Meeting report


A group of ~85 delegates from 28 member countries attended the meeting on June 25, held at Sundby Wardhus, a turn-of-the-century farmhouse surrounded by beech and fir forests on the outskirts of Stockholm, Sweden.

The Chairman of the International MEDPED Steering Committee, Paul Hopkins (US), gave an overview of the organisational structure of MEDPED and emphasised that patient detection and treatment was the prime objective of the program.

Nick May (UK) presented the public relations aspects of the MEDPED program, discussing the value of the program to the public and how it could reach its target population more effectively.

Joep Defesche (NL) presented a report on WHO collaboration, in particular the second WHO report which required correction and updating of tables. The report will be forwarded to delegates when further copies become available.

Daniel Rader (US) was invited to address the topic of gene therapy. He reviewed the use of viral vectors and suggested that MEDPED researchers consider which patients with homozygous familial hypercholesterolaemia (FH) would be appropriate candidates for gene therapy when such treatment becomes available.

Brief summaries of MEDPED activities in various regions were presented by Jose Ernesto dos Santos (South America), Joep Defesche (Europe I), Ian Hamilton-Craig (Asia-Pacific), and Ulrike Beisiegel (Europe II).

Pernette de Sauvage Nolting (NL) presented the current status of the research studies EXPRESS and IMPRESS. EXPRESS concerns both the clinical characteristics of 503 FH patients of whom 315 had 64 LDL-receptor mutations, and also other genes conferring cardiovascular risk such as apoE and ACE. IMPRESS concerns the phenotypic characteristics of FH patients with and without detectable LDL-R mutations.

Yale Mitchell (US) presented a clinical studies update from the MRL laboratories, including current research on lipid-lowering drugs and the results of studies comparing various doses of simvastatin and atorvastatin in relation to LDL-cholesterol and HDL-cholesterol levels.

A case presentation of a 10-year-old girl with homozygous FH by Olivier Descamps (BE) led to a useful discussion of various treatment options as well as a recommendation to routinely assess aortic valve integrity.

In summary, ~39 000 patients with FH are now registered in the MEDPED program world-wide. Active patient support groups linked to MEDPED include organizations in the UK, the Netherlands, and US. Collaborative research programs are being carried out with a view to improving the understanding of the relationship between LDL-receptor type and clinical characteristics. More effective funding from a variety of sources is being actively pursued in order to continue the program.

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