



Serbian Haemophilia Society National & Regional Inhibitor Camp

Why it is good to share the good practices among the NMOs?

It is important, because if you see how other societies are doing activities or practices they have established, maybe you can implement some of those in your society or have an idea how you could use only a part of this practice, or you will get an idea to do something completely new from that best practice that you saw how the other societies are doing.

For example, for the camp and activities maybe some other group in haemophilia community, e.g. women say – PWI have the camp already with good methods, why don't we implement something similar with our own topics.

The European Inhibitor Network is a programme of the European Haemophilia Consortium (EHC).

It seeks to understand and address the personal and systemic challenges people who have haemophilia with inhibitors face, and aims to build a European community of people with inhibitors and their families and caregivers - because the numbers nationally are too small.

European Haemophilia Consortium **EHC**

Rue de l'Industrie 10, Brussels, Belgium

www.ehc.eu | www.inhibitor.ehc.eu

EHC

Good practice publication series

Introduction to the project

The Serbian Haemophilia Society has been organising a National Inhibitor Camp since 2013. In 2019 the seventh National and first Regional Inhibitor Camp took place in Belgrade, Serbia. The camp is organised by a group of committed volunteers that represent variety of people affected by inhibitors – a mother of a child with inhibitors, adult with inhibitors, healthcare professionals.

How was the project conceived? What triggered it?

We realised that this part of the community – people with inhibitors – faces the most difficult problems. So we decided to offer such a camp where they can meet in person with other PWI, share and exchange, listen to new information and take part in different workshops. There are doctors, physiotherapists and other healthcare professionals present at the camp – a situation from which the PWI can greatly benefit from. They can hear more about novel treatments and educate themselves about their condition, because they do have a special condition, if we compare it to regular haemophiliacs.

The first camp took place back in 2013 and now we can say that it has become a tradition. It is a four-day event with workshops and different sessions.

What have been the outcomes and changes taking place so far? How do the people benefit from the project?

The most beneficial for the PWI is that they can educate themselves about their condition and inhibitors. This has resulted in raised awareness among PWI regarding their condition and their willingness to improve their health condition. Before the camp the situation was that some of the PWI did not want to visit doctor or devote time to physiotherapy or dental care. When we have all the people in one place, we can better educate them about importance of their health and tell them that it is something not that scary to visit doctor or dentist. The advantage of the camp is that during the four days of it the PWI can speak in quiet atmosphere with the doctors or other healthcare professionals and they have the opportunity to ask their questions in detail. This is where and why the PWI get convinced that they should take appointments and be mindful of their health condition. In addition, we can directly schedule an appointment with the relevant specialist, because we invite dentists to speak about dental care, physiotherapists about importance of physiotherapy etc..

Furthermore, there is the psychosocial support and advocacy that we try to build for those patients; For example, many of them did not know how to communicate properly with their doctor, so we organised a workshop and the training for them to learn to communicate clearly with their doctors.

What is the impact on the NMO? Has there been some change because of this project?

Quite a few people have been engaged in the activities of the NMO through the camp. The PWI have been quite isolated and they did have social barrier and fear to get involved in the work of the NMO. However, we managed to dissolve their fear and get them interested during the camps, so they decided to become active and get involved in the society. We are speaking about 10 people. Usually, we have between 10 and 15 people on the camp, but a couple of people are not yet involved in the NMO actively or are starting very slowly. But 10 is a good number.

What are/ have been the biggest challenges for the project? How do you overcome them?

Back in 2013 the camp started as a one-time event with a hope that participants will like it and they will be willing to take part next year again. We have a very small group of PWI in Serbia. The biggest challenge was to convince them to come to the camp. Some of them have mobility issues and it is hard for them to travel, some did not feel they belong to the society. This was because when they attended the Annual Conference they heard only the topics about haemophilia and new treatments for those without inhibitors, so they felt left out of the NMO. We did overcome that with enormous support from the camp coordinators, who explained what kind of activities we will have in the camp and why it is important for each participant to come to the camp. This way the barrier was overcome and the number of participants has been increasing each year. We have 16 known PWI in the NMO and 10-11 PWI attend the camp each year. Two of the 16 are children therefore they do not attend the camp as it is intended for adult patients. Unfortunately, we cannot organise the activities for the children with inhibitors in parallel with such a small number of children. That is why we decided that the camp will be aimed at the adult PWI, and the children would attend the children camp of the NMO.

How is the project implemented/organised?

What? Having a small group of people with a specific problem of inhibitors, a lack of support and feeling isolated, resulted in an idea to organise a camp for those people. Gathering all people that have the same issues to exchange and share ideas on how some of these problems can be overcome, as well as educating them, was found to be more than useful.

The National Inhibitor Camp is a huge opportunity to empower PWI and provide them with additional information. Like in any project, education, the ability to communicate with their doctors and among themselves, is essential during the weekend. In the camp setting everybody feels that they are in a safe environment, they feel relaxed and that they can speak freely.

In terms of the Regional Camp, it was felt that the Balkan region altogether has a very small number of PWI, so it was decided to extend the invitation to other Balkan NMOs to take part in the camp.

Who? For whom? With Whom? The National Inhibitor Camp is organised by the Serbian NMO for adult PWI, together with healthcare professionals from all HTC, who work daily with PWI. They are included in the activities of the camp through the medical sessions and panel discussions. An important part of the camp are the nurses, they give their support on site with treatment and provide education on self-infusion. Some of the patients are very old and cannot treat themselves with bypassing agents, so the nurses help and show them how to find veins and how to inject properly.

Why? The most important part is establishing a connection between the PWI and building a community. This way we can include them in the NMO and help them overcome social barriers caused by mobility issues. Most PWI in our NMO have mobility issues and do not have much possibility to socialise in their daily life and to have a normal social life. That is why this small part of the year when the camp takes place is the time when they can feel like themselves and they can see that there are other people who experience the same problems and see how others cope with those problems.

How? The National Inhibitor Camp is a four-day event. On Thursday afternoon we welcome participants, the medical staff and someone from the NMO is on site to welcome them. On the agenda there are various medical and educational sessions – mostly they are related to inhibitors, e.g. physiotherapy education and practice and we also practice in the swimming pool; orthopaedic surgery, the current possibilities and a recommendation for each patient for orthopaedic surgery; dental care – what should be done for each patient, what are the new technologies in dental care, pain therapy, haematology and upcoming treatments. Also, participants discuss current issues and we offer recommendations on how each patient should be treated. Individual and group psychosocial sessions are offered as well. We had a couple of round tables with discussions between the patients and doctors, for example about on-demand treatment with bypassing agents or the importance of physiotherapy.

The inhibitor camp focuses on a different theme every year, giving people with inhibitors an opportunity to explore in depth certain aspects of inhibitor treatment and care. Among the themes addressed have been dental care, psychosocial support and orthopaedic surgery.

When? The Serbian National Inhibitor camp always takes place in spring, i.e. March-April. We try to always do it before World Haemophilia Day. We found it should be done once per year to keep people engaged, because the longer time period between the two camps can result in losing interest in participation.

Where? It is always held in the same place, in a hotel close to Belgrade. It is very important where the event is held. Most of the participants have on-demand treatment and there is a high risk of bleeding, so the venue should be close to an HTC and it has to be haemo-friendly and accessible for people with disabilities, so that people do not have to walk too much in the hotel.

We had one venue for 5 years, but now we decided to have 2-3 venues and use them in rotation, so that the participants do not lose interest in participating. Because if it is the same place, the same people, the same doctors – it can happen.