and that her country should also build local stroke association and take action to help stroke survivors.

Register with SSOFT today
<https://academy.ssoft.info/login/signup.php>
... pic.twitter.com/Z2CvFtLwFc

Impressions	310
Total engagements	11
Likes	3
Profile clicks	3
Media engagements	2
Link clicks	2
Retweets	1

SSOFT ENGAGEMENT

The Greek stroke support organisation HAAS set up a great example



SSOFT

SSOFT tool helped me in many different ways. I developed my knowledge and that's the most important thing. Now I feel glad that I can prevent, diagnose, treat and take care of a stroke. I definitely will use the information in my everyday life!

Vasiliki Exintara
Special education teacher



GEORGIA PENEKELI
Student

I did not know that there are so many people suffering from brain episodes and that there are organizations playing such an important role in helping them. Through my SSOFT learning journey I gained a whole different perspective in this topic and I can tell for sure that one day I would like to be part of an organization like SSOFT.



SSOFT
Stroke Support Organization Quality Tool



“

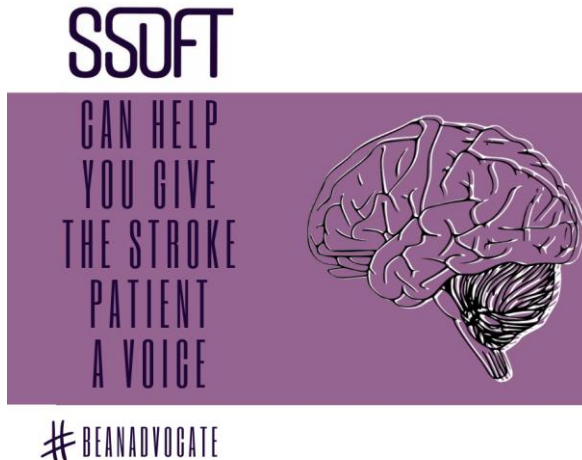
SSOFT can help stroke patients becoming a voice. We should get inspired in my country Greece and build local stroke associations. We must use theory and practice and take action to help these people.

AISIPOULOU ANTONIA
Teacher

SSOFT


Conclusion

- SAFE needs you!
- Your engagement with this tool is crucial
- Please share your feedback with us on how you would like to be supported in promoting SSOFT in your country*



**Translation to your language is not available in the near future*



EU Research Update

Dr. Gary Randall
EU Research Manager
June 2019

Patient voice in H2020

- EC strongly encourages patient representation
- Dissemination to the non-scientific community is compulsory
- Press releases, websites, patient literature, social media etc.
- SAFE uses EU funding to help small stroke organisations to grow

Currently a partner in 5 funded EU projects



What is common in
stroke and dementia



Thrombectomy in severe stroke up to
12 hours



Common complications
and acute stroke



High dose oxygen
Therapy in acute stroke

Research Booklet

Together, our projects
will provide €280k
funding to SAFE



Our European
Research
Partnerships



Current projects

SVDs@target



What is common in stroke
and dementia?

SVD refers to cerebral small vessel disease. It affects small arteries and capillaries in the brain and accounts for most cases of haemorrhagic (bleeding) stroke, a quarter of ischaemic (blockage) strokes, and contributes to at least 40% of dementia cases.

There are currently no treatments for SVDs and they are only partially understood. This new project will look at the common factors in multiple SVDs and will try to develop new treatments for the particular diseases that lead to dementia and stroke.

For more information about the project, please visit the SVDs@target website: www.svds-at-target.eu

Dissemination – Press releases

PRESTIGE-AF

PREvention of Stroke in Intracerebral
hemorrhage survivors with Atrial Fibrillation



Lançamento de projecto internacional para prevenir a ocorrência de novo Acidente Vascular Cerebral em pessoas com fibrilhação auricular que já tiveram um AVC provocado por hemorragia no cérebro.

Uma nova iniciativa, de vários milhões de euros, financiada pela Comissão Europeia, terá lugar para ajudar a prevenir acidentes vasculares cerebrais em doentes nessas condições.

O projecto de 6,9 milhões de euros destina-se a doentes com fibrilhação auricular (AF) - uma doença cardíaca que provoca batimentos cardíacos irregulares e anormalmente rápidos - que já tiveram um AVC provocado por hemorragia no cérebro (denominado hemorragia intracerebral - ICH). A prevenção de novo acidente vascular cerebral em sobreviventes de hemorragia intracerebral com fibrilhação auricular (PRESTIGE-AF), reúne cientistas e médicos de toda a Europa com o objectivo de reduzir o risco de novo AVC neste grupo de doentes.

PRESTIGE-AF

PREvention of Stroke in Intracerebral
hemorrhage survivors with Atrial Fibrillation



Internationaal project onderzoekt hoe een tweede herseninfarct bij mensen met hartritmestoornissen voorkomen kan worden.

Er is een nieuw, grootschalig miljoen project gestart, gefinancierd door de Europese Commissie, waarin onderzocht gaat worden op welke manier nieuwe beroertes bij mensen met boezemfibrilleren voorkomen kunnen worden.

Het project, dat totaal 6,9 miljoen euro kost, richt zich op patiënten met atriumfibrilleren (AF), dat wel boezemfibrilleren genoemd, die als gevolg daarvan een herseninfarct kunnen krijgen. Atriumfibrilleren is een hartritmestoornis, waarbij het hart onregelmatig en meestal sneller klopt. Het hart heeft als functie om het bloed naar alle delen van het lichaam te pompen: de longen, de hersenen en de rest van het lichaam. Als bloedstolsels losraken van de boezemwand worden ze met de bloedstroom meegevoerd, via de bloedvaten het lichaam in totdat ze ergens vastlopen. Bij boezemfibrilleren gebeurt dit meestal in de bloedvaten van de hersenen. Deze verstopping veroorzaakt een beroerte.

PRESTIGE-AF

Forvarmir gegn heilaslagi hjá einstaklingum
sem lifað hafa af heilablæðingu og eru með gáttatíf



Alþjóðlegu verkefni hefur verið hleypt af stokkunum til að koma í veg fyrir heilaslag hjá sjúklingum með heilablæðingum.

Nýju margra milljóna evra verkefni sem hefur fengið fjármagnað er af framkvæmdastjórn Evrópusambandsins hefur verið komið á fót til að koma í veg fyrir heilaslag hjá sjúklingum með núverandi bláðröma.

Þetta 6,9 milljóna evra verkefni beinist að sjúklingum með gáttatíf (AF), algengan hjartakvilla sem veldur óregulegum og óeðlilega hröðum hjartslætti, sem áður hafa fengið heilaslag vegna blæðinga í heilanum (sem kallast heilablæðing eða ICH). Forvarmir gegn heilaslagi hjá einstaklingum sem lifað hafa af heilablæðingu og eru með gáttatíf (PRESTIGE-AF) safnar vísindamönnum og læknum í Evrópu saman með það að markmiði að draga úr hættu á frekara heilaslagi hjá þessum hópi sjúklinga.

PRESTIGE-AF

PREvention of Stroke in Intracerebral
hemorrhage survivors with Atrial Fibrillation

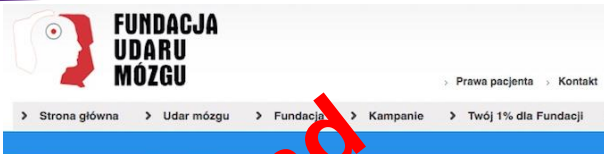


Nemzetközi projekt indul az agyvérzéses betegek új stroke megelőzésére

Az Európai Bizottság finanszírozásával egy több millió eurós kezdeményezést hoztak létre, hogy segítsen a fenyegetett helyzetben lévő betegeket érintő stroke megelőzésében.

A 6,9 millió eurós projekt az atriumfibrillációval (AF), azaz gyakori, szabálytalan és rendellenesen gyors szívverés okozó szívélgtelenséggel érintett betegeket célozza, akik korábban agyvérzés (intracerebrális vérzés vagy ICH) által okozott stroke-ért. A Stroke megelőzés a pitvarfibrillációval érintett intracerebrális vérzés túlélők körében (PRESTIGE-AF) Európa-szerte egyesítette a tudósokat és klinikusokat azzal a céllal, hogy csökkentsék a további stroke előfordulásának kockázatát ebben a betegcsoportban.

Dissemination - Web



NOVINKY

- SAFE - PRESTIGE - AF
- SAFE - TENSION - mezinárodní studie
- Nabídka rekondiční pobyty 2018
- Předvánoční setkání 2017
- Pacientské organizace chtějí být více slyšet
- Pozvánka na předvánoční setkání
- Změna konání klubu SCMP Praha 5
- Konference



PREvention of Stroke in Intracerebral Hemorrhage survivors with Atrial Fibrillation
Zahájil mezinárodní projekt k prevenci mozkových iktů u pacientů po mozkovém krvácení
Byla přijata iniciativa, financovaná Evropskou komisí mnoha miliony EUR, k prevenci mozkových iktů u pacientů s přetrvávajícím rizikem.



Ajankohtaista AVH:sta

7.5.2018

Kansainvälisen hankkeen tavoitteena on aivoinfarktien ehkäisy aiemmin aivoverenvuodon sairastaneilla.

Euroopan komission rahoittamilla miljoonalla eurolla uutta hanketta, jonka tavoitteena on ehkäistä aivoinfarkteja aivoverenvuodon sairastaneilla, on sydämen eteisvärinä.

Yli 6,9 miljoonaa euroa EU-rahoitusta saaneen hankkeen kohderyhmänä ovat eteisvärinää sairastavat henkilöt, joilla on ollut aikaisemmin aivoverenvuoto, ICH

(IntraCerebral Hemorrhage). Eteisvärinä ("flimmeri") on yleinen sydänsairaus, jossa oireena on epäsäännöllinen ja epänormaalin tiheä syke. PRESTIGE-AF on Euroopan laajuinen yhteistyöhanke, jossa tutkijat ja terveydenhuollon ammattilaiset pyrkivät yhdessä löytämään keinoja infarktin riskin vähentämiseksi tässä potilasryhmässä.

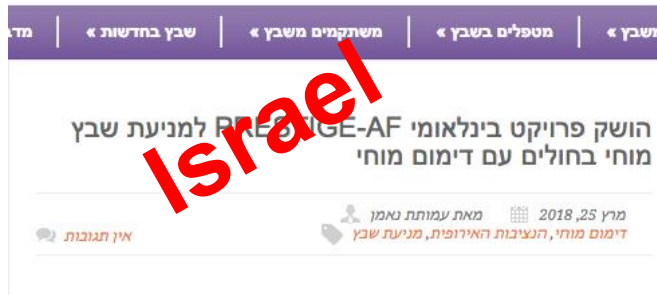
Internationales Projekt startet: Schlaganfällen bei Patienten mit Hirnblutung soll vorgebeugt werden – PRESTIGE AF

by Chantal Keller · 6. Mai 2018 · Neugierheiten

Die Europäische Kommission hat eine neue Initiative gestartet, um das Vorgehen soll, Schlaganfällen bei Menschen mit Vorerkrankungen vorzubeugen. In das Projekt werden mehrere Millionen Euro investiert.

Rund 6,9 Millionen Euro fließen in das Projekt "PRESTIGE-AF", das an Patienten gerichtet ist, die sowohl Vorhofflimmern haben – eine häufige Herzerkrankung, die unregelmäßigen und außergewöhnlich schnellen Herzschlag verursacht – als auch bereits einen Schlaganfall durch eine Hirnblutung erlitten haben (so genannte intrazerebrale Blutung). Im Rahmen der Projekt-Initiative zur Vermeidung von Folge-Schlaganfällen für diese Zielgruppe werden Wissenschaftler und Mediziner aus ganz Europa zusammenarbeiten.

Dissemination - Social Media



Stroke Europe
@StrokeEurope

Following

PRESTIGE AF: A new multi-million Euro initiative funded by the European Commission has been set up to help prevent stroke in patients with existing conditions.



PRESTIGE AF: International project launches to prevent str...
PRESTIGE AF: International project launches to prevent stroke in patients with brain bleeding. This new multi-million Euro initiative funded by the European Commission has been set up to help p...
safestroke.eu



Cyprus Stroke Association

April 3 · 🌐

Διεξάγεται διεθνές πρόγραμμα για την πρόληψη του εγκεφαλικού επεισοδίου σε ασθενείς με εγκεφαλική αιμορραγία.

Μια νέα πρωτοβουλία πολλών εκατομμυρίων ευρώ που χρηματοδοτήθηκε από την Ευρωπαϊκή Επιτροπή, ήδη προγράφηκε για να βοηθήσει στην πρόληψη του εγκεφαλικού επεισοδίου σε ασθενείς με υπάρχουσες παθήσεις.

Το έργο των 6,9 εκατομμυρίων Ευρώ αφοσιώνεται σε ασθενείς με κοιλιακή μαρμαρυγή (AF), μια κοινή καρδιακή κατάσταση που προκαλεί ακανόνιστους και ασυνήθιστα γρήγορους καρδια...

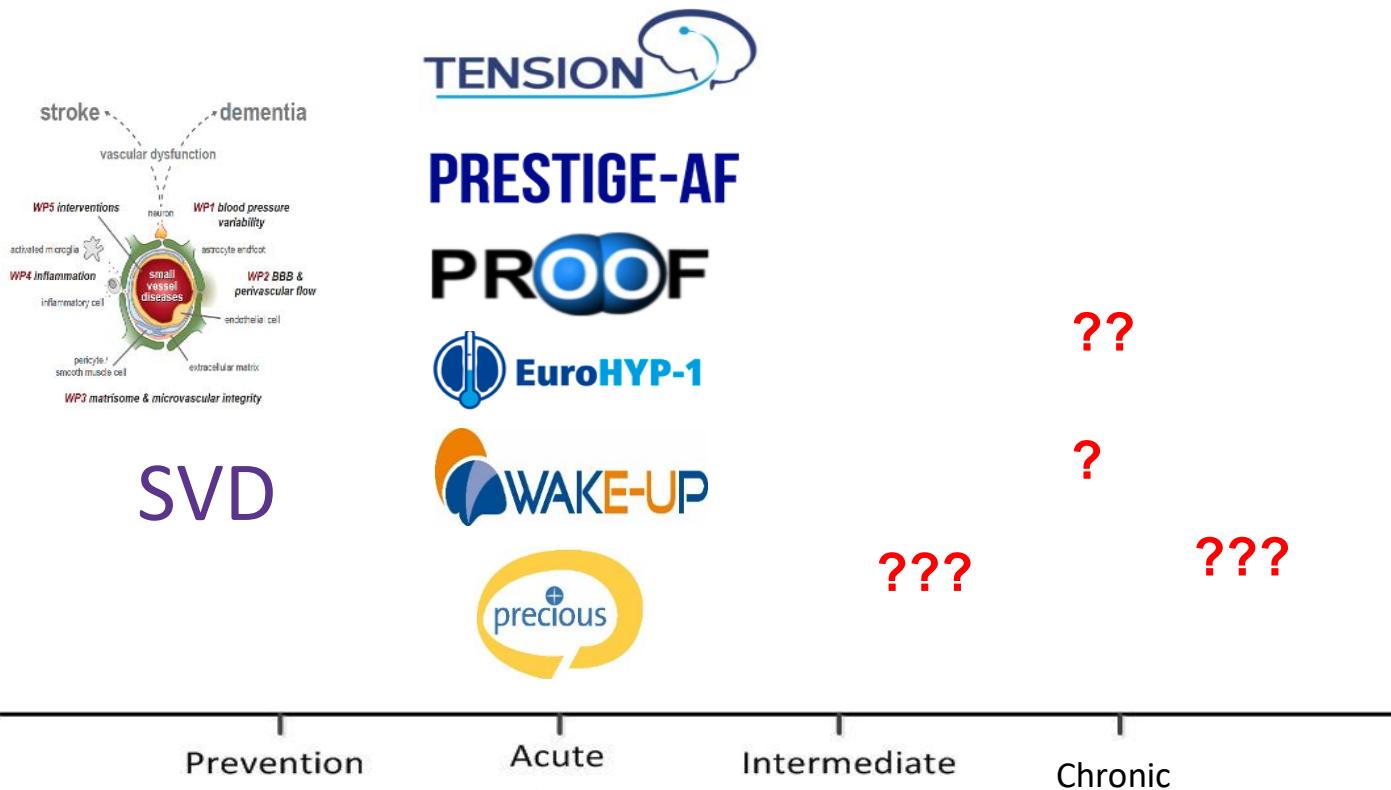
[Continue Reading](#)

[See Translation](#)

RESTIGE-A

PREvention of Stroke in Intracere
hemorrhage survivors with Atrial Fibrilla

Focus of research



Raising SAFE profile



Burden of
Stroke



ESO – TIA guidelines
development group

Policy papers
across diseases



POLICY WHITE PAPER
TOWARDS OPTIMIZING
RESEARCH AND CARE
FOR BRAIN DISORDERS

EBC RESEARCH PROJECT - THE **VALUE OF TREATMENT** FOR BRAIN DISORDERS



Stroke Action Plan
for Europe

Economic Burden of Stroke



We support many new EU proposals

2018 - 2019

- PREVENTICUS – new wearables for AF detection
- EVERBRAIN – use brain-on-a-chip to model stem cell behaviour
- MICROBioSIS – does your gut composition contribute to post-stroke pain and depression?
- DECODE CM – how do different co-morbidities contribute to cognitive decline?
- TOPMED – using very big data to customise stroke treatment
- ENTRAIN – the role of white blood cells in inflammation

Dissemination to SSO

- In 2018 we paid €19,938 to SSO members for dissemination of EU funded research projects
- So far in 2019 we have paid €13,500

The amount paid for dissemination covered the membership fee for the smallest organisations.



Reaching wider audiences

Translation of the
the Stroke.Prevention website

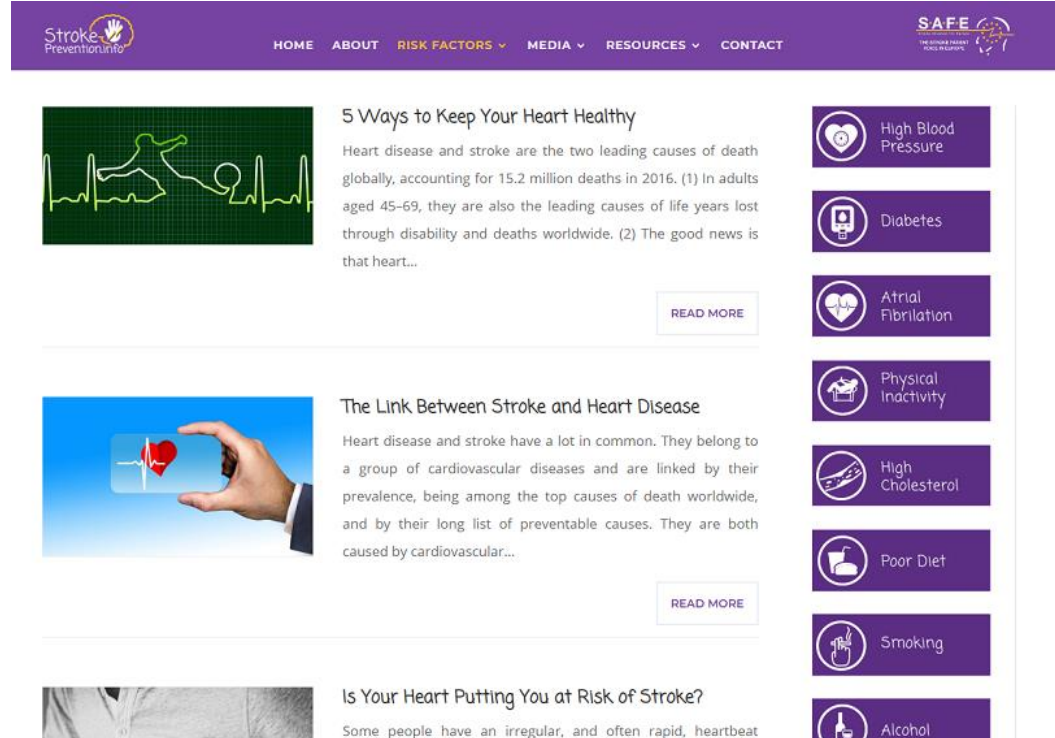
Stroke.Prevention.info / Introduction

- We know from the INTERSTROKE study that 90% of strokes are avoidable if we make changes to our lifestyle and behaviour.
- SAFE developed this resource once it realised there was no website that provided neutral information about the ten modifiable risk factors for stroke in one place.
- The official language of SAFE is English although for many members this remains a challenge.
- To overcome this obstacle, the website will be translated from English to French, Polish, Portuguese, Russian and Spanish by mid-September 2019, on the 1st anniversary of the website launch.



Website core content (1/3)

- 38 evidence-based articles
- Each stroke risk factor covered by three articles
- Additional reading and useful links provided for people who want more information



The screenshot displays the SAFE website's core content. The header features the 'Stroke Prevention' logo on the left, a navigation menu with links to HOME, ABOUT, RISK FACTORS (highlighted), MEDIA, RESOURCES, and CONTACT, and the SAFE logo on the right. The main content area is divided into three sections, each with a title, a brief introduction, and a 'READ MORE' button. The first section is '5 Ways to Keep Your Heart Healthy', the second is 'The Link Between Stroke and Heart Disease', and the third is 'Is Your Heart Putting You at Risk of Stroke?'. To the right of these sections is a vertical sidebar with eight purple buttons, each containing an icon and a text label for a stroke risk factor: High Blood Pressure, Diabetes, Atrial Fibrillation, Physical Inactivity, High Cholesterol, Poor Diet, Smoking, and Alcohol.

Stroke Prevention HOME ABOUT **RISK FACTORS** MEDIA RESOURCES CONTACT **SAFE** THE STROKE PATIENT VOICE IN EUROPE

5 Ways to Keep Your Heart Healthy
Heart disease and stroke are the two leading causes of death globally, accounting for 15.2 million deaths in 2016. (1) In adults aged 45-69, they are also the leading causes of life years lost through disability and deaths worldwide. (2) The good news is that heart...
[READ MORE](#)

The Link Between Stroke and Heart Disease
Heart disease and stroke have a lot in common. They belong to a group of cardiovascular diseases and are linked by their prevalence, being among the top causes of death worldwide, and by their long list of preventable causes. They are both caused by cardiovascular...
[READ MORE](#)

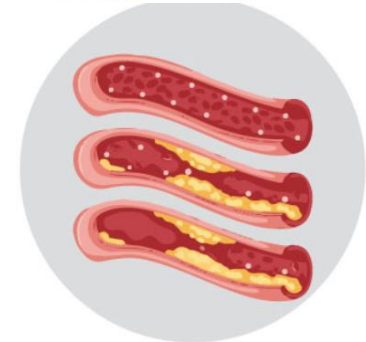
Is Your Heart Putting You at Risk of Stroke?
Some people have an irregular, and often rapid, heartbeat

- High Blood Pressure
- Diabetes
- Atrial Fibrillation
- Physical Inactivity
- High Cholesterol
- Poor Diet
- Smoking
- Alcohol

Website core content (2/3)

Five infographics

- 5 ways to keep your heart healthy
- Can high cholesterol be an inherited condition?
- 8 facts about smoking and stroke
- 10 fascinating things about stroke and high blood pressure
- 5 signs of post-stroke depression



Website core content (3/3)



Three animated videos are there to make the facts visually interesting

- Do you know what is a DASH Diet? Some experts recommend following the DASH Diet (Dietary Approaches to Stop Hypertension) to lower your risk of developing high blood pressure.
- Ever wondered what you could do to lower your cholesterol or cut back on your alcohol intake?

Additional content

In addition to the content which will be translated, there are exclusive podcasts with top-class stroke experts, covering various subjects around stroke prevention.



SAFE PODCAST
Topic: Stroke and Women

Valeria Caso, MD, PhD, FESO



SAFE PODCAST
Topic: Stroke Prevention

Dr Eda Richard
NEUROLOGIST, RABBOUD UNIVERSITY
MEDICAL CENTER, NIJMEGEN,
NETHERLANDS



SAFE PODCAST
Topic: Atrial Fibrillation and Stroke

Anita Arsovska
MD, PHD, FESO, SAFE BOARD MEMBER



SAFE PODCAST
Topic: Three-dimension
view on stroke

Ivraje Jurlina M.D.
SECOND VICE-PRESIDENT OF
CROATIAN STROKE SOCIETY

Stroke.Prevention.info / Acknowledgements

- The website's development was supported by AMGEN.



- The translation of the website's core content is supported by Boehringer Ingelheim.



Life with Spasticity Project Update

**Michiel Lindhout,
Project Coordinator on behalf of SAFE,
Netherlands**

About Life with Spasticity

- An educational online platform intended to provide comprehensive information and motivational support for stroke survivors who experience poststroke spasticity.
- Designed by and for individuals living with spasticity, the project is funded by Merz and has been developed in partnership with Stroke Alliance For Europe (SAFE).
- SAFE's input to this project:
 - ✓ Patient Advisory Board
 - ✓ Patient Ambassadors
 - ✓ Videos and FAQs on the website



- Another 14 FAQ's asked by stroke survivors for stroke survivors are just finished and will be released every other week.
- New video released end of May
- We are looking into working with Merz US to generate even more attention for spasticity and the website.
- Working with SAFE on social media publicity for the spasticity project. Once a week SAFE will communicate through their channels about spasticity.

- Currently we are waiting for input from the US as well as the patient board to decide what we are going to do next.
- The Netherlands has a great and very good contact with Merz Benelux because of this project.
- The Netherlands will be stepping down from this project come August 1st 2019. Given the result for the Netherlands we encourage other countries to apply for this project.



SAFE Angels Project in 2019

The need for an increased number of brochures in even more languages

Project overview



- SAFE is proud to be an active partner in the Angels Initiative project, bringing the patient perspective and providing evidence-based and patient-centred information to stroke survivors when they most need it: in the stroke unit.
- The realisation of this joint project began in May 2018 simultaneously in twelve European countries: Spain, Serbia, Poland, Czech Republic, Latvia, Croatia, Macedonia, Greece, Ukraine, Georgia, Hungary and Turkey.
- The texts were kindly provided by Stroke Association UK
- Angels Initiative: Overall winner of the EFPIA Health Collaboration Award for 2018
- The SAFE Angels project is already positively influencing communication between healthcare professionals and patients. The information-rich brochures enable patients to understand more about their condition and to be more actively involved in their treatment decisions, with the aim of improving outcomes.

Project participants' feedback



“Patients and medical staff like the brochures. Everyone thinks they are very helpful.”

Adam Siger, Polish stroke support organisation Fundacja Udaru Mozgu

“We consider this as a pilot project, because we already distributed the whole quantity of the patient information brochures and now both patients and medical staff are asking when we will have it again. For now, we are signposting people to visit SAFE’s website and download the PDF versions.”

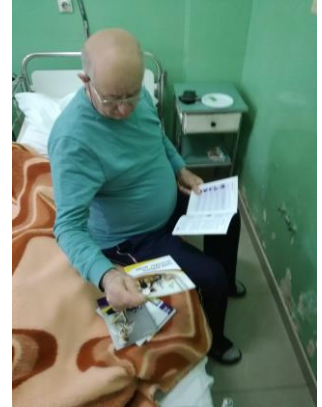
Ivan Milojevic, Serbian stroke support organisation Mozdani udar

“We didn’t have similar patient materials in the past. Now that we do, patient often take all five different brochures and even try to take more copies, for relatives and neighbours.”

Mikheil Shavgulidze, Georgian stroke organisation Mkurnali Foundation

The patients' benefit

Patient information brochures are being given to patients in designated hospitals.



Online Angels Survey

From end of July 2018 onwards, an online satisfaction survey was launched in 13 languages + English, assessing the quality and quantity of information patients are provided with during their stay in the hospital.

The results of this survey will be assessed and published towards the end of 2019.



Angels survey (English) – [Link](#)

Angels anketa (Croatia) – [Link](#)

Angels anketa (Serbia) – [Link](#)

Angels aptauja (Latvia) – [Link](#)

Angels encuesta (Spain) – [Link](#)

Angels přehled (Czech Republic) – [Link](#)

Angels survey (Georgia) – [Link](#)

Angels survey (Greece) – [Link](#)

Angels survey (Hungary) – [Link](#)

Angels survey (Macedonia) – [Link](#)

Angels enquesta (Catalonia) – [Link](#)

Angels survey (Ukraine) – [Link](#)

Angels survey (Turkey) – [Link](#)

Angels survey (Poland) – [Link](#)

Current update

- The new project proposal for 2019 is in the approval procedure by the sponsor, Angels Initiative (BI)
- In addition to 13 languages from 2018, in 2019 SAFE plans to include Slovakian, and Hebrew and Arabic for distribution in Israel and East Jerusalem
- It is planned to have 1.000 copies of brochures per language
- Brochures in Serbian, Macedonian, Croatian, Georgian and Ukrainian have already been revised according to the Stroke Association information standards; These brochures are currently being visually updated and adapted to the new format.
- Other project languages are in process of revision of the last years' versions
- Slovakian translation is agreed and ready to start

