Report on 2nd Balkan Alport Meeting, Ohrid, North Macedonia, September 23-25, 2022

The 2nd Balkan Alport Meeting was held in Ohrid, North Macedonia from September 23-25, 2022. The Meeting was attended by health professionals from the country and abroad, as well as patients/families with Alport syndrome. Experts from North Macedonia, the Balkans and Germany gave their lectures. Let's mention just a few names: Prof. Constantinos Stefanidis (Greece), Prof. Maria Gaydarova (Bulgaria), Prof. Danko Milosevic (Croatia). In a language understandable to all, they spoke about the diagnostic possibilities and treatment of Alport patients in their countries. Jasmina Comic from the Institute for Human Genetics, Technical University of Munich spoke about their Microhematuria Project. With this research project, many patients from North Macedonia and the Balkans received a correct diagnosis and appropriate treatment. Among the local speakers, let's mention Prof. Velibor Tasic, Dr. Nora Abazi Emini, Dr. Nikola Gjordjievski. Alport patients/families asked questions which were answered by experts.

I had the honor to open the second Balkan meeting for Alport syndrome in my hometown Ohrid and to be one of the organizers. I presented my work on the visibility of rare diseases in front of the attending lecturers, patients and parents with Alport syndrome, but I also advised the parents not to be stigmatized in front of society, certainly not to hide from the child that he has a rare condition (this often happens in Macedonia) but to find a way to bring the disease closer to him and learn to live with the challenges that the disease itself brings.

We hope that at the next Alport meeting there will be more talk about studies and innovative treatments and their availability to patients from North Macedonia and the Balkans.

Photos from the event can be found here.

President of the Alport Macedonia Association "RARE IS TO BE RARE"

Loleska Gordana