

STROKE ALLIANCE FOR EUROPE (SAFE)

General Assembly 2022

Minutes

Wednesday 17 June 2022

Hotel Catalonia, Plaça d'Espanya, Barcelona

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 26 with 3 proxy votes, sufficient to be quorate. Those present were:

Belgian Stroke Council	Belgium
Association for Stroke and Aphasia	Bulgaria
Fundacio Ictus	Catalonia
Croatian Stroke Society	Croatia
Cyprus Stroke Association	Cyprus
Sdruzeni CMP	Czech Republic
Cerebrum	Czech Republic
Aivoliitto ry	Finland
Hellenic Action / Alliance for Stroke	Greece
Nemzeti Stroke Liga	Hungary
Heilaheil	Iceland
Irish Heart Foundation	Ireland
Neeman Association for Stroke survivors	Israel
Associazione Lotta Ictus Cerebrale (ALICE)	Italy
Association for a fight against stroke, STROKE Ohrid	North Macedonia
Norsk forening for slagrammede	Norway
Stroke Foundation	Poland
Portugal AVC	Portugal
ALIA – The Association for a Fight Against Stroke	Romania
Serbian Stroke Association	Serbia
Porazka	Slovakia
Združenje bolnikov s cerebrovaskularno boleznijo	Slovenia
STROKE-Riksförbundet	Sweden
Turkish Cerebrovascular Society	Turkey
Stroke Association	United Kingdom
Different Strokes	United Kingdom

The following organisations passed proxy voting rights to other member organisations:

Mozdani Val	Croatia
BLETZ Asbl	Luxembourg
Frenco al Ictus Fundacion	Spain

Also present, without voting rights, Associate Members:

Medical Foundation “Mkurnali”	Georgia
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Apologies for non-attendance were received from:

Stiftung Deutsche Schlaganfall-Hilfe	Germany
Hersenletsel.nl	Netherlands
Ukrainian Association of Stroke Patients	Ukraine

Not attending without apology

France AVC	France
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2. Approval of previous minutes and matters arising

Resolution: The minutes of the GA held in June 2021 were unanimously approved as a true and accurate representation of the General Assembly.

There were no matters arising from the June 2021 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.

At this General Assembly, Grethe Lunde retired from the board after serving two terms. Chris Macey and Marina Charalambous had served their first three-year term and were eligible to apply for a second term.

In addition, Dymtro Gulyayev resigned his position on the board in March 2022.

With our remaining 6 board members staying on in their roles on the board, there were five board positions available. We received seven applications from our members and a competitive election was held.

Board membership applications were received from:

- Chris Macey, Irish Heart Foundation
- Marina Charalambous, Cyprus Stroke Association
- Antonia Nucera, Associazione Lotta Ictus Cerebrale (ALICE), Italy
- Dorina Dobрева, Association for Stroke and Aphasia, Bulgaria
- Mika Pyykko, Aivolitto, Finland
- Marianne Tangen, Norsk forening for slagrammede, Norway
- Jan Konig, CEREBRUM, Czech Republic

All applicants introduced themselves to the membership, and a confidential vote took place. The votes were counted, with Sarah Belson from the World Stroke Organisation being an independent vote checker, in addition to Caroline Moye from SAFE.

Resolution: *After the votes were counted and verified, the following were approved as board members of SAFE:*

- *Chris Macey, Irish Heart Foundation*
- *Marina Charalambous, Cyprus Stroke Association*
- *Dorina Dobрева, Association for Stroke and Aphasia, Bulgaria*
- *Marianne Tangen, Norsk forening for slagrammede, Norway*
- *Jan Konig, CEREBRUM, Czech Republic*

4. Review of the year and plans for 2022

SAFE Director General, Arlene Wilkie, presented a review of SAFE's work during 2021. Many projects had been reviewed and amended due to the COVID19 pandemic.

Arlene reviewed the successes of 2022, with retaining the majority of our members as a main success. During 2021/2022 new applications for membership were received and approved by the SAFE board from ALIA – The Association for a Fight Against Stroke (Romania), Freno al Ictus Fundacion (Spain) and just yesterday from Federacio Ictus de Catalonia. Resignations from SAFE membership were received from Federacion Espanola de Ictus (Spain) and the Ukrainian Anti Stroke Association. The Turkish Cerebrovascular Society made amendments to their Articles of Association and have now been accepted as an ordinary member of SAFE.

During 2021/2022, we retained five sponsors (Boehringer Ingelheim, Ipsen, Angels, Merz and Bristol Myers Squibb/Pfizer). We have several potential partners for the future including Novartis, Johnson and Johnson, Stryker, Abbvie and Siemens Healthineers. We have also made new contact with the food company Danone and hope to update you with good news and new sponsors next year. We unfortunately lost two sponsors (Bayer and AstraZeneca).

Arlene updated the General Assembly on our current projects:

- Stroke Action Plan for Europe and EU work:
 - Throughout the year we have been working really closely with the European Stroke Organisation – our aim is to have national coordinators in each country whose role it is to work with their Governments to develop and implement a stroke strategy in each European country.
 - Over the last 18-months 93 people from 52 countries have stepped up to take this role. Many of these roles are taken up by SSO representatives – such as in Greece, Portugal and the UK.
 - 9 countries have signed a Declaration with their governments to support the Stroke Action Plan development in their countries – the most recent signing was Spain.
 - Many are already working with the governments on developing new stroke plans such as Serbia and Bulgaria. We also have other organisations – such as Cyprus who recently presented the Stroke Action Plan to the Cyprus parliament, so hopefully this is the start of something good there.
 - A new key activity is that the national coordinators are working on providing national data into the new services stroke tracker. This will be a powerful database in the future.
 - The European Commission launched a consultation on a Non-communicable disease plan to be published in June 2022. This is the first plan to follow on from the Cancer Plan that was launched a few years ago. It is the result of lots of campaigning from the community and also likely as a result of us coming through the pandemic and the realisation that non-communicable diseases suffered immensely during this time
 - The Plan will be taken on by members states and it will link into the budgets that were announced for the EU 4 Health programme and others.
 - We worked with the European Stroke Organisation on our submission, and many of our members contributed their suggestions.
 - We also submitted joint submission with the European Cardiovascular Alliance and also the European Federation of Neurological Alliances – to ensure that stroke was covered in all scenarios.

- Our plan for this year is to do more work with key EU actors – MEPs, the presidencies, the relevant health, care, workforce departments etc. We hope to do this in partnership not only with ESO but with other organisations we have newly partnered up with. Our aim here is to ensure that stroke is on all relevant agendas.
- European Life After Stroke Forum (ELASF):
 - We had hoped to hold a face-to-face conference on this in 2021. We quickly had to change this to a series of webinars.
 - We held five over the last 15 months with 2,000 people attending from all over the World. It has been a fantastic opportunity to raise the profile of the issue, to raise the profile of the Forum in the build-up to the first face-to-face meeting on 10 March 2023.
 - AW said that SAFE was particularly proud of all the stroke survivors who took part.
- European Stroke Organisation Conference (ESOC):
 - We attended the ESO conference in May and it was a great experience. On our stand we highlighted the ELASF and our Angels leaflets. The footfall at our stand was fantastic and we met some new industry contacts.
- European Stroke Awareness Day (ESAD):
 - For European stroke awareness day we took the opportunity to update our stroke prevention information website. We updated the evidence provided for the 10 modifiable risk factors and had all that information translated into the languages it had already - Spanish, Portuguese, Polish, Russian and French.
- Angels Patient Information
 - We have translated brochures into 13 languages, which have been distributed in 14 countries.
 - We received funding to update the current leaflets and to translate into two new languages – Romanian and Bulgarian.
 - Our thanks once again go to the UK Stroke Association for supplying the original information leaflets.
- Needs and Wants Report
 - As previously reported, SAFE has received funding for desk-based research and the draft report has been received. This is a report 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. The report will be published later in 2022.

- Stroke Support Organisation Faculty Tool (SSOFT)
 - We are currently updating the six modules on SSOFT and this will be relaunched later in 2022.
- SAFE's involvement in European research projects:
 - SAFE is currently involved in six research projects: Angie, Precious, Prestige AF, Proof, Tension, SVDs@target
 - Three new projects have been accepted for funding by the EC and will start in 2022/2023: Validate; RES-Q and Neuro4All
 - In 2022 17 out of 34 member organisations took part in the research dissemination.
- Strategy Development:
 - We have also started the task of reviewing and updating SAFE's strategy for 2023-2027
 - The board has a sub-group which has met on two occasions in Munich and in Barcelona and they will lead on the discussion after the General Assembly on the progress to date.

5. Approval of the 2021 Annual Accounts

SAFE Treasurer Chris Macey presented the final accounts to December 2021 for approval.

In 2021, income was €517,716.89 (€455,555.50 in 2020). This decrease was expected and budgeted for.

- Sponsorship of €398,800 (€363,968 in 2020) was received from Amgen, AstraZeneca, Bayer, BMS-Pfizer Alliance, Boehringer Ingelheim, Ipsen and Merz.
- Membership income increased slightly to €47,024.20 (€45,543.60 in 2020) due to new organisations joining SAFE. There was no increase in membership fees in 2021.

We also showed an increase in income on two further budget lines:

- The €69,454.73 (€21,889.81 in 2020) received from partnerships with European research organisations shows SAFE's continuing importance to the consortium involved in these research projects. The increase in income was partly due to SAFE becoming involved in the new ANGIE project, and continued involvement with five other projects.

- SAFE received a donation of €500 from Cittadinanzattiva APS due to Arlene Wilkie's participation in the Cardiovascular Protection Active Citizenship Network, and €1,750 from Novartis Pharma due to Jon Barrick's continued participation in the International Cardiovascular Council. Further small donations of €188.16 have been received via the SAFE website, making the total donations €2,438.16

Our thanks go to all our supporters in 2021 for their continued support and recognition of the importance of the voice of the stroke survivor.

In 2021, our expenditure was €258,611.80 (€265,501.79 in 2020). This expenditure was low compared to the years preceding the pandemic largely as we were unable to spend our funds on face-to-face meetings.

As a result, we had an overall surplus of €259,105.09 (€190,053.71 in 2020). This, plus our brought forward figure from 2020 of €718,344.43, results in €977,449.52 carried forward to 2021.

We intend to spend this as follows:

EU Research funding	€127,880.32
Project funding	€488,796.00
Deferred charges	€1,785.92
New strategic projects 2023-2027	€158,987.28
Reserves	€200,000.00

This is described in the accounts which need to be submitted to the Belgian authorities

CM and the SAFE board endorsed the 2021 accounts presented on p14 of the financial report and present them to the General Asseembly for approval

- **Resolution:** *A vote was taken and the accounts for 2021 were received by a unanimous vote*

6. Approval of 2022 budget

Based on the outline description of the work SAFE is doing in 2022, CM presented our budget as follows:

Income

- Membership fees are €49,821 – slightly up from last year as a few of the members had moved up a fee band

- Sponsorship – this is €331,159 – this is down by about €30,000 from last year. As Arlene explained we have lost three sponsors this year due to patents coming to an end and industry moving away from the patient liaison side of things. Arlene has a good pipeline of new partners that she is working on and we will be exploring new avenues for income this year.
- Donations – this is at €1,500
- Research income is at €11,527 – this is down from last year, but it reflects what we have claimed based on what we have spent on the dissemination with you. We may receive pre-financing from new projects but we do not know when we will receive this.

Expenditure

- Projects – we will spend €610,599 – up from last year – this is good news that we are able at last to spend money on events like this
- Core - €52,772 – this covers costs such as accountancy fees, web hosting, and strategy meetings etc. This has increased from last year because of the ESO conference and the strategy meeting costs
- EU research projects - €- 11,527
- Salary costs – for two full time and two part time – € 207,945. This is as last year – however this has increased as our VAT review indicated to us that we need to pay VAT at Belgian rate on these costs

We are working towards a €0 deficit/surplus this year

Resulting in carry forward of €488,653 which we will spend as

Reserves	€ 200,000
EU research	€ 127,880
Unrestricted	€ 160,773

Overall, CM reported that he is happy with our financial progress this year, and congratulated Arlene and the team for all their hard work. However, it is essential that we expand our industry partner list to ensure that we remain in the situation in the coming years.

Resolution: A vote was taken and the budget for 2022 was received by a unanimous vote

7. Approval of Power of Attorney

SAFE President Harriet Proios described to the meeting the process of preparing and signing of documentation for signature for the Belgian authorities, with paperwork being sent from London to Cyprus to Greece and then on to Brussels.

In order to save time and eliminate errors, the SAFE board recommends that the General Assembly grants a special power of attorney to Peter Van Loock, Lindsey Van De Velde and each employee of SBB Gecertificeerde Accountants en Belastingconsulenten bv (with registered office at 3000 Leuven, Diestsevest 32, bus 1a and company number 0459.609. 556) each separately and with the right of substitution, in the name and on behalf of the Association, vis-à-vis the Register of Legal Persons, the Companies Court, the Crossroads Bank for Enterprises, a Companies Counter of the Agent's choice, and to do everything useful or necessary for the publication of the decisions of the General Meeting in the Annexes to the Belgian Official Gazette, and for the modification of the registration with the Crossroads Bank for Enterprises.

In lay language, this means that on the instruction of the board, SBB Accountants & Adviseurs will be able to submit relevant documents to the Belgian Authorities directly on our behalf.

Resolution: *A vote was taken and the Power of Attorney was approved by a unanimous vote.*

8. Removal of a SAFE Member

According to Article 8 of our current constitution, a member can be excluded if it fails to pay its dues. Also, according to Article 8, the expulsion of any member of SAFE can be proposed by the board, after having heard any defence of the interested member concerned. The final decision to expel the member is taken at the General Assembly, by a two-thirds majority of the members attending.

During 2021 and 2022, we made many attempts to contact Jean Michel de Bray (the notified representative to SAFE), the previous and new President via the general email number from France AVC, our French SSO member, with respect to payment of the invoice and continued membership and attendance at SAFE meetings. However, despite our efforts, we have not received membership payment. The SAFE Secretariat wrote to Jean Michel de Bray and Isabelle Florentin to let them know that if we did not hear from them before the General Assembly, we will propose to the ordinary members to remove their organisation from SAFE's membership. We received nothing back in writing from either.

The board recommended that SAFE remove France AVC, our French SSO member, from our membership.

Resolution: *A vote was taken and removal of France AVC as a member of SAFE was approved by a unanimous vote.*

9. Approval of Officers to the Board

Chris Macey and Marina Charalambous were voted to serve a second term on the SAFE board and applied to retain their officer positions.

Resolution: *A vote was taken and Chris Macey was approved by a unanimous vote to retain the position of SAFE Treasurer.*

Resolution: *A vote was taken and Marina Charalambous was approved by a unanimous vote to retain the position of SAFE Secretary.*

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

Hariklia Proios, (Greece)	President	(to 2023)
Anita Arsovska, (North Macedonia)	Vice President	(to 2023)
Marina Charalambous, (Cyprus)	Secretary	(to 2025)
Chris Macey, (Ireland)	Treasurer	(to 2025)
Ivan Milojević, (Serbia)	Member at large	(to 2023)
Pnina Rosenzweig, (Israel)	Member at large	(to 2023)
Hrvoje Jurlina, (Croatia)	Member at large	(to 2023)
Rubina Ahmed, (UK)	Member at large	(to 2024)
Jan Konig. (Czech Republic)	Member at large	(to 2025)
Dorina Dobрева, (Bulgaria)	Member at large	(to 2025)
Marianne Tangen, (Norway)	Member at large	(to 2025)

10. Appointment of Honorary Members

Hariklia Proios advised the General Assembly that the board had agreed to confer Honorary Membership status on two long-serving board members and supporters of SAFE – Grethe Lunde and Jon Barrick.

Grethe has been a long-term supporter of SAFE through her affiliation with the Norwegian Stroke Support Organisation and joined the board in 2016.

Jon has also been a long-term supporter of SAFE through his affiliation with the UK Stroke Association. He joined the board and was Secretary from 2006 to 2012 and

President from 2014 to 2020. Both brought their own personal experience to SAFE. Grethe suffered her stroke many years ago as a young woman. And Jon's parents also suffered the impact of stroke. They were both able to bring this invaluable lived experience of stroke to SAFE's work and have been instrumental in ensuring that the patient voice is always heard in our work.

Through his role as President, Jon was a great leader of SAFE and had a great vision of where SAFE should be and always had stroke support organisations and those affected by stroke at the forefront of his mind. Indeed, many of the successes that you will hear about today are a result of his and the board at the time's work.

The General Assembly thanked both Grethe and Jon for their outstanding contribution to SAFE and for raising awareness of SAFE across Europe.

11. Any other business

There being no further business the meeting was closed.

12. Date and venue of next General Assembly

June 2023 – venue to be confirmed.

Signed and ratified by

A blue ink signature, appearing to read 'Marina', written on a light blue rectangular background.

Marina Charalambous
(Secretary)

A purple ink signature, appearing to read 'Hariklia Proios', written on a white background.

Hariklia Proios
(President)