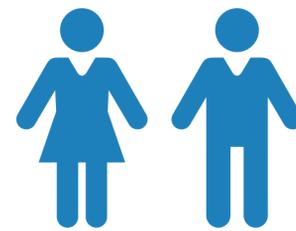


INFORMATION ABOUT THE MEMBER ORGANISATION

1 major achievement of member organization for patient community



One major achievement as of lately is the participation of 3 Greek patients and one caregiver in the HAE South Eastern European Conference in Skopje, where we got to discuss the issues with legal and other issues of our NMO with our regional advocate and other attendees and received important information and have taken steps towards creating an active NMO hopefully in this year.



We are currently in the process of registering as an official patient organization

Barriers to accessing treatment

Although there is Berinert iv and Fyrazir being covered by public insurance, there are still barriers.

For example, access to more different kinds of medication because of shortage of Berinert and Fyrazir not working for some. Also, although it is not unpermitted by law to self-administrate, it is not something most people, even medical professionals are familiar with patients doing by themselves, so it creates fear to most of them if it's ok to get a nurse to teach you to do it, especially in the case of underage patients.



People living in the capital can wait countless hours to get done with paperwork in the hospital, which can ruin a whole day of work or school for them.

People living in remoted areas and especially islands(which our country has thousands of small ones) have little to no medical professionals in the first place and access to sufficient medication and on time gets difficult.



YOUNGSTER'S EXPERIENCE



Common challenges that young patients experience

They're either missing school because they need to go to the hospital for every attack they have or they sometimes have to let some attacks untreated, which they try to hide because they can avoid bullying. It's common to be advised avoiding doing activities like sports or other things that can cause attacks, which can create frustration, social isolation, fear and negative feelings.

What does "Creating a path to better health" mean to you?

"Creating the path to better health is, of course, striving to get access to medication for patients around the globe, but also bettering HAE patient's lives as a whole. Not only access to medication, but also medication that best works for them and their needs, SUFFICIENT medication, ability to have it on time and on demand, not only emergency situations. Also, raising awareness for medical stuff on the complexity of the disease and the parameters it can have in someone's life, so they understand to protect their patients accordingly."