

**REPORT TO THE GOVERNOR
AND GENERAL ASSEMBLY**

**IOWA HEMOPHILIA ADVISORY
COMMITTEE**

March 2009

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Governor**

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EXECUTIVE SUMMARY

There are two divergent populations represented by the Iowa Hemophilia Advisory Committee (HAC): 1) those with bleeding disorders (who have problems getting their blood to clot) and 2) those with clotting disorders (whose blood clots excessively or too easily).

The advisory committee has not met since the release of the annual report in January of 2008. Since that time, there has been staff turnover in the Hemophilia of Iowa organization, the University of Iowa Hemophilia Treatment Center, and the Iowa Department of Public Health HAC staff coordinator position.

The new IDPH HAC staff coordinator has met with a representative of the hemophilia community and staff of the Iowa Hemophilia and Thrombosis Center to outline a plan for going forward with the HAC and to address recommendations made in the previous annual report.

The HAC previously identified several activities to educate communities about hemophilia and bleeding and clotting disorders and advocate for individuals with bleeding disorders and their families. Committee members will work toward carrying out these activities over the coming year.

- The committee recommends that basic health insurance policies cover the cost of clotting factor concentrate administered outside the hospital setting and that hospitals providing out-patient care to people with hemophilia be sufficiently reimbursed for clotting factor concentrates. The goal is to ensure continued appropriate out-patient services without financial penalty to the provider.
- Hemophilia is a life-long disease with no cure. Treatment is very expensive, so the committee recommends that lifetime insurance caps be eliminated or raised to a more appropriate level for individuals with hemophilia. Existing insurance caps have not kept pace with the rising cost of medical care and have not changed significantly in the last 30 years.
- Factor replacement is not readily available in local communities. Therefore, it is recommended that persons with a bleeding disorder in Iowa have a current supply of their treatment product available in the home. The person can either use the factor at home or take it to their local hospital to treat an injury or bleeding episode. It is necessary that these products be covered by insurance programs.

Updated Needs Assessment

The medical needs of hemophilia patients are emergent, episodic and ongoing. However, some patients continue to receive nearly all medical treatment in the hospital emergency room despite the fact that comprehensive care is available at comprehensive treatment centers. While the primary care physician might be contacted by telephone, unless hospitalized, a physician with hemophilia experience might not see the patient. Such fragmented, crisis-oriented care persists for many individuals with hemophilia.

Health Insurance

In recent years, the driving force within the health insurance industry has been cost containment, posing a challenge for carriers, providers and patients. Most health insurance coverage provided by employers involves managed care arrangements that attempt to limit access to specialty care by using patients' primary care physicians as "gatekeepers" to these services.

Prompt access to essential emergency clinical services has been hindered by problems associated with required determination of medical necessity prior to authorization for care. Many individuals with hemophilia report limitations on the frequency of visits and/or reimbursement problems for specialized emergency and consultative services received at their hemophilia center. Annual and/or lifetime caps are frequently imposed on routine and preventive office-based services, as well as specialty and hospital-based care and clotting factor concentrates. Moreover, even when these services are available, they may be subject to high deductible payments. Coverage for clotting factor concentrates can be subject to co-payments that are unaffordable for many families. Coordination of care between the primary care physician and the specialist is imperative in order to maintain the standard of care for this chronically ill population and, therefore, maximize treatment outcomes.

Because of inadequate health insurance coverage, many adult patients and parents of pediatric patients must choose between viable careers and working in lower-paying positions or not working at all, in order to qualify for government assistance.

Medicaid

Many hemophilia patients do not qualify for Medicaid benefits simply because of their present ability to work. Significant concerns have been raised that restrictions in future health insurance benefits may lead to impoverishment of more persons with hemophilia and the need for expansion of Medicaid benefits.

Medicare

Most people with hemophilia are under 65 years of age and, as a result of hemophilia treatment, are not permanently disabled. Those under 65 with

permanent disabilities are eligible for Medicare benefits after a two-year waiting period. Medicare reimburses up to 80 percent of approved blood product costs incurred on an outpatient basis. Recent increases in clotting factor price make the 20-percent Medicare co-payment impossible for most beneficiaries to meet.

Supplemental Security Income (SSI)

Eligibility requirements for Supplemental Security Income (SSI) as a means of accessing disability benefits have been tightened. Many people with hemophilia are likely to be adversely affected by such a change because their disabilities are made less evident through treatment. Yet, without this entitlement, they may not be able to continue to receive comprehensive treatment.

Hospital Inpatient Care

Hospitals providing in-patient services to people with hemophilia must be adequately reimbursed by all third parties for the cost of administered clotting factor concentrates. These costs must be “carved out” of contractual arrangements between the treating hospital, private health plans, and government payors.

Beginning in 1998, federal law has provided for a “pass-through” of clotting factor concentrate inpatient charges for Medicare patients. This provision allows the hospital to bill Medicare for actual charges for clotting factor concentrates administered to inpatients. The Hemophilia Advisory Committee strongly recommends that Iowa consider a similar inpatient pass-through for Medicaid patients’ clotting factor charges.

Cost of Care

Self-treatment at home has been tremendously successful in reducing the cost of care, limiting disability and decreasing unemployment. Analyses by the National Hemophilia Foundation have shown that hemophilia treatment centers have saved federal and state governments, as well as commercial insurers, hundreds of millions of dollars by reducing the need for hospitalization and decreasing clinic or emergency room visits. The savings are realized because the nurses at the treatment center provide patients with education on self-treatment.

Most clotting factor concentrate (90 percent) is administered at home, with its final price dependent upon the nature of the distribution system and how much health insurers are willing to pay. Fully developed distribution systems provide medical treatment coordination, shipment of concentrates and collection of used injection materials for medical waste disposal.

Even with these measures in place, clotting factor replacement therapy represents the most costly aspect of hemophilia treatment. The following is an example of the expense involved:

For a factor VIII deficient patient with an elbow bleed, the patient, who weighs 165 pounds (75 kg), would need to treat themselves with 25 units of factor/kilogram (kg). This dose may need to be repeated in 12 – 24 hours pending the severity of the bleed. The average cost of factor is approximately \$1.00/unit.

$$75 \text{ (kg)} \times 25 \text{ (units/kg)} = 1875 \text{ units} \times \$1.00/\text{unit} = \$1875.00.$$

After an individual has met insurance deductibles, most insurance plans pay on an 80%/20% basis (if the factor is paid from the major medical portion of their insurance). The standard policy would pay 80% of the cost (\$1500.00), leaving the patient with a \$375.00 liability for that single dose of factor replacement. Many patients with hemophilia meet their annual maximum out-of-pocket expenses early in the year. Many patients also reach their insurance's lifetime caps at a young age due to the expense of their treatments.

Survey Results

Results from a bleeding disorders community survey recommend action on the following topics.

- ❖ Health Insurance Caps:
 - The impact of annual and lifetime caps on the hemophilia community and state safety net programs in Iowa
 - Health options for bleeding disorders community members who are at risk of losing insurance coverage due to a cap
 - Potential legislative and administrative remedies to address cap issues
- ❖ Outpatient Reimbursement of Clotting Factor within IowaCares Program:
 - Review of current usage among individuals with bleeding disorders
 - Examine available data to understand potential cost savings and quality improvement opportunities available if outpatient coverage of clotting factor were available
- ❖ Access to Hemophilia Therapies:
 - Review of current Medicaid PDL status of hemophilia clotting factors on “not recommended” list due solely to perceived cost concerns
 - Individualized patient response to therapies
 - Need for continued open access to all hemophilia therapies
- ❖ Dental care:
 - Current access to dental care for individuals with bleeding disorders
 - Unique challenges of hemophilia community
 - Opportunities for collaboration with state and private entities to improve access and outcomes
- ❖ Health Care Reform Law (HF2539):

- Review of opportunities to improve access to care presented within law
- Potential areas for review could include providing input to the Health Choice Coverage Council and the Chronic Care management Advisory Council on standards of care and comprehensive treatment of lowans with bleeding disorders
- Additional opportunities to increase health insurance coverage may be available through continuation of dependent coverage for students age 25 and under who are full-time students in an accredited post secondary institution

Committee Activities

The advisory committee has not met since the release of the annual report in January of 2008. Since that time, there has been staff turnover in the Hemophilia of Iowa organization, the Iowa Hemophilia and Thrombosis Center, and the Iowa Department of Public Health HAC staff coordinator position.

The advisory committee has previously identified several activities to educate communities about hemophilia and bleeding and clotting disorders and advocate for individuals with bleeding/ clotting disorders and their families.

- Make an easier, “no gap” transition between Medicaid and Medicare.
- Utilize out-patient treatment and home care for patients.
- Promote independence in patients.
- Increase awareness of bleeding and clotting disorders in the medical community to reduce misdiagnosis and mistreatment.
- Protect free choice of factor products as there is a difference in efficacy for some patients.
- Provide education about bleeding and clotting disorders to the general public.
- Present legislative issues to the committee for advice and information.
- Assure that every patient in Iowa with bleeding or clotting has access to proper medical care with no cap on insurance to assure that care.
- Educate patients and families about stop-gap measures.

Action Plan Activities 2008

To address the above action topics, Kimberly Noble Piper, the Iowa Department of Public Health Hemophilia Advisory Committee liaison, met with representatives from the Iowa Hemophilia and Thrombosis Center: Tamara Bullock, RN, BSN; Karla Wilkinson, RN; and Michael Lammer, Social Worker; and Terry Morrow, parent/consumer from the hemophilia community. The following action plan was developed.

- ❖ Health Insurance Caps:
 - Hemophilia of Iowa will address insurance caps with legislators.
- ❖ Outpatient Reimbursement of Clotting Factor within IowaCares Program:
 - Hemophilia Treatment Center staff has been put in contact with the IowaCares representative at the Iowa Department of Human Services.
 - A meeting will be held with representatives of the Iowa Hemophilia and Thrombosis Center, members of the hemophilia community, and representatives from the IowaCare program to clarify options regarding reimbursement of clotting factor on an outpatient basis.
- ❖ Access to Hemophilia Therapies:
 - Hemophilia of Iowa will address access to treatment issues with legislators.
- ❖ Dental care:
 - Dr. Bob Russell, Dental Director for the Iowa Department of Public Health Oral Health Bureau, will work with staff of the Iowa Hemophilia and Thrombosis Center to address the special needs of the hemophilia community regarding oral health care.
- ❖ Health Care Reform Law (HF2539):
 - The IDPH HAC coordinator recommended that Hemophilia of Iowa representatives monitor activities of the Health Choice Coverage Council and the Chronic Care Management Advisory Council, and become involved in attending meetings of these committees. As these are meetings that are open to the public, hemophilia community representatives will have an opportunity to provide information to committee members.

Conclusions

- The principal obstacle to accessing comprehensive hemophilia care is unavailable or insufficient health insurance. Approximately 30 percent of people with hemophilia have nonexistent or inadequate health insurance coverage. In light of modern therapies available, a person with hemophilia need not be disabled or impoverished. Universal and unrestricted access to health insurance could prevent a life-long medical condition from becoming a personal or societal catastrophe.
- At the present time, no publicly sponsored medical insurance plan addresses the hemophilic individual's requirement for lifelong treatment without prior assessment of financial need or designation of a disabling condition. Moreover, *hawk-i* does not include clotting factor concentrate in its outpatient formulary.

- Variations in medical benefits offered by private and public health plans prevent smooth transition of families undergoing changes in their hemophilia care eligibility and entitlements.
- Development of genetically engineered clotting factor products and changes in production methodology offer the hope of diminishing the incidence of transfusion-associated diseases, but at increased costs. Adequate supplies of clotting factor concentrates must be produced at affordable prices.

The HAC will work with the IDPH to address recommendations from the 2007 annual report to the general assembly, and will re-establish regular meetings as per legislation.

APPENDIX A

For more information regarding emergency management of hemophilia and other congenital bleeding disorders, contact the Hemophilia Treatment Center of Iowa.

Iowa Hemophilia and Thrombosis Center
University of Iowa Hospital and Clinics
200 Hawkins Dr. 4022 BT
Iowa City, IA 52242
800-272-3547 (Toll-free from Iowa)
319-356-4277

APPENDIX B
Hemophilia Data
Hemophilia & Thrombosis Center of Iowa Patients
Through December 2008

Deficiency	Mild	Moderate	Severe	Total
Factor VIII	68	24	72	164
Factor IX	27	53	17	97
Von Willebrand factor				145
Platelet/ other				52

Table 1. Patients by Factor Deficiency

Table 2. Patient by Age and Race

Age (years)	White	Black	Hispanic	Asian
0-4	23	4	2	1
5-15	73	4	2	0
16-21	65	4	1	1
22-40	142	3	2	1
41-60	83	6	0	0
>60	40	1	0	0
Total	426	22	7	3

Table 3. Primary Source of Insurance Coverage

Age (years)	Private Insurance	Medicaid	Medicare	Other	No Coverage	Unknown
0-4	15	17	0	0	3	3
5-15	56	51	0	1	9	0
16-21	34	20	0	2	6	0
22-40	80	20	8	10	15	2
41-60	52	6	6	2	6	0
>60	6	0	26	0	1	0
total	243	114	40	15	41	5

APPENDIX C

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