



## I. STEPS TO SET UP A NATIONAL ACTION GROUP -> NATIONAL BRAIN COUNCIL

### Phase 1: Preparatory actions

Timing: 2-3 months to organize a kick off meeting.

1. Recognizing the priority countries.
2. Setting up a database.
  - a) Who should be members of an NBC?

An NBC should have representatives of:

- the main academic and medical fields (neuroscience, psychiatry, neurology and neurosurgery),
- neurological & psychiatric patient groups,
- industry (pharmaceutical and non-pharmaceutical).

The relevance of industry participation varies very much from one country to another, depending, for example, on whether there is an industrial research base, and whether medicines and treatments are fully reimbursed by the state. The EBC will be able to advise on how to manage industrial sponsors and supporters in order to preserve a suitable board structure.

There should be a proper balance between clinical and basic neuroscientists, and between academic and industrial representatives.

While the EBC Board is restricted to those organisations that have a European span and represent large constituencies, an NBC can be as broad and inclusive as it wishes.

b) Research:

- Identifying presidents of major national organisations representing brain researchers. Keeping in mind that these are usually very busy people, trying to get their general support for the idea and if needed, asking for delegates who could represent them.
- Identifying major national patient organizations
- Connectivity to European organizations: Checking all the EBC member organizations for representatives from the respective countries.
- Consulting EBC Board Members in order to get further feedback on the proposed participants and to identify a person who will be suitable to take the lead.

3. Making first contact:

- a) Approaching the possible leader/coordinator and consulting him/her on the names of possible participants



- b) Sending an official letter to all identified people to introduce the EBC, to describe the idea of setting up NAG/NBCs and to invite them to participate in the kick off meeting.

## **Phase 2: A kick off meeting:**

Timing: 1 day

1. Objectives:

Gathering a small number of people (8-15) in order to:

- a) Present the EBC and its activities
- b) Introduce the idea of setting up NAGs/NBCs
- c) Hearing what participants have to say and what are the particular needs for their discipline or area of interest in their country.
- d) Looking into possible ways of creating a NAG and setting up a draft action plan

## **Phase 3: Actions leading to setting up a NBC:**

Timing: One-two years between a kick off meeting of NAG and forming NBC.

1. Following up with a country leader regarding the progress in establishing NBC. Offering any possible help, including :
  - a) English version of constitution that could be then adapted to national needs.
  - b) Contacts of potential member organisations and representatives e.g. the EBC's industrial partners could use their national subsidiaries to help in the task of identifying industry participants
  - c) Providing a standard slide set about the EBC and other NBCs.
  - d) Support/visits from EBC Board members in the early stages of discussions to help catalyse the establishment of the NBC.



## **II. BACKGROUND INFORMATION:**

### **1. Difference between NBC and NAG.**

NAG is a multidisciplinary informal body consisting of individuals from the different clinical specialties, the basic scientists, patient organizations and national industries. Over time NAG could evolve into a formal legal entity – NBC – in which the individuals are now representatives of their relevant national organizations.

### **2. Arguments for creating NBCs:**

- a) The EBC studies demonstrate how expensive brain disorders are in every European country, how little public money is spent on brain research and finally what could be obtained if funding is increased.  
In this respect, the most important task for NBCs is to influence national research programs, where the greatest part of European funds is available. In this way, there will be more money to be spent on the national level.
- b) National research policy should be aligned with EC policies in order to create the European Research Area. This is an official policy of the EC and of all the Member States who have voted in favour of FP 6 and FP 7.  
Broad scope and unified efforts to speak with one voice are needed to influence the policy makers and budget holders at the national level.
- c) A national brain council can help the EBC with efforts to increase EC funding of brain research.
- d) An NBC is ideal to increase public awareness of the brain, its diseases and the importance of brain research.

### **3. How should an NBC be governed?**

The President and Vice-President should come from different stakeholder groups. A General Secretary should be appointed for administrative matters. The Board should consist of the Presidents of the various member societies or their deputies plus elected representatives from industry. In some countries patient organizations and professional organizations have an equal number of board members.

A proper balance should be kept regarding NBCs' presidents – there is a tendency that most of the presidents come from neurological societies and psychiatry field is neglected.

#### **4. Actions that can be taken by NBC at the national level:**

An NBC should have goals reflecting national needs and should develop its own processes for the achievement of its aims. The most important task for NBC is to influence national research programs, where the greatest part of funds is available. This can be achieved through:

- a) Organising conferences to gain broad stakeholder support, and the involvement of parliamentarians and other policy makers. Using the conferences as leverage to campaign for a national assessment of current activities and gain governmental support for an action plan to meet gaps and needs.
- b) Further mobilising national forces such as government agencies and decision makers, MPs and other stakeholders to support brain research e.g. through presentations to government Ministers and National Research Councils about European, as well as national policy, priorities and needs.
- c) Leveraging 3<sup>rd</sup> party events to convey the message by influencing the agenda, distributing info materials, making a use of media presence.
- d) Increasing public awareness of the need for more brain research, e.g. by targeting media through: organizing round tables, participating in radio shows, writing contributed articles, looking for the interview opportunities.
- e) Focusing on informing and alerting national patient groups, scientists, physicians and health care providers about the impact of brain disorders and the importance of brain research e.g. through organising national initiatives and multidisciplinary conferences on brain research.
- f) Improving/working towards the prevention, early diagnosis and optimal treatment of neurological and psychiatric diseases.

Ideally an NBC should also have aims that are aligned with those of the EBC:- to promote brain research in Europe and to improve the quality of life of those affected by brain diseases. These might be:

- g) Supporting the EBC's European initiatives e.g. through influencing MEPs and facilitating access to them for the EBC
- h) Acting as the vehicle for dissemination of national versions of the EBC's main European projects
- i) Organizing together with the EBC, policy forums in countries where the EU presidency takes place.



## **5. Relations between EBC and NBCs**

Although enjoying independence from the EBC, it still leaves great scope for interactions that could benefit the aims of both organisations.

When the NBC is established, there should be formal contact with the EBC in order to ensure mutual alignment and to encourage joint working. This contact could include:

- a) An annual meeting of the Presidents of the NBCs to be held in conjunction with the EBC's Annual Alliance of NBC's Forum.
- b) Invitations to the Presidents of newly established NBCs to attend a Board meeting of the EBC, and to attend occasional meetings thereafter.
- c) Invitations to the President or a Board Member of the EBC to attend occasional meetings of NBCs and present a report on EBC activities.
- d) Attendance by NBC members at the EBC's General Assembly with the possibility to present achievements and projects.
- e) Exchange of minutes of board meetings and newsletters between the NBCs and between the NBCs and the EBC.
- f) A section of the EBC website devoted to news from the NBCs and vice versa.
- g) Joint work on approaches to MEPs to further both European and national goals.
- h) Joint work on dissemination of European projects and documents at national level.

The EBC could play a role in helping the national councils in their endeavours through the following actions:

- a) Providing names of prominent scientists, policy makers and contacts within patient organisations for inclusion in the action group or as participants in any conference.
- b) Providing information on the EBC's activities, especially its major projects.
- c) Providing information on brain research activities within the EC.
- d) Providing contacts with potential sponsor organisations.
- e) Providing the national data on brain research and brain diseases that have been previously prepared by the EBC.

## **6. Clearing out misconceptions about NBC and the role that the EBC is playing:**

- a) The EBC is not going to compete with anyone over the available funds. The aim of joint actions is to make overall funds bigger.
- b) The EBC will not endanger the sovereignty of national councils but is rather designed to be a service facility for its members.
- c) There is no intention that NBC's should become the national subsidiaries of the EBC and conversely, the EBC is not planning to be an umbrella organisation except where this serves the interests of the NBCs.