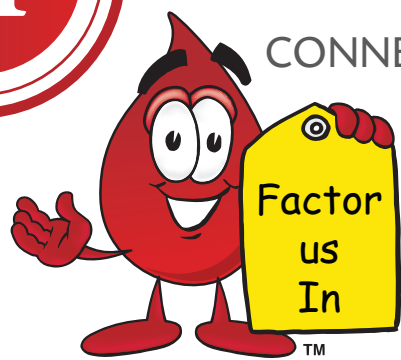




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CONNECTICUT HEMOPHILIA SOCIETY, INC.

Buddy Buzz

NEWSLETTER

News & Information for the Bleeding Disorder Community

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A New Chapter For The Bleeding Disorders Community



Buddy & I at our 2011 Snowshoe Event



Scan me with your smartphone to visit our new website.

On behalf of The Connecticut Hemophilia Society, Inc., I would like to welcome you to the first edition of the Buddy Buzz! (Named after our mascot, Buddy)

Founded on February 17, 2010, the Connecticut Hemophilia Society, Inc., or CHS, is a non-profit corporation that is dedicated to improving the quality of life of persons with bleeding disorders and their families through education and financial support, and by supporting scientific research that is aimed at finding a cure for hemophilia.

Now in our second year, CHS continues to meet the needs of the bleeding disorders community through our events, educational information, meetings and social networking.

The Connecticut Hemophilia Society, Inc. is also pleased to announce the launch of our new and improved website! www.cthemophilia.org is full of useful information including events, helpful links and online registration/donation forms.

In conclusion, I would like to thank all of you who have helped found this great organization, to our volunteers that have helped make all of our events a success and to our members and friends. Without your support, CHS would not be possible. Here's to the first two years and to MANY more to come!

Synthia Liska
President



YALE HTC Update

As many of you know, over the past year, the Yale Hemophilia Treatment Center (HTC) has gone through some big changes. After the sudden passing of our long-time director Dr. Diana Beardsley in March of 2010, Dr. Gary Kupfer assumed the Medical Director's position. Dr. Kupfer has been at Yale since 2007, as the Section Chief of Pediatric Hematology Oncology and Director of the Pediatric Oncology Program. He came to us from the University of Virginia where he had most recently been the Medical Director of their Hemophilia Treatment Center.

CHS Board Member, Dr. Salley Pels, also joined the Yale HTC after having finished her fellowship training in Pediatric Hematology Oncology here at Yale. Dr. Pels had focused on the care of patients with bleeding and clotting disorders during her fellowship and had been the recipient of the National Hemophilia Foundation-Baxter Clinical Fellowship award in 2009.

With Bernadette Bimonte-Hackett, LCSW, moving to a new position within Yale, we were delighted to find another social worker with as much enthusiasm for her work with our families as Bernadette, Jan Lenkoski-Mueller. Jan joined us in September and had most recently been working at Waterbury Hospital. With all of the new staff coming on board, we were happy to continue to work with three familiar faces, our nurse Debra Cummings, physical therapist Paul Bernier and our administrator Susan Marino.



Region 1 Comprehensive Hemophilia Treatment Centers

By Dr. J. Nathan Hagstrom

Supporting each other to continuously improve treatments and care delivery for people living with bleeding disorders.

Comprehensive Hemophilia Treatment Centers provide people living with bleeding disorders expert care, disease education and assist the patient and family with managing and coordinating treatment around surgeries, dental work and trauma. The comprehensive care provided by these treatment centers leads to better outcomes for patients. These centers are made possible by funding through the federal government, funding that has been decreasing considerably over the past 10 years and will continue to decrease if not disappear over the next few years.

Comprehensive Hemophilia Treatment centers form a network that facilitates surveillance, research as well as the development and sharing of best practices. The national network is divided into regions. Connecticut is part of region 1 (Maine, New Hampshire, Vermont, Rhode Island, and Massachusetts are also part of region 1). There are two comprehensive treatment centers in Connecticut (Yale and University of Connecticut), both of which have adult and pediatric components that share resources and healthcare team members.

An important part of the regional networks is to support each other in continuously improving treatments and care delivery for people living with bleeding disorders. A key component in this process is an annual meeting that lasts less than 24 hours, but is invaluable to the member centers.

This year's annual meeting took place near Burlington, Vermont (University of Vermont hosted the meeting). Among the topics presented and discussed were obesity in people with hemophilia, use of medical alert jewelry, joint replacement, and evolving therapies in hemophilia and the impact these new agents may have on how we care for patients.

The medical alert discussion was especially interesting for what may at first glance seem to be a rather dry subject. The potential benefits of a medical alert device or process is obvious, but some of the assumptions we've been making about these devices are incorrect. It turns out that medical alert jewelry that can be easily found by EMT personnel, which simply states the disease name in a way that makes it easy to understand that there is a risk of bleeding and what treatment will help, is the best way to go. Cards in wallets or other places aren't typically found or even looked for. Tattoos aren't reliable and not even considered by EMT personnel to contain worthwhile information. Besides, the fade and lose definition over time. The earlier a child begins wearing the alert device the better. Be sure that you buy something the child can't choke on.

Dr. J. Nathan Hagstrom of CT Children's Medical Center recently became a member of the CHS's Board of Directors.

Dr. Hagstrom is the Director and Division Head of the Hematology / Oncology Dept. at Connecticut Children's Medical Center in Hartford, Connecticut. Prior to joining CCMC, Dr. Hagstrom completed his fellowship and internship in the pediatric Hematology / Oncology Department at the Children's Hospital of Philadelphia.

We are simply delighted that Dr. Hagstrom has joined the board as he brings years of expertise and knowledge in treating children with bleeding disorders to the table. Welcome Dr. Hagstrom!



HFA's Annual Symposium

By Mandy McCullough

I attended this year's Symposium and walked away not only with a plethora of information but with connections that I made with many other attendees who I know will be lifelong friends of mine. This year's Symposium was held in the hospitality laced Louisville, KY.

The Symposium kicked off Thursday night with registration and a chance to peruse the exhibit hall where everything was offered to attendees, from soup to nuts, relating to bleeding disorders. The exhibitors ranged from pharmaceutical companies, to homecare companies, to chapters and non profits. The hall was filled to the brim with information, resources and literature to take home.

A highlight for me was the Welcome and Recognition Luncheon followed by keynote speaker Clifford C. Kyhn, MD. The luncheon began with a video that was made as part of HFA's Voices Campaign. The video featured two young boys living with hemophilia ... one of which was Kyle, my 8 year-old son. I was so incredibly proud to see my son up on these big screens as the entire room full of people watched intensely as Kyle talked about what it is like living with hemophilia. People became emotional watching the video and also laughed hysterically when Kyle talked about his "butt bleed."

HFA's leadership and Board of Directors recognized leaders in our community. It was amazing to see the amount of dedicated individuals in the room and to hear of their many accomplishments!

The keynote speaker, Dr. Clifford C. Kyhn, got the audience going with his infectious humor, as he believes laughter is the best medicine. He spoke (with many jokes in between) about the importance of enhancing performance, productivity and health by having fun.

After lunch, I attended a session about Healthcare Reform. This session went over the latest in reform and gave a summary of where we are now. The bleeding disorders community may benefit from the elimination of both lifetime caps and the preexisting condition clause. In addition, I know I will feel better when my sons are able to focus more on their academics than worrying about where their insurance will come from because they will be able to stay on their parents' health insurance plan until the age of 26.

The next morning I woke up early to attend the Living Fit breakfast session and wasn't disappointed. Celebrity Bernie Salazar from The Biggest Loser got the audience up and moving providing some inspiring tips on how to be healthy and why it is so important to get moving. The Biggest Loser gave great ideas on how to fit family friendly exercise routines into your daily life. Salazar also showed the audience how to make a meal not only healthy, but also delicious. The breakout rap sessions are always a favorite and as always, we ran out of time. I attended the rap session for moms (and as most of you know, moms like to talk). There were many great conversations regarding school transitions, 504 plans, parenting, and the list goes on and on and on.

Another interesting session was Medical Advancements on the Horizon. I don't want to begin to summarize the new advancements as I may not explain it properly, however I will mention there are many studies in the pipeline and the future is looking good for the bleeding disorders community. There were discussions on many studies currently taking place. There are studies with products that can produce longer lasting factor, new ways to treat inhibitors, as well as ways to prevent inhibitors from developing in the first place.

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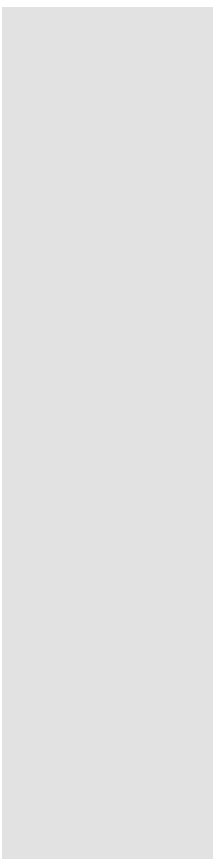
The Women's Health & Wellness reception was a fun-filled couple of hours. We got our own personal demonstration from a professional chef AND we got to sample everything, yum! Everything was simple to prepare and healthy.

The symposium concluded with Thunderfest. A delicious dinner was served to all the attendees. The evening also included a live band that played all night, hat making, a photo booth, caricature drawings, and these hilarious flip books that people could make by acting silly in front of a camera. It was a great opportunity to wind down, network with other families and say our good byes. Following the event, many of us walked outside and a few blocks down to watch Thunder Over Louisville, the largest fireworks show in the country! Talk about incredible.

As you can see it was a jam packed week with tons to learn. To anyone who has ever thought of attending an annual meeting, I highly recommend HFA's Annual Symposium!

You can download a copy of the slides from many of the Symposium's sessions on HFA's website (www.hemophiliafed.org) should you want additional information.

Mandy is a Client Relations Advisor for American Homecare Federation (AHF), a specialized homecare pharmacy for individuals living with bleeding disorders, a board member of the Hemophilia Federation of America, and a mother of a son with severe hemophilia A.





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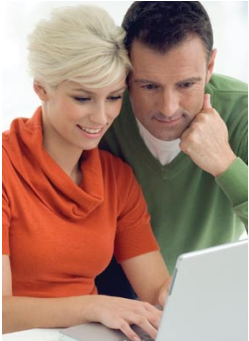
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Hemophilia Community Encouraged to Explore Insurance Options During “Open Enrollment” Periods



Health insurance experts strongly recommend that people with hemophilia and their families explore their insurance options during your employer's “Open Enrollment” periods. According to the federal website www.healthcare.gov, the Open Enrollment Period is the time set up to allow you to choose from available plans, usually once a year.

In 2011 the need to be prepared for Open Enrollment is greater than ever. With last year's signing of The Affordable Care Act, many insurance companies are making changes to their policies. For example, young

adults who may have lost coverage through a parent's insurance due to age, may now be eligible to re-enroll during the Open Enrollment period. The new healthcare reform law requires employers who provide coverage for family members of employees to offer coverage to include children under the age of 26. If parents want a child under the age of 26 to be included on their policy, this is the time to enroll the dependent.

Another change involves “annual caps” on health insurance coverage. With the new healthcare reform law, the annual limit on benefits paid in 2011 can be no less than \$750,000. Many plans do not have an annual limit. Some insurance plans have received exemptions that allow them to cap benefits below \$750,000. It's important to know if your current plan has an annual limit and if one exists, where that limit has been set.

Worth noting is another benefit included in the healthcare insurance reform law: the elimination of “lifetime caps.” There is no limit on the amount of insurance benefits a person can receive over the course of his or her lifetime for group and individual policies that began after September 23, 2010.

Insurance experts also remind people that even if their policy comes from the same company as they had last year, it is important to not assume that benefits have remained the same. Now is the time to read the policy closely and ensure that the coverage is most suitable to a family's needs.

“Many of the improvements to the nation's health insurance industry are the result of the hemophilia community's hard work and tireless energy,” said Mike Bradley, Vice President of Healthcare Economics and Reimbursement for Baxter Healthcare Corporation. “They helped make these changes happen, not only for themselves but for people with other serious and chronic conditions. They deserve to take advantage of the new benefits they earned through their efforts and concerns for their families and for other Americans.”

Prior to researching options with an insurance company or a benefits professional in the workplace, patients and caregivers can gather more information by calling Baxter's Insurance Assistance Helpline at 1-888-229-8379, or by visiting www.healthcare.gov.

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1 800 549-2654

7th Annual Katzman Family Snowshoe Walk



The Connecticut Hemophilia Society was pleased to host the 7th Annual Katzman Family Snowshoe Walk on March 19, 2011! The weekend was full of fun, food and friends. The weather was perfect for a scenic snowshoe walk through the woods at Stratton Mountain Resort. Over 150 people enjoyed Saturday night dinner. The night was filled with music from Peter Miles, magic by Bill Hoagland and wildlife courtesy of the Vermont Institute of Science. The silent auction was packed with great items such as an autographed NFL hockey jersey, weekend getaways, spa services and more!

Thanks to everyone that helped make this event such a huge success.

Mark your calendars now for next year!

Snowshoe will take place March 17, 2012.

Rooms are available at a discounted rate from 1-800-STRATTON.
Mention The Connecticut Hemophilia Society at time of booking.



2011 events

10

October 1

CHS' First Annual Meeting

October 29

First Annual Hemophilia
Fun 5 K Run/Walk

12

December 2

2nd Annual Comedy
Night Fundraiser

December 10

2nd Annual
CHS Holiday Party

For more information or
to register for these or
other CHS events,
please visit us online at:
www.cthemophilia.org

6

June 12

Strike Out Hemophilia
with the Brockton Rox

June 15

CHS to Benefit From
Lenny & Joe's Carousel

June 18

2nd Annual
Lake Compounce Picnic

7

July 15-21

Hero's Journey /
Hole in the Wall Gang Camp

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