

## BECAUSE YOU MATTER TO US.



When autumn is here and the holidays are around the corner, take time to reflect on the bigger picture. What am I grateful for? What dreams am I working towards? How can I make the world a better place?

Contemplating these questions and pursuing the answers can remind us that life's value is not in the destination, but in the journey. When we connect with people we love and support each other's dreams, we discover additional beauty in life.

This issue features an inspiring story from cyclist and bikepacker Chris Seistrup who has hemophilia and works hard to make his dreams a reality. Also, you'll find details about changes to insurance and immigration rules as well as a reminder about mindful eating.

Enjoy,  
—Jessica Steed, Editor

## UPCOMING EVENTS

- NHF Bleeding Disorders Conference  
Anaheim, CA October 3-5, 2019

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- LHF Annual Meeting  
Baton Rouge, LA October 11-12, 2019

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- MHA Wichita Education Day  
Wichita, KS October 19, 2019

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- HASDC Unite Walk Liberty Station Park  
San Diego, CA October 20, 2019

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- AHA Top Golf Fundraiser  
Scottsdale, AZ November 1, 2019

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- OKHF Family Retreat  
Tulsa, OK November 1, 2019

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- HFM National Conference for Women with Hemophilia  
Detroit, MI November 1-3, 2019

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- HFNC Family Education Day  
San Jose, CA November 2, 2019

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- HFSC Unite Walk Griffith Park  
Los Angeles, CA November 2, 2019

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- HOPE Annual Conference  
New Orleans, LA November 7-10, 2019

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- NE NHF Industry Symposium  
Mahoney State Park, NE November 9, 2019

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- NV NHF Annual Family Conference  
Las Vegas, NV December 7, 2019

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- HFSC Snowflake Festival  
Santa Ana Zoo, CA December 14, 2019

For more info, contact your local chapter  
or [info@brothershealthcare.com](mailto:info@brothershealthcare.com)

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# COMMUNITY CORNER

## INTERVIEW WITH CHRIS SEISTRUP, WINNER-TOUR DIVIDE 2019

By Jessica Steed



**“It’s just a bike ride, but it’s my dream,”**

said Chris Seistrup of Prescott, AZ about winning his first attempt at the Tour Divide. The bikepacking race is mostly off-road 2,745 miles across the continental divide from Banff, Canada to Antelope Wells, NM. Chris completed this feat while battling a combination of rain, snow, and excess heat on June 29, 2019 after a grueling 15 days, 11 hours and 24 minutes.

Living with mild hemophilia B, Chris has rarely treated his condition, but it still influences his life and race strategy. He describes how careful he is with his body, “I can’t crash, I can’t ride until I fall asleep. I have to be smarter than that.”

**EARLY YEARS** As a child, Chris enjoyed North Carolina hemophilia camp. Although Chris didn’t participate in team sports and had no major bleeds, he rode bikes all through his youth. Chris said, “I wore the gear: elbow pads, knee pads, helmet.” He focused on developing his skills gradually. “I didn’t start by jumping off a loading dock [on my bike], I jumped off the curb, then off a height of two curbs and built my way up to the loading dock. I didn’t push myself so hard I got hurt. I didn’t really crash, I was fortunate.” Safety and skill were his priorities.

**PREPARATION** It’s truly remarkable how Chris made preparation for the Tour Divide part of his daily routine. He wove his dream into his life. In



2016, Chris did his first long bikepacking ride down the Pacific Coast Highway from Vancouver, BC to Imperial Beach, CA.

This ride was a turning point for Chris because he raised \$5500 for HFA and he realized he could handle a long ride with uncertain weather conditions. That’s when he took the leap to integrating his dream into his life, “I wanted to do this so bad, I figured out how to do it.” Chris quit his office job and started working for himself. He sold his car and started riding his bike to his work appointments, taking the most difficult routes with his bike weighted to simulate carrying race supplies. “You have to make it your number one thing, day in and day out.”

Part of Chris’s training was riding from Prescott, AZ to San Diego, CA for HFA symposium in April, 2019. He rode 400 miles in 41 hours. “That’s how I knew I could do [the Tour Divide]. It made the dream seem achievable.” His training schedule was so fully integrated into his life of managing family and customer needs, that when the race came, Chris said, “It felt like a vacation. My bike weighed less. I had a break from my normal responsibilities. All I had to do was ride and eat.”

**SETBACK** Originally slated to ride the Tour Divide in 2018, Chris sustained a serious hip bleed in a short local race in Sedona, AZ that year. This injury kept him in bed for two weeks. “I couldn’t even walk from the bed

# ADVOCACY UPDATE: COPAY ACCUMULATORS

By Jessica Steed

There’s mixed news for people whose health plans have co-pay accumulator adjuster programs. Over the last few years, insurance companies have implemented these programs to steer patients away from expensive brand name drugs to cheaper, generic drugs. They’ve done this by not allowing manufacturer co-pay assistance to be used toward patients’ out-of-pocket maximums. The unintended side-effect of these policies is much higher costs for patients with expensive drugs with no generic options, like those used to treat bleeding disorders.

Due to local advocacy efforts, a few states (WV, VA, AZ, IL) have passed legislation banning co-pay accumulators for drugs with no generic alternatives. Then, on April 18, Centers for Medicare and



Medicaid Services (CMS) finalized a rule allowing the programs, but banning it for drugs with no generic, or for which the brand-name drug is medically necessary. However, CMS released FAQs on August 26 which reversed the decision because of conflicts with IRS regulations.

Stay tuned to NHF and HFA to learn more about what’s happening and how you can make your voice heard to ensure

access to affordable, quality healthcare for the bleeding disorders community. 🌊

Sources:

**Final Rule** - <https://www.cms.gov/newsroom/press-releases/cms-issues-final-rule-2020-annual-notice-benefit-and-payment-parameters>

**FAQ Update** - <https://www.cms.gov/CCIIO/Resources/Fact-Sheets-and-FAQs/Downloads/FAQs-Part-40.pdf>

to the bathroom. I was getting down [emotionally] and my wife told me, 'You're the most positive person I know!' That's when I started focusing on what I could do." While still recovering, Chris was invited to receive the Terry Lamb Health and Wellness Award at the HFA Symposium in Cleveland, OH. In his acceptance speech, Chris explained his motivation, "I always try to focus on what I can do. Not on the things I can't do. I want to build more things I can do."

**EXPERIENCE** From heat to snow and rain, Chris competed with the elements and other riders. At one point, he was walking up a mountain in the snow, following the footprints of the only racer ahead of him. Chris thought, "If he can do it, I can do it." "The weather makes it hard to plan beyond the next 4 hours," even where he would sleep. For example, one day after Chris had to carry his bike through an icy cold creek and eventually made it to a campground, he chose to clean off the bathroom floor to sleep on instead of camping outside. "It was 50 degrees and dry in the bathroom. Outside was colder and wetter. It sounds gross, but it was the right choice."

Beyond sleeping, eating enough food—400 calories per hour of riding—was a challenge. Chris had prepared elevation maps which included places he could buy food and the hours they were open. At one point, he had to carry enough food for 250 miles of riding, in addition to all of his gear. In the end, a combination of hard work, excellent preparation, and good choices won Chris the Tour Divide as a rookie.



**INSPIRATION** The entire race, Chris explains, "is enormously mental." During the most challenging sections of the race, Chris found inspiration in many sources. "I thought about Chris Bombadier [who climbed the seven summits,

including Mt. Everest], Chris has done this." In fact, Chris Seistrup's fundraised more than \$30,000 for Save One Life. When he reflected Save One Life's mission, he said, "The people who we are helping in other countries, they have to walk through worse mud than we do. It always gets better if you just keep moving through it." Also, avid cyclist and friend, Barry Haarde's memory was an important inspiration for Chris and he thought of him often during the race.

Even as he draws inspiration from others with bleeding disorders, Chris also inspires young people in the community, "Take it easy, step by step. Sort out what you can do. Don't put yourself into a corner by focusing on what you can't do." To illustrate, Chris reflected on a moment at the end of the race when he was approached by a rider who attempted the Tour Divide and is also the father of 3 boys with hemophilia. "He told me that I give him such hope for his boys. I feel like it's my responsibility to try to get the next generation to see they aren't a weird anomaly. I want to tell the youth to do all the things you can do with your lives. It doesn't have to be athletic. Maybe you help people you don't know or volunteer as the fun counselor at camp, just do whatever you can do. Most people have 'a thing' you can't or don't see every day. Hemophilia may be your thing, but it doesn't have to hold you back." **Congratulations, Chris!** 🌊



<https://www.adventurecycling.org/routes-and-maps/adventure-cycling-route-network/great-divide-mountain-bike-route/>

Photos by: Tomas Jonnson and Chris Seistrup

# MINDFUL Eating



Holiday celebrations can be a great time to connect with friends and family. They can also include delicious food. When it's mealtime, consider these mindful eating tips.

1. **Reflect**- Before you eat, consider how you feel. Are you bored, stressed, sad, or hungry?
2. **Screens** - Turn off screens and other distractions.
3. **Water** - Drink plenty of water.
4. **Portions** - Serve a portion on a smaller plate, don't eat from the box or pot.
5. **Table**- Sit down to eat.
6. **Gratitude** - Before you eat, pause to express gratitude for your food.
7. **Time** - Slow down, savor your food, try to chew 30 times.
8. **Music** - Relaxing music, or even silence, can add to your experience.
9. **Taste** - Focus on the taste of each bite, remember, you don't have to finish all your food. 🌊

Adapted from: <https://www.health.harvard.edu/blog/10-tips-for-mindful-eating-just-in-time-for-the-holidays-201511248698>

# PUBLIC CHARGE RULE CHANGE: IMMIGRATION

By Jessica Steed and Veronica Diaz, LCSW

New rules may make it more difficult for immigrants to get US citizenship if they are using government programs like Medicaid and food stamps. For people in the bleeding disorders community who may be applying for citizenship, it's important to know the details of these changes.

Patient health groups are concerned that these rules may result in poor health outcomes for immigrants and their US citizen family members. Fear surrounding using programs may cause people who need and *qualify* for important benefits to not use them.

From Hemophilia Federation of America's Washington Wire:

HFA urges community members who are concerned about the public charge rule to keep the following in mind:

- **The public charge rule does not go into effect until October 15, 2019.**
  - Numerous lawsuits have already been filed to block implementation of the rule.
  - Even if implemented, the rule will apply only to applications submitted on or after October 15th.
  - Even if implemented, the new rule will NOT count food, medical, and/or housing benefits used BEFORE October 15th.



- **Not everyone is subject to the rule.**

- Many people are exempt from the rule: green card holders, asylees, etc.
- Not all benefits count as negative factors: CHIP, WIC, school lunches, state and locally funded programs are not counted. The use of Medicaid benefits will not count against children under 21 or against pregnant women.

- Benefits used by family members will not be counted against an individual applicant.

- **Every situation is different. You may want to consult with an immigration attorney if you have questions about your own case.** There are resources that can help you make the best choices for your family."

Contact your local chapter if you have questions about the public charge rule change. 

Resource:

<https://www.hemophiliafed.org/news-stories/2019/08/washington-wire-august-2019/>

## ASK US!

Call or email us with any questions you have about sports, life, relationships or your managing your medical condition and we will lend our expertise to help you in any possible way.

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