



BRAINS FOR BRAIN FOUNDATION

HUNGER FOR KNOWLEDGE: Investing in Brains to deliver research value in the EU

Brussels, 26 November 2013 - The B4B Roundtable rallied stakeholders to discuss initiatives aiming to create a model of intersectoral cooperation that could facilitate the set-up of a European PhD Programme in the area of rare neurometabolic paediatric diseases.

Maurizio Scarpa and David Begley, Co-founders of the Brains for Brain Foundation presented the reasons underpinning the Manifesto entitled “Investing in Brains to deliver research value in the EU”, which puts the foundations of a multi-disciplinary PhD bringing together patients, families, clinicians, scientists and industry partners to advance medical research and overcome the “Blood-Brain Barrier”.

Panellists and stakeholders shared views on new ways of collaboration that can address the existing gaps in research and limit the brain drain in this field in the European Union.

MEP Amalia Sartori, Chairwoman of the Parliament’s Industry, Research and Energy (ITRE) Committee, opened the discussion with a description of the B4B manifesto as a practical way of responding to a number of gaps in the scientific, knowledge sharing, professional training and healthcare delivery when it comes to the field of rare neurological disorders. She explained that the Brains for Brain (B4B) initiative was actively seeking solutions to identified challenges and with that, Mrs Sartori became the first MEP during the session to sign the manifesto to support patients, families and Europe’s bright, young researchers.

MEP Maria da Graça Carvalho emphasised her support for the B4B Manifesto as a relevant action on rare diseases to speed up results for patients. She also mentioned that within Horizon 2020 the area of health is specified as a priority societal challenge, with rare diseases given particular attention.

MEP Oreste Rossi, who had been the Shadow Rapporteur on the patients’ rights directive in crossborder healthcare then asked that more funds be dedicated to exchange of best practices that can result in better diagnosis and treatment.

MEP Angelika Werthmann stated her full support to the initiative and stressed the importance of providing support to families who have children with rare neurometabolic diseases since the diagnosis of their children is often accompanied by feelings of isolation and uncertainty.

Patricia Reilly, Cabinet Member of Maire Geoghegan-Quinn, responsible for research and Michel Goldman, Chairman of the Innovative Medicines Initiative mentioned opportunities to secure EU funding through Horizon 2020, through measures earmarked for personalised medicine as well as IMI calls. Both stressed the importance of coordination across borders and promotion of partnerships between private and public actors as key. Other financial tools fostering excellence through cross border and cross sector mobility were illustrated by Mario Roccaro from DG Education.



Nathalie Moll, Secretary General of EuropaBio, commended the initiative since it aimed to overcome the “silos” that impede collaborations between the private and public sector and across sectors. This point was also elaborated by Roberto Bertollini, WHO Representative to the EU, who highlighted the role of the WHO in working with Member States to raise awareness of the need to improve knowledge-sharing as a means to improve standards of care across the European Region.

Mary Baker, President of the European Brain Council and Paul de Raeve, Secretary General of the European Federation of Nurses emphasised the need to include patient organisations and the healthcare professionals who are closer to the patients in any collaborative effort aiming to advance medical treatment.

Frank Stehr, NCL-Stiftung, and Vassili Valayannopoulos, Society for the Study of Inborn Errors of Metabolism have both highlighted the need for holistic strategies aiming to enable translational research from the laboratory to the clinical practice. In particular, it was stressed the importance of earmarking budget to attract young biomedical scientists to the area of rare neurometabolic paediatric diseases.

It was generally agreed that overcoming barriers in health research and reversing the brain drain should be made political priorities at European level. This will require action from policy makers, hospital administrators, healthcare providers, patient groups and citizens across Europe. The B4B roundtable has rallied multi-stakeholder partners to take the first step to seek endorsement for the set-up of a European PhD Programme in the area of rare neurometabolic paediatric diseases. Stakeholders from 20 European organisations active in the field of health have signed the B4B Manifesto to maximise investments in health research and advance care for children with rare neurometabolic diseases.

For more information:

B4B Manifesto: http://www.brains4brain.eu/site/assets/files/B4B_Manifesto.pdf

Brains for Brain Website: www.brains4brain.eu

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