

## The Value of Treatment

Joke Jaarsma President, EFNA

The Brain, A New Approach to Brain Diseases

ENVI Committee Workshop, European Parliament 21 November 2018







European Brain Council

#### Mission:

Advance the understanding of the healthy and diseased brain to improve the lives of those living with brain disorders



# The Cost of Brain Disorders (2005/2010)

➤ Value of Treatment Study Builds upon EBC report "The Economic Cost of Brain Disorders in Europe (2005, updated 2010)

This report gave a solid estimate of cost of Brain Disorders in Europe

➤Indirect Cost 40% of total cost of €800 billion / year in Europe

## The Value of Treatment for Brain Disorders

## The cost of non-treatment

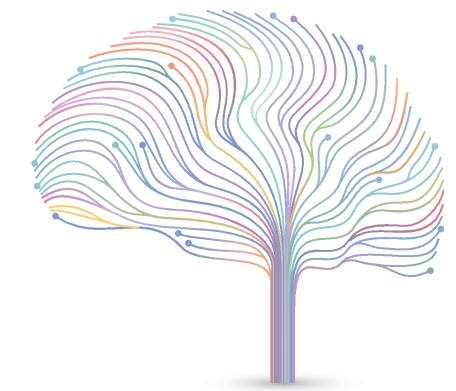












# Value of Treatment Main objective

Assess the socio-economic impact of clinical interventions, or the lack thereof,

and provide evidence and tools that can assist policy makers and healthcare workers in shaping effective policy responses for some of the most prevalent brain disorders.



## Disorders of the Brain: the big picture



- Highly prevalent and disabling conditions across all life span
- Growing burden of brain disorders: 35% of Europe's total disease burden with a yearly cost of 800 billion€ [1]
- Major impact on health care (sustainability, quality, access) and society as a whole
- Need for more basic, clinical and translational research

[1] Di Luca, M. & Olessen, J. (2014) The cost of brain diseases: a burden or a challenge? Neuron, 82, 1205-1208.

Neuro View



#### The Cost of Brain Diseases: A Burden or a Challenge?

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Brain diseases represent a considerable social and economic burden in Europe. With yearly costs of about 800 billion euros and an estimated 179 million people afflicted in 2010, brain diseases are an unquestionable empre

#### The Cost of Brain Disorder

Europe: The Grand Challenge
Brain research is at the forefront of science but extensive work is still neoded to understand brain functioning at molecular, cellular, and system levels as well as to unravel the pathogenesis of complex brain diseases. Brain research and brain diseases are relatively new terms. The former covers neuroscience, neurological, and psychiatric research and the latter includes disorders that might be classified as neurological or psychiatric, even though they can be also cared for by other specialists and general physicians. Both terms are better understandiscians. Both terms are better understandiscians described in the proposed by the European Paria not under Studies of all major European organizations interested in the brain and its diseases. FENS, the Federation of European Neuroscience sted in the participated in a long and successful driven to EICC since its inception and has participated in a long and successful drive to increase the support of

There is no way to escape from the fat that brain disorders are a major publication in Europe and the rest the world. The World Health Organization (WHO) global burdon of disease study an two major pan-European studies on the cost of brain disorders were of seminimportance in disclosing this major challenge. They demonstrated that, beyon doubt, brain disorders were the major public health problem in Europe and a other high-income countries.

Brain diseases were included in the global burden of disease study by the MHO (World Health Organization, 2008) Murray and Lopez, 1997), and the burden of brain disease was collected in a single article in 2003 (Disean and Loonard), 2003, it showed that brain diseases are responsible for 35% of Europe's total disease burden. This figure was, however, calculated in terms of so-called DALYs, or disability-adjusted life years, which difficult for politicaries and other decision

In 2003, the EBC decided to fill this knowledge gap by providing sound estimates of the cost of as many brain disorders as data would allow for all of European commitments. Since data for each disease were only available in a few countries, a health economic model was developed using the imputation of missing values. The calculations were based on the cost of a given disorder in one single person for 1 year and the 1-year prevalence of the disorder. More than 100 epidemiology and health economic experts made the best-possible estimates from existing data. Prevalence and cost values were given as a European mean using all available entire and the size of the control of the disorder. Prevalence and cost values were prevalence of the total cost in each single country the cost of a given brain disorders, some traditionally classified as psychiatric, some as neurologic. Because data were considered too weak for the inclusion of other brain disoasses at the time, several major disorders were

by child and adolescent disorders as well as mental retardation. The document included both direct and indirect costs of diseases. Two typos of direct costs over analyzad. All costs nelated to health care, such as hospital care, doctor's visits, and drugs, regardless of who pays—the individual, a private insurer, or the public through taxes and social insurance—were intended as the direct health care cost. Costs outside the medical sector, both private and public, such health care cost. Costs outside the medical sector, both private and public, such promises for intention in function caused by dementia, multiple solerosis, or schizo-private or stream of the disorders, in terms of services or goods, formed the direct normedical costs. Indirect cost included the days that can be take off work due to illness, no matter if this means a short-term absenteeism from work or early retrement. Presenteeism, intended as limitations in one's work capability while at work, was not evaluated as it was consid-

Following this accurate methodology, the above study already pointed out that, in 2004, 127 million European citizens were living with a brain discrete, for a total annual cost of 385 billion euro. Psychiatric discrders accounted for 62% of the total cost, while the remaining 38% were caused by neurological diseases including dementia. These data highlighted that brain discrders were more costly than cardiovascular disorders or cancer. The results of this study were made available to the European



Neuron 82 June 18 2014 @2014 Elecuier Inc. 1205



## Disorders of the Brain: VOT studies





- Mental disorders: Schizophrenia
- Neurological disorders: Alzheimer's, Epilepsy, MS, Parkinson's, RLS, Stroke, Headache and NPH.



## Value of Treatment: 9 case studies

	chizo- hrenia	Stroke	Epilepsy	Multiple Sclerosis	Head- aches	Restless legs	Alzheim ers' disease	Parkins ons' disease	Normal pressure hydro-cephalus
Etiology un kn		Neuro- vascular	Multiple etiolo- gies	Immuno logic	Un- known	Un- known	Degene- rative	Degene- rative	Degene- rative, immunolo gic
No of subjects in Subjects Europe*	5 Mio	1.3 Mio	6 Mio	0.7 Mio	50 Mio	20 Mio.	8,7 Mio	1,3 Mio	0,15 Mio

~ 100 Mio European inhabitants affected by these diseases (\*EU 28)



## VoT Research Framework



## **☐** Overall objective of the case study:

To provide **policy recommendations** on how to provide optimal care in the disease area under study by addressing the current treatment gaps.

## **☐** Specific Objectives:

- 1) Identify the current treatment gaps and patient needs along the care pathway and analyse the underlying causes & Identify/propose solutions addressing the them
- 2) Evaluate the **costs and burden** associated with the treatment gaps and the socio-economic impact of closing/reducing them by applying the solutions identified/proposed
- 3) Propose policy recommendations on how to improve the care pathway



## alue of Treatment | What is ....

Case study will value healthcare interventions in comparison with the costburden of misdiagnosis, non-treatment, non-adherence

<u>Value of Treatment</u>				
Cost analysis	Value mapping (identification of current and potential values)			
Cost impact analysis (with or without simulation)	Value optimizing healthcare initiatives			
Model calculations (health economics) incl. QALY, ICER	New value creating initiatives (integrated care model)			

**Combined methodology** 

Policy White Paper and Scientific Publications of the Results in 2017

Objectives of the combined case studies methodology are twofold:

- Patient's care pathway analysis to assess needs and identify gaps and opportunities for improvements in the current care pathway (SWOT analysis patients and clinicians perpectives with a set of outcomes indicators)
- economic modelling assessing the socio economic impact of specific clinical interventions targeted to close some of the gaps identified in the patient journey analysis





# What do we mean by treatment gap? What is a patient care pathway?

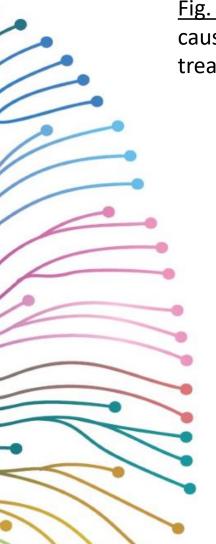


Fig. 1: Possible cause of the treatment gaps

#### **NATURAL HISTORY OF THE DISEASE**

- Asymptomatic phase of illnesses
- Illnesses usually with no symptoms
- Low understanding of the disease aetiology, symptoms, risk and preventive factors

#### DEFICIENCIES IN HEALTH SERVICE ALONG THE CARE PROCESS (PREVENTION, SCREENING, DIAGNOSIS, TREATMENT, FOLLOW-UP AND REHABILITATION)

- Not available services, systems or policies
- No health insurance
- Limited access to care (primary and secondary care)
- Fragmented, poorly organised or or uncoordinated care
- Lack of primary and secondary prevention programs
- Delay in detection and diagnosis leading to late treatment
- Drugs not available for whatever reason
- Physician misses detection, diagnosis
- Inadequate treatment
- Low disease awareness in general public and lack of training, expertise from healthcare providers
- No patient empowerment to facilitate adherence, compliance non-adherence to treatment being intentional or unintentional
- Absence of support for caregivers

#### **ECONOMIC FACTORS**

- Costs of treatment
- Limited access to drugs and devices

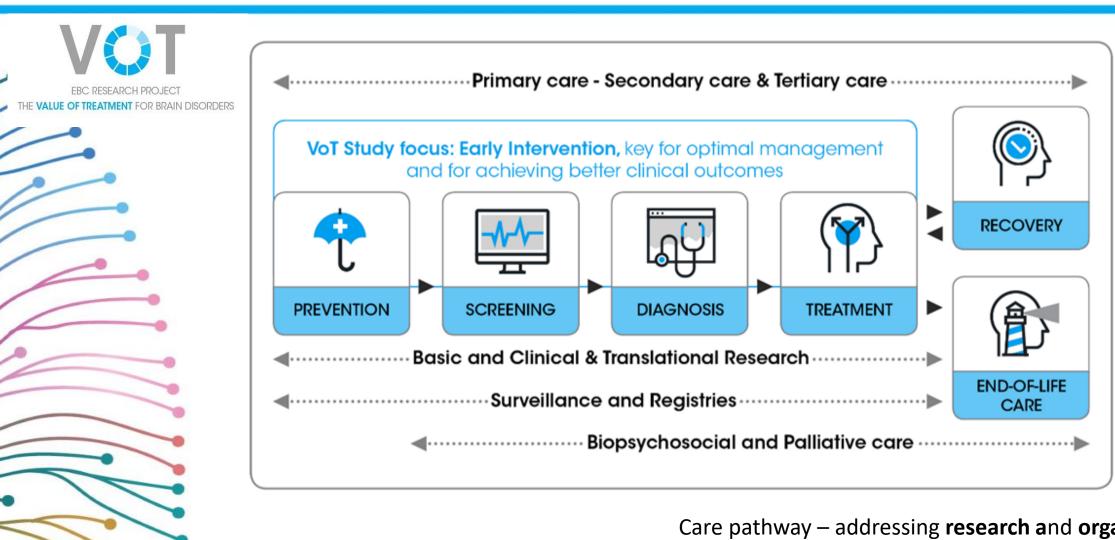
#### **SOCIAL FACTORS**

- Fear of disclosure
- Stigma discourages seeking treatment (e.g. epilepsy, mental illnesses)
- Isolation and vulnerability

OTHER FACTORS (unknown because of lack of research)



## From **issues** (treatment gaps analysis) to cost effective **solutions...** for the benefits of the patient



Care pathway – addressing **research** and **organisational** needs for brain disorders



## Benefits of targeting these gaps?

## **Economic evaluation:**

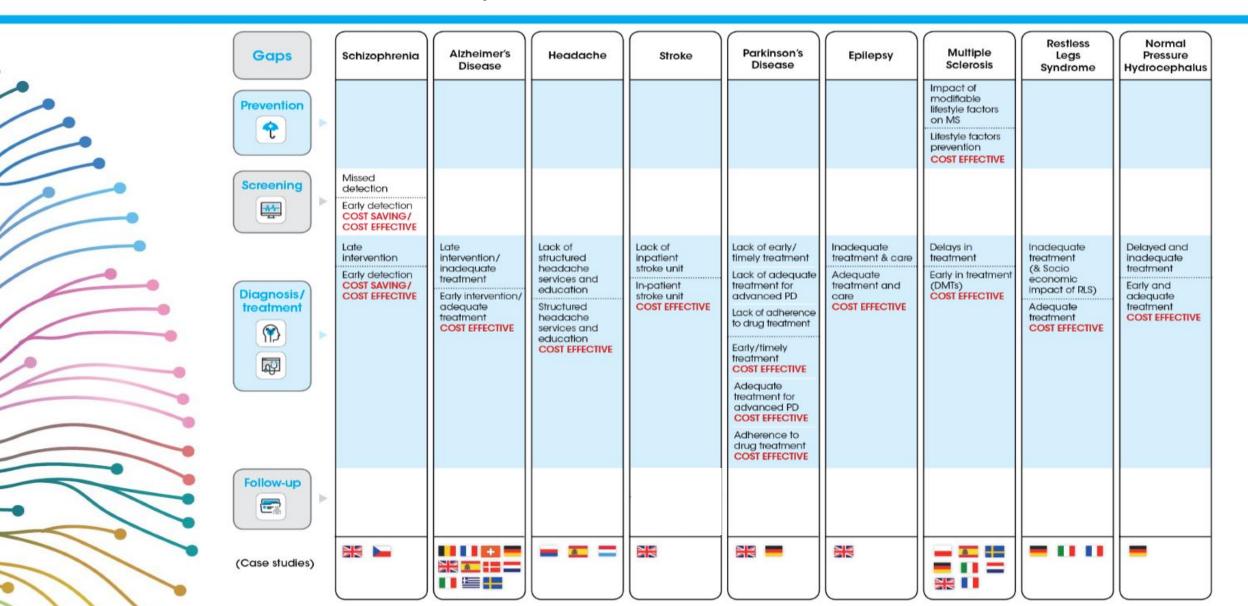
cost effectiveness analysis/cost saving analysis of best practice healthcare intervention

versus

standard care or non-treatment



## VoT Scope





## Two case studies



2. Restless Legs Syndrome



## Stroke: the big picture





- A leading cause of disability and death among adults.

  1.3 million people affected in Europe each year.

  One third will make a good recovery, but one third will not survive or will live with long-term disability.

  Strokes are more likely to occur with ageing [2]
- Aetiology: Neurovascular



# Identifying the treatment gap and improving care for ischemic stroke patients



In the Stroke case study, both approaches are analysed with recommendations on how to improve stroke care:

- The patient care pathway analysis: key issues and unmet needs for stroke patients are described along the care pathway from prodromal, diagnosis, disease management to patient empowerment;
- The delivery of evidence-based interventions within the stroke unit: the economic impact of a full implementation of stroke unit care is evaluated.



# Identifying the treatment gap and improving care for ischemic stroke patients

## The case for integrated Stroke Units

Fig. 1: Hospital intra-extra mural care pathways and seamless care



Recognize symptoms & call ems

Timely ems response

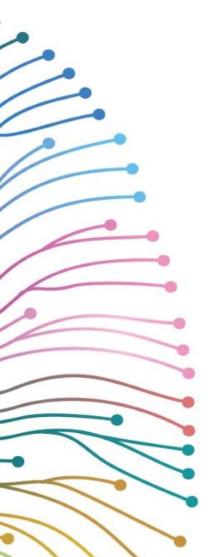
Transport & notify stroke center guidelinebased stroke care

Increasing survival rate

**Improving** patient QoL Reducing the overall burden associated with stroke



## **BC** Conclusions VOT-Stroke



- Major treatment gaps need to be addressed:
  - Inadequate treatment of atrial fibrillation
  - Low number of stroke units
  - Low access to stroke units
  - Full implementation of stroke services would be a costeffective treatment for acute ischemic stroke. Although provision of comprehensive stroke services represents a significant logistical and financial challenge the ultimate benefits are likely to be extensive, both in terms of cost and burden of death and disability.



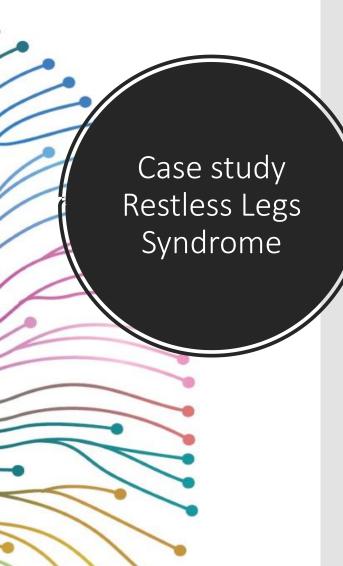
## Restless Legs Syndrome: the big picture





- Highly prevalent brain disorder which is not commonly recognized and as a result is often not/too late diagnosed and/or treated
- Aetiology: Neurological





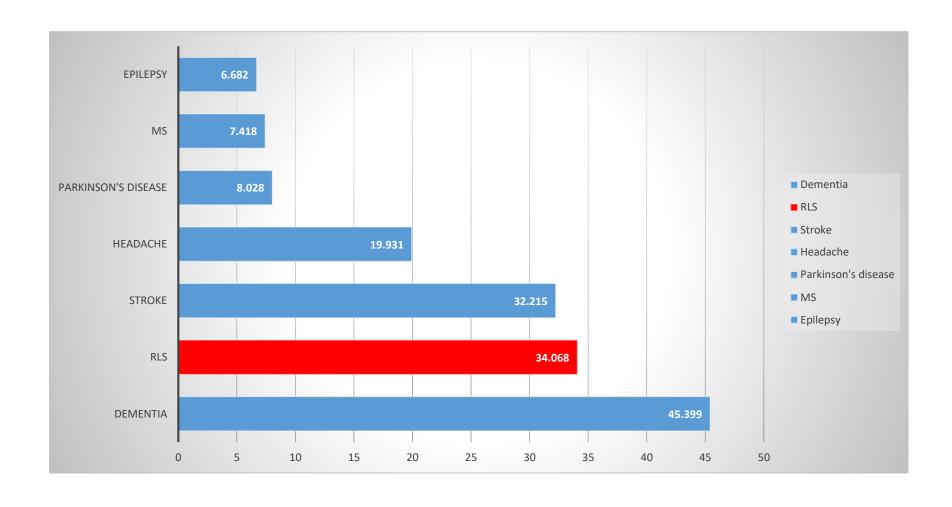
## Treatment gaps and unmet needs

- There is a huge lack of awareness and knowledge of RLS. As a result patients are not taken seriously, wrong diagnoses are made and false treatments given
- The knowledge among in particular primary care physicians leaves much to be desired, referrals to specialists ar often not done, resulting in delayed or false diagnoses and no or wrong treatment
- Medicines for RLS do exist. Treatment of first choice to date are the dopamine agonists. If applied incorrectly, adverse reactions to these drugs in RLS patients are frequent, the most severe adverse reaction being the paradoxical phenomenon called augmentation
- The number of truly knowledgeable RLS specialists in Europe is very limited
- Due to lack of awareness medicines are not reimbursed in many European countries
- All available medicines were registered for other diseases in the first place, there is no pharmacological research for RLS per se.

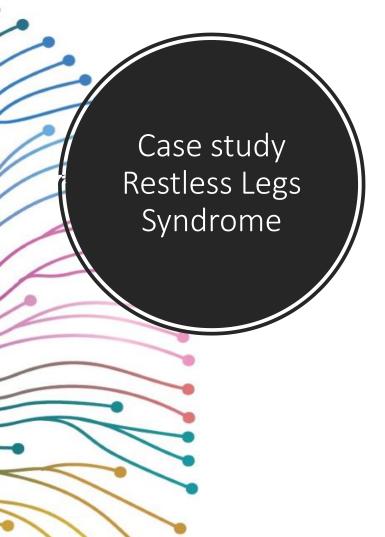


## Ranking Yearly total cost — NEUROLOGY







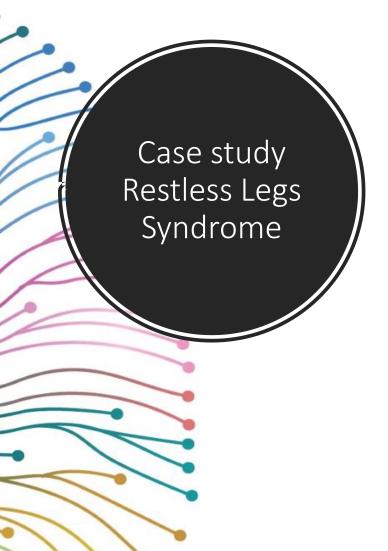


It is safe to say

......when translating RLS costs (and the impact of RLS inadequate treatment) to the general population we foresee substantial economic impacts. For example if we consider current epidemiological figures in the literature (2.7% with severe RLS) closing the treatment gaps in RLS may result in a few billions of euros saved annually by each of the EU country-specific healthcare systems.

LSE: July 2017



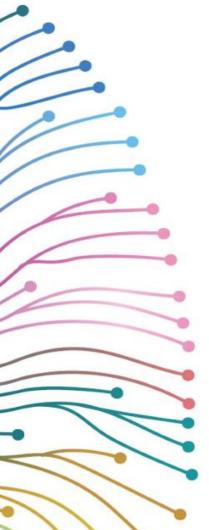


#### **Conclusions:**

- 1. Education about RLS is urgently needed to increase expertise of healthcare workers
- 2. The search into the cause(s) of RLS and for new treatment strategies has to be intensified in order to reduce the suffering of people with RLS and the high societal cost



## Overall Conclusions VoT



- 1. Position brain research on the strategic research agenda
- 2. Ensure brain disorders prevention and management are part of policy prioritization, implementation and evaluation

AT MACRO HEALTH SYSTEM GOVERNANCE LEVEL, **OUR ROLE** IS TO ADVOCATE FOR THE TRANSLATION OF POLICY RECOMMENDATIONS

INTO THE DEVELOPMENT OF RESEARCH AND PUBLIC HEALTH **BRAIN PLANS**