

Letter to the editor

Report from a rare diseases event in Târgu Mureș, Romania

A meeting “Hereditary Angioedema & Primary Immunodeficiency Congress - East meets West” was held in Târgu Mures 24-26 April 2014, Romania. Hereditary angioedema (HAE) and primary immunodeficiency (PID) are two rare diseases both suffering from inadequate spreading of knowledge and low awareness. It was the first meeting in Romania joining experts and patients from two rare disease fields. By reviewing pathogenesis, diagnosis and treatment the joint congress offered a common stage for clinicians, researchers and patients interested in/being affected by PID and HAE. The joint congress made possible exchange of valuable information and thus to increase awareness and spread knowledge in Romania. Furthermore, it became evident that the establishment in Romania of diagnostic centres of excellence is well progressing. This in turn will allow rapid feeding of registries with relevant data, which in turn are key for better care of patients. The bodies organizing this conference were the University of Medicine and Pharmacy, Târgu Mureș, the University of Medicine and Pharmacy Victor Babeș, Timișoara, the Romanian Network for Hereditary Angioedema, the Romanian Immunodeficiency Study Group, and the Jeffrey Modell Center, Timișoara. The programme of the conference can be accessed via <http://www.haenet.ro/en/node/209> (accessed May 2014).

PID and HAE are rare diseases and a considerable part of patients in both conditions are treated with human plasma derived medicinal products, i.e. immunoglobulin concentrates and plasma-derived C1-esterase inhibitor concentrates. It is notable that the first J-Project meeting was held in Târgu Mures in 2004 (<http://jproject.dote.hu/2004booklet.pdf>; accessed May 2014). The J Project is an initiative of the East-Central European Infectiology and Paediatric Immunology Center for Training and Research lead by Prof. László Maródi, Debrecen, Hungary and is supported by ESID, pharmaceutical companies and foundations. The J Project has started as a collaborative network of infectiologists and immunologists of the East-Central European region and had gradually developed into a clinical research collaboration programme. Meanwhile 23 countries have joined the J Project including those outside the East-Central European region (1). The success of the J-Project becomes apparent when one considers that at the joint meeting PID & HAE was also the 102nd J-Project meeting.

Although the first HAE workshop in Romania, “Hereditary angioedema: present and future”, was held in Cluj at occasion of the National Conference of the Romanian Society of Allergy and Clinical Immunology, 24-26 March 2006, with respect, it has to be valued highly that

research and clinical care for HAE patients living in Romania was initiated and built up from the scratch by Dr. Dumitru Moldovan, Allergy-Immunology Department, University of Medicine and Pharmacy, Târgu Mureș. The taking off of the care for HAE in Romania was very much helped by offering diagnostic help from Prof. Henriette Farkas and Dr. Lilian Varga, Semmelweis University in Budapest, Hungary. Since 2006, at an approximately biannual frequency the HAE-meetings were repeated, all in Târgu Mureș. Clinicians, emergency care givers, researchers, patients and industry could exchange ideas, discuss the progress in the field, report on clinical trials, raise awareness and elaborate treatment recommendations. Furthermore, the Romanian Network for Hereditary An-

gioedema (<http://www.haenet.ro>) has initiated the Romanian Hereditary Angioedema Registry (2) and placed the cornerstone for better understanding HAE in Romania.

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References

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