

**REPORT TO THE GOVERNOR  
AND GENERAL ASSEMBLY  
2009**

**IOWA HEMOPHILIA ADVISORY  
COMMITTEE**

**March 2010**

**Chester J. Culver,  
Governor**

**Patty Judge,  
Lt. 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 met on a quarterly basis in 2009.

The 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, 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 improved 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.

#### IowaCares

People with hemophilia relying on the IowaCares program for coverage are required to receive factor replacement and treatment at only two approved facilities (UIHC and Broadlawns). This complicates and limits availability and limits treatments. Due to delays in treatment, this creates an undue health risk. It would be beneficial and most cost effective for IowaCares patients to have a home supply of clotting factor readily available.

#### 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. 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***

The HAC continued work on items identified from a bleeding disorders community survey in 2007, which 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 met on a quarterly basis in 2009, alternating face-to-face meetings with evening conference calls. IDPH has been unable to recruit a representative from the health insurance sector, and the hemophilia patient representative has been unable to attend the meetings this past year.

The following issues were addressed

- ❖ 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.
  - The HAC drafted a letter to the director of the IowaCare program at the Department of Human Services, Iowa Medicaid Enterprise, asking for consideration of a policy that would provide coverage for factor replacement therapy for in-home self administration. The chair of the Hemophilia Advisory Committee, Andrew Meyer, was to follow up the letter with a phone contact to the director.
- ❖ 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.

## ***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 2009**

**Table 1. Patients by Factor Deficiency**

<b>Deficiency</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Total</b>
Factor VIII	70	20	77	167
Factor IX	20	53	16	89
Von Willebrand factor	Type I 73	Type II 37	Type III 7	117
Platelet/ other				52

**Table 2. Patient by Age and Race**

<b>Age (years)</b>	<b>White</b>	<b>Black</b>	<b>Hispanic</b>	<b>Asian</b>
0-2	10	0	0	0
3-12	82	3	4	1
13-17	40	1	0	2
18-21	39	1	1	0
22-24	28	0	0	1
25+	28	0	0	1
Total	373	11	7	6

**Table 3. Primary Source of Insurance Coverage**

<b>Age (years)</b>	<b>Private Insurance</b>	<b>Medicaid</b>	<b>Medicare</b>	<b>Other</b>	<b>No Coverage</b>
0-2	7	1	0	0	2
3-12	39	43	0	0	8
13-17	22	18	0	0	3
18-21	24	10	0	2	5
22-24	20	2	0	2	5
25+	126	6	25	4	23
total	238	80	25	8	46

## ***APPENDIX C***

### **Members of Iowa Hemophilia Advisory Committee**

#### **Physician, Specializing in Treatment of Hemophilia, Bleeding and Clotting Disorders**

Steven Lentz, MD  
Iowa Hemophilia & Thrombosis Center  
University of Iowa Hospital & Clinics  
200 Hawkins Dr.  
Iowa City, IA 52242  
319-359-4277 or 1-800-272-3547  
[steven-lentz@uiowa.edu](mailto:steven-lentz@uiowa.edu)

#### **Nurse, Specializing in Treatment of Hemophilia, Bleeding and Clotting Disorders**

Tami Bullock, RN, BSN  
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#### **Social Worker, Specializing in Treatment of Hemophilia, Bleeding and Clotting Disorders**

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#### **Hemophilia Treatment Center Representative**

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Iowa City, IA 52242  
319-356-4271 or 1-800-272-3547  
[karla-watkinson@uiowa.edu](mailto:karla-watkinson@uiowa.edu)

**Health Insurance Representative**

Vacant

**Member of Voluntary Health Organization Serving Hemophilia, Bleeding and Clotting Disorder Community**

Kari Atkinson, Chair

Hemophilia of Iowa

1-866-464-8061

[caklatkinson@aol.com](mailto:caklatkinson@aol.com)

<http://hemophiliaofiowa.com/>

**Hemophilia Patient or Caregiver**

Dave Postel

301 S Parkview Dr

Eldridge, IA 52748

563-579-5058

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**Bleeding Disorder Patient or Caregiver**

Andrew Meyer, Chair

929 Boston Way #9

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319-3303-1670

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**Clotting Disorder Patient or Caregiver**

Carol Hans

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**Iowa Department of Human Services, Ex-officio**

Sally Nadolsky

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**Iowa Department of Public Health**  
**Center for Congenital and Inherited Disorders, Ex-officio**  
Kimberly Noble Piper  
State Genetics Coordinator  
321 E. 12th St.  
Des Moines, IA 50319  
515-281-6466  
[kpiper@idph.state.ia.us](mailto:kpiper@idph.state.ia.us)

## **Appendix D**

### **Letter to Jennifer Vermeer, Director, Iowa Medicaid Enterprise**

November 23, 2009

**Physician Specialist**  
Steven Lentz, MD

**Nurse Specialist**  
Tamara Bullock, RN BSN,  
Vice Chair

**Social Worker  
Specialist**  
Michael Lammer,  
LMSW

**Hemophilia Treatment  
Center Representative**  
Karla Watkinson, RN

**Member of Voluntary  
Health Organization  
Serving Hemophilia,  
Bleeding and Clotting  
Disorder Community**  
Kari Atkinson

**Hemophilia Patient or  
Caregiver**  
Dave Postel

**Bleeding Disorder  
Patient or Caregiver**  
Andrew Meyer, Chair

**Clotting Disorder Patient  
or Caregiver**  
Carol Hans

**Iowa Department of  
Human Services**  
Sally Nadolsky

**Iowa Insurance Division**  
Angela Burke Boston

**Iowa Department of  
Public Health  
Center for Congenital  
and Inherited Disorders**  
Kimberly Noble Piper,  
RNC, BS, CPH, CPHG

Jennifer Vermeer  
Director  
Iowa Medicaid  
100 Army Post Road  
Des Moines, IA 50315

Re: IowaCare coverage and access for outpatient hemophilia therapies

Dear Ms. Vermeer:

I am writing on behalf of the Iowa Department of Public Health Hemophilia Advisory Council to bring a couple of issues to your attention.

A situation was brought to the council's attention regarding an individual with severe hemophilia. This individual had sustained a bleeding episode, and had gone to Broadlawns Medical Center to receive factor replacement for his hemophilia condition. Broadlawns reported they did not have any factor in stock, necessitating travel to Iowa City for the treatment (through IowaCare), since Broadlawns and the University of Iowa Hospitals and Clinics (UIHC) are the only facilities approved to provide services through IowaCare. .

As one of the medical facilities accessible to Polk County residents through the IowaCare program, we feel it is imperative that Broadlawns has this treatment, including hemophilia factor replacement therapy, available to hemophilia patients in Polk County. We respectfully request that this issue be addressed with Broadlawns Medical Center, to assure that all IowaCare members have timely access to this treatment.

The second issue we would like to present is the process of IowaCare coverage for factor administration to hemophilia patients. As we understand it, the present policy requires a patient to receive factor infusions on the premises of UIHC or Broadlawns, either as an admitted inpatient or through the emergency department or outpatient clinic settings. Because hemophilia patients often require doses to be administered as frequently as every 2-24 hours for multiple days, this imparts unnecessary expense, time, hospital bed space, and paperwork, when compared to treatment in the home setting.

Ideally, factor should be available to the patient for in-home self administration. When an individual with a bleeding disorder experiences a bleed, self administration of factor product allows for early, treatment and is considered to be the national standard of care as recommended by the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation. Home treatment prevents complications of bleeding episodes and also decreases the cost of serving this population. When bleeds are not treated promptly in the home, patients often require an increased amount of factor replacement, have an increased utilization of supportive services (physical therapy, crutches, splints), and an increased likelihood of hospitalization for pain control, all of which inflate the cost of care. Currently there is no generic form of factor replacement, further affecting the cost to IowaCare. Continuing to deny the availability of home treatment will cause harm to Iowans with hemophilia and increase the overall cost of the IowaCare program.

Thank you very much for your attention and consideration.

I will contact you within the next week to discuss these issues in more detail.

Sincerely,

Andrew Meyer, Chair  
Hemophilia Advisory Committee  
[Meyer\\_50@hotmail.com](mailto:Meyer_50@hotmail.com)

Cc: Kimberly Noble Piper  
State Genetics Coordinator

