

**Texas Bleeding Disorders Advisory Council  
Report to the Texas Legislature  
December 1, 2008**

Prepared by the  
Texas Bleeding Disorders Advisory Council  
in compliance with  
S.B. 1566 by Senator Dan Patrick  
80<sup>th</sup> Legislature – Regular Session

## Preface

Samuell has lived with severe Hemophilia A his entire life. Since he was a young boy he has struggled with the trials that come with unstable medical coverage. “During periods of low medication supply, I often would be bed-bound or wheel-chair bound for days or weeks. The limited human interaction greatly lowered my self-esteem, and helped to create limited social interaction skills,” Samuell recalls. “As a young adult I went on Medicaid as a disabled individual, not because of Hemophilia, per se, but because of the lack of medication as a young boy. My joints became so damaged due to severe bleeding, that I was, and still am, classified as disabled.” Samuell, like so many others living with bleeding disorders, faces challenges such as lack of adequate insurance coverage and the financial toll of the disease.

Jorge, a 13-year-old living with severe Hemophilia A, must administer a medication called factor intravenously three times a week to prevent bleeds. Jorge’s factor costs over \$250,000 a year. Although Jorge’s family is grateful to have the medication, they know that it is not a cure. “He still has bleeds because it is only active in his body for about 18 hours and we have a maximum on our insurance of \$5 million.” Jorge’s parents anticipate that their son will be out of coverage by the time he is 20 because the amount of factor he receives is dependent upon his weight.

High costs of medication are not the only setbacks faced by individuals with bleeding disorders. Mary Evelyn is a 26-year-old who, after being admitted to a hospital critical care unit for multiple pulmonary embolisms, was diagnosed with a form of thrombophilia, factor V Leiden. Mary recalls the dilemma and tragedy she faced due to so few physicians being aware of clotting disorders such as factor V Leiden. “Experiencing difficulties breathing, I went to my university’s infirmary to have my problem diagnosed and to receive treatment. I was misdiagnosed with bronchial spasms and continued to have problems until I wound up in the hospital.” Even after an eventual correct diagnosis and treatment, Mary still encounters complications. “I continue to experience difficulties breathing despite the absence of the clots. These breathing problems sometimes interfere with my ability to exercise or even sleep,” Mary says. Like so many others, including Samuell and Jorge mentioned above, Mary’s treatment is quite expensive. “Despite the absence of clots, my medical history and breathing problems require that I get expensive routine medical tests yearly...ultrasounds, CT scans, computerized breathing tests.”

These individuals have more than a bleeding or clotting disorder in common. They each yearn for security and peace of mind. They look forward to a future where medical coverage is the least of their problems. Samuell reflects, “I don’t want to be the bed-ridden father that has to sit and watch his kids grow up without him. I need to spend active time playing with my son so we can bond. I want my daughter to be able to have her wedding dance with me one day. I want to be able to stroll down the street with my wife in our old age. But, I cannot have these things so many others take for granted if I do not have the medical coverage that provides full and adequate care for my needs as a hemophiliac.”

*See more personal stories in Appendix A*

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Questions regarding this report may be directed to:

Carol Labaj, RN, BSN, Manager, Purchased Health Services  
Department of State Health Services  
512-458-7111, extension 3104  
Carol.Labaj@dshs.state.tx.us

## **EXECUTIVE SUMMARY**

Senate Bill 1566, 80<sup>th</sup> Regular Session, established the Texas Bleeding Disorders Advisory Council (TBDAC) to study and advise the Texas Department of State Health Services (DSHS), the Health and Human Services Commission (HHSC), and the Texas Department of Insurance (TDI) on issues that affect the health and well-being of persons with hemophilia and other bleeding or clotting disorders. In accordance with the legislation, the Council was required to address five issues as they pertain to both bleeding and clotting disorders:

1. Legislative or administrative changes to policies and programs that affect the health and wellness of persons with hemophilia and other bleeding or clotting disorders, including access to appropriate health insurance or similar health coverage;
2. Legislative or administrative changes to policies and programs that affect product-specific reimbursement to providers, including various reimbursement methodologies for anti-hemophilic factors in the Medicaid program that provide access to appropriate treatment;
3. Best practices in standards of care and treatment for persons with hemophilia and other bleeding or clotting disorders;
4. Establishment of community-based initiatives to disseminate information on services and related activities for persons living with hemophilia and other bleeding or clotting disorders to the medical and health care community, the academic community, primary caregivers, advocacy associations, and the public; and
5. Coordination of public and private support networking systems for persons living with hemophilia and other bleeding or clotting disorders and primary caregivers.

Governor Rick Perry signed S.B. 1566 into law on May 23, 2007. The TBDAC members were appointed on October 17, 2007 and the group has met quarterly since their first meeting on November 29, 2007. The Council will serve until it expires on September 1, 2009 as stated by law.

The Council's philosophical approach in addressing charges from the Texas Legislature was that those affected by bleeding and clotting disorders and their caregivers should have access to and choice of providers of services, treatments and products. Additionally these individuals should have access to a multitude of information on their bleeding and clotting disorders. Those affected should also have the ability to increase their personal base of knowledge on their disorders through social networks and advocacy groups. Finally, the Council agreed that access to information should increase knowledge leading to improved quality of life for those faced with bleeding and clotting disorders, that the medical and health care community should have quick and convenient access to information needed to diagnose patients with bleeding disorders including treatment protocols, methods and products and should also have access to subject matter experts in the treatment of bleeding and clotting disorders.

The Council recommends:

- Re-establishing the Council beyond September 1, 2009 and appropriately fund the Council activities by providing staff and financial resources to the state department responsible for the Council, including the ability to reimburse travel expenses under state guidelines for the Council members.
- Adding hemophilia to Children with Special Health Care Needs (CSHCN) Services Program as an eligible condition to receive CSHCN Services Program benefits without age restriction, similar to Cystic Fibrosis (CF).
- Providing factor and other treatment benefits to persons with hemophilia during the 24-month period until Medicare disability benefits begin.
- Increasing funding for the existing Hemophilia Assistance Program (HAP) or abolish the HAP and redirect HAP funding from purchase of blood factor to assistance with premium payments for the Texas Risk Pool.
- Providing payment for anti-hemophilia pharmaceutical products through a state-purchase program to members that qualify.
- Asking the Health & Human Services Commission to re-evaluate the current reimbursement rates and policy for all medically necessary services, supplies, and factor concentrate so as to ensure that the bleeding disorders community continues to have access to these products and services.
- Increasing access and decreasing barriers to Hemophilia and Thrombophilia Treatment Centers (HTCs) for pediatric and adult patients with congenital hemophilia and other serious bleeding disorders, as well as patients with congenital thrombophilia (increased tendency to thrombosis or clotting).
- Establishing a website providing “one-stop” access to persons desiring more information on bleeding disorders by linking to the HAP website, Centers for Disease Control & Prevention, and HTC websites.
- Establishing a statewide task force to stay abreast of legislation important to the bleeding disorders community and to increase collaboration among existing community based initiatives (public and private networks), thus increasing access to information and resources statewide.

The following report includes a rationale for the recommendations, some of which could be accomplished through private sector initiative rather than legislation, and background information on hemophilia, thrombophilia and other bleeding and clotting disorders.

## I. INTRODUCTION

Senate Bill 1566, 80<sup>th</sup> Regular Session, established the Texas Bleeding Disorders Advisory Council (TBDAC) to study and advise the Texas Department of State Health Services (DSHS), the Health and Human Services Commission (HHSC), and the Texas Department of Insurance (TDI) on issues that affect the health and well-being of persons with hemophilia and other bleeding or clotting disorders. In accordance with the legislation, the Council was required to address five issues as they pertain to both bleeding and clotting disorders:

1. Legislative or administrative changes to policies and programs that affect the health and wellness of persons with hemophilia and other bleeding or clotting disorders, including access to appropriate health insurance or similar health coverage;
2. Legislative or administrative changes to policies and programs that affect product-specific reimbursement to providers, including various reimbursement methodologies for anti-hemophilic factors in the Medicaid program that provide access to appropriate treatment;
3. Best practices in standards of care and treatment for persons with hemophilia and other bleeding or clotting disorders;
4. Establishment of community-based initiatives to disseminate information on services and related activities for persons living with hemophilia and other bleeding or clotting disorders to the medical and health care community, the academic community, primary caregivers, advocacy associations, and the public; and
5. Coordination of public and private support networking systems for persons living with hemophilia and other bleeding or clotting disorders and primary caregivers.

## II. OVERVIEW

The TBDAC was charged with addressing the above-listed issues for both bleeding and clotting disorders. Although the issues are of importance to both sets of disorders, the differences between bleeding and clotting disorders are vast. Treatment, disease management, and standards of care vary tremendously between the two.

### A. Bleeding Disorders

**Hemophilia** is a rare inherited bleeding disorder in which the blood does not clot properly. The most common form of hemophilia is caused by a defect in the gene located on the X chromosome that contains the genetic code for one of the clotting factor proteins necessary for normal blood clotting. The defect usually occurs on one of the two female X chromosomes and results in a carrier state. When the defect occurs in males on their only X chromosome, the result is hemophilia disease. Therefore, hemophilia usually occurs only in males. Currently, there are approximately 18,000 persons in the U.S. with hemophilia and every year about 400 babies are born with Hemophilia (1).

Hemophilia results from deficiencies in blood clotting factors and can lead to spontaneous internal bleeding and bleeding following injuries or surgery. These bleeding episodes can cause severe joint damage, neurological damage, damage to other organ systems involved in the hemorrhage, and, in rare cases, death. Treating the bleeding episodes involves the prompt and proper use of clotting factor concentrates.

People with severe hemophilia can experience serious bleeding into tissues, muscles, joints, and internal organs, often without any obvious trauma. Repeated bleeding into joints without adequate treatment results in crippling chronic joint disease which is one of the severe complications of bleeding disorders. Hemophilia is treated by replacing clotting factor, referred to as Replacement Therapy. Replacement Therapy can be administered as a preventive measure (prophylaxis) or on an “as needed” basis. The type of treatment prescribed depends on several factors including the severity of hemophilia (2).

Rare bleeding disorders may occur from inherited deficiencies of other clotting factors. These disorders manifest variable amounts of bleeding, from very mild to severe and life-threatening episodes.

The most common bleeding disorder is **von Willebrand Disease** (vWD). Although the prevalence of this disease is not known, it is estimated between approximately 1-2% of the U.S. population are affected. vWD results from a deficiency in the body's ability to make von Willebrand factor, a protein that helps blood clot. vWD occurs in men and women equally (3). vWD is characterized by heavy or prolonged menstrual bleeding, easy bruising, frequent or prolonged nosebleeds, and prolonged bleeding following surgery, dental work, childbirth or injury.

## **B. Clotting Disorders**

**Thrombophilia** is a condition where the blood has an increased tendency to clot and can be either inherited at birth or acquired later in life. Acquired thrombophilia may result from a serious trauma, surgery, or other medical condition, such as cancer. Persons with an inherited form of thrombophilia possess a genetic or protein mutation that increases their risk of developing a life-threatening clot. Thrombosis may be treated with anticoagulants, such as Coumadin, heparin, and/or low-molecular weight heparin.

For the purposes of this report the only forms of thrombophilia discussed will be those inherited disorders. The two most common forms of inherited thrombophilia are factor V Leiden (FVL) and prothrombin G20210A (4). Prevalence estimates for factor V Leiden in the United States are 5% (one in 20) in Caucasians and 1-2% (one in 100 to one in 50) in African Americans, Hispanic Americans, and Native Americans (5). As for prothrombin G20210A, 2-4% (one in 50 or one in 25) of the American Caucasian population and 0.4% (one in 250) of the African American population are estimated to have the mutation (6).

These conditions are most commonly found in Caucasians and are associated with serious complications including venous thrombosis (DVT), stroke, transient ischemic attacks, heart attack, miscarriage, preeclampsia, and eclampsia (7). A person's risk of such complications is further increased when combined with other contributing risk factors, including the use of oral contraceptives, smoking, pregnancy, hormonal replacement therapy, high blood pressure, obesity, and/or surgery.

### **C. Treatment of Bleeding and Clotting Disorders**

Hemophilia is a life-long disease with no cure. Treatment is very expensive. The main treatment for hemophilia is called replacement therapy—giving or replacing the clotting factor that is too low or missing. Concentrates of clotting factor VIII (for hemophilia A) or clotting factor IX (for hemophilia B) are slowly dripped in or injected into a vein. Over time, hematologists began to recognize that solely offering hemostatic therapy during a bleeding crisis, i.e., arresting the hemorrhage, was not sufficient in improving patient prognosis.

Thrombophilia is a group of conditions in which there is an increased tendency for excessive clotting. People with thrombophilia may receive medications that affect the coagulation system, just as people with hemophilia do, but not always in the same manner. Some people with thrombophilia may receive “replacement factor concentrate” to treat their thrombophilia either on a long term or an intermittent basis, depending on the underlying cause of their thrombophilia. People with thrombophilia may receive medications only during a time of increased risk of thrombosis or for a prolonged period of time (even for a lifetime), depending on their specific diagnosis and clinical circumstances (8).

In 1975, a national network of hemophilia treatment centers (HTCs) developed around the country with support from the Health Services & Resources Administration (HRSA). The mission of the HTCs is to provide and coordinate comprehensive, multi-disciplinary services, including hematology care, dental care, orthopedic care, physical therapy, psychosocial support, infectious disease care, and financial, vocational and genetic counseling to persons with bleeding disorders. The HTC concept was so successful that the scope of care to be provided by the HTCs was expanded to include patients with clotting disorders. The development of comprehensive care over the past 30 years has greatly improved the quality of life for people with bleeding disorders, helping them to be more independent and productive (9). A 2006 study by the Centers for Disease Prevention & Control (CDC) found that hemophilic patients involved with a HTC are less likely to be hospitalized for bleeding complications and have a 40% decrease in mortality compared with those not enrolled (10). Similarly, the *Journal of Thrombosis and Hemostasis* reported in 2007 that it has been demonstrated in studies that “hemophilia patients who receive health care within these federally supported centers have better health outcomes and decreased mortality compared with hemophilia patients treated outside such centers” (11).

Texas maintains seven HTC, six of which are federally recognized bleeding and clotting disorders centers for the state (12):

- Gulf States Hemophilia and Thrombophilia Program - Houston
- Fort Worth Bleeding Disorders Program
- North Texas Hemophilia and Thrombosis Program – Pediatric Program - Dallas
- North Texas Hemophilia Treatment Center – Adult Program - Dallas
- South Texas Hemophilia and Thrombophilia Center – San Antonio
- Texas Children’s Hemophilia and Thrombophilia Center - Houston
- Galveston Hemophilia Program (not federally funded)

*See Appendix B*

HTCs also coordinate home care programs which enable persons with hemophilia to lead normal, productive lives. Home care programs allow for immediate treatment, thus avoiding the delay, stress and cost of emergency room care. Self-treatment at home has been tremendously successful in reducing the cost of care, limiting disability and decreasing unemployment. HTCs have saved millions of dollars by reducing the need for hospitalization and decreasing clinic or emergency room visits. Yet, even with these measures in place, clotting factor replacement therapy is the most costly aspect of hemophilia treatment.

Current factor concentrates are among the most costly therapies in the world. It is important for consumers to be well-informed about finance, reimbursement and healthcare issues. The social worker or financial reimbursement specialist at a HTC can provide assistance with treatment. While organizations and treatment professionals can educate people to better understand insurance, it ultimately falls on individuals to manage their own healthcare reimbursement.

#### **D. Resources, Gaps in Resources, and Barriers to Care**

A review of the available programs to support persons with a bleeding disorder revealed numerous gaps and adverse impacts, especially for adults. The goal of effective care and management of this population is to prevent adverse events that result in permanent disability and reliance on the state or federal government for subsequent care. Failure to provide services for this special population results in increased burden on the health delivery system, premature disability—both medical and behavioral – and reduced productivity as this population leaves the workforce. The special circumstances of this population often result in their inability to find affordable insurance outside of large-group settings. Support decreases significantly as these patients move from childhood to the adult world.

The seven HTCs located in Texas are structured to be Centers of Excellence that aim to provide comprehensive medical services to persons with bleeding and clotting disorders. HTCs are staffed by multi-disciplinary teams of medical specialists to assess, treat, and prevent complications associated with inherited bleeding disorders. HTCs also include outreach and education programs. Although data are not available regarding the exact

percentage of hemophilia patients provided treatment in the HTC, it is estimated that approximately 60-70% of hemophilia patients receive services in these centers (13). Federal funding of the treatment centers, however, does not extend to financial support of pharmaceuticals and other measures of treatment. Appropriate treatment and access to comprehensive care in combination are required for the adequate care of patients with bleeding disorders.

In fact, the primary issue for people living with hemophilia and other bleeding and clotting disorders is the tremendous cost of treatment. Publicly-financed health care coverage is limited and, even for those with health insurance, treatment costs can far exceed maximum coverage amounts. Comprehensive access to treatment could prevent or reduce costs associated with longer-term disability coverage.

See Appendix C for Data and Analysis (Methods; Prevalence data; Hospitalization data)

### **III. COUNCIL PROCESS**

Governor Rick Perry signed S.B. 1566 into law on May 23, 2007. The TBDAC members were appointed on October 17, 2007 and the group has met quarterly since their first meeting on November 29, 2007. The Council will serve until it expires on September 1, 2009 as stated by law.

The Council is made up of ten voting members:

- A physician licensed to practice medicine in the state of Texas that treats individuals with hemophilia or other bleeding or clotting disorders;
- A licensed nurse who treats individuals with hemophilia or other bleeding or clotting disorders;
- A social worker who treats individuals with hemophilia or other bleeding or clotting disorders;
- Two representatives of hemophilia treatment centers in this state, one of which is a federally-funded facility;
- A representative of a health insurer or other health benefit plan certified by TDI;
- A representative of a volunteer or nonprofit health organization that serves persons with hemophilia or other bleeding or clotting disorders;
- A person who has hemophilia or a caregiver of a person with hemophilia;
- A person who has a bleeding disorder other than hemophilia or a caregiver of a person who has a bleeding disorder other than hemophilia;
- A person who has a clotting disorder or caregiver of a person with a clotting disorder.

In addition, the Council may have up to seven non-voting members:

- The commissioner of DSHS or their representative;
- The commissioner of TDI or their representative;
- Additional persons with hemophilia or other bleeding or clotting disorders or caregivers of people with hemophilia or other bleeding or clotting disorders;

- Additional persons experienced in the diagnosis, treatment, care, and support of people with hemophilia or other bleeding or clotting disorders.

In accordance with the legislation, all members were appointed by the commissioners of State Health Services and Insurance. The commissioners appointed five non-voting members. A list of the Council members is available in Appendix D.

During their meetings the TBDAC received information from HHSC staff on Medicaid eligibility, the Medicaid Buy-In Program, and the Vendor Drug Program. HHSC staff also provided information on the Texas Health Care Reform initiative and data on bleeding and clotting disorders among Texas Medicaid and CHIP clients. DSHS staff, at the Council's request, researched and presented the data found in Appendix C. DSHS staff, in addition to the data research and ongoing administrative support, provided the TBDAC with information on the Hemophilia Assistance Program (HAP) and the Children with Special Health Care Needs (CSHCN) Services Program.

DSHS staff also created a web page to house information pertaining to the TBDAC. The TBDAC web page may be accessed at: <http://www.dshs.state.tx.us/tbdac/>

In addition to the recommendations listed below, the TBDAC requests that the Texas Legislature reestablish the Council beyond September 1, 2009. The Council requests that the Legislature appropriately fund the Council activities by providing staff and financial resources to the state department responsible for the Council, including the ability to reimburse travel expenses under state guidelines for the Council members.

#### **IV. APPROACH TO RECOMMENDATIONS**

The Council's philosophical approach in addressing charges from the Texas Legislature was that those affected by bleeding and clotting disorders and their caregivers should have access to and choice of providers of services, treatments and products. Additionally these individuals should have access to a multitude of information on their bleeding and clotting disorders. Those affected should also have the ability to increase their personal base of knowledge on their disorders through social networks and advocacy groups. Finally, the Council agreed that access to information should increase knowledge leading to improved quality of life for those faced with bleeding and clotting disorders, that the medical and health care community should have quick and convenient access to information needed to diagnose patients with bleeding disorders including treatment protocols, methods and products and should also have access to subject matter experts in the treatment of bleeding and clotting disorders.

The following recommendations focus on improving access to care and treatment for persons with bleeding disorders. The Council acknowledges that the recommendations pose fiscal implications for the State, but an investment now could result in future savings in relation to emergency hospitalizations, disability costs and lost productivity. The recommendations are presented as different options for the Legislature to consider in improving access to care for this community.

## V. RECOMMENDATIONS

*Recommendations #1-3 relate to “legislative or administrative changes to policies and programs that affect the health and wellness of persons with hemophilia and other bleeding or clotting disorders, including access to appropriate health insurance or similar health coverage.”*

**RECOMMENDATION 1: Add hemophilia to Children with Special Health Care Needs (CSHCN) Services Program as an eligible condition to receive CSHCN services without age restriction, similar to Cystic Fibrosis (CF).**

Rationale: The DSHS Children with Special Health Care Needs Program (CSHCN) Services Program provides services to children with extraordinary medical needs, disabilities and chronic health conditions. Services are limited to persons under the age of 21, with the exception of persons with cystic fibrosis who can be served at any age. Currently, children and youth under 21 who are diagnosed with hemophilia can receive CSHCN services if they meet income and other eligibility criteria. The TBDAC proposes expanding coverage to persons of any age who have hemophilia (using existing income and other eligibility criteria).

**RECOMMENDATION 2: Provide factor and other treatment benefits to persons with hemophilia during the 24 month period until Medicare disability benefits begin.**

Rationale: Under federal law, a person who qualifies for Medicare disability coverage must wait 24 months for that coverage to begin. For persons with hemophilia and bleeding or clotting disorders, the waiting period presents a serious risk of severe bleeding episodes during that period, resulting in additional disability. In 2007, Texas Congressman Gene Green introduced the Ending the Medicare Disability Waiting Period Act (HR 154) which would phase out the waiting period for disabled individuals and eliminate the waiting period for individuals with life-threatening conditions. Congress, however, has not yet taken action on this legislation.

Medicaid does provide coverage during the 24-month period for persons meeting certain disability and income requirements, however the eligible population is very limited. Coverage is based on federal policy, therefore it cannot be modified at the state level. As a result, the TBDAC recommends that the Legislature consider providing factor and possibly other benefit assistance, funded by the State, to persons with hemophilia who qualify for disability benefits but must wait 24 months for coverage. The benefit assistance would run only through the 24-month period. Such an assistance program could be discontinued with the passage of HR 154 or similar federal legislation.

**RECOMMENDATION 3: Redirect Hemophilia Assistance Program (HAP) funding from purchase of factor concentrates to assistance with premium payments for the Texas Risk Pool and increase funding for the existing HAP.**

Rationale: The HAP, administered by DSHS, provides blood, blood derivatives, or manufactured pharmaceutical products to Texas residents who are 21 or older with a diagnosis of hemophilia and an income at or below 200% of the Federal Poverty Level. Benefits are capped at \$25,000 per person per year. Under current funding levels, the HAP is able to serve only a dozen Texas citizens with this condition. Redirecting the funds to Texas Risk Pool premiums would have two benefits:

- more efficient use of scarce resources through the purchase of insurance with a coverage level well in excess of \$25,000 per year, potentially permitting additional eligible citizens to participate at current funding levels; and
- broadening the scope of coverage available to eligible participants, because Texas Risk Pool insurance coverage would allow reimbursement for a broader range of healthcare products and services in addition to the pharmaceutical products covered under HAP.

In addition, the TBDAC recommends increasing the amount of funding for the HAP to reach all eligible citizens.

*Recommendation #4 relates to “legislative or administrative changes to policies and programs that affect product-specific reimbursement to providers, including new payment for anti-hemophilia factor, including various reimbursement methodologies for anti-hemophilic factors in the Medicaid program that provide access to appropriate treatment.”*

**RECOMMENDATION 4: Provide payment for anti-hemophilia pharmaceutical products through a state-purchase program to members that qualify.**

Rationale: The primary challenge of hemophilia is related to the cost of and access to anti-hemophilia products. Patients that are receiving appropriate management and prophylaxis are much less costly than those that seek care for acute bleeding incidents. Also, insurability in the private market is challenging, especially for members with this condition in small business settings. One or two members with hemophilia in a small or moderate sized company can result in premiums that exceed what the average worker can afford. This causes frequent insurance “shopping” and/or employers dropping insurance coverage altogether subsequently decreasing their competitiveness in the marketplace. A suggested solution is for the state to cover the cost for only the blood product/factor component of treatment for eligible bleeding disorder conditions for persons who are otherwise covered by their small employer health insurance plan. Such state support would greatly enhance the insurability and affordability of such insurance for these members and their respective employers. The private insurance sector would carry the risk for all other care including unexpected acute bleeding costs (less factor).

*Recommendations #5-6 relate to “best practices in standards of care and treatment for persons with hemophilia and other bleeding and clotting disorders.”*

**RECOMMENDATION 5: The Council urges the Health and Human Service Commission to reevaluate the current Medicaid reimbursement rates and policy for all medically necessary services, supplies, and factor concentrate so as to ensure that the bleeding disorders community continues to have access to these products and services.**

Rationale: The current Vendor Drug Program formula used to determine the reimbursement rate for factor concentrate to pharmacy providers is the estimated acquisition cost of the drug plus \$7.50 dispensing fee plus 2% up to \$200.00. There are, however, other costs associated with this medication and its administration. Texas reimbursement rates are among the lowest in the nation. Continuation of current rates may create a situation in which Medicaid families with bleeding disorders would not be able to obtain their medication through home health delivery systems. This would necessitate travel to hospital emergency rooms in order to obtain factor. This alternative would prove more costly to the Texas Medicaid program and would negatively impact treatment outcomes and quality of life for bleeding disorder patients.

**RECOMMENDATION 6: Increase access and decrease barriers to Hemophilia and Thrombophilia Treatment Centers (HTCs) for pediatric and adult patients with congenital hemophilia and other serious bleeding disorders, as well as patients with congenital thrombophilia (increased tendency to thrombosis or clotting).**

Rationale: Such Centers of Excellence, currently exemplified by Texas’ seven Hemophilia Treatment Centers (HTCs) have consistently superior patient outcomes, as well-established in the medical literature, when compared with patients treated by individual practitioners. Currently some Hemophilia Treatment Centers (HTCs) in Texas also diagnose and treat patients with Thrombophilia. While the conditions are very different clinically, the same physicians and health care providers have the needed expertise, hence the rationale for combining these two patient groups. To date there is evidence from pilot studies that managing thrombophilia patients in specialized centers is advantageous, as their issues are complex, and overall physician knowledge and expertise is limited. Access to care can be improved through:

- Providing comprehensive treatment for both bleeding and clotting disorders, combining both patient groups. There should not be a double standard of care. This applies particularly to patient 18 years old or older, since children with serious chronic illnesses, such as hemophilia, usually have coverage available.
- Transportation assistance for patients or for staff to visit underserved and remote areas on a regular basis.
- State funding for HTCs. The state should provide general revenue for treatment of Thrombophilia. Hemophilia Treatment Centers in Texas receive very modest (and shrinking) funding nationally through the Maternal and Child Health Bureau and the Centers for Disease Control and Prevention (CDC). There is no specific funding for Thrombophilia.
- Allowing patients and HTC physicians to choose the laboratory at which the specialized testing for bleeding disorders and thrombophilia is carried out, rather than have this

mandated by insurers. This type of testing needs to be carried out at specialized laboratories, preferably affiliated with, or approved by, the HTC.

In addition to the previously addressed charges, SB 1566 directed the TBDAC to make recommendations on the establishment of community-based initiatives to disseminate information to various stakeholders, and on coordination of public and private support networking systems for persons living with hemophilia and other bleeding or clotting disorders. The Council members agree that information and education should be an essential component of any effort to improve the lives of people living with these conditions.

The following recommendations should be considered as private sector initiatives rather than statutory changes. The TBDAC will continue to discuss these issues and determine how any or all can be implemented.

*Recommendation #7 relates to “the establishment of community-based initiatives that will disseminate information on services, networks and information to persons with bleeding and clotting disorders, to the medical and healthcare community, the academic community, primary caregivers, advocacy associations and the general public.”*

**RECOMMENDATION 7: Establish a website providing “one-stop” access to persons desiring more information on bleeding disorders by linking to the HAP website, CDC and HTC websites.**

Rationale: The internet has brought a transformation in many aspects of life. It is one of the biggest contributors in making the world into a global village. Most people have computers in their homes but even the ones who don't can always go to cyber cafes or their local library where this service is provided. The “one-stop” access web site for persons desiring more information on bleeding disorders should provide an avenue to pursue links to national and local organizations that support persons with bleeding disorders, have the capacity for blog and Wiki capabilities, and offer a regular newsletter via online registration. Sections of the website should be established for various audiences, including specific information for persons living with a bleeding disorder, educational materials for health professionals, and general information for the public. Links should be developed to the HAP, CDC, and HTC websites. This information should be presented in multiple languages in both online and print formats.

*Recommendation #8 relates to “coordination of public and private networking systems for persons living with hemophilia and other bleeding and clotting disorders and primary caregivers.”*

**RECOMMENDATION 8: Establish a statewide task force to stay abreast of legislation important to the bleeding disorders community and to increase collaboration among existing community based initiatives (public and private networks), thus increasing access to information and resources state wide.**

Rationale: This task force would operate as a virtual community – utilizing the website in Recommendation 7 for communication and dissemination of information. Links to the existing

DSHS hemophilia assistance program web site would be available on the proposed “one-stop” access web site. To enhance the effectiveness of the task force, membership will be structured to include individuals and organizations across Texas who specialize in the treatment and support of individuals with bleeding/clotting disorders.

## Appendix A

### PERSONAL STORIES

*Mary Evelyn S., 26, Houston, Texas*  
Living with Factor V Leiden

Experiencing difficulties breathing, I went to my university's infirmary to have my problem diagnosed and to receive treatment. I was misdiagnosed with bronchial spasms and made frequent return visits for continuing health problems.

Less than a year later I was admitted to a hospital critical care unit with *multiple pulmonary embolisms* (blood clots in the lungs), and eventually diagnosed with having a form of thrombophilia, factor V Leiden, the "most common hereditary blood coagulation disorder in the United States" ([www.factorvleiden.org](http://www.factorvleiden.org)). This situation could have been fatal.

After release from the hospital, I was placed on a standard six-month treatment of Coumadin, a blood thinner. Because diet and other medications can alter the blood's viscosity, I had to go to a clinic as many as three times per month to monitor the thinness of my blood and possibly change the dose of my medication as needed. I was grateful to live near a clinic that operated for the sole purpose of monitoring patients on Coumadin and understood my need for accurate results in a timely manner. Many persons living with factor V Leiden must remain on Coumadin for life, but because of my particular genetic make-up, I have not had a reoccurring episode, and am able to go without blood thinners except during long trips.

In addition to the psychological stresses of having thrombophilia, a history of pulmonary emboli, and frequent problems breathing, it is often difficult finding a physician who is aware of factor V Leiden and the special medical treatment for persons who are carriers of the genetic mutation. It is vital that as a person living with this disorder, I stay updated on the latest news of my blood disorder, so that I may educate my physician and not take a medication that could be potentially harmful.

*Jorge, 13, Texas*  
Living with severe Hemophilia A

My son, Jorge, is 13 and has severe hemophilia A. This means that his blood does not clot and he is prone to have bleeding episodes in his joints, muscles, and internal organs. He must administer a medication called factor intravenously three times a week to prevent bleeds. His factor cost over \$250,000 a year. Although we are very grateful to have this medication it is not a cure. He still has bleeds because it is only active in his body for about 18 hours and we have a maximum on our insurance of \$5 million. To most people this would seem like adequate coverage but the amount of factor my son uses is dependent upon his weight. We anticipate that he will be out of coverage by the time he is 20. Our son, and others like him, have many challenges. The Texas Bleeding Disorders Advisory Council is an opportunity to have a voice and begin to address the needs of this community.

*Susan C. Z. RN CPN, Fort Worth Texas*

Nurse to patients living with severe Hemophilia A

I care for a Hispanic family with two boys who have severe Hemophilia A. They both also have inhibitors to factor VIII, resulting in extremely expensive treatment methods. The youngest boy qualifies for Medicaid and the older boy, VL, (age 10) receives services through the Children with Special Health Care Needs (CSHCN) Services Program, but thank goodness we have that available. VL is still an active, normal ten year old, except for arthropathy in one knee. Though he limps and cannot straiten his leg fully (damage from repeated internal bleeding into the joint), he plays and goes to school with his siblings.

Without the expensive intravenous treatment of the bypassing factors, which the mother provides at home for both boys, these brothers would be severely crippled, unable to walk or even be out of a wheelchair. I have seen patients in other centers who have not been given aggressive therapy and I have seen inhibitor patients in developing countries where there is no treatment and amputation is the only answer for repeated joint problems. It is not a good future, but it would be their future if we couldn't give them health care.

We have tried to eliminate the inhibitors, but immune tolerance has not worked for either brother, so we continue with our current treatment. At least they run, they play and they still have a future.

*Samuell P.*

My name is Samuell and I have lived with severe Hemophilia A all of my life. As a young boy growing up I was dependant on my parents more so than most young boys. I depended on them to be able to acquire my medication. Their lives were dedicated to all six children, but more so at times to my younger brother and me who both have severe Hemophilia A. Their job choices were not always based on best pay, but usually on quality of insurance coverage for our medication. We often moved to chase the next opportunity to keep our medication coming with the help of the next job and insurance. Being disabled at a young age was hard enough, but having to make new friends every couple of years is even harder. The frequent changes you have to go through to emotionally survive a disability that is magnified without medication are not always socially beneficial.

There were periods of time while growing up that my parents did all they could for me and still came up short on funds to cover medications and medical services. Thankfully a friendly hand stepped in a times and eased the burden. Often we never saw that hand that helped. During periods of low medication supply, I often would be bed-bound or wheel chair-bound for days or weeks. The limited human interaction greatly lowered my self-esteem, and helped to create limited social interaction skills. These skills I had to learn later in life in order to catch up with my peers.

As a young adult I went on Medicaid as a disabled individual, not because of Hemophilia, per se, but because of the lack of medication as a young boy. My joints became so damaged due to severe bleeding, that I was, and still am, classified as disabled. I went to college and attempted to earn a degree to better myself. After college I obtained a job with a major corporation but

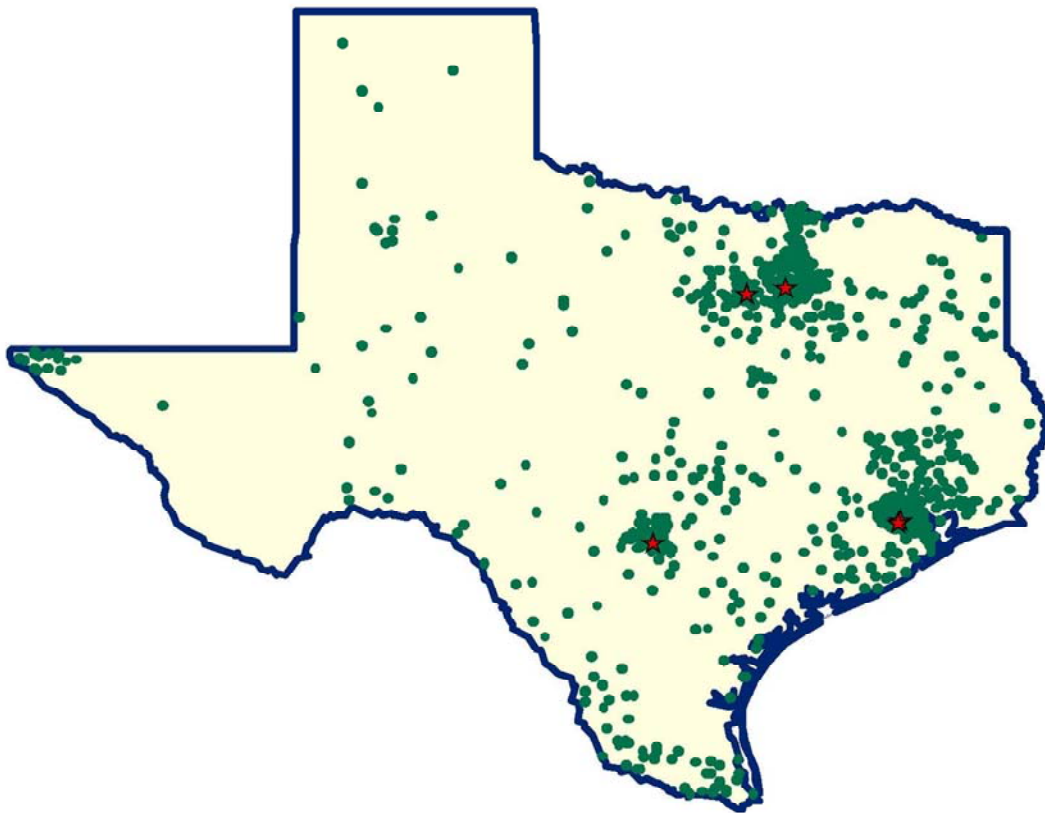
could not receive their insurance coverage even after a year-long waiting period. During those three years while I was earning “substantial” income, I lost my disability SSI and Medicaid. I lost my link to adequate medical care. I had to accept batches of factor from a local hospital in order to obtain any medication. I often went without my medicine and had to miss work. My health deteriorated to a point that I could not work. I took a medical leave from work and soon found myself in the hospital due to other health complications. The day I checked in, I received a letter from my provider letting me know I was dropped from coverage.

In the years since, I have qualified for disability coverage (and waited the mandatory two years for coverage to begin), gone to college, married and started a family. I have a good job with people who are willing to work around my disability. But I cannot have and enjoy all the things so many others take for granted if I do not have the medical coverage that provides full and adequate care for my needs as a hemophiliac. My joints will eventually be useless and damaged without factor and physical therapy.

Years ago, my grandfather worked and lived with hemophilia just as I do today. He was in his early thirties, when he sustained a blow to the stomach while working. He died because back then there was no support for Hemophilia when he needed it. Today, I and others like me need that support more than ever. I want to see my grandkids one day and be able to tell them about life. I don't want my grandkids wondering who I was, and why I did not survive to old age when the government had the power to act and save my life.

**Appendix B:  
UDC Maps**

**Federally Funded  
Texas Hemophilia Treatment Centers (HTC)  
UDC Males with Hemophilia\***



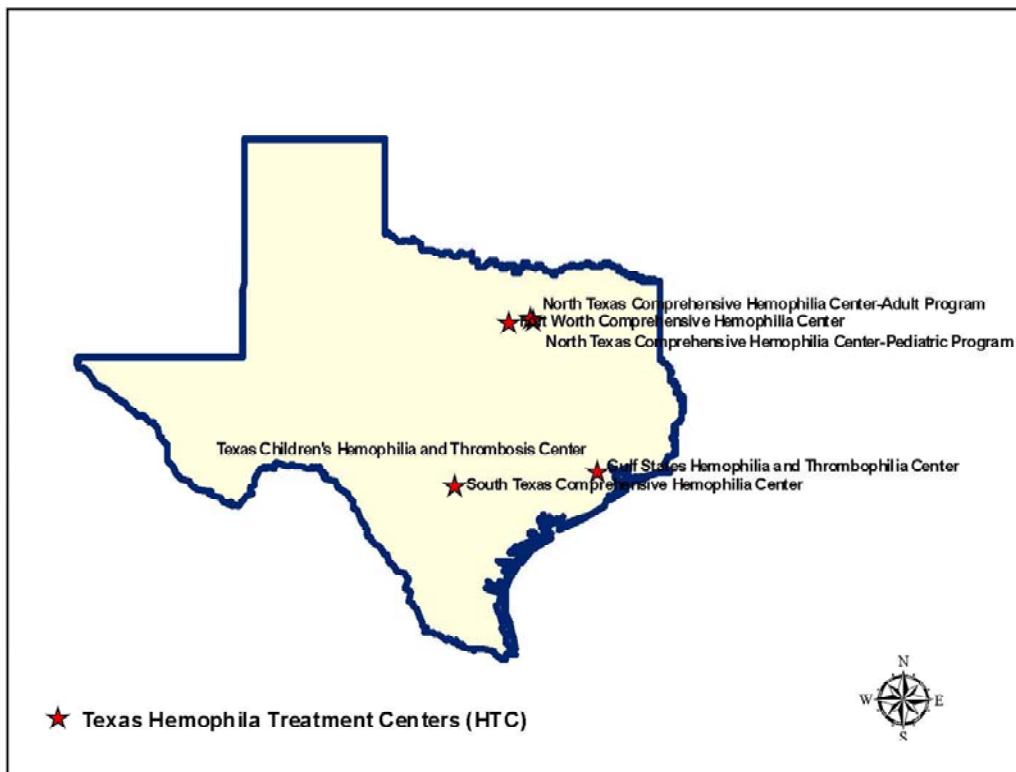
★ Texas Hemophilia Treatment Centers (HTC)

1 dot = UDC male with hemophilia  
Dots random within 3-digit zip code area



Source: 2007 Universal Data Collection (UDC) Data\*  
Division of Blood Disorders (DBD) NCBDDD CDC

# Federally Funded Texas Hemophilia Treatment Centers (HTC)



Source: 2007 Universal Data Collection (UDC) Data\*  
Division of Blood Disorders (DBD) NCBDDD CDC

## Appendix C

### Data and Analysis (Methods; Prevalence data; Hospitalization data)

#### Methods

In 1998, the CDC developed the Universal Data Collection Program (UDC) to monitor the occurrence of potential risk factors for infectious diseases and joint complications among the population with bleeding disorders. Patient-level data gathered at HTC are transmitted to the CDC for the UDC program. As such, the HTCs effectively function as sentinel sites for passive surveillance and the UDC program as a type of surveillance system for hemophilia and other bleeding disorders.

DSHS obtained data on the prevalence of bleeding disorders in Texas from the coordinator of the HTCs in the Health Resource and Services Administration (HRSA) Region VI, which includes the states of Arkansas, Louisiana, New Mexico, Oklahoma, and Texas.

To supplement the information on patients with hemophilia and other bleeding disorders collected from the HTCs and to obtain some information on patients with clotting disorders, Texas hospital discharge data was also analyzed.

The Texas Health Care Information Council (THCIC) was created by the 74th Texas Legislature in 1995. According to Chapter 108 of the Texas Health and Safety Code (THSC), Sections 108.011 through 108.0135, the THCIC is responsible for collecting hospital discharge data from all state licensed hospitals except those that are statutorily exempt from the reporting requirements.<sup>1</sup> THCIC became part of the Texas Department of State Health Services (DSHS) effective September 1, 2004 and DSHS is now responsible for the collection and release of hospital discharge data. Sections 108.011(a) and 108.012 of the THSC require THCIC to provide public use data. The Texas Hospital Discharge Data Public Use Data File (PUDF) contains data on inpatient hospital stays in Texas hospitals. Data from 2004, 2005, and 2006 PUDF files were used in these analyses.

The hospital discharge data were culled for information on patients with hemophilia and other bleeding or clotting disorders who were Texas residents and had been hospitalized anytime during 2004-2006.

The two outcomes of interest were hemophilia and other bleeding disorders (defined as any hospital discharge with any one or more of the following ICD-9 codes: 286.0, 286.1, 286.2, 286.3 286.4) and thrombophilia or clotting disorders (defined as any discharge with ICD-9 code 289.81). All fields where an ICD-9 code could be recorded (admitting diagnosis, principal

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<sup>1</sup> Exempt hospitals include those located in a county with a population less than 35,000 or those located in a county with a population more than 35,000 and fewer than 100 licensed hospital beds and not located in an area that is delineated as an urbanized area by the United States Bureau of the Census (Section 108.0025). Exempt hospitals also include hospitals that do not seek insurance payment or government reimbursement (Section 108.009).

diagnosis, and any of 24 additional diagnosis codes) were searched for the presence of codes for either outcome of interest.

The International Statistical Classification of Diseases and Related Health Problems (most commonly known by the abbreviation ICD) provides codes to classify diseases and a wide variety of signs, symptoms, abnormal findings, complaints, social circumstances and external causes of injury or disease. Every health condition can be assigned to a unique category and given a code, up to six characters long.

For the purposes of this analysis, the following ICD-9 codes were used:

### **Hemophilia and other bleeding disorders**

- (286) Coagulation defects
  - (286.0) Congenital factor VIII disorder (Hemophilia A)
  - (286.1) Congenital factor IX disorder (Hemophilia B)
  - (286.2) Congenital factor XI deficiency
  - (286.3) Congenital deficiency of other clotting factors
  - (286.4) von Willebrand's disease

### **Thrombophilia or clotting disorders**

- (289.81) Primary hypercoagulable state

### **Prevalence**

#### **Texas: Hemophilia and other bleeding disorders**

In 2006, 1,148 patients with hemophilia or other bleeding disorders were seen at HTC's in Texas. Of these, 638 (56%) had a diagnosis of hemophilia A, 166 (14%) hemophilia B, 294 (26%) vWD, and 50 (4%) other factor deficiencies. The majority of these cases were treated with home intravenous therapy or intranasal administration of Stimate® Nasal Spray (14).

One estimate of the prevalence of hemophilia or other bleeding disorders during the period from January 1, 2006 to December 31, 2006 is 5 cases per 100,000 population (1148/23,407,629) or 0.005% of the population in Texas (15). However, it is likely to be an underestimate for several reasons. First, a patient had to be seen anytime during 2006 at one of the federally funded HTC's to count as a case of hemophilia or other bleeding disorder. Therefore, this estimate is based on patients who were seen at least once a year in a HTC. Some patients with hemophilia or other bleeding disorders, especially patients with mild vWD, may visit a HTC less frequently, such as once every two to three years. Second, patients receiving outpatient care at a private medical provider's office and not at an HTC are not counted in this estimate. It is thought that about 60%–70% of the hemophilia population receives care in HTC's. One study found that approximately 67% of the hemophilia A and B cases identified in 1994 received care at an HTC during 1994 (16).

Further information on prevalence of hemophilia and other bleeding disorders among Texans, stratified by age, sex, and race is illustrated below.

Table 1: Hemophilia patients by type of hemophilia/bleeding disorder —Texas, 2006

	<b>Hemophilia A</b>	<b>Hemophilia B</b>	<b>vWD</b>	<b>Other Factor Deficiencies</b>	<b>Total</b>
<b>Number</b>	638	166	294	50	1148
<b>Percent</b>	56%	14%	26%	4%	100%

Table 2: Hemophilia patients by Age—Texas, 2006

<b>Age</b>	<b>Number</b>	<b>Percent</b>
0-17	778	68%
18-24	162	14%
25+	208	18%
<b>TOTAL</b>	<b>1148</b>	<b>100%</b>

### **U.S.: Hemophilia A & B**

An age-adjusted prevalence estimate of hemophilia in a six-state (Colorado, Georgia, Louisiana, Massachusetts, New York, and Oklahoma) surveillance area in 1994 was 13.4 cases/100,000 males (10.5 for hemophilia A and 2.9 for B) with a range of 12.8 to 13.7 (17). Although Texas was not one of the six states included in the surveillance, two of the six states (Oklahoma—13.0 and Louisiana-12.9) included in the surveillance are part of HRSA region 6, the region in which Texas is included. The age-adjusted and sex specific hemophilia prevalence rates in this six state hemophilia surveillance system (HSS) can be generalized to other states, including Texas.

The prevalence of hemophilia for the HSS was defined as the number of identified definitive and presumptive hemophilia cases residing in one of the six states in 1994 divided by the estimated male population in these states in 1994 and multiplied by 100,000 (cases per 100,000 males). In this surveillance system, a definitive hemophilia case was defined as an individual with physician-diagnosed hemophilia A or B and a baseline clotting factor activity level of  $\leq 30\%$ . A presumptive hemophilia case was defined as a person with either a physician diagnosis of hemophilia A or B or a measured factor VIII or IX activity level of  $\leq 30\%$  (18).

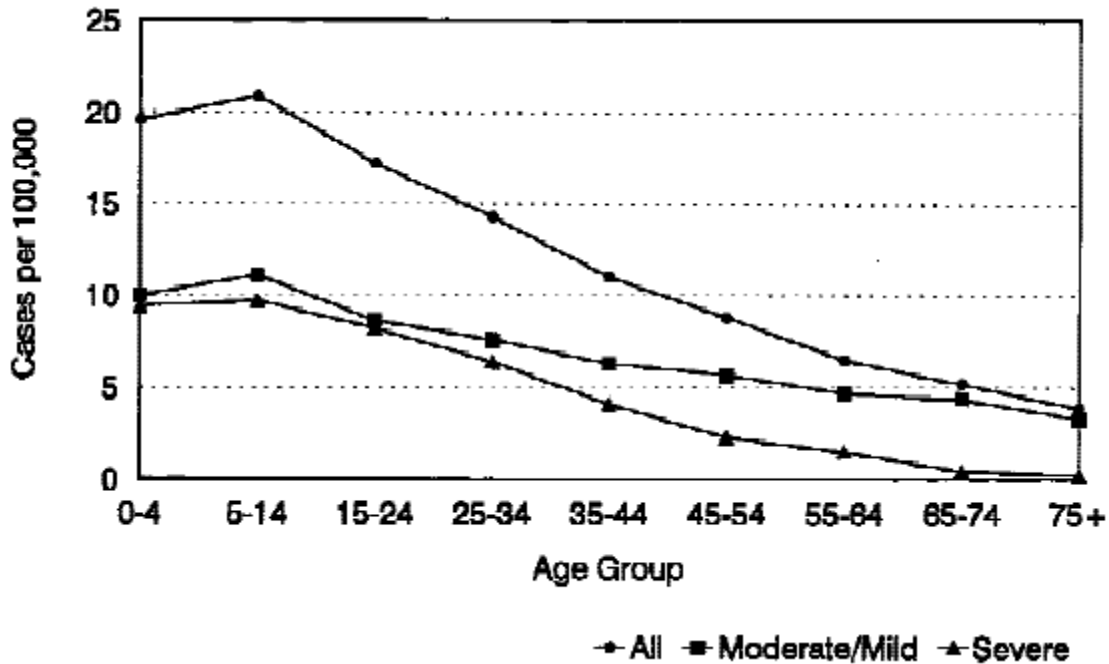


Figure 1. The age-specific prevalence of hemophilia A and B in six U.S. states in 1994 according to the severity level. Severity was assessed by factor activity and categorized as severe if < 1% and moderate/mild if 1% - 30% of normal (19).

The mean ( $\pm$ SD) age of all cases was 25.4 ( $\pm$ 18.4) years, and half of the population was younger than 23 years of age. Compared with the overall U.S. male population, the hemophilia population had a much greater proportion of males younger than 25 years. The HSS also found that the prevalence of hemophilia was highest for younger males and declined steadily with increasing age from a high of 20.9 cases/100,000 for 5-14 year old males to a low of 3.9 cases/100,000 for males 75 years of age and older. The lower prevalence observed in the youngest males 1-4 years of age, as compared with 5-14 year olds is likely a result of delayed diagnosis of milder cases. The lower prevalence among older populations is likely due to higher rates of mortality from hemophilia in the past due to lack of effective treatment, as well as the HIV and hepatitis introduced through the use of plasma-derived factor concentrates (20).

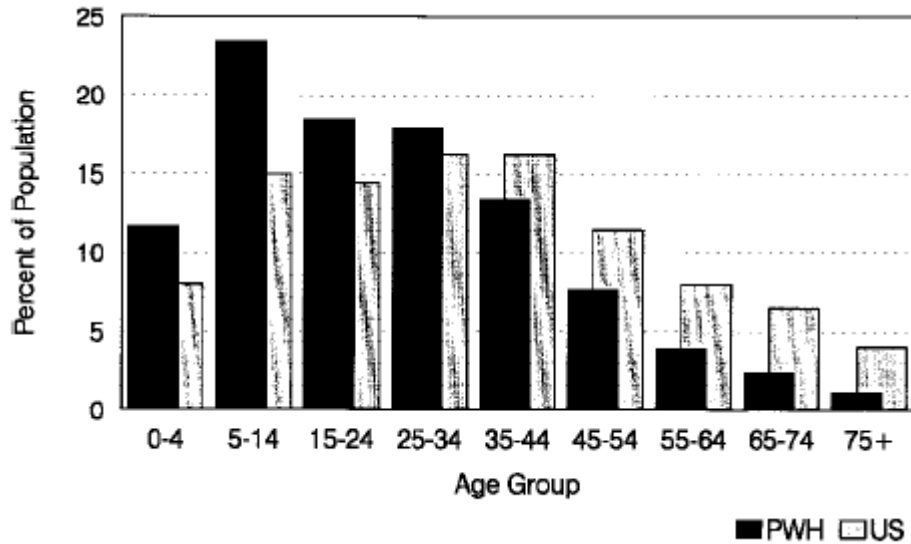


Figure 2. Distribution by age of male population for persons with hemophilia (PWH) and for residents of the United States (US) in 1994 (21).

Race/ethnicity-specific prevalences were 13.2 cases/100,000 among white males, 11.0 among African American males, and 11.5 among Hispanic males. For the 10-year period 1982–1991, the average incidence of hemophilia A and B in the six hemophilia surveillance system (HSS) states was estimated to be 1 in 5,032 live male births (22).

### von Willebrand disease (vWD) and other bleeding disorders

Prevalence estimates for vWD and other bleeding disorders are harder to define. Although vWD is far more common than hemophilia, since it is less severe it may often go undetected and hence untreated. The best estimate of prevalence of laboratory-confirmed vWD is 1%-2% of the general population (23). This would put the number of cases in Texas between 239,000 and 478,000 in 2007 (24). While only a proportion of patients with laboratory-confirmed vWD will have clinically significant vWD, this number is harder to define (25).

### Hospitalizations

Although treatment for hemophilia is generally provided on an outpatient basis, complications resulting from hemophilia, which usually are related to the joints, may be cause for hospital admission. In addition, hemophilia and other bleeding or clotting disorders may be present and diagnosed as co-morbid conditions during the hospitalization of a patient for another illness or condition. As such, the number of hospital admissions with a diagnosis of hemophilia or other bleeding or clotting disorders that are presented are just that and not the number of hospital admissions due to hemophilia/other bleeding and clotting disorders. It should be noted, however, that the number of hospital admissions due to hemophilia/other bleeding & clotting disorders (as an admitting or principal diagnosis) are included in the total count of admissions.

In 2006, a diagnosis of hemophilia or other bleeding disorder was present for 372 or 12.8/100,000 hospital admissions among Texas residents.

Table 1: Hospital admissions for hemophilia and other bleeding and clotting disorders—Texas, 2004-2006

Year	Condition			
	Hemophilia & other bleeding disorders <sup>a</sup>		Thrombophilia/other clotting disorders <sup>b</sup>	
	Number	Rate*	Number	Rate*
2004	138	4.9	44	1.6
2005	139	4.9	49	1.7
2006	126	4.3	65	2.2
All 3 years	403	4.7	158	1.8

<sup>a</sup> defined as an admission with any of the following ICD-9 codes as the admitting diagnosis, principal diagnosis or one of 24 additional diagnoses codes: 286.0, 286.1, 286.2, 286.3, 286.4  
<sup>b</sup> defined as an admission with ICD-9 code 289.81 as the admitting diagnosis, principal diagnosis or one of 24 additional diagnoses codes  
\* Rate per 100,000 hospital admissions

## Age

While half (range 46%-54%) of the hospital admissions due to hemophilia or other bleeding disorders were for patients over 65 years of age, there is more variation in the age distribution of hospitalized patients with clotting disorders. These data are represented in Tables 2 and 3.

Table 2: Hospital admissions for hemophilia and other bleeding disorders<sup>a</sup>, by age—Texas, 2004-2006

Age	2004		2005		2006		All 3 years	
	#	Percent	#	Percent	#	Percent	#	Percent
<18	77	56%	61	44%	54	43%	192	48%
18+	61	44%	78	56%	72	57%	211	52%
<b>Total</b>	138	100%	139	100%	126	100%	403	100%

<sup>a</sup> defined as an admission with any of the following ICD-9 codes as the admitting diagnosis, principal diagnosis or one of 24 additional diagnoses codes: 286.0, 286.1, 286.2, 286.3, 286.4

Table 3: Hospital admissions for thrombophilia/clotting disorders<sup>a</sup>, by age—Texas, 2004-2006

Age	2004		2005		2006		All 3 years	
	#	Percent	#	Percent	#	Percent	#	Percent
<18	6	14%	3	6%	4	6%	13	8%
18+	38	86%	46	94%	61	94%	145	92%
<b>Total</b>	44	100%	49	100%	65	100%	158	100%

<sup>a</sup> defined as an admission with ICD-9 code 289.81 as the admitting diagnosis, principal diagnosis or one of 24 additional diagnoses codes

## Race

For both conditions queried, most cases were White. Race data were missing for all hospital discharges in 2005. Further investigation found that while race information is missing for all 2005 cases identified, it is missing for only 0.2% of all 2005 hospital discharge records. Race is changed to "Other" and ethnicity is suppressed if a hospital has fewer than ten discharges of a race protect patient identities. Therefore, it is possible that these discharges with no race information were from small hospitals with few discharges.

## Primary Payer

Medicare was the primary payer for hospitalizations related to hemophilia and other bleeding disorders. While there was variation between the years 2004 to 2006 regarding the primary payer for thrombophilia/clotting disorders, private health insurance comprised a large portion. Distribution of primary payer is shown in Tables 4 and 5.

*Table 4: Hospital admissions for hemophilia and other bleeding disorders<sup>a</sup>, by primary payer—Texas, 2004-2006*

Primary Payer	2004		2005		2006		All 3 years	
	#	Percent	#	Percent	#	Percent	#	Percent
<b>Medicare</b>	27	20%	31	22%	20	16%	78	19%
<b>Medicaid</b>	57	41%	51	37%	42	33%	150	37%
<b>Private</b>	40	29%	35	25%	41	33%	116	29%
<b>Other</b>	14	10%	22	16%	23	18%	59	15%
<b>Total</b>	138	100%	139	100%	126	100%	403	100%

<sup>a</sup> defined as an admission with any of the following ICD-9 codes as the admitting diagnosis, principal diagnosis or one of 24 additional diagnoses codes: 286.0, 286.1, 286.2, 286.3, 286.4

*Table 5: Hospital admissions for thrombophilia/clotting disorders<sup>a</sup>, by primary payer—Texas, 2004-2006*

Primary Payer	2004		2005		2006		All 3 years	
	#	Percent	#	Percent	#	Percent	#	Percent
<b>Medicare</b>	13	30%	19	39%	29	45%	61	39%
<b>Private</b>	8	18%	5	10%	10	15%	23	15%
<b>Medicaid</b>	10	23%	16	33%	14	22%	40	25%
<b>Other</b>	13	30%	9	18%	12	18%	34	22%
<b>Total</b>	44	100%	49	100%	65	100%	158	100%

<sup>a</sup> defined as an admission with ICD-9 code 289.81 as the admitting diagnosis, principal diagnosis or one of 24 additional diagnoses codes

## Hospitalization Costs

While data on the cost of hospitalizations is not available and because hospitals provide data regarding the amount they charge and hence bill for services, charge data can be used as a proxy for hospitalization costs. Hospital-specific cost-to-charge ratios are routinely calculated for health services research, but obtaining and analyzing such detailed information is beyond the scope of this report. As such, since costs remain a relatively stable proportion of charges at an aggregate level, total charges will be used as a proxy for the total cost of services provided.

Tables 6 and 7 show median hospital charges by age for the years 2004-2006 for the conditions of interest. Since the distribution of cost/charges data is typically skewed and contains outliers, it is more meaningful to present median charges as opposed to mean amounts.

*Table 6: Median charges by age, for hospitalizations with hemophilia and other bleeding disorders<sup>a</sup>—Texas, 2004-2006*

Age	2004	2005	2006	All 3 years
0-17	\$35,542	\$63,361	\$64,550	\$58,449
18+	\$45,602	\$24,565	\$50,456	\$39,262
<b>Total</b>	\$42,236	\$35,713	\$61,314	\$45,905

<sup>a</sup> defined as an admission with any of the following ICD-9 codes as the admitting diagnosis, principal diagnosis or one of 24 additional diagnoses codes: 286.0, 286.1, 286.2, 286.3, 286.4

*Table 7: Median charges by age, for hospitalizations with thrombophilia/clotting disorders<sup>a</sup>—Texas, 2004-2006*

Age	2004	2005	2006	All 3 years
0-17	\$20,438	\$13,252	\$7,509	\$13,647
18+	\$11,412	\$20,757	\$14,279	\$15,299
<b>Total</b>	\$12,792	\$19,653	\$13,672	\$14,521

<sup>a</sup> defined as an admission with ICD-9 code 289.81 as the admitting diagnosis, principal diagnosis or one of 24 additional diagnoses codes

## Data Limitations

While data from the Hemophilia Treatment Centers represent patients in Texas with hemophilia and other bleeding disorders; however, it is important to note that the hospital discharge data represent individual inpatient hospital admissions and not individual patients. Each hospitalization counts as a separate record. Therefore, a single individual who has had multiple hospitalizations would result in multiple records. At this time, it is not possible to estimate how many individual patients the hospitalization discharge records represent. Another limitation is that federal hospitals and smaller, rural hospitals are exempted from the reporting requirements. Therefore, not all hospitals in Texas are included in the data.

**Appendix D:**

<b>Texas Bleeding Disorders Advisory Council</b>			
<b>Member Name</b>	<b>City</b>	<b>Council Position</b>	<b>Voting/ Non-Voting</b>
Michael Rash (Chair)	Kingwood	Person/Caregiver of person with bleeding disorder other than hemophilia	Voting
Cynthia J. Rutherford, M.D (Co-Chair)	Dallas	Representative of a hemophilia treatment center	Voting
Patricia Amerson	San Antonio	Nurse	Voting
Elizabeth Bailey	Waller	Person/Caregiver of person with clotting disorder	Voting
George Buchanan, M.D.	Dallas	Physician	Voting
Shannon Carpenter, M.D.	San Antonio	Representative of a hemophilia treatment center	Voting
Katrina Daniel	Austin	Texas Department of Insurance Commissioner's designee	Non-Voting
Debbie de la Riva, M. Ed.	Houston	Person experienced in diagnosis, treatment, care, and support of persons with bleeding disorder	Non-Voting
Michael Farnell	Dallas	Representative of a volunteer/non-profit organization	Voting
Charles Garcia	Dallas	Person/Caregiver of person with hemophilia or other bleeding disorder	Non-Voting
Brendan Hayes	Plano	Person/Caregiver of person with hemophilia or other bleeding disorder	Non-Voting
Becky Brownlee	Austin	Department of State Health Services Commissioner's designee	Non-Voting
Katherine Lipsky, LCSW, ACSW	Dallas	Social Worker	Voting
Mark Netoskie, M.D.	Houston	Representative of a health insurer or other benefit plan	Voting
Mary Evelyn Schuwerk, MPH	Houston	Person/Caregiver of person with hemophilia or other bleeding disorder	Non-Voting
Maria Yu	El Paso	Person or caregiver of a person with hemophilia	Voting
Susan Zappa	Fort Worth	Person experienced in diagnosis, treatment, care, and support of persons with bleeding disorder	Non-Voting

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