

Hemophilia Advisory Board Meeting Minutes
Springfield Location: 607 E. Adams – 7th Floor Video-Conference Room
Chicago Location: 401 South Clinton, 7th Floor Video-Conference Room

Date:	July 20, 2010
Chaired:	Bob Robinson
Convended:	1:00 PM
Adjourned:	2:00 PM

Members		7/20/2010	4/20/2010	3/2/2010	10/20/2009	7/21/09	4/21/2009	1/20/2009	10/28/2008
Mary Davis		PO	PO	PO	PO	P	P	A	P
Dave DuRoss		PO	PO	PO	A	A	A	A	P
Taylor Eshleman		PO	PO	A – Excused	P	P	A		
Susan Gamerman		P	P	P	P	P	A	P	A
Bob Johnson		A	P	P	A	P	A	P	P
Mike Jones		PO	PO	A	A	A	A	P	P
Bobbie Kincaid		P	P	P	P	P	P	P	P
Greg McClure		A	A	P	P	A	A	A	A
Kathy Prunty		P	A	P	P	P	P	P	P
Tess Rhoades		P	P	P	P	P	P	P	P
Bob Robinson		P	P	P	P	P	P	P	P
Sydney Ross-Davis		A	A	A	A	A	P	A	P
Cindy Sgro		P	P	P	P	P	P	P	P
Mike Tarantino		P	A	A	P	A	A	P	P
Len Valentino		P	P	P	P	P	A	P	P
Erv Zander		P	P	P	P	P	A	P	P
Guests		Eva Kraemer		Bill Reiland			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 4/21/10	The minutes from the April 20, 2010 meeting were presented. Those in attendance concurred that they accurately reflected an overview of this meeting.
State Program Update – Year-to-Date Usage	Staff reported that \$10.7 million has been spent to date. It is anticipated that the Program will run out of allocated dollars prior to the end of the fiscal year. The group was reminded that since we accepted the Legislatures inclusion of the program as a part of the overall HFS funding we do not need to go back to the General Assembly to ask for additional dollars. This can be done with a line item transfer. The staff will explore this when it becomes necessary.

State Hemophilia Program Funding for FY 2009/2010 Update	Budget was \$10.587 million for FY 2009/2010. We have spent approximately \$14.4 million for the program. We were able to do this without going back for an additional appropriation since our program was funded as a block grant under HFS total funding. Program staff were able to ask for line item transfers, which were approved, to cover the level of need presented for this year. For the record the line item transfer dollars came from Medicare Part B dollars.
General Assembly Budget Process	Nothing is anticipated to be done with the budget until after the election. Expenses are currently being covered by extending lapsed spending for the current fiscal year until 12/31.
Federal Health Care Reform and Its Implications on Bleeding Disorders <ul style="list-style-type: none"> - High Risk Pool Expansion – New Federal Program - Increase in Lifetime Caps 	<p>The Board discussed how we are going to be proactive regarding healthcare reform. While some on the Board feel that there is still the possibility that some, if not all, of the legislation may be overturned things are moving forward that are going to impact the bleeding disorder community and possibly the program.</p> <p>We would like to explore with the Department of Insurance ways to possibly expand the program to cover premiums in addition to factor. Two things have occurred with the high risk pool, an increase in the lifetime cap to \$2 million dollars and the addition of a new federal program in response to reform that requires that insurance be available for pre-existing conditions, that make this a viable option now for some, if not many, on the current state hemophilia program. Program staff are going to work with Bob Robinson to set up a meeting with HFS staff to strategize how to move forward with this.</p> <p>Also, the Board asked that Program Staff explore whether HFS is establishing an implementation committee. If so, we are requesting that a member of the Board seek an appointment to this committee.</p> <p>Once again the Board used this opportunity to discuss the lack of dental care for our patients. The Board has decided to develop a white paper regarding access to dental care. Representatives from RUSH, The Bleeding and Clotting Disorders Institute and Children’s Memorial Hospital will work together to determine the problems surrounding access to dental care to present to the State. This will be presented at the October meeting.</p>
Other Business	<p>Nominations will be accepted until the end of September for the consumer position and two non-voting positions on the Board. The Board will consider nominations at the October meeting.</p> <p>The Board agreed to move meeting times back to 2:00pm and established meeting dates for 2011. Dates are listed below.</p> <p>RUSH and Children’s Memorial announced the addition of new physicians to their programs. RUSH: Mindy Brunski, MD and Neisha Kakodkar, MD Children’s Memorial: Ruckhmi Bhatt, MD</p>
Meeting Schedule	The upcoming schedule for 2011 meetings is as follows: Jan. 18 th . 2011 2pm April 19 th , 2011 2pm July 19 th , 2011 2pm October 18 th , 2011

Minutes submitted by: Bob Robinson, Executive Director

Approved Date: _____ Signed: _____