

EHC NOW!



2018 Meeting of the Nordic Haemophilia Societies

Interview taken by Laura Savini, EHC Public Policy Officer

Each year the haemophilia societies from the Nordic countries (Denmark, Finland, Iceland, Norway and Sweden) meet to touch base on their respective activities, discuss common issues and exchange on best practices. For the 2018 edition, countries' representatives met in Helsinki, Finland. Naja Skouw-Rasmussen, member of the Steering Committee of the European Haemophilia Consortium (EHC) attended this year's event and reports on the main discussions and take-aways from the event.

Naja tells me that there are many similarities within Scandinavian countries not only culturally and from a socio-economic point of view, but also with regard to how haemophilia care is organised and delivered. The standard of haemophilia care is also famously high in the region. This is not only due to the generally excellent health care services but also to the contributions made by key haemophilia clinicians who work together through the Nordic council, a clinician-driven body that develops guidelines and principles of care for the region.

Much ado about novel treatments

So what were the 'hot' topics discussed by these patient communities over the weekend? Seeing the standard of care is very good, one of the most discussed topics over the weekend was the availability of novel therapies. Participants focused in particular on how government procurement bodies will look at these treatments and how they might prioritise availability given some unanswered questions. Another issue that came out of the weekend is that, because the standard of care is so good, many patients do not invest in learning about haemophilia and how the treatment works. Therefore, these patient organisations feel that there was a real need for increased patient education.

Compliance, compliance, compliance

In this regard, one of the most exciting sessions looked at treatment compliance in younger patients. Excellent standard of care means that some patients have never experienced a single bleed. Naja told me that for some patients this creates a real disconnect as they are 'sick' but have never experienced any symptoms and therefore this can create a false feeling of being safe from the disorder. This sense of safety can push younger patients to 'test' their limits and see for how long they can go without treatment, hence creating the number one issue in haemophilia care in developed countries: lack of compliance to prophylactic treatment.

One suggested strategy to improve compliance is to ensure that children as young as seven or eight are put in charge of their own treatment and are taught to self-infuse. In fact, it is believed that this may help develop a routine and sense of responsibility that will carry on later in life. If self-care begins at around 15 or 16 years, it will coincide with adolescence and the appetite to break rules and push boundaries. The main issue with this strategy is, understandably, that many parents want to ensure that their children comply with their prophylactic regimen and so take responsibility for their treatment. The trick would be for parents to let go and give responsibility to their children.

With regard to compliance, an important role can also be played by patient organisations to strengthen activities that would include young children and their families and to create a peer support system to which

patients can turn in case of need. Having strong ties within the community could be particularly valuable during teenage years when patients struggle more to manage their disorder.

PK as a tool to increase compliance

On the topic of treatment management there were also discussions on understanding pharmacokinetics (PK). Again this was found of interest as many patients have little knowledge about their disorders and concepts like PK can help to improve compliance by underlying how treatment is ‘processed’ by their body and what levels of protection they can expect. The Nordic countries want to achieve a reality of ‘no bleeds’ but it should go hand-in-hand with an understanding of what haemophilia is and how the disorder needs to be cared for. In fact, at the moment many patients feel anxiety towards bleeds because they fear that, should they have a bleed, they would not recognise it or have any idea about how to treat it.

Naja also stressed that despite many patients receiving excellent health care and being in very good health, there are of course still patients facing hurdles and for whom life is not all that perfect; this is for instance the case for people affected by inhibitors.

All in all the weekend was spent highlighting the need for increased patient education, in particular with the youth, and exploring collaboration amongst countries to move forward together.

The EHC would like to thank Naja Skouw-Rasmussen for sharing her impressions on the weekend and giving us a little insight into this year’s Nordic meeting.

