Dear UEMS Sections Presidents and Secretaries,

The purpose of this letter is to seek partners in the task of a joint approach in drafting the goals of a newly formed MJC, the "Rare and Undiagnosed Diseases" Committee.

Rare disease have been attracting special attention for the last decade, and we are now at the start of a new era, hopefully a rewarding 'golden age', largely brought about by the introduction of game-changing new genetic technologies, namely whole exome and genome sequencing, following on from the progress achieved through various forms of array technology.

Among humankind there are some 6,000-8,000 rare diseases, some of them being relative common and well known, while others are extremely rare. The term "Diagnostic Odyssey" has been coined to describe numerous such patients who circulate in the non-harmonized labyrinths of various branches of medicine.

Most of these rare diseases have a genetic basis; therefore we, as clinical geneticists, frequently coordinate care and play a kind of harmonizing role in the management of these patients, fully aware that a multidisciplinary approach is needed, and that many, if not all subspecialties within the medical professions make a significant contribution to this important task.

Our goal is to establish the MJC of "Rare and Undiagnosed Diseases", as this daily, fast-moving area also has clear educational consequences that should be harmonized. We, the Clinical Genetics section of the UEMS, will be proposing the creation of this MJC in the forthcoming Warsaw meeting. We are ready and willing to receive any suggestions or comments you may have, up to the end of July. Please also let us know if you have suggestions for any position or volunteering role – this would be welcome. To keep to the schedule, we then have until mid-August to finalize our supporting evidence and credentials the Sections who are actively participating, with the final submission of materials to the UEMS SG due by the end of August.

Yours sincerely,

Ulf Kristoffersson
Past-President

Bela Melegh
President