

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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Education Dayz: Learning & Connecting



Patients and families participating in a class on advocacy at Education Dayz. Photo: NHF Colorado

On April 8th the Colorado Chapter of the National Hemophilia Foundation kicked off the annual Education Dayz at the Sheraton Denver Tech Center hotel with a dinner where they honored members of the bleeding disorder community who have made particular contributions over the past year. Both Judy Primeaux and Brenda Riske of our HTC were honored with the Dr. William Hathaway Visionary of the Year Award. NHF Colorado works closely with our HTC to bring learning opportunities, support, and a chance for families in our area to meet others with similar challenges. Education Dayz is one of these wonderful opportunities and our HTC is proud to sponsor and provide support to this event every year.

Dr. Tyler Buckner, one of our doctors here at the HTC, was able to teach a session about pain management and was thrilled to meet with many of the families who were in attendance. Dr. Mike Wang, also from our center, was able to attend and spoke on new medications that have recently been approved or are being developed. Their question-and-answer panel on these medications was a wonderful opportunity for patients to discuss their needs and concerns.

Amber Casey and Chris Mashburn, both nurses from the HTC, hosted an Infusion Session as one option for those in attendance. They were pleased to have a great turnout for their session, with close to 10 children and their parents joining them to learn about infusions.

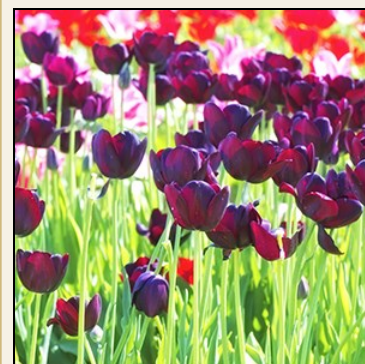


George Weilert and his parents participating in a session on infusions at Education Dayz. Photo: Chris Mashburn.

Several additional families joined to watch, listen and learn while the others gained hands on experience. Many of the families, who already have experience with infusing, were open and honest with newer families, providing insight and tips for successful home infusion of factor products.

One family whose baby had recently received an implanted port was generous enough to demonstrate their technique for accessing the port and infusing factor. They did a wonderful job and their

Continued on page 3



INSIDE THIS ISSUE

- Education Dayz!
- HTC Spotlight: Chris Mashburn
- Award given to Judy Primeaux and Brenda Riske
- Registration for Mile High Camp
- Outreach Clinics
- Events
- News

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HTC SPOTLIGHT: CHRIS MASHBURN, RN, BSN



Chris Mashburn, RN, BSN
HTC Clinical Manager

If you have been at our clinic in the past several months, you may have met Chris Mashburn, our new Clinical Manager here at the HTC. While Chris is responsible for managing our nursing staff, she also regularly works with patients when they come into our clinic. She has worked for many years for Children's Hospital and has vast experience with pediatric care, including pediatric cardiology and pediatric heart transplants.

She is thrilled to be learning a new sub-specialty in hemophilia and blood disorders as she works with patients at our center.

Chris is a registered nurse and holds a Bachelor of Science degree in nursing from the University of Colorado School of Nursing. She is native to Colorado and has lived most of her life here, enjoying a close family, including two children and three grandsons. Though she only started at our clinic in January, she already has been active in working with our staff to help with team development, program development, and with representing the nursing staff at HTC and hospital-wide committees.

One of the things that Chris has enjoyed about working here at our HTC is the focus on teamwork and the

comfortable rapport between physicians and nurses. She has always been involved in research and loves seeing research integrated into the day to day activities of the nursing team. *"It is exciting to be a part of this team who is such an active part of improving the future for patients with hemophilia and blood disorders."*

One of Chris' current efforts is the ATHN QI project, which is focused on putting into place a sustainable process for evaluating and improving on the care provided to our patients. Chris loves the interactions she is able to have with patients and families and she relishes the opportunity to teach and empower families to manage their health issues in a positive manner. *"Patients we see are so inspiring; they teach me real life lessons every day and for that I am grateful!"*

Like many in Colorado, Chris loves the outdoors and doing anything outside. Snowshoeing, biking and walking are among her favorite activities. She also enjoys photography and quilting. She loves to visit the beach and her favorite place to vacation is Hawaii.

Chris looks forward to getting to know more families and helping the HTC continually improve. She welcomes feedback from patients and families, and hopes they will get to know her and feel comfortable sharing with her both things we are doing right and areas where we can get better. We at the HTC are thrilled to have Chris and her bright personality and experience with us in our clinic and hope our patients benefit from her care.

REGISTER FOR MILE HIGH SUMMER CAMP

Mile High Summer Camp will be here before you know it!

This year camp will be on **July 10-15, 2016** at Rocky Mountain Village at Easter Seals in Empire, Colorado. The Leadership Camp begins two days earlier on July 8th and is for those ages 14-18.

This year children ages 12-13 can also sign up as part of the BOEC Wilderness program as an option. Campers must be 12 by the first day of camp to participate in the BOEC Program.

There is also a CIT (Counselor in Training) program for those 'graduated' campers who would like to be involved.

For more information and to find registration forms, please go to cohemo.org and find their camp pages and links to the forms.

All registration fees and forms are due by **June 1, 2016**. **NO EXCEPTIONS.**



demonstration was both helpful and reassuring to other families with similar needs. The willingness to share experiences with each other is what makes the bleeding disorder community so special.

Our nurses enjoyed working one-on-one with these families, answering their questions as they navigate the often scary and confusing world of home infusion. Our other staff members who were able to attend reported that the best part of being a part of Education Dayz is the chance to visit personally with families in a non-clinic environment.

Sharon Funk, one of our Physical Therapists, spoke with many families and appreciated their honest feedback. Having the opportunity to visit with everyone from clinic staff, other families and various pharma or medical representatives can help families stay informed and support one another. Quite a few newer families were in attendance and our staff was thrilled to get to know some of them better or meet them for the first time.

We encourage these families and those who were unable to attend this year, to attend Education Dayz in the future to continue to build support for one another in the bleeding disorders community. It is a wonderful chance for all of our



Malia Jackson receiving the Future Leader of the Year Award. Photo: NHF Colorado

HTC staff to connect with families and we hope all who were able to attend this year learned and benefited from the efforts of NHF Colorado and all who participated.

HTC STAFF HONORED AT EDUCATION DAYZ

Our center was thrilled to see two of our HTC staff honored as recipients of the Dr. William Hathaway Visionary of the Year Award at the annual Education Dayz held on April 8-10, 2016.



Judy Primeaux receiving her award with Victoria Hartman & Amy Board. Photo: NHF Colorado

Judy Primeaux, who has managed our pharmacy and much of our finances for over 20 years, has recently retired and was honored for her dedication, support, and involvement. She has worked tirelessly to manage our pharmacy and make specialized medications available for our bleeding disorder community under the federal 340B program.

Brenda Riske, who has worked at the HTC since 1984 and is currently our Regional Coordinator until her retirement later this year, was also honored for her tremendous efforts to bring our HTC from a small clinic to being the leader in supporting those with bleeding disorders in the entire Rocky Mountain region. Brenda was out of town during the award banquet, meeting with other international leaders in hemophilia.

Both of these remarkable women have been instrumental in the success of our HTC and are well deserving of this achievement.

UPCOMING OUTREACH CLINICS



Outreach Clinic Grand Junction, CO in 2015
Photo: Marilyn Manco-Johnson

The HTC staff regularly visits areas in our region to allow patients to schedule their annual comprehensive visits at a closer location to their homes. Our staff recently developed a test clinic for those patients living near Colorado Springs, and it was a success!

Plans are in the works to have additional clinics in Colorado Springs to bring easier access for those in that part of the state. Please watch our Newsletter, Website, and Social Media outlets for updates and upcoming clinic dates for Colorado Springs.

Upcoming Clinics: June 6-8, 2016: Billings, Montana
Aug 1-2, 2016: Missoula, Montana
Sept 21-23: Grand Junction, Colorado

Details about our Outreach Clinics can be found at our website at www.medschool.ucdenver.edu/htc and clicking on the **CLINIC** tab at the top of the page. Then go to the **OUTREACH CLINICS** tab.

RECENT HEADLINES

These are a few of the headlines that we've recently featured on our home page.

We maintain a Newsroom page at our website with a list of the news we feel may be of interest to our patients and families. To see more head to: www.medschool.ucdenver.edu/htc then find the **RESOURCES** tab, and go to the **NEWSROOM** page.

Biogen Lights Up Major Structures, Raises Funds, and Donates Medications in Honor of World Hemophilia Day

CSL Behring Marks World Hemophilia Day by Donating Medications for Bleeding Disorders to Developing Countries

Youth is Served in Stroke Save

Research on Mice Shows Concurrent Influenza Vaccination Reduces Inhibitors

Study of Hemophilia Care Reveals Progress, Ongoing Health Needs

UPCOMING EVENTS

May 27-29: NHF CO Family Camp--Allenspark, CO

May 30: Clinic and Admin closed for Memorial Day

June 6-8: Outreach Clinic--Billings, MT

June 26: Strike Out Stroke with the Colorado Rockies at Coors Field

July 4: Clinic and Admin closed for Independence Day

Jul 8-10: Mile High Camp Leadership Pre-Retreat-Rocky Mountain Village

Jul 10-15: Mile High Summer Camp-Rocky Mountain Village

July 21-23: NHF Annual Meeting-Orlando, FL

July 24-28: WFH World Congress-Orlando, FL

Aug 1-2: Outreach Clinic-Missoula, MT

See more at our **Events Page** on our website: www.medschool.ucdenver.edu/htc find **RESOURCES** tab, go to **EVENTS**

Hemophilia & Thrombosis Center

13199 E. Montview Blvd., Suite 100
Aurora, CO 80045

Clinic Main: 303-724-0724

or toll free at 888-297-0724

Pharmacy Main: 303-724-0168

or toll free at 888-724-7427

Web page:

<http://medschool.ucdenver.edu/htc>

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