

EBC - Executive Director Report to the Board November 2010

Over the last 5 months it has been my privilege to be Interim Executive Director of the European Brain Council. I have spent 3 days a week pursuing two main aims, firstly leading the EBC executive function, working with the officers of EBC on EBC strategy and our operational capability. Secondly by leading efforts with board members to achieve the goal of making 2013 'The European Year Of the Brain (EYOB)'. This report covers activities for the whole year

Executive Function

Considerable activity has occurred to move the executive function from an operationally effective team to a team which will be able deliver the EBC strategy even more effectively, planning ahead to ensure that the mission of EBC can be delivered. The team has been mentored and challenged to become even more professional and able to represent EBC at the highest level. My time has included providing support to Board members before and during meetings with external stakeholders e.g. European Commissioners, improving communications with member organisations, presenting at their conferences and working to better understand the environment in which we work and the needs of all our members. Further progress will need to be made at all levels over the coming months including even more engagement with our members, further improved communication activities, an even better website and development of common key messages.

Support has been provided to the Officers to improve the governance of EBC, its processes and better targeting of key personnel in the European institutions. A series of recommendations have been made and broadly discussed with the President and Officer's regarding the role of the Executive Director and the needs of the organisation, particularly if the EYOB is progressed.

Costs project Led by Jes Olesen and Eveline Sipido

The Cost project is running as planned. In January 2011 there will be the last meeting of all participants to discuss the preliminary results. The report is expected to be ready for launch in the European Parliament in September 2011 preceded by a short publication in a high impact journal. During 2012 and 2013 disease specific and country specific papers will be generated.

Consensus document Led by Monica di Luca and Eveline Sipido

The EBC completed the revision and update of the in 2006 published "Consensus Document on European Brain Research". The revised Consensus Document reflects changes in research priorities and advances in brain research that have taken place since 2006. The same approach and format have been used as in the previous version.

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Multinational and multidisciplinary teams have once again come together to express their views, not only on what needs to be done, but also on the current strengths in European research. The 43 themes included in the new version are again written by groups of experts from across Europe representing a wide range of disciplines. In agreement with European scientific organizations, patient associations and industry, pharma and device, more than 200 experts contributed to this revised version. Each theme not only underlies the advances made by European research in the field but also contains potential proposals for future research and unmet needs. Themes focus on major diseases and then describe the basic research needed to understand, treat or even cure those diseases. As in its previous version the themes are designed “from man to molecule” with equal importance attached to basic and clinical research. The revised Consensus Document has been submitted for publication to the EJM, official journal of FENS.

National Brain Councils Led by Tadeusz Hawrot and Monica Di Luca

The meeting to consider launching an Irish National Action Group or National Brain Council was held in the European Union House in Dublin on the 9th March. The meeting was attended by 10 people; the EBC was represented by Ian Ragan (IR) and Tadeusz Hawrot (TH). The participants agreed to form an Irish Brain Council.

A Hellenic Action Group for Brain (HAG) kick off meeting took place in the Athens University Club on the last day of March. The reason for targeting Greece is that they will be part of the same trio of Presidencies as Ireland and Lithuania. Again 10 people participated, including IR and TH. The participants agreed on a number of concrete actions such as developing a press release about the formation of the HAG, drafting a series of articles and conducting several meetings with governmental representatives. A timeline for all the agreed actions was made and the persons responsible were nominated.

On the 23rd June another meeting to talk about formation of Danish Action Group was held. 12 participants, including Eveline Sipido (ES) and TH discussed the situation of brain research and patients affected by brain diseases in Denmark. Co-operating with patients and patients' organizations became a main issue as there are a number of potent patient groups in Denmark who should participate in the initiative. The best ways of involving these organizations were debated and as a result it was decided that the unifying theme for the DAG will be the creating a Danish Brain Package.

Actions were taken to investigate the creation of an Israel Action Group. The date of the meeting was set up in October and was then postponed to the 16th December. Nineteen persons were invited of which there have been so far around 10 confirmations. The meeting will be held in the Division of Psychiatry, Chaim Sheba Medical Center in Tel Hashomer, Israel.

There has been an attempt to create a Dutch Action Group. However, EBC was informed that there are already 3 somewhat similar groups existing in the Netherlands therefore it was felt that at this point there is no need to create a new one.

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It is likely that the kick of meeting for a Romanian Action Group will take place in January 2011 in Bucharest.

PARADISE project Led by Tadeusz Hawrot and A. Benbow

PARADISE, Psychosocial Factors Relevant to Brain Disorders in Europe, is a new coordination action funded by the EC through FP7, having the goal, over three years, to coordinate the development of a comprehensive and cross-cutting or horizontal epidemiology of those psychosocial difficulties.

The EBC, which is one of 10 partners in the project, is responsible for creating and maintaining the PARADISE website, devising a dissemination plan and ultimately, disseminating the results. It will also organise a meeting of stakeholders whose goal will be to present those results to the scientific and policymaking communities.

The kick off meeting for PARADISE took place in late January in Munich and was attended by TH and ES. The timeline for future work was established.

The draft of the PARADISE website was completed and approved by the project coordinator. The website has been put online in late May. The EBC is responsible for regular updates and has been implementing them ever since. In addition, the PARADISE dissemination plan was drafted and the database for dissemination was created. It has been submitted and subsequently approved by the project coordinator in April. A press release to the scientific community was drafted and sent out to the database in early June. Project brochure and poster have been designed and printed out by EBC respectively in June and August. This project has been led by Tadeusz Hawrot

European Presidencies

Upcoming European Presidencies in 2011 (Hungary and Poland) will both feature Brain diseases as part of their Presidential Priorities and we aim to continue this into future Presidencies

European Year of the Brain Led by Mary Baker

The strategy for The European Year of the Brain was developed, discussed and short terms aims and objectives agreed by the Officers.

A series of meetings have been held with key personnel from within the European institutions, (European Commission, European Parliament, European Council) and key groups within and outside Brussels. Considerable progress has been achieved and it looks highly likely that DG research will partner with EBC to progress with planning for delivery of 2013 as The European Year of the Brain. This is a considerable achievement and thanks are particularly due to the Officers and Board for the support that has been given to progress this. The next key decision point is the DG Research cabinet meeting, attended by the Commissioner, Maire Geoghegan-Quinn, on the 10 November 2010. If approval is given at this meeting EYOB planning should be commenced without delay as this is the green light to proceed.

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A series of steps will be necessary, particularly fundraising and commitment to participate in planning activities within EBC and as partners to the European Commission. We have never had such an opportunity and must make the most of this.

An EYOB business plan has been prepared and this is presented for Board discussion and approval. This is a living, dynamic document which will serve as the basis for resourcing, fund raising target and strategy over the plan period (2011-2014). It is divided into phases leading up to and beyond the European Year Of the Brain. It should reflect the current state of our organisation, particularly with respect of the operational capability and the future needs of EBC. Further detail will be provided at the Board meeting.

I would like to thank Tadeusz and Eveline for their diligent support of me over the past months and to the President, Officers and Board who have provided support and guidance to me, as well as to Ian Ragan for leading the executive function in the earlier months of the year. We have achieved much by working together in single minded pursuit of our aims; the challenge over the next years is daunting but exciting. If the Board believes I can provide the leadership required to lead EBC's executive function and deliver the EYOB I would be delighted to continue as EBC's Executive Director and project leader for EYOB.

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Interim Executive Director

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