NEWSLETTER | AUGUST-SEPTEMBER 2022 | N° 50

# **BELGIAN BRAIN COUNCIL**



#### IN THIS EDITION

BBC, EBC, the European Comission and health policy

BBC and ERASMUS+ in 2022

What is Tinnitus?

Save the dates!

## **Belgian Brain Plan**

Like Operation Warp Speed (OWS), the BBC has launched the implementation of a public-private partnership to facilitate and accelerate the development of this BRAIN plan. Phase 1 and its budget have been negotiated with our partners from the pharmaceutical industry and to date 8 partners (Bristol Myers Squibb, EISAI, Ipsen, Janssen, Lundbeck, Merck, Pfizer and UCB) have accepted to participate in this challenge.

## BBC, EBC, the European Commission and health policy

The BBC has endorsed the EBC's letter to the European Commission calling for a thematic network on brain health. In this regard, the EBC (on behalf of its members and like-minded partners) supports and appreciates the focus on mental health, but calls on the European Commission to go further, urging the expansion of the proposed topic to "brain health", covering both mental and neurological disorders.

You will find below the full letter submitted to the European Commission - we call on the community to pledge support for the letter (on an individual or institutional basis) to help amplify our call and show the European Commission the importance of addressing the brain (preventive health and ill health) as a whole. Join us in our quest to get brain health fully recognized on the health policy agenda!

"The European Brain Council (EBC) and its members, as members of the European Health Policy Platform, would like to respond to the European Commission's call for a new cycle of thematic networks, organized under the European Health Policy Platform.

The EBC is particularly interested in the proposed theme of "mental health"; however, it would very much like to see the proposed theme expanded to "brain health", covering both mental and neurological disorders.

Some 179 million Europeans live with brain disorders, both mental and neurological. Brain disorders result in loss of quality of life, costs to the individual and society (health care costs, lost productivity) and lost opportunities. Currently, particular attention is being paid to neurological disorders such as Alzheimer's disease, Parkinson's disease and epilepsy. While it is positive that these brain disorders are receiving the attention they require, however, this leaves many others, including burdensome disorders such as stroke, multiple sclerosis, headaches, and sleep disorders still in the shadows and in need of increased attention. According to the World Health Organization (WHO) and recent studies, at least one in three people of all ages will suffer from a neurological disorder in their lifetime, making it the highest of all non-communicable diseases. In Europe, the cost of neurological disorders amounts to more than 800 billion euros, with dementia, stroke, headache and sleep disorders being the main cost drivers. With over 600 known neurological diseases and more than 450 known psychiatric disorders, many continue to be endured without appropriate preventive measures, interventions/treatments and virtually no cure. Many neurological diseases are accompanied by psychiatric symptoms and vice versa, as both mental and neurological diseases are due to the malfunction of the same organ, the brain.

This creates a massive, yet neglected, burden on society. In fact, it is a pandemic in its own right for our populations, which certainly deserves much greater awareness and attention than it currently receives. For a more holistic approach, addressing "brain health" as a whole also recognizes the need to care for our brains, whether through lifestyle or at a more complex level, such as neural development, plasticity, function, and recovery across the lifespan (as defined by the WHO)."

The European Brain Council proposes to lead the **Brain Health Thematic Network** in collaboration with its Member Organisations.

In addition to the National Brain Councils from Belgium, Greece, Serbia and Spain, this letter is supported and co-signed by the following organisations: EFNA, EAN, EANS, EPA, FENS, IBRO, ESO, SERVIER, Brain Capiltal Alliance.

## From Our Members

Congratulations to all members from de Steven Laureys' team, Research Director F.R.S.-FNRS Université de Liège

- → Ranked 1st worldwide by expertscape in consciousness expertise
- → Ranked 1st worldwide by expertscape in locked-in syndrome expertise
- → Ranked 1st worldwide by expertscape in persistent vegetative state expertise

#### BBC and ERASMUS + in 2022

The BBC is active in 2022 in 4 projects: Share4Brain, Care4Autism, E-CARE4PD and SAMENTA



The **Share4Brain** project for which the BBC was the coordinator ended on May 31, 2022 and was evaluated by the European Francophone Agency (EFA) very positively (score 83/100). The partners are from 5 countries Belgium, Spain, Greece, Serbia and Italy



The **Care4Autism** project, coordinated by the BBC, held its kick-off meeting in a hybrid way in Brussels on March 14, 2022. The partners are from Belgium, Spain, Greece and Latvia. The next transnational meeting is planned for May 17-19, 2023 in RIGA invited by the Autism Association of Latvia.



The **E-Care4PD** project is coordinated by the Asociacion Parkinson Madrid. This project is co-financed for a period of 24 months (from March 2022 to January 2024) by the European Commission. The main objective is to provide solutions and leverage technology and best practices as enabling tools to contribute to the well-being and improved quality of life. The Belgian Brain Council called upon the Parkinson Association who agreed to participate as an associate partner in the project and with whom we have already interacted on the occasion of the World Parkinson's Day in April 2022. The European Brain Council has also agreed to join the project.



The **SAMENTA** Project (SAnté MENTale des proches Aidants - Mental Health of the Family Caregivers) has just been selected by the Erasmus+ France Agency. It will start on October 1, 2022 and end on August 31, 2024. It is coordinated by the ASSOCIATION MARTINIQUAISE DES AIDANTS FAMILIAUX. The general objectives of SAMENTA are:

- 1) Strengthen the support for families of people with chronic diseases;
- 2) Improve the social participation of these families;
- 3) Create a network of partners and thus a community of practice to develop knowledge and skills. The partners are :







#### What is tinnitus?

Tinnitus is the hearing of a sound in the absence of an external sound. Often described as a buzzing sound, it can also sound like a clicking, hissing or rumbling noise.

A recent systematic review made by several departments (epidemiology, pharmacology, psychiatry, ...) of different European universities published in the JAMA (Journal of the American Medical Association) (ref.) estimates that more than 740 million adults are affected by tinnitus, which in severe cases constitutes a major health problem affecting mainly people over 65 years old. The authors conclude that this public health problem should be better known by policymakers and accompanied by an effort in funding tinnitus research.

The BBC can only agree with this conclusion and supports the efforts of the BBC member association Acouphène Belgique.

In 2016, the Federal Minister of Health, recognizing the impact on public health, sent a request for advice on tinnitus.

#### Tinnitus is an important public health issue

There is a need for research to assess and quantify the burden of tinnitus for Belgium. This study should not only focus on healthcare costs, but should also assess and quantify the burden associated with the impaired functioning of patients as well as with their increased susceptibility to other syndromes, such as depression and anxiety disorders.



#### ADVISORY REPORT OF THE SUPERIOR HEALTH COUNCIL No. 9332

Prevention, diagnosis and therapy of tinnitus. Health effects of recreational sound in children and young adults

This scientific advisory provides recommendations to improve care for tinnitus patients and to reduce and prevent health effects of recreational sound exposure.

With an executive summary in English, Dutch and French.

Validated by the Board in June 7, 20171

We do not know today if this 72-page report written by 11 experts has been followed up.

Carlotta M. Jarach, M.Sc.1; Alessandra Lugo, Ph.D.1; Marco Scala, M.Sc.1; et coll.Piet A. van den Brandt, Ph.D.2,3; Christopher R. Cederroth, Ph.D.4,5,6; Anna Odone, Ph.D.7,8; Werner Garavello, MD9; Winfried Schlee, PhD10; Berthold Langguth, MD10; Silvano Gallus, PhD1 JAMA Neurol. Publié en ligne le 8 août 2022. doi:10.1001/jamaneurol.2022.2189

## The US Now Has a Research Plan for Long COVID

The new plan recognizes the urgent need for research to elucidate the biological mechanisms underlying the more than 200 symptoms and signs and 50 conditions attributed to long-term VaDOC and to develop evidence-based treatments. But some say the plan - while a step in the right direction - references already existing federal initiatives that are insufficient and slow.

August 12, 2022 The US Now Has a Research Plan for Long COVID—Is It Enough? Jennifer Abbasi JAMA. Published online August 12, 2022. doi:10.1001/jama.2022.14536

## **Obituaries**

**François Mauguière**, 1st president of the French Brain Council until February 2022, has just lost his wife, Christine Baleydier Maugière. The BBC, which worked closely with François, sends him its condolences.

# Become a member Devenez membre Lid worden

Support our actions and become a personal member by paying 30€ on the account BE87 7512 0194 0094 by indicating your name and email.

Soutenez nos actions et devenez membre à titre personnel en versant 30€ sur le compte BE87 7512 0194 0094 en indiquant votre nom et email.

Steun onze acties en word persoonlijk lid door €30 over te maken op rekeningnummer BE87 7512 0194 0094, met vermelding van uw naam en e-mail.



The BBC is on the following social networks:











## Composition of the Executive Committee for the period 2021-2022

President: Professeur Laurence RIS

Secretary General: Professeur Roland Pochet

Vice-President: Professeur Chris Bervoets, Docteur Gianni Franco,

Baron Charles van der Straten-Waillet

Treasurer: Baron Charles van der Straten -Waillet

Secretary: Madame Lia Le Roy

# **Dates to remember**

## September 17

Francophone

Migraine Summit

with Pr. Jean

Schoenen as

speaker

## September 19

Conference by
Bart De Strooper
on Alzheimer's
disease

## September 20

Conference by Rik
Vandenberghe on
dementia



Activity of the Leuven Brain Institute with the support of the BBC



# **Dates to remember**

## 27 Septembre

Early Care Planning.
Thinking about your
care of tomorrow.
Linde Vande Casteele,
Consultante LEIF.
7-8pm

From the Flemish Parkinson's League: Online info sessions on living with Parkinson's disease

29-30 Septembre

"Endoderm and endoderm derivatives in development and disease" by the BSCDB

#### October 1st

5th Belgian
Scientific Stroke
Workshop

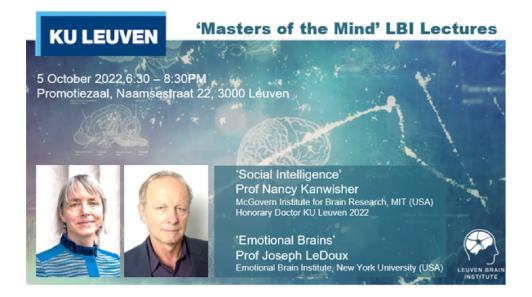




# **Dates to remember**

#### October 5

KU LEUVEN:
"Masters of the Mind"
LBI lectures



## October 14

<u>Autumn BASS</u> <u>meeting Nivelles</u>

## October 25

7pm-8pm
Parkinson's and
sexuality Jesse
Verschueren,
sexologist

#### October 15

Congress of the GRID
"DIALOGUE GENERAL
PRACTITIONERSALGOLOGISTS" Namur
- online enrolment
before 30/9



# **Dates to remember**

## September 21

**Implementing** precision and preventive psychiatry in **Europe** 



Wednesday, 21st September 2022, 13:00 - 17:30 CET









WHAT ACTIONS IMPROVE NUTRITION FOR BRAIN HEALTH FOR EUROPEAN CITIZENS?

Thursday, 22nd September 2022, 13:00 - 15:00 CET



## September 29

What actions improve nutrition for brain health for european citizens?

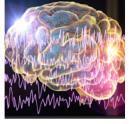
## September 29

Shaping the future of epilepsy research in <u>europe</u>















All of these hybrid meetings are happening online (Zoom) and at Rue d'Egmont 11, 1000 Brussels, <u>Belgium</u>