Hemophilia of Georgia
It takes more than medicine...

Do the UDC at the HTC for the CDC

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Horizons in Hemophilia, Winter 2006

If you have been to a Hemophilia Treatment Center (HTC) since May of 1998, you have probably been asked to participate in a project called the Universal Data Collection Program (UDC). It was developed by the Centers for Disease Control and Prevention (CDC). In other words, at the HTC they ask you to do the UDC for the CDC.

The UDC has two purposes. First, it is a system to monitor the safety of blood products used by people with bleeding disorders. Second, it is a way to collect information about potential risk factors for infectious diseases and joint problems. The goal is to use the information to improve the health of people with bleeding disorders. All of the 140 HTCs in the country participate in the UDC. Anyone with an inherited bleeding disorder such as hemophilia or von Willebrand Disease can be part of the UDC.

Information for the UDC is collected during a patient's annual comprehensive exam at the HTC. Basic information is collected. A blood sample is drawn for hepatitis and HIV testing, and measurements are made of joint range of motion. These are all sent to the CDC without names or other information that could identify an individual. A person must agree to be part of the UDC before any of this is done, and a consent form has to be signed every year.

The CDC publishes a report each year on the data collected by the UDC. These reports are available on the Internet at http://www.cdc.gov/ncbddd/hbd/. Some of the highlights of the most current report (data collected through December 2004):

- Since May 1998, 15,682 people with bleeding disorders have agreed to be a part of the UDC and data has been collected at 38,385 HTC visits. Nationally, 7.6% of the people seen at the HTC refuse to participate.

- Just over 50% of the people with hemophilia in the UDC are 20 years old or younger. Over 60% of the people with vWD fall into this same age range. Of the people with hemophilia, 25% are mild, 23% are moderate, and 51.5% are severe. The majority (71.8%) of people with vWD have Type 1; 10.6% have Type 2; 6.8% have Type 3; and 10.8% are classified as other or unknown type of vWD.

- Eleven percent of the people with hemophilia had an intravenous access device, such as a port, in the year before their HTC visit. Of these people, 11.4% had had an infection in their port.

- Approximately one-third of the people with hemophilia between the ages of 21 and 60 have HIV. Factor concentrate was known to transmit HIV between 1978 and 1985. There has been no transmission of HIV by factor products since that time.

The UDC has revealed one particular area of concern. People with hemophilia and vWD aged 13 to 19 are almost twice as likely to be overweight as children of the same age in the U.S. population as a whole. In our

region, Region IV-South, which includes Mississippi, Alabama, Georgia, and Florida, 50% of the people with hemophilia age 20 and older are overweight or obese. This percentage increases to almost 70% for people with vWD. Hemophilia of Georgia has focused on this issue at Camp Wannaklot and at our other client programs in an effort to get young people with bleeding disorders to exercise more and maintain a better diet.