

The Elderly Hemophilia population

- A Swedish / Norwegian prospective



Background

The number of senior persons with severe and moderate hemophilia is increasing in the Nordic countries due to better care and treatment. During the last decade this fact has had a big impact on the Hemophilia Societies and the situation for the ageing hemophilia population has frequently been discussed, whenever the Nordic Societies get together.

From several perspectives there is a lack of knowledge how to handle ageing problems affecting also the elderly PWH; among the hemophiliacs themselves and their relatives as well as within the medical health care system and social authorities and institutions.

In order to address these issues a three year project was formed last year by the Swedish and Norwegian Hemophilia Societies with support from Bayer AB.

Results

During the first project year identified ageing problems of elderly PWH will be communicated through:

- Information material and checklists on the needs of elderly PWH produced in close contact with the medical profession, the local care and social authorities.
- A produced Patient Self Record to be used in contact with the local care.

The work of the Nordic Hemophilia Societies during the years to come will hopefully contribute to a better life for the ageing hemophilia population.

Aim of the project

The aim of the project is to identify new needs of elderly PWH in two Nordic Hemophilia Societies, Sweden and Norway, and to communicate these needs further to members, the medical profession and social authorities in the countries.

Methods

A steering group from each country takes the project forward and communicates results. Yearly gatherings of elderly members in both countries are used as reference groups.

The needs of elderly PWH are also subject of cooperation between the Nordic Hemophilia Care within an Advisory Board. The Advisory Board will, when needed, serve as medical back up and have access to results from the project.



Parts of the steering groups from the Swedish and Norwegian Hemophilia Societies.

