

The European Brain Council Annual Review



2011

The European Brain Council

Moving beyond the successes of 2011

Words like 'momentous' and 'historic' slip easily off the tongue, Justifying their use often proves to be much harder. For The European Brain Council (EBC), however, 2011 was just that – momentous, historic and a perfect launch pad for tackling the challenges ahead.

Over the past 12 months, the EBC's activities have attracted more attention and media coverage than ever before.

Two major European Presidency meetings were supplemented by two benchmark publications. More National Brain Councils have been established, while plans for the 2014 European Year of the Brain continue to gather both support and momentum.

The EBC, as a co-ordinating body representing European organisations in neurology, neurosurgery, psychiatry, basic brain research (neuroscience) as well as patient organisations and industry, is ideally positioned to champion and promote brain research in Europe. Equally, it is perfectly placed to drive the agenda in improving the quality of life for all those affected by brain diseases.

During 2011, its voice has become increasingly loud and influential, to the point, indeed, where it is coming to be regarded as the primary commentator on such issues.





A year of key European-level meetings

The first major event of the year came in March during the Hungarian Presidency of the European Union. Organised by Professor Tamas Freund in collaboration with the Hungarian Government under the title “Discovery research in neuro-psychiatry: depression, anxiety and schizophrenia in focus”, it was the main R&D meeting of the Presidency.

That was followed in November by the equally well-attended inaugural “European Day of the Brain” which focused on “Ageing, Stroke and Alzheimer’s Disease - Finding Innovative Solutions”. This conference, organised in conjunction with the Polish Ministry of Health and the European Commission’s DG SANCO (Department of Health and Consumers), featured videos of endorsement from the Commissioner of Research and the President of the European Parliament.

Most significantly, it concluded with a call to make 2014 the European Year of the Brain. That conclusion was presented to European Union Health Ministers in December, while a file was also submitted to European Commission President José Manuel Barroso, with the goal of acquiring his official support for the project.

These meetings clearly underline the council’s success in interacting with and influencing the European Commission, European Parliament and other relevant EU and international institutions such as the World Health Organization (WHO).

A year of milestone publications

The publication of the “Consensus Document on European Brain Research” and the “Cost of Disorders of the Brain in Europe 2010”, however, were as noteworthy.

The Consensus Document, a revision of the original milestone paper produced in 2006, detailed the need for and the achievements of brain research in the region while also presenting prioritised proposals for future programmes.

A collaboration between more than 200 European scientist and patient organisations, the document was published in the European Journal of Neuroscience in March, as well as being presented to the European Commission and other stakeholders. This was essentially a policy proposal document.

The “Cost of Disorders of the Brain in Europe”, however, was very different.

This second publication, an update of a paper of the same title based on 2004 statistics, had a striking message to convey to a much broader target audience – the general public (via the media) as well as policy makers.

Comprising more detailed data covering 19 diagnostic groups rather than 12, the report revealed that the annual cost of brain disorders in Europe had

soared from 386 billion euros to 798 billion in six years - a figure representing more than the annual cost of heart disease and cancer combined.

It also estimated that more than a third of the continents population of 514 million are in some way affected by brain disorders, either as sufferers, part or full-time carers. The numbers go even higher when family members are taken into consideration.

These findings, described as “a ticking time bomb under the European economy and the EU society as a whole”, clearly provide an economic justification for the greater funding of brain research. As such, they will act as a key information source for policy makers as well as interested groups submitting grant applications.





The 'Cost of Brain Disorders': A massive media impact

Their impact, however, was made all the greater by the massive coverage in both the health and mainstream media which ensued. In all, more than 1,000 media outlets carried the story, in more than 30 countries.

The original publication, in the 'European Neuropsychopharmacology' journal in October, was matched by a big launch in the European Parliament attended by an unprecedented number of MEPs. Various EBC board members and the Executive director gave more than 10 media interviews at the event.

It is highly unlikely that any work previously commissioned by the EBC has attracted comparable attention.

The council can be justly proud of its success in presenting such a compelling case. The report identified the problem of brain disorders - and the fact that they attract inappropriately low levels of research funding - in such a way that it cannot be ignored, either by policy makers or the general public.

More than this, though, it provided a raft of proposals and suggested solutions to a problem that can only get worse. The cost of brain disorders, as the report underlined, will continue rising implacably as a greater proportion of Europe's population moves into old age.

The EBC: A success story with a long way to go

It is evident that the EBC should not be shy of its successes as it approaches its 10th birthday.

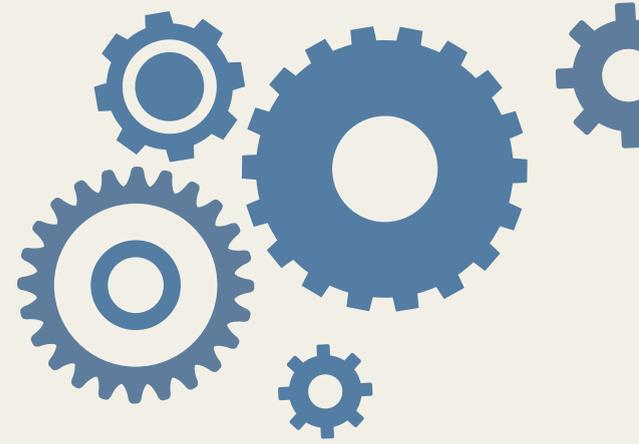
While it is difficult to ascribe an exact value to the council's informing and lobbying of European Union leaders and decision makers – political influence is, at best, a subjectively nebulous concept – there are nevertheless statistics that hint strongly at the scale of the organisation's contribution.

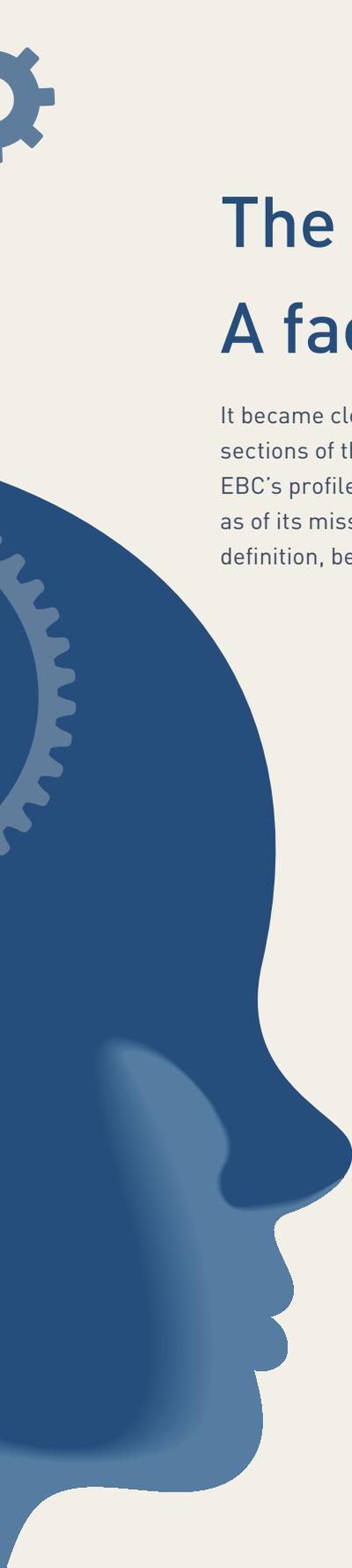
During the European Union's Fifth Framework Programme (FP5) from 1998-2002 – before the EBC was established – 85 million euros were spent on research into brain diseases. That has since risen to 260 million during FP6, and 381 million euros during the first three calls of FP7.

The EBC has clearly had a massive role to play in this upward trend and will continue to do so.

The disparity between research funding and the cost of brain disorders, however, remains stark. If the council has come a long way, then it also has an even longer way to go.

Inadvertently, the "Cost of disorders of the brain in Europe 2010" report, compiled by leading epidemiologists and health economists affiliated to the council, also highlighted one major weakness.





The importance of public profile: A face to go with the voice

It became clear during the launch that large sections of the media were largely unaware of the EBC's profile as a campaigning organisation as well as of its mission - a lack of awareness that must, by definition, be duplicated among the general public.

Why does this matter? Because the media, always in a hurry to identify the most attention-seeking headlines, pay more attention to faces – and voices – that they recognise. And because the media, in terms of setting the policy agenda, are hugely influential. Politicians, after all, like members of the lay public, get the huge majority of their information from them.

This lack of recognition emphasises the need for the council to markedly increase its efforts in projecting itself as the central co-ordinator in the field of brain disorders.

The EBC and its members have important – and very practical, rather than merely theoretical - things to say and big messages to diffuse. As amply illustrated in 2011, the organisation can command major media coverage internationally, beyond the boundaries of Europe itself.

Clearly, however, it must do so on a much more regular basis so that, when the media see the words “European Brain Council” tagged to press releases, reports and events, they automatically expect to be confronted with issues of paramount, wide-ranging importance.

The EBC: A unique organisation

Could any other organisation have produced such a comprehensive, wide-ranging and well-sourced report?

Probably not. No other organisation in this field can lay claim to such an all-encompassing membership. The council's board, with representation from EFNS, EANS, ECNP, EPA and FENS, as well as patient organisations EFNA and GAMIAN-Europe and industrial partners from the pharmaceutical and medical device industries, amply reflect this.

The EBC's ability to bring together the majority of stakeholders, indeed, is one that is envied in many other areas of health care where research efforts can appear uncoordinated and 'siloed'.

More than that, the council, by its very existence, hugely simplifies the life of policy makers. Before the advent of the EBC in 2002, Europe's politicians faced a deeply fragmented picture of brain health, with a host of organisations and interest groups representing conditions as diverse as stroke, depression, epilepsy and Alzheimer's all competing for attention.

There are, indeed, around 200-300 such diseases. The composite term 'brain disorders', therefore, is most welcome shorthand allowing for macro rather than micro management.



The challenge of 2012:

A more proactive approach

What does this mean? It means that the EBC must take a hard look at itself, its way of working and its organisational structure, while also attempting to become more pro-active in driving forward its key messages.

The council is perfectly placed to do this. Its members are all highly respected leaders in their fields. Look at the EBC board and you see an impressive array of expertise. The challenge is to use them to greater effect.

The council's individual members, of course, have their own important and exacting commitments. But their interests and those of the EBC dovetail to the point that they could - and, indeed, should - in some cases be jointly sponsored under the same banner.

The basic truth is that greater, more constant efforts are required to publicise the disparity between the financial and social costs of brain disorders and the current lack of adequate research funding. And it is equally true that the EBC is the organisation to make this happen.

Similarly, if the EBC wishes to present itself as the lead commentator in its field, then it must ensure that it is ready to cope with the extra demands of that situation.

It should encourage and promote greater interaction with the media, just as it should promote greater communication with, say, national politicians and civil servants rather than just ones at the European level.



The vital role of National Brain Councils and action groups

There is no reason why the council's success with the European Parliament and European Commission should not be replicated with national governments. Indeed, the two should go hand in hand, and particularly so in the coming year.

A central focus of the EBC during 2012 will be to build on the success of the "Costs of disorders of the brain in Europe 2010" by producing a series of follow-up reports on individual countries, detailing their national situation and priorities.

Extending the organisation's reach, nation by nation, will best be achieved through the European Brain Council's partnership with its affiliated National Brain Councils and National Action Groups.

In 2011, Bulgaria, Romania, Latvia and Finland held meetings to set up a National Brain Council or Action Group, taking the total of European nations thus represented to more than 20. Since research funds in member states far exceed those available at European level, the creation of active, campaigning national bodies, affiliated yet independent of the EBC, is crucial.

Such groups are much more effective in approaching their own national health ministers, politicians and MEPs. It is thus important for the council to improve its communication with them through, for instance, regular newsletters, briefings and meetings, in order to facilitate their work and increase their effectiveness.

A meeting involving the entire network of National Brain Councils and Action Groups, indeed, was held in Brussels in October to discuss individual and common projects and to better define a common strategy.

This work will continue throughout 2012, as will the continuing preparations for 2014 and the European Year of the Brain.



The European Year of the Brain: A life changing event



It is entirely appropriate that this review of the EBC's activities should conclude with the European Year of the Brain. This programme may or may not ultimately receive the European Commission's official recognition – despite the almost unparalleled backing of 13 Commissioners – but it will undoubtedly go ahead, and it will undoubtedly transform the council in the process.

What organisation would not be transformed by a year-long event, supported by around 200 European organisations and with a budget forecast of between 50-70 million euros?

There will be three central pillars to the project. The first will consist of a huge, exciting and interactive road show, its exhibits explaining the wonders of the brain on the one hand and the best ways of nurturing and caring for it on the other. The cavalcade will travel across Europe, visiting 900 cities and towns over the course of 12 months.

It will be supported by a schools and universities programme majoring on public health messages while also infusing students with a love of science and scientific research. The third pillar will exploit the digital and social media to reach its audience, reiterating the main messages of the campaign through a diversity of tools ranging from information videos and audio podcasts to, say, brain training

games. Conferences, scientific meetings and sporting, cultural and artistic events – the Vienna Opera House, for instance, has already signed up – will be organised as well.

The project, due to be supported by around 100 celebrity ambassadors, is designed to reach beyond the EBC's traditional sources of support, expanding the organisation's coalition of members by approaching a wide range of corporations and commercial interests. Put simply, the EBC and its members and partners have never before been offered such an opportunity to change lives for the better. The European Year of the Brain is a perfect vehicle by which to inspire political and legislative changes, as well as social and personal ones, extending way into the future.

To succeed, however, the council will have to re-examine its 'modus operandi'. Everyone, from members, board members and National Brain Councils and Action Groups, will need to play their part. When needed, outside expertise will have to be brought in to supplement the effort. The years ahead, culminating in 2014, are not 'make or break'. There is no question of the EBC 'breaking' in any way. But these years could certainly help 'make' the organisation – make it into a responsive, engaged, well-governed and highly professional organisation that lives up to its name.



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