Health for all begins with health literacy

(article by Liesbeth Siderius – EAP Working Group on Rare Diseases; Velibor Tasic – EAP Working Group on Rare Diseases; and Ivan Petrovski – Macedonian Alport patient representative)

At the first Balkan meeting for Alport syndrome patients, families, doctors and public health officials gathered in Ohrid, Macedonia. To purpose of this meeting was to better understand all aspects of having a rare diseases in a middle-economy country.

Many issues relevant to people living with rare diseases were raised, including how to get access to the most efficient and affordable diagnostics. Collaboration with laboratories across the border is a possible solution; however, nationally performed diagnostics may need a considerable out of pocket payment. More multidisciplinary actions are essential, including psychological support to help patients cope with the realities of chronic illness. For instance, people suffering from Alport syndrome eventually end up with renal failure, and the lack of kidneys for transplant is a source of distress for patients. Regulations need to be optimised to increase the rates of organ donation. New therapies bring hope, but also worry: will the drug work? Will it be affordable?

No one understands the needs of individuals with rare diseases better than they themselves. When patient groups are empowered to work with doctors and policymakers, they can innovate healthcare systems that will accomplish more than merely to alleviate symptoms or treat disease. They will improve patient wellbeing, further their inclusion into society and strengthen their ability to lead a normal life.