MRC | Centre for Neuropsychiatric Genetics and Genomics

Science v Society: reducing the stigma of epilepsy

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PRIFYSGOL CAERDYDD

My aims

- To debate the issue of how scientific advancement can be focussed to reduce the stigma of epilepsy.
- To find a solution to the words of Wolf:
- " epilepsy exists in two parrallel worlds-one of scientific advances in the management of epilepsy where enormous progress has been witnessed and the other, a darker world of superstition and prejudice that remains quite resistant to the numerous initiatives for people with epilepsy"*

Qouted in Sanjeev V et al Ann Indian Acad Neurol 2011 jul-sep: 14 (3): 158-163

The structure of my talk

- The nature of stigma in epilepsy
- Lessons from other conditions – how to reduce stigma the role of science in other conditions
- Putting it all together - The role of science in reducing the stigma of epilepsy

Stigma and epilepsy -definition

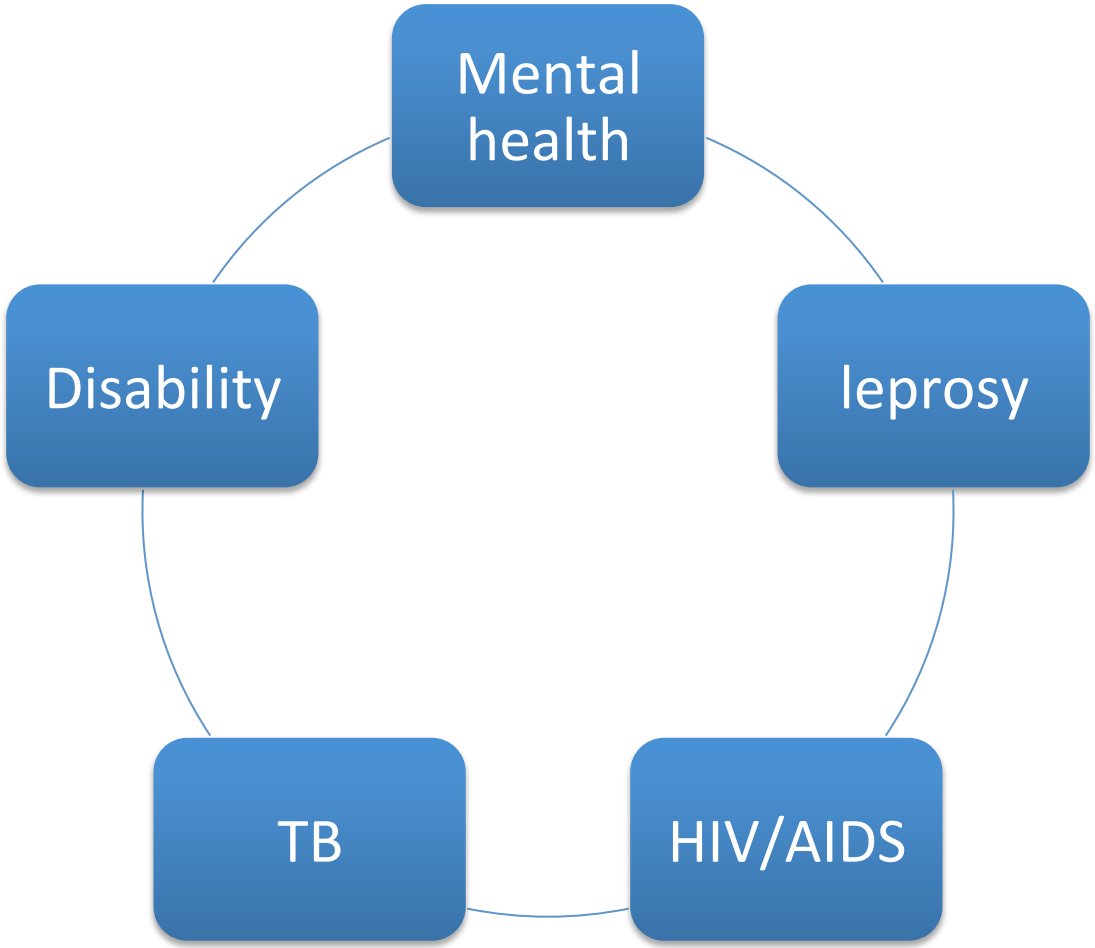
- " an attribute that has the potential to discredit an individual….those with the attribute become targets for stereotypes built around the trait"

The negative impact of stigma in epilepsy?

- Family functioning
- Mood and self-esteem
- Independent living
- Impact of statutory conditions such as:
- Driving
- Employment

Stigma reduction - lessons from other areas of healthcare

Shared goals-yes, but not shared solutions?



Severe mental illness

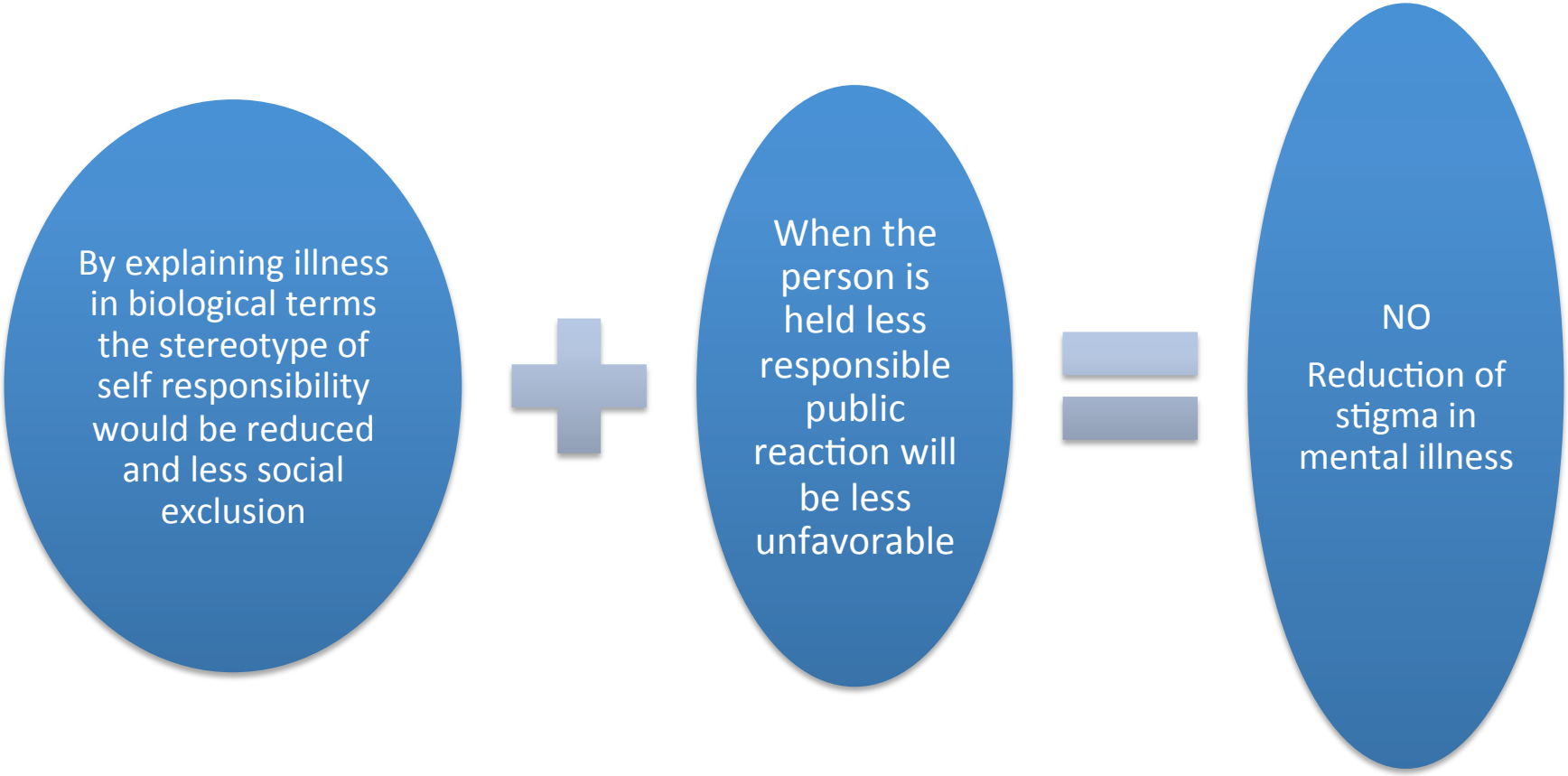
Understanding stigma

- Stereotypes-perceived dangerousness
- Prejudice: why are people with mental illness considered bad?
- Discrimination

How to change?

- Education-myths v facts
- Contact
- Protest –invoking shame by reviewing stigmatizing images

Biogenetic causal explanations-can they reduce stigma in mental illness?



Why does this theory not work?

- May be specific to mental illness
- Becoming more treatable does not reduce stigma-but this is with AIDS/HIV
- Other factors such as fear of contagion are stronger that stigma

Lessons from HIV*

- Anti retroviral drugs are reducing stigma through weakening HIV/AIDS link with disfigurement and death, also they have enabled establishment of spaces of support which reduce stigma through normalisation of the disease
- Though self stigma reduces community stigma can increase related to how the dugs are received
- In general most work has looked at how reducing stigma can increase uptake of treatment

*Zuch & Lurie AIDS Beh; Roura et al Sex Transm Inf 2009 85: 308-312

Consensus statement on interventions for stigma*

It is impossible to produce a single generic intervention that will address all aspects of stigma

An empowerment model is the best option

Such a model could contain: social marketing, contact, education and training.

*Voorend et al Lepr Rev (2011) 82. 188-201

Where does this leave the power of science to reduce stigma?

- We really do not know as has not been looked at in epilepsy
- BUT
- We can use advancement to help individuals:
- 1. Remove the condition-treatment cure or change
- 2. Dispel Myths by research –e.g. Violence and epilepsy
- 3. Remove secondary handicaps such as depression

Reduce seizures-

Why

Drugs

Surgery and imaging

Perceived impact of frequent seizures

	Seizure activity:	
	None in last year	**1+ per month**
Impacts a lot/some on:		
Relationship with family	13%	37%
Social activities	18%	55%
Ability to work	18%	45%
Overall health	21%	60%
Relationship with friends	11%	41%
Feelings of self	25%	55%
Plans for the future	24%	56%
Standard of living	16%	49%

UK MESS Study: 2-year outcomes of continuing seizures

	No further Szs	Continuing Szs	P-value
Health 'fair/poor'(%)	17	36	<.001
Anxiety caseness (%)	12	28	<.001
Depression caseness (%)	6	13	<.01
Mastery score (med; IQR)	8(5-11)	6(3-9)	<.01
Stigmatised (%)	14	44	<.001
Socially restricted (%)	14	43	<.001
In paid work	56	39	<.01

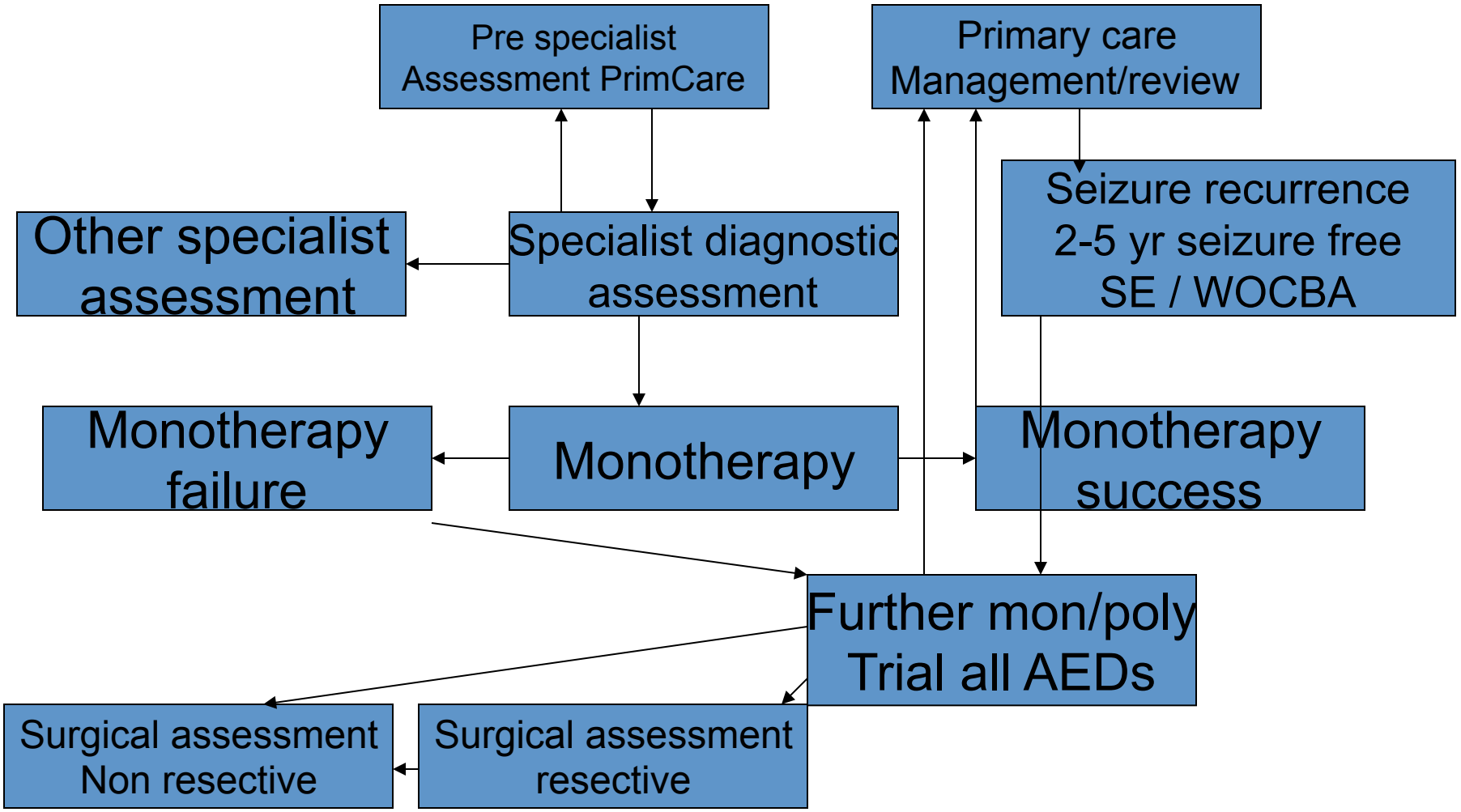
Jacoby et al, Neurology 2007

Treatment cure or change?

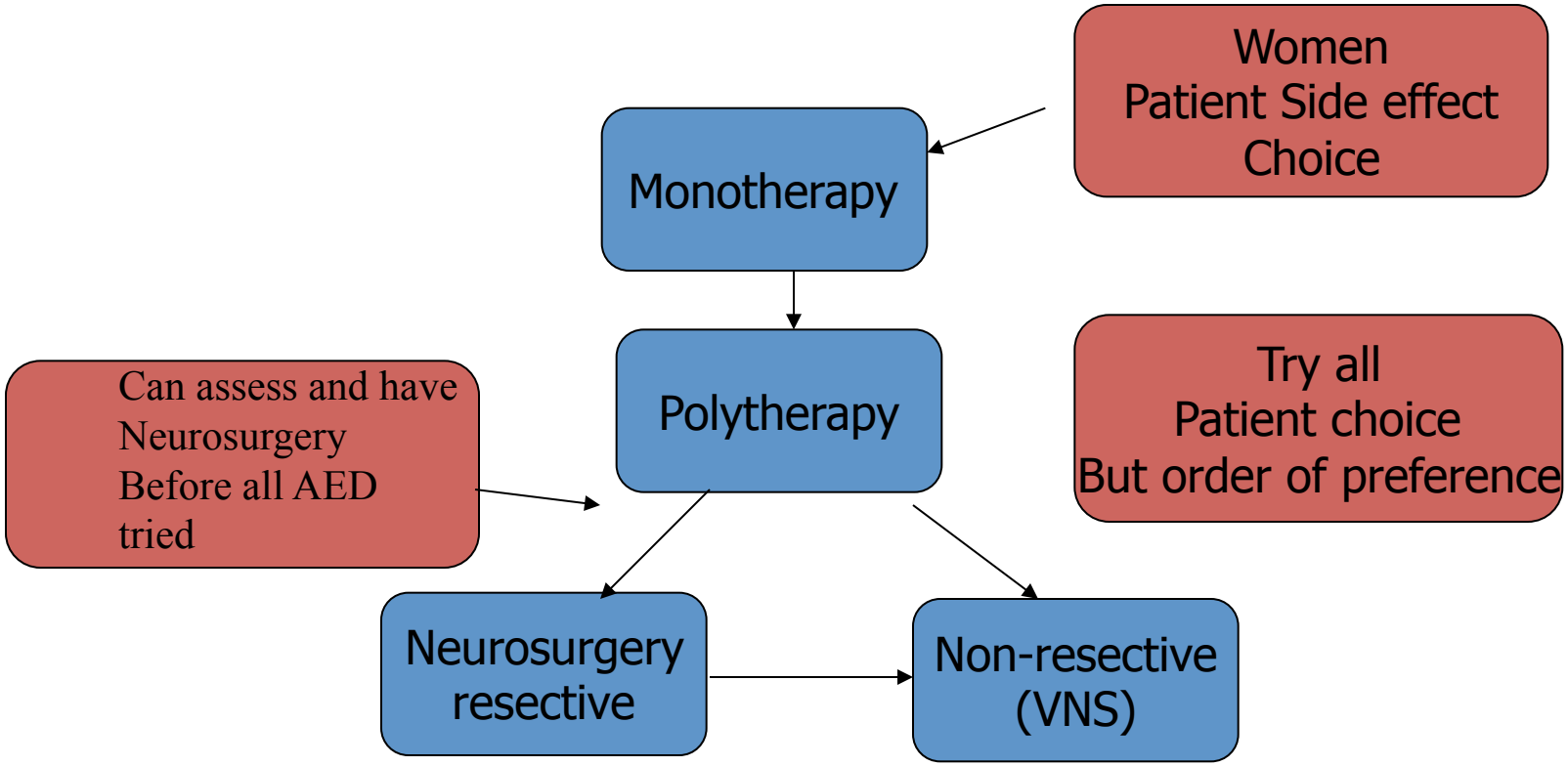
Yes

- Advances in Neurosurgery
- Advances in New Medications

Pathway-the big picture

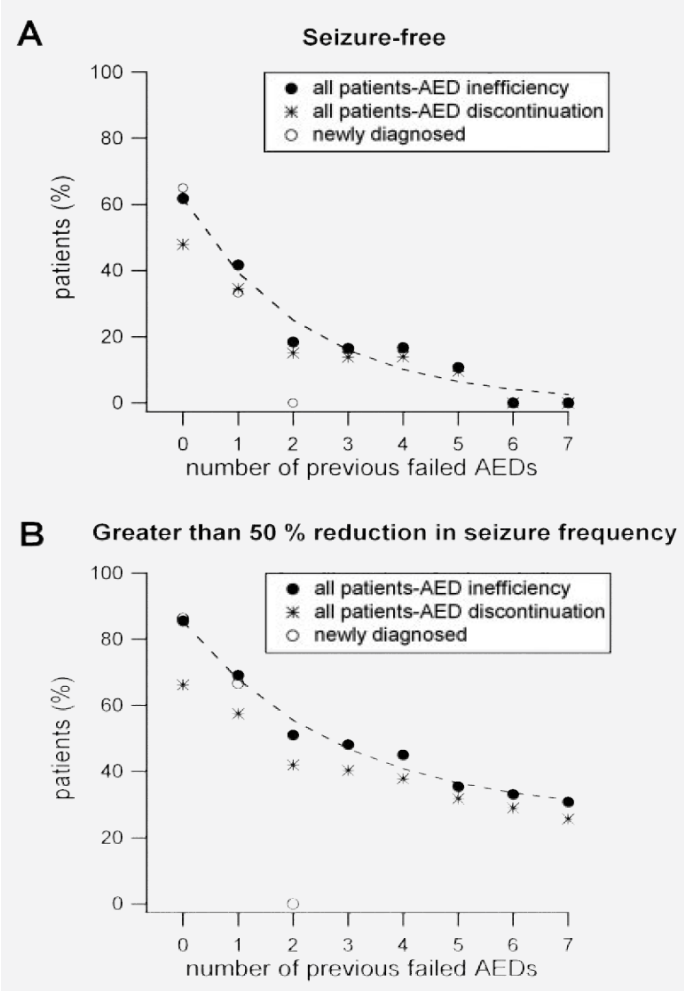


Treatment options



Relative and Absolute Drug-resistant Epilepsy

- Drug resistance is a graded process that follows a mono-exponential course with a half-decay constant of 1.5 to 2 AEDs
- Relative drug-resistant epilepsy can be diagnosed after failure of two past AEDs
- Absolute drug resistance requires failure of six AEDs, as a significant minority of patients (16.6%) is rendered seizure-free by addition of newly administered AEDs even after failure of two to five past antiepileptic drugs.



Schiller Y, Najjar Y. (2008) Quantifying the response to antiepileptic drugs - Effect of past treatment history. Neurology 70:54–65[1]

Monotherapy epilepsy:
two steps to resistant epilepsy?

- Step one: First drug failure *switching drugs*

  1st attempt monotherapy 47% seizure free* 2nd attempt monotherapy 60% seizure free (cumulative).

- Step two: *resistant epilepsy*

  3rd attempt monotherapy 64% (cumulative)

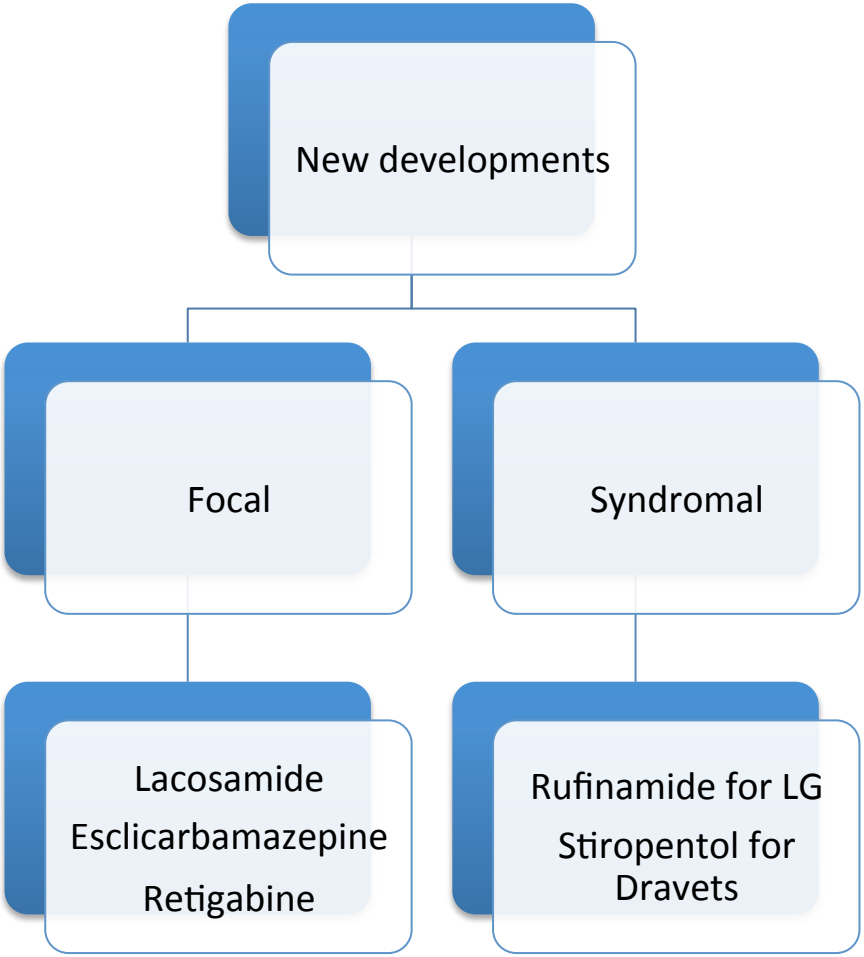
* Kwan & Brodie N Engl J Med. 2000: 342:314-9

Efficacy in resistant epilepsy

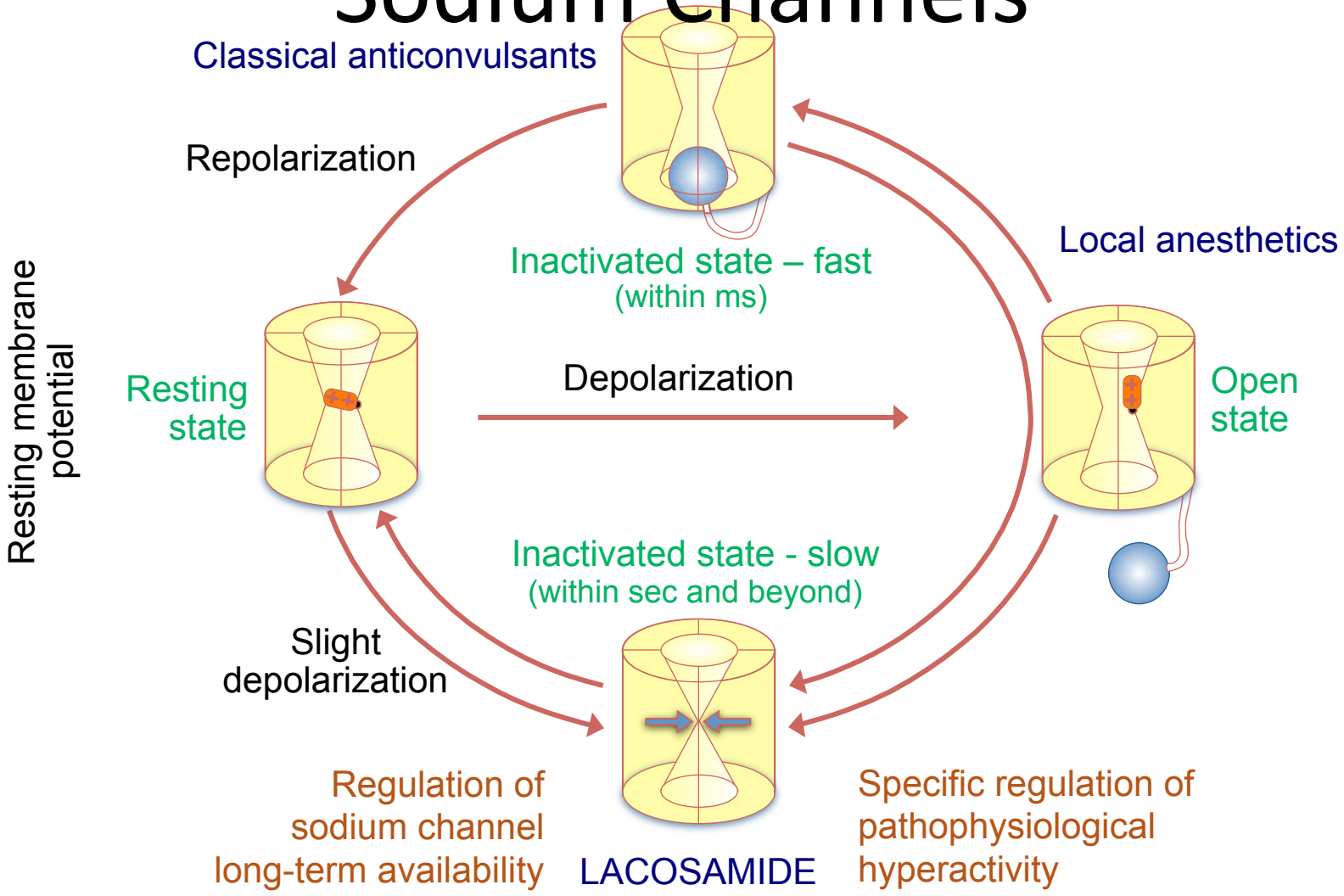
- Clinic population had 1617 pts seizure free. 21% taking more than one AED*
- 287 patients on two drugs – in 40 combinations
- 42 on three drugs – in 28 combinations
- 3 on four drugs
- Treatment with 2-3 drugs may be useful therapeutic option.

* Stephen & Brodie. Seizure 2002 sep 11(6):349-51

Major developments

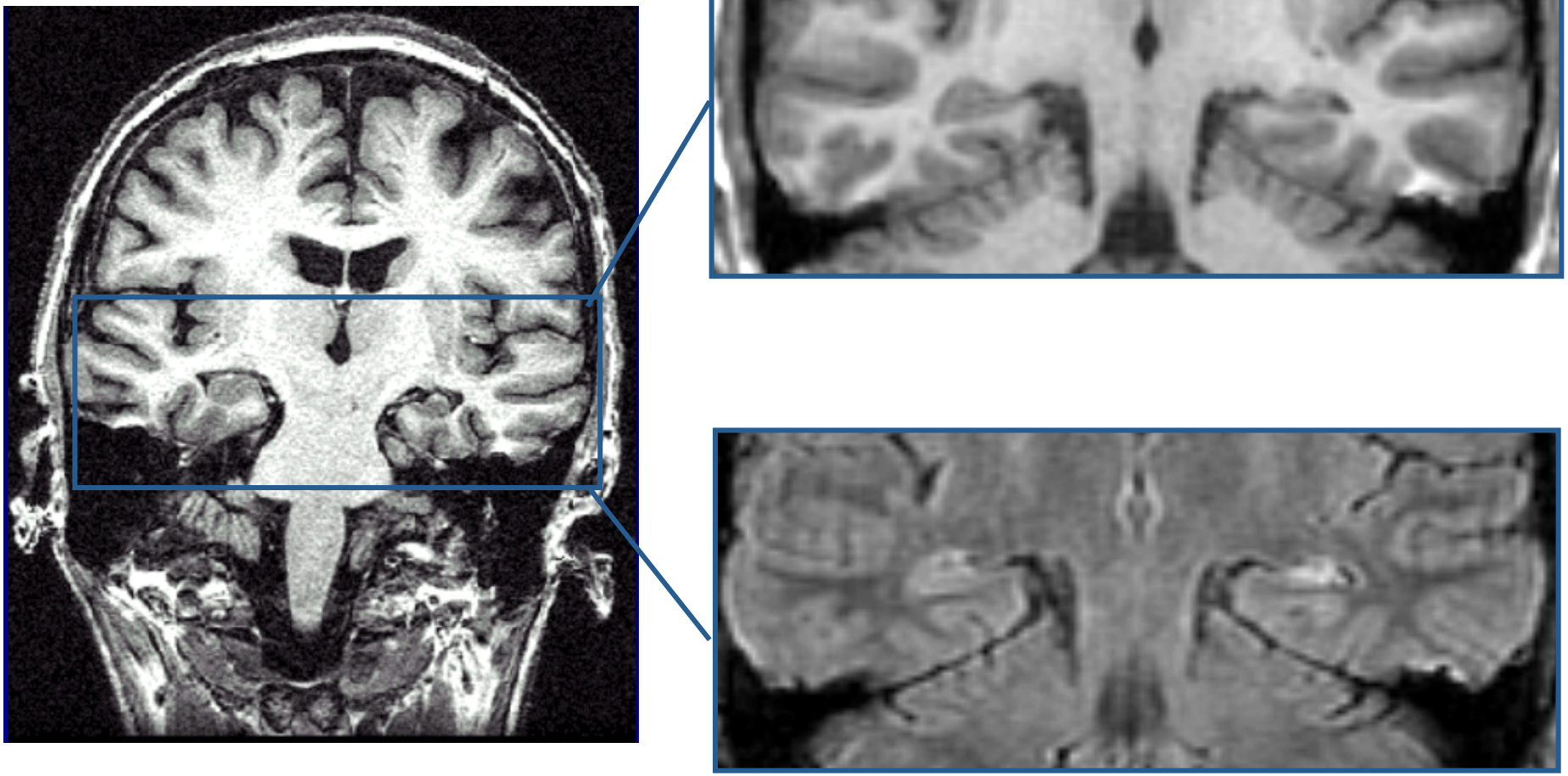


Physiology of Voltage Gated Sodium Channels



Epilepsy surgery and brain imaging

Hippocampal sclerosis



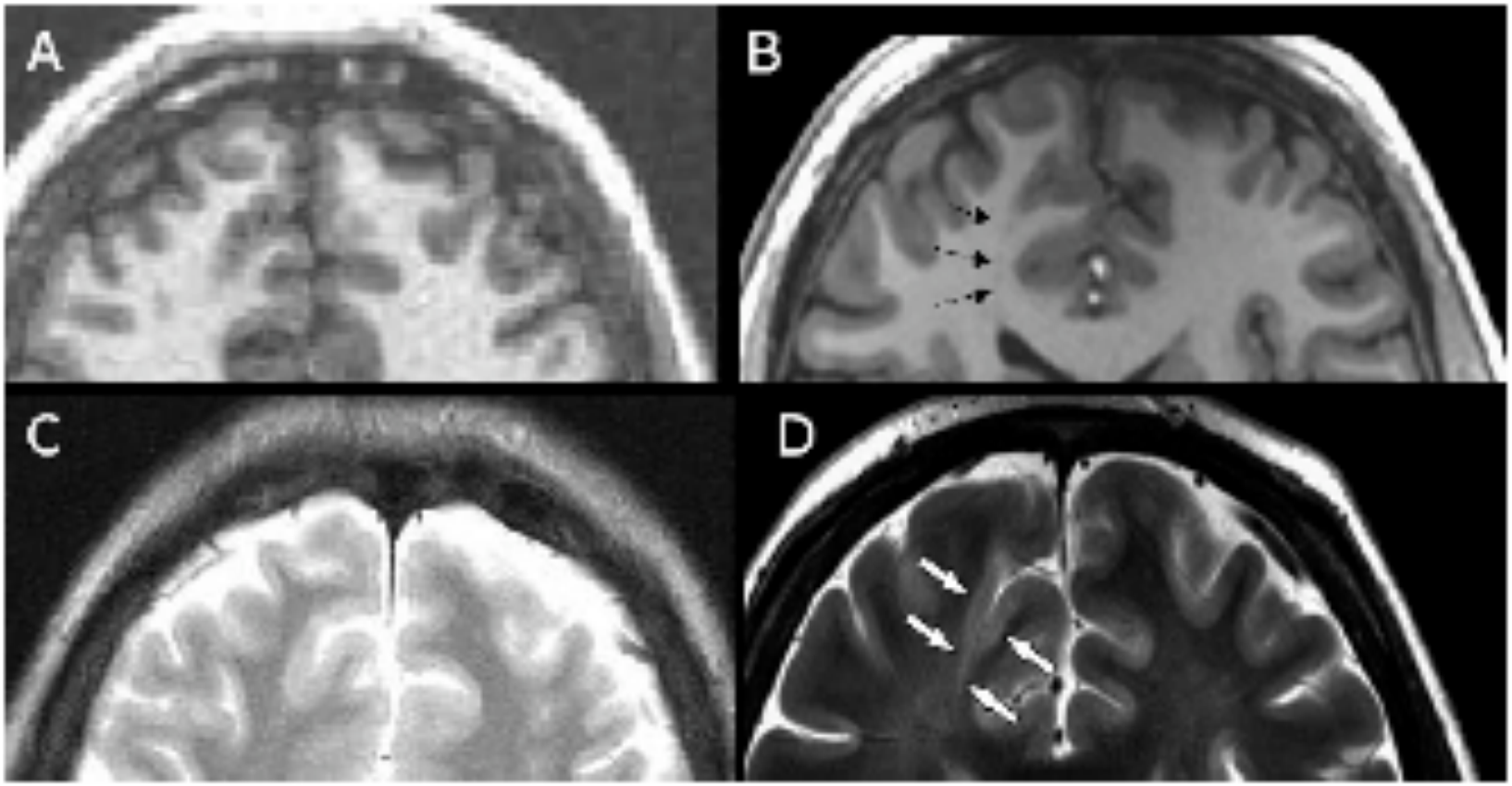
HIGH LIGHT

3T phased array MRI improves the presurgical evaluation in focal epilepsies

A prospective study

S. Knake, MD; C. Triantafyllou, PhD; L.L. Wald, PhD; G. Wiggins, PhD; G.P. Kirk, MS; P.G. Larsson, MD; S.M. Stufflebeam, MD; M.T. Foley; H. Shiraishi, MD, PhD; A.M. Dale, PhD; E. Halgren, PhD; and P.E. Grant, MD

NEUROLOGY 2005;65:1026–1031



Ultra high field – 7, 9.4T and beyond

- Micron resolution

- SAR
- Fringe fields
- Patient effects
- Artifacts

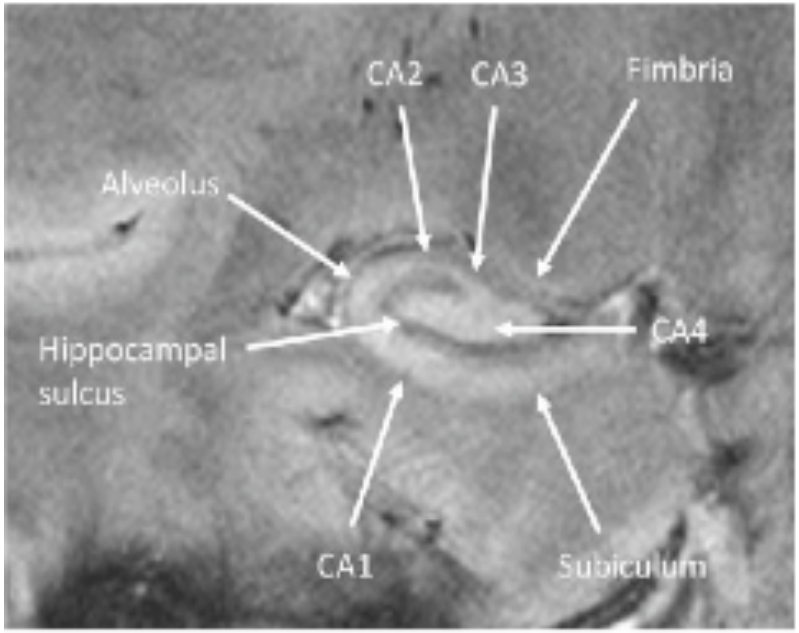
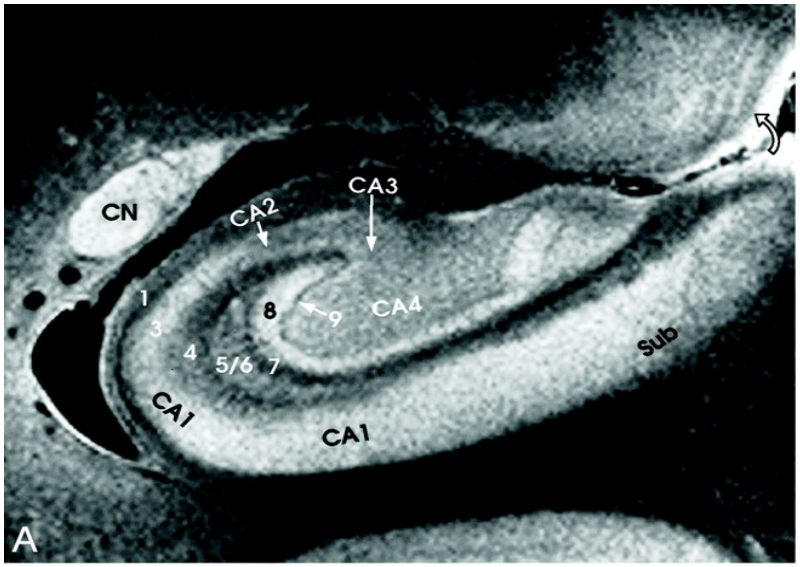
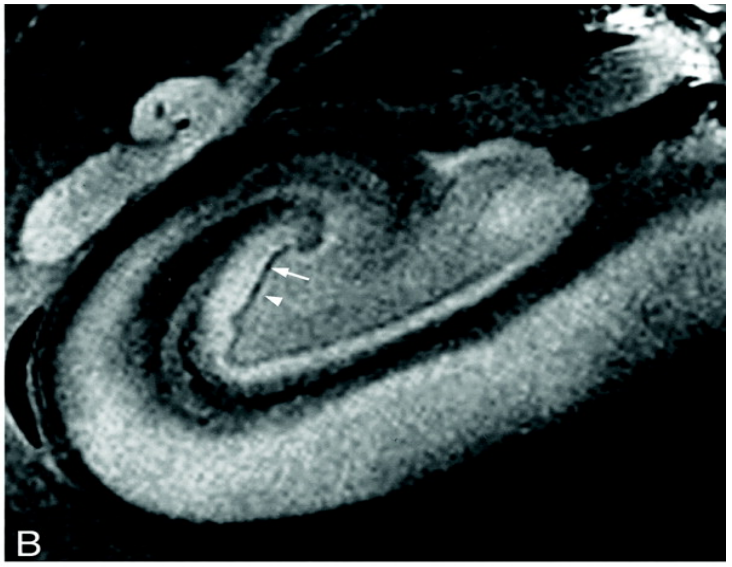
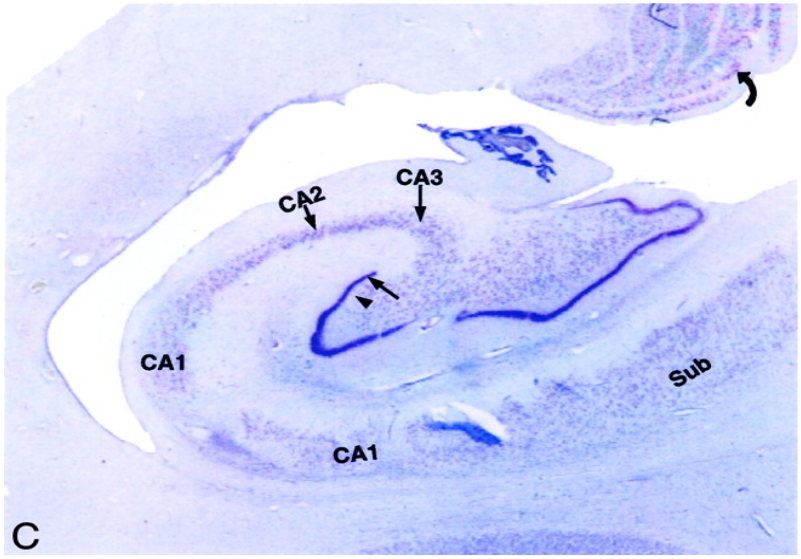


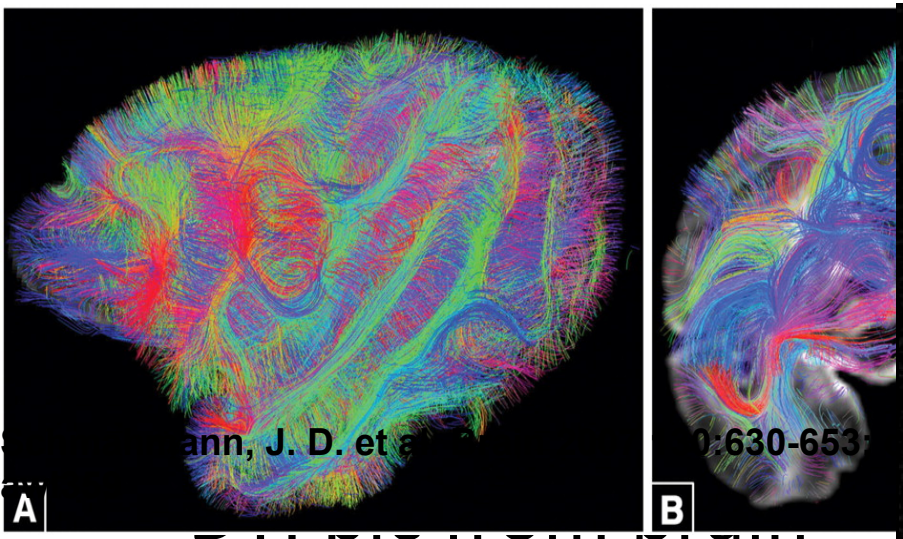
FIGURE 2. Hippocampal anatomy; coronal T2* at 7 T.

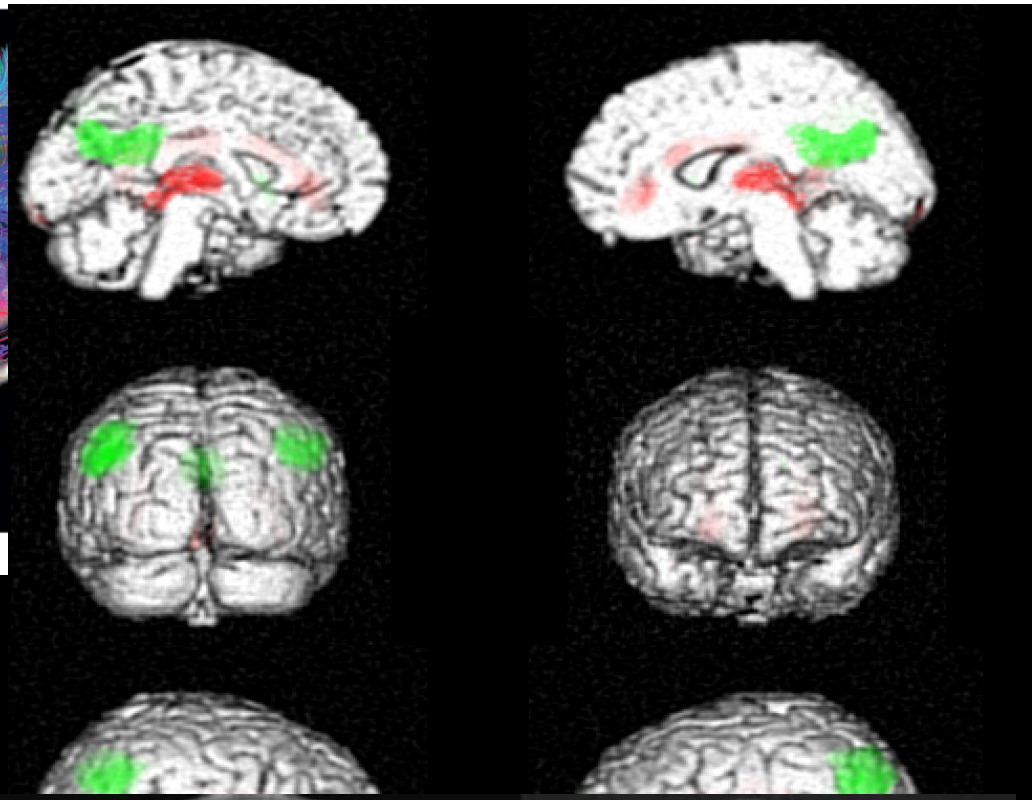
High field MRI 9.4T

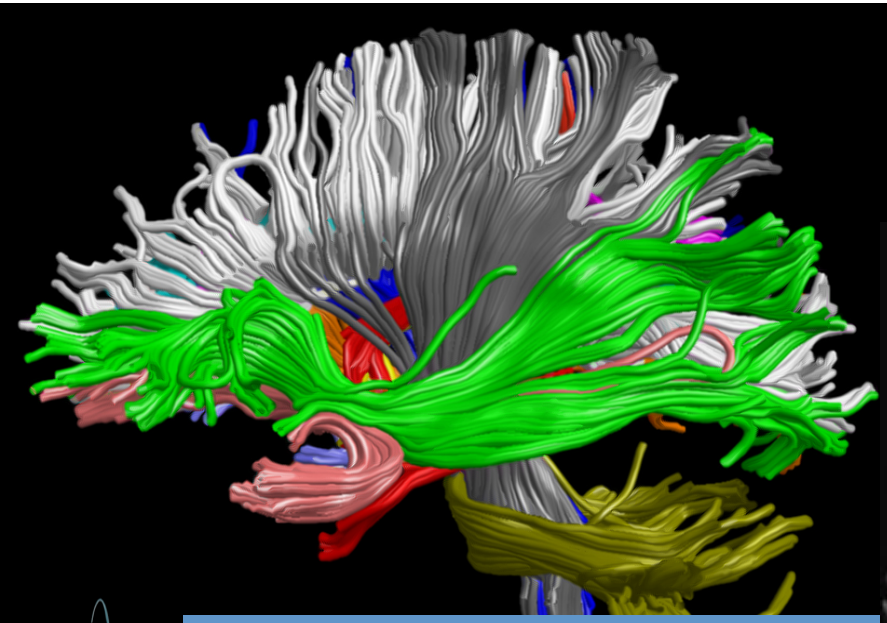


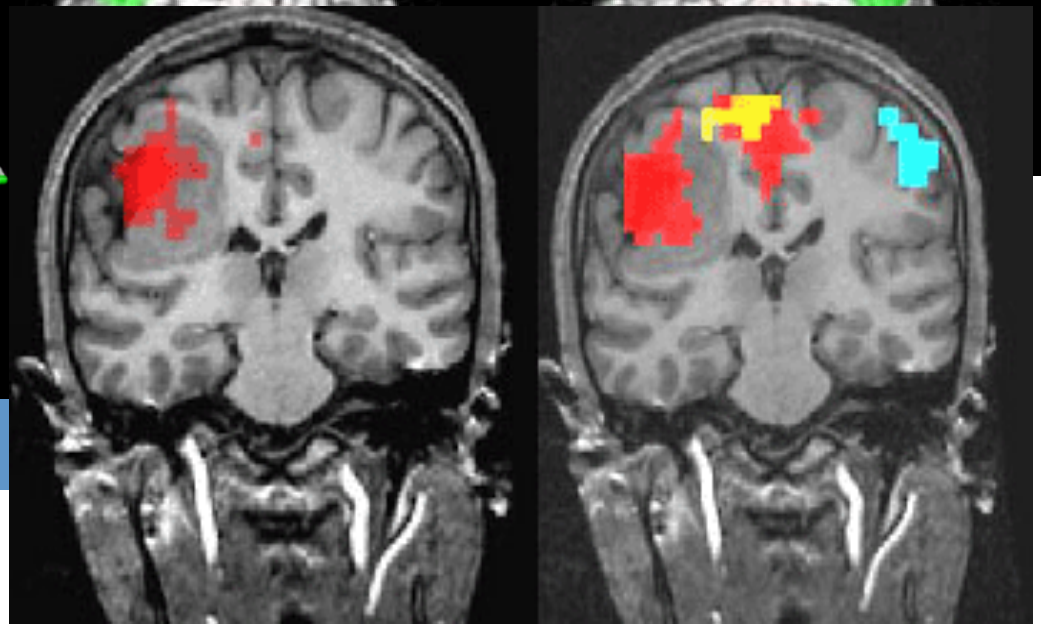










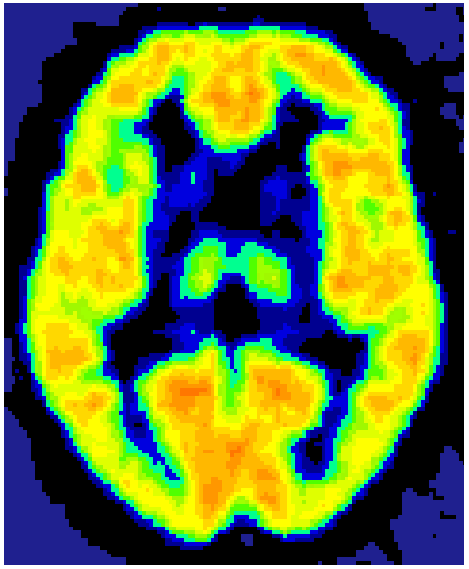


CUBRIC

Diffusion Tensor Imaging - Data courtesy of Alexander Leemans and Derek Jones

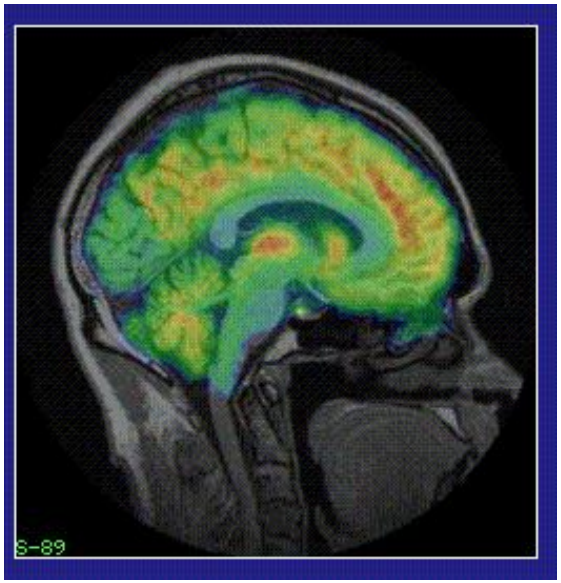
Examples of receptor studies

[^{11}C]flumazenil



$GABA_A$ receptors (with α 1/2/3/5 subunit)

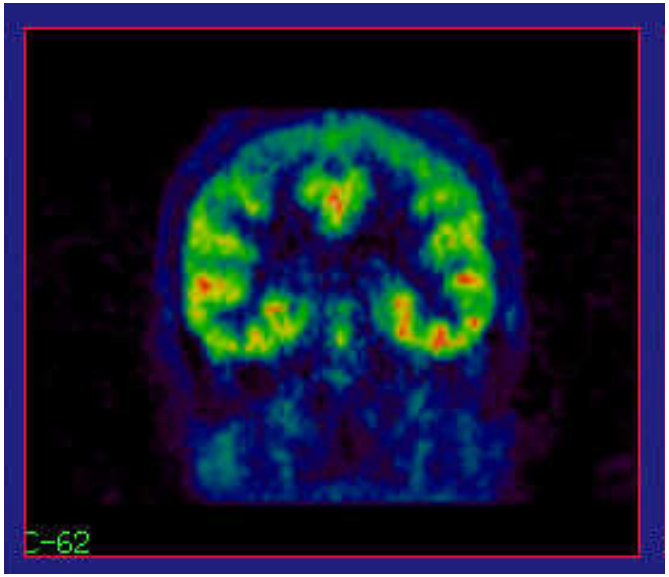
[^{11}C]diprenorphine



Opioid receptors

(μ, κ, δ)

[^{11}C]WAY100635



Serotonin receptors

($5\text{-}HT_{1A}$)

Dispel myths

- Epilepsy and violence

- Recent research confirms no link with epilepsy and violence

Epilepsy & Violence*

- Looking at a very large sample of 22,947 people with epilepsy in Sweden they showed 4.2 % committed a violent offence after diagnosis
- This was higher than controls
- But, the people with epilepsy were no different than their siblings

* Fazel et al. PloS Medicine, 2012.

Remove secondary handicaps

- Major current illness that impact on life
- Depression

Screening Secondary Care

- Diagnostic processes can be confusing
- Patients often have cognitive impairments and communication difficulties
- Patients communicate concerns about epilepsy and side effects rather than emotional state
- A possible solution is screening
- With depression as an example Epilepsy researchers in the US have recently developed the Neurological Disorders Depression Inventory for Epilepsy (NDDI-E) as a valid and reliable 6-item depression screening tool.*

- Everything is a struggle
- Nothing I do is right
- Feel guilty
- I'd be better off dead
- Frustrated
- Difficulty finding pleasure

*Gilliam et al lancet neurology Vol5 May 2006 399-405

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Screening Primary Care*

Depression screening for patients with epilepsy in a primary care setting using the PHQ-2 and the NDDI-I

Background
Depression amongst people with a diagnosis of epilepsy (PWE) is common and is under-recognised.

Aims
To examine a process of screening for depression in PWE in primary care using the two item Patient Health Questionnaire (PHQ-2) and the six item Neurological Disorders Depression Inventory for Epilepsy NDDI-E.

Method
PWE were screened via their GPs A subset of participants underwent structured clinical interview to assess screener accuracy. Logistic regression was used to determine epilepsy related risk factors.

Results
As compared to clinical interview both questionnaires performed well in identifying PWE with depression (39.5% NDDI-E, 35.5% PHQ-2). Use of either instrument almost doubled the proportion of GP recognised depression. 94% of those interviewed found screening acceptable. More recent and frequent seizures predicted screening positive.

Conclusions
Screening for depression in PWE via GPs is an acceptable process that improves detection of depression.

* Personal communication Margrove 2010

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Depression treatment

- **<u>86 people included in final sample.</u>**

- **In response to the question: 'If you were feeling stressed, worried or low and it was affecting your daily life, would you . . .'**
-
- 43.7% Deal with it on your own
- 43.7% Like some help
- 5.7% Not sure
- 6.9% missing

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Treatment choice

Treatment Preferences	*n*	%
Advice from GP/Nurse	47	54.7
Advice from Family/Friends	35	40.7
Exercise, Sport or Hobbies	33	38.4
Counselling/Psychology	24	27.9
Medication	22	25.6
Self-Help Leaflets/Books	12	14.0
Watchful Waiting	10	11.6
Religious/Spiritual support	10	11.6

Treating depression
ILAE Standards

International Consensus Clinical Practice Statements for the Treatment of Neuropsychiatric Conditions Associated with Epilepsy

Assessment and management of depressive disorders in epilepsy

- 1. Screening for depression using the NDDI-E or PHQ-2 (or equivalent) should be undertaken for all new PWE, and for all PWE attending epilepsy review with their primary care, secondary or tertiary care physicians on an annual basis.
- 2. There should be no watchful waiting even in those deemed to be having milder depressive episodes because of: (1) increased risk of suicide, (2) adverse impact of depression on quality of life and seizure control, and (3) a significant overall increase in healthcare costs irrespective of seizure severity or duration. In such cases, refer to or seek advice from specialist mental health services. If the episode is severe or if suicidal ideation or risk is present, refer urgently to a psychiatrist.
- 3. Supportive therapy, including psychoeducation provided by trained therapists, social workers, epilepsy nurse specialists, or other suitably trained professionals, should be provided to all newly-diagnosed PWE and their families. This should also include educating PWE and their families about epilepsy, determining their emotional reactions to the condition, and correcting false beliefs. CBT (where available) should be offered to improve coping skills and strategies; particularly in people with a more pervasive sense of loss of control following diagnosis.

Conclusion

- Science is an important component of the fight against stigma, in the main through cure but also by reducing secondary conditions and through dispelling myths

Finally – a Welsh Story

- Gold medal hero Dai Greene: “Athletics freed me from my battle with epilepsy”
- Watch the 400m hurdles at the Olympic games London 2012!

- Read More http://www.walesonline.co.uk/news/wales-news/2011/09/08/gold-medal-hero-dai-greene-athletics-freed-me-from-my-battle-with-epilepsy-91466-29384454/#ixzz1iONvvUYl


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