

Press Release Re: Women and Bleeding Disorders Symposium 2011

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From: The Irish Haemophilia Society

Date: April 12th 2011

Re: Women – A Bleeding Problem?

Haemophilia is an inherited bleeding disorder which primarily affects males but this does not tell the full story. There are also 1,165 Women with bleeding disorders diagnosed in Ireland and registered at the National Centre for Hereditary Coagulation Disorders (NCHCD) in St. James's Hospital, Dublin. These women suffer from von Willebrand's disease, mild Haemophilia or rarer bleeding disorders. The Irish Haemophilia Society (IHS) provides services, information and support to these women as well as to men with Haemophilia.

"Women rarely suffer from severe Haemophilia. However, it is quite common for female carriers of Haemophilia to have relatively low factor levels which categorise them as having mild Haemophilia" stated Brian O'Mahony, Chief Executive of the Irish Haemophilia Society. There are 114 females currently diagnosed in Ireland as carriers of Haemophilia. Von Willebrand's disease affects both sexes. Of the 939 persons in Ireland known to have von Willebrand's disease, 578 are female.

Many will not require therapy on a regular basis but for females, menstruation is often characterised by haemorrhagic, pregnancy by additional concern about bleeding and contraception more often a therapeutic requirement than a life choice.

Rarer bleeding disorders also affect females. Currently registered in Ireland at the NCHCD are 32 females with Factor V deficiency, 27 with FVII deficiency, 42 with Factor X deficiency, 55 with Factor XI deficiency, 2 with Factor XIII deficiency, and 259 with uncharacterised bleeding disorders.

In the past women with undiagnosed bleeding disorders often faced long delays before adequate treatment, frequently heavy menstruation and all too often unnecessary hysterectomy. Concerns now can include menstrual problems, pregnancy, carrier status and inheritance, menopause and treatment.

Knowing about your particular bleeding disorder and its severity, symptoms and treatment is vital. "We have produced specific information booklets on Women and Bleeding Disorders and on Rare Bleeding Disorders. These are available free of charge from the Society." stated Brian O'Mahony.

In addition to these Publications, the IHS have organised specific Information Days on the topic of Women and Bleeding Disorders which will take place in: Rochestown Park Hotel, Cork on Saturday, April 16th from 1pm to 4pm and Hilton Hotel, Kilmainham, Dublin on Sunday, April 17th from 1pm to 4pm.

"We would encourage any woman with a known or suspected bleeding disorder or any health care professional who would like to learn more about these issues to attend one of these information conferences" stated Brian O'Mahony.

The date of the Conferences is particularly appropriate as April 17th is World Haemophilia day.

There is no charge for attendance and all are welcome.

Speakers will include Dr. Paul Giangrande a Consultant Haematologist from Oxford and Eadaoin O'Shea a Clinical Nurse specialist from the NCHCD.

“Knowledge is power and we hope that these publications and these meetings will help empower women to understand and to live positively with their bleeding disorder.” stated Brian O'Mahony.

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