



EHC HOLDS ROUNDTABLE ON WOMEN WITH BLEEDING DISORDERS

BY SIADA EL RAMLY AND LAURA SAVINI



RECENTLY THE EUROPEAN HAEMOPHILIA CONSORTIUM (EHC) held a roundtable on women with bleeding disorders, attended by PPTA staff. The event featured presentations from patients and physicians and was moderated by Prof. Paul Giangrande (left) from the Oxford Haemophilia & Thrombosis Centre and Nuffield Department of Clinical Medicine, University of Oxford, United Kingdom.

Although bleeding disorders in men are widely recognized, diagnosed and treated, the same cannot be said for bleeding disorders in women. The conditions are rarer in women than in men and are frequently overlooked and remain untreated, often until patients reach middle age. This can be attributed to several factors. First of all, even among the patient community there is a lack of aware-

ness that female carriers can be affected by lower levels of clotting factors; and, therefore, they tend to ignore symptoms such as menorrhagia (heavy menstrual periods), nose bleeds or easy bruising.

Another factor in the under diagnosis of women with bleeding disorders is the fact that even among physicians there is a misconception that bleeding disorders oc-

cur exclusively in male patients. This may cause physicians to overrule the diagnosis in women. For instance, Dorothée Pradines, one of the attendees of the EHC roundtable and a French patient with severe hemophilia A, described a situation that she faced as a child when she was on vacation in the French countryside. After she had cut her hand and needed treatment for heavy bleeding, she



Although bleeding disorders in men are widely recognized, diagnosed and treated, the same cannot be said for bleeding disorders in women.

went to the local hospital. The hospital's physician proceeded to tell her that women do not suffer from hemophilia and denied her the treatment necessary for her condition. This lack of awareness led to her having to go through an extended healing period instead of being treated effectively.


It is essential that more awareness is raised among general practitioners, gynecologists and obstetricians who, due to the rarity of the disorders, might never come across women with bleeding disorders. These practitioners need to be aware of the symptoms of these disorders and pick up on them when they encounter a patient

who actually has these symptoms.

During the event, several female patients were present and they expressed the need for education beyond the medical professionals. They stressed the importance of efforts to educate women on bleeding disorders in women, including symptoms and implications for these disorders. Patient communities have started to organize events and campaigns to raise awareness among women, which have had varied success so far.

Following a series of factual, interesting presentations the participants discussed what needed to happen next

and several recommendations were made on how to raise awareness among women regarding bleeding disorders.

Bleeding disorders in women, like in men, not only occur but have a detrimental impact on the patients' lives and more work is needed to ensure that these patients receive the care they need. 

SIADA EL RAMLY is PPTA Europe's Director, Public Affairs and LAURA SAVINI is PPTA Europe's Manager, National Affairs