SWEDEN

LIFE AFTER STROKE

SMIL - STROKE MITT I LIVET

STROKE IN THE MIDDLE OF LIFE - HOW TO COME ATTRACTIVE?









CHALLENGE: BECOME ATTRACTIVE TO YOUNGER STROKE SURVIVORS

- THE MAJORITY OF MEMBERS ARE OF WORKING AGE, BUT MOST ARE OLDER
- LOW NUMBER OF YOUNG PEOPLE IN WORKING AGE IN THE BOARDS OF OUR ASSOCIATIONS
- PROBLEMS TO APPOINT BOARDS, A THREAT TO THE LOCAL SOCIETIES' SURVIVAL
- UNATTRACTIVE ACTIVITY FOR YOUNGER STROKE SURVIVORS.
- COMPETITION FROM SOCIAL MEDIA
 - "WHY SHOULD I BE A MEMBER, GET ALL THE SUPPORT THROUGH FACEBOOK"



OUR PLANS TO MEET THE CHALLENGES

- PEER SUPPORT
- FACE TO FACE SERVICE
- ATTRACTIVE ACTIVITY FOR YOUNGER STROKE SURVIVORS
- MORE FOCUS ON ISSUES THAT CONCERN YOUNGER STROKE SURVIVORS
- BE PROUD OF AND TALK MORE ABOUT ALL THE INTEREST-POLITICAL SUCCESSES WE HAVE
- USE SOCIAL MEDIA IN A SMART WAY





SAFE REGIONAL CONFERENCE STOCKHOLM JUNE 2019



RAISING STROKE AWARENESS CONFERENCE 2019 under the Global Activities for the World Stroke Day

Cyprus Stoke Association in collaboration with the Department of Rehabilitation Sciences at the Cyprus University of Technology, HOSTED a stroke awareness day conference.

The conference was held under the Global Activities for the World Stroke Day (29th of October) and the promotion of the Burden of Stroke Report of the Stroke Alliance for Europe.









Annual CSA Marathon and Triathlon March 2019







European Stroke Awareness Day Event 2019 Annual Stroke Survivors Swimming Contest May 2019







European Stroke Awareness Day Event 2019 CYCLING EVENT







European Stroke Awareness Day Event 2019















CSA APHASIA COMMUNICATION GROUPS 2019

Aphasia conversation and communication group in collaboration with the Cyprus University of Technology









Marika Railila, Finnish Brain Association



Our goal: stroke rehabilitation has to meet real needs

- The Finnish Brain Association (FBA)urges Finland's new decision-makers to remedy the flagrant inequality in stroke rehabilitation.
- In Finland, access to rehabilitation is arbitrary and depends on both the affected person's domicile and age. Those over 65 are the most disadvantaged.
- Overall situation is poor: only 10–20 percent of stroke victims are referred to multiprofessional rehabilitation. That is less than half of those who need rehabilitation.
- Those affected by aphasia are also in a difficult position. Therefore, the FBA
 demands that people with a speech impairment also be provided with
 immediate, appropriate therapy and the possibility to express themselves.



Finding the ways to make a change

- We have called together Brain and Stroke group in Finnish Parliament. It has members from all political parties.
- They are going to be best informed MPs concerning matters in stroke and aphasia.
- One of the tools we can use to educate MPs is Stroke Action Plan for Europe. We are now having it translated in finnish.





In politics, money talks!









SAFE REGIONAL CONFERENCE ON 26TH JUNE 2019 STOCKHOLM

WEHEABERDERORFLATIR OKE INCMARING PUMBELUSAND ANITHEOSOLUNFIRYLANDGUSEDTHIS ORROPTOWERFUR BOMFIBURDATION ARTHESS OF THEA FIRMST SKECKEN DEASTONDEKE!



SAFE REGIONAL CONFERENCE ON 26TH JUNE 2019 STOCKHOLM



EMERGENCY LINE

112

HEILAHEILL HAS RELEASED AN APP IN SMARTPHONES WITH INFORMATION ON THE FIRST SIGNS OF STROKE. AND WHEN IT IS INSERTED IN THE BEGINNING YOU PLACE YOUR SOCIAL SECURITY NUMBER, IT MAKES IT YOUR PERSONAL SAFETY BUTTON TO THE EMERGENCY LINE AND THEY POSITIONING THE DEVICE WITH PRECISION. THE SMARTPHONE TELLS WHO IS CALLING FOR HELP, AGE, GENDER, WHEREVER YOU ARE IN THE COUNTRY!





WHEREVER YOU ARE! USE THE APP!

THE BENEFITS OF TPA IN PATIENTS WITH ACUTE ISCHEMIC STROKE ARE TIME-DEPENDENT, AND GUIDELINES RECOMMEND A DOOR-TO-NEEDLE TIME OF 60 MINUTES OR LESS. PROFESSIONALS IN ICELAND SAY THE AVERAGE HAS DROPPED FROM 80 MINUTES TO 25 MINUTES IN THE LAST THREE YEARS!

Heilaheill

SAFE REGIONAL CONFERENCE ON 26TH JUNE 2019 STOCKHOLM



ICELAND

ANY QUESTIONS?

THANK YOU!

Heilaheill

ISRAEL

The problem: How to ensure a steady cash flow to stroke survivors social clubs

Existing situation: We run 14 clubs whose regular budget depends on our ability to raise funds every year from foundations, donors and drugs companies. An ability that changes from year to year and puts at risk the ability to run them over time

Poor municipalities are unwilling to budget for the activities.

The Solution: We invest a lot of focused work each year in 2 clubs. We identify the stakeholders at each municipality, the government and the health system level, set up steering committees and do lobby work to ensure that the community will take the responsibility and finances the activity for long term.

The results:7 out of 14 clubs are regularly budgeted by the municipalities and the government by the end of this year!

And we are moving on





NORSK FORENING FOR SLAGRAMMEDE (NFS) The Norwegian Association for Stroke Survivors www.slagrammede.org

ACTIVE ORGANISATION

- Growing membership
- More local clubs



NORSK FORENING FOR SLAGRAMMEDE (NFS) The Norwegian Association for Stroke Survivors www.slagrammede.org

Main aim:

- 1. Information about stroke
 - Open meetings
 - Neurologists
 - Local health personnel
 - Stroke survivor
 - Membership magazine
- 2. Help stroke survivors and their families
 - Peer work
 - Local clubs activities
- 3. Research
 - Through National Foundation
 - Doctor degree



Portugal AVC - Union of Stroke Survivors, Familiars and Friends

is living its 3rd year

With big tasks:

- to participate in stroke prevention;
- to contribute to a response to the needs of survivors and caregivers.

In three fundamental axes:

- Information
- To be a voice
- Mutual help
 - ✓ at distance
 - ✓ locally through GAM (help groups)

Helping to live better after stroke!







- We already have a national dimension
- With various activities, in different parts of the country
- Always in total volunteering
- And, often, with protagonism of the stroke survivors





Also having difficulties

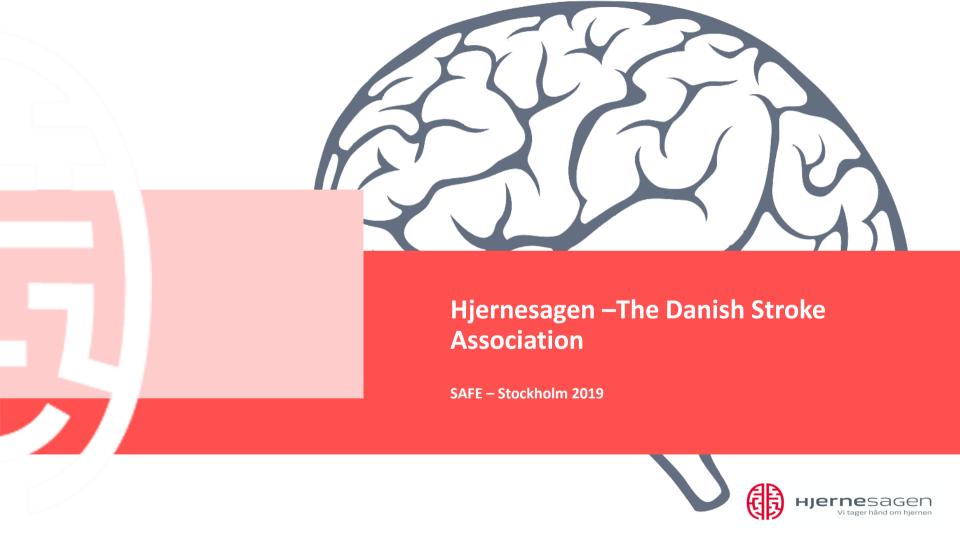
- We feel more and more the need for permanent support
- Each place has its autonomy
 The "standardization of principles" is not always easy
- The difficulty in attracting stroke survivors to participate in a few "GAMs" (help groups)



In the next months

- Continue and expand our current activity
- Launch more activities with the protagonism of stroke survivors
 Motivating them, valuing their work, making them feel useful to society

Thank you and see you soon



The Danish Stroke Association

- Was founded 1994 25 years jubilee 2019!
- 9.500 members (DK: 5,7 mil. inhabitants)
- Address Høje –Tåstrup, together with 35 other NGOs



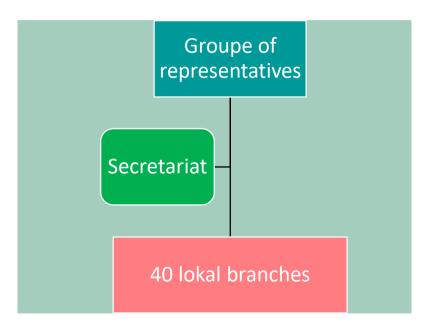






The Danish Stroke Association

- National President: Lise Beha Erichsen
- 40 local branches





Our goal:



- Preventing strokes
- Improving treatment and rehabilitation
- Supporting stroke victims and their family /bystanders



How do we work:

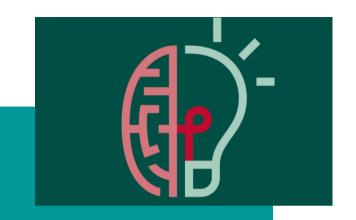


- Lobbyism
- Campaigning: "Hjernen er hovedsagen", May 10th National blood pressure day
- Help-line
- "HjerneSagen" magazine
- Educational activities for members and professionals



Our main political issues:

- Preventing strokes
- Stroke Units high quality for all!
- Nothing about me with out me!
- National standards for rehabilitation
- Data driven quality assurance
- Better rights for family /bystanders





Følg Hjernesagens daglige arbejde



Se nyheder, aktiviteter m.m. på Facebook



Læs relevante nyheder på LinkedIn



Følg med i vores aktiviteter på Instagram



Bland dig i debatten på Twitter



Med din støtte kan vi gøre en forskel. Støt via MobilePay på 85727



Activity of Polish Stroke Fundation 2019











Iprevent.pl / www.zapobiegam.pl









Running events







Stroke Magazine 1in6









Cooperate with government









National Stroke Prevention and Rehabilitation League

HUNGARY

András Folyovich MD PhD Katalin Anna Béres-Molnár





STROKE SCREENING DAY – BUDAPEST 12. DISTRICT - SZENT JÁNOS HOSPITAL











Twice a year (spring and autumn)

PUBLICATIONS







Edynck A. Black A. Marier, A. Berden A. Marier, E. Zaige E. Laker, B. Valed K. Stocks prevention. A population screening day in district XII of Budapest Storle prevention. In Section 1982, p. 1888, p.

10.000 primace-rown annual control of the February and th





Guideline clinical nutrition in patients with stroke

Bainer Wirth^{1,27}, Christine Smoliner¹, Martin Jäger², Tobias Warnecke⁴, Andreas H Leischker⁵, Rainer Dziewas⁴

Kenwede Dorobania Guideline Strole Tube feeding

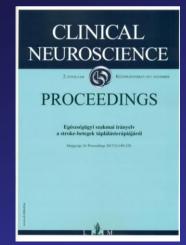
Introduction
In the acute stage of strake 30 to 50% of paintst sulfer:
by the DGIM. Six working group nectures were rowered to the control stage of strake 30 to 50% of paintst sulfer:
by the DGIM. Six working group nectures were read by the paint of the paintst sulfer:
by six monde later. Alfried patients are not only
to see such was last updated December 33, 2011. The
transport to deleptration and malaurituous burse also sat an infollowing the shakes were screened for relevant Horsztone stages. tocresed risk of acquiring aspitation presumonia. Seeturn: Medium/Pubbled. National institute for Hodrin and
studius have shown the risk for this complication.

Gail Lindeane (sow-south, pagin). Exclude places and the processing of the control related desphagia and a suitable nutritional management included to the literature search: stroke AND nutrition is therefore of utmost clinical importance. NOT prevention; intracerebral bleeding AND nutrition; stroke AND prev²; stroke AND enabse²; stroke AND gaste², stroke AND tube feeding; stroke AND enteral feeding, stroke AND nutritional supplements²; stroke

Methodology Authors are representatives of three German medical so-cieties: the German Society for Clinical Nutrition (DGEM), the German Society for Neurology (DGN) and the German Genstric Society (DGG). All guthers worked on an honorum

AND eral supplement", stroke AND aspiration; stroke AND dysphagis, stroke AND maleutrition; stroke AND undernatrition; stroke AND swallowing; stroke AND in-fections, stroke AND gastric medialry; natrition AND rehabilitation; matrition AND persons soon; natrition AND quality of life; nutrition AND infections; nutrition

CLINICAL **NEUROSCIENCE PROCEEDINGS** Stroke-irányelygyűjtemény Az akut ischaemiás stroke diagnosztikájáról és kezeléséről A nem traumás intracerebralis vérzések diagnosztikájáról és kezeléséről Az akut ischaemiás stroke/TIA szekunder prevenciójáról A stroke-betegek táplálásterápiájáról Az ontimális betegkiválasztást támogató képalkotó diagnosztika alapelyei akut ischaemiás stroke-ban



After stroke the incidence of ...

• Malnutrition: 8.2 - 49.0 % (with diabetes mellitus 58-71 %)

Sarcopenia: 50-53.5

Dysphagia:

24.3-



STROKE AWARENESS

PRESENTATIONS in

Secondary schools (exist) General schools (planned)



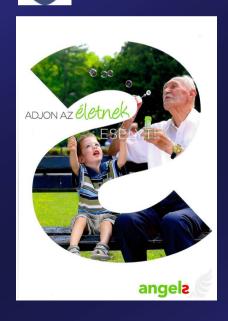




SAFE - ANGELS Kindergarten programme FAST HEROES 112











CZECH REPUBLIC

CEREBRUM

Association of People after Acquired Brain Injuires and their Families



Jana Bára-Dobrkovská



Cerebrum 2019

- Czech government has not provided any finance this year
- As an outcome the existence of our organization is in danger
- ANYWAY we do fundraising in 110 % of our time ©



Cerebrum in figures

```
Number of clients
```

2018 8

2019 28 (up to date)

Number of therapists

2018 4

2019 7

Number of volunteers

2018

2019



Caregiver Project

- Centres for brain damage, where our specialists provide advice and
- Support patients returned back to the home. Advice covers all practical issues such as where to buy
- Compensation aids, how to ergonomically adjust housing, legal counsel and support navigating
- Government social care programmes



Thank you for your attention



Medicine adds days to life...

OT adds life to days

ACTIVITIES 2019 N. Macedonia



Activities 2019 N. Macedonia





www.mld.mk







Stroke in Ukraine: Light of hope





Dmitriy Gulyayev & Roman Shwed

World Stroke Day in Ukraine: National motives and interest of nation



Getting partnership with state (UASA experts invited to Ministry of Health)



Stroke survivors: tough way from being aphatic to becoming voice of stroke community



Positive points

- Collaboration with colleagues for acute and chronic stroke treatment
- Community activities
- Implementation of MT
- Angels initiative

Next steps

- 1. Guide for national strategy
- 2. Implementation of stroke care protocols
- 3. Staff and population education
- 4. Creation of stroke network
- 5. Data registry and analysis

Need for improvement

- number of centers for acute stroke management
- acute stroke treatment (% of IVT and MT)
- DTN time
- dysphagia screening and rehabilitation assessment
- NIHSS and other stroke scales
- Neurorehabilitation center(s)
- Palliative care center(s)

CZECH REPUBLIC

STROKE ACTIVITIES 2018/2019

ERGO Aktiv neurorehabilitaion center

CHATBOT

What is stroke and description of treatment

Complex rehabilitation

Rehabilitation providers throughout CR

- Contacts
- Description of services

Means of transport for people with disability

• Including contacts on providers of the services

Social rehabilitation

- Description
- Social allowances
- Contacts



CASE MANAGEMENT

Case management as a part of consulting services

Piloting CM in 2 Prague districts

1 x week

Promoting the pilot to other districts

Case management is becoming trendy

Very limited experience







DRIVING SIMULATOR

Diagnostics and rehabilitation

- Fatique
- Time of reponse
- Split concentration
- Multitaskling

Cooperation

- CVUT faculty of biomechanical engineering
- INESAN intitute for evaluations and research
- Traffic psychologist
- Neurologist





STROKE MANAGEMENT IN ODESSA 2018

Epidemiology of CVD in Odessa 2011-2018



Jatte Jatze Jatze Jatze Jatze Jatze Jatze Jatze

→ Series1

Dynamic of hospitalization patients with TIA



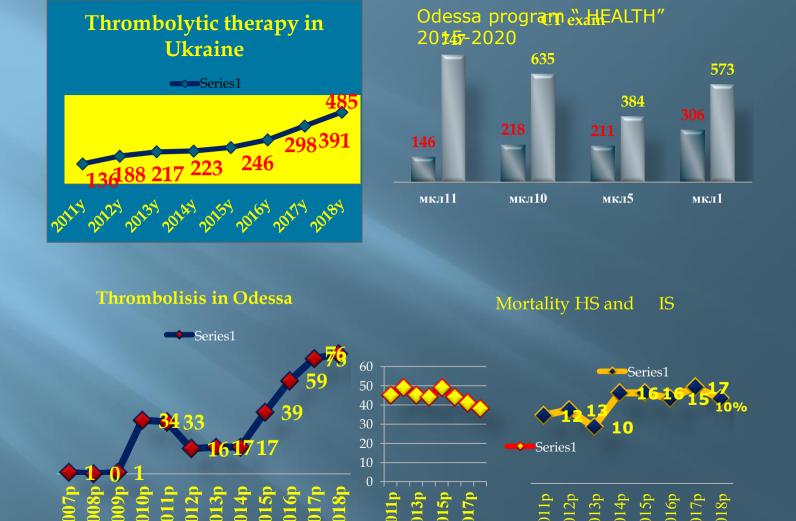
■виклики
■Госпіталізація

Dynamic of stroke

Patty Patty Patty Patty Pates Patty Pates

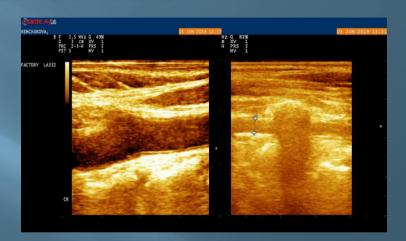
Age and gender characteristic of stroke patients





Center of TIA





aorta



In Stroke unite- 5th day



Conference stroke rehabilitation



International projects





EAN RTC











School participants recognized stroke sign and were able to help one of wisiter immediately



BRAIN WAVE(Moždani val) - ASSOCIATION for better quality of life after stroke CROATIA

Established in November 2016., Zagreb - Croatia



- Life quality improvement of stroke survivors and their families
- High awareness about meaning of stroke consequences
- Society with easy access to quality and systematically organised after- stroke help



WHY?

Because of RECOGNIZED NEED for SUPPORT AFTER STROKE in order to ease the difficulties in managing with stroke consequences, overcoming obstacles in resocialization and raising stroke awareness

HOW?

by actively informing, counseling, educating... ...researching and cooperating.. ...implementing projects, organizing and taking part

in public actions

WHO?

JOINED EXPERIENCE neurorehabilitation experts + people with personal experience with stroke



BRAIN WAVE ACTIVITIES (SO FAR...)



COOPERATION AND RECOGNITION
BY CITY GOVERNMENT – NOV 2017

www.mozdanival.hr and f





PUBLIC PRESENTATION AND MEMBERS GATHERINGS



EDUCATION-PSYCOLOGIST IN THE PROCESS OF STROKE RECOVERY



WORKSHOP FOR PEOPLE WITH APHASIA – COLLABORATION WITH THE SUVAG POLYCLINIC





COLLABORATION WITH DIABETES SOCIETY

- Stroke Awareness raising through media:
- interview for local TV Network station
- guests in local radio "Sljeme" contact broadcast regarding stroke problems
- Short TV story about stroke problems and "Brain



moždani val







Jan 2019 – BROCHURE FOR STROKE PATIENT AND FAMILIES – ALL YOU NEED TO KNOW AFTER STROKE

OUR ACTIVITY CHALLENGES - ?!







www.aliceitalia.org

A.L.I.Ce. Italia: ongoing projects at Institutional level - ESAP

Claudio Mari, ALICe Emilia Romagna

On behalf of

ALICe Italia Onlus

ALICe Italia Onlus



- Concept: federation of local, regional SSOs acting at different level
- National Level: Collaborate with policymakers and national and regional institutions to promote health rights implementation policies
- Examples: "The Italian Alliance for Cardio-Cerebrovascular Diseases"







Ictus, Al via l'Osservatorio italiano, E in Affari Sociali alla Camera si lavora a una risoluzione ad hoc

Le novità sono state presentate nel corso di una conferenza al Senato. L'osservatorio è stato lanciato dall'Associazione per la Lotta all'Ictus Cerebrale (A.L.I.Ce.) e dall'Intergruppo Parlamentare sui problemi sociali dell'Ictus. Resi noti i risultati del primo screening di prevenzione sui parlamentari italiani: all'86% dei 334 che si sono sottoposti agli accertamenti è stato consigliato di cambiare stile di vita oppure di approfondire gli esami.

> oz LUG - Al via l'attività dell'Osservatorio Ictus Italia, presentato oggi in una conferenza stampa al Senato, con l'obiettivo di promuovere interventi di carattere normativo, legislativo, tecnico ed economico in materia di prevenzione e cura. Il progetto è stato promosso dall'Associazione per la Lotta all'Ictus Cerebrale



(A.L.I.Ce.) e dall'Intergruppo Parlamentare sui problemi sociali dell'Ictus, con la partecipazione di Italian Stroke Organization (I.S.O.) e European Stroke Organization (E.S.O.). Il pilastro dell'iniziativa risi de nell'informazione, dato che sono in pochi a sapere che l'ictus non solo si può curare, se tempestivamente trattato, ma nell'80% dei casi si può addirittura prevenire. Ogni anno in Italia si registrano guasi 200mila nuovi casi di ictus cerebrale, di cui circa 10.000 riguardano soggetti di età inferiore ai 54 anni, responsabili del 10-12% di tutti i

Osservatorio Ictus Italia

Joint initiative:

- A.L.I.Ce. Italia Onlus.
- Parliamentary Intergroup on Social and Health Issues related to stroke
- **European Stroke Organization**
- **Italian Stroke Organization**
- National Institute of Health: the Department of Cardiovascular, Dismetabolic and Aging
- Italian Society of General Medicine and Primary Care

Implementation of best clinical practice in stroke care

Standardize the care in Italian regions

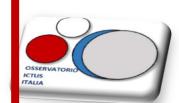
Improve access to care in all Italian Regions: overcome social and gender disparities

Promote stroke research

Through

institutional activities and lobbying





To do list:

- Creation of a local implementation working group within the Osservatorio lctus Italia
- Translate documents
- Disseminate the documents (web, social networks, media)
- Joint action with professional organizations and regional and national institutions

The ESAP In Italy



What has been done till now?

- ✓ ESAP rehabilitation domain presented during meeting at MoH on new ministerial order about rehabilitation (Nicoletta Reale, Fabrizio Pennacchi)
- ✓ Press release about ESAP in June (Nicoletta Reale, Danilo Toni, Valeria Caso, Francesca Romana Pezzella)
- ✓ Create a National group of implementation in collaboration with European group with A.L.I.Ce. Italia Onlus, Parliamentary Intergroup on Social and Health Issues related to stroke Italian Stroke Organization National Institute of Health: the Department of Cardiovascular, Dismetabolic and Aging Italian Society of General Medicine and Primary Care

ESAP in Italy.....what would you suggest?

We are here to collaborate!!

Slovenian Stroke Support Organisation May activities

J Janša, M Čuček, T Erjavec



Activities:

- Posters for FAST (GROM) (April 23 May 6)
- Traditional city walk in Ljubljana (May 14)
- Traditional press conference (May 9)
- Intergenerational conference (Ljubljana, May 14 -16); SSSO invited (lecture, stand)
- Exhibition in the house of elderly

Media coverage (22 hits)

Activities in photos

Posters for GROM

- 348 around Slovenia
- 2 digital posters in 2 main Ljubljana streets



City walk: 258 participants, preventive measures, Mayor's speech







Art exhibition in House for Elderly by mr. Rupnik

UK



Campaign on PFO Closures

- In collaboration with a technological manufacturing company, running campaign to raise awareness of this issue
- Aim is to get funding reinstated by NHS England
- Will benefit stroke survivors, Different Strokes, and our partner



Multi-stranded campaign:

- Info on our website and social media channels
- E-mail blast to 2,600 neurologists and cardiologists
- Featured in our newsletter
- Radio interviews







SPAIN



Paris, 09 de May 2019



The Spanish Stroke Federation is a nationwide, non-profit organization, founded in 2006.

This year participates in the following programs or projects.

Generation Invictus. An educational campaign for women and for women. **FEI-Boehringer Ingelheim**

Knowledge and attitudes about stroke in primary care physicians. **FEI-SEMG** Spanish Society of General and Family Doctors.

#We speak, project to see the needs of stroke patients and their families, through web surveys, social networks, emails. **FEI-SEDENE** Spanish Nursing Society.

FEI Participation as Advisory Council with the Spanish Network of Health Technology Assessment Agencies, of the Ministry of Health of Spain.

Serious games for health and sports, two scholarships to participate in the School of new interactive technologies.



Contact details

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Contact person: Carmen Aleix



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@ictusfederacion



Federación Española de Ictus



www.facebook.com/ictusfederacion



Activities of HAS-SSO Greece





Greek Translation of Stroke Plan 2018-2030

Το Σχέδιο Δράσης για τα Αγγειακά Εγκεφαλικά Επεισόδια στην Ευρώπη 2018-2030





The Hellenic Neurological Society, the Hellenic Society of Cerebrovascular Diseases and the HAS-SSO organized an event at Athens (Crowne Plaza Hotel), 8th & 9th March 2019 in order to promote the foundation of stroke units at the Greek Hospitals.

Invited speaker: Ulrike Waje – Andreassen (Norway) She established the ESO Stroke units certification process



HNS SCIENTIFIC BRANCHES	11th SCHOOL OF THE HELLENIC NEUROLOGICAL SOCIETY, 08-09 MARCH
NEUROLOGICAL CLINICS & DEPARTMENTS	2019, STROKE UNITS
NEUROLOGICAL CLINICS ANNOUNCEMENTS	
HNS SCHOLARSHIPS	Download the programme here
EDUCATIONAL MATERIAL	
USEFUL LINKS	
THIRD-PARTY ANNOUNCEMENTS	

FUNDACIÓ ICTUS

CATALONIA

In 2018:

- 1. World Stroke Day '18:
 - 1.1. Gospel concert
 - 1.2. Presentation of RAPID Campaign
- 2. Press releases about:
 - 2.1. Prevention (9 out 10 strokes are due to modifiable risk factors)
 - 2.2. Rehabilitation (Stroke in young women in working age)
- 3. Social media: Twitter and Facebook



Follow us @Fundacioictus

FUNDACIÓ ICTUS

RAPID Campaign

Stroke awareness campaign focus on kids, starred by superheroes who lost their superpowers:

- (1) Roger smile
- (2) Arnau strength
- (3) Paquita sing
- (4) Dani fast





In 2019:

- 1. New headquarters
 - *New address: Aribau, 162-166, entl K
- 2. New managing director
- 3. Redefine strategy of the organization
- 4. Redefine strategy of communication

Northern Ireland Chest Heart & Stroke



WE'R ON YO SIDE Chest Heart& Stroke

Current challenges & opportunities

- Re-Shaping of Stoke Services in Northern Ireland Consultation Closing July 2019
- Partnership and structured collaboration across 3rd Sector and the Health and Social Care System – regional consistency
- Referrals into existing NICHS services
- Collecting data and demonstrating impact
- Developing new services to meet the needs of Stroke Survivors
- "Taking Care" of the Carers
- Working with and not just for stroke survivors and their families





We're On Your Side







UK

Every five minutes, stroke destroys lives. Help us rebuild them.

Find out more: stroke.org.uk/RebuildingLives



The Stroke Association is registered as a charity in England and Wales (No 211015) and in Scotland (SC037789). Also registered in Isle of Man (No 945) and Jersey (NPO 369).

