

### 8 October 2020

Dear Members of the Stroke Alliance for Europe (SAFE)

I am writing on behalf of the Board of SAFE to invite you to our virtual 2020 General Assembly to be held on Wednesday 25 November @ 10:00 CEST.

We are holding our General Assembly virtually because it would not be safe to meet for a face-to-face meeting due to the ongoing pandemic.

We have attached the following documents, which we are obliged to send every member of SAFE:

- Notice of the meeting
- Agenda
- Minutes of General Assembly June 2020
- For approval
  - o Amendments to the Articles of Association
  - o Budget 2021
  - New member applications
  - Board members applications
  - Board officer applications

I hope we will see you at the General Assembly but if you are unable to attend, please forward any questions you may have to Sandra Jackson, SAFE Secretariat at <a href="mailto:info@safestroke.eu">info@safestroke.eu</a>

Yours sincerely

Jon Barrick President



## THE STROKE ALLIANCE FOR EUROPE NOTICE OF ANNUAL GENERAL ASSEMBLY

Notice is given that the 2020 General Assembly of the Stroke Alliance for Europe (SAFE) will be held as a virtual meeting on Wednesday 25 November at 10:00 CEST to consider and to approve the following:

- To adopt the changes to the Articles of Association of SAFE in the form attached to this notice which shall replace the existing Articles.
- 2 To approve the 2021 annual budget for 2021 as attached
- 3. To elect the following as new members of SAFE

Ordinary (full) membership: Fundacion Freno al Ictus, Spain

4 To elect the following as a Board members of SAFE:

Hariklia Proios Hellenic Action for Stroke, Greece.

Rubina Ahmed The Stroke Association, United Kingdom

6 To elect the following Board members as Officers of the Board

Hariklia Proios Hellenic Action for Stroke, Greece

Next General Assembly June 2022, venue TBD

On behalf of the Board

Jon Barrick President



### SAFE ANNUAL GENERAL ASSEMBLY - AGENDA

### Wednesday 25 November 2020 @ 10.00 CEST

### **Virtual Meeting**

- 1. Welcome, apologies and opening comments
- 2. Discussion and vote: Minutes of the General Assembly June 2020
- 3. Discussion and vote: Amendments to the Articles of Association 2020
- 4. Review of the year
- 5. Discussion and vote: SAFE Budget 2021
- 6. Discussion and vote: New SAFE member applications
- 7. Discussion and vote: Election of new members
- 8. Discussion and vote: Nomination of board members and officers of SAFE
- 9. Any other business
- 10. Date of next General Assembly: June 2022, venue to be determined.

Close

# JUNE 2020 FOR APPROVAL





# STROKE ALLIANCE FOR EUROPE (SAFE) General Assembly 2019

### **DRAFT Minutes**

Wednesday 24<sup>th</sup> June 2020 Virtual Meeting

### **AGENDA ITEMS and DECISIONS**

### 1. Welcome and Apologies

The President Jon Barrick (JB) welcomed the members to the General Assembly.

The number of member organisations present was 24 sufficient to be quorate.

These were:

Fundacio Ictus Catalonia
Croatian Stroke Society Croatia
Mozdani Val Croatia
Cyprus Stroke Association Cyprus

Cerebrum Czech Republic Sdruzeni CMP Czech Republic

Stiftung Deutsche Schlaganfall-Hilfe Germany
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)

Hersenletsel.nl

Italy

Netherlands

Association for a fight against stroke, STROKE Ohrid North Macedonia

Norsk forening for slagrammede Norway
Portugal AVC Portugal

Serbian Stroke Association

Združenje bolnikov s cerebrovaskularno boleznijo

STROKE-Riksförbundet

Sweden

Bevinder

Beyinder Turkey
Ukrainian Anti Stroke Association 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:

Belgian Stroke Council

Aivoliitto ry

Finland
France AVC

Medical Foundation "Mkurnali"

ParSirdi.lv

Belgium

Finland

France

Georgia

Latvia

BLETZ Asbl Luxembourg
Stroke Fundation Poland
Porazka Slovakia
Federacion Espanola de Ictus Spain

### 2. Approval of previous minutes and matters arising

The minutes of the GA held on 29 November 2019 were unanimously approved as a true and accurate representation of the General Assembly.

### 3. Matters arising

There were no matters arising from the GA 2019 minutes.

## 4. Review of the 2019 Annual Accounts and the SAFE Work Plan 2020

The Treasurer Chris Macey presented the final accounts to December 2019 for approval.

Thanks were given to all our supporters in 2019 for their continued support and recognition of the importance of the voice of the stroke survivor. We hope to continue our relationships with these organisations, whilst always looking for new ones.

Looking ahead to 2020, Chris presented the meeting with a revised finance review showing an expected increase in income from sponsorship, and donations received of €24,000. The increase in sponsorship resulted in an increase in expenditure on projects, and in an expected surplus instead of the previously forecasted deficit.

SAFE Director General, Arlene Wilkie, presented an updated work plan for 2020. Many projects had been reviewed and amended due to the COVID19 pandemic.

- The 1<sup>st</sup> European Life After Stroke Forum (ELASF) originally planned for November 2019 had now been postponed to 12 March 2021. The venue in Barcelona remains the same.
- With respect to the Economic Impact of Stroke in Europe report, scheduled for launch at the joined ESOC/WSC in November 2020. The congress had now been changed to a virtual meeting. SAFE will be looking at how the launch of the report will be changed and the membership will be informed as soon as possible.

- SAFE has previously held three regional conferences during May and June each year. The result of the European travel ban had meant a change in our intentions, and we have therefore held the first virtual meeting of the SAFE membership. Plans are being made for one conference to be held in Ljubljana on 23 November 2020, but this will of course depend on the situation with the COVID19 pandemic. Again, this will be confirmed with members as soon as possible.
- SAFE is continuing to work on the Stroke Action Plan for Europe with the European Stroke Organisation (ESO) and have three places on the Implementation Committee. Plans are being made for this work to progress at EU level and at national level with our members.
- Our partnership with the Angels project has been extremely successful. Currently we have translated brochures into 16 languages, which have been distributed in 15 countries. We are in negotiations with Angels for new translations, updates and reprints. Our thanks go to the UK Stroke Association for supplying the original information leaflets.
- SAFE's involvement with EU funded research projects continues, remaining partners with five projects and in 2020 becoming involved with a sixth. We will continue to use the funding from these projects for dissemination amongst our membership, for which grants are paid.
- We are looking at how we can better communicate with our members. We are currently sending a bi-monthly newsletter to members and will shortly be circulating a member's survey asking what the membership would like from SAFE. A membership information pack will shortly be available on the SAFE website, we are proposing to hold further virtual meetings, and also virtual catch-ups with the Director General and Secretariat.

### 5. Resolutions

The accounts for 2019 were received by a unanimous vote.

### 6. Any other business

There being no further business the meeting was closed.

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

23 November 2020, Ljubljana, Slovenia.

Signed and ratified by

Marina Charalambous (Secretary)

Jon Barrick (President)



# AMENDMENTS TO THE SAFE ARTICLES OF ASSOCIATION

FOR APPROVAL

### For approval:

1. Article 6: To simplify our ordinary member eligibility category, delete the specific statement mentioning founding members, as they should now fall into the 'all other European national organisation' statement.

### Current text:

Article 6: The following are eligible for ordinary membership and can vote at General Assemblies on any issues:

- the founding members; and
- all other European (as defined by the World Health Organisation) national organisations constituted according to the laws and customs of their country of origin, which support those at risk of and affected by stroke.

### New text:

Article 6: The following are eligible for ordinary membership and can vote at General Assemblies on any issues:

- all European (as defined by the World Health Organisation) national organisations constituted according to the laws and customs of their country of origin, which support those at risk of and affected by stroke.
- 2. Article 12: To allow SAFE to hold virtual General Assemblies

New addition to Article 12:

The members can attend the meeting remotely by teleconference, Microsoft Teams or a similar means of communication provided that the means of communication allows the other members of the General Assembly to identify the member participating remotely at any time during the meeting. Participation via such means of communication is the equivalent of attendance in person.

3. Article 20: To amend this article to clearly state that when a board member leaves the board, that their powers and responsibilities can cease as of the board meeting when the resignation is accepted.

### Current text:

Those board members who retire shall remain in office until their successor(s) are put in place

### New text:

Following his/her resignation, a Board Member is obliged to continue to perform his/her duties until a replacement can be found in all reasonableness without this taking longer than three months, unless agreed upon at the time of resignation

### 4. Article 22: To allow SAFE to hold virtual board meetings

New addition to Article 22:

The members of the Board can attend the meeting remotely by teleconference, Microsoft Teams or a similar means of communication provided that this means of communication allows the other members of the Board to identify the member participating remotely at any time during the meeting. Participation via such means of communication is the equivalent of attendance in person.

### SAFE BUDGET 2021 FOR APPROVAL

### **BUDGET 2021**

### To approve:

	Budget 2021	Forecast 2020
Income		
Membership fees	€ 36,348	€ 45,439
Industry	€ 392,500	€ 375,418
Donations	€ 500	€ 24,000
Research	€ 22,000	€ 22,000
	€ 451,348	€ 466,857
Expenditure		
Staff costs	-€ 155,000	-€ 154,739
Board costs	-€ 14,000	-€ 13,015
Core costs	-€ 27,000	-€ 26,359
Projects	-€ 294,375	-€ 75,000
	-€ 490,375	-€ 269,113
Surplus/deficit	-€ 39,027	€ 197,744
Carried forward	€ 637,245	€ 676,273

#### Notes:

### *Income summary*

Total budget income: €451,348 (2020 forecast €466,857)

- Membership fees: The membership income has been predicted to fall by half across all members. And the board have waived a fee increase for 2021. 2021 budget is €36,348 (2020 actual €45,439)
- Industry: the income for 2021 has been budgeted in line with 2020 and we hope to bring in new partners in 2021. 2021 budget is €392,500 (2020 forecast is €375,418)
- Donations: we have marked this down from last year. 2021 budget is €500 (2020 forecast is €24,000)
- Research: as at 3 October 2020 we have received no EU research funding but we anticipate that we will receive €22,000 by the end of 2020. We have estimated the same for 2021.

### Expenditure summary

Total budget expenditure: €490,375 (2020 forecast €269,113)

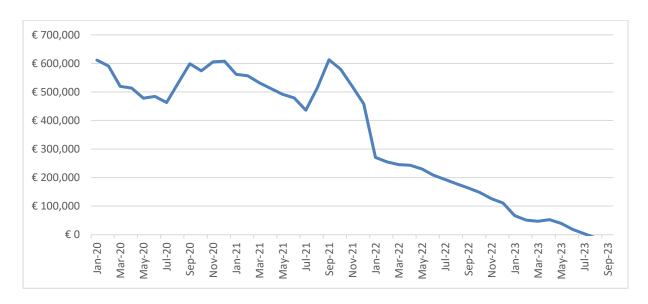
• Staffing: staffing costs for a full time Director General and Secretariat and part time policy/advocacy and communications functions have been included. 2021 budget is €155,000 (2020 forecast is €154,739)

- Board and core costs: have been based on the 2020 spend. 2021 budget is €41,000 (2020 forecast is €39,374)
- Project costs: 25% of the total costs has been deducted for staff costs, the remaining is for the project costs. 2021 budget is €294,375 (2020 forecast is €75,000)

### Deficit/surplus

The 2021 budget shows a deficit of approximately €39,000. This is due to the staffing costs. These costs will come from the 2021 income and the carried over funds as this income has already been received for the European Life After Stroke Forum and Stroke Action Plan for Europe implementation work for example but not all has been spent in 2020

### Cash flow as at 3 October 2020



The cashflow is based on known income from both industry and members in 2020, the known expenditure on core and projects we have received commitment for and 2021 budget. For the years beyond this, we have only included the members fees (so no industry income) and expenditure for on our core costs such as salary, board costs and core organisational costs such as the website. Under this scenario, the forecast predicts that funds are positive until around July 2023.

### Overall

Overall, our position looks good when you view the cashflow and the forecast budgets. However, until we receive the full corporate funding we must move forward cautiously. In addition, our income from industry may reduce over the coming years along with membership income.

# APPROVAL OF NEW MEMBERS OF THE STROKE ALLIANCE FOR EUROPE FOR APPROVAL

**Fundacion Frenco al Ictus** 



### Application for membership

### a. Your organisation

Name of applying organisation		Fundación F	reno al ICTUS	
Legal registration number		G88366281		
Registered address		Av Soller 97	- 28290	
		Las Rozas -	Madrid	Ē
Correspondence address (if diffe	erent)			
Phone number		+34 657714	222	
Website		www.frenoal	lictus.org	
Twitter name (please follow us @StrokeEurop	oe)	@frenoalictu	ıs	
Latest income (Year 2019 as the FY of incorporation)	Curr	ency: Euro	Amount: €5k	

**Type of organisation**: (Federation of groups in Europe, pan-European organisation of individuals, national organisation for disease with small numbers of patients, etc. Please give brief details)

National Organisation Foundation of national scope of action incorporated under Spanish Law 50/2002 on 2 April 2019. Also supported on its aims by Freno al Ictus Patients Association.

Description and aims of organisation: (brief description, no more than 50 words)

Freno al lctus Foundation has extensively work to fight against stroke focusing its resources on making this disease known to society, reaching all social groups by developing education and awareness activities.

The main mission of Fal is to reduce the social impact of the stroke in our environment, and in order to get this objectives we work on three main lines:

- Social awareness projects to inform the population how to prevent and act about the stroke.
- Support research related to stroke and acquired brain damage.
- Improve social inclusion of stroke and acquired brain damage patients in our society.

### Names and titles of board members

Julio Agredano – President José María Gómez– Secretary Irene Prieto – Board member

Registered Address: Rue Washington 40, 1050 Bruxelles, Belgium

www.safestroke.eu

### b. Which membership are you applying for?

$\boxtimes$	Full membership
	Associate membership

## c. To show your organisation meets membership criteria, please complete the following:

We are a voluntary organisation	Yes
Voluntary organisation – an independent, self-governing body of people who had together voluntarily to take action for the benefit of the stroke community. It may paid staff or volunteers, and must be established to benefit the public, not specified individuals.	y employ
Our work covers stroke issues in the country we are registered	Yes
We are properly constituted having been formed and organised in a correct and legal way.	Yes
Our aims, objectives and methods of governance are written down in a publically available document	Yes
Our organisation holds a bank account in the name of the organisation (not that of an individual)	Yes

### d. Contact information (including at least one English speaker)

Name (Senior contact)	Enara Herran
Job title	Collaborator
Email address	enara.herran@frenoalictus.org
Phone number	+34 657714222

Name (2 <sup>nd</sup> Senior contact)	José María Gómez
Job title	Secretary
Email address	josemaria.gomez@frenoalictus.org
Phone number	+34 630 935 496

Registered Address: Rue Washington 40, 1050 Bruxelles, Belgium

www.safestroke.eu



Pedro Montarelo - Board member Miren Aramburu - Board member Ignacio de Miguel - Board member

www.safestroke.ed

### e. Additional required information

Along with this agreement, I have sent:

- A copy of our Statutes (Articles of Association/Constitution) in English
- ☐ The legal registration document of your organisation
- A copy of our latest published accounts, advising the turnover in English.

### f. Your authorisation

I am authorised to sign on behalf of the above organisation

I am authorised to apply for membership on behalf of my organisation.

Date: ...22/06/2020......

Name: ...JULIO AGREDANO..

Title: ...PRESIDENT...

Signature: ..

Thank you for your application.

Please send all your information to info@safestroke.eu

Registered Address: Rue Washington 40, 1050 Bruxelles, Belgium

www.safestroke.eu

# NOMINATION AND ELECTION OF BOARD MEMBERS OF THE STROKE ALLIANCE FOR EUROPE FOR APPROVAL

Hariklia Proios

**Rubina Ahmed** 



### Application for board member role (Please complete all sections)

Full name: Hariklia Proios

Name of member stroke support

organisation:

Hellenic Alliance for Stroke.

Position held in member stroke support Vice President

organisation:

Country of member stroke support

organisation:

Greece.

### What contribution do you hope to make to SAFE and the stroke patient community as a member of the board?

I hope to align with members of the board inleuding stroke survivors, therapists like myself as well as with medical professionals and carers to help improve support services for sso's; collaborate with BMs to convince EU lawmakers and MEPs to coordinate actions along the lines of the Stroke Action Plan for Europe and also help encourage new member organizations to join and understand the need for policywork, lobbying for stroke.

### What personal, expertise and professional strengths will you bring to SAFE and the stroke community? Mention any relevant experience.

I have been involved in the organization of community support groups over 25 years; In Greece the "Aphasic Group of Thessaloniki" (started 2006), which build on my experience with similar groups in Princeton (1990) and Boston (1997-2000) in the USA and I was involved with the aphasia Suisse group Zurich, Switzerland (2000-2002). I was a member of the Multicultural Task Force of the National Aphasia Association (NAA) since 2007 and, also a member of the National Aphasia Association Advisory Council from 2009 to 2016.

Since 2016, I am actively involved in SAFE – the Stroke Alliance for Europe – representing the Hellenic Alliance for Stroke SSO (HAS-SSO) and I am a full member of the Academy of Aphasia. In December 2017, I was elected as Board Member in SAFE at the SAFE General Assembly meeting in Zagreb, Croatia.

In April 2018 I was selected as member of the World Heart Federation (Salim Yusuf

Emerging Leaders Program) focusing on Stroke Rehabilitation and attended a "think tank" meeting at Duke Kunshan University, China in June 2018.

I am academically responsible for the second year for the educational program, FASTHEROES 112 Angels BI and the Hellenic Alliance for Stroke is winner of the Brain Life Goals 2020 from the European Federation of Neurological Association, EFNA.

I serve on the Life after Stroke consortium for the Stroke Action Plan and now serve on organizing committee for upcoming SAFE Life After Stroke Forum. Also, I am member of ESO.

I serve as a contact person in Greece and member for the AIA (Association Internationale Aphasie) since 2016.

I was selected by World Stroke Organization in April 2019 to become a member of the "Development Group - STROKE" contributing to the development of WHO's (World Health Organization) Package of Rehabilitation Interventions (PRI). As of 2019, I serve on the Stroke Task Force for the American Congress of Rehabilitation Medicine (ACRM) and will present stroke-related conference contributions from Greece at their upcoming annual conference this month.

### How would your election to the SAFE board benefit your organisation?

The Hellenic Allaince for Stroke is a long time SAFE member and supports my candidacy. As VP of HAS-sso, a position on the SAFE Board will play a key role in strengthening stroke survivor organizations within Greece and encouraging decision makers to take stroke care seriously.

I confirm that the information contained in this application is correct.

Signature:	Harlle Hous	<b>Date:</b> 30/9/2020

Once completed please return this form to the SAFE Secretariat at info@safestroke.eu

### Completed application forms must be received by 30 September 2020

Documents you need to submit together with your application		
A letter from your stroke support organisation supporting your nomination		
	A recent curriculum vitae.	

### Hariklia Proios

Dept. of Educational and Social Policy, University of Macedonia Thessaloniki, 54636, Greece, e-mail: <a href="https://doi.org/10.1007/jpersity-10.1007/jpersity

### 1. Education:

- PhD, Graduate School of Arts and Sciences, Columbia University, Dept. of Speech and Language Pathology (advisor S.Rigrodsky), 1993
- M.Phil. Teachers College, Columbia University, Dept. of Speech and Language Pathology, 1992
- M.Sc. Teachers College, Columbia University, Dept. of Speech and Language Pathology, 1989
- B.A., Hofstra University, Dept. of Speech/Language Pathology & Psychology (double deg), 1986

### **Academic Employment:**

2019-	Associate Professor, Dept. of Educational and Social Policy, University of Macedonia
2014-	Assistant Professor, Dept. of Educational and Social Policy, University of Macedonia
2004-2012	Special Scientist, PD407/80, Dept. of Educational and Social Policy, University of
	Macedonia, School of Philosophy - Department of Psychology, Aristotle University of
	Thessaloniki, Medical School, Aristotle University of Thessaloniki
2003-2004	Assistant Professor, Dept. of Speech Therapy, Technological Educational Inst. Patras
2000-2002	Research Associate, Dept. of Neurology, Neuropsychology Unit, Univ. Hospital Zurich
1998-1999	Research Associate, Lab. of Cognitive Psychology, Dept. of Psychology, Harvard Univ.
1993-1998	Assistant Professor (Tenure 1997), Department of Communication Sciences and
	Disorders, Montclair State University

### **Clinical Employment:**

2005-2014	Head of Speech Language Pathology Unit, Nea Raidestos, Anagennisi Rehab. Center
2000-2002	Logopaedin, Neuropsychology Unit, Dept. of Neurology, University Hospital Zurich
2000	Adj. Clinical Assistant Professor, Dept. of Communication Disorders, Boston University
1999-2000	Speech Pathologist, Speech Pathology Dept., Spaulding Rehab. Hospital, Harvard Univ.
1993-1998	Clinical Supervisor, Dept. of Commun. Sciences and Disorders, <i>Montclair State Univ.</i>
1993	Clinical Supervisor, Dept. of Speech and Language Pathology, Teachers College,
	Columbia University
1989-1993	Clinical Consultant, Dept. of Speech Pathology, Medical Center at Princeton

### **Research Interests and synergistic activities:**

Research interests include adult aphasia, visual hemi-spatial neglect, and number processing difficulties in aphasic subjects; development and implementation of theoretical constructs for evaluating neurological cases, extension and development of standardized tools for patient screening and testing, such as the Aachen Aphasia Test. She has been involved in the organization of community support groups in Greece, such as the "Aphasic Group of Thessaloniki", as well as virtual support groups, which build on experience with similar groups in Princeton and Boston in the USA and in Zurich, Switzerland.

### **Professional Activities**

She is actively involved as Board member in SAFE – the Stroke Alliance For Europe – since 2016, representing the Hellenic Alliance for Stroke SSO, and is currently the President-elect. She was member of the National Aphasia Association Advisory Council since 2009 and of the Multicultural Task Force. Since 2016 she is a full member of the Academy of Aphasia. In 2018 she was selected for the Emerging Leaders Program of the World Heart Federation (WHF). She is active in committees on Stroke and Rehab in the World Health Organization (WHO) and the American Congress of Rehab Medicine.

### **Books:**

- 1. Dysphagia, Dysphasia, Dysarthria, H. Proios, Giapoulis Publ. (in Greek), Thessaloniki, 2003
- 2. Dysphagia, Dysphasia, Dysarthria, H. Proios, Speech Pathology for adults and children, 2nd Ed. (enhanced with material for children), *Grapholine*, Thessaloniki, (in Greek) 2005
- 3. Chapter "Chapter: Stages of semantic and lexical development", H. Proios, pp. 231-276, in the book Linguistic development and disorders, Ed. D. Nikolopoulos, *Topos Publ.* (in Greek), 2008
- 4. Chapter «Ανάπτυξη του λόγου και της ομιλίας και διαταραχές», Χ. Πρώιου, σελ. 65-80, στον Τόμο «Επιμόρφωση εκπαιδευτικών γονέων παιδιών με αναπηρίες και γονέων μαθητών με αναπηρίες», Επιστ. Υπεύθυνη Α. Καρλοβασίτου, Ειδική Υπηρεσία Διαχείρισης ΕΠΕΑΕΚ, ΥΠΕΠΘ, 2008
- 5. Supervision in Rehabilitation, H. Proios, *University of Macedonia Press* (in Greek), 2015

### **Publications** (10 selected):

- 1. Multidisciplinary assessment of visual hemi-spatial neglect: A case report of a bilingual patient, (full paper), H.Proios, D.Chialant, and D.Caplan, *Journal of Medical Speech-Language Pathology*, **9(10)**, p.277-289, 2001.
- 2. Preserved Orthographic Length and transitional probabilities in written spelling in a case of acquired dysgraphia, D. Chialant, K. Domoto-Reilly, H. Proios, and A. Caramazza, *Brain and Language*, **82**, 30-46, 2002.
- 3. Number representation deficit: a bilingual case of failure to access written verbal numeral representations, H. Proios, D. Weniger, and K. Willmes, *Neuropsychologia*, **40**, 2341-2349, 2002.
- 4. The influence of color on number perseveration in a serial addition task, H. Proios and P. Brugger, *Perceptual Motors and Skills*, **98**, 944-946, 2004.
- The dominant hemisphere is more "active" but also more "stable"? A functional Transcranial Doppler study, K. Vadikolias, N. Artemis, P.D. Mitsias, I. Heliopoulos, G. Tripsianis, H. Proios, I. Milonas, *Journal of Cerebral Blood Flow and Metabolism*, 27, 1870–1877, doi:10.1038/sj.jcbfm.9600484, 2007.
- 6. Random Number Generation in Aphasic Patients: A Test of Executive Functions, H. Proios, S. Asaridou, P. Brugger, *Acta Neuropsychologica*, **6**(2), 157-168, 2008.
- 7. Taste Perception Analysis Utilizing a Semantic Verbal Fluency Task, M. Ghemulet, M. Baskini, L. Messinnis, H. Proios, *Psychology Research and Behavior Management*, 7, 261–272, 2014.
- 8. Quality of Communication in the Rehabilitation of Persons with Stroke and/or Dementia: The Caregivers Perspective, E. Tsioupinaki, A. Serdari, E.-P. Kouki, E. Mouza, H. Proios, *Neurology* **26**:1, 45-52, 2017
- 9. The physiological experiments of Constantin von Economo on the central pathways of mastication and deglutition, V.G. Petousi, H Proios, L.C. Triarhou, *Revue neurologique*, **175**(9), 506-518, 2019
- FAST 112 HEROES: A kindergarten-based educational stroke intervention for the whole family, K Tsakpounidou, A Loutrari, F Tselekidou, M Baskini, H Proios, *Health Education Journal*, 0017896920911675, 506-518, 2020

### **Awards and Honors:**

- Emerging Leaders program of the World Heart Federation 2018
- Member of the Board of SAFE (Stroke Alliance For Europe), 2017 ; President elect 2019
- Member of the Academy of Aphasia, 2016 –
- National Representative and founding member of Hellenic Alliance/Action for Stroke SSO, 2016 -
- Member of the National Aphasia Association Multicultural Task Force, 2007 2016
- Member of the National Aphasia Association Advisory Council, 2009 2016
- Honorary Adj. Assistant Professor, Columbia University, NY, Dept. of Biobehavioral Sciences, 2006 2009

#### Member in:

- American Congress of Rehabilitation Medicine (ACRM) Stroke Task Force 2018
- Development Group-STROKE for the World Health Organization (WHO) on Rehab interventions 2019
- Greek Neuroscience Association, 2007 -
- Psychology Association of Northern Greece, 2005 -
- Committee of Greek Scholarship Foundation (IKY) for graduate studies in SLP, 2003 2004
- Schweiz. Zentralstelle fuer Heilpaedagogic (license in SLP), 2001 2002
- Massachusetts State License in Speech-Language Pathology, 1998 2000
- New Jersey State License in Speech-Language Pathology, 1989 1998
- New Jersey Higher Education Council for Speech-Language, 1994 1997
- American Speech and Hearing Association (ASHA), ASHA Certificate of Clinical Competence (CCC), 1989 –



## Application for board member role (Please complete all sections)

Full name: Dr Rubina Ahmed

Name of member stroke support

organisation:

The Stroke Association.

Position held in member stroke support

organisation:

Research Director

Country of member stroke support

organisation:

UK.

What contribution do you hope to make to SAFE and the stroke patient community as a member of the board?

The Stroke Association is the largest stroke support organisation in Europe and we are systems leaders in the space. As well as providing direct support to people affected by stroke through our services, we are also key drivers of stroke policy and advocacy, and a leading funder of stroke research in the UK. We can use our influence to drive and advocate for the activities promoted by stroke, whilst at the same time bring the voice of the UK patient community to the SAFE Board.

I currently lead on a number of enagagement activities for the Stroke Association, including international engagement, researcher engagement, and bringing the voice of lived experience into our funding decisions. This also includes leading the James Lind Alliance Priority Setting Partnership programme, which aims to determine the priorities for people affected by stroke and healthcare professionals. I hope to bring this experience to the SAFE Board - specifically experience of patient engagement, setting organisational strategy, and understanding the challenges of working at the international level.

In addition, I work closely with the policy and influencing team on engagement with national stakeholders in stroke clinical delivery such as with the British Association for Stroke Physicians and the Clinical Director for Stroke in England. My broad understanding of the stroke pathway in the UK and the wider stroke landscape is something that I can bring to the SAFE board, as well as using my influence at the national level to help with the delivery of SAFE programmes.

What personal, expertise and professional strengths will you bring to SAFE and the stroke community? Mention any relevant experience.

My personal experience is in scientific and research funding and strategy and in policy and public affairs. In my previous role at another charity, I led the commissioning and delivery of a report into the economic and personal impact of sight loss in the UK (see: https://www.fightforsight.org.uk/media/3302/time-to-focus-report.pdf). As SAFE continues to implement the Stroke Action Plan for Europe and publish the Economic Impact of Stroke in Europe report, I can contribute my experience and learning from this area.

I am a Council Member for the British Science Association which is a large charity in the UK tasked with increasing public engagement in science. I therefore have Board and Trustee level excperience including in governance and the legal obligations of the role and in broader organisational strategy setting.

On a more personal level, I am a strong advocate for collaboration and international engagement. Single organisations often do not have the resources, influence or experience to bring about all the changes that are needed, but by working together effectively, I believe are better-placed to achieve the greatest impact for as many people as possible affected by stroke.

### How would your election to the SAFE board benefit your organisation?

As the leading stroke charity in the UK it is of strategic importance for the Stroke Association to have membership on the SAFE Board. Our ambition is to grow our systems engagement and international influence and our relationship with SAFE is considered a priority for us in our international work. We already support a joint post with the World Stroke Organisation which helps our influencing activity at a broader international level, and ensures we are broadly aware of what is happening in WSO member organisations.

With my membership of the SAFE Board I would be able to ensure we are aware of the priority activities for SAFE and other European organisations. We could help promote SAFE activities through our networks and communication activities, and also align our own policy and influencing activities where appropriate. .

confirm that the information contained in this application is correct.		
Signature:	Date:	
Once completed please return this for info@safestroke.eu	orm to the SAFE Secretariat at	

### Completed application forms must be received by 6 October 2020

Documents you need to submit together with your application		
A letter from your stroke support organisation supporting your nomination		
	A recent curriculum vitae.	

### **Dr Rubina Ahmed**

Address: 204 Clock House Road Tel: 020 3662 6451

Beckenham **Mobile:** 07956 166 315

Kent **E-mail**: <a href="mailto:rubina\_ahmed@hotmail.co.uk">rubina\_ahmed@hotmail.co.uk</a>
BR3 4LB

**United Kingdom** 

### **EDUCATION**

2014: MSc Management, Birkbeck, University of London.

Grade achieved: **Distinction** 

**2010: PhD in Immunology** from the Royal Veterinary College, University of London

Title of thesis: "Elucidation of the role of mannose binding lectin and ST2 in the immune response to *Brugia malayi*."

**2002: BSc (Joint Hons) Immunology and Biochemistry**, King's College University of London. Grade Achieved: Upper Second Class (**2:i**)

**1999:** A' levels gained in 1999 in Biology, Chemistry and Mathematics. 11 GCSEs gained in 1997, Mulberry School for Girls, London

### **EMPLOYEMENT HISTORY**

### From 04/2020 – present: Director of Research – Stroke Association

Key member of the senior leaders' group, working collaboratively across the organisation and with the Board of Trustees to deliver the charity's strategic goals. Lead the implementation of the Stroke Association's research strategy. The role has a strong externally-facing component, engaging funding bodies, major donors, individual researchers and research groups, and also other charitable research organisations, both in the UK and also in Europe and globally, through membership of the World Stroke Organisation.

Drive the development of partnerships to deliver stroke research that is of most importance to people affected by stroke, and to leverage more funding into stroke research. Leading the James Lind Alliance priority setting partnership for stroke research, currently underway with the charity as its convenor.

Internally, the role has a management component, responsible for a team of staff who manage a portfolio of research awards for projects and for Fellows and Lecturers; for the communication of research stories and impact; for ensuring that Stroke Voices are strong in Research; and for international activities.

Working with external communications and fundraising colleagues to promote our research and to encourage donation of new funds into research, with a particular focus on ensuring that the value and impact of research is understood and embedded within the wider work of the charity.

### 07/2018 – 04/2020: Head of Research and Policy - Fight for Sight

Providing overall strategic leadership for the research, policy and public affairs activities of the charity. Acting as the scientific lead for the charity and representing the organisation at senior levels

internally and externally with other funders, the research community, and donors. Building networks and advocating for the importance of scientific research and the value and impact it can have.

- Leading on the delivery of the research strategy, including production of a "theories of change" report and resulting implementation plan for the four strategic programme areas for the charity.
- Ensuring that research funding and policy activities meet the overall strategic goals of the organisation and contributing to the development of a new organisational strategy map in 2019.
- Leading on building research partnerships to generate income for the charity and jointly fund research. I have grown research partnership income from £160K in 2017/2018 to £450K in 2018/2019.
- Leading the policy and public affairs strategy, including commissioning a major health economics and landscaping report for the charity which is the first of its kind for the sight-loss sector in the UK. The report will be published in 2020 and set out the health economic impact of sight-loss, a bibliometric analysis of research funding, as well as the personal impact of visual impairment on patients and their carers.
- Working with the fundraising team to generate income through developing funding proposals, case for support, and meeting with donors.
- Building on the work of the James Lind Alliance Priority Setting Partnership on Vision and Sight Loss, leading the development of a cross-organisational patient and public involvement strategy, including how those affected by sight-loss can be better represented on research funding decisions.
- Acting as a spokesperson for the charity and providing scientific input into press releases and communication activities. I have given interviews on national TV including Sky News, ITV and the BBC and radio interviews for the BBC, RNIB and other local channels.
- Line-management of a team of four providing regular support, objective setting and personnel development.

### 02/2016 - 07/2018: Senior Research Funding Manager, Clinical Research - Cancer Research UK

Senior role within the Clinical Research department tasked with overseeing alignment of funding of awards with Cancer Research UK's strategic plan and research priorities and leading on the project management of large strategic initiatives and infrastructure awards.

- Portfolio lead for CRUK core funded Clinical Trials Units (CTUs). Tasks include developing the
  processes and managing the high profile, international review of CTUs for core funding in which
  ~£48M of funding is awarded. Acting as the primary point of contact for CTUs, organising CTU
  Directors meetings and working with the group on areas of strategic importance such as clinical
  trial set-up times, patient recruitment, industry collaborations and regulatory processes.
- Developing the CRUK CTU network strategy and liaising with other national and international groups as necessary including the NCRI and UKCRC.
- Direct line management of a Clinical Research Liaison Manager, graduate trainees and interns in the team. Mentoring of other team members and act as the senior contact in the absence of the Head.
- Leading on the public and patient involvement (PPI) strategy for the clinical research team, including working with the wider CRUK PPI team, supporting researchers on the PPI within their projects, recruiting patient representatives on the panels and committees, and supporting the CTU network in integrating PPI into their units.
- Leading on co-ordinating CRUK's relationship with the European Organisation for Research and Treatment of Cancer (EORTC) and the International Rare Cancers Initiative (IRCI)
- Ensuring delivery of the Clinical Research Committee and associated funding panel meetings and managing a portfolio of grant awards including the peer review process and managing the end-to-end grant giving process. Managing the governance of awards including ensuring they

are compliant with policies and regulations, such as those relating to clinical trials, ethics and drug development.

- Identifying areas of collaboration with other departments across CRUK and externally, including
  with the Experimental Cancer Medicine Centres (ECMC) team, Centre for Drug Discovery,
  Policy, and Cancers of Unmet Need. Active current projects include working on overcoming
  challenges on clinical trial set up and delivery such as industry collaborations, opening first
  and subsequent sites, working with regulators such as HRA and MHRA on regulatory approvals.
- Oversight of complex clinical trials and strategic initiatives such as PRECISIONPanc, TracerX, LungMatrix and SMPaeds. Processing complex funding applications when they are submitted, including convening bespoke panels as necessary, through to issuing the award and monitoring delivery. Working with grant holders and the external community.
- Attendance at meetings of national and international groups including NCRI CSGs and CTU Directors meetings, EORTC, IRCI, and UKCRC Directors meetings and working groups.
- Analysis of the clinical research funding portfolio and continual monitoring and evaluation of the
  portfolio to ensure strategic objectives are being met, using data from internal databases and
  the Researchfish system. Conducting specific quantitative research projects, such as analysis of
  the time taken to set-up clinical trials.
- Horizon scanning of the cancer research landscape to identify areas of unmet need. Current project includes looking at the paediatric clinical trials capability in the UK and how this can be strengthened/supported.
- Keeping abreast of the policy and legislative clinical research arena and acting as the point of contact for external organisations.

## 02/2011 – 01/2016: Research Funding Programme Manager - National Centre for the Replacement, Refinement and Reduction of Animals in Research (NC3Rs) (Medical Research Council employee)

Leading the strategic direction of the Centre's funding schemes. Continual evaluation of the impact of funded research and whether it is meeting Centre objectives. Implementing new schemes as appropriate and if financial resources allow. Developing existing programmes and introducing new policies and procedures that maximise the impact of investment. Line management of a team of three administrative and scientific staff involved with grant processing and funding.

- Overall responsibility for the Research Grant schemes Project grants, Pilot Study grants, Infrastructure Awards and ad hoc Strategic Awards. Managing the end-to-end grants life cycle, from initial application through to grant closure and follow-on.
- Managing the annual research funding budget to ensure equitable distribution across the schemes and based on priorities. Seeking opportunities for joint funding and collaborations with other funders to leverage additional resource.
- Matrix management of staff working with the team including research administration, communications, policy and the website.
- Overseeing all activities related to grants funding and funding committee management, including: liaison with potential applicants and pre-application scientific assessment; coordinating the peer review process to ensure sufficient reviews are received; setting up the Panel Meetings including recruitment of Panel members to cover all scientific expertise needed; working with the Panel Chair and advising on policy and process; Secretary for the Funding Panel recording decisions, writing minutes and providing feedback to applicants.
- Monitoring of grants post-award: visiting grant holders; ensure grant holders report into the Researchfish evaluation portal; work to promote the research e.g. through press releases; authorise extensions, sanctions and payments on grants.
- Working closely with Research Councils such as MRC, BBSRC and EPSRC and UK Shared Business Services, to develop cross-council policies, strategies and joint funding initiatives.
- Arranging conferences and workshops for grant holders, stakeholders or the external community.

- Acting as an ambassador for the NC3Rs via attendance at international conferences and meetings, and representing the Centre on forums and external groups.
- Building relationships with other funders, universities, learned societies and Government departments to drive forward the Centre's strategy and objectives, including securing additional funding for Centre activities.
- Giving regular lectures to undergraduate and Master's students on the use of animals in research at universities such as Kings College London, University College London, Cranfield University and any others making this request.

### 02/2008 – 02/2011: Grants Adviser and Expert Review Group Manager - Pathogen Biology and Disease Transmission, Wellcome Trust

- Grants adviser in the Immunology and Infectious Diseases grants management team. Promoted to Expert Review Group Manager for the Pathogen Biology and Disease Transmission Expert Review Group, when Investigator Awards were introduced.
- As Expert Review Group Manager I was the secretary for the Committee, liaising with the Chair and Committee Members on all aspects of the Committee, from setting the agenda to advising the Committee on Trust policies etc.
- Responsibility for the Veterinary Interview Committee and the Veterinary Fellowships scheme
  including liaising heavily with the UK Veterinary Schools, arranging workshops, and sitting on
  panels to promote the research agenda of the Trust in animal health.
- Wellcome Trust grants management specialist on the use of animals in research, preparing various reports and papers on animal usage and sitting on different committees. Liaising with the NC3Rs and other funders such as the MRC and BBSRC to ensure a consistent cross funder policy on animal research. Visiting Trust funded laboratories that use non-human primates in research. Provide expertise to others within the Trust on the use of animals in research.
- Other day-to-day activities included managing a portfolio of fellowships and ad hoc grants and preparing them for consideration at Funding and Interview Committees, from selecting referees for the peer review process to delivering the final decision and award letters to applicants. Providing advice to potential applicants on funding opportunities and their competitiveness. Dealing with queries from award holders. Taking minutes and managing the budget for Committee meetings.
- Interacting with the scientific community by giving presentations at Universities and other institutes and attending careers fares etc. Attending conferences and other relevant external meetings of interest.
- Building relationships with fellowship and grant holders by visiting them in their lab and acting as a point of contact.
- Acting as the Wellcome Trust representative on International Scientific Advisory Boards for Trust-funded Centres and PhD programmes.

### 01/2003 – 09/2004: Editorial Officer, British Society for Immunology

- Role involved over-seeing the peer-review process for the journals *Immunology* and *Clinical and Experimental Immunology*.
- Liaising with publishers, editors, authors and referees via e-mail and over the phone. Including, requesting peer-review from appropriate referees and sending out decisions to authors and ensuring all accepted papers were accompanied by necessary paperwork.
- Arranging annual meetings with the editors and publishers as necessary.
- Commissioning reviews and editorials
- Proof-reading the Society's membership publication (*Immunology News*) and abstracts submitted for the Society's annual congress.
- Helping with the organisation and smooth-running of the annual BSI conference, including liaising with speakers and Chairs, registering delegates on the day and answering any queries, assisting Chairs of conference sessions as necessary.

 Attendance of scientific conferences in-order to promote the journals and to act as a BSI representative.

### **VOLUNTARY POSITIONS**

08/2020 – Present: British Science Association – Council Member (Trustee) including Member of the Finance and Resources Committee

### **OTHER SKILLS AND TRAINING**

I have attended courses run by external training companies on:

- Institute of Management and Leadership accredited Emerging Managers Course
- Media training and public speaking
- Clinical Trials Management
- Clinical Trials Regulatory Environment
- Minute writing
- Writing with impact
- Chairing successful meetings
- Time Management
- · Scientific writing and fine editing
- Statistics
- Presentation skills
- Home Office Licence for work on small animals (modules 1 − 3)

### Other skills I possess are:

- Highly computer literate with both PC and MAC, with advanced knowledge of Microsoft Programs such as Word and Excel and specialist statistics software such as GraphPad Prism and SPSS. Also very experienced in Research Grant Management Systems including JeS, Siebel, eGrants, CC Grant Tracker, AS400, eGMS.
- Project Management experience including proficiency in the use of MS Projects software
- Experience of setting up new software systems, including databases, websites and bespoke programmes, including setting up the ResearchFish research evaluation system.

### **REFERENCES**

Available on request

# NOMINATION AND ELECTION OF OFFICERS OF THE STROKE ALLIANCE FOR EUROPE FOR APPROVAL

**Hariklia Proios** 



### **SAFE President Application Form**

Full name: HARIKLIA PROIOS

Name of member stroke support

organisation:

HAS-sso.

Position held in member stroke support

organisation:

VP

Country of member stroke support

organisation:

GREECE.

Please explain, in a maximum of 250 words, why you are interested in the position of President of SAFE giving brief details about your background, reasons for standing, what skills and knowledge you can bring and your suitability for this role. In doing so, please make reference to the person specification and role description

Having a background in organizing support groups for more than 25 years and having worked on stroke related rehabilitation in academic, research and clinical setups in the US and Europe, I have seen individuals, families, and communities at their best as well as at their worst, being stagnant, and defenseless. This is why I feel it is so important to keep empowering SSOs throughout Europe with the knowledge and guidelines needed to motivate them and to make extraordinary differences. When I look at what SAFE has achieved so far, I fully realize how likeminded, dedicated members and staff that are passionate for their work can translate their individual efforts into a synergy of service to SAFE and to the Stroke community at large.

Good governance is crucial for SAFE at the association and at the European level. Dealing methodically with complex issues, setting high standards and converging in parallel with a clear-cut setting of priorities and goals is very important. This past year, as President -Elect I have been working closely with Jon Barrick, the President of SAFE and with Arlene Wilkie, SAFE's Director General to learn more and to understand better the role and the challenges of the position.

If given this honour and opportunity to be President of SAFE, my dedication will be to strategically develop a sustainable SAFE as well as continue to honour its culture. I plan to continue Jon's legacy and to keep the current momentum going by ensuring that all mission objectives are met. I believe that this is achievable in close collaboration with all stakeholders for the benefit of the Stroke community in Europe.

I confirm that the information contained in this application is correct.



Signature:	Harklin Roms	Date:	27-9-2020	

Once completed please return this form to the SAFE Secretariat at info@safestroke.eu

### Completed application forms must be received by 6 October 2020

Documents you need to submit together with your application		
	A letter from your stroke support organisation supporting your nomination	
$\boxtimes$	A recent curriculum vitae.	