

DEMOGRAPHIC ASPECTS OF HAEMOPHILIA. A NATIONAL OVERVIEW

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Haemophilia is a rare, costly disease. The registration of haemophilia patients is therefore a valuable indispensable tool. It is essential for tracking the identification and diagnosis of people with the disease, for monitoring of their health, as well as long-term planning for hemophilia organizations and priority setting for health care.

Having a national patient registry means being able to answer fundamental questions about the hemophilia population within the country, information which are essential for lobbying government and advocating for improved care.

In our country we have organized and managed a registry set up in a mixed system, with the cooperation of the National Hemophilia Organisation, National Insurance House and Ministry of Health.

The prevalence of 7,8/ 100.000 is comparable with that of developed countries, with large significant differences between counties; the proportion of minor forms is significantly lower than in other countries, as it is the proportion of persons with haemophilia with the age > 50 years.

Maintaining, up-dating and using this registry is a future permanent task aiming an improvement of hemophilia country-wide.