

Swedish National Registry for bleeding disorders

First report

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Conclusion

The establishment of a Swedish National Registry for bleeding disorders enabled us to have a close follow-up of our patients and perform clinical research. Currently we are working on an on-line patient treatment application to report treatment data and bleedings to the registry. Data from the registry will be an important tool for further evaluation of the treatment of hemophilia and how it affects the long-term consequences of the disease.

Introduction

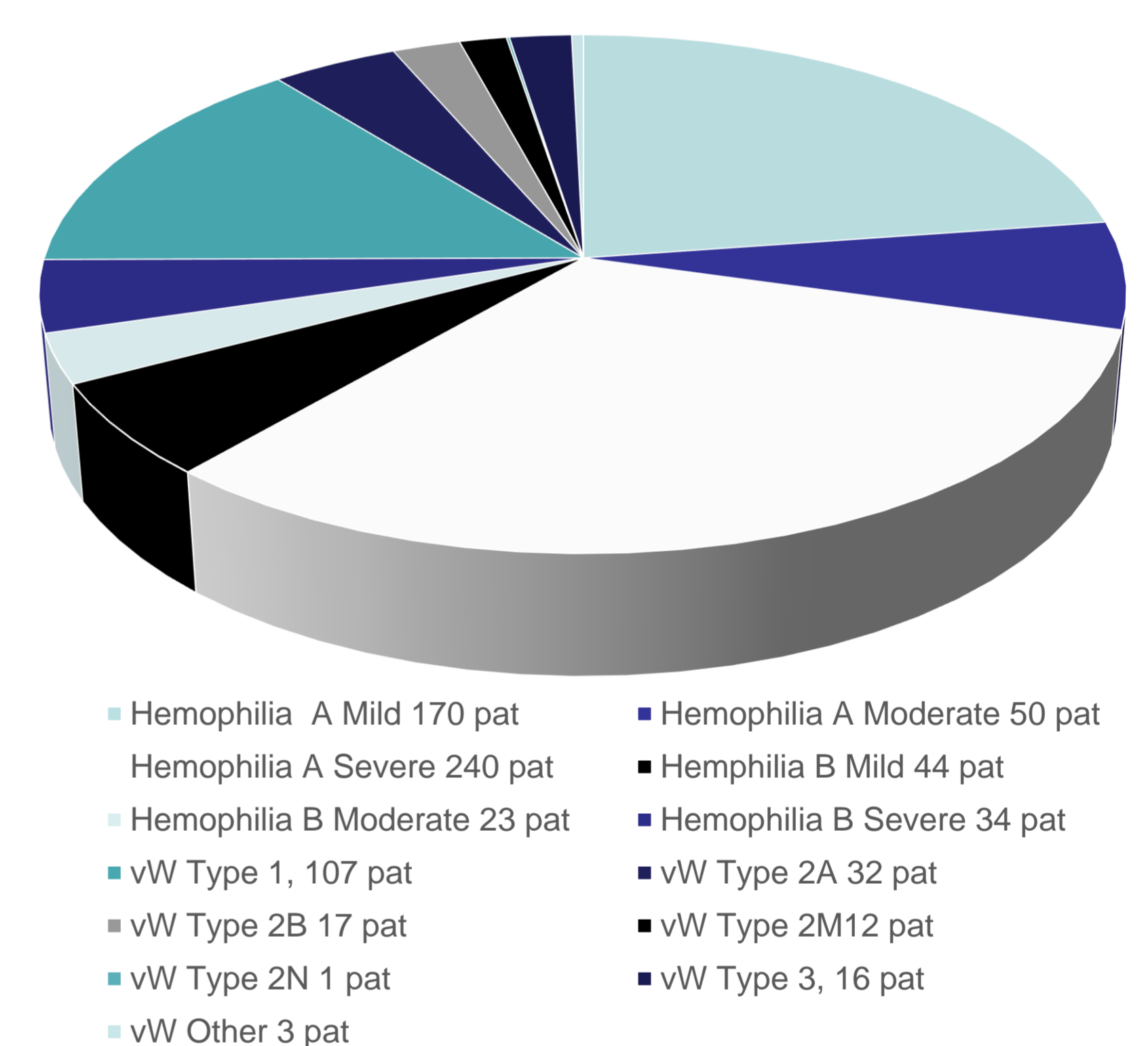
Hemophilia Care in Sweden is centralized to three centers localized in Gothenburg, Malmö and Stockholm. All centers are certified as European Hemophilia Comprehensive Care Centers (EHCCs). Recently a web-based Swedish National Registry has been established with funding from Swedish Authorities

Methods

One of the conclusions from the earlier reports from the Swedish agency for Health Technology Assessment and Assessment of Social Services (SBU) was that a National Registry for hemophilia and other bleeding disorders was needed to be able to follow the long-term consequences and treatment strategies of hemophilia and other bleeding disorders



Total numbers of patents 749



Results

A total number of 749 patients with bleeding disorders have been included in the Swedish National Registry

Data regarding bleedings, treatment with factor concentrate, inhibitor status, mutations, viral infections such as hepatitis C and HIV are collected. Patient reported outcome measurements (PROM)- such as pain and quality of life – HJHS and the number of target joints are followed continuously