

Meeting report for the 8th Pan-Asian Consortium for Treatment and Research in ALS (PACTALS)

The 8th PACTALS Satellite meeting was held on 7 December 2018 at Room Alsh2, Scottish Event Campus, Glasgow, Scotland in conjunction with the 29th International Symposium on ALS/MND.

The meeting began at 1pm with welcome remarks from Professor Matthew Kiernan (Australia). This was followed by the meeting report from Professor Seung Hyun Kim (Korea) on the 1st stand-alone PACTALS meeting, which was held in Seoul, Korea from 20-21st July 2018. Professor Kim reports a total number of 220 attendances at the meeting. A video montage was also shared and will be made available on the PACTALS website later.

The second session focused on potential study topics that could be done within the PACTALS structure. Professor Dongsheng Fan (China) presented a proposal on the comparison of in-hospital factors between different countries in PACTALS. Professor Nortina Shahrizaila (Malaysia) provided an overview of the minimum core dataset that each country might adopt within their own patient registers, extrapolating from other Registry examples including that of ENCALS and the Australian Register. Having a common minimum core dataset would facilitate future studies between different patient cohorts.

The third session discussed some of the clinical trials within PACTALS. Professor Seung Kim (Korea) shared plans for their Phase 3 clinical trial of bone marrow originated stem cell therapy for ALS. Professor Minsheng Liu (China) presented their current study on the randomized, double blind trial of dl-3-n-butylphthalide in the treatment of ALS.

The fourth session discussed operational matters relating to PACTALS. Professor Seung Kim (Korea) led the discussion with an update on the income generated from the PACTALS meeting in Seoul. Suggestions were made on establishing a dedicated bank account for PACTALS. Further details on where the official PACTALS account can be hosted will be determined at a later date with input from other key leads. Professor Kim went on to propose a PACTALS organisational structure for consideration by the key members. Instead of the current structure of country leads and representatives, the proposed structure would see PACTALS led by a Committee with Core Office Members (President, Vice-President) and an Executive Committee represented by country leads. As several key leads were not present at the meeting, it was agreed that further discussion will take place through email communication between the key leads.

Carol Birks (Australia), representing the International Alliance of ALS/MND Organisations, discussed the MND organisations from the PACTALS region currently in the International Alliance. Carol encouraged the participation of other countries and shared opportunities that can be gained through its membership. Carol also expressed their appreciation to the organising committee of PACTALS Seoul 2018 for providing the MND organisations with a platform for discussions during the meeting. It is hoped that future PACTALS Symposium will adopt a similar format and provide an opportunity for the MND organisation to participate.

In the penultimate session, Professor Kiernan invited members to suggest potential new topics that might be considered for a review article. Professor Kiernan also took the opportunity to invite

everyone to attend the next International ALS/MND Symposium which will be held in Perth, Australia from 4-6th December 2019. The next PACTALS Satellite meeting will be held in conjunction with this.

In the final session, A/Professor Naoki Atsuta (Japan), presented, on behalf of Professor Gen Sobue and the Japanese Consortium on ALS (JaCALS), plans for the 2nd International PACTALS Symposium in Nagoya, Japan in the year 2020. The theme for the meeting will be "Clinical Trials and Disease Registries". Speakers will primarily be from the Asian-Oceanian region with invited speakers from US and Europe. Dr Atsuta concluded by providing an overview of some of the current and future clinical trials in the region.

The meeting adjourned at 1355.