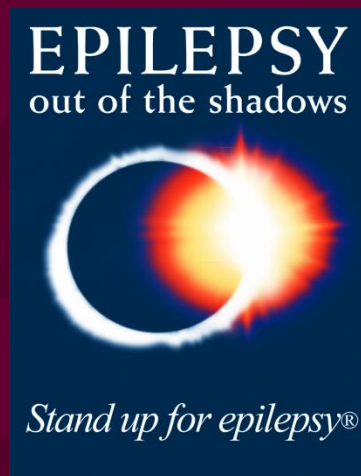


# How to measure and reduce stigma & the experience from other conditions



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# Epilepsy



## Epilepsy: Facts

One of the most common serious brain disorders affecting > 60 million people world wide

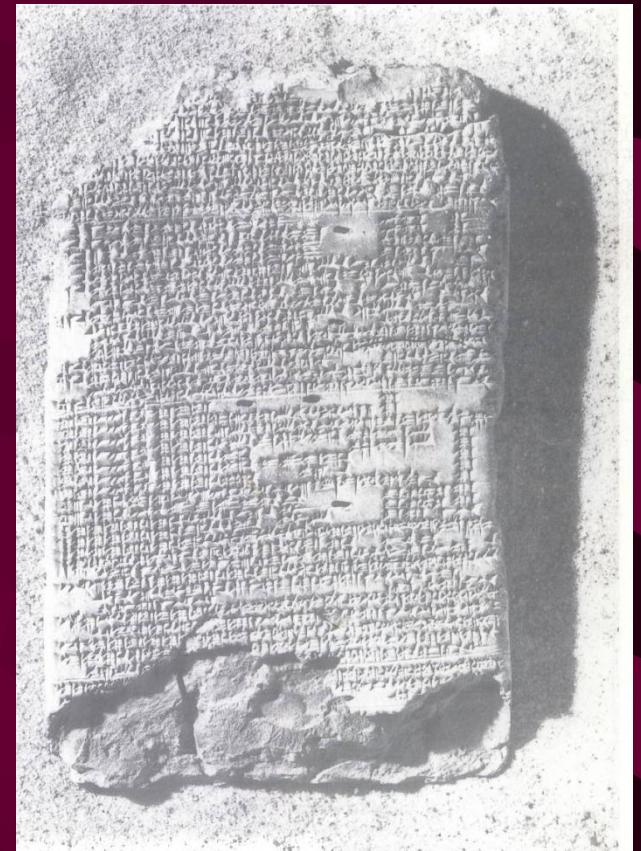
- no age, racial, national or geographical boundaries
- universal condition
- profound physical, psychological and social consequences
- seizures can cause **misunderstanding, fear, secrecy, stigmatisation and social isolation**
- misconceptions and prejudice lead to:
  - rejection
  - denial of education
  - isolation

# Concept of Epilepsy in History

## Concept of epilepsy in history

Hammurabi code, dated 1750 BC

- person with epilepsy not to marry
- not to testify in court,
- *“if a man buys a male or female slave, and before one month has passed, bennu falls upon him, he (the buyer) will return him to his seller and the buyer will take back the silver that he paid”.*



# Concept of Epilepsy in history *cont.*

- Ancient Indian medicine  
(4500-1500 B.C.)



Loss of consciousness

- Mesopotamian civilisation  
(3500-1800 B.C)

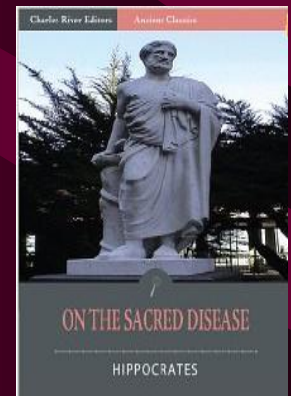
"hand of sin", god of the moon.

- Follower Hippocra-tes ( 400 BC), (*On the Sacred Disease*):

“...alleged divine character of epilepsy

- shelter for igno-rance + fraudulent practices
- gods do not make men's bodies unclean
- no more divine than other diseases,
- it's hereditary, cause lies in brain,

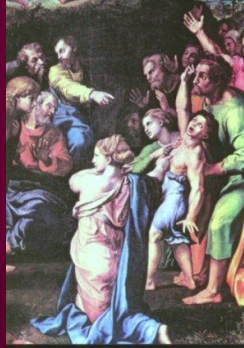
Thus: Epilepsy not be treated by magic but by diet + drugs".



# Concept of Epilepsy in history *cont.*

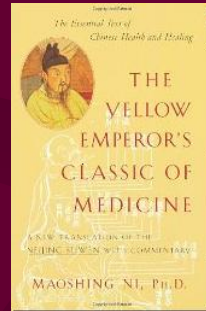
- Christian world (70 AC)

*Gospel according to  
Mark (9:14-29)*



"epileptics demoniacs + epilepsy caused by unclean + deaf spirit"

- Ancient China (100 A.C.)



"epilepsy is the disease of the head"

- Arab-Persian manuscripts: (600 A.C.)

*Zoroaster  
Zarathuštra Spitāma*



Direct reference to epilepsy as sickness caused by de-mons scarce or non-exist

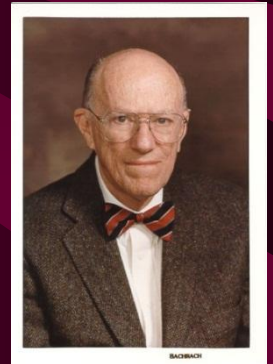
# Concept of Epilepsy today

Western world  
17<sup>th</sup> + 18<sup>th</sup> century

fight against supernatural + occult started with  
final step progress en-lightened medicine



denial demoniac influence.



Leon Eisenberg (20<sup>th</sup>/21<sup>st</sup> century):

*“Epilepsy ancient disease “explained” for as long as it has been perceived. Its manifestations invite arcane theories of its causes + meanings.*

*Seizures dramatic, public + frightening. They occur with unpredictable frequency in unexpected places.*

*Forced cry, loss consciousness, fall, twitching + foaming at mouth, all suggest possession by spirit”.*

# Epilepsy and Stigma

Stigma and exclusion are common features of epilepsy; a major contributor to the burden associated with the condition



Quality of life: reducing the stigma of epilepsy is key to improving an individuals' life opportunities



Measuring stigma

# Methods to measure stigma

## Quantitative

- Questionnaires
  - Single indicators
  - Scales

## Qualitative

- Observation
- In-depth interviews
- Focus group discussions
- Media content analysis
- Policy and legislation audits

## Combination of the above

---

### Survey the Stigma of Epilepsy in Europe

- Data collected from > 5,000 patients
- Living in 15 countries

#### Results

- 51% reported feeling stigmatised,
- 18% of these reported feeling highly stigmatised



# Stigma Survey at school globally

- Kentucky: parents - epilepsy in classroom: negative
- Germany: 15% parents - children not to play with child with epilepsy
- Taiwan, China: 72% parents - child not to play with child with epilepsy
- Liberia: children with epilepsy not allowed to go to school
- Nigeria: 47% teachers - children with epilepsy insane  
32% epilepsy contagious  
27% not to play with other children  
20% not to attend normal schools
- Tanzania: heads of households - child with epilepsy not to go to school
- Ecuador: child with epilepsy does not have right to study

# Stigma Surveys re employment

- Indonesia: problems in employment
- Ecuador: people with epilepsy do not have right to live full life
- India: rural: help in family trade  
urban: unemployment problem
- Nepal: 24% people with epilepsy (PWE): not able to work
- China: discrimination at the work place
- China, Taiwan: 31% PWE not to be employed like others
- Germany, Italy, USA: 40-60% unemployed  
15-20% unemployed  
20% retire early
- Germany + Netherlands: 15%: epileptic personality exists  
32%: epilepsy affects intellectual performance

# Stigma in epilepsy

Combatting stigma essential in order to improve quality of life of people with epilepsy

How?



Raising awareness – Public Education

How?

# Epilepsy and Stigma

- Learning from each other:



- Learn from others



Alzheimer  
HIV  
Migraine  
Leprosy  
Asthma  
Diabetes  
Etc.

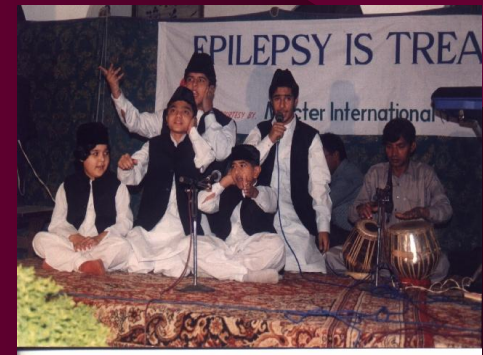


# Raising awareness

## Public Education

Special Target groups:

teachers, police, politicians, health care providers, religious leaders, people with epilepsy, their relatives and friends, etc.



# Learning from each other



## Brazil: Raising awareness – Paula Fernandez

Take into account:

- Magnitude stigma different within different segments society.
- Demographical + socio-cultural factors important predictors epilepsy stigma.
- Mass media campaigns to target these social segments



Important: correct information **with** emphasis on attitudes and behaviour

# Learning from each other

“Epileptic” or “Person with epilepsy”

Epileptic



Person with epilepsy

Group 1:

- 105 students
- mean age = 16
- 23.8% men

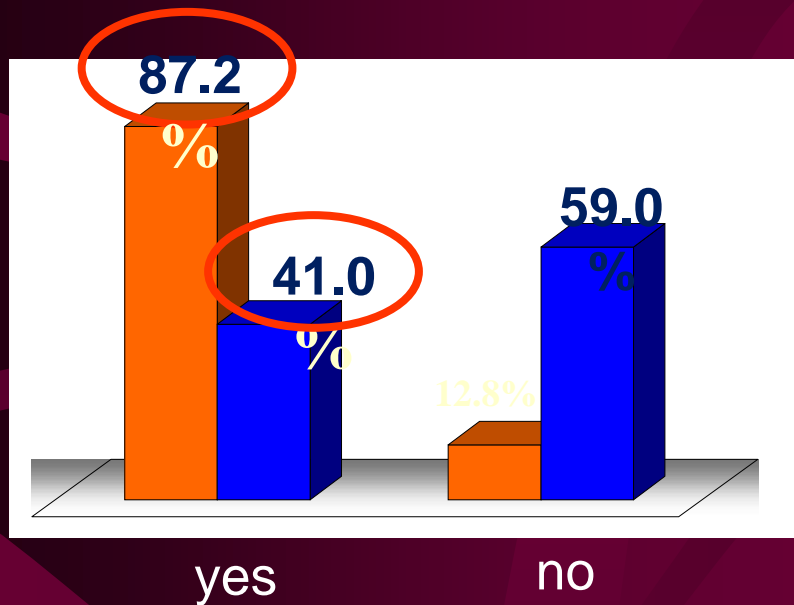
Group 2:

- 109 students
- mean age =16
- 33.9% men



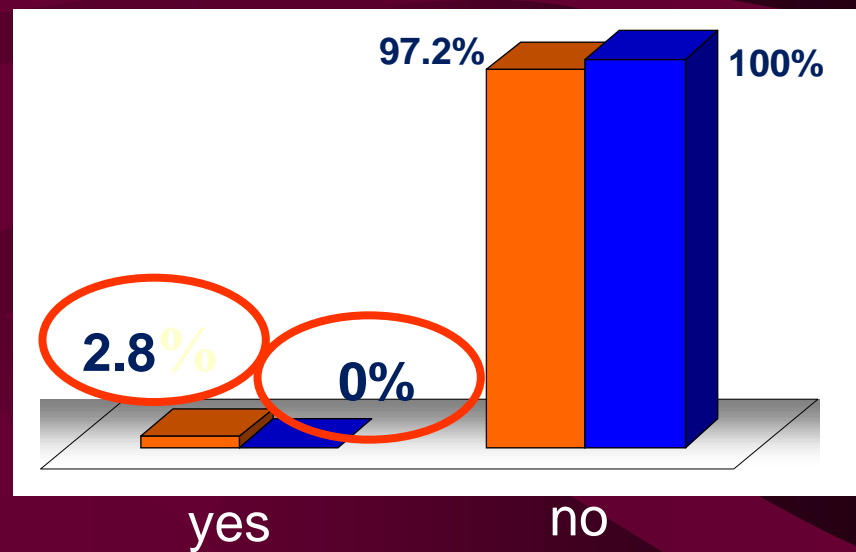
# Learning from each other

Do you think that people with epilepsy/epileptics are rejected by society?



p < 0.001

Do you have negative feelings about people with epilepsy/epileptics?



p = 0.08

 EPILEPTICS

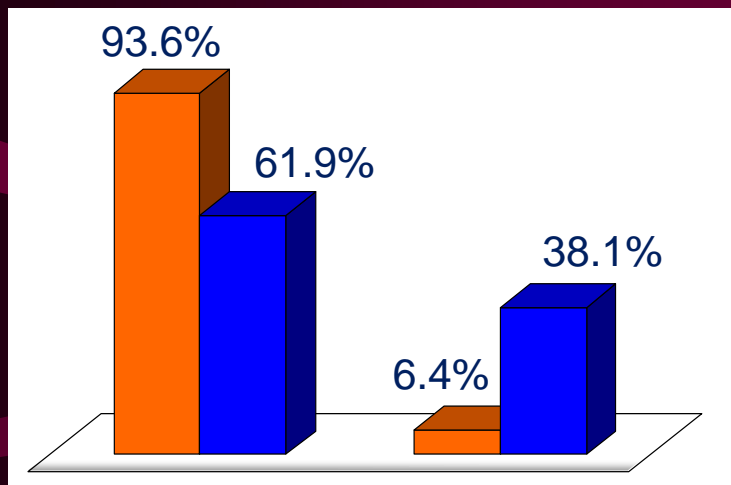
 PEOPLE WITH EPILEPSY





# Learning from each other

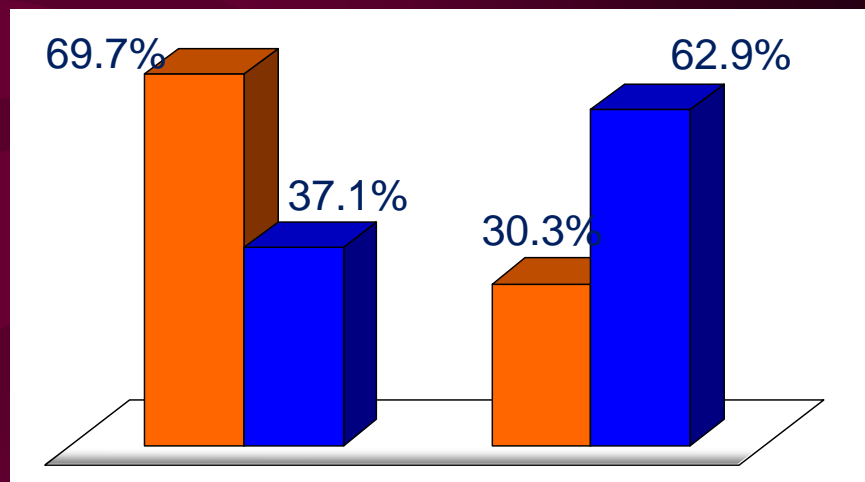
Do you think that people with epilepsy / epileptics have more difficulties to get employed?



Yes No

$p < 0.001$

Do you think that people with epilepsy / epileptics have more difficulties at school?



Yes No

$p < 0.001$

 EPILEPTICS  PEOPLE WITH EPILEPSY



# Learning from each other



Language can influence imaginary perception



social stigma

Using "inadequate social labels"



Contributes to increase psycho-social difficulties +  
stigma

# Learning from each other

Epilepsy



Alzheimer , HIV, Mental illness

Migraine



Epilepsy



All groups mention legislation issue to be investigated:

- EPILEPSY** (hear say)
- Laws impacting PWE's lives outdated
  - Laws fail to promote + protect human rights
  - Laws sometimes actively violating rights
  - In many countries no legislation
  - Legislation based on ages of stigmatisation

ILAE/IBE/WHO within the framework of the Global Campaign conducted Project on "epilepsy and legislation"

Aim:

“to collect information on existing legislation + regulations related to epilepsy in areas civil rights, education, employment, residential + community services + provision of appropriate health care”

# Epilepsy, Stigma and Legislation

Right to equal treatment described in international law:

- \* United Nations Declaration of Human Rights
- \* **Convention of the Rights of People with Disabilities**
- \* African Charter on Human and Peoples' Rights
- \* **Treaty of Amsterdam**

therefore:

- People with epilepsy should not be treated less favourable than others
- Blanket restrictions in response to epilepsy should be prohibited
- People should be entitled to individual assessment of abilities and risks

# Epilepsy and Stigma

## Convention for the rights of Persons with Disabilities (CRPD)

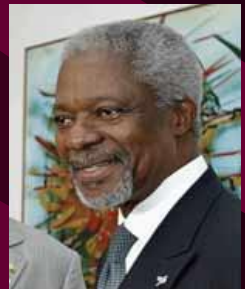
- December 13, 2006: Convention on the Rights of Persons with Disabilities. adopted by General Assembly

### Purpose:

- To promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity

UN Secretary General, Kofi Annan,

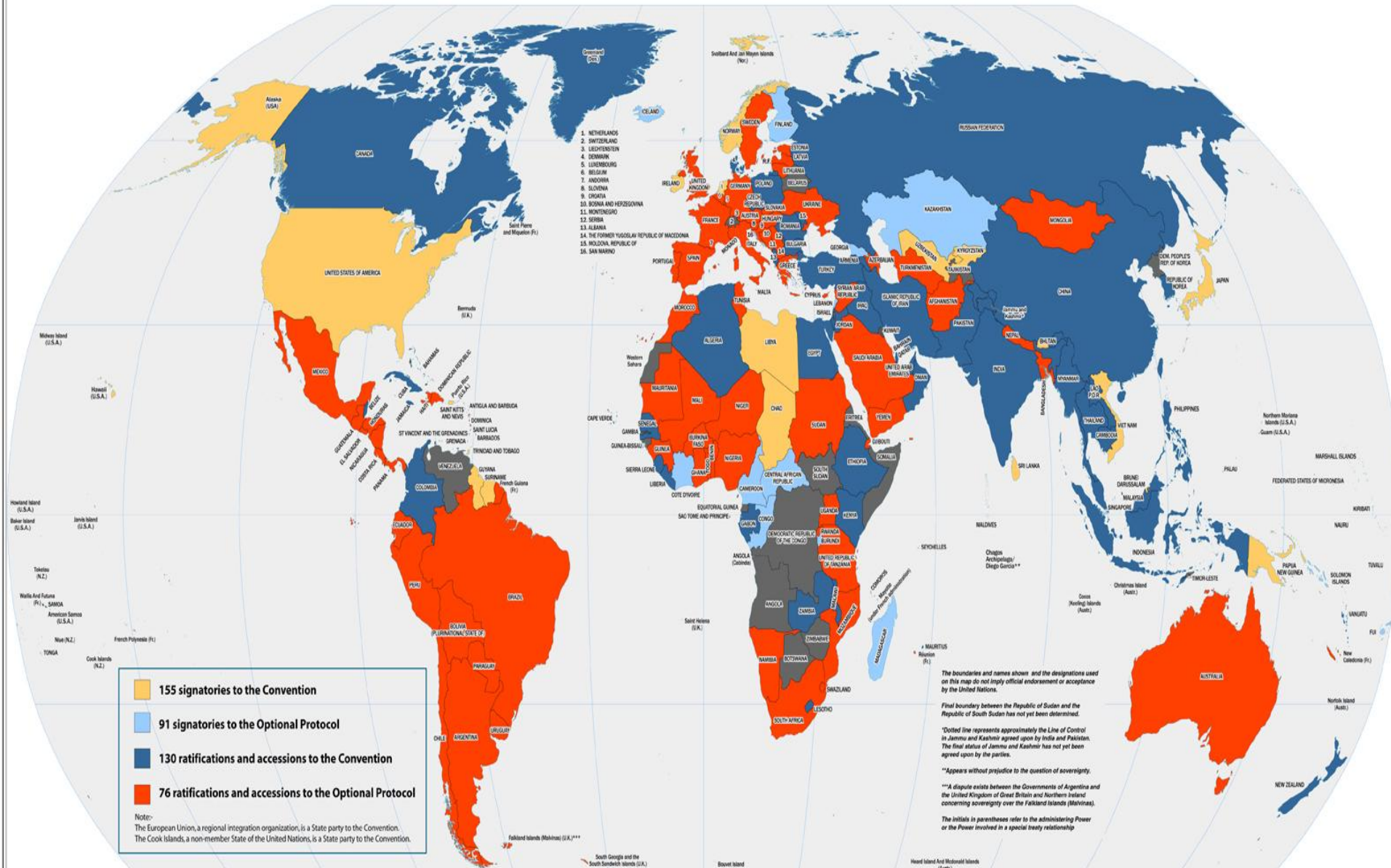
*"Today promises to be the dawn of a new era – an era in which disabled people will no longer have to endure the discriminatory practices and attitudes that have been permitted to prevail for all too long. This Convention is a remarkable and forward-looking document."*



# CRPD and Optional Protocol Signatures and Ratifications

Not Signed    
  Signed Convention    
  Signed Convention & Protocol    
  Ratified Convention    
  Ratified Convention & Protocol

As of 20 March 2013

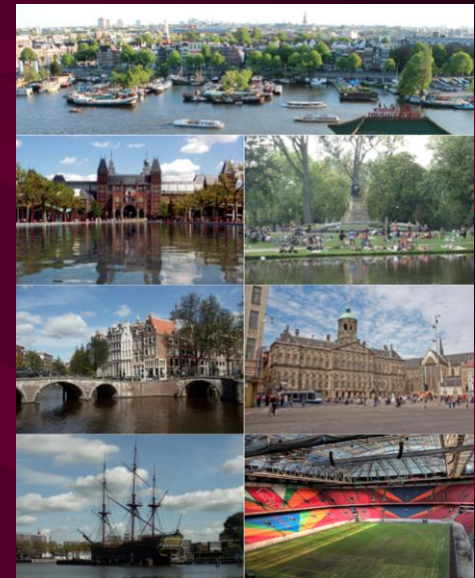


# Treaty of Amsterdam



Combating discrimination in European Union

Treaty of Amsterdam, equipped European Union to take measures against discrimination based on sex, racial or ethnic origin, religion or belief, **disability**, age or sexual orientation



02 October 1997

Treaty of Amsterdam signed

19 November 1997

Formally signed and approved by European Parliament

01 May 1999

Treaty came into force





# How to measure and reduce stigma & the experience from other conditions

Stigma and exclusion are common features of epilepsy



To reduce stigma + improve quality of life



Raising awareness



Learning from each other



Legislation



Check legislation  
Change legislation  
Develop legislation



Measuring results awareness raising efforts

# How to measure and reduce stigma & the experience from other conditions



Go raibh maith agat

Thank you

Merci beaucoup

Danke vielmals

Muchas Gracias

Dank u

Grazie molte

Благодаря ти много

Madlobt

Mulțumesc

Спасибо

Tak

Obrigado

Tusen takk

Köszönöm

Tack så mycket

Ευχαριστώ

Kiitos paljon

Ačiū

Ďakujem

Děkuji

Aitäh

Hvala

Paldies

Dziękuję

Grazzi ħafna