

Last year, the National Hemophilia Foundation's Medical and Scientific Advisory Council (MASAC) adopted new guidelines for pre- and postpartum care for women with bleeding disorders (or at risk for a bleeding disorder) and those who are carriers for hemophilia A and B.

(For more information, see the full article in this issue of the BloodLine)

EDITOR:
Nancy Patrilla

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From the President . . .

By Kari Atkinson and Brian Unruh

With each Annual Meeting comes many changes for HOI. During the annual meeting, we say welcome to new Board members, farewell to some Board members, and sometime shift the officers for the HOI Board leadership. A special Thank You to our past Board members: Jennifer Adams, Ashely Druckenmiller and Cathy Treichel. Your dedication, passion and special skill set you each brought to the table during Board meetings will be missed. On a happier note...We welcome the following new Board members: Julie Castenson, Bobbie Kincaid, Nancy Golden and Bill Laughlin.

This past April, I announced my intention to step down as the President of HOI to the Board of Directors. The past 4 years as your president have been an unbelievable experience for me and my family. My current position and role for the HOI Board is now the newly created position of...HOI Past President. This new role will allow me to work with the executive committee to help with transitions and to share the knowledge I have learned over the past 4 years as your leader. In writing my last president's article, I would like to share with you that Craig and I felt so welcome in this community when our son Beau was diagnosed with hemophilia in 2003. We still remember like it was yesterday coming to our first Annual Meeting with Jordyn, then 6 years old, and Beau, almost 2 years old. We did not know a soul except for the Hemophilia Treatment Center nurses. We had decided it would be best to get involved, and little did we know how wonderful this community would be! It truly is a 2nd family to us, and we do not plan to be strangers at all in the upcoming years. Because of this community, we feel we have great tools and resources to raise a happy, healthy family, even with a bleeding disorder involved.

With that said, this article is now going to be concluded with something from your

(continued on page 6)



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Fall Family Day at the Pumpkin Patch

By Kari Atkinson

Sunday, October 17, 2010, the First Step group had a Fall Family Education Day. Mike Parker from Iowa City was our guest speaker and Mike spoke on the topic of "The Motivating Parent." Mike's summary of the talk to all of us is this: *"Motivation affects everyone's life every day. When you are motivated, you are much more likely to achieve your goals and overcome your challenges. As motivated parents, you will inspire others to do the same as well."*

I think I can speak for everyone in attendance by saying that there were many things that Mike talked about that we could all implement into our lives. These things would have a positive impact on our children and how we react to different situations. After a great lunch and camaraderie by all the families in attendance, we were off to the Pumpkin Patch. Carroll's Pumpkin Patch in Grinnell, Iowa, was the scene for us to have a great day. The weather was perfect, and Mary McCarthy planned a wonderful day. All families were treated to a Halloween Safety Tip Treat Bag, a family pumpkin to take home, small pumpkins to paint for the kids and some Pumpkin bucks so families could enjoy the things that cost a little also.

We want to say a special Thank You to Mary McCarthy for all her work

helping me plan the event, Tammy & Whitney Bullock for helping plan and execute the childcare and, of course, to our SPONSORS.

Watch your mail for the upcoming 5th Annual First Step Family Education Weekend coming in January 2011.

If anyone is new to receiving this BloodLine and wonders what First Step is, it is a program offered through the National Hemophilia Foundation and is designed to provide education and support for families with children aged 0-8 who have a bleeding disorder. Please feel free to contact your First Step Parent Coordinators, Kari Atkinson (319)721-3964 caklatkinson@aol.com or Mary McCarthy (641)895-2214 johnclaudesmom@yahoo.com. If you are not comfortable contacting us directly, please feel free to contact either Mike, Tami and Karla at the treatment center so they can share with you information about this program. We would be more than happy to help you and your family in any way that we can.

This event would not have been possible without the financial support of our the following sponsors:

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Annual Meeting 2010

The HOI Annual meeting was held on September 17-19, 2010, at the Cedar Rapids Marriott, Cedar Rapids Iowa. The weekend was packed with education, camaraderie and downright FUN.

Friday night we enjoyed time together as a community. It is often like a family reunion as families arrive; and, during this time, we were welcomed to our vendor area where companies were set up to showcase their products and services that are available to our members.

Saturday the kids were off to Camp Tanager for the childcare program with some light hemophilia education, teen workshop and then off for even more fun at either the Playstation or Planet X. They were exhausted when they got off the bus, which is usually a clear sign that pure fun was had by each of them!

Saturday for the adults included more vendor time during various time slots, sessions on the Past, Present & Future of Bleeding Disorders, a woman's session of HELP! My Merry Go Round is in Full Speed, and a men's session of A Time to Connect. Then concurrent sessions were held the rest of the day which consisted of Pain Management, Helping Your Child through School, Encouraging Independence, Infusion,

Overview of vWd, and Clients and Families in Crisis.

Our Saturday evening festivities included heading out on school buses to Bloomsbury Farms. The group enjoyed a great home-cooked meal, activities, haunted houses and a bonfire with s'mores. The weather was a little difficult but the rain did stop long enough for us to truly enjoy the evening there; we just cut it a little short. Back at the Marriott, some enjoyed the pool, some watched the Hawkeyes or some just found a couch and got caught up with other members.

Sunday morning we enjoyed a nice breakfast, a program called Living Fit Diet and Exercise. Our scholarship recipients were recognized, raffle prizes given out and announcement were made of the names of the newly elected HOI Board members. It was a fun, energizing, exhausting weekend all wrapped into one. A special Thank You to the committee....Stacie Cowen, Ashley Druckenmiller, Jennifer Adams, Kari Atkinson, Rachelle Nolan and Laurie Anderson-White.

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Family Fun Education Day

By *Rachelle Nolan*

On Sunday, July 18, nearly 100 members of Hemophilia of Iowa attended Family Education Day at Lost Island Water Park in Waterloo, Iowa.

The morning started out early, before the park even opened actually, with breakfast, social time and a chance for families to visit with sponsoring vendors. The theme of the event was Hemophilia Around the World, and each family was sent home with a book full of interesting facts about what it is like to have hemophilia in different countries. The book featured chapters on Botswana, Japan, Russia, Nepal, Mexico, France and Egypt. The treatment of bleeding disorders in these places is significantly different than here in the United States. Many families commented on how much they appreciated reading about hemophilia around the world and how lucky we are to live in the United States to receive such excellent health care.

Tracey Peters, from the University of Iowa Hemophilia Treatment Center was the featured speaker on Research. She discussed how the HTC determines which research studies and clinical trials to participate in, how every study is optional to patients and families to participate in, and what lies on the horizon for future research studies. At the conclusion of the research session, members were allowed to enter the water park for the day. The group reconvened at lunch time for more social time and then families were free to enjoy



the rest of the beautiful day in the water. It was a fun and educational day that all who attended enjoyed.

Thank you to all who attended; and, if you weren't able to make it to this event, we hope to see you at our next event!

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Scholarship Thank You



Thank you for selecting me as a recipient of the Hemophilia of Iowa Scholarship award. I will be in my second year at Hawkeye Community College this fall trying to finish my Gen Ed courses. I am exploring different career opportunities and plan on attending UNI next fall. Your financial support is greatly appreciated!

Sincerely,
Heather Hauser

New York Governor David Paterson signs S. 5000-B into Law!

S. 5000-B gives the New York State Insurance Department the authority to deny requests from insurance companies to create specialty drug pricing tiers, also known as Tier IV drug pricing. These types of tiers have been used by insurance companies in other states to require patients to pay higher co-payments and co-insurance based on the costs of the drug or the condition it is prescribed for. New York State has become the first state to pass a bill banning cost sharing deductibles and co-pay practices.

For more information on S. 5000-B, go to the New York State Assembly website.

(Editor's Note: Why print something about New York? Because if it can happen in one state, it could happen in Iowa!)

Board Profile



Beate and Jerry Keith

Beate Keith has served on Board since 2009

My husband (Jerry) and I have enjoyed being HOI members for many years. We have 6 children and 21 grandchildren. We reside in Muscatine, Iowa.

I retired July 1, 2010, from HNI (Customer Service Rep.) in Muscatine; and my husband retired 3 years ago from Muscatine Power & Water (Inventory Control Warehouse Supervisor). Even though we are retired, we are busy with church, volunteer work, grandchildren's athletic/school events, camping, sewing, knitting, gardening, woodworking and other hobbies.

Doctors told my parents that I was a bleeder but it wasn't until I was seen at the Hemophilia Treatment Center in 1990 that I was diagnosed with a rare Dysfunctional Platelet Disorder.

I have had the privilege of serving on the Hemophilia of Iowa Board since 2009; and through the bleeding disorder community we have had the opportunity to participate in numerous educational, family, and adult events.

Thank you for giving me the opportunity to serve on the Hemophilia of Iowa Board!

Beate Keith, HOI Board Member

Did you know . . .

that the membership application, payment of your dues and/or making a donation can now be done online?

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www.hemophiliaofiowa.com

for more details.

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From the President . . .

(continued from page 1)

newly elected President, Mr. Brian Unruh:

We are in the midst of the season change from summer into fall, and then into winter. Hemophilia of Iowa is also going into a transition of change. At this past Annual Meeting, I was fortunate to receive my second term on the Board; and I was also voted in to carry on the work that Kari has done as president.

I want to take this opportunity to thank Kari again for all of her talents and energy she has spent over the past four years as president. We have gotten stronger and better as an organization under her leadership, and we are lucky to still have her on the Board for at least another year.

I look forward to working with the Board and am excited at what we have in store for the upcoming year. There is a lot to be done to continue to meet the needs of our families in Iowa. Our executive committee will be an important part of the leadership as well this year. Julie Castenson is our Secretary. Laurie Anderson White is our Treasurer, and Rachele Nolan is our Vice President.

As an executive committee, we look forward to serving HOI this year. Feel free to contact any of us for more information on getting involved with HOI.

HFA Educational Symposium 2011

Mark your calendars for the HFA Educational Symposium scheduled for April 14-16, 2011 at the Marriott Downtown, Louisville, KY.



Pfizer Receives FDA Approval for Prefilled Dual-Chamber Syringe for Use in the Treatment of Hemophilia A

Pfizer Inc. announced that the U.S. Food and Drug Administration (FDA) has granted approval of the use of a Prefilled Dual-Chamber Syringe for administration of XYNTHA® Antihemophilic Factor (Recombinant) Plasma/Albumin-Free to hemophilia A patients. XYNTHA is a recombinant factor VIII product indicated for both the control and prevention of bleeding episodes in patients with hemophilia A (congenital factor VIII deficiency or classic hemophilia) and for surgical prophylaxis in patients with hemophilia A. XYNTHA does not contain von Willebrand factor and, therefore, is not indicated in von Willebrand's disease.

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Hemophilia & Genetics

One hundred years ago, the term genetics didn't even exist in the English language. At that time, scientists were just beginning to see and understand what would eventually blossom into the young science of human genetics.

Today, we know that there are thousands of genetic diseases, and we seem to hear or read about new genetic medical discoveries and breakthroughs every month. We've come a long way in a short time.

But just what does the term genetics actually mean?



Hemophilia through History

Let's take a look at hemophilia. Since Biblical times, people have recognized that hemophilia runs in families. Men with hemophilia tended to have male relatives with the same disease, usually on the mother's side of the family. Despite this recognition, the way in which a disease like hemophilia was transmitted within families remained unclear until well into the 20th century.

Now we know that hemophilia is a genetic disease, which means the disease occurs because specific genes are not properly working. Genes and other pieces of the genetic puzzle may sound intimidating, but they're really

not, as you'll see below.

The Genetics Home Reference of the National Library of Medicine provides basic information about genetics in clear language. Their website hosts a handbook that can be downloaded. <http://ghr.nlm.nih.gov/handbook>

Understanding How Hemophilia Occurs

For many people, understanding the term genetics represents a giant, unsolvable puzzle. But genetics doesn't have to be complex. To begin building a solid understanding of the genetic nature of hemophilia, you really need to be familiar with only five straightforward pieces of the puzzle.

Genes: Genes are the master planners of the body. They are tiny units of heredity within each of the millions of cells in your body. Genes are the blueprints that tell cells what to do. The 30,000 or so genes in our bodies contain instructions that determine everything physical about us. For example, some genes tell eyes to be blue or brown. Other genes result in brown, blonde, or red hair. Some genes tell cells to make clotting factors to help blood clot. We get our genes from our parents.

Chromosomes: Genes live on structures within each cell called chromosomes. Think of chromosomes as tiny, threadlike packages of genes. Each cell contains 46 of these packages arranged in 23 pairs. You get half of each pair from your mother and the other half from your father. One pair of these chromosomes determines your gender. Females have two X chromosomes, while males have an X and a Y chromosome.

The genes responsible for the production of Factors VIII and IX reside on the X chromosome. That's why hemophilia is sometimes called an X-linked disorder. It's also why males

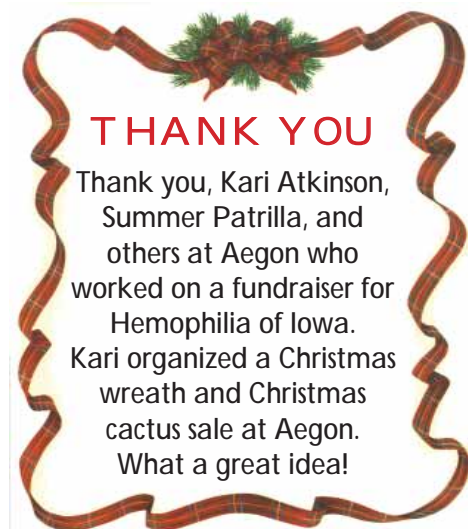
typically get hemophilia, as you'll see below.

We've already discussed how genes determine your physical traits and tell cells what to do. Sometimes there are problems with the genes that result in disease. Genetic disorders are caused by mutations in a gene or a set of genes. Mutations are changes in the gene that can happen at any time, from when we start out as a single cell to when we are 100 years old. In the case of hemophilia, a mutation causes a single gene to be altered or missing.

Hemophilia is an X-linked disorder. Hemophilia is more common in males because males have only one X chromosome. Hemophilia is usually not seen in females because females have two X chromosomes and one X chromosome can mask the problem of the other. Instead, the female is a carrier of the disease. She has the potential of passing on hemophilia to her children. Recent advances in genetic testing allow women from families with hemophilia to learn whether they are carriers and therefore at risk for having children with hemophilia.

Intrigued?

Visit the following website for the rest of the story...<http://thereforyou.com/about-hemophilia/gist-of-genetics>



Research Update: Lab Rats Could Enhance Hemophilia Research

In September, investigators from the Yale School of Medicine (YSM) revealed the discovery of a new animal model for future hemophilia A research—lab rats. The lead investigator of the study was Carmen Jane Booth, DVM, PhD, assistant professor of comparative medicine and co-director of Mouse Research Pathology at YSM.

Booth and her colleagues made their discovery among a previously healthy colony of inbred lab rats that began showing symptoms of hemophilia, including bruising, prolonged bleeding from minor wounds and swollen joints. Once environmental factors were ruled out, the researchers suspected an inherited bleeding disorder. They sequenced the rats' DNA and found a mutation similar to the one responsible for hemophilia A in humans. Additional tests confirmed that the rats had decreased levels of factor VIII, consistent with

a diagnosis of hemophilia. "When we discovered that I was like a kid in a candy shop," Booth said.

Other animals used as test subjects for hemophilia research have limitations—mice are too small for some studies and dogs are too expensive, concluded the authors. Ethical considerations associated with using dogs can also be a potential obstacle. In contrast, rats could make ideal subjects due to their size, unique genetic mutation and bleeding manifestations.

"First, the location of the mutated gene [for hemophilia A] is different than it is in other animals, so both males and females are affected equally," said Peter W. Marks, MD, PhD, an associate professor at YSM. "Rats are also a nice size, large enough to test a pump and other treatment methods that wouldn't quite work on a mouse."

"Ultimately, we plan to translate this

model for use in developing gene therapies and evaluating novel therapeutics for treating people with hemophilia A," concluded Booth.

The study, "WAG-F8m1Ycb Rats Harboring a Factor VIII Gene Mutation Provide a New Animal Model for Hemophilia A," was published in the online version of the *Journal of Thrombosis and Haemostasis*.

Sources: Yale School of Medicine, September 2, 2010, and *Yale Daily News*, September 8, 2010

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Plants Help Prevent Inhibitors and Allergic Reactions

Using genetically modified plants, researchers from two Florida universities are developing a technique that could help prevent treatment-related complications such as inhibitors, an immune reaction that neutralizes infused factor, and anaphylaxis, severe allergic reactions, in people with hemophilia B. The lead authors of the study were Dheeraj Verma, PhD, Department of Molecular Biology and Microbiology, College of Medicine, at the University of Central Florida (UCF) in Orlando and Babak Moghimi, MD, Department of Pediatrics, College of Medicine, at the University of Florida (UF) in Gainesville.

Inhibitors result in approximately 25% of patients with hemophilia A and up to 4% of patients with hemophilia B. Clinicians often use immune tolerance (IT) induction to eliminate an inhibitor. By administering daily doses of factor over time, the body begins to tolerate the therapy. The process is similar to desensitization therapy used to treat food and environmental allergies. The technique is less effective in individuals with hemophilia B than in those with hemophilia A. In addition, because of the large amounts of factor used, IT becomes very expensive. The approach being developed by Verma, Moghimi and colleagues could be more cost effective.

The researchers used a so-called “gene gun” to insert the genetic material that manufactures factor IX (FIX) into chloroplasts, the energy production centers of plants. They then fed the modified plants to mice with hemophilia B for a prolonged time period. Insulated from digestive acids and enzymes by durable plant cell walls, the FIX protein traveled through the stomach and into the small intestines. Once inside the small intestines, bacteria then broke down the cell walls and released the protein, which induced tolerance by the immune system.

“We have made them develop tolerance, and removed the allergic part of this treatment,” said coauthor Henry Daniell, PhD, a Pegasus professor and University Board of Trustees Chair in the College of Medicine at the UCF.

Later the mice were infused with factor product, which triggered little to no inhibitor responses and no anaphylactic events. “I think this is a milestone - nobody has previously achieved such levels of robust immune tolerance by any means using a noninvasive procedure,” explained Thierry Vandendriessche, PhD, an associate professor of medicine at the University of Leuven in Belgium, who was not involved in the study. He is president of the European Society of Gene Cell Therapy.

Investigators will conduct follow-up studies to test the approach in mice with hemophilia A and then carry out

trials in humans using lettuce to produce the therapeutic proteins.

“We’re hoping that our research will, in the future, result in better and more cost-effective therapies,” said study co-author Roland Herzog, PhD, an associate professor of pediatrics, molecular genetics and microbiology in the UF College of Medicine and a member of the UF Genetics Institute. Herzog received the National Hemophilia Foundation’s Career Development Award in 2000.

The study, “Oral Delivery of Bioencapsulated Coagulation Factor IX Prevents Inhibitor Formation and Fatal Anaphylaxis in Hemophilia B Mice,” was published in the April 2010 issue of the Proceedings of the National Academy of Sciences.

Source: *e! Science News*,
March 30, 2010

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LOG NOW...You'll be Grateful Later

What is so important about an infusion log? A lot! Infusion logs, when used appropriately, can help keep you organized and provide clues into your therapy's effectiveness. In essence, they provide two valuable things: information and insight.

Information: Let's face it, our memories sometimes fail us. We all have days when we can't remember what we ate for breakfast, let alone when we last infused or ordered supplies. Keeping an infusion record takes the pressure off you and having to rely on your memory. Here's a helpful trick to make logging easier: When you infuse, take the sticker off the factor bottle and apply it to that day's date on your log's calendar with a short note (i.e., "prophylaxis" or the type of bleed). By applying the sticker to the calendar, not only do you have a record of the date you infused but also the factor's date of expiration, the number of units received as well as the factor's lot number if there's a product recall.

Insight: If bleeds start occurring more frequently and you're not sure why, your infusion log could provide some clues. Maybe your weight has changed, requiring a change in dosage amount. Maybe the bleeds are happening on days when you're more active and you need to adjust your infusion schedule accordingly. If you're having recurring bleeds that are not responsive to factor, your body might be developing an inhibitor. Whatever the case, make sure you bring your infusion log with you when you see your hemophilia provider. He or she can review it for clues to what's causing your bleeds and then adjust your treatment plan.

While it might seem like a hassle now, recording the details of your therapy makes life easier for you and helps your care team better manage your bleeding disorder. So take the time to use your infusion log--make it a habit and make it a priority!

Source: Walgreens *The Infusion Inquirer*,
Volume 10, Number 4

SEVEN REASONS TO KEEP AN INFUSION LOG

1. Serves as an accurate record of your bleeding history.
2. Assists in the development of an individualized treatment plan.
3. Over time, reveals patterns of bleeds and helps prevent the possible development of a target joint (a joint that has had repetitive bleeds).
4. Helps monitor appropriate dosage; for example, when your weight changes, the dose may need to be adjusted.
5. Helps identify the development of an inhibitor.
6. Assists in accurately monitoring product usage and home inventory.
7. Provides important information if there are any product recalls.

Source: Walgreens *The Infusion Inquirer*,
Volume 10, Number 4

Did you know?

People who have a regular primary care provider:

- Are more than twice as likely to receive recommended preventive care.
- Are less likely to be hospitalized
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Pregnancy Guidelines Help Define Proper Prenatal, Delivery and Postpartum Care

Last year, the National Hemophilia Foundation's Medical and Scientific Advisory Council (MASAC) adopted new guidelines for pre- and postpartum care for women with bleeding disorders (or at risk for a bleeding disorder) and those who are carriers for hemophilia A and B. While the guidelines are largely intended for healthcare professionals, they are worth knowing if you're a woman with a bleeding disorder or are a carrier and you plan to become pregnant.

PRECONCEPTION

Girls and women who are at risk for being carriers of hemophilia A and B, severe von Willebrand disease and other severe bleeding disorders should have their bleeding disorder status determined before they become pregnant. This may include:

- Testing levels of clotting factor
- Genetic mutation analysis (if those clotting factor levels prove inconclusive)
- Preconception genetic counseling

PREGNANCY

Pregnancy should be managed by a multidisciplinary team of specialists knowledgeable in bleeding disorders. This includes a coagulation disorders specialist, an obstetrician and an anesthesiologist.

LABOR AND DELIVERY

Because women with bleeding disorders are at risk for bleeding complications during pregnancy and during and after delivery:

- Women should give birth in a facility that has the appropriate laboratory, pharmacy and blood bank support.
- A plan for the management of childbirth should be in place well before delivery. This includes discussing the maternal and fetal risks of a vaginal delivery versus a planned caesarean delivery.

UMBILICAL CORD BLOOD SAMPLING

- Umbilical cord blood should be obtained through proper technique at the time of delivery in order

to ensure earliest testing and avoid having to draw blood from the infant.

POSTPARTUM

Postpartum care should include active monitoring and management to reduce blood loss and the risk of postpartum hemorrhage. Depending on the woman's bleeding disorder and health status, this includes:

- Administration of antifibrinolytics (agents that promote clotting)
- Monitoring of factor levels
- Prophylaxis therapy for at least three to five days postpartum (if the woman's bleeding disorder requires clotting factor replacement therapy)

Your OB/GYN and primary care physician should be familiar with the guidelines. If not, you can provide a copy from the NHF website: www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=57&contentid=1436

Source: Walgreens *The Infusion Inquirer*, Volume 10, Number 4



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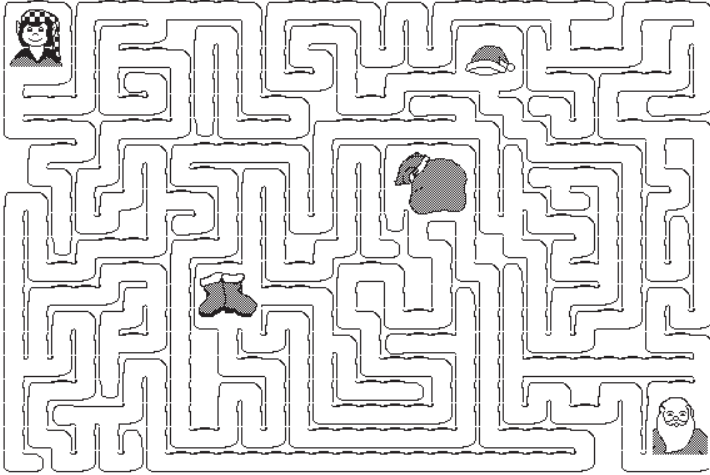
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Baxter Announces Acquisition of All Hemophilia-related Assets of Archemix and an Exclusive License of its Anti-TFPI Aptamer Technology

Lead Product ARC19499 Is Potential Subcutaneous Hemophilia Therapy Currently In Phase I Clinical Development

DEERFIELD, Ill., November 19, 2010 - Baxter International Inc. (NYSE: BAX) announced today that it has entered into a definitive agreement to acquire all of the hemophilia-related assets of a privately-held biopharmaceutical company, Archemix, and entered into an exclusive license agreement for certain related intellectual property assets.

The lead product associated with the arrangement is ARC19499, a synthetic, subcutaneously-administered hemophilia therapy currently in a Phase I clinical trial in the UK. ARC19499 blocks Tissue Factor Pathway Inhibitor (TFPI) activity, thereby augmenting and improving blood clotting, potentially reducing replacement factor therapy for patients with hemophilia A and B...

About ARC19499

ARC19499 is part of a new therapeutic class referred to as "aptamers." As an aptamer is smaller than a protein or biologic, these molecules have the potential to be developed for subcutaneous administration. The Phase I clinical trial for ARC19499 was initiated by Archemix in the UK in August 2010 and continues to enroll patients. Currently there is one aptamer approved by the U.S. FDA and available to patients today: Macugen®, for the treatment of age-related macular degeneration.

Taken, in part, from the Baxter website.

Bipartisan Bill Would Allow State Waivers From Health Law Provisions

Sen. Ron Wyden, (D-OR) and Sen. Scott P. Brown, (R-MA) collaborated on a bill (Empowering States to Innovate Act), that proposes to move up the date when states would be allowed to opt out of certain obligations in the health care overhaul law — including the controversial requirement that all people purchase health insurance. The bill is the first time a Democrat has teamed up with a Republican to try to modify the health care law. It is also the first time a Republican has offered legislation to ease a requirement in the law rather than repeal it. The Department of Health and Human Services would have to confirm that the state provides coverage at least as affordable and as effective as what the law requires. In addition, the state alternative would have to insure a comparable number of residents and not increase the federal deficit.

Taken, in part, from the e-mail listing HFA November 16, 2010, Updates

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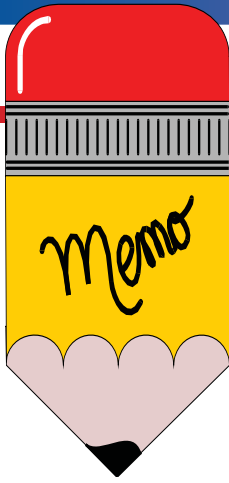
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SAVE THE DATES 2011

March 1, 2011Hemophilia of Iowa Scholarship application available online at www.hemophiliaofiowa.com

April 9-10, 2011Adult Retreat

May 23, 2011 ...Annual Golf Fundraiser

July 17, 2011.....Family Fun Education Day

Oct. 7-9, 2011.....Annual Meeting

What's the Difference?

Find the seven differences between the two holiday pictures below.



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New Consumer Protections Under the Affordable Care

Definitions:

The **Affordable Care Act** is the name given to the comprehensive health care reform law enacted on March 23, 2010.

A **pre-existing condition** is any physical or mental health condition, disability or illness that you had before you applied for health care coverage for you or a covered dependent.

A **plan year** refers to a 12-month period of benefits coverage--which may not be the same as the calendar year. This period is called a **policy year** for individual health insurance policies. To find out when your plan or policy year begins, you can check your plan or policy document or contact your employer or insurer.

Grandfathered plans are health coverage plans that are exempted from some parts of the Affordable Care Act in order to ensure that people who like the coverage they have can keep it. Your health policy must disclose in its plan materials whether it considers itself to be a grandfathered plan and must also advise consumers how to contact the U.S. Dept of Labor (for consumers in employment-based group health plans) or U.S. Dept of Health and Human Services (for those with individual health insurance policies) for further information.

Lifetime Limits: The Affordable Care Act prohibits health plans from putting a lifetime dollar limit on most benefits you receive. If the protections from dollar limits apply to your plan or policy, they will affect you as soon as you begin a new "plan year" or "policy year" on or after September 23, 2010. The Act also restricts and phases out the annual dollar limits a health plan can place on most of your benefits--and does away with these limits entirely in 2014.

The phase out of annual limits applies to all employment-based group

health plans and individual health insurance policies *except* an individual health insurance policy you purchased for yourself or your family on or before March 23, 2010. This is known as a "grandfathered" individual health insurance policy.

- Be aware that your plan or policy can put an annual dollar limit and a lifetime annual dollar limit on spending for health benefits that are not "essential health benefits" as defined in the law. (Essential health benefits include, but are not limited to, doctor office visits, hospitalizations, and prescriptions.)

- Some plans or policies may be eligible for a waiver from the rules concerning restricted annual dollar limits if complying with the limit would mean a significant decrease in your benefits coverage or a significant increase in your premiums. Plans granted such waivers are listed at: <http://www.hhs.gov/ociio/regulations/patient/appapps.html>

Access to Preventive Services helps make wellness and prevention services affordable and accessible to you by requiring health plans to cover all evidence-based, recommended preventive services and by eliminating cost sharing. If you or your family enrolls in an employment-based group health plan or an individual health insurance policy that was created after March 23, 2010, your plan will be required to provide certain recommended preventive services without charging you a copayment, coinsurance, or deductible.

Depending on your age, you may have free access to such preventive services as:

- Blood pressure, diabetes, and cholesterol tests
- Many cancer screenings, including mammograms and colonoscopies (the test used to screen for colon cancer)

- Counseling from your health care provider on certain topics; e.g., quitting smoking, losing weight, treating depression, etc.

- Routine vaccinations against diseases such as measles, polio, or meningitis

- Flu and pneumonia shots
- Counseling, screening and vaccines to ensure healthy pregnancies
- Regular well-baby and well-child visits from birth to age 21

This preventive services provision applies to people enrolled in employment-based group health plans and individual health insurance policies that are not grandfathered. There are a couple of other items to be aware of so be sure to check the following website: <http://www.healthcare.gov/law/about/provisions/services/lists.html>

Adding Adult Children to Your Health Plan is required of most health plans that cover children. They must make coverage available to children up to age 26. By allowing them to stay on a parent's plan, the Affordable Care Act makes it easier and more affordable for young adults to get or keep health insurance coverage. This rule takes effect for plan years or policy years beginning on or after September 23, 2010.

Insurance Cancellations are stopped by this Act to keep health plans from retroactively cancelling your insurance coverage solely because you or your employer made an honest mistake on your insurance application.

Pre-Existing Conditions cannot be used to deny coverage or limit benefits for a child because of a health problem or disability that the child had before applying to join the plan. The same protection will be extended to Americans of all ages starting with plan or policy years that begin on or after January 1, 2014.

Victory for Women with Blood Disorders

We are proud to announce our new women's health and bleeding disorder initiative --**Victory for Women with Blood Disorders**, an endeavor that builds upon and expands the former Project Red Flag. With the assistance and expertise of volunteers on our education/outreach committee, public awareness committee, and the National Hemophilia Foundation's (NHF) Medical and Scientific Advisory Council (MASAC), the **Victory for Women with Blood Disorders** program will incorporate education, advocacy, and support for women diagnosed with a blood disorder as well as raising awareness among women who have not yet been diagnosed.

Victory for Women with Blood Disorders Initiative 2010 – 2011

Awareness and Education

- Women 18-25 years old who are symptomatic but have not yet been diagnosed
- Mothers of teenage daughters who may have symptoms but have not yet been diagnosed
- Healthcare providers and others who do not know how to identify a girl or woman with acute symptoms of a bleeding disorder

Support

- Women 18-25 years old who have questions or concerns about accessing medical or support services

Iowa Pre-Existing Conditions Insurance Plan (PCIP) Program's Low Enrollment

Very few people have applied for the Iowa PCIP (temporary high risk pool). An estimated 34,500 people would qualify for the program that has enough funds to cover approximately 975 Iowans. Iowa received roughly \$35 million in federal funding to pay for the temporary program called HIP-Iowa Fed.

The PCIP is a temporary program that provides health coverage to people who have a pre-existing condition and who have gone without coverage for at least six months. The program opened enrollment to the public on July 1, 2010 and started to offer coverage on August 1, 2010.

To read this complete article highlighting the Iowa PCIP and other similar articles on general information about the PCIP, please visit www.hemophiliafed.org and select the Advocacy tab and then the Advocacy Blog from the drop down list.

- National Hemophilia Chapters serving women in their communities
- Community health organizations interested in partnering to improve the health of all girls and women

Advocacy

- Empowering women to seek accurate diagnosis and healthcare

V4W Current Projects

- Marketing campaign and other activities to raise awareness for women not yet diagnosed
- Chapter grants to support programs for women with bleeding disorders
- Training for chapter staff
- Building relationships with community health organizations
- Scholarships for women with bleeding disorders
- Web page with information and resources
- Participation at health professional conferences

We welcome inquiries and suggestions. Please contact Patrice Flax, NHF Manager of Education: 734.890.2504 or pflax@hemophilia.org

Taken from the NHF website: www.hemophilia.org



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Women Also Bleed



Women can have bleeding disorders, too. A bleeding disorder results from a flaw in the body's clotting system. Specialized proteins in the blood are called clotting factors. If they are missing or do not work properly, a bleeding disorder can result. Most bleeding disorders are inherited, caused by a genetic mutation, but some can occur spontaneously. People with bleeding disorders bleed longer, not faster, than those who do not.

You may have a bleeding disorder if you have one or more of the following symptoms:

- I have heavy menstrual periods
- Bleeding for more than 7 days, from the time it began until it stopped
- Flooding or gushing of blood, limiting daily activities such as housework, exercise or social activities
- Passing clots that are bigger than a quarter
- Changing tampon and/or pad every 2 hours or less on heaviest day
- I have been told I am "low in iron" or I was treated for anemia
- I have bleeding symptoms and someone in my family has a bleeding disorder, such as von Willebrand disease, or a clotting factor deficiency, such as hemophilia
- I have experienced heavy bleeding from dental surgery, other surgery, or childbirth and/or have other additional bleeding symptoms such as:
 - frequent prolonged nose bleeds (longer than 10 minutes) or
 - prolonged bleeding from cuts (longer than 5 minutes) or
 - easy bruising (weekly, raised and larger than a quarter)

If you have one or more of these symptoms, please speak with your doctor or other healthcare professional.

The most common bleeding disorder in women and girls is von Willebrand disease (VWD). It affects up to 1% of the U.S. population. VWD is an inherited bleeding disorder. It is

caused by a defect in or deficiency of von Willebrand factor, a protein the blood needs for clotting.

Women and girls can also have the most common types of hemophilia--hemophilia A, or factor VIII deficiency, or hemophilia B, factor IX deficiency—both of which are hereditary. Some are symptomatic carriers of hemophilia, meaning that they not only carry the gene, they also display symptoms. Further, they can have any of the rare factor disorders, such as factor I, II, VI, VII, XI and XIII deficiency.

Although men and women with bleeding disorders have similar symptoms, such as bleeds into joints and tissues, women can experience added complications during menstruation, pregnancy, labor and delivery. Some doctors are not familiar with bleeding disorders in women, many of whom are undiagnosed or misdiagnosed. Women with undiagnosed and untreated bleeding disorders risk serious complications.

In 2000, the National Hemophilia Foundation (NHF) kicked off its "Project Red Flag: Real Talk About Women's Bleeding Disorders," a national awareness campaign targeting undiagnosed women with bleeding disorders and their physicians. Many of its best components, including peer mentoring, public outreach, grassroots community efforts, professional education programs and publications, will now be found in NHF's Women's Health and Bleeding Disorders Initiative, which will be launched sometime in 2010. Many of its best components, including peer mentoring, public outreach, grassroots community efforts, professional education programs and publications, will now be found in the Victory for Women program. To learn more about it, visit Victory for Women? (Editor's Note: Also see the article in this issue of the BloodLine entitled "Victory for Women with Blood

Disorders."

If you have symptoms of a bleeding disorder, it is important to get a proper diagnosis and treatment from a specialist, called a hematologist. In the U.S., there is a network of hemophilia treatment centers (HTCs) that provide comprehensive care to patients with hemophilia and other bleeding disorders. HANDI, the National Hemophilia Foundation's information resource center, can provide information on bleeding disorders and the nearest HTC. Contact HANDI: handi@hemophilia.org or 800.42.HANDI.

Taken from the NHF website:
www.hemophilia.org



Did you know that...

Abraham Lincoln, the 16th president of the United States of America was a Hemophilic. Despite his delicate condition he successfully led his country through its greatest internal crisis, the American civil war. He is remembered for his great leadership during the civil war of 1860's and for his emancipation proclamation that led to freeing of confederate slaves.

Taken from <http://historyking.com/Famous-people/Famous-People-With-Hemophilia.html>

Do you want \$100 for the holidays?

HOI is looking for your opinion. Take a couple minutes to complete this survey and mail it in or complete it online for a chance at prizes and a grand prize of \$100.

Please complete this form and mail it to Brian Unruh, 849 Latham Place, Cedar Falls, IA 50613 or complete the online version at <http://bit.ly/hoi2010> by January 17, 2010 to be eligible to win. Only one member per family can win.

Name _____

Address _____

City _____ State _____

Phone # _____

Email _____

Type of Family's Bleeding Disorder _____

Check any committee you would be interested in volunteering and working with for 2011

- | | |
|--------------------------------------|-----------------------------------------------|
| <input type="checkbox"/> Scholarship | <input type="checkbox"/> Wine Tasting |
| <input type="checkbox"/> Website | <input type="checkbox"/> Annual Meeting |
| <input type="checkbox"/> Fundraising | <input type="checkbox"/> Family Education Day |
| <input type="checkbox"/> Golf | |

HOI is striving to meet the needs of our members via our education programs that we offer at various events. Please share with us some topics that would be beneficial to you and your family.

How many HOI events did you attend in 2010? _____

HOI is doing this Needs Assessment to reach out to members of the community who have or have not attended events in 2010. Please share with us the reason you either chose not to attend or the obstacles you encountered that did not allow you to attend.

Thank you for your input. This information will help the Board in providing educational opportunities for our community for 2011.

HEMOPHILIA OF IOWA, INC



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To become a member of HOI
or register for events, go to:

www.hemophiliaofiowa.com

And Finally...

This new season signals a new season in life for our family. Over 25 years ago, Vance and I met for the first time with the people who would go on to organize Hemophilia of Iowa. Many of those original (there were 7 of us) people have since passed away. Vance and I are, obviously, still around. The owner of Midland Information Resources is another one who is still actively involved in our hemophilia community by the consistent and long-standing commitment to helping us publish our newsletter. It is hard to believe that more than 25 years have passed since the day we met in a small meeting room at the University of Iowa. We all had one overriding desire--to learn more about this bleeding disorder and to spread that information to others who were similarly affected. Looking back, it is amazing that we have had a hand in creating an organization that has far exceeded what we wished for. Our hats are off to those of you who have also worked so tirelessly to keep Hemophilia of Iowa going strong! I know that John, Mike, and JJ would be proud of what has developed from that meeting so long ago!

When I speak of a new season in our own lives, the past 3 months have seen our family gain a second precious granddaughter (who joins her big sister) and a new daughter-in-law. Matt, who was a baby when we started Hemophilia of Iowa, married his sweetheart in October. So, we truly are empty nesters now. At first it felt sad and quiet. Now, it feels pretty good. I remember there were times when we struggled so hard against this bleeding disorder and what it was trying to do to our son and to our family but now we can look at our kids and take pride in the fact that they are upstanding, confident young adults making their own way in the world.

Have a blessed Holiday Season!



The medical information contained in this newsletter is for information purposes only and is not to be taken as medical advice. If you have any questions or concerns, always, check with your healthcare provider.