

WOMEN WITH VON WILLEBRAND DISEASE

A GROUP NOT MENTIONED ENOUGH

Introduction and objectives

50 000 Swedish women are estimated to have a mild form of von Willebrand Disease but only 1000 have received a diagnosis. In February 2015 the Swedish Hemophilia Society started a three year information project to create awareness of VWD among women/girls, financed by the General Inheritance Fund in Sweden. The aim of the project is to increase knowledge about women's bleeding issues among health care professionals, so more women/girls with VWD get a proper medical investigation, receive a diagnosis and appropriate treatment.

Materials and methods

With support from the Women's Committee a project manager is employed full time to coordinate project activities. For medical backup the project group collaborates with doctors and nurses from the Coagulation and Women's Clinic at the Karolinska University Hospital in Stockholm.

Results

So far the project has resulted in regular lectures for health care professionals in primary care, among them midwives, gynecologists and school nurses. During our visits at different clinics in Sweden we have provided information material developed within the framework of the project. We have also attended several congresses for the target audience and been invited to give lectures for school nurses in leading positions. To raise public awareness about VWD among women we have appeared in several newspapers.

Conclusions

Our experience when encountering health care professionals is that many of them are unaware of the fact that women are equally likely as men to suffer from VWD. Although it is scientifically known that there is a link between bleeding disorders and heavy menstrual periods, it is something that the primary care doesn't seem to have sufficient knowledge about.

We hope our work will contribute to a greater understanding of different symptoms that could be caused by a bleeding disorder. That it is something which has to be taken seriously. Without proper medical investigation of the cause, treating merely the bleeding symptoms, these girls/women have an increased bleeding risk if they are ever in an accident or during childbirth.

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Blood Loss Assessment Chart
Download at: fbis.se/kommitteer/kvinnor/fragor-svar

