



### A meeting to consider establishing a Romanian Brain Council.

A meeting to discuss the formation of a Romanian Brain Council was held on 08 February 2011 at the Faculty of Medicine of Carol Davila University of Medicine and Pharmacy in Bucharest. It was attended by nineteen people.

List of participants, RBC

| LP | Name                       | Affiliation  |
|----|----------------------------|--|
| 1  | Vasile Barbu               | President, National Association for the Patients' Protection of Romania  |
| 2  | Prof.Ovidiu Al. Bajenaru   | "Carol Davila" University of Medicine;<br>President, Romanian Society of Neurology                                   |
| 3  | Ovidiu Brazdau, PhD        | Editorial Director, Scientific American Mind Romania,<br>Consciousness Quotient Institute                            |
| 4  | Ioana Cacovean, PhD        | President, Pharmacists Owners Association, Romania.  |
| 5  | Dr. Axinia Corches, PhD    | President, Romanian Society of Child and Adolescent<br>Neurology and Psychiatry                                      |
| 6  | Prof. Dana Craiu           | "Carol Davila" University of Medicine;<br>President, Romanian Foundation for Neurology and<br>Epileptology           |
| 7  | Dr. Aurelia Curaj          | President, Geron Fondation   |
| 8  | Dr.Radu Georgescu          | Medical Adviser, Lundbeck Export A/S-Romania   |
| 9  | Dr. Mirela Manea           | Romanian Society of Child and Adolescent Neurology<br>and Psychiatry   |
| 10 | Raluca Ileana Nica         | Past-President, GAMIAN-Europe;<br>Executive Director, The Romanian League for Mental<br>Health                       |
| 11 | Dr. Daniel Popescu         | Corporate Affairs Manager, Eli Lilly, Romania  |
| 12 | Dan Raican                 | President, Romanian Association Against Parkinson  |
| 13 | Prof. Luiza Spiru          | "Carol Davila" University of Medicine and Pharmacy;<br>President, Ana Aslan International Foundation                 |
| 14 | Prof. Cristina Tiu         | University Hospital Bucharest;<br>Romanian Society of Neurology (RSN); Delegate of the<br>RSN for the EFNS           |
| 15 | Dr.Catalina Tocea          | Romanian Society of Child and Adolescent Neurology<br>and Psychiatry   |
| 16 | Prof. Catalina Tudose      | "Carol Davila" University of Medicine<br>President, Romanian Alzheimer Society                                       |
| 17 | Prof. Tudor Udristoiu      | University of Medicine and Pharmacy, Craiova<br>Romanian Society for Biological Psychiatry and<br>Psychopharmacology |
| 18 | Dr. Ana-Maria Zagrean, PhD | "Carol Davila" University of Medicine and Pharmacy;<br>Secretary, National Neurosciences Society of Romania          |
| 19 | Prof. Leon Zagrean         | "Carol Davila" University of Medicine;<br>President, National Neurosciences Society of Romania                       |
| 20 | Tadeusz Hawrot             | European Brain Council   |



The agenda was as follows:

Morning session:

- 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 Romania - open discussion.
- Conclusions and way forward.

Meeting co-chairs Leon Zagrean and Tadeusz Hawrot welcomed everyone and the introductory round of all the participants followed. Apologies were presented for the absence of the EBC Executive Director Dr. Alastair Benbow who could not attend but called into the meeting and stayed connected throughout the whole duration of it.

Leon Zagrean expressed his contentment that the meeting could take place, especially in view of his earlier efforts aiming at bringing neuroscientists to one table.

Tadeusz Hawrot introduced the EBC, its main activities, goals, studies and strategy as well as the concept of the National Action Groups and National Brain Councils.

Following the presentation participants were invited to discuss a need to form a Romanian Brain Council (RBC) and what would be specific country problems that could be dealt with.

Ovidiu Al. Bajenaru mentioned two fields of particular importance:

1. Important health problems concerning brain diseases, in particular stroke that is a first cause of death in Romania, dementias and other neurodegenerative disorders
2. A need to increase the amount of research

Dana Craiu pointed out to a need for better transition in healthcare from children and adolescents to adults. She added that awareness should be raised of both paediatric and adult neurological problems.

Tudor Urdistoiu expressed his concern that it would be challenging to advocate for a better recognition of brain disorders as many other disorders claim to be a priority too. Tadeusz Hawrot remarked that data on brain disorders show that these diseases are much more burdensome and costly than disorders like cancer or cardiovascular diseases, therefore there is a need for a concrete data when talking to politicians in order to be more convincing and effective.

Ovidiu Al. Bajenaru seconded, giving an example of WHO data that show it very clearly.

Raluca Ileana agreed that unless having these data, it would be difficult to move any further as health advocacy is a very competitive area. Tadeusz Hawrot said



that with an update of the EBC study on the cost of brain disorders in Europe that should be ready towards the end of 2011, there will be country specific data available also for Romania. In anticipation of concrete data, European studies demonstrating the huge discrepancy between the impact of brain disorders and a modest allocation to brain research can be used as an argument.

Participants agreed that there is a need to make a national registry on brain diseases. More emphasis should be also placed on defining clearly risk factors in order to raise awareness about it in general public.

Dana Craiu remarked that there are already several registries, among others in paediatric neurology, cerebral palsy and epilepsy. In order to create a complementary register there would be a need for funding.

Ioana Cacovean stressed the importance of evidence based medicine approach. She also expressed her concern about safety of medicines and saw patients as important partners to work with in this regard.

Catalina Tudose complemented it mentioning that risk factors on patients with dementia were recently published.

Ioana Cacovean pointed out that there is a new EU directive obliging the EU Member States to reimburse costs of treatment of their citizens when treated abroad. This could stimulate politicians to standardise health care, especially when a cheaper but equally effective treatment could be offered in Romania.

Aurelia Curaj saw a need to improve the quality of services and support of families of people living with dementias.

Luiza Spiru pointed towards others pressing issues like ethics, stigma, and migration of talented researchers to other EU countries.

Ovidu Brazdau expressed his concern that there are no rehabilitation centres for drug addicts in Romania.

Leon Zagrean saw a big fragmentation in neuroscience field by too many too societies as one of the main problems in neuroscience activity in Romania.

Cristina Tiu expressed her concern that unless legally constituted, RBC would not work efficiently. A label of an officially registered RBC has a chance to make it more vocal.

Bogdana Tudorache saw epidemiology as the issue being of an importance for RBC.

Leon Zagren encouraged industry participants to share their views on what are the problems of industry in Romania.

Radu Georgescu saw preserving drugs affordable for patients as one of the most pressing matters. Unfortunately, currently government is cutting down budget for drug reimbursement.



Tudor Urdistoiu asked if there are any European Initiatives fostering a cooperation of industry and academia. Tadeusz Hawrot mentioned Innovative Medicines Initiative, Europe's largest public-private initiative aiming to speed up the development of better and safer medicines for patients.

After the lunch break the participants focused on concrete actions that would be undertaken in the coming weeks.

There has been a consensus about the need to form the RBC. Meeting participants are considered as founding members.

The RBC board, comprising 9 persons was proposed. It will be finalised on the next meeting.

Ovidiu Al. Bajenaru suggested that every participant makes a list of around 5 issues that are pressing and should be dealt with by RBC as well as suggestions of how these issues could be tackled. Participants were asked to send their feedback in the coming days after the meeting.

Tadeusz Hawrot will circulate:

- Meeting minutes
- A list of persons who participated in the meeting as well as other interested individuals who could not made it but would like to be involved in the initiative. Participants are to add more suitable organizations.
- EBC bylaws and logo
- Executive summaries of main EBC studies translated to Romanian (translation not yet done)

Ovidu Brazdau offered help in dissemination of information on the RBC through Scientific American Mind Romania magazine and other dissemination channels that he can utilize. Further to that, he saw the opportunity for conducting an educational campaign.

Tadeusz Hawrot suggested drafting a news release about the formation of RBC. Ovidu Brazdau agreed to draft and send it out. Tadeusz Hawrot will circulate it to Romanian MEPs (in Romanian).

The next meeting of RBC will take on the 1<sup>st</sup> March 2011 at 4pm.

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