

Advocating in Wisconsin

Great Lakes Hemophilia Foundation
Headline News - April 2010

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Advocacy efforts have been in full swing at Great Lakes Hemophilia Foundation. To date, 15 individuals and their family members have committed to meeting with their local legislator in-district to tell their story, educate and inform them about bleeding disorders, and discuss important issues concerning the bleeding disorders community. The senators include: Sen. Jon Erpenbach (D-Middleton), Sen. Mary Lazich (R-New Berlin), Sen. Fred Risser (D-Madison), Sen. Judy Robson (D-Beloit), Sen. Russ Decker (D-Weston), Sen. Scott Fitzgerald (R-Juneau), Sen. Tim Carpenter (D-Milwaukee), Sen. Alberta Darling (R-River Hills), Sen. Pat Kreitlow (D-Chippewa Falls), and Sen. Joseph Leibham (R-Sheboygan). The representatives include: Rep. Sandy Pasch (D-Whitefish Bay), Rep. James Soletski (D-Green Bay), Rep. Steve Kestell (R-Elkhart Lake), and Rep. Joan Ballweg (R-Markesan).

GLHF advocates will discuss an Assembly bill to fund the BadgerCare Basic Plan, with their legislators. An additional goal of the meetings is to develop and/or strengthen relationships with legislators in the event legislation is presented in the future that may positively or negatively affect individuals with bleeding disorders.

Individuals meeting with members of the Assembly will be encouraging their representatives to pass the BadgerCare Basic Plan funding bill that has already been approved by the State Senate. The BadgerCare Basic Plan, is a limited health plan that will enable individuals on the waiting list for BadgerCare to access care when they need it.

The meetings will also provide an opportunity to remind legislators about the importance of the following issues:

- ◆ Health Insurance Risk Sharing Plan (HIRSP), which offers health insurance to Wisconsin residents who either are unable to find adequate health insurance coverage in the private market due to their medical conditions or who have lost their employer-sponsored group health insurance.
- ◆ Wisconsin Chronic Disease Program (WCDP), funded entirely by state dollars, which offers assistance to Wisconsin residents with chronic renal disease, hemophilia, and adult cystic fibrosis. The WCDP pays health care providers for disease-related services and supplies provided to certified participants after all other sources of payment have been exhausted.

- ◆ Prophylaxis, or the preventive measure against spontaneous bleeds by infusing factor product on a consistent and proactive basis may appear to be expensive, but actually proves to be more cost-effective in the long-run by minimizing long-term joint damage and the ensuing disability of patients with bleeding disorders that treat on an episodic basis.

Advocates will also be discussing the concern of the state engaging a Sole Source Pharmacy Provider, which is the designation of a pharmacy contracted and without competition to be the sole supplier of factor product. Although a sole source pharmacy provider may be appealing for its administrative ease, in the long run an inability for patients to choose among various clotting factor products may cause a variety of negative consequences. These include reducing market competition, elevating the cost of factor, and potentially increasing the likelihood of expensive and even life-threatening complications, such as inhibitors.

If you are interested in meeting with your local legislator, Great Lakes Hemophilia Foundation will help you set up a meeting. Even if you have had no prior experience in advocacy—not to worry. If you have a story to share, then you are already an advocate! GLHF is happy to help you out with the rest.

If you have met with your legislator, please email or call GLHF to let us know how the meeting went. This will help us keep our advocacy files up-to-date.

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