



BBC newsletter n° 40 May 2021-ENG

Huntington's disease: Roche-Tominersen clinical trial abandoned

EDITO by Albert Counet, President of the French-speaking Huntington League

Communication crisis in a patient's association

“Inform - Listen - Support - Accompany”

In a patient's association, communication is sometimes very complicated, far from being a quiet river. This spring 2021 the Huntington Community was confronted with the immediate and unexpected Tominersen-Roche trial. This clinical trial in the phase three, after promising preliminary phases, gave hope for a significant decrease of huntingtin gene, the protein responsible for the formation of Amyloid plaques, one of the supposedly main causes of Huntington neural degeneration.

The Committee of Independent Experts that accompanied the trial has considered the balance of risks and benefits as not sufficient enough and recommended an immediate cessation. The details have been published copiously on the reliable sources (www.eurohuntington.org, www.ehdn.net, www.HDBuzz.org, www.huntington.be, ...so I won't go into it again).

However, the “after-sales service” for the event had to be provided quickly.

The shock among the Huntington Community was commensurate with the hope that was present in this clinical trial, the first to reach the phase three, 25 years after the discovery of the “cursed gene” responsible for the disease and after decades of unsuccessful searches, tests and trials...

It was necessary to explain what an “inadequate balance of risks and benefits” meant. As a reminder, the mutated gene that produces the “bad” huntingtin is “only” on one helix of genome, whereas its counterpart on the other helix remains unaffected and produces “good” huntingtin that we need. To put it simply, while the tested drug reduced the level of the bad protein, it also reduced the good one and the balance between the two processes was unfortunately not satisfying.

We also had to thank these patients, these companions of misfortune, our heroes, who for years have subjected themselves to painful lumbar injections into cerebrospinal fluid, also known as cerebrospinal fluid (CSF), first monthly, then fortnightly, and finally quarterly. To appreciate their dedication, their abnegation, their eagerness to take the risk and to show the empathy for their great disappointment.

Moreover, we had to restore confidence, to keep alive the belief that a solution would eventually be found. To insist that other trials must continue, some are already in phase two that will target “only” the mutated protein without affecting the right one. We have expressed our belief that solutions will come when the technology can correct the genetic abnormalities, regardless of what generally misinformed “anti-all-progress” claim. What we have to keep in mind is that the participation of patients in clinical trials is crucial if we want to succeed one day, that the reservoir of volunteering patients, like 25.000 from four continents that take part in Enroll-HD, is an exceptional factor of acceleration. “Ensemble plus forts – stronger together!” is our motto.

In fact, just stay tuned, maintain a reasonable optimism, like Prof. Bernhard Landwehrmeyer who predicted “Huntington, the most curable of all the incurable diseases!” At the same time, we are realistic: we have faith in the future, but we are aware that the way ahead is still long and full of pitfalls.

This is, in a few words, an illustration of what a banal announcement such as a “Committee of Independent Experts recommends stopping the Tominersen-Roche trial” has done to the Huntington Community worldwide.

Research and clinical trials are not just about Petri dishes (also known as Petri cells), test samples, rodents, primates, dedicated volunteers and not just about scientists in white coats, no matter how exceptional they may be.

It is also a whole community of patients and families who are involved and who must be continually “Informed – Listened to – Supported - Accompanied”.

Far from being a quiet river.



General assembly of 18 May

Appointment of two new members to the Management Board



Ann van der Jeugd is the new Program Manager at KU Leuven Brain Institute (LBI), she is also the President of Belgian Women in Science (*BeWiSe*). Ann

has a PhD in Psychology from KULeuven, specialized in neurodegenerative disorders, cognitive psychology and neurobiology. Ann did also an internship at UCSF and 2 post docs, one at University of Lisbon and another in University of Queensland (Australia).



Professor Chris Bervoets is a psychiatrist. He is responsible for the Transcranial Magnetic Stimulation and Deep Brain Stimulation Care Programme Coercive Disorders Care Programme (University Centre for Obsessive-Compulsive Disorders) at the UPC KU Leuven. Chris Bervoets is a chairman of the medical council of the UPC KU Leuven, a chairman of the Flemish Psychiatric Association, a director of the Foundation for Brain Stimulation and a member of the editorial board of the Tijdschrift voor Psychiatrie. Chris Bervoets conducts scientific research on neuromodulatory treatments for psychiatric syndromes. Chris Bervoets has been appointed vice-president of the BBC, replacing Professor Chris Baeken.

Membership of the Executive Committee for the period 2021-2022

President: Professor Laurence RIS

General Secretary: Professor Roland Pochet

Vice-Presidents: Professor Chris Bervoets, Doctor Gianni Franco, Baron Charles van der Straten-Waillet

Treasurer: Baron Charles van der Straten-Waillet

Secretary: Madame Lia Le Roy

Honorary Presidents: Professor Jean Schoenen, Rufin Vogels, Dirk Van Roost

BBC and Erasmus+

Following the new call for projects, the BBC made an effort to get involved in the **2021 call: Small-scale partnerships in an adult education – KA210-ADU** launched by the Commission, and submitted three projects, one as coordinator and two as partners.

- Project 1 “**Care4Autism**” with the BBC as coordinator and four other associations.



- Project 2 “**Care4Brain**” coordinated by the Leuven Brain Institute (Ann van der Jeugd) and three other associations, it is the continuation of the project **Share4Brain** which ends in May 2022.



- Project 3 “**E-Care4PD**” coordinated by the Madrid Parkinson Association and three other associations.



The projects are evaluated by the local agencies of the coordinator; for the BBC it is AEF-Europe, for LBI it is EPOS and for Madrid Parkinson Association it is SEPIE. The result will be known in September. Each project lasts 24 months and its budget is 60.000€.

7th NBCs Academy: Statement of Mr. Pierre Delsaux



We encourage you to listen to the messages and the statement of Mr. Pierre Delsaux, General Deputy Director of DG HEALTH at the European Commission in favour of openness towards research on the brain, mental health and brain diseases (to be listened to between **16 min 45 sec and 27 min 30 sec** of 36 min recording), as well as the dialogue between the CEO of the EBC and Mr. Delsaux who insists on our role in our policies (**between 27 min 18 sec and 33 min**).

<https://www.youtube.com/watch?v=VIZML3cSxrc&t=1749s>

Parkinson followed by awareness campaign

Dr. Gianni Franco informs us that the 1.5 hour video he hosted, in which the patients expressed their opinions has been viewed more than 100 times. A success.

See: <https://www.youtube.com/watch?v=p6M9U0g346c&t=4576s>

22 June Parkinson conference

By Dr. Dominique-Jean Bouillez : The effectiveness of complementary treatments
In person at Chaussée de Vleurgat 109, Brussels, registration via e-mail:
cecile.gregoire@actionparkinson.be

Reminder from the Belgian Stroke Council

The President of the Belgian Stroke Council, Peter Van Acker, reminds young people (<35 years old) of the Healers Prize. Deadline for submission of a research project is by the end of June

see: [https://belgianstrokecouncil.be/wp-content/uploads/2021/03/Application-form Helaers Research Prize 2021.pdf](https://belgianstrokecouncil.be/wp-content/uploads/2021/03/Application-form_Helaers_Research_Prize_2021.pdf)



BELGIAN COLLEGE of NEUROPSYCHOPHARMACOLOGY and BIOLOGICAL PSYCHIATRY

Le Président du BCNP, Martin Desseilles, vous invite à :

Virtual National Evening ‘Somatic and psychiatric care: living apart together’

Friday, June 11, 2021

Programme

Chair: Martin Desseilles, President

20:00 ‘Mental disorders and risk of COVID-19 related mortality, hospitalization and intensive care unit admission’,

Livia De Picker, Psychiatrist & Postdoctoral Researcher, University Psychiatric Hospital Campus Duffel.

20:20 ‘Physical illness in patients with severe mental disorders’,

Marc De Hert, Center for Clinical Psychiatry, Department of Neurosciences, KU Leuven.

20:40 ‘The KCE report: Somatic care in a psychiatric setting’,

Vicky Jaspers, Medical Expert, Epidemiologist, Belgian Health Care Knowledge Centre.

21:00 ‘Lifestyle psychiatry, the evidence and its use in clinical practice’,

Wiepke Cahn, Research Psychiatrist, University Medical Center Utrecht, NL.

Free registration. Registration: lieve.rousseau@me.com, Accreditation has been requested.

“Impact of COVID-19 on brain diseases and mental health”

List of the eight sponsors supporting the WEBINAR on 11 September



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

**BECOME A MEMBER
DEVENEZ MEMBRE
LID WORDEN**

30€ at BE87 7512 0194 0094 with name + email

Tool for our member to use in any promotional action: Evidence on the exceptionally high burden of brain disorders

see: https://braincouncil.be/en/burden-of-brain-diseases_evidence

Dates to remember (see more details online at braincouncil.be).

| | |
|---------------------|--|
| 30 May | Wereld MS-dag / World Multiple Sclerosis Day |
| 4 June | BASS Spring Meeting |
| 11 June | BCNP Meeting |
| 12 June | Charcot Foundation-MS Symposium |
| 22 June | Parkinson Conference: Complementary treatment effectiveness |
| 11 September | BBC WEBINAR |