

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



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BLEEDING DISORDER ADVOCACY



Members of the Colorado NHF community advocating for bleeding disorders. Photo NHF Colorado.

Next month is Bleeding Disorders Awareness Month and there are a variety of ways you can make a difference. Bleeding Disorders are rare, their treatment is costly, and bleeds can often be painful and damaging. Bringing awareness not only helps those with bleeding disorders feel seen, but it is an opportunity to make policy makers aware of the impact on these patients and families when medications are approved, restricted, or programs changed that impact their ability to pay.

Many of our patients and their families advocate for support at local, state, or national levels. We have several great opportunities coming up next month that

are easy ways for you to get involved and help support our bleeding disorder families.

NHF Colorado is hosting their State Advocacy Day on **March 4, 2022** at the Colorado State Capitol. This event allows patients and families to meet with local legislators to share stories, concerns, educate them about bleeding disorders, and to advocate for policies that can help. Registration includes a training program before you meet with your local leaders. [Register and learn more at cohemo.org](https://www.cohemo.org).

NHF Washington Days is a national level advocacy program where people affected by bleeding disorders can meet with legislators in Washington DC to discuss federal level funding of bleeding disorder programs. This year will be an all-virtual experience and will be held **March 1-2, 2022**. While registration is closed for 2022, [NHF has several other great ways to advocate and bring awareness during Bleeding Disorders Awareness Month at hemophilia.org](https://www.hemophilia.org).

[The City and County of Denver building](https://www.cityandcounty.com) will be lit up red for Bleeding Disorders Awareness **from Feb 28- March 4, 2022**. This is a great chance to take a picture and show your support online in an easy and fun way. You should tag the City and County of Denver by using @CityandCountyofDenver when sharing. We'd also love to see your pictures if you tag us at @ColoradoHTC on Facebook or @HTCColorado on Twitter.

[The Fitzsimons Building in the heart of the CU Anschutz Medical Campus](https://www.cuanschutz.edu) will also be lit next month as well! Many of you may remember this as the building where the HTC used to be located. You can see it lit up red from **March 7-14, 2022**.

The [HFA also has some great resources to advocate for those with bleeding disorders at hemophiliafed.org](https://www.hemophiliafed.org). You can change your social media profile, share educational cards to let others know what hemophilia, or vWD are, or even [learn more about the history of bleeding disorders](https://www.hemophiliafed.org). Remember that local NHF Chapters, national programs like NHF or HFA, and centers like our HTC all have options for donations if you feel inclined to provide financial support. Sign up for newsletters or event notices from your local [NHF Colorado chapter at cohemo.org](https://www.cohemo.org), or the Montana based [RMHBDA at rmhbda.org](https://www.rmhbda.org).

Make this March a month to remember and find new ways to advocate for bleeding disorders and make a difference in 2022!



The Fitzsimons Building, located on the CU Anschutz Medical Campus, and where our HTC was located a number of years ago, will be lit up red from March 7-14, 2022 for Bleeding Disorders Awareness Month. We encourage you to snap a picture and share to bring awareness. Photo: CU Anschutz Medical Campus.

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



Go to [facebook.com/ColoradoHTC](https://www.facebook.com/ColoradoHTC)



Go to twitter.com/HTCColorado



Website: Go to

medschool.cuanschutz.edu/hemophilia-thrombosis



Email:

HTC.Newsletter@ucdenver.edu

THIRD NATIONAL SURVEY OF US HTCS— OVER 5300 PATIENTS REPORT ON CARE OBTAINED IN 2020



From March through August 2021, over 5300 of patients or caregivers from 92% of U.S. Hemophilia Treatment Centers (HTCs) joined the third HTC Patient Satisfaction Survey. This is the largest number of people to ever take the survey.

What questions were asked? The survey asked how satisfied patients were with HTC team members, care, and services received in 2020. Other questions asked how often insurance, language, and COVID-19 were a problem with getting HTC services. The survey asked for patient age, diagnosis and severity, gender, race, ethnicity. Patients or their caregivers could add comments about their HTC care.

Who answered the survey? The 5308 patients who answered the survey had hemophilia A or B, von Willebrand disease, other factor deficiencies, or other rare inherited bleeding disorders. Patients were from many racial and ethnic backgrounds, ages, and areas of the country. The survey was anonymous and in both Spanish and English.

What questions were new in the Third Survey? New questions asked about telehealth (video visits) and COVID-19.

Results: Patients were very satisfied with HTCs!

Overall HTC Care: 97% were ‘always’ or ‘usually’ satisfied with their overall HTC care. This is like the high satisfaction levels reported for 2014 and 2017.

HTC Team: Over 97% were ‘always’ or ‘usually’ satisfied with the HTC doctor, nurse, nurse practitioner, social worker, or physical therapist.

HTC Clinical Services and Care: Between 93% - 98% were ‘always’ or ‘usually’ satisfied with HTC services and how HTCs provided care.

HTC Pharmacy Services: Over 97% were ‘always’ or ‘usually’ satisfied with HTC pharmacy services.

Getting Ready for Adulthood: Over 90% of 12–17-year-olds were ‘always’ or ‘usually’ satisfied with how their HTC talked about how to care for and become independent in managing bleeding disorders as they became an adult.

Telehealth: Over 35%, or 1875 patients, reported that they had at least one HTC telehealth visit in 2020. Over 96% of those who had a telehealth visit were ‘always’ or ‘usually’ satisfied with their overall care.

Insurance Problems: Just over 16%, or 779 patients, reported that insurance was ‘always,’ or ‘usually,’ or ‘sometimes’ a problem to getting needed HTC services. 93% of those reporting insurance problems were still ‘always’ or ‘usually’ satisfied with HTC care.

Language problems: Only 1%, or 66 patients, reported that language was ‘always,’ or ‘usually,’ or ‘sometimes’ a problem to getting needed HTC services.

COVID-19: 701 (13%) persons reported COVID-19 was a barrier to care. For those 701 persons, 90% were ‘always,’ or ‘usually,’ or ‘sometimes’ satisfied with overall HTC care, 80% were satisfied with HTC staff, and 72% were satisfied with HTC services.

How can these data be useful? What’s next?

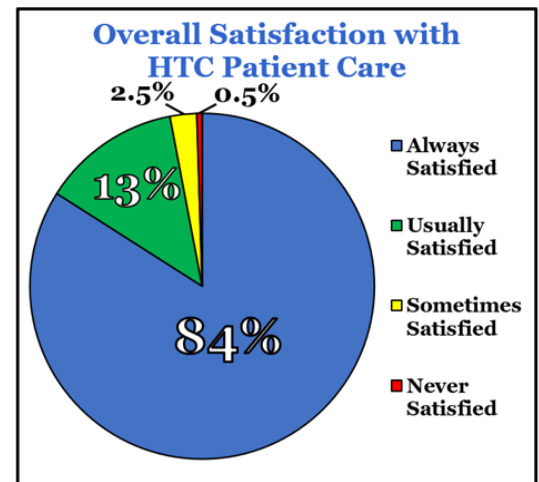
These results show that patients nationwide were generally very satisfied with HTCs in

2020, even though the COVID-19 pandemic required many HTCs to provide services using telehealth. That’s important because being satisfied with medical care means people are more likely to get the care that they need. Knowing when and why patients are not satisfied helps HTCs to focus on what services need to improve at the local, regional, and national levels.

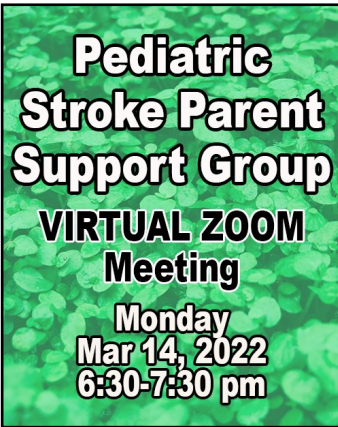
Results were sent to each HTC. They will be compared to the 2014 and 2017 surveys to see changes over time. Highlights of national results are presented at many national bleeding disorders conferences.

Articles about what we learn from the US HTC Patient Satisfaction Survey are added on our website. The next survey is planned for 2024. We thank all patients and caregivers who joined the survey, and all the HTCs for their work. For more information: www.htcsurvey.com

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PEDIATRIC STROKE PARENT SUPPORT GROUP



Our Pediatric Stroke Parent Support Group will be on **Monday, March 14, 2022 at 6:30 pm** on Zoom. This group invites parents of children who survived a stroke to meet with one another and our stroke team each month.

Normally we meet in person, but with the COVID-19 pandemic restrictions we are continuing to have these meetings on Zoom until things improve.

We are meeting on the second Monday of the month from 6:30 to 7:30 pm. Meetings are open to families of children of all ages and all types of stroke. Your child does not need to be seen at our stroke clinic to join our meetings.

For more details, see our [website](#), or [follow us on Facebook](#). To join our meeting, please RSVP to strokesupport@ucdenver.edu or call 303-724-8520.

PHARMACY MANAGER PAUL LIMBERIS TO RETIRE



Popsicles with Papou! Paul Limberis sharing popsicles with his grand children. Photo: Paul Limberis.

The past few years have been full of tumult and change, and we are so grateful to have had so many of our employees valiantly find ways to get things done, despite challenges. One of those has been our Pharmacy Manager, Paul Limberis. Paul will be retiring as our Pharmacy Manager at the end of February and shifting to a part-time role as an

of Greek descent and he and his wife Marina, who is also Greek, try to keep up many of the traditions of their Greek heritage. They have both enjoyed traveling and included Greece and the islands in their adventures.

When Paul joined our pharmacy, he knew that bleeding disorder patients have unique challenges that regular pharmacists didn't regularly see. He enjoyed learning about the specific therapies to treat bleeding disorder patients. His understanding and experience were a great fit for our 340B specialized pharmacy program that makes much of our HTC comprehensive care possible.

During the pandemic Paul showed great leadership in keeping the pharmacy running. The pharmacy provided essential needs and never shut down. Paul shared, ***"Our patients were our top priority and we needed to come up with solutions that would work to continue to serve our patients within the restrictions."***

The pharmacy divided up as teams, with one team working remote, and the other in-person on a rotating basis to make sure we always had healthy staff on site. During the initial nine months when things were mostly shut down, Paul was at the pharmacy every day to make sure things continued to operate. The pharmacy team's dedication was amazing, and their teamwork allowed all our patients to receive their medications with no problems.

Paul shared his gratitude for working at the HTC by saying, "I want to thank you all. You have inspired me to look beyond and do my best. Always remembering to treat everyone with courtesy, dignity, and respect!"

Our HTC and pharmacy patients are grateful for how Paul always went the extra mile to make days brighter for everyone around him. We wish him the best and will miss him! Desiree Hill, one of our Senior Clinical Pharmacists, has been promoted to our new Pharmacy Manager.

inspector/surveyor with the National Association of Boards of Pharmacy. He has been with the HTC for just over 8 years and has worked tirelessly with our pharmacy team to get our HTC Pharmacy accredited with both URAC and ACHC. This was a goal for the HTC pharmacy for many years and it was Paul who worked with our HTC team to get all the requirements to get these accreditations.

Paul joined us in 2014 after many years as an accomplished pharmacist and leader in the industry. He graduated from the University of Colorado, Boulder in 1979 and spent most of his career in hospital settings. Over his career he has earned many awards and accolades. Some of these included Pharmacist of the year in 2005 from the Colorado Pharmacists Society, Distinguished Coloradan in 2009 from the University of Colorado School of Pharmacy, and Bowl of Hygeia in 2001 from APHA and NASPA for outstanding civic leadership and involvement in the community.

Paul grew up in Salida, Colorado and has a great understanding of the state and all its natural beauty. He is

RECENT HEADLINES

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

Vibrating Microbubbles May Improve Gene Therapy Delivery for Hemophilia A

The Legacy of HTCs: Article from HFA's Dateline Federation

Bleeds, Physical Limitations, Affect Severe Hemophilia A Patients Despite Prophylaxis

Study Shows Low Dose ITI Partially Successful in 80% of Children with Hemophilia A

BioMarin Announces Positive Results in Gene Therapy Study for Hemophilia A

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. Go to medschool.cuanschutz.edu/hemophilia-thrombosis/resources/newsroom to read more. We also share news on our [Facebook](#) and [Twitter](#) accounts.

UPCOMING EVENTS

Mark Your Calendars:

Please note. These dates may be tentative and subject to change. Please check appropriate websites for confirmation of events.

Feb 28: Rare Disease Day

Feb 28-Mar4: City and County of Denver Building Lit Red for Bleeding Disorders Awareness Month

Mar 1-2: NHF Washington Days-Virtual

Mar 4: NHF Colorado State Advocacy Day

Mar 7: NHF Colorado Bowling & Buds, a Men's Event

Mar 7-14: Fitzsimons Building Lit Red for Bleeding Disorders Awareness Month

Mar 14: Pediatric Stroke Parent Support Group

Mar 26: Backpacks + Bleeders: Skiing at Winter Park

See more at our Events Page on our website:
medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar

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:

medschool.cuanschutz.edu/hemophilia-thrombosis

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