

Virginia Bleeding Disorders Program Fact Sheet October 2012

What is the Virginia Bleeding Disorders Program?

The Virginia Bleeding Disorders Program is a legislatively-enacted program established by the Commonwealth of Virginia through the Virginia Department of Health, Office of Family Health Services for the care and treatment of persons with hemophilia and other inherited bleeding disorders.

What services does the Virginia Bleeding Disorders Program provide?

Funding for the VBDP supports five areas:

- 1) Supports a network of comprehensive, multidisciplinary bleeding disorder programs that focus on the physical, emotional, social, educational, financial and workplace impact of inherited bleeding disorders. These services include
 - u *Information and referral*
 - u *Care coordination and case management*
 - u *Home infusion training*
 - u *Family-to-family support in collaboration with the local hemophilia chapters*
 - u *Transition from child to adult oriented health care system.*
 - u *Education for community health care providers*
 - u *Outreach to women*
 - u *Outreach to unserved or underserved persons with inherited bleeding disorders*
- 2) Provides a Pool of Funds to obtain medications to treat the bleeding disorder for patients who are uninsured and financially-eligible. This funding acts as a “safety net” for patients as the VBDP and Comprehensive Bleeding Disorders Centers (CBDCs) assist patients and families obtain coverage for their health care needs.
- 3) Provides health insurance consultation to CBDCs to help patients and their families evaluate their options in accessing health care services. This may include helping families make choices about employer-based or individual health insurance options, accessing SSI or SSDI, referral to patient assistance programs or hospital financial assistance programs.
- 4) Contracts with Patient Services, Incorporated, a nonprofit organization that provides health insurance premium assistance to eligible persons.

- 5) Provides leadership to enhance quality, comprehensive specialty care for patients through public health assessment, assurance, leadership and policy development. This includes:

- § *Identifying trends in health care for persons with inherited bleeding disorders*
- § *Evaluating the accessibility and quality of health care services to patients and the broader bleeding disorder community*
- § *Assuring a competent health care providers*
- § *Developing policies and plans to improve the health of this community and mobilizing community partners including hemophilia chapters to identify and solve barriers to quality health care.*

How can the program help me if I do not have health insurance?

About 15-20% of employers change their health insurance coverage annually. Additionally, persons may also change their health coverage related to divorce, job changes, loss of Medicaid, temporary unemployment or the increased cost of premiums. Given the expensive nature of hemophilia care, such costs can be overwhelming. Moreover, some families are not aware of their options in maintaining health insurance during such transitions. A important service of the program is health insurance case management that assists persons in considering their options in paying for health care services and helping families completing the application and enrollment process for assistance programs and health insurance. During lapses in health insurance coverage, patients may be eligible to receive medications through VBDP Pool of Funds or access to patient assistance programs. The VBDP works closely with the nurse or social worker at the comprehensive bleeding disorders center to help patients during these difficult transitions.

How can the VBDP help me if I have good health insurance?

When patients and families complete a VBDP application, they help the goals of the program in two ways:

- 1) The VBDP is a “safety net” program that keeps abreast of changes in personal health insurance coverage and trends in health care reimbursement. The annual application is one way for the program to anticipate and identify changes in health insurance coverage for patients enrolled in the program.
- 2) The information obtained from the application forms helps the VBDP monitor trends in the health of persons with inherited bleeding disorders in the Commonwealth. No other unduplicated source of this

information is available to assess unmet needs, underserved and unserved persons, outreach needs and quality of care trends.

Where are the comprehensive bleeding disorder centers in Virginia?

Pediatric Centers

Bleeding Disorders Center of Hampton Roads Children's Hospital of the King's Daughters

Division of Hematology/Oncology
601 Children's Lane
Norfolk, VA 23507
757-668-7613
Website: www.CHKD.org

Children's National Medical Center

Falls Church Satellite Center
6565 Arlington Boulevard, Suite 200
Falls Church, VA 22042
703-531-DOCS
Website: www.childrensnational.org
(search comprehensive hemophilia and thrombosis center)

University of Virginia

Department of Pediatric Hematology
Box 800386
University of Virginia Hospital
Primary Care Center, Room 4001
Charlottesville, VA 22908
434-924-8499

Pediatric and Adult Center

Central Virginia Center for Coagulation Disorders

Virginia Commonwealth University
PO Box 980461
1000 East Marshall Street, Room 332
Richmond, VA 23298
804-827-3306
Website: www.vcuhealth.org/cvccd

Who should I contact for more information about the Virginia Bleeding Disorders Program?

The program coordinator may be reached at (804) 827-3306. The mailing address is:

**Virginia Bleeding Disorders Program
VCU Station
P.O. Box 980461
Richmond, VA 23298-0461**

Toll free #: 1-866-228-2516

Website: www.vahealth.org/bleedingdisorders