

Copenhagen, November 2019

To the National Health Ministries of Denmark, Estonia, Finland, Island, Latvia, and Sweden

From our meeting in Copenhagen the 15-17 November 2019 the National Haemophilia Societies in Denmark, Estonia, Finland, Island, Latvia, and Sweden send the following statement:

The Nordic National Hemophilia Societies continuously strive to support the improvement of treatment for people with rare bleeding disorders. The societies see the European standards for certification of Haemophilia Centers from June 2013 as an important step to strengthen and streamline the treatment in the Nordic and Baltic countries for the safety of patients and to ensure effect and optimal outcome of expensive medicine.

We recommend that all Haemophilia Centers in the Nordic and the Baltic countries are certified or re-certified as either European Haemophilia Treatment Center (EHTC) or European Haemophilia Comprehensive Care Center (EHCCC). As a minimum, one national Hemophilia Center should live up to the criteria for the comprehensive care centers (EHCCC).

Inherited bleeding disorders are rare and complex conditions to manage. Patient safety and treatment outcome improves when patients are managed in specialized Haemophilia Centers. Various health care professionals may need to be involved in the care of an individual patient, including not only a specialized and experienced haematologist and nurse but also specialized orthopaedic surgeons, physiotherapists, laboratory technicians, hepatologists and infectious disease specialists, dental surgeons, and psychologists.

Today only Estonia, Finland, Norway and Sweden have certified Haemophilia Centers. With regard to patient safety and optimal use of expensive medicine, we highly recommend, that the health authorities in the Nordic and the Baltic countries ensure, that the national Haemophilia Centers meet the criteria and take initiative to ensure certification as either European Haemophilia Treatment Center (EHTC) or European Haemophilia Comprehensive Care Center (EHCCC).

As new technologies and products become available, haemophilia treatment will become more complex and individualized. This urges access to highly specialized medical on call service 24/7 and lab service for patients and other health professionals to ensure patient safety and optimal use and outcome of expensive medicine.

More attention to rehabilitation after bleeds and surgery and access to specialized physiotherapy is highly needed in order to limit functional impairment. If physiotherapist locally handles the rehabilitation, the Haemophilia Center should supervise the rehabilitation program.

The Nordic and Baltic Hemophilia Societies also urge the Haemophilia Centres to establish national database registries to document the patient's status and use of medicine. The data should be comparable between the Nordic and Baltic countries.

For more information regarding the certification and application process, please contact the European Association for Haemophilia and Allied Disorders, EAHAD (www.eahad.org).

On behalf of

Denmark: Danmarks Bløderforening

Estonia: Eesti Hemofiliaühing

Finland: Suomen Hemofiliayhdistys ry

Iceland: Blæðarafélag Íslands

Latvia: Latvijas Hemofilijas biedrība

Sweden: Förbundet Blödarsjuka i Sverige

European Haemophilia Treatment Centre (EHTC)

- A EHTC should normally care for at least 10 people with severe haemophilia A or B or VWD type 3.
- A European Haemophilia Treatment Centre (EHTC) carries out the following functions and activities:
 - Provides care for patients, including diagnosis, treatment, follow-up and rehabilitation.
 - Provides patients with safe and effective treatment products.
 - Provides a 24 hour emergency treatment service.
 - Provides basic diagnostic and monitoring laboratory support during normal working hours for the more common inherited bleeding disorders.
 - Has access to multidisciplinary support, locally or in conjunction with EHCCC (physiotherapy and orthopaedics, surgery, dental care, hepatology, infectious diseases, obstetrics and gynaecology, paediatric facilities if children are treated, genetics, clinical psychology and social worker).
 - Offers specific treatment for patients with inhibitors and immune tolerance in collaboration with a EHCCC.
 - Provides advisory service, including genetic counselling, to patients and healthcare professionals.
 - Promotes information and training programs on inherited bleeding disorders to patients and healthcare professionals.

European Haemophilia Comprehensive Care Centre (EHCCC)

A EHCCC should normally care for at least 40 people with severe haemophilia. A European Comprehensive Care Haemophilia Centre (EHCCC) carries out the following additional functions and activities:

- Co-ordinates the delivery of haemophilia services-both in hospital and in the community including liaison with affiliated EHTCs.
- Provides a 24 hour advisory service for patients, families, hospital doctors, general practitioners and affiliated EHTCs health care professionals.
- Provides specialist care for patients with inhibitors, including surgery.
- Provides a diagnostic and reference laboratory service with a full repertoire of tests for the diagnosis and monitoring of inherited disorders of haemostasis.
- Provides a 24 hour laboratory service for clotting factor assays and inhibitors screens.
- Has access to orthopaedic and/or rheumatological service with provision of surgery.
- Has access to physiotherapy service.
- Has access to a specialised obstetric and gynaecological service for the management of haemophilia carriers and women with vonWillebrand Disease and other hereditary bleeding disorders.
- Has access to paediatric facilities if children are treated.
- Has access to a genetic diagnosis service providing also carrier detection and antenatal diagnosis. □ Has access to dental service.
- Has access to hepatology and infectious diseases service for patients with HIV and/or viral hepatitis.
- Offers professional psychological support.

- Has access to social worker and welfare advice.
- Collates data (e.g. product usage, patient demographics).
- Participates in research, including clinical trials.

European guidelines for the certification of Haemophilia Centres, June 2013