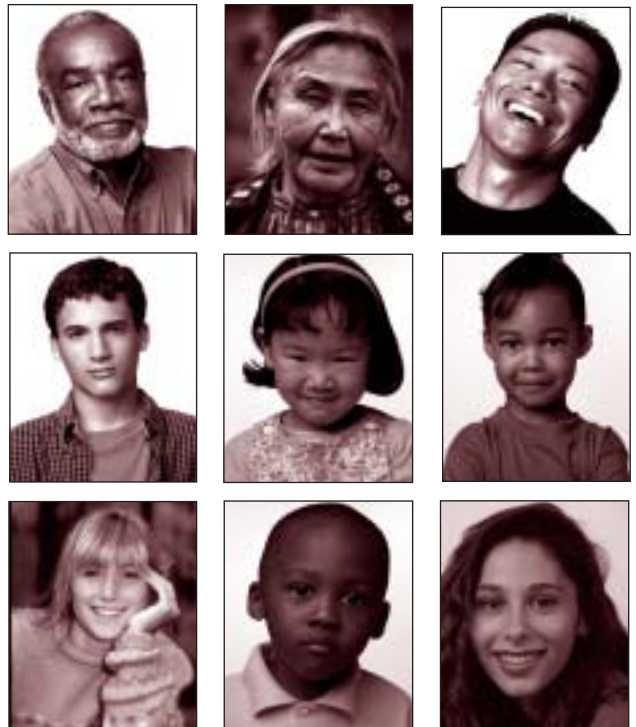


UDC

THE UNIVERSAL DATA COLLECTION PROGRAM

For People with Bleeding Disorders



Health Surveillance

Information for life.

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SAFER • HEALTHIER • PEOPLE

DEPARTMENT OF HEALTH & HUMAN SERVICES

Information for People with Bleeding Disorders

What is the UDC?

UDC is a national program conducted by federally funded hemophilia treatment centers (HTCs) with support from the Centers for Disease Control and Prevention (CDC). Health information, range of motion measurements and a blood sample are obtained from each person who chooses to participate.

What is the purpose of UDC?

To monitor two major health complications of bleeding disorders:

- bloodborne diseases
- joint disease

What are the benefits of participating in UDC?

UDC Blood samples stored at CDC will allow rapid investigation of any new infectious agents potentially spread through blood products.

- In the first year of participation, patients are tested for hepatitis A, B, and C viruses and HIV, results are provided to the participant's doctor. Then, each participant is retested every year for viruses for which he/she previously tested negative to determine that no new infection has occurred
- Collecting the same information from as many persons with bleeding disorders (in the United States) as possible will provide the best information to determine why some people with bleeding disorders develop problems or complications and others do not

- Monitoring joint disease will help researchers identify patterns and develop new approaches to help prevent or reduce joint disease
- Participants will have the personal satisfaction of knowing that they and their health care providers are working together to search for solutions to prevent the complications of bleeding disorders.

Who can participate in UDC?

Any person who has an inherited bleeding disorder (including hemophilia, von Willebrand disease, and other hereditary factor deficiencies) or an acquired inhibitor.

Is the program confidential?

Yes! An identification number will be placed on the blood sample and UDC forms so that a patient's name is never revealed to anyone outside the HTC.

How do I enroll in UDC?

Contact your HTC or call the National Hemophilia Foundation's information center at 1-800-42-HANDI to locate the center nearest you.

For more information about the CDC's bleeding disorders programs, visit

www.cdc.gov/ncidod/dastlr/hematology