



European Brain Council Greek Meeting. Athens, 31th March 2010

The meeting to consider launching a Hellenic Action Group for Brain (HAG) was held in the Athens University Club in Athens. The meeting was attended by 10 people; the EBC was represented by Ian Ragan and Tadeusz Hawrot.

LP	Name	Organization
1	Aleksandra Stroumpou	Vice-President, P.O.S.O.P.S.I.
2	Anastasios Orologas	Prof. University of Thessaloniki
3	Christiana Stanellou	General Manager, Varelas S.A.
4	Domna Karagogeos	Prof. University of Crete; President of the Hellenic Society for Neurosciences
5	Fotini Stylianopoulou	Prof. University of Athens; Secretary General-elect, FENS
6	Magda Tsolaki	Prof. University of Thessaloniki, Chair, Greek Federation of Alzheimer Disease
7	Nikolaos Smyrnis	Prof. University of Athens
8	Spiros Efthimiopoulos	Prof. University of Athens; Secretary, Hellenic Society for Neuroscience
9	Ian Ragan	Executive Director, EBC
10	Tadeusz Hawrot	Project Manager, EBC
11	Ioannis Tsoukalas	Member of the European Parliament - apologies
12	Marietta Giannakou	Member of the European Parliament - apologies

The agenda was as follows:

Morning session:

- Welcome speeches: Prof. Ioannis Tsoukalas – Member of the European Parliament.
- Participants' introduction.
- European Brain Council: Background and aims, National Action Groups and National Brain Councils.

12.30 - Lunch

Afternoon session:

- The situation of brain research and patients affected by brain diseases in Greece - open discussion.
- Conclusions and way forward.



Fotini Stylianopoulou welcomed everyone and gave a brief introduction to EBC activities. Subsequently, all the participants introduced themselves.

Following that, a letter of Prof. Ioannis Tsoukalas, a Greek Member of the European Parliament was read. Prof. Tsoukalas expressed his full support for the initiative of creating a HAG in order to “to exert strong influence on the relevant decision bodies and to raise public awareness”.

Please see the annex for the full text of the letter.

Ian Ragan presented the EBC structure and projects.

Tadeusz Hawrot continued, elaborating on the National Action Groups and National Brain Councils.

After these two presentations, Ian Ragan encouraged the participants to discuss the situation of brain research and patient organizations in Greece and the need to form a HAG.

Fotini Stylianopoulou expressed her view that it will be more advantageous to start off with an unofficial body that could take a legal form with time. She added that identifying 10-15 appropriate people who would show interest and commitment might be as equally challenging as securing a funding.

It was seconded by Anastasios Orologas who admitted that in view of the current economic situation in Greece the goals of HAG need to be realistic.

Following Ian’s Ragan question on what could be done in Greece to put brain higher in the agenda, Nicolaos Smyrnis noted that in Greece there is no national body dealing with funding the research and the HAG could stimulate the creation of such a body.

Some participants agreed that it could be considered as a starting point, however Fotini Stylianopoulou remarked that this would be a rather ambitious task and pointed out that there are other sources to look at, such as foundations and individual donations. She added that there exists a national body for funding research, however the level of funding is extremely low .

It was remarked by the others that there is a need to increase cooperation between societies in order to apply for funding from existing foundations.

All agreed on the need to seek cooperation with other societies outside the brain field and get better organized, in order to advocate for creation of an effective national body for funding. Industry involvement is needed as they have an interest in brain disorders and will benefit from supporting the research.

Domna Karagogeos added that there has been effort undertaken to restructure the General Secretariat of Research and Technology as well as the Ministry of Education – the two institutions merged - and it is worth discussing how this institution could operate more effectively.

Ian Ragan shared his conviction that getting together is an important aspect – scientists and patients speaking in one voice will be more influential at the political level. Next, he asked what the participants would identify in the field of patients’ needs. Fotini Stylianopoulou answer that there needs to be an improvement in interactions between basic scientists, clinicians and patients as there is little contact between them at the moment.

Magda Tsolaki added that there is a certain interaction between patient organizations and clinicians, however there is much more to be done on the level of collaboration



between these two groups and neuroscientists. When speaking about the patients' situation in Greece, one needs to look at different groups of patients as governmental policies vary from one disease to another.

Ian Ragan asked about other audiences, e.g. general public and media, and gave an example of a dramatic change in prioritizing breast cancer in the UK after revealing that UK, comparing to other countries, ranked very low in the diagnosis and treatment of breast cancer. Others agreed, that based on the existing data related to treatment of brain disorders, the Greek government should be encouraged to take concrete actions to improve the situation.

Ian Ragan added that the government should be approached with facts and figures as well as comparisons with other countries in the EU, to prove the need to invest more in brain research for the benefit of health and the economy.

Nikolaos Smyrnis seconded the idea, adding that the government should be approached on behalf of the thousands of people and families that are affected by mental and other brain disorders.

Domna Karagogeos confirmed that the key strategy is a merger of all the brain-related organizations, patients and society when speaking with government, in order to create stronger influence.

Nikolaos Smyrnis remarked that the government needs to be persuaded that basic research should receive greater support in Greece as Greek research is much under-appreciated.

Domna Karagogeos agreed that one of the first goals of HAG should be to show that the basic research is strong in Greece.

Ian Ragan gave an example of several countries that developed national papers supporting a need for conducting more brain research. Fotini Stylianopoulou expressed her doubt whether there are any existing data for Greece (the EBC to check).

Towards the end of the meeting, the participants discussed the Greek name of the Hellenic Action Group for the Brain. It has been agreed to call HAG: (a Greek name *Elliniki Omada Ergasias gia ton Egkefalo*)

Participants agreed on the following actions:

- Developing a press release about the formation of the HAG.
Responsible: Fotini Stylianopoulou.
Timing: Mid April.
- Preparing a short article on the current situation of brain research to be published in a newspaper that reaches a broad audience. The text is to convey a message that there should be more support both on the social and research level. It needs to be done by a professional science writer. Ioanna Soufleri will be contacted
Responsible: Domna Karagogeos
Timing: End of May
- Drafting a series of articles on different brain disorders, including MS, Alzheimer, Parkinson, epilepsy as well as mental disorders. The articles are to be published in a Greek scientific journal.



Coordination: Magda Tsolaki

Timing: End of June

- Identifying Greek patient organizations that can be included in the HAG and/or for dissemination of information.
Responsible: Spiros Efthimiopoulos
Timing: Mid April
- Identifying contact persons in Greek pharmaceutical companies that have an interest in brain research.
Responsible: Christiana Stanellou
Timing: ?
- Organizing a second meeting of the HAG.
Coordinator: Christiana Stanellou
Timing: September
- Sending a press release to all the Greek MEPs
Responsible: Tadeusz Hawrot – providing the list of MEPs. Fotini Stylianopoulou – sending the press release.
Timing – Mid April
- Meeting with the General Secretary of the General Secretariat of Research and Technology.
Responsible: Domna Karagogeos
Timing: End of June
- Contacting relevant people who might be potentially interested in joining the HAG, and subsequently making a list.
Responsible: Everyone is to make contacts.
Timing: ?
- Writing a meeting report and sending it to all the participants along with contact details of all the participants and people who have been invited but couldn't make it:
Responsible: Tadeusz Hawrot
Timing: Beginning of April.

T. Hawrot

Annex 1.

A letter from Prof. Ioannis Tsoukalas, a Greek Member of the European Parliament.

Ladies and Gentlemen, dear esteemed colleagues,

I would like to express my joy for having the privilege to welcome you all here today in the kick-start meeting of the Greek Brain Council. I find that this is an extremely significant initiative, with a great potential to develop into a reference point for doctors, scientists and patient organisations. I am sure that the Greek Brain Council will be able to coordinate the efforts of the research community and doctors, to exert strong influence on the relevant decision bodies and to raise public awareness. You will have my strong support in your endeavour.



I am sure that all of you know the numbers by heart:

- Brain diseases account for 35% of the overall disease burden for European citizens, with an annual cost of more than 400 billion Euros.
- However, the funding for brain research is only 1% of that amount and only 20% of this percentage comes from public sources.
- At the same time, US funding in brain research is more than ten times of the EU equivalent.

If we want to be competitive in this field, if we want to be able to help the millions of Europeans that are suffering from brain related diseases and to reduce the enormous strain this situation poses on our health system, we must increase our public investments and we have inconvenience to better coordinate our efforts, both at local and European level.

I want to assure you that we, in the European Parliament, and especially the Committee on Industry, Research and Energy, of which I am a member, are aware of these facts and of our responsibilities. We have already taken some actions, like the initiative "Joint Programming of research actions for Alzheimer's and other neurodegenerative diseases". But much more needs to be done. We must help the development and coordination of national plans; we must raise public awareness and we must act decisively in the field of prevention. Above all, we should be more daring when it comes to the allocation of public funding through the Research Framework Programmes.

I wish you all a fruitful discussion and I am looking forward to learning more about the progress of your work and to receiving your recommendations.

Prof. Ioannis A. Tsoukalas
Member of the European
Parliament