

Volume No 69
Fall 2006

HORIZONS IN HEMOPHILIA

IN THIS ISSUE:

FEATURE

Client/Volunteer
Spotlight6

DEPARTMENTS

Hot News2

Dear HoG5

Hemophilia Happenings7

Pharmacy Update11

Women's Wellness14

Keeping You Posted15

Making A Difference20

Health News23

Hemophilia of Georgia, Inc.

8800 Roswell Road
Suite 170

Atlanta, Georgia 30350

(770) 518-8272 1-800-866-4366

<http://www.hog.org>

Email Address: mail@hog.org

Hemophilia of Georgia is not engaged in the practice of medicine and does not endorse or support any particular factor concentrate or treatment protocol. HoG recommends that you consult with your physician prior to starting any course of therapy. Occasionally HoG disseminates information on new treatments or therapies. HoG shares this for informational purposes only and makes no claim as to its accuracy or effectiveness.

World Meeting

By Bill Riley

Big, comprehensive, intelligent, thought provoking and fun are all words that describe the recently held meeting of the XXVII International Congress of the World Hemophilia Foundation in Vancouver, Canada. Big in that over a dozen hotels were needed to accommodate the seemingly endless number of attendees and speakers. Comprehensive in that almost every aspect of hemophilia from gene therapy to musculoskeletal disorders was covered in literally hundreds of sessions available to those in attendance. Intelligent because every session was led by one or more of the top minds in the chosen field. Thought provoking in that each session created additional information like small pieces of a much larger puzzle. Place each piece in its rightful spot and you create the larger picture that is hemophilia. And finally, fun because with Vancouver as its backdrop, the meeting brought together people from all over the world to discuss the issues so dear to our hearts.

This was my first World Congress meeting. As a person with hemophilia approaching the age of forty, I had talked with only a few hemophiliacs in my lifetime who were not from the United States. This meeting offered me the chance to meet many more and to see what life outside the US is like for those affected by hemophilia. Until hurricane Katrina paralyzed the city of New Orleans, effectively interrupting care for the state's hemophilia population, I hadn't thought much about the effects of natural disasters on our population. In Vancouver, I was able to hear first hand about one such situation. I talked with an older hemophiliac who was still recovering from injuries sustained in the earthquake that hit Pakistan in October, 2005. Struggling with his English,

he told me that his leg was injured in the quake and that he was unable to receive care for several days. Surprisingly though, he had put his experience behind him and was more excited about the opportunity to be in Vancouver. He proudly showed me a large poster in the exhibition area that detailed the earthquake as well as gave information about the hemophilia organization in Pakistan.

As I spoke with others from around the world, I found that excitement was a common emotion among many of the hemophiliacs that I met. Most were very happy to have the chance to attend the meeting and to bring home some of the vast amount of knowledge available at the meeting. As a board member for HoG, I was asked to attend a meeting with members from the hemophilia organization from Honduras. HoG and Honduras are currently participating in the World Federation of Hemophilia's twinning program. We met with several members from the team from Honduras including one young man with hemophilia. Although there was a definite language barrier, there was no hiding the excitement around the table. The group from Honduras was eager to learn how to improve their organization and the staff from HoG was willing to help.

Continued on page 2



It's a jungle out here! For more camp

The New Hemophilia of Georgia Web Site: Valuable Information at Your Fingertips

By Bill Davis, Marketing Writer

Have you visited the Hemophilia of Georgia web site lately? If not, we encourage you to stop by for a visit at www.hog.org. The HoG web site has been completely redesigned to make it more attractive, more informative, and easier to navigate.

The web overhaul project originated when Hemophilia of Georgia received the 2005 Technology Innovation Award from TechBridge. TechBridge is an Atlanta-based nonprofit organization that works to provide technology solutions to other nonprofits. Receipt of the award allowed us to use TechBridge services to redesign our web site at no cost.

A committee consisting of HoG employees worked long and hard to determine the look, feel and functionality that they felt would best serve clients in the online world. After identifying new content, features to be added and a new design, work began in earnest on the new web site. The site officially launched during the first week of May.

It has never been easier to get information about the full range of services available from HoG. Thanks to drop-down menus on our home page, you're just one click away from details on our pharmacy, our outreach nursing and social support programs, and volunteer opportunities. In fact, when you visit the site you'll find that you can

jump directly to information about all of our programs and services, plus educational information on hemophilia and related bleeding disorders. In the coming months we'll also be adding lots of new material as well, so check back often.

One of the changes that we're most excited about is a feature which allows visitors to register with the site. This allows us to more accurately share specific information about events and legislation with those who are most likely to benefit from exposure to it. For example, clients and other eligible parties who register with the site can be notified of Hemophilia of Georgia

events in their area. We can also provide a "heads-up" when there are important legislative issues which might affect your insurance or access to treatment.

Of course, the ultimate success of the new web site will be determined by you, the end-user. We'd love to hear what you think, and what we can do to make the site even better. When you visit us online, please click on the "contact us" link at the bottom of the home page and send us an email with your comments.



Visit Hog's redesigned web site at www.hog.org.