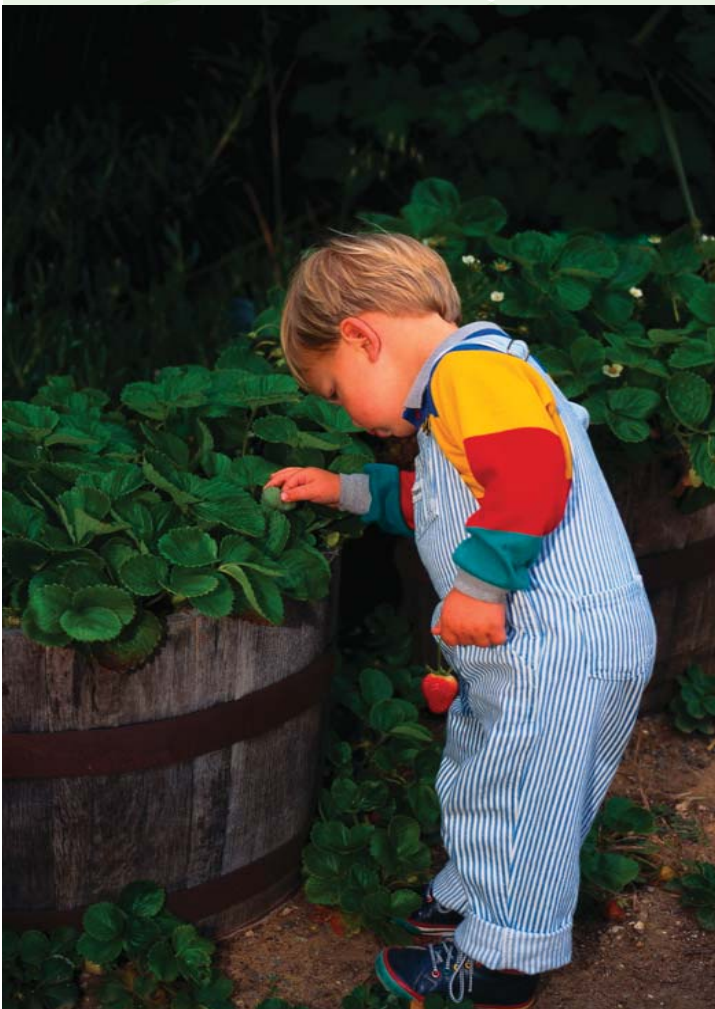




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World Federation of Hemophilia

Istanbul, Turkey

June, 2008

Submitted by Barbara Chang

This year I had the honor and privilege of attending the WHF meeting in Istanbul. The World Federation of Hemophilia has played a key role in bringing about great improvements in the diagnosis and treatment of all people with bleeding disorders, according to data presented by President Mark Skinner at the organization's XXVIII annual meeting. "We can demonstrate the quantifiable and significant impact of WFH development programs" he said. "Daily, the work of the WFH is making a difference in the lives of individuals with bleeding disorders around the world".

The flagship program known as GAP – Global Alliance for Progress, has grown out of the organization's forty-five years of experience in working with national hemophilia organizations to improve treatment and care of those in developing countries. Its purpose is to "close the gap between the estimated and the actual number of people with bleeding disorders; between the amount of treatment products needed versus that available; the gap between the number of people born with hemophilia and the number who reach adulthood" Skinner explained. The WFH's success in these endeavors is supported by data from the global survey which has been conducted annually since 1998.

It was very exciting to be among about 4,000 people from all over the world representing over 100 countries; all with an interest in hemophilia and bleeding disorders. Many patients attended the meeting along with a wide variety of caregivers, physicians and researchers. Representatives from all of the manufactures were present in a jam-packed exhibit hall. NCHS was the only Healthcare Service Company present at this Congress. A large number of scientists and investigators had an opportunity to share their findings at the poster exhibits; approximately 300 per day were on display.

I was able to attend a variety of sessions including:

- Nurses Workshop, Orthopedic Workshop
- Plenary Session with Mark Skinner reviewing 45 years of Progress
- Plenary Session with Dr. Giangrande (United Kingdom) and Dr. Gringeri (Italy) - Discussing Quality of Life in Hemophilia
- Plenary Session with Dr. Saint-Remy (Belgium) How to get rid of Inhibitors
- Plenary Session with Dr. Maureane Hoffman (USA) Animal Models of Bleeding
- The Natural and Unnatural History of Hepatitis C Virus Infection with Dr. Harvey Alter (USA)
- New Assays for Monitoring Hemophilia Treatment with Dr. Midori Shima (Japan)
- Plenary Session with Dr. Alter (USA) Advances in Management of Viral Hepatitis
- Plenary Session with Dr. Pier Mannucci (Italy) Back to the Future: A History of the Treatment of Hemophilia
- Hemophilia Care in China with Dr. Man-Chiu Poon (Canada)
- Hemophilia Care in Guam with Judith Baker (USA)

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The hospitality of the Turkish people was simply amazing. The Social program was fantastic and included a welcome ceremony opened by the Prime Minister of Turkey. There was a wide variety of typical Turkish entertainers singing and dancing with the highlight being the incredible dancers commonly known as the Whirling Dervishes.

I had the opportunity to eat wonderful food at all types of restaurants from local city street vendors to fine dining in palaces. Few people are aware of the fact that Istanbul is the only city with a bridge connecting two continents; Europe and Asia embracing crossroads of culture. Fortunately I was able to spend time after the Congress Meeting to take in some sightseeing. One cannot miss seeing the ancient architectural structures, the "Blue Mosque" the Topkapi Palace, the underground cistern, the military museum and the shopping bazaar. I took an all day tour to the city of Troy—famous for the Iliad legend of the Trojan Horse; and visited the hills of Gallipoli which commemorates thousands of fallen heroes.

In summary, this trip was a wonderful time to revisit many acquaintances throughout the world, to share thoughts and dreams of a brighter future for the bleeding disorder community and to enjoy the beauty and history of Istanbul.

Putting on a good Face

By David S. Espinosa
President



At National Cornerstone, much of our success is due to the NCHS team and the ability of each member to work and otherwise interact with clients and each other. Professional ability alone isn't necessarily enough—it's important to develop relationships. No one symbolizes that quality more than Tami Velazquez, our administrative assistant who, in many respects, is the "face" of our company.

The Covina native has an unusual background. She graduated from Northern Arizona University with two very disparate degrees: a Bachelor of Science degree in chemistry and a Bachelor of Arts degree in music appreciation and theory. After graduation she helped establish a home health agency before joining a major health provider as a surgery scheduling coordinator/unit secretary, both of which set her on the path to joining NCHS in December 2004.

At NCHS, Tami greets visitors, including vendors, receives and routes incoming phone calls, creates correspondence, processes mail, compiles meeting informational packets, makes travel reservations, orders supplies, and more.

"I suppose in some respects I am the "face" of the company," she said, "since I am often the first person that visitors or callers come in contact with."

That in itself is a big responsibility and one that Tami doesn't take lightly.

"I try to let everyone know they're appreciated, whether it's co-workers or external customers—even if I don't know them personally. I try to show them consideration and a welcoming attitude. If I treat my co-workers and our visitors the way that I hope they'll treat me, then everyone comes out ahead."

The Golden Rule seems to work. Tami finds the pleasant way that others react to her positive demeanor and her success meeting their needs—the overall friendly manner in which she is treated—among the most rewarding aspects of her work.

On the personal side, Tami and her husband, Fernando, have a 2-year-old daughter, Zarina.

Although Tami has been with us for three years, her pleasant, caring attitude is new every day. We're pleased to introduce her as a valued member of the NCHS team!

Mark Your Calendars

Reaching New Heights

The National Hemophilia Foundation (NHF) will host their 60th Annual Meeting in Denver, Colorado; November 13-15, 2008. The hotel will be the Hyatt Regency at the Colorado Convention Center.

Plan to stop at the NCHS exhibit **booth #411**. Meet new and old friends and gather some goodies along with educational information about health and fitness.

Join us at the meeting for three full days of programs, workshops, networking opportunities and fun social activities. This year individuals and families are urged to attend two preconference symposia just for them – "Empowering at Every Life Stage" and "Insurance – Playing the Game to Win". Harvey Alter, MD, an NIH premier research physician who identified the hepatitis C marker, will provide a special plenary session for providers. Don't miss the kung fu workout for consumers. There is something for everyone! See you in Denver!

Denver has been voted the most fit and we might add, most beautiful city!

For more information please visit the NHF website www.hemophilia.org

Bio2008

Heal Fuel Feed

A report by Barbara Chang

There was an unexpected opportunity to attend a Biotech Conference Jun 20-23, 2008 offered to me. The Hemophilia Federation of America was given a complimentary admittance to this meeting; I was selected because of my geographical proximity to San Diego, California.

At first, I had minimal interest; after all – how exciting could a meeting be with such a short title: Bio2008? There were many surprises in store for me.

Who would have imagined 30,000 people attending this annual convention? There was a wide range of personnel from corporations; including CEOs and Presidents as well as students and lab bench technicians. The audience included manufacturers, researchers of all levels, venture capitalists, non-profit organizations and many consulting firms. Many components of the Bio tech world were represented; people from 70 countries, 48 states, and over 4000 persons from California. The types of business represented included large pharmaceutical manufacturers, research of every kind from both large and small facilities, financial institutions and investors. Many representatives from foreign countries as well as various US locations shared their capabilities and demonstrated the opportunities of their locale.

The San Diego Convention Center is a huge facility and Bio2008 made use of all of the space. One needed a guide map to

Kids Corner



Hemophilia Cartoon

Would you believe, a cartoon about hemophilia has been produced in India.

This is a great educational and public relations cartoon from the Hemophilia Federation of India. Check it out on You Tube: <http://www.youtube.com/watch?v=F0ZoEGnTAM0>

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navigate through the 4000 exhibits. In spite of the immense size everything was relatively easy to find. Color coordinated maps, online help and personal guides everywhere all provided assistance. A three course meal was served for lunch each day to 30,000 people.

Guest speakers included the Bio President & CEO, Jim Greenwood, Dr. J. Craig Venter known worldwide for his pioneering work in sequencing the human genome, Governor Arnold Schwarzeneger and Governor Sonny Perdue of Georgia (2009 meeting site), and the absolute best, most impressive speaker General Colin Powell (Ret.).

In essence, my attitude toward Biotech has greatly expanded. The "tag line" used throughout the entire meeting: **Heal Feed and Fuel the World** sums up the need for Biotech. Admittedly, my personal focus was tainted and only encompassed my interest and knowledge of health care. Little did I consider the ramifications of Biotech Research for increasing and enhancing our food supply and alternate sources of energy.

Yummy Honey Chicken Kabobs

Submitted by Tami Velazquez

Ingredients:

1/4 cup vegetable oil
1/3 cup honey
1/3 cup soy sauce
1/4 teaspoon ground black pepper
8 skinless, boneless chicken breast halves-cut into 1 inch cubes
2 cloves garlic
5 small onions cut into 2 inch pieces (optional)
2 red bell peppers cut into 2 inch pieces (optional)
2 baskets of mushrooms (optional)
2 zucchini, cut into 2 inch pieces (optional)
Skewers

Directions:

1. In a large bowl, whisk together oil, honey, soy sauce, and pepper. Before adding chicken, reserve a small amount of marinade to brush onto kabobs while cooking. Place the chicken, garlic, onions, mushrooms, zucchini, and peppers into the bowl and marinate in the refrigerator at least 2 hours (the longer the better).
2. Preheat the grill for high heat.
3. Drain marinade from the chicken and vegetables, and discard marinade. Thread chicken and vegetables alternately onto the skewers.
4. Lightly oil the grill grate. Place the skewers on the grill. Cook for 12 to 15 minutes, until chicken juices run clear. Turn and brush frequently with reserved marinade.

NCHS Awards Scholarship



This year we received many applications from students throughout the U.S. We are committed to the hemophilia community and we are proud to offer this assistance.

Juanita Fish from Detroit, Michigan is a nursing student and the proud mother of her son, Johnathan.

Here is a quote from Juanita's essay:
"When you are down and out and don't know where you will get money

needed for books and supplies, a scholarship award is like receiving a million dollars. Humbly receiving this scholarship has renewed my zeal for becoming a nurse. I am grateful to NCHS for offering this opportunity to families in the hemophilia community. It has been my great honor to receive it."

One Family's Dilemma

For years, 5-year-old Mason Harrison, who has mild hemophilia A, received all the factor he needed. It arrived quickly with all the required ancillaries, and his specialty pharmacy was well-informed and always available to answer any questions that his parents had.

Out of the blue the Harrisons learned that a Blue Cross-owned pharmacy would now provide their factor. They did not receive the 30-day change notice Blue Cross said it had mailed; only when Mason's mother, Monica, called to place his usual order was she advised of the change. No appeal process was provided.

Since then, things have gone from bad to worse for this family—and for many other families who were notified that they must begin receiving their factor from Blue Cross-owned pharmacies. The last straw? The new pharmacy does not have a special fund, and the Harrisons must pay a share-of-cost totaling \$5,000 annually—a cost they cannot afford. The pharmacy's hardship coordinator denied the Harrison's request for an application for a financial hardship after deliberating for less than a minute. Monica called the entire scenario "stinky."

"When I called to fill Mason's prescription, the pharmacy had no idea what diagnosis the medication he takes was for," Monica said. "I had to educate them all the way through the conversation."

Under the new arrangement factor arrives in up to a week instead of one day. Ancillaries are no longer included. Instead of the usual 12 applications of 1,000 units each, the Harrisons now receive 24 applications of 500 units—meaning Mason's infusions, which he fears, must be mixed and now take longer to complete.

There have been other problems. The Harrisons hesitate to call with questions because the new pharmacy appears to be uninformed about hemophilia. In fact, the family was sent port ancillaries (Mason receives injections), leading Monica to believe the company is unfamiliar with both Mason and the infusion processes. Factor is short-dated (approx 8 months), making the expiration of factor likely since Mason is a mild hemophiliac.

"Our service has been awful," Monica said. "We never had a problem with our other pharmacy. They were available 24/7 if we ever had a problem, and they anticipated our needs. Now, we're in a bind both service-wise and cost-wise."

She added, "I really believe they couldn't care less. I don't know what we're going to do."



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Gettin' in the Game

Junior National Championship

The Junior National Championship presented by CSL Behring and hosted by Michigan State University Center for Bleeding and Clotting Disorders was a huge success! Only four locations throughout the United States were selected for this event. On Saturday August 9th the families in Michigan gathered at the Forest Akers West Golf Course at Michigan State University for a day filled with fun, friendship, and a little competition. There were two categories golf, and baseball and kids ranging from ages 7-18. There were three winners in each category. Each participant received a medal. Three children – the baseball competition winner, the golf competition winner, and the raffle prize winner all received a trip for themselves and two accompanying adults to Denver, Colorado to attend the 2008 NHF Annual Meeting, plus a huge trophy. Second and third place winners received a framed certificate. All the participants were given autographed baseballs and golf balls from two very special quests.

Perry Parker a professional golfer who has played on the Asian, Australian, Canadian, Nike and PGA tours, and in three US Opens. He has won more than 30 professional golf tournaments in California. Perry has mild hemophilia A.

Jesse Schrader is a left-handed pitcher who plays semi-professional baseball for the Canton Stallions in the Cleveland, Ohio area. Previously, Jesse was drafted by the Florence Freedom and played a year of minor league baseball. Jesse has moderate hemophilia A.

We could not have asked for a better day. The weather was perfect. The families had an opportunity to socialize and enjoy this event that was safe and healthy for their children. I was truly amazed to see how many of the boys my eight year old son Stone already knew. These boys had bonded at other events like hemophilia camp and Lansing Days and were excited to see each other. Stone entered into the baseball competition and took home a third place award. Younger children were allowed to participate although they were not eligible to win. I overheard a young boy, about 4 years old say "This is the best day ever".

Thank you CSL Behring and MSU Center for Clotting and Bleeding Disorders for making this a special day. A special thank you to Jean Huebner with CSL and Karen Boyd with MSU for making this event happen.

Wyeth's XYNTHA Approved by FDA for Treatment of Hemophilia A

Announcement by Richard Aguilar, Pharm.D., Aero Apothecary

Collegeville, Pa., Wyeth Pharmaceuticals, a division of Wyeth (NYSE:WYE), announced that it has received approval from the U.S. Food and Drug Administration for XYNTHA™ (Antihemophilic Factor [Recombinant], Plasma/Albumin-Free),

a recombinant factor VIII product, for patients with hemophilia A for both the control and prevention of bleeding episodes and surgical prophylaxis. XYNTHA (pronounced "ZIN-tha") is manufactured using a completely albumin-free process and state-of-the-art nanofiltration purification technology. In addition, XYNTHA is the only recombinant factor VIII product to utilize an entirely synthetic (non-human and non-animal based) purification process in its manufacture.

Until now, the purification process for all recombinant factor VIII products used monoclonal antibodies derived from mouse cell lines. In the manufacture of XYNTHA, the mouse monoclonal antibody is replaced with a synthetic peptide ligand, which was invented by Wyeth scientists.

"XYNTHA is important for hemophilia A patients because it establishes a new standard in recombinant factor VIII product purification technology," says Robert R. Ruffolo, Jr., Ph.D., President, Wyeth Research, and Senior Vice President, Wyeth. "This is another example of Wyeth's continued commitment to the advancement of science in the treatment of hemophilia."

The safety and efficacy of XYNTHA in the prevention and control of bleeding episodes and for surgical prophylaxis for patients with hemophilia A has been demonstrated in pivotal clinical trials.

Genetic Information Nondiscrimination Act Passes in House and Senate

On May 1, 2008, the United States House of Representatives passed the Genetic Information Nondiscrimination Act (GINA, S.358) by a vote of 414-1. A week earlier, on April 24, 2008, the United States Senate passed the bill by a vote of 95-0. The passage of this historic legislation follows a 13 year effort by a broad coalition of grassroots organizations including the National Hemophilia Foundation and the Hemophilia Federation of America.

The bill prevents employers and insurance companies from requesting genetic testing or information. It also prevents discrimination against someone because of his/her genetic markers, not those who have been diagnosed with specific conditions. However, it helps individuals make proactive decisions about genetic testing and counseling without fear of certain negative consequences, including employment or insurance discrimination.

It is important to educate all affected groups and individuals about the implications of the new law, and to be vigilant about its observance.

About Hemophilia A

Hemophilia A is a rare, inherited blood-clotting disorder. People with hemophilia A are deficient in a key protein — factor VIII — which is vital in the clotting mechanism to prevent bleeding. Hemophilia A can be characterized by spontaneous hemorrhages or prolonged bleeding, typically into joints and soft tissue. Most patients with hemophilia A are dependent on factor VIII replacement therapy.

Indication

- XYNTHA™ Antihemophilic Factor (Recombinant), Plasma/Albumin-Free is indicated for the control and prevention of bleeding episodes in patients with hemophilia A and for surgical prophylaxis in patients with hemophilia A (congenital factor VIII deficiency or classic hemophilia).

- XYNTHA does not contain von Willebrand factor and, therefore, is not indicated in von Willebrand's disease.

Important Safety Information

- Allergic type hypersensitivity reactions are possible. Patients should be informed of the early signs or symptoms of hypersensitivity reactions [including hives (rash with itching), generalized urticaria, tightness of the chest, wheezing, and hypotension] and anaphylaxis. Patients should be advised to discontinue use of the product and contact their physicians if these symptoms occur.

- Inhibitors have been detected in patients receiving factor VIII containing products. In a pivotal phase 3 study, two of 89

patients (2.2 percent) who completed > 50 exposure days developed factor VIII inhibitor. These results were consistent with the pre-specified endpoint of the study. Patients using coagulation factor VIII products, including XYNTHA, should be monitored for the development of factor VIII inhibitors. If expected factor VIII activity plasma levels are not attained, or if bleeding is not controlled with an appropriate dose, an assay should be performed to determine if a factor VIII inhibitor is present.

- XYNTHA contains trace amounts of hamster proteins. Patients treated with this product could develop hypersensitivity to these nonhuman mammalian proteins.

- When clinically indicated, patients should have plasma factor VIII activity levels monitored by the one-stage clotting assay to confirm that adequate factor VIII levels have been achieved and are maintained.

- The most frequently reported adverse reactions in clinical studies were headache and fever.

Please see XYNTHA full Prescribing Information available at www.wyeth.com.