



2024 Activity Report

to online General Assembly on 26 May 2025
Fondation Universitaire, rue Egmont 11, 1000 Brussels

Presented by

Jean Schoenen
Secretary



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Executive Summary

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.

1. Foreword

The Belgian Brain Council is moving forward with a strong conviction: pooling our energies to improve brain health and develop innovative solutions.

This 2024 Activity testifies to our collective commitment, adaptability and will to innovate in the face of challenges. Our mission is clear, our members are mobilised, our projects are evolving and our voice is increasingly being heard.

This report shows that the BBC is not just witnessing change: it is a key player. Thanks to everyone who supported us in this challenging and exciting adventure!

2. A Message from the President



Dear members of the Belgian Brain Council,

As a scientific member and representative of the Belgian Association for Neuroscience for the past 10 years, and as president of the Belgian Brain Council for the past 4, it is with great emotion that I address these words to you.

The Belgian Brain Council is distinguished by its ongoing commitment to bringing together everyone involved in improving the treatment of disorders of the nervous system.

“ We aim to inform and educate the general public about the brain and its disorders, to advocate for more resources for neuroscience research, and to support the activities of our members while promoting exchanges between them. The organisation of the BBC Congress in Mons in 2016, participation in Erasmus+ projects and Brain Awareness Weeks, and the launch of the new Brain Data Hub adventure are highlights of these 10 years ”

I would like to express my deep gratitude to the members of the Executive Committee, patient associations, scientific societies, our industrial partners and the CEO of the Belgian Brain Council for their support and dedication to our mission.

Today I give the floor to Alain Maertens de Noordhout, who will become President after our next General Assembly. I am sure he will continue to uphold the values of the Belgian Brain Council and lead our organisation to new horizons.

Thank you for your trust and cooperation.

Laurence Ris

3. 2024 Activities

3.1. BBC Newsletter

During 2024, the Belgian Brain Council published 10 newsletters, numbered 62 to 72. Each edition provided an opportunity to share important news about association, progress in brain disease research and invitations to our events and partner initiatives. The newsletters can be accessed at any time on our website: <https://www.braincouncil.be/news>, and are also sent by e-mail to our community.

The mailing list, which had 3,450 addresses in 2024, is regularly updated to ensure the quality and relevance of the mailings. The newsletters are sent with the technical support of the ULB-VUB Computing Centre.

3.2. New statutes

At the Extraordinary General Meeting held on 23 January 2024, new articles of association were adopted to align with the stipulations of the Belgian Companies and Associations Code. These articles were subsequently published in the Belgian Official Gazette on 17 April 2024.

These new statutes have expanded its objectives (see article 2.1) and actions by highlighting participation in and support for altruistic initiatives in the realm of data at both the Belgian and international levels. This includes engagement with international associations and the development and management of IT tools that facilitate the creation of a database concerning mental and brain health (see article 2.2).

Furthermore, Article 3 delineates the three categories of members and specifies the qualifications of partners within the pharmaceutical and medical equipment sectors.

3.3. 1.1.10th National Academy of Brain Councils

The 10th National Academy of Brain Counselling (NBC) was held on 8 and 9 May 2024 in Pula, on the island of Brijuni in Croatia. This year's meeting was integrated with the 3rd International Conference on Neurological Disorders and Neurorehabilitation, which took place from 9 to 12 May 2024. This annual event brought together several representatives of European NBCs, both online and in person. No fewer than 11 countries were represented, including Belgium, Croatia, Finland, Germany, Greece, Italy, Norway, Serbia, Spain, Sweden and Switzerland.

3.4. BBC and Brain Awareness Week 2024, scheduled from March 11 to March 17, 2024

Brain Week is a global initiative to raise awareness and interest in brain science. Every year in March, a variety of creative events are organised in communities to draw attention to the fascinating mysteries of the brain and the impact of discoveries from neuroscience on our daily lives.



Brain Week was celebrated at UCLouvain Brussels Woluwe and Wolubilis. UCLouvain, Arte-Fac, the Institute of Neuroscience (IoNS) and the UDA pooled their talents for a week of exciting activities! Shows, lectures, art workshops, debates, meetings and film screenings were the order of the day on campus, bringing together hundreds of curious students, staff and external visitors around the theme 'The Creative Brain'. Details of our members' programmes can be found in Newsletters 64 in March and 65 in April, which you can view on our website.

3.5. National Congress



symposium, entitled "Is data the future for better brain and mental health?", was part of phase III of the Belgian BrainPlan and was held over 2 days. By bringing together politicians from all government parties, patient associations and health experts, the symposium succeeded in creating a real dialogue between all players involved.

The entire symposium was recorded in FR and NL and can be viewed via the following links:

- Day 1 FR: <https://youtu.be/wF21bIPBLWE>
- Day 1 NL: <https://youtu.be/pCj33oj5q4s>
- Day 2 FR: <https://youtu.be/1xPMOUX0dUc>
- Day 2 NL: <https://youtu.be/ZcDego4-Uxs>
- Day 2 FR: <https://www.braincouncil.be/brain-data-hub>
- Photos: <https://drive.google.com/drive/folders/1V8dnXNccpKr6fAcOoBf7y8ZjqrR7WtJm>



3.6. Establishment of the European Brain Data Hub, a strategic step towards a data-driven Belgian Brain Plan

For more than a decade, the Belgian Brain Council has been pushing for the development of a Belgian Brain Plan, similar to the Belgian Cancer Plan. A major obstacle to this ambition soon became apparent: the absence in Belgium of a registry of health data that can quantify the exact number of patients with a given brain disorder. At present, for example, it is impossible to obtain from institutions such as the INAMI (Institut national d'assurance maladie-invalidité) a reliable estimate - even approximate - of the number of patients suffering from Parkinson's disease.



1. Constructive discussions with Nick Marly, adviser to the federal health minister;
2. A collaboration with Professor Gregory Lewkowicz, an expert on law and artificial intelligence;
3. Financial support from eight pharmaceutical industry partners (BMS, Eisai, Ipsen, Janssen, Lundbeck, Merck, Pfizer, UCB), allowing the first 2 phases of this project to start.

The first phase laid the foundations for a new framework: data altruism, an innovative legal concept introduced by the European Data Governance Act. It means that anyone can voluntarily donate their data for public interest purposes, without compensation, in areas such as scientific research or the improvement of public policies.

This principle was approved by the General Assembly on 23 May 2023, paving the way for a second phase: the creation of a dedicated structure on a European scale. The result is the European Brain Data Hub, an AISBL (Association Internationale Sans But Lucratif), registered as an altruistic data organisation.

This pioneering approach has also resonated at the institutional level. On 8 May 2024, a session of the Belgian federal parliament the federal government officially transposed the European Data Governance Act into Belgian law, thanks to the commitment of Deputy Prime Minister Pierre-Yves Dermagne. On this occasion, Mr Dermagne expressed his support for the Belgian Brain Council, congratulating the association for its driving role in this legislative breakthrough and praising the civic innovation it embodies.

The mission of the European Brain Data Hub is to enable citizens to donate their health data relating to the brain and mental health, within a secure and ethical framework, so that it can be used for scientific research projects and to improve public policy .



Gregory Lewkowicz, Philip Gorwood, Thomas Mockrusch, Roland Pochet, Christina Dalla, Le Notaire

The founding act of this NPO was signed at a notary's office on 14 May 2024, following the jubilee symposium of the Belgian Brain Council. It marks a first step in building a European ecosystem data, ethics and the public interest are central.

STATUTS



L'acte fondateur a été officiellement signé le 15 mai 2024, au siège de cette organisation internationale à but non lucratif, la prestigieuse Fondation Universitaire. Cliquez ci-dessus pour accéder à nos statuts complets.

DÉCRET ROYAL



L'European Brain Data Hub (EBDH) a été officiellement doté de la personnalité juridique par le Roi des Belges le 25 juillet 2024. Veuillez cliquer ci-dessus pour accéder à l'arrêté royal.

3.7. Involvement in Erasmus+

Involved in projects to share good practice in brain education in Europe. The BBC is recognised as a host organisation for the EU4EU programme as part of its Erasmus+ projects to host students and trainees.



**Co-funded by
the European Union**

Three actions are active in 2024

The **Care4Autism** project, coordinated by the BBC, has ended and has been positively evaluated with a score of 72/100 (see table). This project promoted the exchange of good practices for adults with autism and their family carers. Visit the website: <https://care4autism.eu/>



Sharing4Employment share good practices for brain education in Europe. This EU-funded project, with partners Greece, Italy and Belgium, is committed to creating workplaces where mental health is valued and supported.

<http://www.sharing4employment.eu/>

Start date: December 11, 2023.

End date: January 11, 2025



Sharing4Employment



E--care4PD a is focused on the use of the technology, digital content and best practices with of partnerships in Spain, Belgium, Serbia and Greece to improve the quality of life of people with Parkinson's disease. In February, 2024 was evaluated by the Spanish agency with a remarkable score of 92 out of 100.



EU4EU

Three EU4EU (Erasmus+) scholarship holders supported our organisation's activities. They come from different countries and have studied in Europe. Fatemeh Saber, from Iran, has a bachelor's

and master's degree in biomedical engineering and is currently completing her master's degree in industrial bioengineering at the University Federico II in Naples, Italy.



Muhammad Omar Faruk is Bangladeshi and holds a degree in computer science and engineering. Omar studied for a master's degree in circular economy at the University of Tuscia (Italy). Jhosep Fajardo, a Colombian business administrator, has a master's degree in international development cooperation from the University of Burgos (Spain).

3.8. Lobbying

In Newsletter No 71 of November 2024, we expressed our support for Alzheimer Europe's statement in response to the European Medicines Agency's (EMA) initial refusal to grant marketing authorisation for Leqembi (lecanemab) for the treatment of mild cognitive impairment (memory and thinking disorders).

Since then, the EMA has reconsidered its decision and approved the marketing of Leqembi in Europe.

This development illustrates the essential role that associations such as Alzheimer Europe and the Belgian Brain Council play in the healthcare ecosystem. As influential mediators between patients, researchers, the pharmaceutical industry and regulators, we demonstrate that our ability to change decisions is based on our credibility, our expertise and our unwavering commitment to defending the interests of patients with chronic diseases.

4. Governance and internal administration

4.1. Annual General Assembly

A meeting in a hybrid format was held on 25 July to discuss progress and future plans, approve the balance sheet and income statement, review the MATS auditor's report and approve the 2025 budget. The accounts were approved at the annual general meeting on 11 June 2024, subject to approval by the .

The treasurer confirmed that there had been no changes.

The treasurer therefore moved that both the income statement and balance sheet be approved. This proposal was passed unanimously.

4.1.1 Executive committee meeting of 23 September

Laurence Ris completes her 4-year term and does not stand for re-election.

A committee comprising Jean Schoenen, Laurence Ris, Charles van der Straten Waillet and Dirk Van Roost is responsible for launching the call for candidates and selecting the future chairman, who will be presented to BBC AGM on 21 June 2025.

4.1.2. Budget 2025

Category	Amount	Additional details
Office costs	1 500,00 €	Rent + other costs
Insurance	200,00 €	
Finance & Admin	11 500,00 €	EBC secretariat + MATS
Telecoms	1 200,00 €	50€ mobile + 50€ internet (x12 months)
IT (subscriptions)	873,76 €	Adobe + Youtube + ChatGPT + others (250€)
Consultants	2 500,00 €	Legal advisement and others
Communication & Dissemination	2 000,00 €	newsletters/content creation/website update
Travel & Accomodation	5 100,00 €	figures of 2024 + 2% increase
Business meetings	1 632,00 €	figures of 2024 + 2% increase
Membership costs	3 000,00 €	NBC Academy
Belgian Brain Plan - phase 3	60 000,00 €	
Brain Awareness Week	2 500,00 €	
BBC 20th anniversary	20 000,00 €	
Bank charges	200,00 €	
Miscellaneous costs	1 000,00 €	
	113 205,76 €	

The treasurer suggested that in future, the budget should be prepared in December and approved at an extraordinary general meeting. The chairman and other members pointed out that this might be difficult because of the lack of a quorum.

4.2. Transparency

The Belgian Brain Council attaches the utmost importance to the transparency of its actions and institutional relations. That is why it is officially registered with the European Union Transparency Register (no. 712814020585-47) since 9 February 2016, as a non-profit organisation. This registration is regularly updated and guarantees clear, accessible information that complies with European transparency requirements.

This register, jointly managed by the European Commission, the European Parliament and the Council, ensures the traceability of interest representation activities. By May 2024, it will be a public database containing the following information 12,600 registered entities, including 3,399 NPOs like ours.

This demonstrates Belgian Brain Council's commitment to open, accountable governance in line with European Union standards.

4.3. BBC Website

The annual presentation of website traffic is part of the BBC's transparency policy. It allows us to measure our impact and reputation. Moreover, since members are generally spread over a wide geographical area, our site is an essential tool for promoting emerging opportunities, offering membership or renewal information, and distributing members-only content and resources.

In 2024, the site recorded 1,935 visits with an average duration of 5 min 4s seconds (which is remarkable!).

Most visitors are in Belgium (80%), with 59% in Brussels and 39% spread across 133 cities. The remaining 20% are spread across 38 countries

4.3.1. BBC website traffic



4.3.2. Temporal Analysis of Sessions

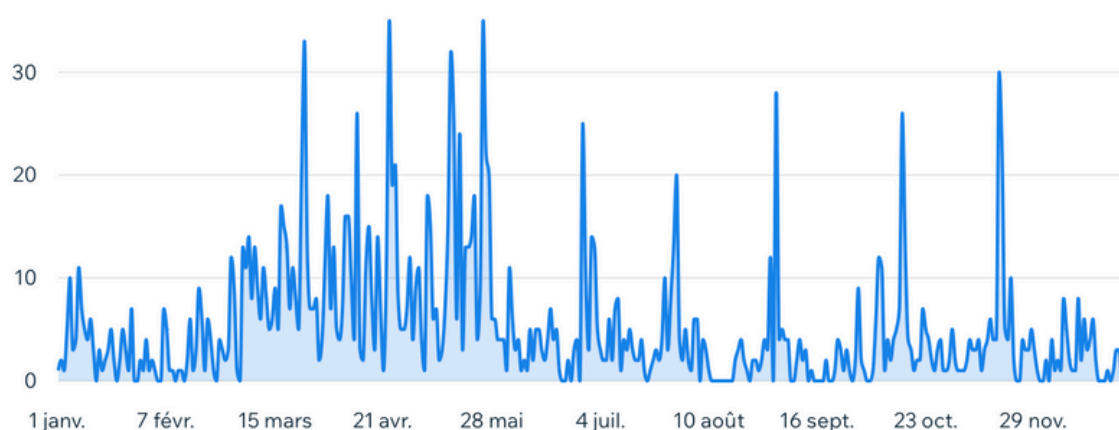
Sessions sur le site

1947 ↑ 7%

Visiteurs uniques

811 ↑ 24%

Sessions au fil du temps



The notable rise in the number of visitors from outside Belgium can be attributed to the distribution of the newsletter in four languages, sent to 3,500 email addresses beyond Belgium.

4.4. Social Networks

1446

subscribers

414 likes

432 followers

5. Treasury

The consolidated 2024 financial statements will be presented at the meeting.

Here is the provisional balance sheet.

The provisional result for 2024 is negative (€20,955.47), heavily impacted by the 'clean-up' carried out on expenses that were not going to be paid, for a total amount of €28,842.87. In a gross analysis, had this not occurred and adding in the financial effort to support EBDH, BBC would close 2024 in the black. However, as BBC has a cumulative profit from previous years of €81,511.54, the overall provisional result for 2024 will be positive and BBC will carry forward a provisional profit of €60,556.07 to 2025.

6. Conclusions

2024 was a crucial year for the Belgian Brain Council. It demonstrated our association's ability to combine continuity, innovation and influence in the service of brain health.

Through its many actions - adopting new statutes, boosting communication through newsletters, getting involved in European initiatives such as Erasmus+, creating the European Brain Data Hub and organising an ambitious national symposium - the BBC has confirmed its role as a catalyst of interdisciplinary initiatives and as a platform for data-driven social innovation.

Our advocacy efforts have been strengthened, as demonstrated by our active support for Alzheimer Europe in the context of the European debate on the authorisation of Leqembi. The BBC thus confirms its role as a credible intermediary between patients, researchers, the pharmaceutical industry and the .

The transparency of our governance, consolidated by our continued inclusion in the European Transparency Register, as well as the growth of our website and our international presence, illustrate our desire to expand our reach while remaining true to our fundamental values.

Finally, the transition of the presidency, which will begin in 2024, will guarantee our association a stable, forward-looking administration.

On the eve of 2025, the Belgian Brain Council is ready to take on new challenges, driven by an unchanged ambition: to contribute, by mobilising all the forces at work, to improving brain health and mental health in Belgium and Europe.