

World MEN 2016, Utrecht, The Netherlands – September/October

Jo Grey, AMEND CEO

This international scientific meeting on multiple endocrine neoplasia disorders is eagerly awaited by us as it only happens every two years and of course, because it focuses purely on our endocrine conditions. We were in even more anticipation this year, given the involvement that patients had into the organisation and the running of the 3-day event. The Dutch MEN patient group, Belgangengroep MEN, which is an EMENA member, were heavily involved as a member of the organising committee, in developing a patient/nurse session running parallel to the main scientific sessions (which patients were also able to attend), in running the registration booth for the entire conference and in organising and hosting all the social events for the patient attendees. In addition, it was being held in a trendy venue (hosts also to a karma sutra conference!) and it was being held in Utrecht; an absolutely beautiful canal-based Dutch city. And so it was that all the stars were aligned for a brilliant conference!

The main scientific sessions kicked off on Thursday 29 September with 'What's hot in MEN1' from AMEND Patron and Medical Advisory, Professor Raj Thakker (Oxford). Of course, hot topics in MEN1 included the slightly increased risk of breast cancer (at a mean age of 48), although more research is needed in this area. The French MEN research database has shown that symptoms of MEN1 tumours can arise earlier in life than previously thought (3% by age 5, 14% by age 10), supporting the recommendation in the 2012 MEN1 guidelines for beginning screening at an earlier age.

Dr Havekes (Maastricht) ran through the hot topics in MEN2/MTC. To date over 100 MEN2-causing gene mutations have been identified and Dr Havekes suggested that the whole gene may be sequenced in the future (rather than a specific area of the gene), since some people have proved to have more than one mutation, which may be linked to a worse outcome or more aggressive disease (including resistance to MTC drug, vandetanib). He emphasised that medication such as omeprazole (PPI) and glucocorticoids (hydrocortisone and fludrocortisone) can interfere with the results of calcitonin testing (hence the usual nil-by-mouth prior to this test). He also

reminded the audience that DOPA-PET CT imaging is useful in locating MTC, but that it is underused and is under-reported in the American Thyroid Association (ATA) guidelines. Consequently, European radiologists do not endorse the guidelines.

The patient and nurse's session began on Friday 30th September with sessions on genetic counselling, nuclear medicine, somatostatin analogues and target therapies. One session saw Professor Dekkers (Leiden) invite feedback from the audience on where patients feel research should focus. I was keen to ensure that more thought is given to inter-disciplinary research (rather than that confined to endocrinology), particularly in addressing the significant impact on quality of life that ganglioneuromas in MEN2b can have. This would involve input from gastroenterology as well as endocrinology. Jo Grey from AMEND gave the audience some information on starting a family, being a parent of a child with MEN, and talking to children, informing the audience on AMEND's 2014/15 work to develop children's information resources.

On Friday afternoon, all attendees were treated to a fascinating session on Quality of Life in MEN1 in the main session. This began with an excellent interview of a brave MEN1 member of the Dutch patient group, Belangengroep MEN which led beautifully on to two presentations about MEN1 Quality of Life studies undertaken in the USA and The Netherlands (unknown to each other at the time). Quality of life in MEN1 patients had been compared to the average population in each country with very similar results; that of a significant decrease in quality of life in MEN1 (slightly more so in the USA than in Europe). Dr Cord Sturgeon (Chicago) who undertook the slightly smaller US study, commented that there was a high number of female respondents to his survey, which it was suggested was likely to be down to sourcing the majority of the patients via patient groups (traditionally it is harder to engage male members than female members in patient groups). Both groups answered positively to the question about whether their surveys would be extended to include MEN2 and MEN3 in the future – so watch this space.

On Saturday 1st October (the final day), the patient and nurse's symposium listened to each of the European MEN patient groups as they described their aims, objectives and work. Professor Raj Thakker (Oxford) gave another round-up of MEN1 news

and endocrine nurse, Nick van der Meij (Utrecht) discussed issues surrounding steroid dependency. Belangengroep MEN Chair, Carla Pietermann then concluded the patient/nurse symposium with an elegant summary of the highlights.

Later in the afternoon, a session entitled 'Back to the future – interactive discussions' was very illuminating. With a room full of clinicians, researchers, nurses and patients, a superb synopsis of the entire conference was given, both from the scientific sessions and from that of the patient/nurse's symposium. Organiser, Dr Gerlof Valk invited patients to speak up too and to give their opinions on foci of future research and on planned parenthood. It gave everyone much to think about and felt for the first time ever as though everyone was working together for the benefit of those affected with these conditions. The session was hugely inspiring.

It was fabulous to have the opportunity to meet the patients and physicians from all around the world. The evening social events were a great chance for us patients to let our hair down and get to know one another as we ate our way around beautiful Utrecht, culminating in a relaxing canal cruise around the city.

Huge thanks must go to the Dutch organisers, Professor Gerlof Valk, Dr Menno Vriens and Belangengroep MEN Chair, Carla Pietermann for organising such an excellent conference, for including patients and ensuring that their voices were heard, and for such wonderful hospitality throughout. Thank you also to all the Belangengroep MEN volunteers who ensured that the conference ran so smoothly. We dearly hope that World MEN 2019 will continue in this vein when it goes to Houston, USA.