

BBC newsletter n° 39 April 2021-ENG

EDITO

The long COVID, a public health problem: it is time to act!

By initiative of the scientific community, which proved the impact of this disease and understood why it takes place, NIH (National Institutes of Health) set aside a budget of \$1.15 billion in favor of research on long COVID¹.

BBC, following its mission to reliably inform the public, joins this movement and pleads for action at Belgian and European levels(in collaboration with the EBC and other national brain councils), wants to be proactive and avoid the chaos and misinformation suffered during the pandemic.

Many of our members have already alerted the public, like Charles van der Straten in his March EDITO² and in a recent article in Standard³ where professor Paul Boon, head of service of the neurology department at UZGent, comments on a testimony of a long COVID patient: *Sometimes I make a phone call and halfway through I don't know who I'm talking to or what we're talking about. (Standard, April 16).*

It is with this vision that BBC has gathered researchers, clinicians and patients to take stock of the situation on Saturday, September 11 and make recommendations to politicians.

Consult the program below Thanks to sponsorship received from 8 pharmaceutical companies, access to the WEBINAR is free of charge, but registration is obligatory.



BBC Webinar: "Impact of COVID-19 on brain diseases and mental health"

SATURDAY, September 11, 2021 10:00 am - 11:30 am

Program

On-line connection: the webinar will be presented bilingually FR/NL with three channels (one FR, one NL and one without translation) in an interactive way thanks to Slido and moderated by Vanessa Costanzo.

Introduction

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¹<u>https://braincouncil.be/files/covid-long-usd/view</u>

² <u>https://braincouncil.be/fr/Newsletter/mars-2021</u>

³ La traduction française de l'article est accessible à : <u>https://braincouncil.be/fr/article-du-standard-16-04-2021-en-fr/view</u>

- Prof. Patrice Boyer, psychiatrist, VP of the European Brain Council⁴ **5 min First part: Impact of COVID-19 on mental health of the general population**
- *Impact of the COVID-19 pandemic on the youth's mental health* by Prof. Fabienne Glowacz (ULiège), specialist in clinical psychology of delinquency. **10 min**
- *Mental health before and after the pandemic: importance of the vagus nerve for biopsychological resilience* by Dr. Marie-Anne Vanderhassel (UGent), Psychologist Department of Head and Skin **10 min**

Debate + Q&A 10 min

Second part: Impact of COVID-19: from the patients' perspective 20 min

The approach of VPP (Vlaamse Patienten Platform) by Eline Bruneel The approach of the LUSS (Ligue des usagers de service de santé) by Sabine Corachan Video testimonies of 2 patients : Françoise Malvaux and Luc Swenters

Third part: The long COVID-19 or post-acute sequelae SARS-CoV-2 infection (PASC)

- *The neurobiological basis of long-lasting neurological symptoms induced by COVID-19* by Prof. Paul Boon (UZGent), neurologist **(10 min)**
- Therapeutic prospects for long covid syndrome by Prof. Paul Verbanck (ULB), psychiatrist (10 min)
- **Debate + Q&A 10 min** with the minister Frank Vandenbroucke *(tbc)* **10 min** With the support of

Débat + et questions-réponses 10 min avec le Ministre Frank Vandenbroucke (tbc) 10 min



EARLY DETECTION OF SIGNS OF PARKINSON'S DISEASE AND ITS COMPLICATIONS, FOR BETTER PROGNOSIS OF LIFE

BY DR. GIANNI FRANCO, president of the EplC (Ensemble pour le Cerveau) and APk.

Between 30.000 and 50.000 suffering from Parkinson's in Belgium, 4 million to 6 million in Europe and between 12 million and 17 million expected by 2040. Increasingly precise genetic profiles and multiple environmental triggers of which pesticides seem to be the most involved. A disease that progressively and insidiously limits autonomy and isolates on a socio-economic and cultural level. More and more treatments with multiple approaches (per os, subcutaneous and transdermal, intraduodenal, intracerebral neurostimulation etc., with a future already wide open thanks to stem cells, immunotherapy, the brain-gut relationship and more).

On the occasion of the DANA Foundation's **Brain Awareness Week 2021**.

⁴ https://www.braincouncil.eu/wp-content/uploads/2021/01/EBC-COVID-19-Statement-Final.pdf

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The EplC (Ensemble pour le Cerveau), member of the BBC (Belgian Brain Council), and supported by APk (Association Parkinson francophone belge), EPDA (European Parkinson's Disease Association), HENALLUX (Haute Ecole Namur Liège Luxembourg), and the EBC (European Brain Council), recalled the benefits of a broad synergistic multidisciplinarity through the awareness and detection campaign "*EplC Parkinson Care Sentinel Network*".

This campaign brings together since 2017 more and more professional stakeholders in health and field research, from doctors, through pharmacists to all paramedics and caregivers, by including patients and their close caregivers as participatory actors in their own future... You can consult the three conferences of the EplC BBC BAW 2021 via the Youtube link: https://lnkd.in/g29quHi .

On the other hand, on the occasion of the **Worldwide Parkinson's Day 2021**, APk (Association Parkinson francophone belge), supported by EplC, BBC, EPDA, EBC has also induced another awareness campaign "*Sleep in Parkinson's disease. How to preserve and improve it in the face of Covid19.* " of which you can consult the video via Vimeo : <u>https://vimeo.com/534440091</u>, and will soon be included in EPDA's European campaign on Parkinson's disease and sleep.

April 15th, BBC took part in the 7th National Brain Councils Academy



There are currently 11 National Brain Councils, i.e. associations with a legal structure (statutes, publication in the Official Journal, etc.)

On the occasion of this Academy, Mr. Pierre Delsaux, Director General (ff) of DG Health expressed the interest of the European Commission for brain research which was also supported by Mr. Tomislav Sokol member of the European Parliament. Mr. Delsaux also insisted on the role of the Member States in this choice of priorities. This presentation encourages all NBCs to act in unison with their state's decision-makers.

The video is accessible via YouTube: <u>https://www.youtube.com/watch?v=VlZML3cSxrc&t=2s</u>

• The BBC has given its support (see call in the March newsletter) to the COMA group of the CGU of Liège, member of the BBC during the photo contest organized by the King Baudouin Foundation.



The COMA group was able to winone of the public prizes (16,000 votes were cast), which will allow them to highlight the importance of patients suffering from neurological diseases and in particular disorders of consciousness!

Link to the video presentation of the winning photos : <u>https://www.youtube.com/watch?v=Z0YyW7S3O8I</u>

• April 22nd

Presentation to project participants of the results of the Global Brain Health Survey, designed to assess people's perceptions of brain health and the factors that influence it. The BBC is one of the partners.



27,590 responses were collected covering 81 countries. The results and recommendations are still under embargo and will be made available through a scientific publication.

If you are interested in our activities, support the BBC and become a member



BBC communication and dissemination tools

Thanks to the assistance of Spyros Zorbas from Epioni (associate and partner of Share4Brain),

Valentina Micco and Mathieu Alberteau, EU4EU trainee, the dissemination via Twitter of the Belgian

Brain Council and Share4Brain reached respectively 1.208 and 258 followers.



Tool for our members to use in any advocacy efforts: Evidence on the exceptionally high burden of brain disorders https://braincouncil.be/en/burden-of-brain-diseases_evidence

Important dates (more details online at braincouncil.be)

May 18th	BBC General Assembly
May 30th	Wereld MS-dag / Journée mondiale de la Sclérose en plaques
	(Worldwide Multiple Sclerosis Day)
June 5th	Charcot Foundation-MS Symposium
June	Leuven BASS spring meeting
September 11th	BBC WEBINAR