NEWSLETTER | NOVEMBER - DECEMBER 2021 | N° 44

# **BELGIAN BRAIN COUNCIL**



#### IN THIS EDITION

Covid Long KCE Report

Music and Medicine

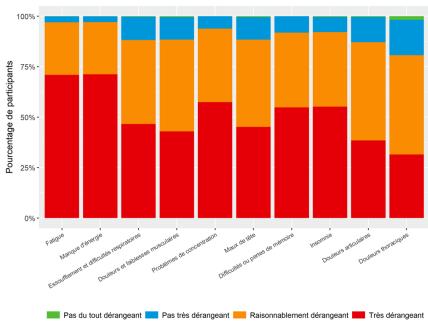
Share4Brain Programme

France mobilises for the brain

# COVID LONG – KCE REPORT SEEN THROUGH THE EYES OF THE BBC

#### BY ROLAND POCHET

One month after our WEBINAR on COVID LONG, <sup>1</sup> already viewed 732 times (between 16/09 and 1/12), the Federal Centre of Expertise, the KCE, publishes a report: NEEDS AND FOLLOW-UP OF PATIENTS WITH COVID LONG. The scientific report and its supplement are in English, the report has 287 pages and a supplement of 160<sup>2</sup> pages. An excellent synthesis of 35 pages was written by Karin Rondia (FR version)<sup>3</sup> and Gudrun Briat (NL version). From this synthesis, I will take some extracts focused on the neurological and mental health aspect as well as figure 4 of this summary which shows the patients' perception of the effect of the different symptoms.



https://052ed37d-b351-47d9-a61c-1368b04db174.filesusr.com/ugd/5e315e\_f59ce237c9f24cbca2b0ba340599296f.pdf

- <sup>2</sup> Castanares-Zapatero D, Kohn L, Dauvrin M, Detollenaere J, Maertens de Noordhout C, Primus-de Jong C, Rondia K, Chalon P, Cleemput I, Van den Heede K. Behoeften en opvolging van patiënten met langdurige COVID Synthese. Health Services Research (HSR). Brussel: Federaal Kenniscentrum voor de Gezondheidszorg (KCE). 2021. KCE Reports 344As. D/2021/10.273/28.
- 3 https://kce.fgov.be/sites/default/files/atoms/files/KCE 344B Covid long Synthese 0.pdf
- 4 <a href="https://kce.fgov.be/sites/default/files/atoms/files/KCE-344A-Langdurige-Covid Synthese\_0.pdf">https://kce.fgov.be/sites/default/files/atoms/files/KCE-344A-Langdurige-Covid Synthese\_0.pdf</a>

On page 19, for example, we read about health-related quality of life (HRQoL): The literature review leads to the conclusion that long COVID has a negative impact on the quality of life of those affected. The KCE online survey confirms this finding.

I will add here a study published on 22 October 2021 on the one-year follow-up of 176 survivors who were hospitalised from COVID which concludes: Deterioration in HRQoL is common one year after discharge from the intensive care unit, and the lowest recovery is in mental health.

- On page 20 on psychological impact: Participants emphasised the importance of informing the general population as well as health professionals about long term COVID so that their difficulties are better recognised.
- On page 22 on treatment: Given the heterogeneity of symptoms, the lack of a clear diagnosis and the absence of knowledge among professionals, the treatment approach is neither coordinated nor standardised. Many participants explain that when they were treated, it was on their own initiative. There is no integrated interdisciplinary approach to care.
- Page 30: With regard to neurocognitive problems, the current rules are not adapted to diagnose and treat the specific problems encountered by patients with long COVID, which require the intervention of neuropsychologists. It seems useful to propose the establishment of a functional, interdisciplinary and holistic assessment, followed by a referral of patients adapted to a care pathway. This seems particularly necessary for patients who have not been hospitalised.

In addition to these recommendations, I would like to quote a few sentences from an article in The Harvard gazette of 19 November 2021, which narrate on a meeting where the topic was: Long-term sufferers of VaDOC face physical pain and physician scepticism by Alvin Powell, Harvard Staff Writer, extracts:

- While the disease remains mysterious, the panelists explained that the way to follow was to start with listening and trusting patients.
- Davis said she finally felt heard when she consulted a doctor with myalgic encephalomyelitis and chronic fatigue syndrome, which have overlapping symptoms.
- Recommendation to convene expert groups who can begin to standardise the knowledge and language around this disease so that health professionals have a common body of knowledge to draw on; and encouragement for patients to remain active and insist on being heard.

In line with the KCE report which notes that much remains to be done, the BBC, with the support of its members, is strengthening its approach and is working to follow up its WEBINAR on 11 September.

If you wish to listen again to some of the speakers here is the link to the video in FR and the time slots for each speaker.

Link to the NL version: <a href="https://www.youtube.com/watch?v=Tc8UYJ-9wd8">https://www.youtube.com/watch?v=Tc8UYJ-9wd8</a> Link to the FR version: <a href="https://www.youtube.com/watch?v=2K|x4|I1|6E">https://www.youtube.com/watch?v=2K|x4|I1|6E</a>

The speakers spoke at the following times:



Patrice Boyer (EBC) <u>5:30</u> - <u>10:58</u>



Fabienne Glowacz (Uliège) 13:06 - 19:28



Marie-Anne Vanderhasselt (UGent) 20:20 - 28:07



Brieuc Van Damme (INAMI) 29:30 - 41:04



Sabine Corachan (LUSS) <u>49:04</u> - <u>53:45</u>



Eline Bruneel (VPP) 58:32 - 1:03:23



Paul Boon (UGent) <u>1:08:51</u> - <u>1:18:13</u>



Paul Verbanck (ULB) <u>1:21:01</u> - <u>1:27:27</u>

Video of patients Françoise Malvaux (45:19 - 48:04) and Luc Swenters (54:43 - 57:44)

The BBC is on the following social networks:









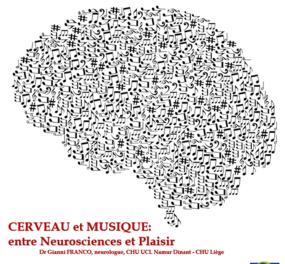


# BECOME A MEMBER **DEVENEZ MEMBRE JD WORDEN**

30€ at BE87 7512 0194 0094 with name + email

Symposium: MUSIC and MEDICINE, IMEP, November 2021 "BRAIN and MUSIC: between Neuroscience and Pleasure.









#### **By Gianni Franco**

In the context of the synergistic links and exchanges created by the Belgian Brain Council, the EpIC and Henallux, I was particularly honoured and enthusiastic to contribute to this symposium organised by the IMEP (Institut Royal Supérieur de Musique et de Pédagogie), in Namur.

Music and the neural symphony. Music engages the brain as a whole, not only the auditory regions, but also the motor areas and reward-related circuits involved in memories and emotions. Visual areas spontaneously associate images and shapes, even textures and colours, with the music being played.

The exercise of music creates new neurons (neurogenesis), but above all multiplies the connections (synapses) to optimise our performance: this is cerebral plasticity.

Music is capable of transforming our brain and its functioning... often for the better.

Between the upper part of the temporal lobe, which processes the most basic components of music (notes, rhythms, melodies), and the inferior frontal cortex, which processes and perceives the more complex components of music, such as its syntax, and also the memories dedicated to music, which largely concern the two hemispheres, the brain of musicians is hyper-connected.

At any age, learning music has measurable effects on verbal reasoning and short-term memory, concentration and performance in mathematics classes, a larger vocabulary, foreign language learning, socialisation, ... a broader "intelligence".

Music stimulates the synthesis of oxytocin, the hormone of love, in infants when they listen to their mother's lullaby, and improves the outcome of patients who have undergone surgery.

Musical anhedonia, amusia and absolute ear are rare variants.

And musical pleasure, ranging from direct sensory stimulation to the "musical thrill" linked to the satisfaction of a constructed expectation, and also to the more refined pleasure of the music lover, is a source of fulfilling harmony.

There are many examples to remind us of the artistic creativity linked to sleep (e.g. Paul McCartney's "Yesterday" 1965 which was created just after waking up one morning)

But what is the impact of Music on brain diseases?

The regions involved in the memories of Music are widely spread over the Brain, which explains their resistance to neurodegenerative diseases.

"Which of the two powers can raise man to the most sublime heights, love or music? This is a great problem. Yet it seems to me that one should say this:

Love cannot express the idea of music, while music may give an idea of love... Why separate one from the other? They are the two wings of the soul."

(Memoirs - Berlioz)

And what would be the soul without the brain? What do you think?

#### BBC, Erasmus +, EBC & NBCs

#### **Share4Brain programme**

- As a reminder, the BBC is the coordinator of this project
- 3rd meeting Madrid (25-26 November 2021).
- The participants were hosted in the prestigious Ramon Y Cajal Institute. The very diversified programme, elaborated by our host, Dr. Jose-Luis Trejo, President of the Spanish Brain Council, allowed fruitful interactions between different stakeholders: patients, researchers, clinicians and the Director of Public Health of the Spanish Ministry of Health (at federal level). Mr. Frédéric Destrebecq, CEO of the European Brain Council, presented the strategy of the EBC which, in collaboration with the NBCs and in particular those of Spain, Greece, Serbia and Belgium, aims to make the brain and its health a priority at both Member State and European Union level. The BBC was represented by its President, Laurence Ris and its Secretary General.







The Brain is a policy priority

and must be addressed as such...

- The European Union is taking it up
  - Horizon Europe's Brain Health Partnership
  - EU Joint Action on Brain Health?
- We need EU Member States to follow and support
  - Develop National Brain Plans
  - Interact &Coordinate between countries

Dia de conclusion de la présentation de Frédériq Destrebecq à Madrid

# **News from our members**

### Patient associations and corona measures. A message from Lia Le Roy

21 July 2021 - a memorable day.

Since March 2020, it has been impossible to organise physical peer-to-peer contacts.

This summer, the measures were relaxed. Brain Tumour Working Group asbl decided to organise a walk in Buggenhout forest. The route was signposted by Camino, wheelchair ramblers. The sun was out and everyone looked radiant. It was such a pleasure to see each other again. And the ice cream afterwards, that tasted ... .

Because of the coronation measures, such contacts between fellow sufferers are difficult to organise. The target group of patient associations are patients, so we have to be extra careful. We do try to keep in touch with members by telephone and e-mail. Following webinars and digital sessions (Teams, Zoom, etc.) is sometimes difficult. You need to have the necessary hardware and software, which is not the case for everyone, and it is sometimes difficult for people with a neurological disorder to learn and use these new applications.

But we remain committed, also in terms of advocacy.

Hoping for better times.

Lia Le Roy, chairperson Brain Tumour Working Group.

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

President: Professor Laurence RIS

Secretary General: Professor Roland Pochet

Vice-Presidents: Professor Chris Bervoets, Dr Gianni Franco, Baron

Charles van der Straten-Waillet

Treasurer: Baron Charles van der Straten-Waillet

Secretary: Mrs Lia Le Roy

Honorary Presidents: **Jean Schoenen, Rufin Vogels, Dirk Van Roost, Philippe Lenders** 

## **Dates to remember**

14-20 March

Brain Awareness WEEK 11 June

**BPS Congress** 

