

NEWSLETTER N°75

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Union-recognized philanthropic data organization

On June 4, 2025, the European Brain Data Hub (EBDH) received official recognition and was registered in the Belgian national register of data altruistic organizations, in compliance with the European Union's Data Governance Act (DGA). This designation now permits it to utilize the label:

“Data altruism organization acknowledged within the Union”

Thanks to this status, the EBDH fosters the trust of patients, researchers, and institutional partners, assuring them that their data will be utilized solely for research purposes, enhancing care and innovation.



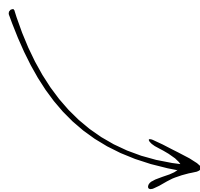
This designation also presents new opportunities for collaboration with European stakeholders and enhances access to specialized funding, particularly within the context of flagship initiatives such as the European Health Data Space (EHDS).

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This phase is marked by robust commitments: the EBDH's complete independence, strict adherence to the principles of protection, transparency, and informed consent, as well as the assurance of secure and privacy-respecting data sharing. Consequently, the EBDH is positioning itself as a pivotal entity in the ethical sharing of brain health data across Europe, fostering a more transparent and secure ecosystem for the advantage of patients, researchers, and healthcare professionals.

We sincerely thank our community for their trust and support, and we reaffirm our dedication to prioritizing innovation and transparency in the responsible sharing of health data.

To gain further insight into this recognition or to explore ways to engage in data altruism, we encourage you to review the activity report.



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EBDH promotes research and treatment for neurological disorders.

The EBDH is officially acknowledged by the Belgian authorities as an altruistic data organization. It adheres to the European Data Governance Regulation (DGA) and the GDPR to ensure the confidentiality and security of your data.

TOGETHER LET US ADVANCE RESEARCH AND MANAGEMENT OF NEUROLOGICAL DISORDERS

Every day, millions of individuals contend with neurological or psychiatric disorders. With advancements in technology, your health data—should you consent to share it securely—can significantly enhance care, expedite research, and inform public health policies.

 **Our objective is to establish a shared health data repository, accessible solely for purposes of public interest.**

WHAT CONSTITUTES ALTRUISTIC DATA SHARING?

Altruistic sharing refers to the voluntary decision to provide a portion of your health data—securely and anonymously—to support non-commercial research focused on enhancing diagnosis, treatment, or the overall quality of life for patients.

This matter does not pertain to the sale of your data or its dissemination without your consent. You have the authority to decide, guided by a clear and transparent mandate.

Enhancing care: Authentic data facilitates a deeper comprehension of care pathways, side effects, and unmet needs.

Advancing research: Researchers frequently encounter a deficiency of concrete data regarding neurological disorders.

Act for others: By sharing your data, you enable other patients to access improved treatments more swiftly.

Be a catalyst for change: You play a vital role in creating a healthcare system that is more equitable, efficient, and respectful of patients.




WILL ENABLE US

1 **Concretely, How does it function?** You provide your consent through a clear and straightforward mandate, which you may revoke at any time.

2 Your data, including medical records and sensor information, is secure, anonymized, and never utilized for commercial purposes.

3 The EBDH ensures that only projects of public interest will have access to them, subject to stringent oversight.

4 You are consistently updated on the projects that are made possible by your contribution.

REACH OUT TO US  info@ebdh.org  Website: www.ebdh.org

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The BBC has acquired new premises.

Subsequent to the dissolution of the logistical assistance agreement between the EBC and the BBC, the BBC proactively sought to lease an office from the University Foundation, situated at 13 rue d'Egmont.

This contemporary and welcoming workspace, featuring an available conference room, supports the organization of meetings and events. This office can also be shared with the EBDH, thereby fostering effective collaboration and synergies between the two entities.



The inaugural meeting of the BBC Executive Committee under this new framework took place in person on July 23, signifying the commencement of a new phase for the team in an environment conducive to reflection and collaborative efforts. Additionally, to enhance administrative management, the BBC's accounting responsibilities have been assigned to the M.A.T.S. office, situated at 18 Lord Byron Avenue in Waterloo.

These developments illustrate a commitment to professionalization and resource optimization within the BBC, aimed at enhancing its projects and supporting its members.

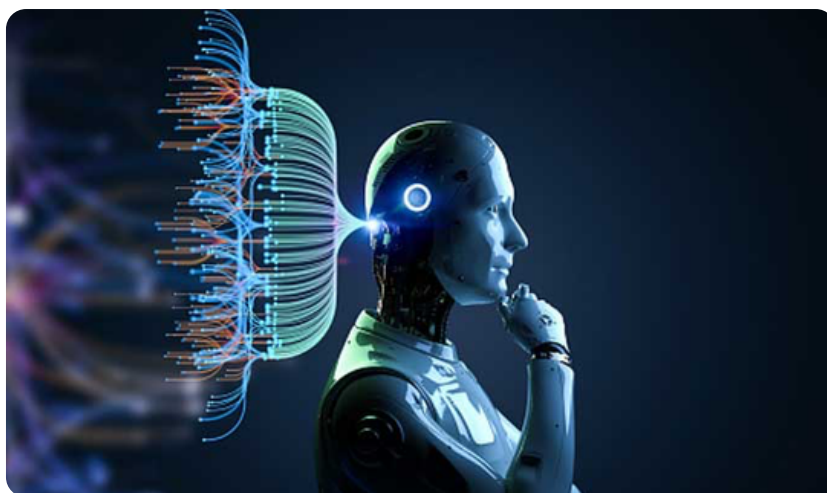


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Artificial Intelligence: What is the Energy Cost?

In a compelling article featured in *Le Monde Diplomatique* (July 2025), sociologist Sébastien Broca (Université Paris-VIII) poses a critical inquiry: the ecological footprint of artificial intelligence. As AI increasingly serves as a pivotal instrument in biomedical research and the management of chronic neurological disorders, it is essential to recognize the concealed energy expenditures associated with these technologies.

The author emphasizes that accurately measuring the energy consumption of a tool such as ChatGPT is highly complex, as it is influenced by various factors (the model employed, the nature of the demand, the location of the data center, the energy source, etc.). Companies frequently cite industrial secrecy to refrain from disclosing this information. Broca concludes that although this quantification is scientifically challenging, it is still essential—not as an absolute truth, but as a means to interrogate the prevailing practices within the technology industry.



In a context where the European Brain Data Hub and similar initiatives leverage artificial intelligence to enhance patient care, this debate encourages us to consider innovation that is sober, ethical, and transparent, while also addressing climate concerns.

For additional information: *Le Monde Diplomatique*, July 2025, “Measuring Digital Gluttony” by Sébastien Broca.

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At the invitation of Servier, the BBC will attend the Federal Parliament.

Join us for a distinguished roundtable on “Advancing Quality of Life and Reintegration for Individuals with Brain Tumors.” This event convenes patients, experts, and policymakers to exchange insights, address real-world challenges, and investigate innovative approaches to enhance care and support. Together, let us strive for a more promising future for those impacted by brain tumors!



Proposal Agenda Policy round table on “advancing quality of life and reintegration for people with brain tumors” – Life beyond the diagnosis

Agenda

October 9th – 1,5h session: 11u30 – 12h30 welcome & sandwich lunch
12-30 – 14h session

Timing	Topic	Wie?
5'	Welcome speech: How can we get more attention for the care and policy regarding brain tumors in Belgium?	Moderator TBD
10'	Brain tumors – State of play in Belgium: prevalence, care, and treatment pathway	TBD
10'	Living with a brain tumor: the hurdles to getting back on track	Proposal: Werkgroep Hersentumoren - Dr Sandor Van Bijsterveld
15'	Brain tumors – Focus on quality of life and reintegration into society	
10'	How do policymakers view the care for people with a brain tumor?	Mvr. Kathleen Depoorter / Mr. Daniel Bacquelaine
35'	Panel discussion where experts and patients engage in dialogue: the main hurdles will be addressed and concrete policy actions will be formulated (mental impact on the patient, caregivers and environment, stigma surrounding the disease, need for an integrated care pathway, importance of reintegration into society and support with administration, insurance, etc.), including 10 minutes of Q&A.	Proposal: representatives of different stakeholders (HCPs, patient representative, policy makers, administrations, ...)
5'	Conclusions and next steps	Moderator

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Conclusions from the 20th Anniversary Symposium held on May 17, 2025.



The BBC's 20th anniversary was commemorated in a celebratory atmosphere, characterized by joy and good humor. This significant milestone united a diverse array of key stakeholders, including experts in the relevant field, patients, and representatives from the pharmaceutical industry, thereby showcasing the richness and variety of perspectives surrounding the BBC.

The presentations from these diverse partners were recorded and simultaneously translated into French and Dutch, demonstrating a commitment to accessibility and inclusion for a bilingual or international audience. These videos are available on the YouTube platform, enabling a broad audience to easily and freely access the content shared during this event.



As of July 17, 2025, these presentations have been viewed and listened to approximately 250 times. This figure reflects the community's clear interest and dedication to the themes explored during this celebration.

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The 2024 Activity Report has been published in four languages.



A one-minute video documents this anniversary.



The conference was recorded and translated in real time into French and Dutch and can be viewed on YouTube:



(already viewed 142 times as of July 31, 2025)



(already viewed 141 times as of July 31, 2025)

October 8, 2026
- Mark your calendar -
European Health Data Altruism
International Symposium

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Updates from our members

Click on each logo to discover more. The schedule of activities is provided there.



- We are delighted to invite you to BrainsUnited, a two-day conference commemorating the 600th anniversary of our universities. This event will convene researchers from the KU Leuven Brain Institute (LBI) and the UCLouvain Institute of Neuroscience (IONS). The conference is scheduled for September 9 and 10 in Leuven and Woluwe.



- Other event: Patient Discovery Project – October 17, KU Leuven Discovery Day focused on neurodegeneration research.

• **Agenda**



The activities schedule has been reinstated.



The Charcot Foundation, a prominent entity in financing multiple sclerosis research in Belgium, is embarking on a new chapter in its history with the appointment of Professor Bénédicte Dubois as its president.



The league announces the establishment of the Huntington Academy, an online educational platform designed to train both formal and informal caregivers (family caregivers) of individuals affected by Huntington's disease.

One course is currently available in French; the others will be introduced shortly. These courses are free, but registration is required.

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Click on each logo to discover more information.
The schedule of activities is included therein.



In celebration of its 30th anniversary, the Belgian Society for Neuroscience is introducing its inaugural award. The recipient of this award will be granted €1,000 at a ceremony during our biannual BSN meeting on October 20, 2025, and will be invited to present the keynote address at the event. Please submit your application by June 20 to robrecht.raedt@ugent.be and info@belgianneuroscience.be.



The agenda for activities and training is included.



The schedule of activities for June has been reinstated.



Do not miss the Neurosonology 2025 conference!

Join global experts at this essential event focused on advancements in neurosonology.

Whether you are a healthcare professional, researcher, or simply passionate about neuroscience, this conference will provide interactive sessions, practical workshops, and the opportunity to explore the latest innovations in the field.

The complete program, along with all pertinent information regarding registration, speakers, and topics addressed, can be found here:





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BECOME A MEMBER
DEVENEZ MEMBRE
LID WORDEN
30€ at BE87 7512 0194 0094 with name + email

**BBC ACCOUNT:
BE87 7512 0194 0094**

The BBC maintains a presence on the
following social media platforms:



Composition of the Executive Committee for the term 2024-2025

President: Professor Maertens de Noordhout

Director: Professor Roland Pochet

Vice-Presidents: Dr. Gianni Franco, Mrs. Lia Le Roy

Treasurer: Baron Charles van der Straten-Waillet

Secretary: Professor Jean Schoenen



NEWSLETTER N°74

DANS CETTE PUBLICATION

- Rapport d'activité 2024 publié en 4 langues.
- Conférence avec l'ordre national des Médecins le 1^{er} avril 2025.
- 20ème anniversaire - 17 mai.
- Historique du BBC par Jean Schoenen, Membre fondateur et Président du Comité Organisateur.
- Conclusions du Symposium du 20ème anniversaire.
- Procès-verbal de l'Assemblée Générale.
- Nouvelles de nos membres.

Rapport d'activité 2024 publié en 4 langues

In 2024, the Belgian Brain Council consolidated its role as the reference platform for brain health in Belgium and Europe. Important steps forward included the adoption of new statutes strengthening our commitment to health data, the creation of the European Brain Data Hub and the organisation of a unifying and innovative national symposium.

Our influence has been strengthened, particularly through our public support for Alzheimer Europe in light of EMA decisions. At the same time, our communication has intensified, with multilingual newsletters and a fast-growing website.

By ensuring transparent governance, mobilising our members and partners and innovating around European projects, the BBC is actively preparing for the future, true to its mission: to promote brain health through commitment, expertise innovation.

Cet rapport a été présenté par notre secrétaire Jean Schoenen, le 27 mai 2025, est consultable dans notre site d'internet.



Cliquez sur chaque drapeau pour plus d'informations



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DANS CETTE PUBLICATION

- BAW 2025 du 10 au 16 mars
- L'IA et l'Ordre des Médecins - 1er avril
- 20ème anniversaire - 17 mai
- Progrès en faveur du traitement de l'épilepsie
- Nouvelles de nos membres

Brain Awareness Week

La Semaine du cerveau, organisée chaque année dans une centaine de pays à travers le monde, est une occasion unique d'échanges entre le public et les scientifiques sur les enjeux de la connaissance du cerveau pour la société.

Voici la liste des événements 2025 organisés en Belgique et coordonnés par Ann van der Jeugd
email: ann.vanderjeugd@kuleuven.be.

Les **Aidants Proches**, le 12 mars 2025 au Château du Karreveld, Av. Jean de la Hoesse 32, 1080 Molenbeek-Saint-Jean L'épilepsie conférence donnée par le Dr. Cathy De Cock, neurologue, membre de la ligue francophone Belge de l'épilepsie. Contact et inscription: Madame Mormal (mmormal@gmail.com).



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DANS CETTE PUBLICATION

- Le 20ème anniversaire
- BAW 2025
- Belgian Brain Plan Phase III
- BBC lobbying

joyeux Noël et bonne année 2025

Dans cette période de fêtes de fin d'année, nous vous adressons nos meilleurs vœux. Puisse la magie de Noël illuminer vos foyers et vos cœurs de joie, de paix et d'amour.

Nous continuerons à travailler, à collaborer à la recherche et aux bonnes pratiques qui favorisent la santé mentale et cérébrale.



Photo: Grand-Place de Bruxelles décembre 2024