

**JOINING FORCES:
Building networks –
Working with other organisations**

**13th European Conference on Epilepsy & Society
28th to 30th August, Ljubljana, Slovenia**

Building networks I

overview

- Compare the Networking within the doctors and the Patient associations.
- Comparing the Networking on the different continents.
- Do we need an European Epilepsy Day?
- What's needed to create a "Global Epilepsy Day"?
- Compare Epilepsy and Aids (why is Aids so funded? Why is nobody ashamed to talk about it?).

Building networks II

Doctors (ILAE) / Patients (IBE)

Item	Doctors	Patients
Language	English - University	Do all know English
Number of meetings	A lot – several national and regional, and 1 international	Some – most are national, 2 are regional and 0 international
Funding	Surplus of meetings	Do the meetings have a surplus?

Building networks III

Networking on different continents

Item	Doctors	Patients
Europe / North America / Australia	Run by doctors	Run by patients (usually) – exceptions are e.g. Georgia
Other continents (Africa, Asia, Latin America)	Both – patient and doctors associations are (usually) run by doctors – exceptions are e.g. Japan, South Korea, Taiwan.	

Building networks IV

Networking on different continents

- Joint conferences
 - Africa – 1st joint ILAE-IBE congress (Nairobi, Kenya / 2012)
 - Asia – 9th joint Asian and Oceanian congress (Manila, Philippines / 2012)
 - Latin America – 7th joint Latin American epilepsy congress (Quito, Ecuador / 2012)
- Stand up for Epilepsy
- PAHO initiative

Building networks V

European Epilepsy Day

- Is it necessary?
 - In my opinion YES
- National Epilepsy days / weeks
 - Additional awareness!
- European Advocacy Europe
- European Epilepsy day
 - Additional awareness!
 - Written Declaration passed by the European Parliament
 - This year activities in Albania, Bulgaria, Finland, Ireland, Netherlands, Slovenia, Norway, Serbia and European Parliament
 - http://www.youtube.com/watch?feature=player_embedded&v=jHKyLI7K_Ps
- European Forum on Epilepsy Research (25th – 27th May 2013, Dublin, Ireland)
 - http://www.youtube.com/watch?feature=player_embedded&v=e7tzRKwWNgc

Epilepsy
Advocacy
Europe

INTERNATIONAL
LEAGUE
AGAINST
EPILEPSY



ILAE-CEA
COMMISSION ON EUROPEAN AFFAIRS



Building networks VI

Global Epilepsy Day

- Is it necessary?
 - In my opinion YES
- When?
 - Different Epilepsy Days throughout the world
- Can the WHO be helpful?
 - Global Campaign
 - Atlas: Epilepsy Care in the World 2005
 - WHO Regional Committee Europe

Building networks VII

Global Epilepsy Day – number of hospital beds for epilepsy care

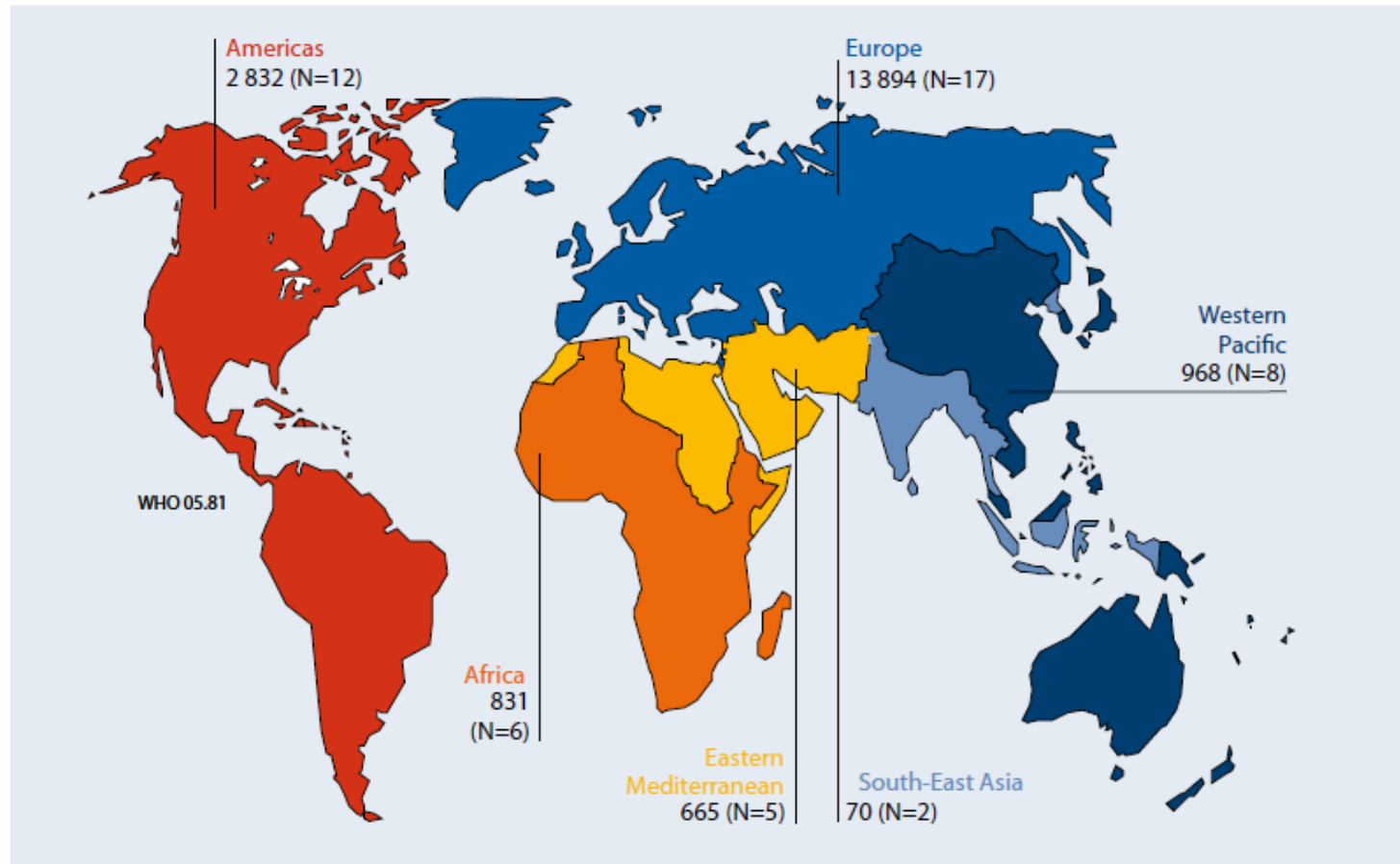


Figure 10: Number of beds for epilepsy care in WHO regions (Atlas: Epilepsy Care in the World 2005)

Building networks VIII

Comparing Aids / Epilepsy

- Aids
 - Prevalence: 33.3 Mio. (2009)
 - Global estimation of costs existing: YES
 - Government pays partly for the costs – even in low and middle income countries: YES
 - Financial donors: YES
 - Everyone talks about it!
 - Life Ball (Vienna)
- Epilepsy
 - Prevalence: 50 Mio. (2005)
 - Global estimation of costs existing: NO
 - Government pays partly for the costs – even in low and middle income countries: YES
 - Financial donors: Not known!
 - No one talks about it!
 - Where is it?

Building networks IX

Comparing Aids / Epilepsy

Financial Resources Needed Categorized by Activity Area (US\$ Million)

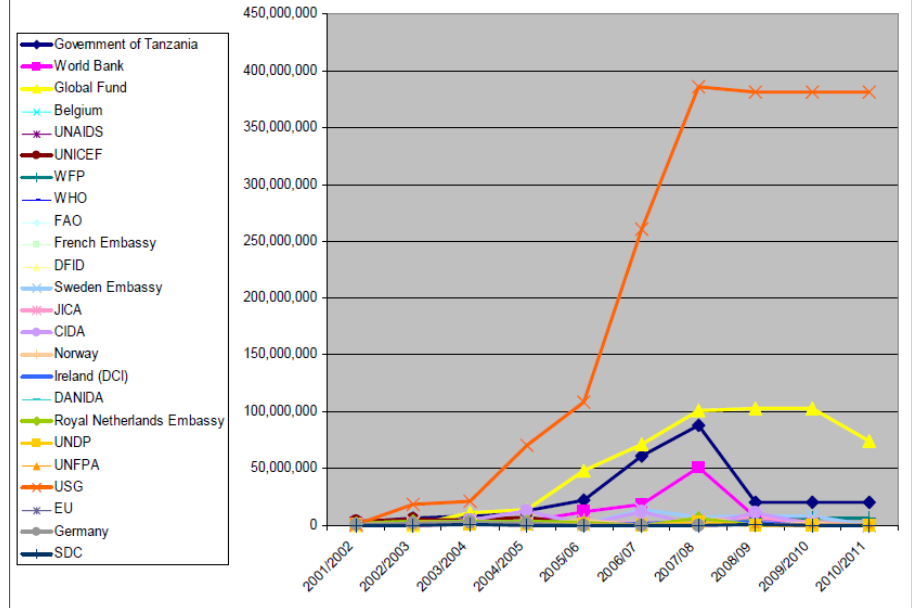


Universal access by 2010	2009	2010	2015
Prevention	11.4	15.1	15.4
Treatment and care (including palliative care)	7.4	9.7	15.4
Orphans and vulnerable children	2.4	4.4	4.4
Programme costs*	6.9	9.5	10.1
Prevention of violence against women	0.6	1.3	1.3
Total	28.6	40.1	46.6

*Cross-cutting activities include: civil society strengthening, global advocacy and coordination, policy, human rights and stigma

National AIDS Spending Assessment "NASA"

All Financiers



Aids

Financial Resources needed

Financiers Tanzania

Building networks X

Comparing Aids / Epilepsy



Sponsoren und Partner des Life Ball 2013 - wir danken herzlich:

*any.act
3 Stone Entertainment
A für Milch
Abfallwirtschaft, Straßenreinigung und Fuhrpark (MA 48)
ADW Netzwerk Produkte & Dienste
AKG Acoustics
ambuzzador
Anlavaro Design
ART for ART
Austrian Airlines
Aox Gazelles
Bauphyzik hoch drei ZT
Beat 4 Feet Productions
Bernie Boess Filmproduktion
Berufshilfe der Stadt Wien (MA 68)
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Brauness Klausner Prändl Rechtsanwälte
Burgtheater
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Concept Patricia Grecht
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Knee Multimedia
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Motto
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Ö-Ticket
Paffly Club
Patara Fine Thai Cuisine
Patronas
PayLife Bank
perfectmakeup by Gabi Grünwald
perfectprops Styling und Produktionen
Pink Orbit
Pitbull
Planter's Club
Positiver Dialog
Primetime Gastro
Puls Multimedia Productions
Radatz Fleischwaren
Red Bull
REWE Group
REWE Group Verlag
Ristorante Francesco

Rochus
Ruefs Reisen
Sabotage Film
Schutzhaus am Predigstahl
Secretary Search Personalberatung
Shofah Spa
Skyliner
SMD
Smirnoff
Stadt Wien
Stefan Riedl „s.r. genannt Trieb“
Stück Brot
Studio67
Swarowski
Tanzschule Willy Elmayr-Vestenberg
the Lounge interactive design
The Wall Group
T-Mobile Austria
Tol Mobile Sanitärsysteme
trafikant - Handel mit Gestaltung
Tüchler Bühnen- und Textiltechnik
Tunesisches Fremdenverkehrsamt
Vanguardist
Verlagsguppe Hermann
vierpunkt - Studio für Grafik und Produktion
Vollgarten
Vöslauer Mineralwasser
Webges
Wiener Linien
Wiener Staatsoper
Wiener Städtische Versicherung
WienTourismus
WIPRA Garagen
Zaruba
Zweigstelle - florale Konzepte



Life Ball 2013 – Sponsors List

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Conclusion I

- Achievements (Europe):
 - Written Declaration on Epilepsy
 - European Epilepsy Day
 - European Forum on Epilepsy Research
- Achievements (Global):
 - Regional Conferences
 - PAHO initiative

Building networks XII

Conclusion II

- What needs to be done:
 - Global Epilepsy Day
 - Joint PAHO / Written Declaration initiative for the rest of the World
 - Global Cost accounting for Epilepsy
 - Life Ball for Epilepsy?
 - How do we get private donors?

Thank you!

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