

A Note from the Executive Director

...And the survey says!

Great Lakes Hemophilia Foundation
Headline News - April 2010

Sandy Lampman



As you know, over the last few months the staff and Board of Directors of Great Lakes Hemophilia Foundation have been engaged in a process to hear from a number of individuals about their perspectives on the role of GLHF. We spoke with current and inactive clients, individuals with bleeding disorders who have never engaged with GLHF, the four Wisconsin hemophilia treatment centers, pharmaceutical industry representatives, and Chapter executives and healthcare leaders from around the country.

We will be using the information to cast the future direction of Great Lakes Hemophilia Foundation. As you would expect, the community has differing views on the future role of the organization, but common threads exist.

Over the upcoming months, we will share some of the information we learned from the market research firm, The Mosaic Group, who interviewed 62 individuals with bleeding disorders (or parents of children with bleeding disorders) – 25 active clients, 25 inactive clients and 12 individuals who have never engaged with GLHF. Individuals from all four hemophilia treatment centers were represented. Both males and females were represented as well as individuals from a broad range of diagnoses and severity of hemophilia, von Willebrand and platelet function disorder.

Here are some of the results...more to come in upcoming newsletters!

What sources do you use to educate you/your family about your bleeding disorder? All that apply.

- ◆ 60 of 62 respondents listed their hemophilia treatment center (HTC) as their primary source for information.
- ◆ 56 of 62 respondents listed newsletters from various sources as their secondary source.
- ◆ 47 of 62 respondents mentioned hemophilia foundations (NHF, GLHF, HFA, Hemophilia of Georgia and Hemophilia Foundation of Illinois)
- ◆ 36 of 62 respondents listed word of mouth/networking as a source of information
- ◆ 33 of 62 respondents listed the internet as a source of education (favorite sites included webMD, MedicalNews.com, nhf.org, glhf.org and the Baxter site)

Do/did you receive information about GLHF from your HTC?

- ♦ 33 of the 62 respondents recall receiving information from the HTC about GLHF.
- ♦ 22 of the 33 took the next step and contacted GLHF about services, camp and other specific events.
- ♦ The 11 who did not contact GLHF did not feel the need to reach out.

How important is it that GLHF arm individuals with bleeding disorders with the knowledge and skills to grow and develop to optimum levels?

- ♦ 60 of the 62 respondents felt it was important or very important that GLHF arm individuals with knowledge and skills, however some respondents remarked it's not the responsibility of the organization and individuals need to take initiative.
- ♦ One respondent said, "Help educate the patients to be pro-active with the doctors", another respondent remarked, "By educating yourself, you are better able to cope with the disorder."
- ♦ Still another thought this was the role of the treatment center to arm patients with knowledge and skills.

Would you like to weigh-in on these three questions? Email your comments to info@glhf.org!

Thanks for helping us cast the future!

 **printer friendly version**

 **email this article**

The material provided in Headline News is for your general information only. GLHF does not give medical advice or engage in the practice of medicine. GLHF under no circumstances recommends particular treatment for specific individuals, and in all cases recommends that you consult your physician or treatment center before pursuing any course of treatment.