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Statement No.: WITN0736001

Exhibits: **WITN0736002 - 04**

Dated:

Infected Blood Inquiry

Exhibit WITN0736003

**THE  
IRISH HAEMOPHILIA  
SOCIETY**



**WOMEN  
and  
BLEEDING  
DISORDERS**



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The Irish Haemophilia Society is a voluntary organisation which provides services for people with haemophilia and other coagulation disorders. Of the coagulation disorders the best known are Haemophilia A which is Factor VIII Deficiency and Haemophilia B which is Factor IX Deficiency. Because of the inheritance pattern of these haemophilias they rarely affect females. These disorders are well characterised and this is reflected in the fact that the vast majority of the membership of the Irish Haemophilia Society is comprised of males with Haemophilia A and B and their

families. However, Haemophilia A and B are not the most prevalent coagulation disorders. The most prevalent inherited coagulation disorder is Von Willebrands Disease which affects both males and females. Von Willebrands is estimated to affect to some degree up to 1% of the population. In Ireland there are 270 people registered with Haemophilia A 109 registered with Haemophilia B and yet there are only 207 people registered with Von Willebrands Disease. In relation to the expected incidents of Von Willebrands Disease, this is a clear sign that Von Willebrands Disease is under diagnosed. In addition to females with Von Willebrands Disease there are also a large number of females who carry the gene for Factor VIII and Factor IX deficiencies and these carriers can themselves often be symptomatic. There are women who suffer from deficiencies in some of the other plasma clotting proteins. If you include women with Von Willebrands Disease, women who carry a Factor VIII and Factor IX Deficiency and women with rare coagulation disorders, the community of women with bleeding disorders in this country is an under recognised and neglected group of people. Von Willebrands Disease remains difficult to diagnose and therefore widely under diagnosed. For carriers of Factor VIII and Factor IX Deficiency carrier detection and prenatal diagnosis have been poorly addressed in this country in the past but major improvements are now taking place. Women with bleeding disorders often suffer severe effects during menstruation and pregnancy without having the underlying bleeding disorder correctly diagnosed.

As an organisation the Irish Haemophilia Society is acutely aware of the under

recognition of the problems faced by women with bleeding disorders.

Consequently we organised a seminar on January 25th and 26th of 1997 which looked exclusively at these aspects of coagulation deficiencies. In this publication we have gathered together the four lectures delivered on the day. The seminar was extremely successful. There were 110 people in attendance at the seminar in Dublin on January 25th and 40 in attendance at the seminar in Cork on January 26th. Despite having to assimilate the content of four 45 minute lectures, the audience remained enthusiastic and attentive throughout the day and indeed we were surprised at the volume and enthusiasm of the audience when it came to asking questions. In terms of increasing awareness, it provided a valuable opportunity for many women with bleeding disorders to network, to meet others in the same position and indeed for most of them it was the first occasion at which their particular problem had ever been addressed. In terms of awareness, the usefulness of the seminar was greatly enhanced by the fact that RTE covered the seminar as a major item on the National Television News on January 25th. This in turn led to an increased number of queries to the society office and referrals from the society office via general practitioners to the National Haemophilia Treatment Centre. Indeed since the seminar in January, the National Haemophilia Treatment Centre has dealt with referrals of 57 women with bleeding disorders who up to that point had been undiagnosed. In addition, many of the women who attended the seminar have become members of the Irish Haemophilia Society and we look forward to their long and active participation in this society in the future. We see this seminar as not the end of our efforts in this area but a beginning.

Brian O'Mahony  
Chairman  
IRISH HAEMOPHILIA SOCIETY