



## BELGIAN CHARCOT FOUNDATION

FIGHTING MULTIPLE SCLEROSIS

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# NEWSLETTER

Belgian Charcot Foundation  
Public interest foundation

Under the Patronage of Her  
Majesty The Queen

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## Research “on the move”

**T**he 30<sup>th</sup> World Multiple Sclerosis Day of 30 May 2022 is a unique opportunity to support MS patients, their families and friends, and inform and increase public awareness of this neurological disease. This year's subject is 'Connections' - the connections not only between patients, but also between patients, carers, and the researchers involved. Exchanges of ideas and results are what enables research to progress.

“On the move” is the watchword of this issue of our newsletter, in which we keep you abreast of the research projects in this area that are funded thanks to the generosity of the Charcot Foundation's donors. Their gifts and legacies are what enable our researchers to explore new possibilities and confirm others, in order to improve the treatment of MS patients.

In this newsletter and on our website, you can read and view an account of a visit to two research labs that are directly involved on research on movement. Both teams are working on the science of rehabilitation and using their research to improve assistance to MS patients.

Thanks to the Charcot Foundation and your support, **Prof. Peter Feys (UHasselt)** and his team have been able to purchase a device and begin researching “double-tasking” in the rehabilitation process. At the Fraiture-en-Condroz Neurological and Functional Rehabilitation Centre, **Dr Olivier Bouquiaux (CHU Liège)** is working on a 'golden ratio', i.e. the achievement of the best balance between medical and physical care to be used by healthcare personnel during the re-education and reactivation of patients.

Finally, may I request that you support our walkers and runners at the 20 km of Brussels race (29 May 2022) by making a donation on our website: [www.fondation-charcot.org/en](http://www.fondation-charcot.org/en).

Prof. Dr Christian Sindic  
Président



# Basic research on neurorehabilitation

**Professor Peter Feys (UHasselt) started his research project in 2020 with the support of the Charcot Foundation: "Implicit and explicit learning strategies to improve the performance of a mobility-related cognitive and motor double task in MS patients".**

The purpose of this research project on the best instruction and feedback methods for teaching new movement tasks is to improve rehabilitation programmes for patients with MS-related cognitive disorders.

This project also studies the manner in which complex lower-limb movements can be taught to people with cognitive and motor impairments. They learn movements in a specific order by receiving various types of instruction or feedback (e.g. sounds or music). The degree of automaticity is then measured during double tasks in which the subjects walk and perform a cognitive task simultaneously. During movement with and without double-tasking, cerebral activity in the areas responsible for movement planning is measured with electrodes placed on the front of the skull. The results of this study may enable rehabilitation programmes for people affected by both motor and cognitive impairment to be improved.

## “ Optimise rehabilitation programmes

Professor Feys explains: "Neurorehabilitation is the rehabilitation that specifically aims to improve cognitive, physical and also psychological function in patients with neurological diseases such as multiple sclerosis. The primary purpose of our research is to map and measure these functional issues.

For instance: physically, we observe the way people walk. We measure the speed of their steps and determine their manner of walking by placing sensors on the feet and body. It's essential to understand how people walk, as walking involves muscles, but also, of course, the brain and the signals it sends to the body. The Charcot Foundation has helped us undertake this mechanical research. We had expertise in measuring the performance of double tasks, but neither the expertise nor the equipment to also measure brain activity. The Charcot Fund has enabled us to purchase specific equipment for that type of measurement."



"When people think of physical training, they think in terms of muscle training with strength equipment, and also cardio training. But we're also looking at combined forms of training such as dancing. We've noticed that the fact of adding rhythm stimulates other cerebral networks and improves patient performance. We've developed a smartphone app that sends highly specific coaching programmes to multiple-sclerosis patients. For instance, the app users can say whether or not they're slowing down, why they're slowing down or if they're tired. We try to measure patient mobility in those terms, and also to coach them, to increase their physical activity."

### A future in 3D

"In order to improve our understanding of movement in MS patients, we use special treadmills combined with virtual learning

# The impact of our donors on MS research



environments. These enable us to take very detailed and accurate measurements of knee, foot, hip, pelvis and torso movements and better understand the control exercised by the brain on those actions. At our movement lab, we also map all everyday actions, as in daily life people walk, encounter obstacles, people move around you, you have to be very attentive to your surroundings, and this device enables us to measure the abilities of MS patients in a single task. The patients wear a kind of balaclava fitted with electrodes. Our ultimate goal is to link movements to brain activity and achieve a full picture of movement in a subject."

Want to know more? You can watch the full video of this interview on [www.fondation-charcot.org/en](http://www.fondation-charcot.org/en).

To overcome MS, we absolutely need to understand the way this disease works. Although university labs and research centres do have MS research budgets, they are limited. Each year, research teams apply to the Charcot Foundation.

**2018-2022: a significant increase in the number of projects, and therefore a major impact on knowledge**

Over the past 5 years, the Charcot Foundation has financially supported 47 research projects, whereas in 2013-2017 it was possible to finance only 30 projects.

The scope of research is both broader and more detailed

- One third of these projects, i.e. 15 projects, relate to the immunopathology of multiple sclerosis. They include research on B lymphocytes (3 projects), T lymphocytes (4 projects), neutrophils (1 project), natural killer cells (1 project), and most of all macrophages and microglia in the central nervous system (6 projects).
- 17 projects focus on the mechanisms of the disease and potential activity markers. They study genetic susceptibility factors, DNA modifications, the presence of extracellular vesicles, protease activity, the role of the gut microbiome, the specific inflammation of the hippocampus (the area of the brain in charge of memory), the pathological accumulation of fatty acids and the measurement of the impairment of the blood-brain barrier.

€7 A MONTH FOR ONE YEAR  
= ONE DAY OF RESEARCH

Donating €7 a month by standing order really supports research into MS in Belgium



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Gifts of €40 or more are tax deductible.



## YOUR WILL CAN MAKE A DIFFERENCE

Has the Belgian Charcot Foundation ground to a halt this year? Far from it. Research into multiple sclerosis has continued unchanged. After all, our researchers know how many MS patients are counting on them to find a solution to a disorder that is still incurable. Their research was made possible by the money raised by the Belgian Charcot Foundation from its donors and testators. That is why we are counting on your help.

*"There were two of us at home, my sister and me. When my sister was 30, she was diagnosed with MS. She'd just had another baby and people didn't know much about multiple sclerosis back then. The doctor said there was nothing to be done. Ten years later, she was in a wheelchair. As the years went by, she became more and more disabled. There was no real treatment at the time. When my sister passed away last winter, we felt a lot of grief, but also regret that we hadn't been able to help her. My husband and I, unfortunately, never had children, so it made sense for us to think of my sister's children. I also felt it was important to make a legacy to the Belgian Charcot Foundation. The research they support helps bring about treatments. I'm so pleased that because of this research MS patients no longer have to end up in a wheelchair. I can only wish that my sister had lived to see this."*

Claire M., Namur

- 12 projects have a therapeutic goal. They include the study of ferroptosis inhibitors (ferroptosis is cell death caused by the accumulation of iron), the study of remyelination by nanoparticles carrying trophic factors, the role of dendritic cells made tolerant to brain proteins, the immune effects of anti-CD20 treatment, the immune effects of autologous haematopoietic marrow transplants, the specific activation of regulator T cells, the use of T lymphocytes that secrete anti-inflammatory molecules further to genetic modification.
- Finally, two projects study the rehabilitation of symptomatic patients and one the potential role of the Epstein-Barr virus as a trigger for multiple sclerosis.

### What next?

The 2023 call for projects will be opened soon and the winners announced at the beginning of 2023. The scientific papers relating to the projects financed in 2021 and 2022 will be published in 2023, 2024, and even later.

We are not able - no one is - to determine which research is the most likely to lead to new, effective treatments. We need to support researchers' 'freedom of enterprise', and it is only to be expected that some projects will not yield the expected results, while others will be successful. The main thing is to constitute a body of knowledge on the disease.

Prof. Dr Christian Sindic

With the support of



### "I would like to help overcome Multiple Sclerosis and I would like to make a gift in my will or living trust to the Belgian Charcot Foundation"

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  - I would like to be contacted without any obligation
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# Clinical research on neurorehabilitation



**Dr Olivier Bouquiaux (CHU Liège) works as a neurologist at the Fraiture-en-Condroz Neurological and Functional Rehabilitation Centre. For a long time, this centre has been treating MS patients in a holistic manner.**

As well as supplying MS patients with rehabilitation tools, the Centre actively focuses on analysing the long-term treatment of patients with cognitive impairments.

Research requires quantitative observation in the form of measurements. In the area of healthcare, this takes the form of scales to assess observation, such as a pain scale, a quality-of-life scale, a coma scale that reflects a person's degree of consciousness, etc.

## Realistic lines

Dr Bouquiaux explains: "My task, and that of our multidisciplinary team, is to work out a 'golden ratio' to support health-care staff in the re-education and reactivation of patients. MS treatment begins with drugs and, in the event of a flare-up or marked change in the patient's motor abilities, this is immediately followed up with a re-education programme.

There's a major difference between rehabilitation, re-education and reactivation here. The purpose of rehabilitation is to retrieve lost movement capability, whereas that of re-education is to enable the patient to find new ways of moving after losing certain capabilities. Finally, the purpose of reactivation is to enable MS patients to make room in their lives for active movement. All three have their place at all times alongside

drug treatment and, like drug treatment, need to be constantly monitored and adjusted.

## “Rehabilitation: a lifelong ‘therapy’

During this assessment, the patient needs to feel comfortable not only physically, but also mentally. My research arose from a pressing need to convert the commonly used scales, which were drawn up in lab environments and are therefore theoretical, into usable directives for the healthcare workers in the field.

For instance, when a subject in a lab environment says that they can do a series of exercises four times a day, this only appears to be true at the beginning. Very soon, motivation decreases, physical reserves become depleted and the proposed schedule just isn't feasible. The 'fun' and 'meaning' factors as a whole are decisive, as well as 'communication between patients and carers', and connections, for instance between patients during a group dance class or with the horse during horseback-riding therapy, are absolutely essential.

In the case of interaction with a horse, we try to find ways of relaxing the muscles, encouraging movement and promoting methods that are new to the patient and bring positive stimulation. The same applies to cooking or handicrafts workshops.

A multidisciplinary team also helps patients practice or learn appropriate ways of doing housework.

When advising MS patients, it's clear that the combination of drugs and rehabilitation that yields the best results and enables patients and their families to display resilience in the face of



the disease. The rehabilitation process – education and reactivation – gives patients a sense of control despite the often unpredictable course of MS."

#### Communication and connection

"Setting up ongoing communication and a connection between patients and the world around them transforms the services on offer from 'care' into lifelong 'therapy', even if the patient's capability is temporarily reduced by a flare-up. The intensity of patient reactions can vary considerably. They may be able to climb stairs rather than take the lift, but also even practice sports intensively.

The EDSS scale enables this to be done safely and avoid overheating or Uhthoff's phenomenon. Uhthoff's phenomenon occurs when the visual symptoms of MS patients are temporarily worsened by an increase in body temperature caused by exercise, sunlight, fever or a hot bath.

For this therapeutic approach to succeed on all levels and without side effects, patients need to begin early and continue in a professional environment in which motivating advice is available."

#### In practice

"Further to a general examination and basic assessment of cardiac function, the patient's ability to walk, balance and segmental muscle strength are tested. The result is an EDSS (Expanded Disability Status Scale) score. Patients are informed of the importance of hydration (before and after exercise) and nutrition (slow carbs 2 hours before exercising), and reassured if their neurological symptoms worsen during warm-up (Uhthoff's phenomenon). The patient wears a cardiac frequency monitor and is given a record book. Further to a flare-up, they are advised to stop all intensive physical activity for a time, then gradually resume exercising."

**Want to know more about the EDSS score or the work of Dr Bouquiaux and his team? You can watch the full video of this visit to CNRF on [www.fondation-charcot.org/en](http://www.fondation-charcot.org/en).**

- ▶ The references of all the studies cited are available on request from the Belgian Charcot Foundation.
- ▶ More information and videos at [www.fondation-charcot.org](http://www.fondation-charcot.org)
- ▶ This newsletter is also available in FR and NL on our website.

Today multiple sclerosis is still incurable, but tomorrow ...

Will you be the driving force behind MS research?



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