



EHC NOW!

Newly-formed youth group in Macedonia

By Marija Aloa Vera Drzmanoska, member Hemolog, the EHC Macedonian National Member Organisation (NMO)

I am delighted to have the opportunity to be a part of our new Youth Group in Macedonia. We created it with the purpose of including younger members and allowing them to build deeper connections with each other, the NMO and society. This will encourage more civil engagement by the youth along with team work and compassion.

Since last month's creation, we have five members including myself and we are looking forward to including more soon. The members in alphabetical order are: Antonio Steva, Bujamin Dauti, Mirsad Jahiu, Vani Nuhi. All youth is welcome regardless of class, religion or social background.

The Youth Group proudly spreads its main message that youth engagement is essential to move forward as a community. Youth these days have different needs compared to the older generations.



Marija, one of the members of the Macedonian Youth Group

This means that their needs must be answered to allow them room for personal growth through increased involvement with the society and the NMO. As of now, all of our young members eagerly await tasks that will help make an impact and look forward to cooperating with the European Haemophilia Consortium (EHC) and the World Federation of Hemophilia (WFH).

Now, let me tell you a little bit about myself. My name is Marija Aloa Vera Drzmanoska and I come from a family that has a long history of haemophilia. I, myself, am a carrier of haemophilia A severe. After hearing about this disorder from a very young age, I am finally old enough to take measures within the community to help my family and other members suffering in the society.

I am especially proud to say that I am part of my own Civic Engagement Project from the United States Agency for International Development (USAID). I was given the opportunity to choose an area of interest that I wish to improve in the Macedonian society. The project includes educational and training programs funded by USAID and I cannot wait to share all the knowledge and experiences I gain with my fellow members in the Youth Group. I personally found raising awareness for bleeding disorders and motivating young people to volunteer to be of great importance and this is why I decided to make this the theme of my project. I am very thankful to be involved in such a project. Needless to say, such a project requires a lot of time, dedication and hard work. However, I am prepared to make such sacrifices that will help me evolve in the long run as an individual part of our society. It gives me the opportunity to lead people in the creation of a more inclusive and humanitarian community. With that being said, I look forward to seeing where this project leads in the next nine months and even more so about the results it will bring.

The Youth Group is still in its early stages but we think its creation is a huge step forward for Hemolog, the Bleeding Disorder Society of Macedonia. We see the phrase “*the whole is greater than the sum of its parts*” very applicable in our case. Instead of having all our young members contributing individually, we believe that by working together they can reach new heights both for themselves and the community.

The EHC works hard to invest in the patient advocacy and leadership skills of the future. This is why we have built a comprehensive youth leadership strategy that takes young leaders on a journey from the EHC Youth Leadership Workshops, to the EHC Leadership Conference and culminates in the EHC Conference, where we invite young patient leaders to debate with established community leaders. These workshops and trainings offer our young leaders the opportunity to explore the patient advocacy environment, to understand the patient-stakeholder roles and responsibilities, but also to develop relationships and share experiences with other NMOs in Europe. Our newest and exciting addition to our Youth Strategy is our Youth Fellowship Programme, which aims to get our trainees working together and to keep them motivated to be an active part of the community! We will establish project teams with participants from across Europe to achieve a mutually beneficial goal, while also enabling our young leaders to develop real hands-on experience and contribute in the right way to the European community.

[Find out more about the EHC Youth Strategy on the EHC website.](#)