

# A Strategy for Women with Bleeding Disorders: The Irish Experience

## Author:

Debbie Greene

Irish Haemophilia Society

Being a women with a bleeding disorder, manifests in difficulties in relation to menstruation, fertility and childbirth. Prolonged heavy menstrual bleeding is one of the most common symptoms for a woman with a bleeding disorder. However, the biggest challenge is for women to know what constitutes “normal” or “heavy” menstruation and to seek help if needed. Women with bleeding disorders are often under diagnosed and undertreated. Many do not require therapy on a regular basis, but knowing about their bleeding disorder is essential.



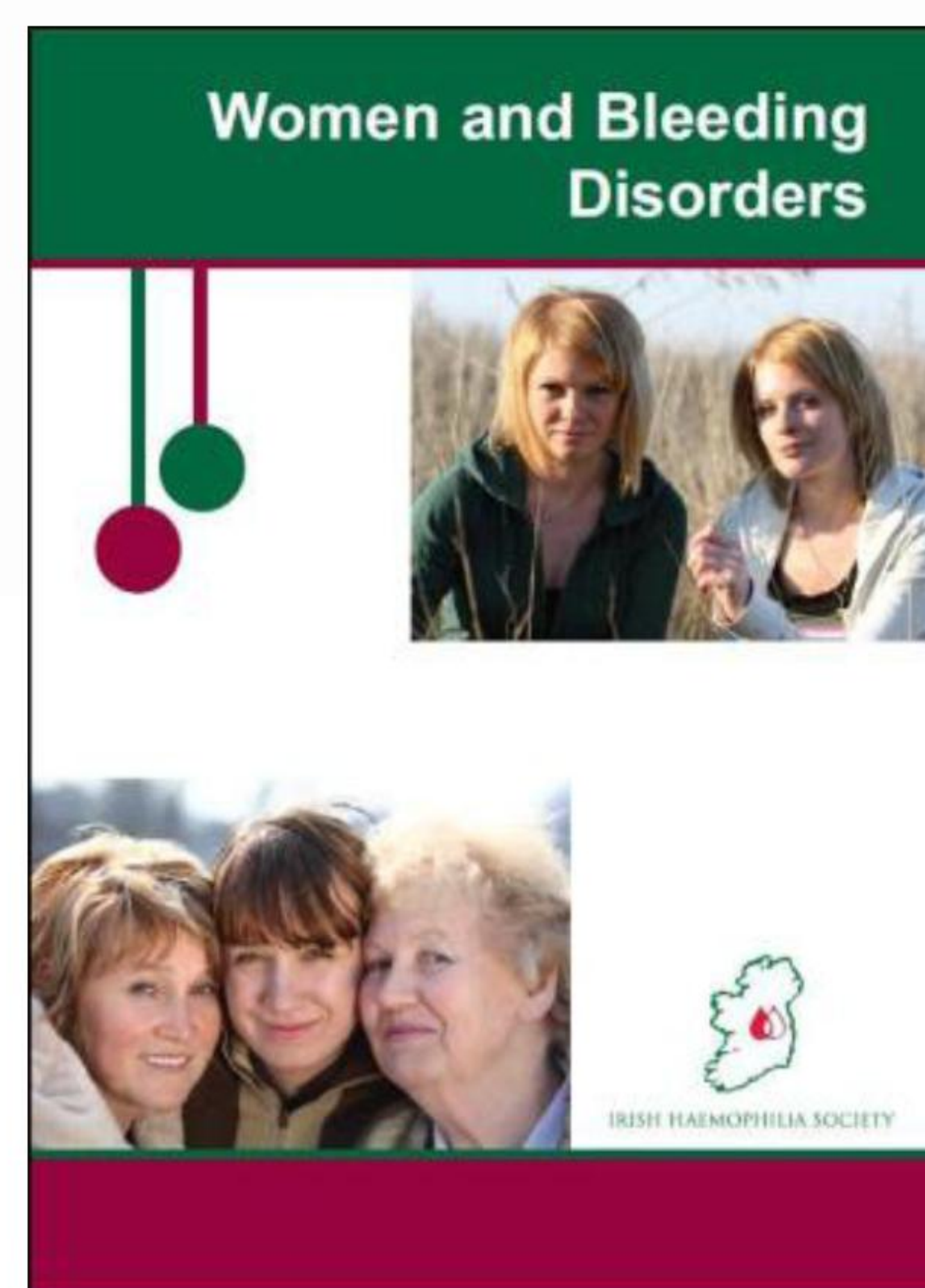
There are 1,115 women with bleeding disorders registered at the National Centre for Hereditary Coagulation Disorders in Ireland. Of these, 114 are carriers of haemophilia, 578 have von Willebrands Disease, 164 have rare bleeding disorders, and 259 have uncharacterised bleeding disorders.

In 2010, we identified that this cohort of members would benefit greatly from a publication for Women with Bleeding Disorders. We produced a publication which was circulated by the Society to members, distributed through the comprehensive care centres in Ireland, and was sent to all the maternity hospitals and obstetricians in Ireland. Following the initial distribution, additional copies were requested by several hospitals.

Following the production of our publication, we organised special meetings on this topic on World Haemophilia Day in 2011. All members of the Irish Haemophilia Society were invited to attend and the meetings were advertised in all the maternity hospitals in Ireland. We also placed advertisements in the comprehensive care centres in relation to our meetings. A press release was issued which resulted in two newspaper articles in the National newspapers.

Our strategies resulted in two very successful meetings in Dublin and Cork attended by midwives, nurses and women with known or suspected bleeding disorders. The combination of the publication and the meetings resulted in a great degree of awareness on this issue nationally.

It is vitally important that women with bleeding disorders understand their condition, and the potential impact it may have on them during menstruation, pregnancy, menopause and surgery. Education and knowledge is power.



**Irish Haemophilia Society**

**Women and Bleeding Disorders  
Information Days**

Rochestown Park Hotel, Cork Date: Saturday April 16th 2011 Time: 1.00pm - 4.00pm	Hilton Hotel Kilmainham, Dublin Date: Sunday April 17th 2011 Time: 1.00pm - 4.00pm
<b>PROGRAMME</b>	
1.00pm - 2.00pm	Women and Bleeding Disorders Speaker: Dr. Paul Giangrande, Consultant Haematologist, Oxford, U.K.
2.00pm - 2.30pm	A Journey Toward a Bleeding Disorder Diagnosis & Beyond Speaker: Eileen O'Shea, Haemophilia Nurse Specialist, N.C.H.C.D., St. James's Hospital
2.30pm - 3.00pm	Tea/Coffee Break
3.00pm - 3.45pm	von Willebrands Disease Speaker: Dr. Paul Giangrande, Consultant Haematologist, Oxford, U.K.
3.45pm - 4.00pm	I.H.S. Services and Support Speaker: Brian O'Mahony, CEO, I.H.S.

Ideal for any woman with a known or suspected bleeding disorder.  
Registration and attendance is free of charge.  
If you would like to attend either of these Information Days, please contact Fiona or Nuala in the office on 01 6579900, or you can register online by visiting our website [www.haemophilia.ie](http://www.haemophilia.ie).

