

Hemophilia Advisory Board Meeting Minutes
Springfield Location: 67 E. Adams – 7th Floor Video-Conference Room
Chicago Location: 401 South Clinton, 7th Floor Video-Conference Room

Date:	April 21, 2009
Chaired:	Bob Robinson
Convened:	2:00 PM
Adjourned:	3:30 PM

Members	7/21/09	4/21/2009	1/20/2009	10/28/2008
Mary Davis	P	P	A	P
Dave DuRoss	A	A	A	P
Taylor Eshleman	P	A		
Susan Gamerman	P	A	P	A
Bob Johnson	P	A	P	P
Mike Jones	A	A	P	P
Bobbie Kincaid	A	P	P	P
Greg McClure	A	A	A	A
Kathy Prunty	P	P	P	P
Tess Rhoades	P	P	P	P
Bob Robinson	P	P	P	P
Sydney Ross-Davis	A	P	A	P
Cindy Sgro	A	P	P	P
Mike Tarantino	A	A	P	P
Len Valentino	P	A	P	P
Erv Zander	P	A	P	P
Guests		Sally Salter	Joy Mahurin	Laura Pancratz, Steve Saunders, Jay Van Sise

AGENDA	DISCUSSION
Welcome and Introductions	A general welcome was provided and everyone was re-introduced.
Review & Accept Minutes from 4/21/2009	The minutes from the April 21, 2009 meeting were presented. Those in attendance concurred that they accurately reflected an overview of this meeting.
State Hemophilia Program Funding for FY 2009/2010 Update	<p>The Governor and the General Assembly finally agreed on a budget compromise at the veto session in June. This document did not include a line item appropriation for the State Hemophilia Program; rather the Director of HFS was given all money for this department and provided with the authority to divide it as the Department sees fit. What this means for the State Hemophilia Program is that 70% of last year's allocation has been currently allocated to the program – just under \$8 million.</p> <p>This is a significant decrease in light of the total amount actually spent last year which was closer to \$15 million. Program enrollment for last year was 256 with 145 – 150 of these individual making claims from the program.</p>
State Hemophilia Program Report – First Draft Review	The first draft of the State Hemophilia Program report to the Governor and the General Assembly was presented. Members at the meeting felt that the report provides a strong overview of the bleeding disorder environment for the state of Illinois. Members did not feel ready to approve this report as it needs to further proofed and edited. A deadline for changes was set

	for September 1. These changes are to be submitted to B. Robinson at the Hemophilia Foundation of Illinois.
State Hemophilia Report – Next Steps	Action on the report will be taken at the next meeting in October. At this time the Board will determine a plan of action for distribution.
Other Business	An issue was raised to B. Robinson regarding reimbursement being made to program participants' who are not seen at a Hemophilia Treatment Center (HTC). The law states that participants in the program are to be seen at an HTC. State program staff reported that this is a very small percentage and the majority of these cases the individual does not have a diagnosis of hemophilia. Staff agreed to provide a breakdown of these situations in order for the Board to consider if there is a way to close this gap.
Meeting Schedule	The upcoming schedule for meetings is as follows: October 20, 2009 – 2:00 PM January 19, 2010 – 2:00 PM April 20, 2010 – 2:00 PM

Minutes submitted by: Bob Robinson, Executive Director

Approved Date: _____ Signed: _____