



Meeting Report

International Brain Research Organization (IBRO) global neuroscience advocacy programme: Four imperative resolutions to strengthen neuroscience research and development in Malaysia

1. Introduction

In year 2012, International Brain Research Organization (IBRO) together with Society for Neuroscience (SfN), Federation of European Neuroscience Societies (FENS), International Society for Neurochemistry (ISN), DANA Foundation, Japan and Australia formed the Global Advocacy Committee chaired by IBRO. The IBRO Global Advocacy Initiative aims to facilitate the development of culturally relevant educational and motivational programs that will garner wider support for neuroscience research across the world (<http://ibro.info/global-advocacy-initiative>).

Three years later, the IBRO Global Advocacy initiative was extended to the Asia-Pacific region (APR), with the First IBRO-APR Committee (APRC) Global Advocacy Workshop held at the Tata Institute of Fundamental Research (TIFR), Mumbai, India on February 3–4, 2015. The goals of the workshop were to understand the situation of neuroscience funding in various APR countries, to learn from the previous successful and unsuccessful attempts of advocacy activities and to identify the possibility to collaborate in advocacy activities across countries (<http://ibro.info/events/first-ibro-aprc-global-advocacy-workshop-in-mumbai-india>). Professor Keiji Tanaka, the Chair of IBRO-APRC, presided the meeting whereas Professor Sten Grillner, Secretary General of IBRO and Chair of IBRO Global Advocacy Committee delivered the plenary talk related to his experience on how to conduct a successful global advocacy programme.

The meeting was also well attended by esteemed representatives from APR including Australia, China, Hong Kong, India, Iran, Japan, Korea, Malaysia, New Zealand, Philippines, Singapore, Sri Lanka and Taiwan. Each representative shared the neuroscience-funding situation in their home countries, the efforts by the community in raising and administering funding for neuroscience research and ideas for international cooperation in advocating the importance of neuroscience research and development (R&D) to policy makers. All the representatives discussed and shared thoughts on how to enhance promotion of neuroscience research funding and related international cooperation. The APR representatives also agreed that the effective neuroscience advocacy initiative is able to increase the awareness of the importance of neuroscience research and education in their respective countries. This includes harnessing support among key policymakers, authoritative leaders and philanthropists to increase resources for research and public education concerning the brain and the nervous system. This encompasses both the healthy and disease-state nervous system in all stages of development. It is strongly believed that effective advocacy will lead to greater political

will and enhance cooperation of stakeholders from various backgrounds.

2. Inaugural IBRO global neuroscience advocacy workshop 2016 in Malaysia

There are approximately 150 neuroscientists in Malaysia (including postgraduate students – an estimation based on the number of attendees in neuroscience-related networking events in Malaysia) who work alongside with more than 1,000 neurologists, neurosurgeons, psychiatrists, specialist trainees, psychologists, neuroengineers and allied health personnel as well as members of neuroscience-related non-profit organizations (based on estimation and exhaustive search for registered specialists at <http://www.nsr.org.my>). This number is relatively small as compared to other global leading neuroscience research countries. Various educational and research programmes in neuroscience have been offered by different universities in Malaysia leading to the increasing number of neuroscientists in the past years signifying the growing needs of the community to address various issues related to the brain.

Advocacy for neuroscience R&D has been poor in Malaysia due to different local requirements among neuroscience societies or non-profit organizations. International Brain Research Organization (IBRO) together with the Malaysian Society of Neurosciences and Universiti Putra Malaysia (UPM) decided to spearhead the task in concerting voices and efforts among all related parties in view of gaining better recognition from the national authority and related-community in general in Malaysia. Dr. King-Hwa Ling, the Malaysian representative to IBRO Governing Council with a supported from the IBRO Global Advocacy Seed Grant, organized and chaired the inaugural neuroscience advocacy workshop in Malaysia (<http://ibro.info/news/ibro-global-advocacy-initiative-2015-seed-grant-awardees>). The inaugural IBRO Global Neuroscience Advocacy Workshop 2016 was held at the Faculty of Medicine and Health Sciences, Universiti Putra Malaysia (UPM), Malaysia, on March 21, 2016 (<http://neuroscience.org.my>). The workshop was themed “Towards National and Global Neuroscience Advocacy: Embrace, Network and Change”.

The one-day workshop received an overwhelming response from various sectors with 67 participants representing academics, neuroscientists, medical specialists, postgraduate students, policy makers, leaders/members of NGOs and industrial players. They are from Malaysian Society of Neurosciences (MSN – <http://www.neuro.org.my>), Motor Neurone Disease Malaysia (MND Malaysia – <http://www.mnd.org.my>), Malaysian Parkinson's Disease Society (MPDA – <http://www.mpda.org.my>), Multiple Sclerosis Society Malaysia (<http://www.msmyasia.com.my>), Alzheimer Disease Foundation Malaysia (ADFM – <http://www.adfm.org.my>), P3Neuro (Universiti Sains Malaysia,

Malaysia – <http://www.p3neuro.usm.my>), Centre for Intelligent Signal and Imaging Research (CISIR, Universiti Teknologi Petronas, Malaysia – <http://cisir.utp.edu.my>), Malaysian Research Institute on Ageing (UPM – <http://www.myageing.upm.edu.my>), Neuroscience Research Cluster (UPM), Novartis Corporation (Malaysia) Sdn. Bhd., scientists, clinicians, nurses and postgraduates students from various public and private academic institutions.

The workshop was aimed to discuss on a streamlined strategy in bringing all neuroscience-related organizations together, to brainstorm on challenges in neuroscience R&D in Malaysia and the relevance of various neuroscience organizations in pushing neuroscience R&D forward in the next decade (Fig. 1). Five speakers were invited to deliver talks pertaining to challenges in neuroscience arena locally as well as internationally. Professor Tadashi Isa (Vice President of Japan Neuroscience Society and the member of IBRO Global Advocacy Committee) shared his experience in neuroscience advocacy in Japan, which led to the formation of the Union of Brain Science Associations in 2014. The union represents 22 associations and serves by providing feedback to the Science Council of Japan as well as the Brain Science Committee that are both answerable to the Ministry of Education, Culture, Sports, Science and Technology, Japan. Professor Dato' Jafri Malin Abdullah (Director of P3Neuro, Universiti Sains Malaysia) presented his findings on neuroscience R&D funding in Malaysia. Based on his finding, there was no dedicated funding for neuroscience with only 35 projects approved between 2007–2013 (a merely 2% of total number of grants) by Ministry of Science, Technology and Innovation, Malaysia. Under the purview of Ministry of Higher Education, Malaysia, a total of 27 neuroscience projects were approved between 2005–2014, about 2% of total grants approved. Overall, research funding allocated for neuroscience-related projects were minute and greater advocacy is needed to improve the sector. In addition, Professor Lim Kheng-Seang (President of Malaysian Society of Neurosciences and Professor in Neurology, University of Malaya) emphasized that a collaborative model is needed between scientists and clinicians from multidisciplines to make sure the right research questions are queried as well as bridging the bench outcome to bedside practice. Such collaboration is less prominent in Malaysia and warrants a greater advocacy between the two groups. Dr Ang Guan-Lee from Novartis Corporation Malaysia Sdn Bhd enlightened the participants on potential industry-academia joint ventures with a focus on projects that are of greatest patients' need and scientific promise. Professor Tengku Aizan Tengku Abdul Hamid (Director of Institute of Gerontology, Universiti Putra Malaysia) put a great emphasis on Malaysian journey towards an ageing nation by 2030 (United Nations, Department of Economic and Social Affairs, Population Division, 2007) and how devastating ageing-associated neurological disorders may have not only on the patients but the family members, caregivers, society as well as the nation. Only 14 years left for Malaysian community to put forward a national blueprint as well as effective implementation to alleviate the effect of ageing-associated neurological disorders.

After each plenary talk, a round table discussion was organised to facilitate greater engagement of the participants from various organisations and backgrounds to discuss on various preset topics such as: 1) challenges in neuroscience R&D in Malaysia in the next decade, 2) problem-based-driven research prioritisation in Malaysia, 3) redefining the roles of academia, societies, agencies and NGOs in neuroscience R&D in the next decade and 4) Embrace, Network and Change: common goals and sustainability. The outcomes of the discussion are presented in the following sections, which discuss each topic in greater depth.

2.1. Topic 1: various challenges in neuroscience R&D in Malaysia in the next decade

Communication barriers exist among neuroscientists, clinicians and industrial partners to understand and appreciate each other. An optimum atmosphere to bridge the gap between clinical-based research and fundamental-oriented research is still lacking. Consequently, there is poor translation of basic research into clinical settings and also limited interdisciplinary neuroscience research. Although the number of neuroscientists in Malaysia has improved, many tend to work in silos lacking concerted effort in championing causes to improve R&D funding in the country, human resources and infrastructures. Resources are scattered and unconsolidated leading to technological and research redundancies.

National registry and online database is not yet available for neuroscientists to be listed and registered to facilitate accessibility by the general public. Malaysian government has not defined national goals for neuroscience R&D and there is relative small fraction of funding dedicated for neuroscience R&D. This could be due to the weak coherent voice among neuroscientists, clinicians, NGOs and the general public. Majority of Malaysian neuroscientists are not only represented in different institutions and societies but they also play an active role in other non-profit organizations related to neuroscience. These organizations, however, suffer from the lack of communications and collaborations leading to the lack of neuroscience agendas in the national blueprint for R&D.

Although neuroscience is a major scientific enterprise in the twenty-first century, advances in fundamental research have not translated into benefits for society. This may be explained by the poor connection between public interests and the research interests of neuroscientists. It is alarming that public awareness of neurological diseases is low including relatively common conditions, such as Alzheimer's disease, Parkinson's disease and epilepsy. In general, the public still feels that the neuroscience research has done little to halt the rising tide of brain diseases, whose costs reach 8.8% (approximately USD1.5 trillion) of the world GDP (Nager and Atkinson, 2016). Malaysia is fast approaching the ageing nation status and must have a national agenda to tackle the challenging issues of dementia and neurodegeneration.

2.2. Topic 2: problem-based-driven research prioritisation in Malaysia

Malaysia has the niche in cultural diversity, ethnicity, socio-economic, urban- and rural-based mental health, disease and healthcare system and development. Hence, it is a rather challenging issue to determine the niche and research priority for the next 5 to 10 years. Brain diseases related to blood vessels (such as stroke), infectious diseases related to the brain (such as meningitis and encephalitis) and neurodegenerative diseases (such as Parkinson's and Alzheimer's disease) could be the focus points of neuroscience R&D in Malaysia. Majority of neuro-afflictions involve chronic or long-term costly healthcare and medications. Outcome-based R&D focusing on improved quality of life and cost effectiveness in the management of chronic neurological disorders afflictions should be prioritized too.

Accessibility to the right information on medications and healthcare related to neurological disorders is relatively difficult for the general public. Caregivers and family members of patients hardly understand and know the importance of neuroscience R&D and the relevance of related research activities to improve patients' quality of life. There should be effort in promoting educational research to improve lifestyle and promote right perception on the progression of various neurological disorders. Although most research aims to treat neuro-related diseases, it is time to acknowledge the importance of preventive care such as embracing early



Fig. 1. Photos depicting the IBRO Global Advocacy Workshop held at the Faculty of Medicine and Health Sciences, Universiti Putra Malaysia on 21 March 2016. (A) A welcoming banner; (B) Registration of participants; (C) Workshop venue; (D) Professor Zamberi Sekawi (Deputy Dean for Research and Internationalization) officiated the workshop; (E) Dr. King-Hwa Ling (Chair of the workshop) presented the concept of neuroscience advocacy; (F) Professor Tadashi Isa (Vice President, Japan Neuroscience Society) delivered the plenary lecture on Japanese experience in neuroscience advocacy; (G) Professor Dato' Jafri Malin Abdullah (Director of P3Neuro, Universiti Sains Malaysia) presented on the neuroscience funding situation in Malaysia; (H) Professor Lim Kheng-Seang (President of Malaysian Society of Neurosciences) presented on strategies for bridging Malaysian neuroscience R&D to healthcare service providers; (I) Dr. Ang Guan-Lee (Head, Clinical Development & Medical Affairs Novartis Corporation Malaysia Sdn Bhd.) presented on the role of industry in Malaysian neuroscience R&D; (J) YM Professor Tengku Aizan Tengku Abdul Hamid (Director, Malaysian Research Institute on Ageing, Universiti Putra Malaysia) presented on the importance of neuroscience R&D to the ageing Malaysian population; (K)–(N) Roundtable and intergroup discussion among workshop participants; (O) Faculty dinner session at Spring Garden Restaurant, Putrajaya.

detection methods, management and formal education in making Malaysian living a healthy life and in the most ideal scenario, free from the devastating neurological disorders.

Neuroscience research in Malaysia includes diverse focusing at different levels of organization, from molecules, cells, microcircuits to macroscopic brain regions. Different groups work on different brain regions, animal models, ethnicities and age groups. Unified strategy can be employed to manipulate the biological mechanisms

and to correlate observations in one species with observations in another. It can also help to build systematic knowledge, which is essential to extrapolate results from animal experiments to humans. Interlinked datasets will eventually provide an increasingly complete picture of a single brain region. A local data on disease burden, phenotypic spectrum and distribution should be generated. It can help to decide direction of the neuroscience research, which should favour local needs and be relevance to

Malaysians. Rather than being trend-follower, local neuroscience research should be the trendsetter, and serve as research hub in drug discovery using natural products to treat neurological diseases owing to rich natural resources in Malaysia.

With the increasing commitment to patient-focused drug development, effort is needed to established academic-industry partnership for neuroscience research. Pharmaceutical industries and neuroscientists have their own interests. Efforts must be implemented to bridge the gap between these two parties, to become more passionate about basic research instead for individual profit. Consequently, there will be efficient initiation of clinical trials for neurological diseases and thus allowing both parties to work collectively to streamline costing and contracting activities.

2.3. Topic 3: redefining the roles of academia, societies, agencies and NGOs in neuroscience R&D in the next decade

To mitigate the shortcomings in facing the challenges while trying to achieve the prioritized neuroscience R&D sectors, the workshop also aimed to redefine the roles of various parties in order to materialize the dream of effective translation from bench to bedside. Academics should understand the impact of translating discoveries, 4As – **affordability, accessibility, availability and acceptability** of culture. Neuroscientists should focus beyond scholarly publication and write general articles to effectively share research findings with the general audience. They should also extend their roles by reaching out to the society to disseminate knowledge on the relevance of their research to management and treatment of neurological diseases, via public lectures and talk shows. Academics will need to train and equip skills to students to cater to the need of the industry.

It is utmost essential to engage the media to generate interest in neuroscience R&D as well as educate the public about living with neurological illness. Neurologists, neurosurgeons, neuropsychiatrists, neuroscientists, psychologists, allied health personnel, neuroinformatic specialists and bioengineers via their professional societies and academia can play essential role to provide accurate information to demystify neuroscience and to improve neuroscience literacy among school children and the general public. They can increase visibility by using social media to excite and engage community via bottom-up approach.

Industrial players such as pharmaceutical companies and professional carers' networks should also widely establish patient relation and advocacy policy to discover unmet needs of patients as well as proactively find interested and experienced investigators in Malaysia so that clinical trials could be conducted effectively in the country. Following that, they can jointly establish a neuroscience foundation or trust to cater for public awareness and educational programmes among neuroscience research community and general public.

2.4. Topic 4: embrace, network and change: common goals and sustainability

The ultimate aim of the workshop was to encourage all parties to embrace each other's differences, to form networks and alliances so a prominent change could be made to alter the neuroscience R&D landscape in the country. In order to achieve that, the workshop discussed the common goals for all parties and how to sustain such effort so that the advocacy work continues into the future. Three common goals were identified and the Malaysian Neuroscience community shall aim to achieve these common goals in order to maintain "Brain Health – The Foundation of Quality Life".

Common Goal 1: To translate discoveries from bench to bedside by performing patients-focused research especially on the improvement of quality of life.

Common Goal 2: To improve neuroscience education, increase awareness and develop neuroscience-literate society by bridging communication of all stakeholders.

Common Goal 3: To improve advocacy for patients' quality of life.

Short-term measurements have been suggested during the workshop in order to lay out an immediate plan to pave the way towards achieving these common goals. This includes the implementation of effective scientific, advocacy and social platforms, make use of telecommunication technology, establish a neuroscience trust to fund neuroscience related educational activities to increase public awareness, invite journalist to write about neuroscience or neurological disorders for long term publicity and organize journalism competition writing on neuroscience by the youngsters. To sustain the advocacy effort in the country for a longer term, all parties shall organise a special neuroscience advocacy session during their annual meetings, seek dedicated funding for advocacy programmes, formal training in neuroscience advocacy, establish international networks with other countries via IBRO and finally engage various stakeholders especially the Ministry of Higher Education, Ministry of Science, Technology and Innovation, Ministry of Health and Ministry of Women, Family and Community Development.

3. Concluding remarks and moving forward

The advocacy workshop was concluded with the following four main imperative resolutions in response to the topics discussed in the previous sections. These resolutions were recommended as general terms of reference to all stakeholders to strengthen neuroscience R&D in Malaysia in the next decade:

Resolution 1: It is timely that the neuroscience R&D resources in the country be consolidated to avoid redundancy and wastage in order to improve efficiency in neuroscience R&D. All stakeholders shall facilitate the establishment of a national neuroscience registry to improve resource sharing, better understanding of each other's research, inculcate healthy competitions and foster more effective communications among stakeholders from different professional backgrounds.

Resolution 2: Future neuroscience research shall take into consideration of multicultural ethnicities and biodiversity in Malaysia. Research focus should be patient-oriented, outcome-based and address the immediate needs of affected patients and their family members. Neuroscience research in Malaysia shall emphasize not only on the treatment of neurological disorders but also on preventive care as well as educational research that improves lifestyle and general awareness and attitude towards the devastating effects of neurological disorders. Fundamental neuroscience research shall sail along when the above neuroscience research priority has been established.

Resolution 3: Stakeholders including academics, neuroscientists, clinicians, neurologists, paediatric neurologists, neurosurgeons, psychiatrists, psychologists, policy makers, students, NGOs, caregivers, allied health personnel (including physiotherapist, specialized nurses and medical laboratory technologists) and etc. shall acknowledge that they have a role to play in making neuroscience R&D in Malaysia as the prime agenda towards better prevention and management of patients affected with neurological disorders. All stakeholders shall be treated equally and respectfully and share the responsibility to reach out to the general public with effective education and right information.

Resolution 4: Advocacy initiative will not achieve its goal overnight. A common and sustainable goals shall be set for all stakeholders so all parties will drive the neuroscience R&D towards a national agenda without losing sight of our commonalities. In other

words, we propose unity in diversity by identifying our ultimate goal among all the diversified fields in neuroscience. All stakeholders shall set their goal to achieve and maintain reasonable brain health as the foundation of quality life. To sustain such efforts by all stakeholders, a long-term programme and independent funding shall be established as soon as possible jointly for and from NGOs, governmental sectors, professional bodies, caregiver groups as well as general public.

The local neuroscience community has benefited immensely from the IBRO Advocacy Seed Grant to kick-start such an inaugural workshop and discussion in Malaysia. However, a long term effort to sustain the programme as well as achieve the common goals based on the proposed resolutions has to be hastily established and implemented so that Malaysia neuroscience R&D landscape will be shaped into the right path in dealing with challenges related to brain health in Malaysia.

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