

# Members meeting

Dublin 12th March 2024

## **Members meeting 12<sup>th</sup> March 2024**

After the European Life After Stroke Forum in Dublin on 11-12 March, we brought together our members to discuss the ELASF, provide an update on members activities and an update on SAFE's planned activities in 2024.

We also welcomed Heart to Heart for Bulgaria for their first meeting.

**These are the key things that the members liked about the ELASF:**



- Good connection between professionals and stroke survivors
- Good mix of sessions and networking time
- 1.5 days worked better than just one day
- The balance of science, practice, lived experience was great and is unique

**These were the key things the members suggested we consider for future ELASF events:**

- Ensure more European healthcare professionals presenting at the plenary and parallel sessions
- Improve visibility of the ELASF in Europe
- Ensure good worldwide attendance - from Canada and Australia for example
- Abstracts published in an academic journal
- Publish - white paper, policy type documents / position statements
- Have a press corner in Prague
- Translation in Czech
- List of participants in advance to use to set up meetings
- Summary of take-home messages of all the sessions – be clear on what we are learning from each session
- Plenary at the end?
- SAFE brand more present
- SAFE stand
- Members area – space to talk to our SSOs

**We also asked the members to share topics they would like to see on the programme for future ELASF events:**

- Life after stroke in women / diversification / geography
- New technology / AI
- Finance / poverty
- Men and women's approach to having a stroke
- Travel and stroke
- Aids and adaptations
- Social reintegration systems
- Breakdown of identity
- PPI in research/guidelines
- The new Stroke Action Plan for Europe
- Lecture from a family caregiver
- Relationships (Note: this has been covered in the 2022 webinar, the ELASF 2023 and 2024)
- Driving after stroke (Note: this was covered at the ELASF in 2023)
- Peer to peer support (Note: this was covered in the ELASF 2024)
- Diet (Note: this was covered at the ELASF in 2023)
- SSOs and fundraising (Note: potentially not an ELASF topic but could be covered elsewhere)

**Each member was then asked to provide a short update on their priorities for 2024**

Bulgaria (Stroke and Aphasia Association)

- Working on free rehabilitation services that are scalable
- Have launched an infobot – to allow free access to resources needed by everyone on prevention, stroke awareness and LAS

Bulgaria (Heart to Heart for Bulgaria)

- Working to increase state awareness of stroke

Catalonia

- Working on PROMs/PREMs within the ABRIC programme
- Instructor interview to gain access to data – to compare with Europe
- Mapping all services in Catalonia to ensure equal access

Croatia (Croatian Stroke Society)

- World Stroke Day – LAS webinar for all caregivers, allied healthcare professionals
- Organised two medical conferences

Czech Republic (CEREBRUM)

- Community programme, peer support, patient meetings, translations of brochures for carers
- Signed SAPE declaration in autumn, meetings with politicians and the Neurological Society to take this further

### Cyprus

- National stroke conference with Ministry of health - half scientific and half LAS

### Denmark

- Updating their national stroke plan
- Conducting a 5-year project focusing on social inequalities
- Funding a PhD study of stroke data
- Holding a conference for stroke coordinators in community
- Providing more rehabilitation for people with aphasia
- Have a well-visited online community

### Estonia

- Building processes, rehabilitation programmes and how to get there
- SAPE update
- Building a stroke competence centre

### Greece

- Carrying out research: neuro-assessment and acute stroke and burnout in caregivers

### Iceland

- Holding conversations between patients and HCPs and authorities on the SAPE in Iceland

### Ireland

- Campaigning to increase funding for the voluntary sector
- Implementing a new case management system – digitising patient support
- Developing their new organisational strategy
- Developing their patient champion programme

### Israel

- Launched a rehabilitation rights campaign – advertising rights for life
- Established a WhatsApp community for young stroke survivors
- Implementing and promoting SAPE

### Luxembourg

- Developing a national stroke plan in line with the SAPE
- Focusing on patient work and peer to peer contact
- Holding events: sports, singing, prevention and education for patients
- Collated and released 10 videos of patient testimonies to support their 10<sup>th</sup> anniversary

### North Macedonia

- Held a rare cases of stroke ESO meeting
- Recruiting students and speech therapists to reduce in equality of access to speech and language therapy

### Norway

- Conference for young stroke survivors
- Conference plan for stroke survivors and carers

### Portugal

- Improving online information to survivors and carers
- Providing an online course for carers
- Providing psychological support
- Growing their support groups – they now have 19 in Portugal
- Providing adaptive sailing for stroke survivors
- Prevention – in schools

### Romania

- Increasing awareness using the FAST Heroes campaign
- Raising awareness of FAST in private companies
- Working on a project with Marina Charalambous/Cyprus SSO about aphasia
- Working with the MoH to secure more finances for thrombectomy

### Slovenia

- Supporting 26 clubs
- Hold events on European and World Stroke Days
- Working with the MoH to raise awareness of stroke

### Spain

- Expanding inclusion project giving support to families with resources to improve QOL
- Focusing on prevention

### Sweden

- Focus on young people – conference

### Turkey

- Social media network – set up
- EU project to increase awareness of stroke
- Hosting webinars and public announcements about prevention

### UK (Stroke Association)

- Launching advocacy campaign focusing on LAS and a 6 months review and access to a key worker
- Continue to grow support they can offer
- Focus on the NHS health system delivering LAS

### UK (Different Strokes)

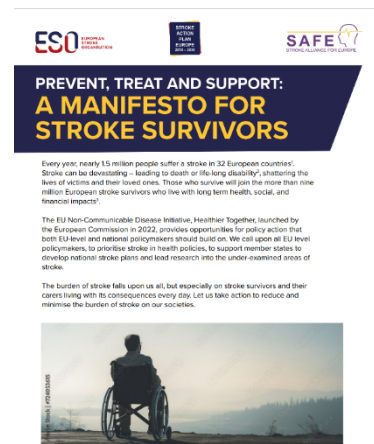
- 2-3 face to face events
- Renewing and updating written information
- Introducing online virtual meetings for carers
- Received a bursary fund to partner with 12 rehab centres to provide subsidised services

**Arlene Wilkie and Anna Scott then gave a brief update on SAFE key activities in 2024:**

### **Strategy – United Together**

We have launched our new strategy – United Together. It sets our new vision, mission and goals for the next five years. You can find all the information here: <https://www.safestroke.eu/our-strategy-the-need-our-vision-for-change-and-how-we-well-get-there/>

### **MEP elections and our new manifesto**



After a very successful event in Strasbourg in December where SAFE and ESO met 35 MEPs to discuss CVH and stroke, on 18 March we will launch our new manifesto for stroke for the build-up to the MEP elections in June. We ask MEPs to support stroke initiatives at the EU level and support national stroke plans at the national level. We will ask SAFE members and Stroke Action Plan for Europe national coordinators to contact MEPs, to use our manifest and ask them to support stroke during their election campaigns. Find out more here: <https://www.safestroke.eu/whatwedo/mep-election-2024/>

We intend to launch the new Stroke Action Plan for Europe, which is currently being updated, at the end of the year in Brussels.

### **SAFE 21**

SAFE will turn 21 years in 2025 and we will use the opportunity to raise awareness, engagement and support for Stroke Support Organisations in Europe. We proposed to celebrate our collective achievements in improving stroke treatment and care for stroke survivors.

## SAVE THE DATES

- 14 May 2024 – European Stroke Awareness Day – with a focus on stroke services across Europe (based on the Stroke Action Plan for Europe stroke services tracker)
- 10 June 2024 – Stroke Action Plan for Europe – update webinar
- 17 June 2024 – General Assembly – webinar
- October 2024 – Prevention website update for World Stroke Day
- 2025 – SAFE's 21<sup>st</sup> anniversary year
- 10-11 March 2025 – ELASF in Prague

