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Annual Mandate Report: Coverage for the Treatment of Bleeding Disorders

Prepared for the Maryland Health Care Commission
Pursuant to Insurance Article 15-1501
Annotated Code of Maryland

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Introduction

Insurance Article, § 15-1501, Annotated Code of Maryland, requires that the Maryland Health Care Commission (Commission) annually assess the medical, social and financial impact of proposed mandated health insurance services that fail passage during the preceding legislative session or that are submitted to the Commission by a Legislator by July 1st of each year. The assessment reports are due to the General Assembly annually by December 31st.

Mercer and its sibling company, Oliver Wyman Actuarial Consulting, Inc., have been contracted as the Commission's consulting actuary. We have prepared an evaluation for the single proposed newly mandated benefit: coverage for the treatment of bleeding disorders.

Patient Protection and Affordable Care Act

On March 23, 2010, President Obama signed the Patient Protection and Affordable Care Act (PPACA), which incorporates significant reforms in the commercial (i.e., non-Medicare and non-Medicaid) market. PPACA requires several benefit reforms to be effective on the first anniversary/renewal occurring on or after September 23, 2010 including:

- Extending coverage for adult children to age 26
- Elimination of lifetime maximums for essential benefits
- Phase in of elimination of annual maximums for essential benefits
- Guarantee issue to children <19 years of age
- Prohibition of policy rescissions in most cases
- Elimination of cost sharing for certain preventive services
- Requiring same cost sharing for emergency services in a non-network facility
- Participant's flexibility to choose providers in plans assigning or designation primary care physicians
- Women's preventative services scheduled to be effective August 2012

Beginning with calendar year 2011, PPACA requires minimum loss ratios of 80% for each insurer's non-group block of business; 80% for each insurer's small group block of business; and 85% for each insurer's large group block of business.

The major insurance reforms under PPACA are effective in 2014, including guarantee issue for all entrants; elimination of medical underwriting; elimination of most rating factors; creation of exchanges for non-group and small group policies; expansion of Medicaid eligibility; availability of premium subsidies for individuals purchasing non-

group insurance through the exchange, among others. The benefit plans to be offered through the exchanges will be based upon "essential health benefits" as defined by HHS.[1.]

In a study completed by the Institute of Medicine (IOM) at the request of the Secretary of HHS, the IOM recommended that the essential health benefits package should be based on the typical small employer benefit plan (as opposed to the "typical employer benefit" plan verbiage in the ACA) and that current mandated benefits not be given preferential treatment for inclusion in the ultimate essential health benefit plan (EHB). Legislators need to consider the possibility that, beginning in 2014, the State will bear the cost of any enacted mandates that have not been included in the essential benefits package. Based on information provided by carriers in Maryland, coverage for bleeding disorders is typically covered in the small group market. However, this does not imply coverage for bleeding disorders will be included in the EHB, as coverage nationally may vary.

This report includes information from several sources to provide more than one perspective on each proposed mandate. Mercer's intent is to be unbiased. At times, as a result, the report contains conflicting information. Although we included only sources that we consider credible, we do not state that one source is more credible than another. The reader is advised to weigh the evidence.

[1] HHS has not yet defined "essential benefits."

Coverage for the Treatment of Bleeding Disorders

Senate Bill 879/House Bill 949 of 2011 requires insurers to provide coverage for all medically necessary and appropriate pharmacy care, home nursing services, treatment at a hemophilia treatment center, and clinical laboratory services that an insured's or enrollee's treating physician determines are necessary to prevent, diagnose, or treat a bleeding disorder. The bill applies to all policies, contracts, and health benefit plans issued, delivered, or renewed in Maryland on or after its effective date.

People with bleeding disorders have problems forming blood clots and may experience prolonged bleeding that is hard to stop. Hemostasis, the body process that stops bleeding, involves three steps: (1) blood vessels constrict (vasoconstriction), (2) platelets form to create a plug at the site of the injury, and (3) clotting factors finish the process. If any of these fail, the body does not make a proper blood clot, and prolonged bleeding results.[2]

The term *hemophilia* may be used in a general sense to describe various bleeding disorders, or in a specific sense to describe a subset of those disorders. (In this paper, we will use the more specific definition of hemophilia and use *bleeding disorders* as the general term).

Bleeding disorders include (1) Hemophilia A, (2) Hemophilia B, (3) von Willebrand's disease, and (4) other clotting disorders.[3] Most bleeding disorders are inherited and result from a low level of proteins needed for normal blood clotting.[4]

Many people use the term *bleeding disorders* to describe only those that are hereditary. (It is unclear which interpretation was intended in the proposed bill). Hemophilia A, caused by deficiency of clotting factor VIII, and Hemophilia B, attributed to a lack or deficiency of factor IX, affect primarily males. Von Willebrand's disease affects both males and females. Hemophilia (A and B) and von Willebrand's disease, the most well-known bleeding disorders, do not appear to discriminate on the basis of race, ethnicity, or economic level.[5] Von Willebrand's disease is the most prevalent blood disorder in the United States, affecting 1 to 2 percent of the population.[6] Although precise numbers are not known, approximately 20,000 males in the US are thought to be living with

[2] Bettermedicine.com. "Bleeding Disorders." www.bettermedicine.com/article/bleeding-disorders-1. Accessed July 2011.

[3] Bleeding Disorder Foundation of Washington. "About Hemophilia." www.scn.org/health/hrw/abouthemo.htm. Accessed July 2011.

[4] National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention. "Hemophilia." www.cdc.gov/ncbddd/hemophilia/data.html. Accessed July 2011.

[5] Bleeding Disorder Foundation of Washington. "About Hemophilia."

[6] Bettermedicine.com. "Bleeding Disorders."

Hemophilia A or B. About 400 babies are born with hemophilia each year.[7] Hemophilia A is about 3.5 times more common than Hemophilia B.[8]

To determine whether a patient has Hemophilia A, Hemophilia B, or another bleeding disorder, a physician typically draws blood for laboratory analysis.[9] Cases are classified as either mild, moderate, or severe. To illustrate, in the general population, the clotting factor in the blood can range from 50 percent to 200 percent of normal. People with mild bleeding disorders have clotting factor levels that are 5 to 50 percent of normal, while people with moderate bleeding disorders have levels of 1 to 5 percent, and people with severe bleeding disorders have levels under 1 percent.[10] All hemophilia patients can experience massive bleeding from major trauma or during surgery, but people with severe hemophilia can also experience spontaneous bleeds in joints and muscles.[11]

About half of all hemophilia patients fall into the severe category. In 2008, the Centers for Disease Control estimated that 54 percent of Hemophilia A cases were severe, 19 percent were moderate, and 27 percent were mild.[12] Similarly, 36 percent of Hemophilia B cases were classified as severe, 37 percent moderate, and 27 percent mild.[13]

Contrary to popular belief, people with hemophilia do not bleed to death from minor external wounds. Minor cuts are treated easily, just as for people without hemophilia. People with hemophilia do not bleed faster than others, but they may bleed longer. The major risk is uncontrolled *internal* bleeding, which can begin spontaneously. If not stanched quickly, internal bleeding can cause pain and swelling. Over time, it can lead to permanent joint and muscle damage and chronic pain.[14] Untreated or undertreated bleeding disorders can lead to serious, potentially life threatening complications. [15]

The states of New Jersey and Virginia currently mandate coverage for congenital blood disorders.[16] New Jersey's mandate, adopted in 1987, identifies certain services that must be covered if a plan covers "treatment of routine bleeding episodes associated with

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[7] Centers for Disease Control and Prevention. "Hemophilia, Data and Statistics." www.cdc.gov/ncbddd/data.html. Accessed July 2011.

[8] Blankenship, C.S., PharmD. "To Manage Costs of Hemophilia, Patients Need More Than Clotting Factor." Biotechnology Healthcare. November/December 2008.

[9] Bettermedicine.com. "Bleeding Disorders: Treatments." www.bettermedicine.com/article/bleeding-disorders-1/treatments. Accessed July 2011.

[10] Blankenship, C.S., PharmD.

[11] Ibid.

[12] Ibid.

[13] Ibid.

[14] Bleeding Disorder Foundation of Washington. "About Hemophilia."

[15] Bettermedicine.com. "Bleeding Disorders: Treatments."

[16] Bunce, V.C. and Wieske, J.P. "Health Insurance Mandates in the States 2010." Council for Affordable Health Insurance. Alexandria, VA. Accessed August 2011.

hemophilia." Specifically it calls for the coverage of expenses incurred in connection with the purchase of blood products, including "Factor VIII, Factor IX, and cryoprecipitate," and all blood infusion equipment required for home treatment of routine bleeding episodes when the program is under the supervision of a New Jersey approved hemophilia treatment center.[17]

Virginia's mandate, adopted in 1998, is essentially the same as New Jersey's[18] and is similar to the proposed mandate for Maryland.

Medical Impact

In this section, we answer questions regarding hemophilia treatment.

- What are the risks from bleeding disorders?
- What are the appropriate standards of care for patients?
- How are expenses associated with bleeding disorders typically covered?

Untreated or poorly treated bleeding disorders can lead to serious complications that can be potentially life-threatening. Examples include:

- Anemia
- Bleeding in the brain (hemorrhaging)
- Deep internal bleeding
- Infection
- Neurological or psychiatric problems
- Scarring of joints, joint disease, etc.
- Severe blood loss
- Shock
- Vision loss [19]

Bleeding disorders cannot be cured but can be managed. Specific treatment depends on the specific disorder. Treatment may include:

- Medications to help prevent the normal breakdown of blood clots after they have formed
- Clotting factor to replace specific clotting factor
- Steroids to suppress the immune system in people who have developed antibodies that inhibit specific clotting factors
- Medications to temporarily increase factor VII clotting
- Immune therapies to suppress the immune system in those with acquired hemophilia

[17] New Jersey Statutes Annotated, 17B: 27-46.1c.

[18] Code of Virginia Annotated, § 38.2-3418.3.

[19] Bettermedicine.com. "Bleeding Disorders: Treatments."

- Plasma transfusions to supplement all clotting factors
- Platelet transfusions to increase the number of platelets in the bloodstream
- Vitamin supplements for disorders caused by vitamin K deficiency [20]

Medical advances in the 1960s greatly improved the ability to manage bleeding disorders. In 1965, scientists developed a process for removing clotting factor from whole blood and then freezing it for future use. Frozen clotting factor and a powdered concentrate made treating hemophilia fairly routine.[21]

During the 1980s, treatment regimens that relied heavily on clotting factor manufactured from human blood introduced a separate set of risks. At that time, this factor had inadequate viral inactivation and, as a result, was sometimes contaminated with blood borne infections such as HIV or Hepatitis C.[22] Because of these considerations, the life expectancy of the hemophilia patient was as low as age 35[23] and, as recently as 2008, only one in seven hemophilia patients survived until age 45 or older.[24] With the subsequent development of clotting factors that were subject to extensive purification and viral inactivation, people with hemophilia today have a life expectancy close to that of a healthy adult.[25] In 2000, the life expectancy for a person born with a bleeding disorder was over 64 years – within a decade of the life expectancy of the overall population.[26] Although mortality risks have declined, the disability risk is still relatively high because of the disease's effect on muscles and joints.[27]

Disease experts advocate a multidisciplinary approach to better manage treatment costs and care. The Medical and Scientific Advisory Council of the National Hemophilia Foundation (MASAC) outlines standards of care for people with *congenital* bleeding disorders. The most recent revision is dated April 2002, although MASAC has released a number of advisories since then.[28]

One part of the proposed mandate calls for coverage of services provided in hemophilia treatment centers (HTCs). According to MASAC, the cornerstone for effective

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[20] Ibid.

[21] Bleeding Disorder Foundation of Washington. "About Hemophilia."

[22] Blankenship, C.S., PharmD.

[23] Soucie, J.M., Nuss, R., Evatt, B., Abdelhak, A., Cowan, L., Hill, H., Kolakoski, M., Wilber, N., and the Hemophilia Surveillance System Project Investigators. "Mortality among Males with Hemophilia: Relations with Source of Medical Care." Blood. www.bloodjournal.hemotologylibrary.org/content/96/2/437.full. March 2000.

[24] Blankenship, C.S., PharmD.

[25] Bleeding Disorder Foundation of Washington. "About Hemophilia."

[26] Soucie, J.M., et al.

[27] Blankenship, C.S., PharmD.

[28] Medical and Scientific Advisory Council of the National Hemophilia Foundation (MASAC). "Standards and Criteria for the Care of Persons with Congenital Bleeding Disorders". National Hemophilia Foundation. New York, NY. April 2002.

hemophilia treatment is the HTC, part of a nationwide network of diagnostic and treatment facilities for people with bleeding disorders.[29] Today, there are approximately 140 such centers, including one in Maryland at the Johns Hopkins University Medical Center.[30] About 70 percent of hemophilia patients in the US receive treatment at these centers. (Almost 15 percent receive care from private physicians, 4 percent from clinics, 8 percent in hospitals and emergency rooms, and the balance from other sources.)[31] Mortality and hospitalization rates are 40 percent lower among hemophilia patients who receive care in HTCs than for those who do not.[32]

MASAC recommends an integrated, multidisciplinary, comprehensive care approach focused on the treatment center. The recommended core team includes:

- a program coordinator, responsible for program development, oversight, etc.
- a hemophilia nurse coordinator, responsible for nursing assessment of health, providing patient/family education, coordinating and evaluating home therapy programs, developing and coordinating the patient plan of care, etc.
- a medical director, who makes medical decisions concerning patient care
- a physical therapist, responsible for assessing musculoskeletal and functional status, developing educational and exercise programs, etc.
- a psychosocial professional (e.g., a licensed social worker), responsible for psychosocial assessments, supportive counseling, health education, counseling source referrals, etc.
- a case manager (who may be one of the other team members), responsible for ensuring that resources are used in a timely and cost-effective manner[33]

Each team member is committed to providing professional, personal care to the individual patient. Other professionals may be called upon as appropriate.[34]

The team provides services to the patient (and members of his or her extended circle of family and friends) in four areas:

- Diagnostics and therapeutics
- Outreach and education
- Communication
- Referrals

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[29] Ibid.

[30] Centers for Disease Control and Prevention. "Hemophilia Treatment Center (HTC) Directory – Facilities Results." www2a.cdc.gov/ncbddd/htcweb/Dir_Report/Dir_SearchOrg.asp?inactive_flag= Accessed August 2011.

[31] Soucie, J.M., et al.

[32] Ibid.

[33] MASAC.

[34] Ibid.

Diagnostics and therapeutics include a comprehensive evaluation (medical history, physical exam, therapeutics, a nursing exam, a physical therapy evaluation, a psychosocial evaluation, genetic counseling, a dental evaluation, periodic laboratory test, and services specifically related to women). Not all need to be provided on each visit. In addition, specialized services may be provided in cases involving HIV or hepatitis.

Outreach and education services are extended not only to the patient, but also to family members, community institutions (such as schools), employers, etc. Again, these services may become more involved where HIV or hepatitis is a factor.

Communication services optimize all communication activities among team members and patients, consultants, primary care physicians, and other community-based health workers.

Referrals are required when the patient requires specific expertise beyond that provided by the treatment center. Possible examples include surgery, orthopedics, special physical therapy/rehabilitation, genetics, psychology/psychiatry, and laboratory services, among others.[35]

The broad wording of the proposed bill appears to cover the cost of all these services as long as they are deemed medically necessary.

It is important to note that, with the possible exception of some limited benefit plans, medically necessary services for bleeding disorders are covered medical expenses, regardless of how they are delivered. Most services are covered as medical expenses. However, pharmaceuticals may be covered either as medical or prescription drug expenses, depending on the site of administration. (Medications administered in a hemophilia treatment center, doctor's office, or hospital are covered as medical expenses. Those administered at home are typically covered as prescription drug expenses).

Social Impact

In this section, we address the following questions:

- To what extent will the proposed mandate generally be utilized by a significant portion of the population?
- To what extent is the insurance coverage already available?
- To what extent does the lack of coverage cause people to avoid necessary health care treatments?
- To what extent does lack of coverage result in unreasonable financial hardship?
- What is the level of public demand for these services?
- To what extent is the mandated health insurance service covered by self-funded employers in the state with at least 500 employees?

[35] Ibid.

Table 1 shows the prevalence of various bleeding disorders:

Table 1

Disorder	Prevalence
Factor XI deficiency	2 – 4 percent of Ashkenazi Jews
von Willebrand's Disease	1 – 2 percent of the general population
Hemophilia A (factor VIII deficiency)	1:5,000 live male births
Hemophilia B (factor IX deficiency)	1:30,000 live births[36]

An estimated 4 to 8 million people in the US have been diagnosed with inherited bleeding disorders. This translates to about 10 to 20 in 1,000 based on a population estimate of 380,000,000.[37] Many people are unaware they have a bleeding disorder.[38]

In 2008, The Hilltop Institute reported in its "Overview of the Existing Insurance Market in Maryland" that there were 3,590,609 individuals with private insurance in Maryland.[39] Based on this estimate of the covered population and the incidence rates reported above, there are approximately 37,000 to 74,000 insured Marylanders with bleeding disorders.

Mercer conducted a survey of Maryland's leading insurance carriers for this report. Based on the number of cases reported in this survey, many of the affected people do not receive medical services. We speculate that many people are undiagnosed, some may not be covered, and some do not require services each year.

For people with bleeding disorders, treatment can be a substantial financial burden. Costs can vary widely from person to person. The cost of factor concentrates may vary from $60,000 to $150,000 annually. Complications can increase these costs exponentially.[40] Another source reports the average cost per individual with a bleeding disorder to be $40,000 annually for what is now a near-normal life span. Complications can more than double the average annual outlay.[41]

Almost all Maryland health plans currently cover bleeding disorders. Table 2 summarizes the carriers' responses to the survey.

[36] Mayo Medical Laboratories. "Von Willebrand Disease (VWD), Part 4: VWF Multimer Analysis." Mayo Clinic. www.mayomedicallaboratories.com/articles/hottopics/2011/07-multimer/index.html. Accessed July 2011.

[37] Ibid.

[38] Womenshealth.gov. "Bleeding Disorders Fact Sheet." Womenshealth.gov. March 2009. www.womenshealth.gov/publications/our-publications/fact-sheet/bleeding-disorders.pdf

[39] Milligan, C. "Overview of the Existing Insurance Market in Maryland." The Hilltop Institute, University of Maryland, Baltimore County. www.healthreform.maryland.gov/workgroups/documents/100810insurancemarketpp.pdf Accessed August 2010.

[40] National Hemophilia Foundation. "Finance and Insurance Issues." New York, NY. 2006.

[41] Bleeding Disorder Foundation of Washington.

Table 2

Health Plan	Percent of Plans Covering Medically Necessary Services for Bleeding Disorders
A	100% referred for case management and factor precertification
B	100%
C	100%
D	100%
E	100%
F	100%

Most employer plans – especially those sponsored by large employers – will have little or no compliance costs, as services are currently covered. Table 3 shows the projected premium impact reported by the six health plans responding to the survey.

Table 3

Health Plan	Predicted Premium Impact
A	None
B	None
C	0 – 0.17%
D	None
E	None
F	Low

None of the surveyed health plans in Maryland reported dollar limits on medically necessary services for bleeding disorders, specifically. On the other hand, most plans reported frequency limits on the number of home visits, and one carrier indicated that some plans limit the number of inpatient days for all illnesses that are covered per year. However, coverage limits on items such as home visits are often waived if they result in other savings, such as eliminating the need for an inpatient hospital stay.

Financial Impact

In this section, we estimate the cost of implementing the mandated benefit and compare the results of our analysis with those of some publicly available sources.

Mercer surveyed six major carriers in Maryland to obtain information on current practices regarding coverage for bleeding disorders.[42] Mercer also asked these carriers to estimate how premium rates would be affected if coverage were mandated for all medically necessary and appropriate pharmacy care, home nursing services, treatment at a hemophilia treatment center, and clinical laboratory services.

[42] The carriers were: Aetna, CareFirst, CIGNA, Coventry, Kaiser, and United Health Care (UHC)

All six carriers currently provide coverage for bleeding disorders at levels consistent with the proposed mandated benefit; four of the six carriers estimated that the financial impact of the proposed mandate would be zero. One carrier estimated that the financial impact could range up to 0.17%, depending on the plan design. (In this instance, there is a limitation on home health visits each year). Another carrier indicated the cost would be "low."

Mercer asked the carriers how coverage for bleeding disorders varied among the self-funded plans they administer. Self-funded plans for three of the six carriers have the same level of coverage provided by fully insured plans. One carrier stated that most of the self-funded plans have comparable bleeding disorder coverage. Of the remaining two carriers, one stated that none of the self-funded plans cover bleeding disorders, and the other carrier replied that the information was "not available."

Mercer also surveyed several large self-funded plans to obtain information on current practices regarding coverage for bleeding disorders. *All surveyed self-funded plans currently offer coverage for bleeding disorders at a level that is consistent with the proposed mandate. Current practice would indicate little or no need for the proposed mandate.*

Even though current practices of Maryland carriers indicate the marginal cost of the proposed mandate is minimal, the full cost of care varies widely among people with bleeding disorders. According to the National Hemophilia Foundation, the annual cost of factor concentrates per person can range from $60,000 to $150,000.[43]

The full cost of treating bleeding disorders may vary significantly by health plan, depending on the concentration of members with bleeding disorders and the severity of those disorders. In the carrier survey, Mercer asked each plan to provide the 2009 cost per hemophiliac member. Out of the six carriers surveyed, only three responded to this question, reporting very large differences in cost treatments for 2009[44].

Using an internal database that contains 2008 medical and prescription drug claims for over 34.5 million members, we estimated the annual claims costs to cover people with bleeding disorders.[45] This is a national database with a significant number of carriers contributing claims data. Due to the time it takes for claims to be fully reported and the time needed to "scrub" the data, 2008 claims data was the most recent data available at the time this paper was written. In 2008 dollars, the average annual cost for an individual with a bleeding disorder was just over $38,000, the prevalence was 3.2 per 1,000 people,

[43] National Hemophilia Foundation. "Financial and Insurance Issues." www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=34&contentid=24

[44] The statistics provided by the carriers varied from an average cost of slightly above $600 per member with a diagnosis of a bleeding disorder to in excess of $107,000 per hemophiliac member. The carrier with the lowest cost provided the cost for procedures ***only*** associated with treating hemophilia. The cost estimates from the other two carriers reflect costs for ***all*** procedures for members diagnosed with hemophilia, which include procedures for other co-morbidities.

[45] Includes all medical and prescription drug claims for members with ICD-9 diagnosis of 286.xx, 287.xx, and 289.9

and the PMPM cost was $10.11. This PMPM cost is roughly 2.9% of an average group policy and 0.24% of the average salary. This cost estimate includes *all claims costs* for people diagnosed with a bleeding disorder, including those costs associated with other conditions present. According to the Bleeding Disorder Foundation of Washington, the average annual cost for treating a person with hemophilia is roughly $40,000,[46] which is consistent with our data observations. In Table 4, we show the 2008 cost and utilization statistics for all claims for people with bleeding disorders as reflected in our database.

Table 4
Bleeding Disorder Cost Distribution

Annual Cost	Avg Cost Per Person with Bleeding Disorder	Bleeding Disorder Member Distribution	Prevalence Per 1,000	PMPM	Cost as % of average group policy	Cost as % of average wage
0 - 500	$ 294	5.1%	0.16	$ 0.00	0.00%	0.00%
501 - 1,000	753	6.9%	0.22	0.01	0.00%	0.00%
1,001 - 10,000	4,176	44.1%	1.40	0.49	0.14%	0.01%
10,001 - 25,000	16,308	17.2%	0.55	0.74	0.21%	0.02%
25,001 - 50,000	35,346	10.9%	0.34	1.01	0.29%	0.02%
50,001 - 75,000	60,888	4.4%	0.14	0.71	0.20%	0.02%
75,001 - 100,000	86,729	2.5%	0.08	0.58	0.17%	0.01%
100,001 - 150,000	122,313	3.1%	0.10	0.99	0.28%	0.02%
150,001 - 500,000	257,038	4.7%	0.15	3.16	0.90%	0.08%
500,001 - 999,999	642,748	0.9%	0.03	1.57	0.45%	0.04%
1,000,000+	1,502,949	0.2%	0.01	0.84	0.24%	0.02%
Total	$ 38,355	100.0%	3.16	$ 10.11	2.89%	0.24%

According to The Centers for Disease Control and Prevention (CDC), treatments for 10 to 15 percent of people with hemophilia are extremely costly due to the development of an antibody that inhibits the action of the clotting factors that are used to treat bleeding disorders.[47] The CDC reports are largely consistent with our own analysis, as indicated in Table 4 above which shows that about 84% of people with bleeding disorders incur an annual cost of less than $50,000. The remaining 16% incur costs ranging from $50,000 to as much as $1 million per year.

Table 4 shows that the cost to provide coverage for people diagnosed with hemophilia is $10.11 PMPM. This is the cost that would need to be charged to all members to cover the cost for hemophilia members. The state of Virginia currently mandates coverage for bleeding disorders at levels similar to those specified in the proposed Maryland mandate. For each mandated benefit in Virginia, the Commonwealth of Virginia has identified the procedures covered under the mandate. *If the cost was limited to include only those services that will be provided under this mandate* (all medically necessary and appropriate pharmacy care, home nursing services, hemophilia treatment center services,

[46] Hemophilia Foundation of Washington. "About Hemophilia." www.scn.org/health/hfw/abouthemo.htm

[47] National Center on Birth Defects and Developmental Disabilities. Centers for Disease Control and Prevention. www.cdc.gov/ncbddd/blooddisorders/documents/BBV_PNV_C0_1159_Hemophilia_R2mtr.pdf

and clinical laboratory services that an insured's or enrollee's treating physician determines are necessary to prevent, diagnose, or treat a bleeding disorder[48]), the PMPM claims cost decreases from $10.11 to $2.15. In other words, the majority of the cost, $7.96 PMPM ($10.11 - $2.15), incurred to treat people with bleeding disorders is attributable to the services for treatment of other conditions that individuals with bleeding disorders incur (i.e. co-morbidity). These other services would not be included in the scope of the proposed mandate. This does not mean the services for the other co-morbidity conditions are not covered at all. They most likely are covered under the existing benefits for hospitalization, professional services, tests, etc. For instance, if people with bleeding disorders have a greater probability of being diagnosed with acquired immune deficiency syndrome (AIDS), the cost to treat AIDS would not be covered under this proposed mandate, but those costs most likely would be covered under the current benefit plans. In 2008 dollars, we estimate the *full* cost of the mandate for only those services directly related to bleeding disorders to be $2.15 PMPM. (This estimate does not include the medical expenses for other co-morbidities). This estimate is approximately 0.72% of an average group policy, or 0.06% of the average salary.

All of the carriers and self-funded plans in Maryland that were included in the various surveys provide coverage for bleeding disorders, and all but one indicated they provide coverage comparable to the proposed mandate. We define the marginal cost of a proposed mandate to be the additional cost carriers will incur as a result of being required to provide coverage for a proposed mandate that they would not have provided absent the mandate. Table 5 summarizes the gross and marginal cost of the proposed mandate.

Table 5

	Full Cost	Marginal Cost
Estimated cost as a percentage of average cost per group policy	0.72%	0.00% - 0.17%
Estimated cost as a percentage of average wage	0.06%	0.00% - 0.01%

Since the majority of the surveyed carriers indicated coverage for the proposed mandate is currently being provided to policyholders, the marginal cost is near zero. One of the carriers did state the cost could range up to 0.17%, depending on the plan design. *Current practice would indicate little or no need for the proposed mandate.*

Currently, Virginia, and New Jersey are the only states that mandate coverage for bleeding disorders.[49] When this report was written, these states had not published estimates on the cost for this mandate. The Council for Affordable Health Insurance (CAHI) publishes an annual report summarizing cost estimates for mandated benefits provided by all states in the U.S. In the 2010 report, CAHI's cost estimate for congenital bleeding disorders was less than 1% of premium, which is consistent with our full cost estimate of 0.72%.

[48] CPT Plus and ICD-9-CM Office Edition. 2010 Edition. www.scc.virginia.gov/boi/co/health/ltcmed/cpt_codes.pdf

[49] National Hemophilia Foundation. "Congress Considers Two Controversial Health Care Bills." www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=117&contentid=530

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Code of Virginia Annotated, § 38.2-3418.3. Coverage for hemophilia and congenital blood disorders.

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