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The disturbance in cerebral perfusion is well documented by technetium scintigraphy (Brain SPECT-CT). However, the lesions are most clearly visible in the first two years.¹

¹ Jamoulle, M., Kazeneza-Mugisha, G., & Zayane, A. (2022). Follow-up of a cohort of patients with post-acute COVID-19 syndrome in a Belgian family practice. *Viruses*, 14(9). 2000. <https://www.mdpi.com/1999-4915/14/9/2000>

² Menezes, S. M., Jamoulle, M., Carletto, M. P., Moens, L., Meyts, I., Maes, P., & Van Weyenbergh, J. (2024). Blood transcriptomic analyses reveal persistent SARS-CoV-2 RNA and candidate biomarkers in post-COVID-19 condition. *The Lancet Microbe*.

The impact on patients' lives is serious as shown in the header figure, which is a word cloud of the reasons for consultations of the first 34 patients in our study, the concept of "Loss" (of self, of faculties) dominates all other complex and unusual symptoms. It is estimated that 7-10% of patients with acute COVID-19 develop some form of Long Covid. Of these, almost half no longer work or hardly at all. Many lives are destroyed. Doctors do not have the means to diagnose this disease, and they tend to disregard what patients have to say, leaving them feeling abandoned.

Three years of support and research.

Here's a look back at the clinical-scientific process I began in July 2021 by creating an online classified bibliography which enabled me to analyze the information gathered from a cohort of 183 patients to date.³

We have collected standardized patient interviews, which are currently being analyzed by Olivier Schmitz, an anthropologist specializing in qualitative analysis (UCL).

Then, thanks to the CHGE network (<https://www.covidhge.com/>) and the help of Professor Casanova (Necker & Rockefeller), I was put in touch with the KU Leuven, Rega Institute. This network also includes the proteomics department at Ghent University, the Brodin Lab in Stockholm, and the Necker lab in Paris (genomics). Blood samples of more than 150 patients have been collected, creating a very substantial clinically documented biobank that we are now making available to Professor Nicaise, a neurobiologist at UNamur conducting in-depth research into anti-neuronal antibodies.

We developed this from our funds, with a little initial help from the King Baudouin Foundation and maximum personal investment from myself and Johan Van Weyenbergh, a senior immunologist at the Rega Institute and a specialist in transcriptomics. We ran out of money to pay for the reagents, so we had to store them in the freezer, so we could restart the analysis at any time if funding is obtained.

Our ongoing projects are as follows;

- Continuing to provide clinical assistance to patients and to receive wandering patients
- Continue to create a clinical/immunological database whose data expressed on the cloud can be used by the various researchers, under strict ethical conditions, a project described in Nature ⁴
- Continue to collect blood from these patients
- Continue to collect qualitative material from the patients
- Resume transcriptomic and metabolomic analyses as soon as we have a budget for reagents
- Proteomic analysis is ongoing (funded by VIB/University of Ghent)

³ Open bibliography classified online on Long covid https://www.zotero.org/groups/4929325/long_covid_open_library/library

⁴ Jamoulle, M., Louazon, E., Antonacci, T., & Van Weyenbergh, J. (2024). Speed up relief for long COVID through grassroots clinical trials. *Nature*, 626(8001). <https://orbi.uliege.be/handle/2268/314613>

- Resume therapeutic trials guided by biomarkers, with patient-reported outcomes before and after taking the drugs being tested ⁵

The financial effort should be focused on

- 1/The purchase of reagents for transcriptomic and metabolomic research
- 2/Development of the clinical-biological information system (data engineering).

The operational network is impressive. The nodes of the network are;

- Cabinet Janson Charleroi, Belgium, Clinical data (ULg)
- Rega Institute, Biobanking, Metabolomics, Transcriptomics, Systems Biology, KU Leuven, Belgium
- Institut de recherche santé et société, Anthropology, UCL, Belgium
- Proteomics department at Ghent University, Belgium
- Brodin Lab, Karolinska Institute, Immunology, Sweden
- Necker genomics lab, Paris, France
- Neurobiology department, University of Namur, Belgium

We are looking for investors in this cutting-edge field of clinical and immunological research.

Thank you



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⁵ UniteToFight. (2024, June 8). Johan Van Weyenbergh: Patient-Driven Long COVID Clinical Trial (UniteToFight2024 Day 1, Block 1). <https://www.youtube.com/watch?v=nQTq6u2H5zk>