



# THE HEMOPHILIA ALLIANCE, INC.

## HAPPENINGS

### Planning For the Future in the French Quarter

On the 26<sup>th</sup> February 2008 the Hemophilia Alliance held its first Strategic Planning retreat. The purpose of the meeting was to look at the immediate and long-term goals and to focus the resources and energy of the Alliance to meet the needs of its members. In addition to inviting members of the Alliance, the Board wanted to get input from outside the Alliance and extended invitations to other people within the Hemophilia community. [Continue](#)

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The Alliance will be sending out a web-based survey to its members. We are in the process of learning more about our members and what is important to them. We will be looking at things such as who the key decision makers are at your center? What are the most important issues for your center? [Continue](#)

### The HAGPO You Ought To Know

#### Hemophilia Alliance Group Purchasing Organization

HAGPO was formed in November of 2005 with the goal of using the aggregate purchasing power of the Hemophilia Treatment Centers (HTCs) to accomplish four primary goals: secure a "guaranteed" supply of product, negotiate better pricing for both 340 B and Non 340 B, better terms (either a prompt discount and/or sixty or ninety day payment terms), and obtain admin fees to reinvest in the HTCs, the patient community and to promote operational excellence. In 2007, HAGPO saved its members over \$1,000,000 in the cost of product and collected over \$400,000 in admin fees. [Continue](#)

### Greener Pastures

It is with great regret that we announce the resignation of Kelly Green from our Board of Directors. Kelly recently resigned from his position at Nationwide Children's Hospital in Columbus, OH after more than 15 years of service to the hemophilia community.

Kelly was a pleasure to work with and a tremendous asset to the Alliance and its Board since he was elected as a Director in 2006. [Continue](#)

### Third Party Payers Update

Anthem has begun to take action with certain independent HTCs in the Midwest, further squeezing the price point for factor distribution. While some pricing appears to be acceptable, certain products are at very low rates, some even at below acquisition. The Alliance has tried to engage Anthem in dialogue, but they are somewhat elusive. The fear is that they are seeking to conquer the network by not allowing joint discussions - the "divide and conquer theory". [Continue](#)

### Putting A New Spin on our Web

The Alliance will be enhancing our website in an effort to make it one of the primary ways to communicate with its members. Not only will we be changing the look of the pages, but we will also be putting more information on the site. The calendar and links to other events pertinent to the Hemophilia community will be updated. We plan to put our meeting presentations online, as we did with the materials from our 6<sup>th</sup> Annual meeting in January 2008 in Las Vegas. In an effort to make the presentations even more interactive we are looking into creating podcasts for our meeting presentations. [Continue](#)

### Behind the Scenes: Understanding Your Board

Like all non-profits, the Hemophilia Alliance (the "Alliance") has a Board of Directors that is charged with the responsibility of making sure the business and affairs of corporation are being managed effectively and efficiently. The Alliance Board is made up of nine dedicated individuals who, in addition to their full time jobs at Hemophilia Treatment Centers, volunteer to take on this tremendous responsibility. [Continue](#)

For information about this newsletter:

Please contact Sean Singh by email at [seanbsingh@gmail.com](mailto:seanbsingh@gmail.com) or by phone at 727-388-7326

For information on HAGPO:

Please contact Joe Pugliese by email at [joe\\_pugliese@hotmail.com](mailto:joe_pugliese@hotmail.com) or by phone at 215-439-7173

## Planning For The Future In The French Quarter

On the 26<sup>th</sup> February 2008 the Hemophilia Alliance held its first Strategic Planning retreat. The purpose of the meeting was to look at the immediate and long-term goals and to focus the resources and energy of the Alliance to meet the needs of its members. In addition to inviting members of the Alliance, the Board wanted to get input from outside the Alliance and extended invitations to other people within the Hemophilia community. To achieve this, we invited Dan Hartman, a consumer, San Francisco CA Bay area, Fran Haynes, Executive Director, Hemophilia Foundation of Greater Florida and Michele Rice, Executive Director, Hemophilia of Indiana, Inc., all of whom are not affiliated with the Alliance.

A SWOT (Strengths, Weaknesses, Opportunities, Threats) analysis was done before the retreat and then was reviewed and discussed during the session. Some noted points were:

### Strengths:

- National Network – The Alliance represents 63 member HTC's from across the United States
- HAGPO – While a separate entity, the joint purchasing organization requires HTC's to be Alliance members before joining
- Institutional Presence
- Alliance Government Knowledge and Relationships
- 340B Factor Program Knowledge and Expertise
- Technical Assistance to Alliance Member HTC's

### Weaknesses:

- New Alliance – only 7 years old Variation in Operating Structures
- Limited Resources – Financial/Personnel
- Relationship with the National Hemophilia Foundation (NHF)
- Marketing/Branding
- Awareness/External Education (i.e., lack of brand image)
- Communication with Membership
- Alliance Dependence on Single Staff Resource
- 340B Program
- Operational Board versus Governance Board

### Opportunities:

- Marketing to Third Party Payers
- Marketing and Branding
- Capitalizing on the “Safety Net Provider”
- HAGPO
- Building on Local HTC Initiatives and Relationships
- Cooperative Initiatives for Standardization
- Changing External Perception of the Alliance
- Engage and Identify Key HTC Decision Makers to Better Understand our Members and their Needs

### Threats:

- Third Party Payer Strategies
- Specialty Pharmacy Development/PBM Expansion
- Manufacturers' Strategies Toward Public and Private Payers
- Breadth of Competition
- Office of Pharmacy Affairs Regulations
- MCHB Policies and Procedures
- Government Regulation (Deficit Reduction Act, etc.)
- Recruitment Strategies By Alliance Competition or Other Organizations
- Community “Noise” is Undermining the Alliance

We then looked at the direction in which the Alliance should be moving and identified seven initiatives that we feel will be in the members' best interest both immediately and into the next three years. The initiatives are:

1. Branding the Alliance
2. Improving government relations and support
3. Capitalizing on and expanding our relationship with HAGPO.
4. Educating public and private third party payers and specialty pharmacies
5. Improving organizational structure and resources
6. Communicating with internal and external stakeholders
7. Increasing Alliance membership

Over the next few months we will be assigning resources and timelines to the initiatives. As the initiatives move along, we will communicate with the members on the progress and impact they are having. We continue to look for input and suggestions from the membership on what you need from the Alliance and how we can accomplish tasks that will meet those needs.

The Board would like to thank Roland Lamy and Sean Singh for facilitating the meeting and putting together the strategic plan. They would also like to thank Derek Robertson for his input and years of service to the organization, without whom the Alliance would not be here today. They look forward to many more years of working together. In addition they would like to thank Mary Ann Barth, Pamela Betz, Patricia Dominic, Robert Fox, Kelly Green, Francine Haynes, Dan Hartmann, Gary Kress, Mark Plencner, Judy Primeaux, Joe Pugliese, Michelle Rice, William Sparrow and Ralph Woods for making the time to attend and for all of their hard work and input. The Board also thanks Katie Kralovetz who, although was not able to participate due to a last minute commitment, expressed a willingness to participate. They would also like to thank Nancy Duffy, Fred Nishioka and Jon Winay for all of their input into the process and continued work.

To obtain a copy of the strategic plan, please visit our website at [www.hemoalliance.org](http://www.hemoalliance.org) and click on the members tab.



## **Greener Pastures**

It is with great regret that we announce the resignation of Kelly Green from our Board of Directors. Kelly recently resigned from his position at Nationwide Children's Hospital in Columbus, OH after more than 15 years of service to the hemophilia community.

Kelly was a pleasure to work with and a tremendous asset to the Alliance and our Board since he was elected as a Director in 2006. Kelly has held various national and regional positions in the hemophilia community in his professional capacity as a social worker. The Alliance Board was the beneficiary of Kelly's insightful approach to issues and his measured tone provided much needed balance to many discussions. His contributions will be sorely missed.

Kelly recognized the importance of a strong Alliance of HTCs. We will continue to work to meet Kelly's high expectations of us as a Board and as an organization. We continually strive to provide the best services to you, our members, and we look forward to your help in doing so.



## **The HAGPO You Ought To Know Joe Pugliese, Executive Vice President of HAGPO**

### **Hemophilia Alliance Group Purchasing Organization**

HAGPO was formed in November of 2005 with the goal of using the aggregate purchasing power of the Hemophilia Treatment Centers (HTCs) to accomplish four primary goals:

1. Secure a "guaranteed" supply of product.
2. Negotiate better pricing for both 340 B and Non 340 B.
3. Better payment terms (either a prompt discount and/or sixty or ninety day payment terms).
4. Obtain admin fees to reinvest in the HTCs, the patient community and to promote operational excellence.

In 2007, HAGPO saved its members over \$1,000,000 in the cost of product and collected over \$400,000 in admin fees.

### **HAGPO donates \$25,000 to NHF in support of MASAC working groups.**

We took our first step in supporting the community when a check for \$25,000 was presented to Ray Stanhope, Board Chair of NHF at the January 2008 Alliance meeting. Planning for launching the HAGPO Foundation continues and we anticipate introducing the Foundation in the second quarter of 2008.

### **HAGPO accesses competitive contracts with an innovative affiliate agreement.**

There is no additional cost, nor purchase commitments for HAGPO members who wish to utilize contracts for overnight shipping, office supplies, medical and surgical supplies and a host of other non-acute goods and services. We continue to look for additional opportunities to develop affiliate and partnership arrangements for the benefit of the HAGPO membership. We are presently working on a contract with a premier coagulation laboratory to run the top twenty specialty coagulation tests at a cost reduction for members.

### **Three new members in 2008.**

We welcome Children's Hospital in Minneapolis, MN, the Nevada Hemophilia Treatment Center in Las Vegas, NV and Rush Presbyterian Hemophilia and Thrombosis Center in Chicago, IL. We now have 26 HAGPO members.

If you have any questions or would like more information please contact Joe Pugliese at [joe\\_pugliese@hotmail.com](mailto:joe_pugliese@hotmail.com) or 215-439-7173



## **Your Opinion Counts**

The Alliance will be sending out a web-based survey to its members. We are in the process of learning more about our members and what is important to them. We will be looking at things such as who are the key decision makers at your center, what are the most important issues for your center, how can the Alliance help your center to better itself and other topics? The survey will be concise and brief. We hope for 100% participation.

Once we gather the data, it will be aggregated and presented to the members at an Alliance meeting and will also be posted on our website. The data will then be used to address the topics and issues noted. If you have any suggestions regarding this process, please contact Sean Singh.

April 2008



## **Third Party Payers Update**

Anthem has begun to take action with certain independent HTC's in the Midwest, further squeezing the price point for factor distribution. While some pricing appears to be acceptable, certain products are at very low rates, some even at below acquisition. The Alliance has tried to engage Anthem in dialogue, but they are somewhat elusive. The fear is that they are seeking to conquer the network by not allowing joint discussions - the "divide and conquer theory".

Derek and Roland spoke to Aetna and received positive feedback on the role of HTC's in the network. There does appear to be certain product schemes however where HTC's are not providing service but rather service is provided by the Aetna Specialty pharmacy model. A direct meeting has been requested to explore opportunities for more formalized collaboration and to determine whether an Alliance level agreement may be a solution to assure that all members have access. We expect to hear back in April about that meeting.



## **Putting A Spin On Our Web**

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## Board of Directors

Like all non profits, the Hemophilia Alliance (the “Alliance”) has a Board of Directors that is charged with the responsibility of making sure the business and affairs of the corporation are being managed effectively and efficiently. The Alliance Board is made up of nine dedicated individuals who, in addition to their full time jobs at Hemophilia Treatment Centers, volunteer to take on this tremendous responsibility.

### How the Board Is Formed

The Board is a self electing board. This means that each year, the Board, amongst itself, elects members from a slate of candidates who are presented to the Board by a Nominating Committee. The chair of the Nominating Committee is appointed by the Board Chair and he or she is tasked with selecting individuals to serve on the nominating committee and to identify interested individuals who will form the slate of candidates. A director’s term is for 2 years, starting in January and ending in December of the following year. A director whose term is expiring can be included as a candidate if the nominating committee chooses to include them in the slate. The Alliance Board does not have term limits.

Once the Board elects the members of the new Board, then this newly formed Board meets to elect their officers. The Alliance Board has four officers: The President, Vice President, Secretary and Treasurer. One individual can not hold two positions and each officer holds their position for one year. However, officers can be reelected to their position for as long as the Board chooses to do so.

### A Brief History of the Alliance Board

The Board was established in March of 2001 when the Alliance was incorporated. At that time the Board was made up of seven directors including a President, Vice President, Treasurer and Secretary. In January 2004, the size was increased to nine directors. Over the past seven years the Board of Directors has included:

<p>William “Bill” Sparrow President 2005 to 2006 Vice President 2001 to 2005 Rotated off 2007 Cascade Hemophilia Consortium Ann Arbor, MI (Founding member of the Alliance)</p>	<p>Bruce King Treasurer 2001 to 2004 Dartmouth Hitchcock Medical Center Lebanon, NH (Founding member of the Alliance)</p>
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<p>Marisela Trujillo Vice President 2005 to 2006 Director 2001 to 2006 Gulf States Hemophilia Center Houston, TX (Founding member of the Alliance)</p>	<p>Jim Richter Director 2001 to 2002 Indiana Hemophilia and Thrombosis Center Indianapolis, IN</p>
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<p>Tim Mulherin Director 2002 to 2003 Indiana Hemophilia and Thrombosis Indianapolis, IN</p>	<p>Jeanette Ashley Director 2004 to 2006 Comprehensive Center for Bleeding Disorders Peoria, IL</p>
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<p>Laurel McKernan Secretary 2006 to 2008 Director elected 2004 Dartmouth Hitchcock Medical Center Lebanon, NH</p>	<p>Sean Singh Secretary 2004 to 2006 Vice President 2006 to 2008 University of South Florida Tampa, FL</p>
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Kelly Green  
Director 2006 to 2008  
Social Worker  
National Children’s Hospital, Hematology  
Oncology Clinic  
Columbus, OH

## Board Operations

The Board meets monthly in various ways: three times a year in person at Alliance meetings and nine times via conference calls. The Board oversees Derek Robertson who has been a consultant to the Alliance since inception and has served as the point person for all issues related to the Alliance. In addition, over the years the Board has retained other consultants and law offices to further meet the needs of its members and to further the agenda of the Alliance.

The current board is:

Robert “Bob” Fox – President since 2007  
Elected 2004  
Treasurer 2004 to 2006  
President and CEO  
Mary Gooley Cancer Center  
Rochester, NY (Founding member of the Alliance)

Pam Betz – Vice President since 2008  
Director elected 2006  
Finance Director and  
Factor Program Manager Hemophilia  
Center of Western Pennsylvania  
Pittsburgh, PA

Jon Winay – Treasurer since 2005  
Director elected 2003  
Pharmacist  
Indiana Hemophilia and Thrombosis  
Center  
Indianapolis, IN

Nancy Duffy – Secretary since 2008  
Director elected 2005  
Nurse Coordinator, Hemophilia Treatment  
Center  
Dayton Children’s Medical Center  
Dayton, OH

Patricia “Trish” Dominic  
Director elected 2001  
President 2001 to 2005  
President and CEO  
Hemophilia of Georgia  
Atlanta, GA  
(Founding member of the Alliance)

Gary Kress  
Director elected 2008  
Division Administrator  
University of North Carolina, Chapel Hill  
Chapel Hill, NC

Fred Nishioka  
Director elected 2007  
Associate Director of Pharmacy Services  
Lucille Packard Children’s Hospital  
Palo Alto, CA

Judy Primeaux  
Director 2001 to 2005, reelected 2008  
Secretary 2001 to 2004  
Director, Pharmacy and Financial  
Operations  
Mountain States Regional Hemophilia and  
Thrombosis Center  
Denver, CO  
(Founding member of the Alliance)

The Board continues to seek input from its members and is looking for ways to better serve and increase communication with the membership. Over the next few months they will be creating committees to oversee some initiatives and look forward to participation by all of its members.