

# BELGIAN BRAIN COUNCIL



## IN THIS EDITION

The BBC, PATIENTS and  
Pharmaceutical Companies

Belgian Brain Plan Phase 2

**WASF3, a protein involved in  
chronic fatigue**

Croatian Brain Council & 10th  
Academy of National Brain  
Councils

News from our members

## 1. BBC, PATIENTS AND PHARMACEUTICAL COMPANIES

Here, **Ipsen** presents how the company can highlight the policy it has recently developed to streamline and integrate systems and processes in order to place patients' needs at the heart of its pharmaceutical activities.

At Ipsen we work *with* patients, *for* patients  
Together, we deliver better access to information and innovation to improve lives

WE WORK WITH MORE THAN **241** PATIENT ORGANIZATIONS WORLDWIDE ACROSS OUR THREE THERAPEUTIC AREAS

**48** RARE DISEASES

**130** ONCOLOGY

**63** NEUROSCIENCE

IPSEN'S COMMITMENT TO PATIENT CENTRICITY

We start the dialogue as early as possible with patients when developing new medicines

We collaborate with patient communities to develop solutions together that deliver long-term impact

We transform Ipsen science to make a meaningful difference to patients' lives

THE academy  
Discover Ipsen Academy, our platform that provides up-to-date information for patients

IPSEN  
Innovation for patient care

DRSC-BE-000068 - May 2023

## 2. Belgian Brain Plan

### Phase 2 is launched

Press release sent to Belgian journalists on 15 September:

#### **Data Governance Regulation: the Belgian Brain Council (BBC) launches the first altruistic brain and mental health data organization to facilitate research and the creation of a Belgian brain plan**

The European Data Governance Act (DGA) comes into force on 24 September 2023. This regulation encourages the voluntary sharing of data for altruistic purposes, such as scientific research or the improvement of public services, through data altruistic organizations.

In this context, the Belgian Brain Council (BBC), which brings together 26 patient associations and 28 scientific societies, is launching the creation of the first altruistic organization for mental health and brain data. It will be responsible for managing the Brain Data Hub, a secure IT platform for collecting and sharing data. The BBC intends to act as an ethical and trusted intermediary for patients wishing to make their health data available for scientific research and the creation of a Belgian brain plan.

The BBC's initiative comes at a time when mental health and brain disorders are at the heart of European concerns. More than a third of Europeans are thought to be affected. In June 2023, the European Commission launched an initiative to promote a global approach to mental health, stressing the importance of better data availability.

At Belgian level, the BBC has long campaigned for the creation of a register and a brain plan along the lines of what has been put in place in the fight against cancer.

*"It has to be said that the project for a brain registry has stalled. By creating an altruistic data organisation, the BBC is mobilising the new European regulations to move things forward and enable patients and their families to play a part in better research and health policy. Our initiative is attracting a great deal of interest beyond Belgium's borders. We are in discussions with several foreign associations who would like to join our project,"* says Roland Pochet, Secretary General of the BBC.

**The BBC is on the following social networks:**



• **Nine partners from the pharmaceutical industry are supporting phase 2 of the Belgian Brain Plan**



Inspired by **patients**.  
Driven by **science**.

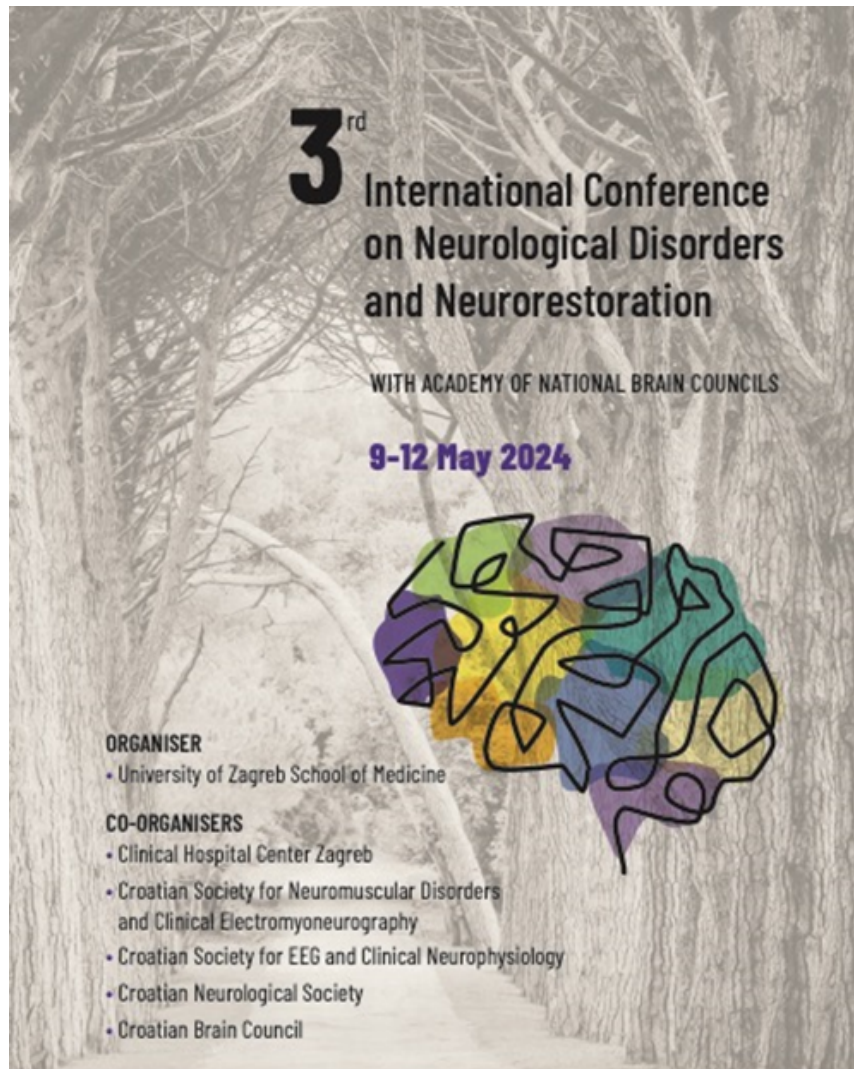
### 3. Research

**A protein that disrupts the energy centres of cells could be at the root of chronic fatigue syndrome and long-onset COVID.**

Researchers at the NIH (National Institute of Health, Bethesda, USA)<sup>1</sup> have found higher levels of a protein called WASF3 in the muscle cells of 14 people with myalgic encephalomyelitis/chronic fatigue syndrome than in samples from 10 healthy people. The exact cause of the excessive levels of WASF3, which interferes with energy-producing mitochondria, is not yet clear. Treatments that target the protein could help to combat related diseases, such as long COVID.

<sup>1</sup> WASF3 disrupts mitochondrial respiration and may mediate exercise intolerance in myalgic encephalomyelitis/chronic fatigue syndrome in Proc Natl Acad Sci U S A. 2023 Aug 22;120(34)

## 4. Croatian Brain Council and 10th Academy of National Brain Councils




**Brijuni National Park / CROATIA**

**The 10th NBCs Academy will be in Pula (Croatia)  
on May 8-9, 2024 hosted by Pr. Dinko Mitrecic**

The event will take place in the Brijuni national park, an island located 10 minutes by boat from the town of Pula. As well as being a magnificent place (protected nature, golf club, private zoo, etc.), the park will be visited and a dinner will be organised in Pula. A visit and dinner will be organized in Pula.

## 5. NEWS FROM OUR MEMBERS

- **SERVIER** has joined us as a partner. 

Servier is a French pharmaceutical group. Founded in 1954, it is present in 150 countries. Servier has been present in Belgium for 50 years. Every year, Servier invests more than 20% of its sales in R&D, particularly in oncology, cardio-metabolism and neuroscience. Servier focuses its R&D efforts on the discovery of new drugs that slow the progression of rare or genetic diseases affecting sub-populations of patients and caused by abnormal proteins (often due to a genetic mutation). This is the case for certain movement disorders, such as certain forms of Parkinson's disease, as well as rare neurodegenerative diseases of genetic origin, such as spinal-cerebellar ataxias or familial forms of amyotrophic lateral sclerosis.

- **DMLA**

To mark World Sight Day 2023, there will once again be three free screening days for DMLA.

We would like to thank the ophthalmology departments that will be providing these services:

- Monday 9 October at CHIREC in Braine L'Alleud-Waterloo from 1pm to 5pm
- Wednesday 11 October at CHIREC - DELTA from 11am to 4pm.
- Thursday 12 October at the CHU BRUGMANN in Laeken from 8am to 11am and from 1pm to 5pm.

These screenings are for people over the age of 55.

More details at <https://www.dmla.be/depistages-gratuits-de-la-dmla/>

- **BASS** is organising a course on CBT-I, cognitive behavioural therapy for insomnia, in Dutch for psychologists



**B**elgian  
**A**ssociation for  
**S**leep research and  
**S**leep medicine



<https://www.belsleep.org/education/cbt-i>

- **The Belgian National Multiple Sclerosis League reports:** WHO decision brings hope to multiple sclerosis sufferers worldwide  
See : <https://ms-sep.be/la-decision-de-loms-apporte-de-lespoir-aux-personnes-atteintes-de-sclerose-en-plaques- dans-le-monde-entier/>
- **University of Antwerp** is organising on 30-31 October the 18th international GEPD (Genetic Epidemiology of Parkinson's Disease consortium) meeting.  
See programme at :  
<https://www.uantwerpen.be/en/conferences/international-meeting-geopd/programme/>
- **The Belgian Society of Paediatric Neurology** is holding its autumn conference in Brussels on 17 November. On this occasion, our President, Laurence Ris, was invited to present the BBC and its interactions with member scientific societies.  
See programm at : <http://www.bspn.be/agenda/index.asp?ang=en&navid=145&id=2328&mod=agenda>

## Support Our Actions I



12 videos about different BBC activities/meetings/webinars are visible on UTube at: <https://www.youtube.com/@BBCBelgianBrainCouncil>

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

Chairman: Professor Laurence RIS

General Secretary: Professor Roland Pochet

Vice-Chairmen: Dr Gianni Franco, Baron Charles van der Straten-Waillet

Treasurer: Baron Charles van der Straten -Waillet

Secretary: Mrs Lia Le Roy

## Dates to remember

<p><b>9-14 October</b> Erasmusdays 2023</p>	<p><b>14 October</b> Zaterdag 14 oktober 2023 van 13 tot 17 uur in Gent Zeventiende en 'Open Geest'-editie</p>	<p><b>26-27 October</b> Brain Innovation Days: The Brain in the 21st Century, Brussels</p>
<p><b>30-31 October</b> 18th international GEPD (Genetic Epidemiology of Parkinson's Disease) meeting. UZ antwerpen</p>	<p><b>16-17 November</b> Société française de mouvements anormaux French-Belgium symposium</p>	<p><b>17 November</b> Belgian Society of Pediatric Neurology Congress</p>
<p><b>21 November</b> Leuven Brain Institute Science Day (see <a href="https://www.kuleuven.be/brain-institute/events-and-outreach/lbi-2023-science-day-november-21st-1-6pm-neurodiversity">https://www.kuleuven.be/brain-institute/events-and-outreach/lbi-2023-science-day-november-21st-1-6pm-neurodiversity</a>)</p>	<p><b>May 8-9, 2024</b> 10th NBCs Academy in Pula (Croatia)</p>	<p><b>May 14-15, 2024</b> BBC International Symposium: Are data the future for a better Brain and Mental Health?</p>