

# WHY IS INFORMATION IMPORTANT & THE ROLE OF STROKE CARE PROFESSIONALS

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## *HELLENIC ALLIANCE/ACTION FOR STROKE SUPPORT ORGANIZATION -*

BOARD OF DIRECTORS. President: A Kortsaris, Vice President : N Artemis, Gen Secretary: K Vadikolias, Treasurer: D Kerameus, Members: C Piperidou, T Birbilis, A Mitsoglou PR - Regional : H Proios, A Tsiakiri P Vlotinou, D Manola, P Georgakarakou, N Foufopoulos

**Stroke Alliance for Europe (S.A.F.E.)**  
**Regional Conference , Athens, Greece**  
**June 1 2016**



# Stroke can be a lifelong chronic state

*preventative curative and rehabilitative*



# Historical Information

- President **Thomas Woodrow Wilson** (1856-1924) had a stroke in 1919 and that is why the US did not get into the **league of Nations**; the stroke disrupted his campaign and his wife, Edith, was the only one allowed to see him and speak for him. In fact, she was believed to have made many important decisions while he convalesced, but never fully recovered.
- He did not have the opportunity to make clear that the US should join the league of Nations,... which was eventually created, but without the participation of the United States. The US would not join a multinational league until after an even larger and more destructive world war forced the League to be reinvented as the **United Nations**.
- **Vladimir Ilyich Lenin** (1870-1924) had 3 sequential strokes from May 22, 1923 on and his last stroke left him communication impaired. He wanted **Trotsky** to be his successor but **Stalin** usurped power and won...
- **if they never had the strokes then history would have been rewritten**



# Strokes in Greece

- Average age in Greece around 70, similar with rest of Europe
- Frequency is similar with other Balkan and Mediterranean countries, like Spain, Portugal and Italy
- Risk factors for Greek population are hypertension, stress and smoking
- Ischemic strokes are overwhelmingly more common than hemorrhagic strokes
- Outcome depends on several factors, such as previous stroke, age, smoking and severity at onset

# Information and Stroke Groups

Research has shown benefits of group treatment over individual therapy as:

- Facilitates the transfer of functional communication skills to outside situations by improving turn-taking, conversation initiation, and increasing other communicative functions, as well as more natural activities and a variety of partners.
- May increase the participation in community life, increase psychosocial functioning and adjustment to life.
- A cost effective model for the participants.

(Elman, 1999)

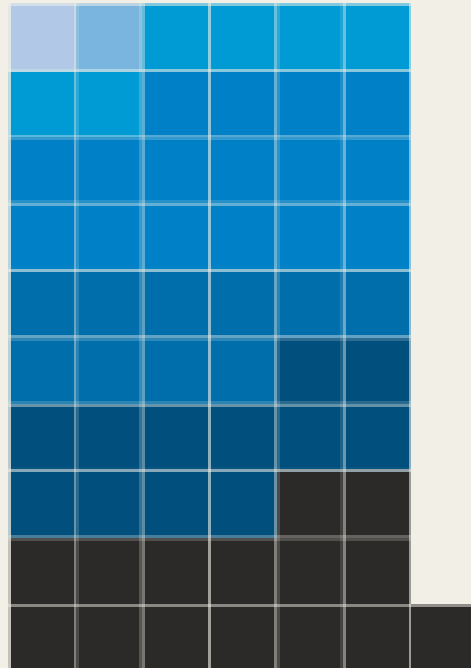
# Don't trust everything you read

## RELIABILITY TEST

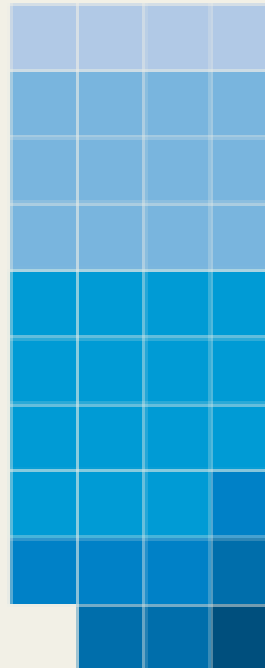
An effort to reproduce 100 psychology findings found that only 39 held up.\* But some of the 61 non-replications reported similar findings to those of their original papers.

Did replicate match original's results?

NO: 61



YES: 39



Replicator's opinion: How closely did findings resemble the original study:

- Virtually identical
- Extremely similar
- Very similar
- Moderately similar
- Somewhat similar
- Slightly similar
- Not at all similar

\* based on criteria set at the start of each study

- Nosek B. 2015  
(Nature, 2015)
- Replication issues
- Unpublished findings

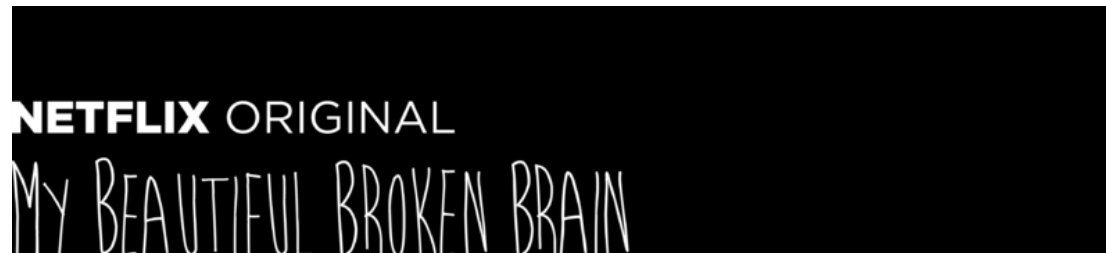
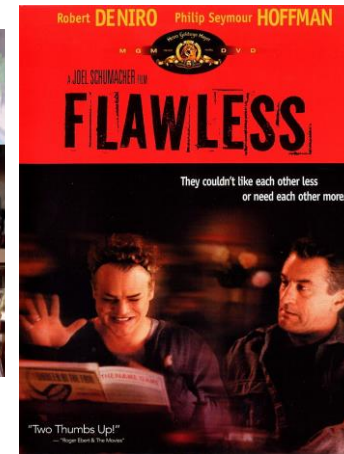
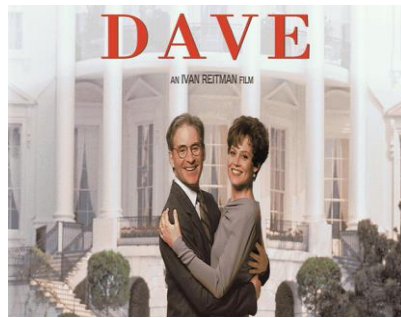
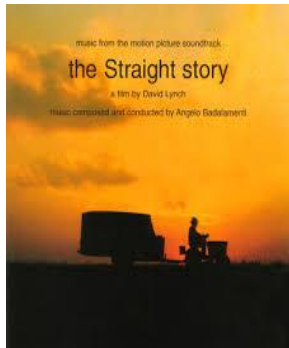
# Information exchange and online Stroke Groups

- People with stroke can benefit from the use of online forums where they can find advice and social support (De Simoni *et al.* 2016).
- Chronic patients, including patients with stroke, use online social support groups, which some times they even prefer from live groups (Owen *et al.* 2010)
- Online social support groups can also benefit the care givers of stroke patients, who can turn to these groups for information about the specific disorder, for emotional support and assistance to adapt to their role (Pierce *et al.*, 2002).
- With web-based supportive intervention, care givers were found to be more informed about disorders and could more effectively communicate with their stroke patients as well as their family (Pierce *et al.*, 2002).

- De Simoni, et al.. (2016). Stroke survivors and their families receive information and support on an individual basis from an online forum: descriptive analysis of a population of 2348 patients and qualitative study of a sample of participants. *BMJ open*,6(4).
- Owen, et al. (2010). Use of health-related online support groups: population data from the California health interview survey complementary and alternative medicine study. *Journal of Computer-Mediated Communication*, 15(3), 427-446.
- Pierce, L. L., et al. (2002). In-home online support for caregivers of survivors of stroke: a feasibility study. *Computers Informatics Nursing*, 20(4), 157-164.
- Pierce, et al. (2015). Qualitative analysis of a nurse's responses to stroke caregivers on a web-based supportive intervention. *Topics in stroke rehabilitation*, 22(2), 152-159.



# Strokes in Cinema-TV





# European perspective

- Much of what is normally considered a part of therapist role in other countries is undertaken by doctors including neurologists, or neuropsychologists and linguists.
- Caring for clients from many different cultural backgrounds; also rehabilitation specialists may come from various cultures (common in Greece)
- Role of rehabilitation is diverse i.e., training experiences vary
- Stroke is shaped by culture

# Background with Support Groups

Early 1990's Creative Cognates of Princeton,

Boston Aphasia Group,

Zurich Support Group and ....

Aphasia Group of Thessaloniki....2006

Board of Directors - National Aphasia Association [www.aphasia.org/board-of-directors/](http://www.aphasia.org/board-of-directors/)

- Lynn Maher, Ph.D. Marsel Mesulam, M.D.. Shirley Morganstein, M.A., CCC-SLP. Janet Patterson, Ph.D., CCC-SLP. Richard Peach, Ph.D. [Hariklia Proios, Ph.D.](#)

ASHA Proposal Guidelines - American Speech-Language-Hearing ...

- [www.asha.org/Events/convention/handouts/2008/1685\\_Liechty\\_John\\_A/](http://www.asha.org/Events/convention/handouts/2008/1685_Liechty_John_A/)
- Collaborative Communication in *Multicultural* Aphasia Intervention. Abstract (not .... The following presenter, [Hariklia Proios, PhD](#), will provide an international ... created *Multicultural Task Force* (MTF) of the NAA, as an illustration of consumer-.

# Creative Cognates at Princeton NJ, 1990





**αφασική  
ομάδα  
ΘΕΣΣΑΛΟΝΙΚΗΣ**

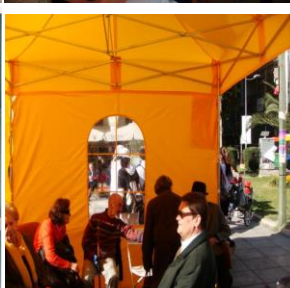
ΕΤΟΣ ΙΔΡΥΣΗΣ 2004

#### MAIN MENU

- Αρχική
- Μέλη ομάδας
- Ερωτήσεις & Απαντήσεις
- Συμβουλευτική
- Συνάντηση ομάδας
- Συνέντευξη
- Περιοδικό
- Επικοινωνία

Facebook APHASIA GROUP OF THESSALONIKI

[www.aphasia-group.gr](http://www.aphasia-group.gr)



<http://aphasia-group.gr/>

Kouki, E.P., Kosmidis, M.H., Proios, H. (2016). Gender issues among users of the internet and social media in aphasia. *Feminism & Psychology*, Submitted 2016



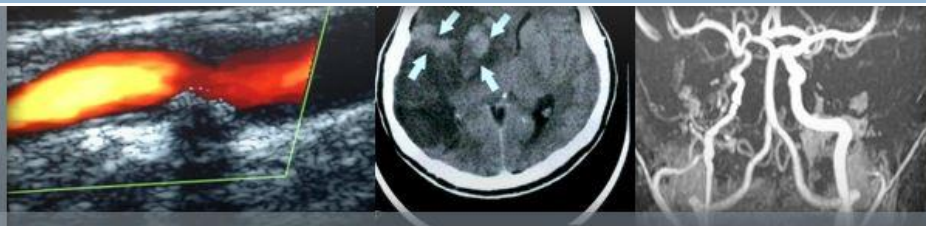


# HAS Website hosted by HSCVD



Ελληνική Εταιρεία  
**ΑΓΓΕΙΑΚΩΝ  
ΕΓΚΕΦΑΛΙΚΩΝ ΝΟΣΩΝ**

HELLENIC STROKE SOCIETY  
(HELLENIC SOCIETY OF CEREBROVASCULAR DISEASES)



ΑΡΧΙΚΗ ΣΕΛΙΔΑ

Η ΕΤΑΙΡΕΙΑ

ΕΠΙΚΟΙΝΩΝΙΑ

ΠΩΣ ΘΑ ΜΑΣ ΒΡΕΤΤΕ



## ΤΕΛΕΥΤΑΙΑ ΝΕΑ

- ▶ 6ο ΠΑΝΕΛΛΗΝΙΟ ΣΥΝΕΔΡΙΟ  
4-6/3/2016
- ▶ ΝΕΔΑΦΙΣΡ- ΠΡΟΓΡΑΜΜΑ  
ΠΡΟΛΗΨΗΣ ΚΟΛΠΙΚΗΣ  
ΜΑΡΜΑΡΥΓΗΣ ΚΑΙ ΑΕΕ
- ▶ ΔΡΑΣΤΗΡΙΟΤΗΤΕΣ
- ▶ ΠΑΓΚΟΣΜΙΑ-ΗΜΕΡΑ-ΑΕΕ
- ▶ 5ο ΠΑΝΕΛΛΗΝΙΟ  
ΣΥΝΕΔΡΙΟ,ΘΕΣΣΑΛΟΝΙΚΗ  
8-9/3/2013
- ▶ 4ο ΠΑΝΕΛΛΗΝΙΟ ΣΥΝΕΔΡΙΟ -  
ΒΙΒΛΙΟ ΠΕΡΙΛΗΨΕΩΝ,ΦΩΤΟ
- ▶ ΚΑΤΕΥΘΥΝΤΗΡΙΕΣ ΟΔΗΓΙΕΣ
- ▶ ΠΑΝΕΛΛΗΝΙΑ ΣΥΝΕΔΡΙΑ ΤΗΣ  
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ΟΔΗΓΟΣ ΓΙΑ ΤΟ  
ΕΓΚΕΦΑΛΙΚΟ
- ▶ ΕΛΛΗΝΙΚΗ ΣΥΝΕΡΓΑΣΙΑ ΓΙΑ  
ΤΑ ΑΕΕ - HELLENIC  
ACTION/ALLIANCE FOR  
STROKE

## ΕΛΛΗΝΙΚΗ ΣΥΝΕΡΓΑΣΙΑ ΓΙΑ ΤΑ ΑΕΕ - HELLENIC ACTION/ALLIANCE FOR STROKE

### STROKE ALLIANCE OF EUROPE - REGIONAL MEETING

**ATHENS, 1 JUNE 2016**

### ΕΛΛΗΝΙΚΗ ΣΥΝΕΡΓΑΣΙΑ ΓΙΑ ΤΑ ΑΕΕ

### HELLENIC/ACTION FOR STROKE

**Συμμαχία - συνεργασία για το εγκεφαλικό** με τον Ευρωπαϊκό Οργανισμό (S.A.F.E.) αλλά και ελληνικές επιστημονικές εταιρείες όπως η Ελληνική Νευρολογική Εταιρεία και η Ελληνική Εταιρεία Αγγειακών Εγκεφαλικών Νόσων, φορείς, επαγγελματίες υγείας, εθελοντικές δομές υποστήριξης, φροντιστές και ασθενείς. Στόχος είναι να καταβληθεί συντονισμένη προσπάθεια τόσο για την ενημέρωση και εκπαίδευση του κοινού σχετικά με την **πρόληψη, έγκαιρη διάγνωση και αντιμετώπιση** ενός εγκεφαλικού επεισοδίου όσο και στις αρμόδιες αρχές και φορείς που χαράσσουν την πολιτική υγείας για την **καλύτερη οργάνωση των υπηρεσιών υγείας** για την αντιμετώπιση, φροντίδα και αποκατάσταση του ασθενή με εγκεφαλικό σε εθνικό επίπεδο.

Περισσότερες πληροφορίες σύντομα

# The role of stroke care professionals

## TEAM EFFORT

- ❑ Resource for peer reflection
- ❑ Maximize motivation in victims and families (increased confidence means generalized success)
- ❑ Analyze one's own assumptions and values
- ❑ Maximizes Quality of Communication within community and Quality of Care as well



# Objectives of HAS

- Greek First Response Units ( community efforts for public awareness –firefighters, banks etc)
- Task Force for Legal and Ethical Issues
- Hellenic Stroke Houses for Support
- Information Resource for Public
- Telecommunication Support
- Palliative Care Support



# Down and Dirty -Challenges

Issues that we predict will hinder HAS growth and need to be addressed in the future are

- “Greek factor” -unlikely that any major investments can be made in the next few years, in view of recent crisis and capitol control.
- Group support not so common or non-existent
- Difficulty in achieving unitary health care and trust as involvement in the organization’s structure and activities –sense of community at large

# Strengths

- Team of professionals with experience and strong interest in making this work
- members are some of the best and most active in the community and
- SAFE's thirteen years of experience and connection with groups around Europe will be very helpful to HAS

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Ευχαριστώ πολύ...

