

**Title: Universal Data and Serum Specimen (UDC) System for Hemophilia:
Collecting Data on Females with Bleeding Disorders**

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Synopsis:

The primary congenital bleeding disorders are Hemophilia A and B, which affect 1 in 5000 males and von Willebrand disease which affects 1 in 100 men and women. Persons with bleeding disorders are either missing a factor in their blood that is essential to the clotting process or the protein is present but does not work. Without this factor, bleeding into muscles, joints, and internal organs often occurs without any noticeable trauma. The treatment of a bleeding episode involves the replacement of the missing protein through the IV administration of factor concentrate which is derived from, or contains components of human blood plasma. The bleeding and secondarily, the necessary intravenous administration of blood products to control this bleeding, are responsible for the two most severe complications of bleeding disorders: the development of chronic and often debilitating joint disease, and infection with viral, blood-borne diseases such as hepatitis and HIV.

The Centers for Disease Control and Prevention (CDC) met with individuals with bleeding disorders and/or their families to discuss the issues of living with bleeding disorders (e.g., von Willebrand Disease). The main concerns are: (i) to prevent the transmission of infection ("seroconversion") through the use of blood and blood products; and (ii) to prevent damage to the joints.

This UDC research project is for females with hemophilia and certain other blood disorders, primarily von Willebrand Disease. This project is expected to last for several years. The information from this project will help the CDC review and create programs to reduce or prevent the complications of hemophilia (for example, joint disease or transmission of blood-borne viruses such as hepatitis or HIV).