

EHC NOW!



EHC Welcomes 46th National Member Organisation (NMO): the *Public organisation “Haemophiles” of the Republic of Tajikistan*

By Azizi Najibi, Chairman of the Tajiki NMO

For this week’s edition of EHC Now, we introduce you to our newest national member organisation (NMO) from Tajikistan. The public organisation “Haemophiles” of the Republic of Tajikistan was officially formed in 2017 and became a member of the European Haemophilia Consortium (EHC) during the 2018 General Assembly. Mr Azizi Najibi, Chairman of the organisation, tells us more about how the association was created as well as challenges for people with bleeding disorders in Tajikistan.

First of all let me express my gratitude to you for all your care about us and for your intention to introduce us to our brothers in blood from the European haemophilia community.

Before our patient organisation became an official legal entity in 2017, the NMO applied several times since 2015 for registration and submitted its draft statutes to the Ministry of Justice. The final edition of the statutes dates 10th November 2016 and was approved by the Ministry of Justice of the Republic of Tajikistan on 21st February 2017.

The primary aim of any public organisation is to protect the rights of and advocate for the interests of the community, which created this organisation. To that end, the leadership of our organisation stands up to defend the rights and interests of its members to ensure equal opportunities with all other citizens, to solve the problems of disabled people, to organise charitable activities, to improve treatment and prophylaxis of the disease and to provide social rehabilitation for patients.

The main founder of our public organisation is the General Assembly. According to our statutes, the General Assembly elects an executive director for a term of five years. I, Azizi Najibi Sharifbek, was elected as the first chairman of the organisation.

In spite of the fact that factor concentrate is not used in the treatment of haemophilia in Tajikistan, the overall situation is tolerable, as the government constantly cares about haemophilia patients, and they receive plasma or cryoprecipitate. We believe that switching to factor concentrates is only a matter of time. At this point we have been liaising with the Ministry of Health and Social Care of Republic of Tajikistan to implement treatment with factor concentrates in the city of Dushanbe. This area includes 76 patients with haemophilia A. This initiative is supported by the World Federation of Hemophilia (WFH), which provided the first tier of humanitarian aid to help achieve this goal. The second tier was scheduled for the second part of 2018.

In Tajikistan, there are 457 patients that are officially recognised. Amongst them, 204 are under 15 years old or younger.

All adult patients with haemophilia are members of our organisation; also, the organisation maintains permanent contacts with parents and caregivers of children with haemophilia. We invite parents and caregivers to take part in all of our activities. The leaders of the central office and regional branches have haemophilia themselves.

The Republic has three regions: Kuhistani Badakhshan (Gorno-Badakhshan) Autonomous Region, Sughd and Khatlon Region. In addition to Dushanbe, there are a number of cities and tens districts in Hisor valley and Rasht valley. To date, we have representatives in Sughd and Khatlon regions.



Our main goal is the protection of rights and interests of people who suffers from such congenital disease as haemophilia, and after weighing up the pros and cons, we decided that we cannot do without support of the international community [of haemophilia].

The way toward connecting with international communities was opened for us at the Almaty Forum, held on 26-28th May 2017 in the city of Almaty, the capital of the Republic of Kazakhstan. At that Forum we were introduced to Mr Yulian Tsolov, representative of the WFH, who delivered our appeal to Mr Alain Weill, President of the WFH.

In October 2017, a working group from WFH arrived in Dushanbe to review our work. During the visit, we organised a conference and workshop for people with haemophilia and healthcare professionals, under the title 'When time afflicts a limb with pain ...'¹ During this conference, we saw attendance from more than 400 participants and we approved an appeal to the President of the Republic of Tajikistan: 'On the [need of] adoption of the Law on Haemophilia.' This conference was highlighted by the local media. We wish to stress that the Russian Haemophilia Society, led by its president, Mr Yury Zhulev, played the key role in our achievements at international level. We are exceptionally grateful to Mr Zhulev for his support of our community.

On 25th May 2018 during the WFH Congress in Glasgow, Mr Alain Weill handed me the certificate stating that our organisation had become a member of the WFH.

At Bishkek Forum in September 2018 we met with Mr Tsolov who helped us to pass our membership application to Mr Brian O'Mahony, representative of European Haemophilia Consortium.

Our organisation is planning to learn from your experience in advocating and protecting the rights and interests of patients with haemophilia. We have the intention to pass the requirements of the patients on to the government and legislative bodies. The organisation strives, whenever possible, to offer legal support to patients and we already achieved some good results in this regard. In 2019 we are planning to organise a 'School for patients.' Although, we have no experience in holding such schools, we'll use

¹ This makes reference to verses of Saadi Shirazi, whose poem is placed at the entrance of the United Nations headquarters: 'When time afflicts a limb with pain, The other limbs at rest cannot remain' – *remark by the translator*

the experience and skills of our Russian colleagues. We are bound to be successful, as we are not alone, and all our brothers in blood, from the entire planet, stand with us.

As the saying goes: to deliver a great hit, you need to gather your fingers together, and we already proved this proverbial wisdom to be true, because when we created our organisation, we no longer needed to fight for our rights alone. During this period we already achieved the results each of us could only have dreamed of when acting separately.

The organisation has its own lawyer and we stood behind those patients who were unable to receive their [disability] pension. After re-assessment by the [medical expert] commission, more than 20 people began to receive this pension again. Also, the organisation prepared an official appeal to the Tajiki General Prosecutor's Office regarding inappropriate actions undertaken by the prosecutor officer in the Asht District of Sughd Region toward patients with haemophilia.

After registering the Haemophilia Society of the Republic of Tajikistan, haemophilia became one of key topics in the national media, including newspapers, radio and TV, who constantly highlighted this topic.

Despite some achievements, we also experience certain constraints and difficulties. First of all, the members of our executive board work as volunteers, due to the lack of funding. To date, our operating account remains empty. Furthermore, we lack basic office devices such as computers, printers and fax machines and also lack access to the Internet and a telephone connection. All of this negatively impacts the efficiency of our work. To date, people with haemophilia in the Republic do not have access to such comprehensive care specialists such as orthopaedists, dentists, surgeons, etc. Patients in Tajikistan are also in need of nurses and laboratory scientists, who should improve their skills through specialised training in European clinics.

In conclusion, we wish to say that, in spite of all the obstacles, we look into the future with optimism, as we believe in the development of medicine.

Azizi Najibi Sharifbek is the Chairperson of the Tajiki NMO. He originates from Sagirdasht, a village in the Darvaz District, in the Kuhistani Badakhshan Autonomous Region of Tajikistan. As part of his higher education he graduated from the Tajik National Conservatoire with a degree in Folk Songs. He has two children, a daughter Aziza and a son Umar.

The EHC wishes to warmly thank Azizi for this introduction. On behalf of all EHC members, we wish to welcome to the Tajiki NMO to the EHC.