

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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CHRIS BOMBARDIER ACHIEVES QUEST



Chris Bombardier hiking Mt. Vinson. Photo: Chris Bombardier

Last month our HTC was thrilled to hear that one of our patients, Chris Bombardier, accomplished one of his biggest dreams by completing the Seven Summits. The Seven Summits is a quest to climb the tallest mountain on each continent in the world. By making it to the top of Mt. Vinson in Antarctica, Chris finished the last of the seven peaks he set out to scale. It is an incredible feat that has only been done by just over 400 people in all of history. Chris is the first person to climb all seven who also happens to have severe hemophilia.

Starting with Mt. Kilimanjaro in Africa in 2011, he worked his way across the world. He scaled Mt. Everest in May of 2017 and that left only Mt. Vinson in Antarctica for him to climb. On January 6th, 2018 he was finally able to reach that goal. He has faced rejection, challenges of weather, injuries, and the

constant need to stay healthy and self-infuse to be able to reach this dream. In the process, he has gained many friends and fans, and met people all over the world who have hemophilia. It is for many of those he has met that he has pushed on when things got tough.

Chris did not just choose to climb these incredibly difficult mountains for his own personal claim to fame. He has used this experience to bring awareness and support to people living with hemophilia throughout the world who do not have access to proper treatment. By supporting Save One Life, a non-profit that raises awareness and funds for people with bleeding disorders around the world, he has brought hope and help to others.

His journey is being captured in an upcoming documentary called Bombardier Blood. The film is slated for release sometime in mid-2018. You can find out more by heading to his [Facebook Page: Adventures of a Hemophiliac – Chris Bombardier](#), and learn more about the documentary at www.bombardierblood.com. To find out more about Save One Life or to donate to support those with bleeding disorders around the world who do not have access to care, please go to www.saveonelife.net.



Chris Bombardier overlooking Antarctica. Photo: Chris Bombardier

Our HTC is overjoyed that Chris has not only accomplished his dream but that he has been such a powerful example to so many patients around the world. Our own NHF Colorado program, Backpacks + Bleeders was started by Chris and is a great opportunity for people with bleeding disorders to get involved in hiking safely. We congratulate Chris on his incredible achievement and we could not be more proud, or more grateful for his safe journey home.



One of our patients, Daryl Shinault, who we highlight this month.

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Find us on Facebook, Twitter, and our website for frequent updates on news and events.



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HTC PATIENT SPOTLIGHT: DARYL SHINAULT

By Audra LeBlanc, Social Worker



Daryl with our social worker, Audra LeBlanc (left) and Amy Cowell from the HTC. Photo: Audra LeBlanc

My New Year's resolution was to be more positive, and I can't think of anything more positive than the man I am about to tell you about. His name is Daryl Shinault, but I secretly call him "Big D." He has severe factor IX deficient hemophilia and he has been coming to the University of

Colorado Hemophilia and Thrombosis Center since he was a baby—for 57 years. He is very well known to many of the staff at the HTC, both past and present.

Daryl is one of the most inspiring people I have ever met. He has faced many struggles throughout his life, but he manages to stay positive, upbeat, and motivated to improve his life and himself. He attributes much of this to his faith in God and the lessons he learned from his mom and Dr. Wiedel. For those of you who don't know Dr. Wiedel, he was an orthopedic doctor who worked with many of our hemophilia patients back in the day. Daryl spent most of his childhood in the hospital because of his hemophilia, and had multiple surgeries, so he got to know Dr. Wiedel well. Given his medical history alone, the fact that Daryl is alive today is a testament to his strength.

I actually think the saying, "you can't keep a good man down," was created based on Daryl. In addition to having his struggles with hemophilia, he has been homeless more than once, incarcerated, faced racial discrimination, and suffered the loss of his mother (who was also his best friend and mentor) a few years ago. But Daryl just keeps on going. His mantra these days is,

"you either have to find a way to fix it, get around it, and get through it, because it isn't going away."

I recently had the pleasure of attending Daryl's graduation from the STAR Transitional Program at the Denver Rescue Mission. This is a program aimed at teaching life skills and helping homeless workers find stable housing and become more self-sufficient. Daryl became homeless in the spring of 2016, and one of the first things he did was to call us to let us know he was okay and to make arrangements for storing his factor. He was homeless and lived in a shelter until he started the STAR Program in October 2016, approximately 6 months. During that time, he came to the Treatment Center to infuse every four days, and every time I saw him he had a smile on his face and expressed hope that something was going to work out. Daryl got into the STAR program on his own and was dedicated to do what he needed to do to succeed. He even provided information to me about resources that I could use to assist other patients. He is a resourceful man and a strong advocate for himself.

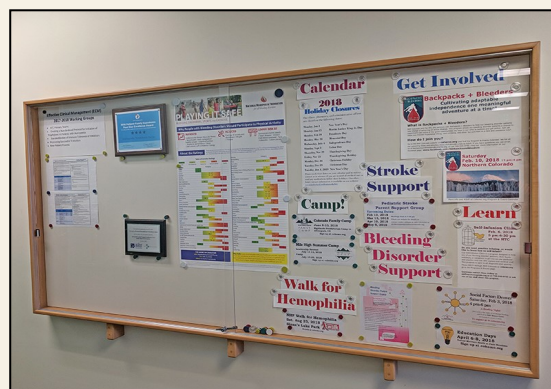
Today, Daryl is living in his own apartment, which he found and secured all on his own. He is saving his money and getting a car. Daryl will tell you that it was the STAR Program that really helped him get where he is, because they offered classes that helped him learn to budget and save money. However, I believe that knowledge was a small contribution compared to the hard work Daryl had to do. He is a very hard worker and will do any job that his body can handle. He also tries to take good care of himself. He does his factor infusions regularly and he calls if he has any concerns. Just recently, one of our doctors came to me and said, "I referred Daryl to several different specialists and he managed to schedule and see all of them within a matter of a few weeks. I have never had a patient do that before." I just looked at him and said, "That's Daryl."

Daryl's resilience is something I wish I could bottle and give to other people. He is one patient I can honestly say does more for me than I do for him. His spirit is truly inspiring.

NEW DISPLAY BOARD

If you have been in our clinic lately, you may have noticed that we have a large display board set up in the hallway. We have started adding dates, information and updates on opportunities and news from our HTC. We have upcoming dates for things like NHF activities, Camp, and our Support Groups that we hope to keep updated.

We are also including information on research studies as well as sharing awards we have received for achievement here at our clinic. We hope you take the opportunity to check it out the next time you are in. Please remember that much of this information can also be found on our website and in our newsletter and social media. You can subscribe to our newsletter and like or follow us on Facebook or Twitter. Go to www.medschool.ucdenver.edu/htc for details.



PATIENT SATISFACTION SURVEY

Patient Satisfaction with U.S. Hemophilia Treatment Centers: Where is Insurance a Barrier to HTC Care?



The first National Patient Satisfaction Survey (PSS) of care received at Hemophilia Treatment Centers (HTC) in the United States was conducted in early 2015. Patients were asked for feedback on their satisfaction of the HTC care they received in calendar year 2014.

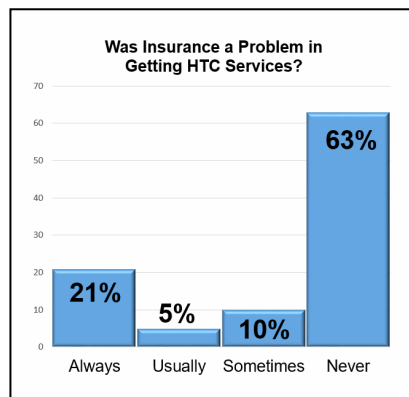
HTCs are specialty clinics. The doctors, nurses and staff are specifically trained to work with bleeding disorders. They can identify problems and find solutions a general doctor or pediatrician may not be aware of. This specialty care requires a unique understanding of how blood and clotting works. In fact, studies show that care at HTCs is linked with 40% fewer deaths¹ and hospitalizations² than bleeding disorder care provided outside HTCs.

However, patients often face the problem of how their care will be covered by insurance, if at all. Many patients struggle to find insurance coverage they can afford. The medication for bleeding disorders is expensive and not always available at a regular pharmacy. It may be hard to find insurance that covers these medications. This can lead to frustrating hoops that patients must jump through to get care to treat their condition.

In the PSS, we asked HTC patients and caregivers how often insurance was a problem getting HTC services. Over 5000 patients or caregivers from over 130 HTC around the country responded.

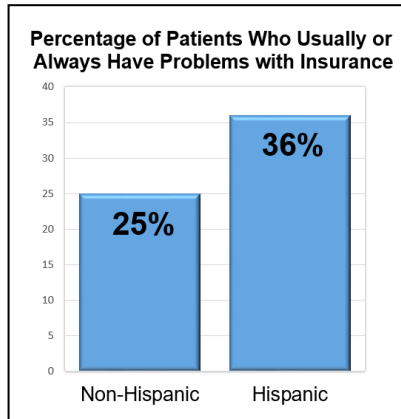
What did we find out?

Overall, one in every four persons (26%) reported that insurance was always or usually a problem getting HTC services. Ten percent more stated that insurance was 'sometimes' a problem getting HTC services.



"They always handle all issues concerning insurance."
34 year old man with severe hemophilia from New York

Which patients reported more insurance problems?



Hispanics indicated insurance was a problem more than ten percentage points higher than non-Hispanics. More than one in three Hispanics (36%) reported that insurance was 'always' or 'usually' a problem getting HTC services, compared to an average of 25% of non-Hispanics. When analyzed, no other

group had as high a percentage that struggled to get HTC services with their insurance.

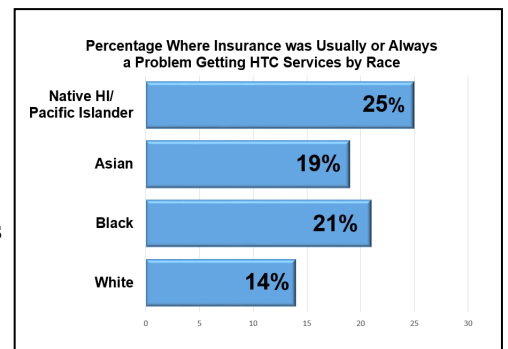
There were also differences by race. Insurance was usually or always a problem getting HTC services the least for Whites (14%), higher for Asians (19%) and Blacks (21%) and the most for Native Hawaiians/Pacific Islanders (25%).

"Need better communication between HTC and Billing."

31 year old man with severe hemophilia from California

What's next?

Because some HTC patients need more help with their insurance plans, many HTCs are focusing on ways to reduce insurance obstacles.



The second national Patient Satisfaction Survey will be available starting March 1, 2018. We will monitor insurance problems in the new survey.

For more details on the PSS please go to htcsurvey.com and direct any questions to HTCSurvey@ucdenver.edu.

RECENT HEADLINES

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

Camp Registration is Open—Deadline is May 1st

Newborn Babies Who Suffer Stroke Regain Language Function in Opposite Side of the Brain

Hemophilia Gene Therapies Show Promise

Barry Haarde, Hemophilia Advocate and Inspiration, Passes Away at 52

NY Times Highlights Patient Voices: Hemophilia

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 go to: www.medschool.ucdenver.edu/htc then find the **RESOURCES** tab, and go to the **NEWSROOM** page. Find other stories at our Facebook page at www.facebook.com/ColoradoHTC/

UPCOMING EVENTS

Mark Your Calendars/Save the Date:

Feb 25: Social Factor: Mom's Brunch

Mar 10: NHF CO Backpacks + Bleeders

Mar 13: Pediatric Stroke Parent Support Group

Mar 24: NHF CO Social Factor: Denver

Mar 27: Bleeding Disorders Parent Support Group

Apr 6-8: NHF CO Education Days

Apr 11: Outreach Clinic—Colorado Springs

Apr 26-29: HFA's 2018 Annual Conference

May 12: Self-Infusion Clinic—HTC

June 8-10: NHF CO Family Camp

June 16-21: Camp for Kids with Neurologic Disorders at Roundup River Ranch

June 19-21: Outreach Clinic-Billings, MT

July 15-20: Mile High Summer Camp

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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