

European Forum on Epilepsy Research 2013

Defining the Burden and Stigma of Epilepsy

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Epilepsy

- Commonest serious neurological condition
 - Affects >60 million people worldwide
 - Globally distributed, no racial or geographic barriers
- High co-morbidity
- High risk of premature mortality
- Heavy burden to the individual, family and society
 - Highly stigmatized

The Burden and Stigma of Epilepsy

- Demographic Burden
- Individual Burden
 - The stigma
- Social Burden
- Economic Burden
- “Lack of Knowledge” Burden
- “Lack of Resources” Burden

New Cases of Epilepsy/year: a Class Divide

Developed world

≈50 new cases

per 100,000 population

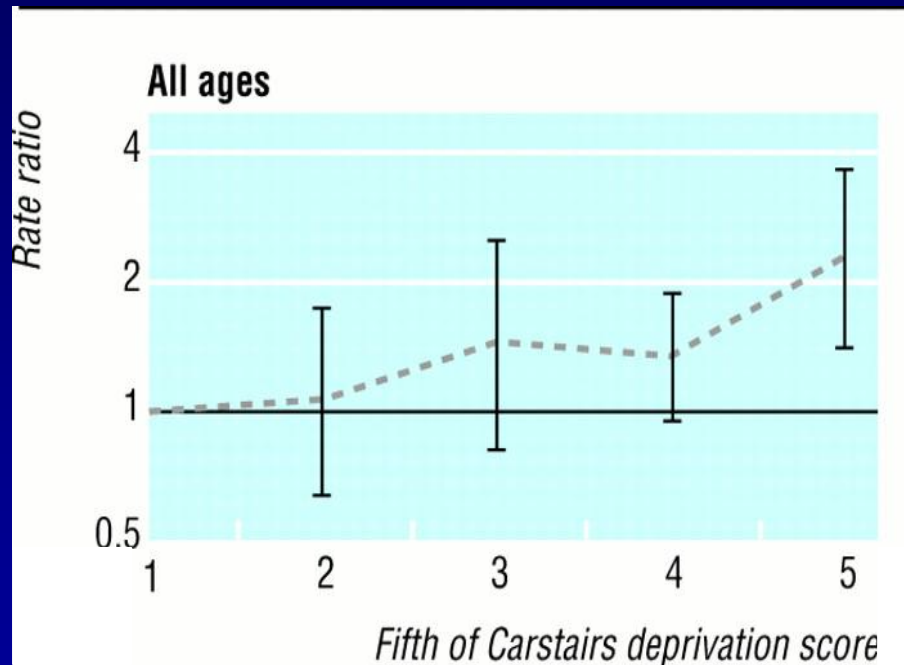
Resource-poor countries

>100 new cases

per 100,000 population

Social Economic Determinants of Epilepsy Risk in Developed Countries

- Socially and economically disadvantaged people more likely to develop epilepsy

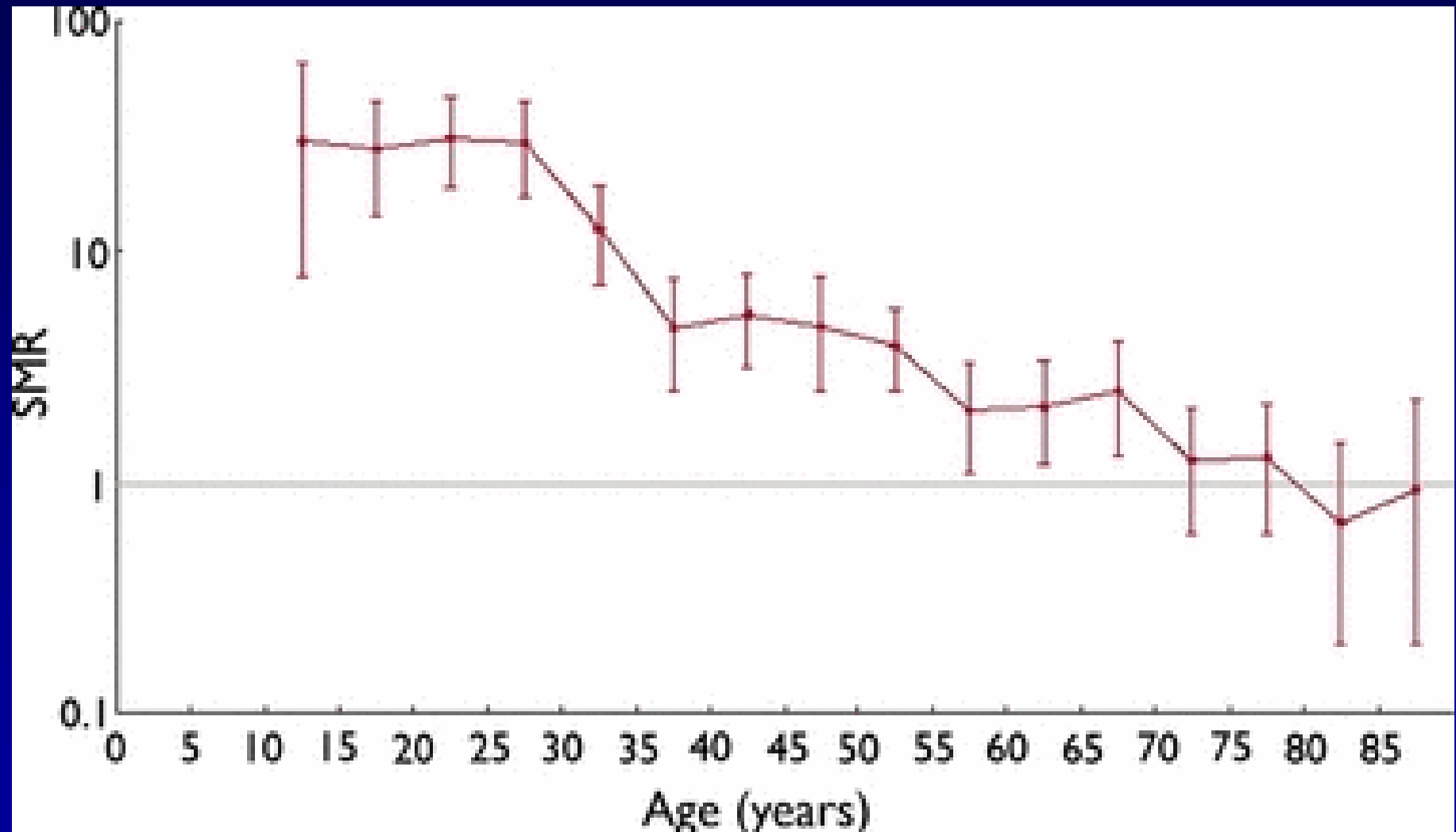


- Incidence in most deprived fifth 2.3 times that in the least deprived fifth

Epilepsy: Not a Benign Condition

- Consistent and overwhelming evidence of premature mortality in people with epilepsy
 - In developed countries 2 -3 fold increase over the general population
- Greatest in the young and those with chronic epilepsy
 - 20 - 40 years: SMR 5 - 8
 - Chronic epilepsy: SMR 8 – 15
- Greater in Resource-poor settings
 - Young in rural China: SMR > 20
 - Young in urban Georgia: SMR > 12

Premature Mortality Risk: Long Follow-up of a Cohort in Rural China



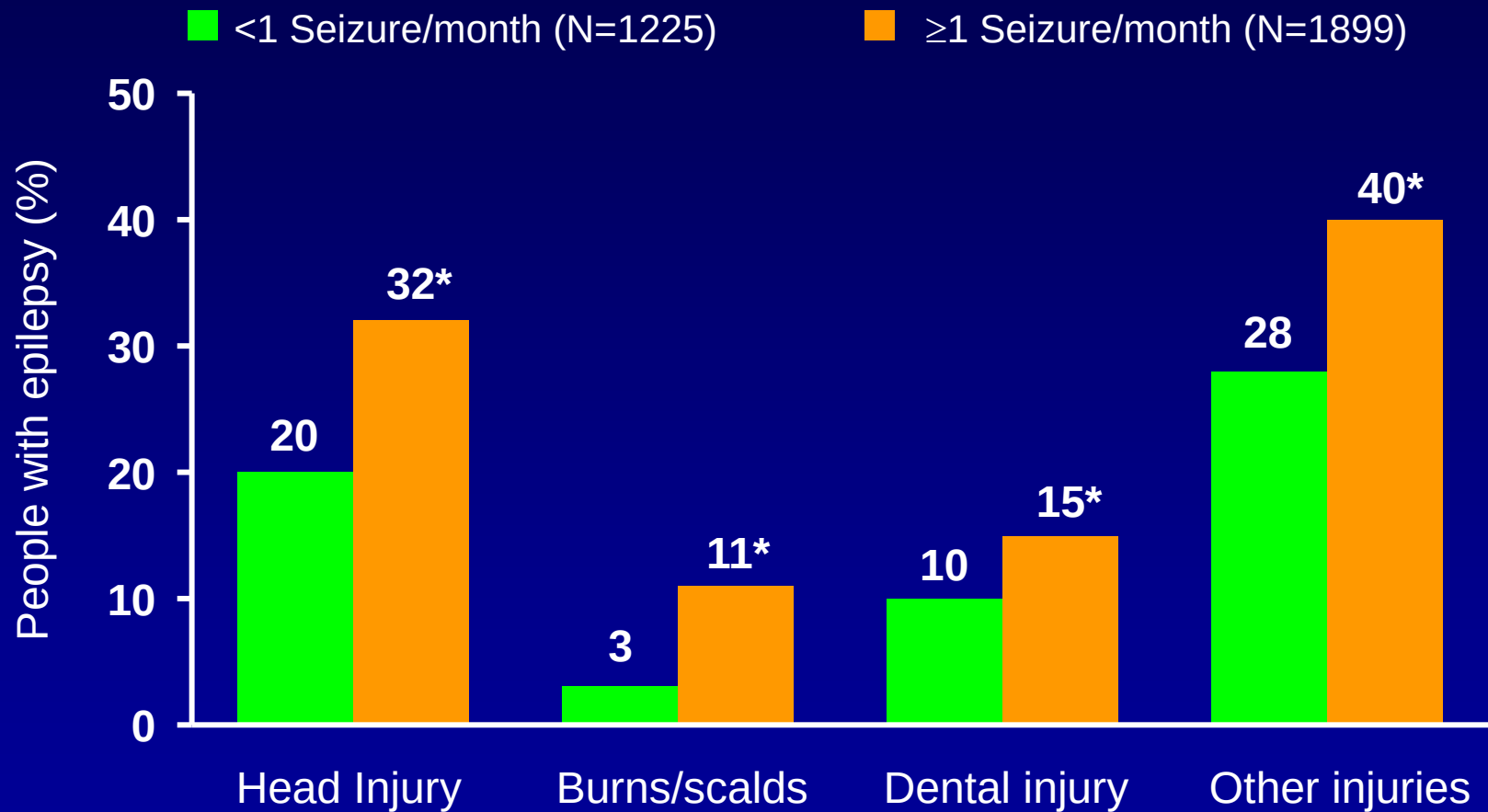
Long Term Mortality in the UK

- 792 people who developed epilepsy over 25 years ago and followed from the start
- Premature mortality persistently elevated despite most becoming seizure-free
 - 82% of people seizure-free at 25 years
- Mortality 2.6 fold increased at 20-25 years from diagnosis
 - Most deaths due to non-epilepsy related causes
- What is this telling us?

Epilepsy: the Individual Burden

- May results in:
 - Social disadvantage
 - Social exclusion
 - Disability and co-morbidity
 - Injuries
- Consequences for:
 - Education
 - Employment
 - Dependency
 - Social relationships
 - Personal development
 - Family life
 - Health

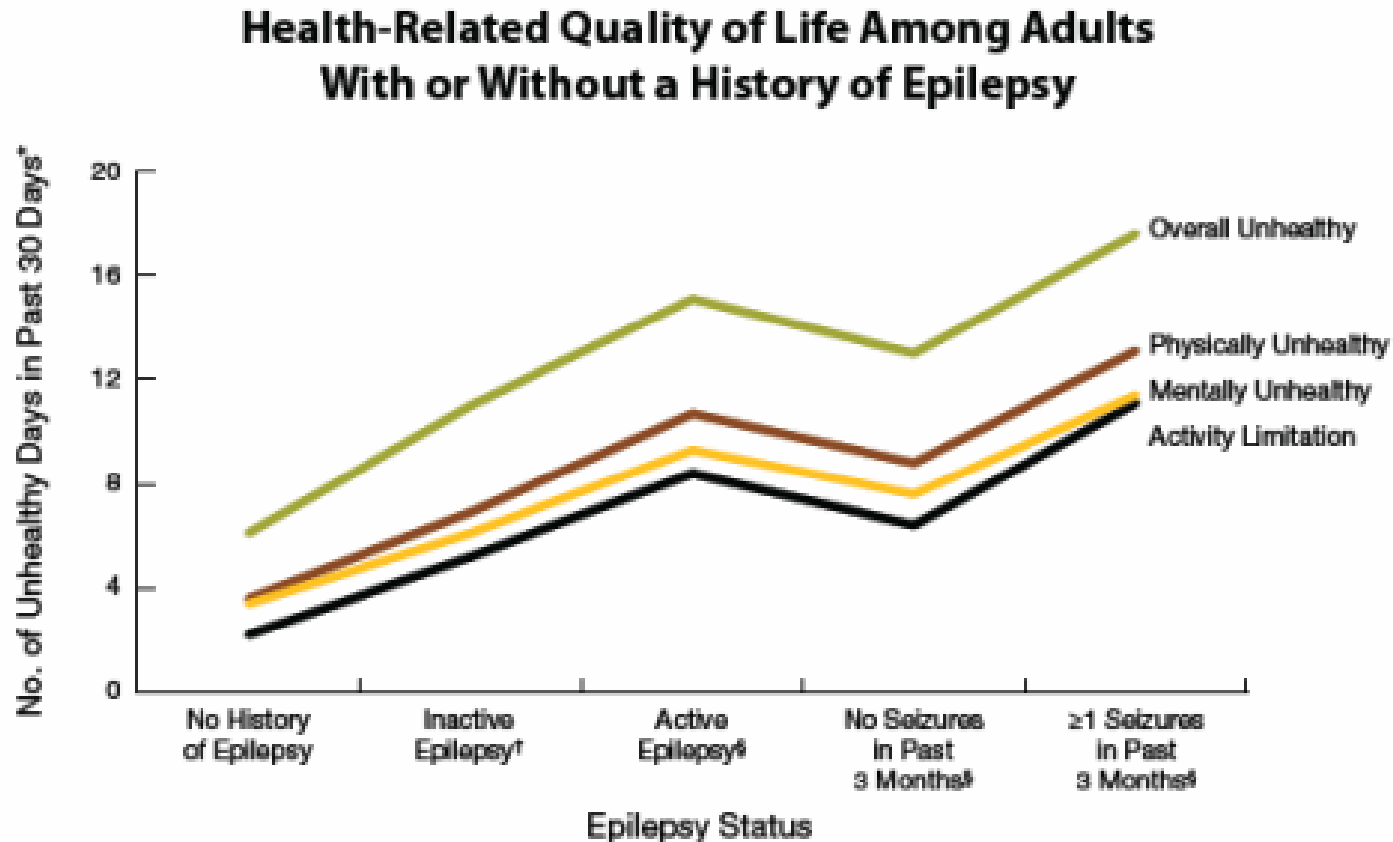
Seizure-related Injuries & Seizure Frequency



N=3124

*P<0.001

Epilepsy Impact on General Health



* Self-reported measure of health-related quality of life (Behavioral Risk Factor Surveillance System data).

† Respondents with self-reported, doctor-diagnosed seizure disorder or epilepsy who had not had a seizure in the past 3 months and were not taking medication to control epilepsy.

§ Respondents with self-reported, doctor-diagnosed seizure disorder or epilepsy who were currently taking medication to control it, had one or more seizures in the past 3 months, or both.

Source: *MMWR* 2008;57(SS-6).

The Comorbidity of Epilepsy

- Co-existence of other medical conditions with epilepsy
 - Physical and psychiatric
- Important part of the burden of epilepsy
 - Increase utilization of health service by people with epilepsy
 - Role in premature mortality?

The Individual Burden: Epilepsy and What Else?

- High prevalence of physical and psychiatric co-morbidity
- Higher risk of vascular disorders (hypertension, strokes, heart attacks and others), migraine, gut disorders, dementia, cancer, sleep apnoea, injuries and fractures

Psychiatric Disorders in People with Epilepsy

	Epilepsy (Range)	General Population (Range)
Depression	11% – 60%	2% – 4%
Anxiety	19% – 45%	2.5% – 6.5%
Psychosis	2% – 8%	0.5% – 0.7%

The Stigma of Epilepsy

- Social process or related personal experience characterised by exclusion, rejection, blame or devaluation resulting from experience or anticipation of adverse social judgment about a person or group identified with a health problem
- Causes as much or more suffering as the physical manifestations
- Affects how people respond to the disease burden

The Stigma of Epilepsy

- Social exclusion as a result of stigma
 - Children banned from school
 - Relationship problems in young people
 - Adults barred from marriage
 - Employment denied, even when seizures would not render work unsuitable or unsafe
 - Civil and human rights violations

The Stigma of Epilepsy

'the social environment for adolescents with epilepsy is characterized by stigma and lack of accurate knowledge'

- In a survey of 20,000 young people, >66% stated they would not date a person with epilepsy
- People's Quotes:
 - '....nine times out of ten times they back off over it, well ten times out of ten actually'*
 - '....a lot of people think "oh she's got epilepsy, can't go out with her"'*

Economic Burden: Disability Adjusted Life Years

- Epilepsy contributed > 17 million DALYs in 2010
(about 1% of all DALYs)
 - MS 1 million
 - PD 2 million
 - Alzheimer 11 million
 - All neurological 74 million
- Most of the burden of epilepsy amongst socially and economically disadvantaged people
- The dragging down effect of epilepsy!

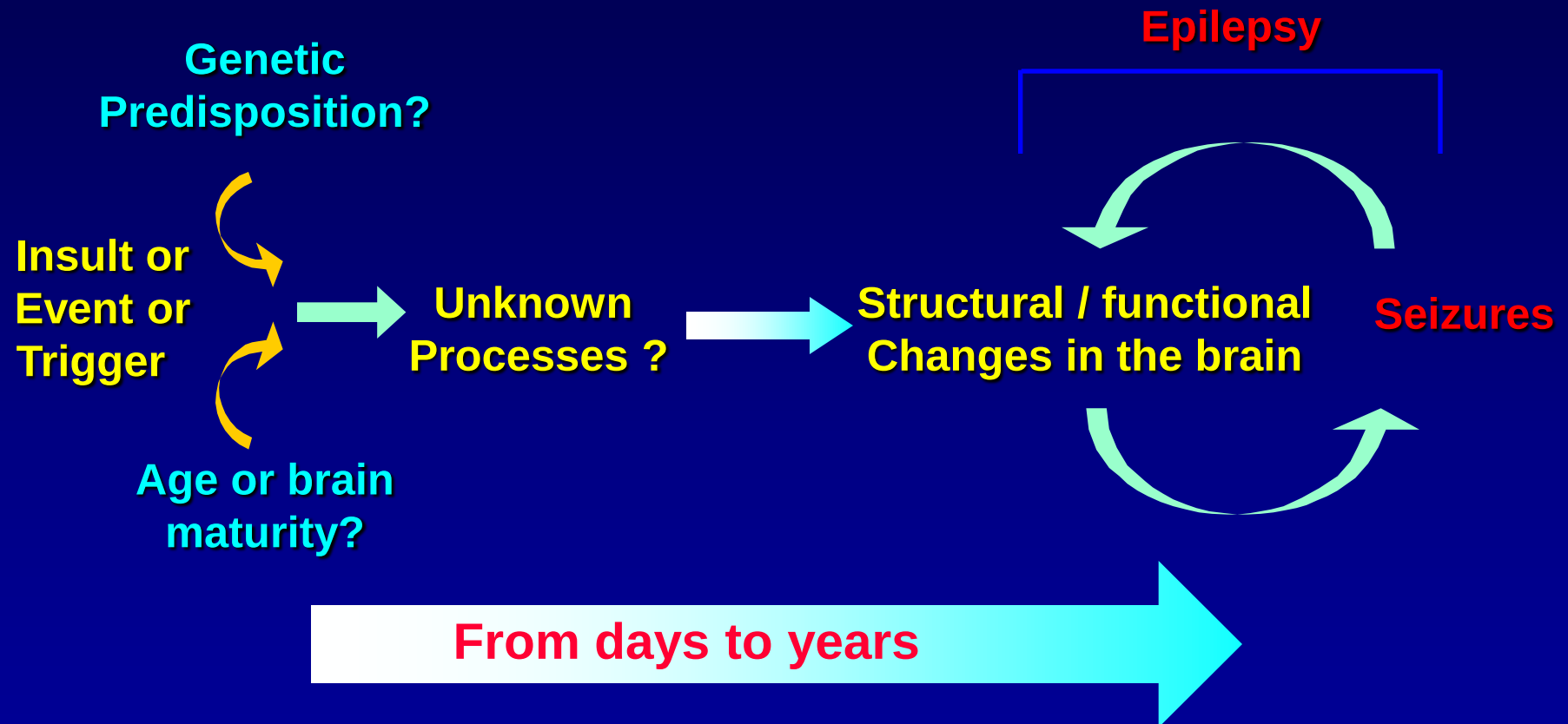
The Economic Burden of Epilepsy

- NHS
 - 0.44% of GP costs
 - 0.93% of hospital costs
 - About 1% of pharmaceutical costs (2009: £300 m)
- Cost of illness:
 - Over €15.5 billion each year in the EU (2004)
 - Over > \$15 billion each year in the US (2008)

The “Lack of Knowledge” Burden or the Burden of Ignorance!!

- Not knowing who epilepsy will strike and when!
 - If it strikes, not knowing which form it will take
- If epilepsy strikes, not knowing what will happen
 - If using drugs, not knowing which and when
 - Shooting in the dark and hoping it will work!
 - ... and outcome in any given person is still a guess

How the Brain Develops Epilepsy



Conceptual Breakthrough

- Epilepsy is always a **symptom** and not a cause
 - Risk factors and not causes!
 - Epilepsy is always associated with the **genetic** blueprint
 - Genetic contribution not always inherited
- Common co-morbidities are telling us something!

Epilepsy: always a genetic condition?

Genetic does not always = inherited!

- Inherited genetic flaw
 - Mutations in gene
- Epigenetic changes
 - Switches in gene function not related to changes in the underlying DNA sequence
 - e.g.: Environmental interaction:
 - Head injury, brain infection
- Localized or organ-specific gene miscopying
 - Deletions, duplications

The “Lack of Resources” Burden

- Epilepsy not on top of agenda
 - Low priority
 - “low” prevalence: 0.4 – 1.0%
 - but prevalence of those affected: up to 5%
- Low resources
 - For health care
 - For social care
 - For research

The Burden of Epilepsy: Conclusions

- Epilepsy a major public health challenge
- High burden to individual and society
 - Highly stigmatised
 - High Comorbidity
 - Premature Mortality
- Big “Ignorance burden”
- “Lack of resource” burden

The Challenges for 2020!

- To conquer epilepsy and ameliorate the burden – much still to be done
 - Characterise the epilepsy spectrum in full
 - Understand contributions of age and genetics
 - Change the treatment paradigm
 - Disease-modifying treatment