

# STROKE ALLIANCE FOR EUROPE (SAFE) General Assembly 2021

## Minutes

Wednesday 24<sup>th</sup> June 2021

Virtual Meeting

## AGENDA ITEMS and DECISIONS

### 1. Welcome and Apologies

The President Hariklia Proios (HP) welcomed the members to the General Assembly.

The number of member organisations present was 28 sufficient to be quorate.

These were:

Belgian Stroke Council	Belgium
Association for Stroke and Aphasia	Bulgaria
Fundacio Ictus	Catalonia
Croatian Stroke Society	Croatia
Mozdani Val	Croatia
Cyprus Stroke Association	Cyprus
Cerebrum	Czech Republic
Aivoliitto ry	Finland
France AVC	France
Stiftung Deutsche Schlaganfall-Hilfe	Germany
Hellenic Action / Alliance for Stroke	Greece
Heilaheil	Iceland
Irish Heart Foundation	Ireland
Neeman Association for Stroke survivors	Israel
Associazione Lotta Ictus Cerebrale (ALICE)	Italy
BLETZ Asbl	Luxembourg
Association for a fight against stroke, STROKE Ohrid	North Macedonia
Norsk forening for slagrammede	Norway
Portugal AVC	Portugal
Serbian Stroke Association	Serbia
Porazka	Slovakia
Združenje bolnikov s cerebrovaskularno boleznijo	Slovenia
Frenco al Ictus Fundacion	Spain
STROKE-Riksförbundet	Sweden
Ukrainian Anti Stroke Association	Ukraine
Ukrainian Association of Stroke Patients	Ukraine
Stroke Association	United Kingdom
Different Strokes	United Kingdom
Also present, without voting rights, Associate Members:	
Turkish Cerebrovascular Society	Turkey

Apologies for non-attendance were received from:  
Hersenletsel.nl

Netherlands

Not attending

Sdruzeni CMP

Nemzeti Stroke Liga

Medical Foundation "Mkurnali"

Stroke Fundation

Federacion Espanola de Ictus

Czech Republic

Hungary

Georgia

Poland

Spain

## 2. Approval of previous minutes and matters arising

The minutes of the GA held on 25 November 2020 were unanimously approved as a true and accurate representation of the General Assembly.

There were no matters arising from the November 2020 GA minutes.

## 3. Appointment of board members

Under Article 20 of our current constitution, the board members shall be elected for a term of three years and are eligible for re-election once. No person shall be eligible for more than six consecutive years. After six continuous years of service on the board, he/she may not again be nominated for re-election until at least one calendar year has elapsed.

Our articles state that we can have a maximum of 11 board members. Currently we have 10. We had one application for this vacant position.

- Jana Bara-Dobrkovska, from Cerebrum – the association of individuals after acquired brain injury in the Czech Republic

Jana introduced herself to the membership via a video.

**Resolution:** A vote was taken on the application and Jana Bara-Dobrkovska was unanimously approved as a board member of SAFE.

As a result of the election, this is the new Board:

Hariklia Proios	President
Anita Arsovska	Vice President
Marina Charalambous	Secretary
Chris Macey	Treasurer
Grethe Lunde	Member at large
Ivan Milojević	Member at large

Pnina Rosenzweig	Member at large
Hrvoje Jurlina	Member at large
Dymtro Gulyayev	Member at large
Rubina Ahmed	Member at large
Jana Bara-Dobrkovska	Member at large

#### 4. Review of the year and looking forward

SAFE Director General, Arlene Wilkie, presented a review of SAFE's work during 2020. Many projects had been reviewed and amended due to the COVID19 pandemic.

- SAFE held five virtual meetings during the period from June 2020 to June 2021:

- The impact of COVID19 on stroke care, stroke survivors and stroke support organisations
- Life after stroke – providing support during a pandemic (x2)
- Providing emotional support for stroke survivors during the pandemic;
- Stroke Action Plan for Europe

- Stroke Support Organisation Faculty Tool (SSOFT)

SSOFT is an online education resource to help us all take action and speak up, connect and make change across Europe. SAFE has received funding in 2021 for:

- Review and update of information
- Supportive webinars
- Promotion
- Maintenance

- Angels Patient Information

Currently we have translated brochures into 16 languages, which have been distributed in 15 countries. Funding has been received in 2021 for:

- A new translation
- Update of current leaflets
- Reprints of current leaflet

Those already involved in the project will be contacted about the update and reprint of the leaflets.

Members who would like to have the leaflets translated and printed into their language were asked to contact Arlene Wilkie.

Our thanks go to the UK Stroke Association for supplying the original information leaflets.

- Prevention website

The strokeprevention.info website is a digital education toolkit and interactive e-learning platform to be accessed across multiple channels

It covers all major modifiable stroke risk factors including hypertension, atrial fibrillation, lifestyle and high cholesterol, and is aimed at stroke patients and their families, those who are at risk of stroke and anyone wishing to learn more about stroke prevention and looking after their health

SAFE has received further funding for:

- Review and update
- Promotion of the website

- Needs and Wants Survey

SAFE has received funding for desk-based research and is in the process of commissioning a survey of the needs and wants of stroke survivors and their families in the different countries of Europe. This will benchmark the key issues and challenges, as well as consider the policies and practices being developed in each country to address the issues and their ongoing impact on people's lives.

- Stroke Action Plan for Europe

Our work on the Stroke Action Plan for Europe continues:

EU level policy work

- Aim: form and informal stroke group formed and increase parliamentary activity

So far:

- Stakeholder analysis - MEPs and European therapy group
- Produced a briefing document
- Started our outreach to form our informal stroke expert group

Next steps

- Reach out to MEPs
- Meetings with stakeholders
- Form & support a Stroke Interest Group at the European Parliament

## National work with SSOs

Aim: to provide SSOs with tools and training to help you achieve a stroke action plan in your countries covering all the points in the Stroke Action Plan for Europe

So far:

### SMART – media and advocacy training

- Four training sessions
  - Effective advocacy strategy, involving politicians, empowering patients, engaging the media
  - next 24 June and then 9 September, 15.00-17.00 CET
- Output
  - recordings of the sessions,
  - PR materials developed and advocacy/campaigning

## Work with European Stroke Organisation

Aim: include rehabilitation and life after stroke issues everywhere and national stroke strategy development

- Representation on the SAFE-ESO implementation committee – Arlene, Grethe and Chris
- Bringing SSOs & national scientific societies together, European wide meetings
- Provide tools for each country
  - Declaration for Action on Stroke
  - Basic stroke care manual - evidence-based interventions covering the entire chain of stroke care
  - KPIs – Stroke services tracker
  - <https://actionplan.eso-stroke.org/>
- European Life After Stroke Forum (ELASF)

Due to continued travel restrictions during the COVID19 pandemic, SAFE was unable to hold the 1<sup>st</sup> Forum in Barcelona as planned, both in 2019 and 2020.

SAFE therefore decided to hold four webinars during the 2020:

- Life after stroke –ways forward (March);
- Intimacy and sex after stroke (May);
- Emotional and psychological support after stroke (29 September);

- And a final one in December topic to be agreed

Feedback from the first two webinars has been extremely good with good attendance at both the free webinars.

SAFE is still planning for a virtual/hybrid Forum to be held in Barcelona on 11 March 2022.

- EU funded research projects

SAFE's involvement with EU funded research projects continues, remaining partners with six projects. We will continue to use the funding from these projects for dissemination amongst our membership, for which grants are paid.

## 5. Approval of the 2020 Annual Accounts

In the absence of the treasurer Chris Macey, Arlene Wilkie presented the final accounts to December 2020 for approval.

Income for 2020 was €455,555 against €615,743 for 2019.

This decrease was as expected and budgeted for and Arlene explained the reasons for this decrease:

- Membership income decreased slightly to €45,654 (€47,448 in 2019) this was due some organisations having a lower income therefore paid less fees to us.
- Sponsorship of €363,968 (€523,947 in 2019) received from Amgen, AstraZeneca, Bayer, BMS-Pfizer Alliance, Boehringer Ingelheim, Ipsen and Merz. This decrease was an expected and budgeted decrease. In 2019 we received approximately €200,000 for our Economic impact report and for the Angels project which we did not approach companies for in 2020.
- Our continued sponsorship from these organisations reflects a number of important initiatives for which we successfully secured funding. We hope to continue our relationships with these organisations, whilst always looking for new ones.
- The €21,890 (€43,609 in 2019) received from partnerships with European research organisations shows SAFE's continuing importance to the consortium involved in these research projects.

On behalf of Chris, Arlene thanked all our supporters in 2020 for their continued support and recognition of the importance of the voice of the stroke survivor.

Expenditure was €265,501 (€607,193 in 2019).

- This decrease was mainly due to the impact of the pandemic in 2020 which meant that several large projects were not able to take place – these projects include the European Life After Stroke Forum which we had originally planned to hold in 2020 as a large conference in

Barcelona. And face to face regional conferences and board meetings not happening in 2020.

- There were also delays to the advocacy work around the Stroke Action Plan for Europe and in starting a new project around the needs and wants of stroke survivors and their carers
- Due to the pandemic, work on the EU research projects did not go ahead as planned. We have carried over €87,887 that we have received in funding for our part in these projects.

Our overall funds carried forward were €720,428 (minus current liabilities of €2,084) – which is reflected in the accounts prepared by our accountants SBB on page 20 of the notice pack.

**Resolution:** A vote was taken and the accounts for 2020 were received by a majority vote

Looking at the mid-year finances of 2021, Arlene presented the meeting with a revised budget. Our position has improved since November and there are several reasons for this:

- Our membership fees income has improved € 36,348 to € 48,368 – we had downgraded our fee income thinking that the coronavirus would have impacted on the income of our members so affecting our income. However, for this year this has not been the case. Arlene thanked all our members for their continued support.
- We received income from a new EU research project – resulting in an income forecast increase from € 22,000 to € 70,000.
- We have commitment from our industry partners and will see €468,300 this year (in line with our original budget).
- In addition, Arlene is working on developing relationships with three new industry partners and we hope that we may see some additional income for our projects in 2021 and 2022.

Overall, our income reforecast is strong for this year.

Our expenditure line has slightly increased and this is due to the increased time needed for both our communications and our advocacy work as we move forward in 2021.

Our carried forward funds at the end of 2021 into 2022 are forecast at €457,661 an increase from € 403,192.

**6. Any other business**

There being no further business the meeting was closed.

**7. Date and venue of next General Assembly**

June 2022 – venue to be confirmed.

Signed and ratified by

A handwritten signature in blue ink, appearing to be 'M. Charalambous', written on a light blue rectangular background.

Marina Charalambous  
(Secretary)

A handwritten signature in blue ink, appearing to be 'Hariklia Proios', written in a cursive style.

Hariklia Proios  
(President)