

# Cascade Hemophilia Consortium

## Letter From Cascade Social Worker Colleen Joiner



### Dear Readers!

There is nothing more exciting than the prospect of going on a trip. With Spring break travel season coming soon, take a moment to review some helpful hints to make your trip safe and enjoyable! We hope you find inspiration in the enclosed article on Henry Quitmeyer, who met his personal travel challenge. As so aptly stated by Cesare Pavese, “We do not remember days; we remember moments”.

Enjoy all that you do, and live life to the fullest!

Colleen Joiner, LMSW

## Living and Thriving: What an Adventure! Meet Henry Quitmeyer

On April 4, 2014, Henry, born with mild Hemophilia, began his journey to walk the Appalachian Trail, which is described as the “longest hiking-only footpath in the world.” The trip began in Fannin County, Georgia and nearly 6 months later and 60 pounds lighter, he completed the 2,185-mile hike in Maine.

### What Inspired a Young Man to Hike the Appalachian Trail?

Henry decided that he needed a change. He was in his early 20’s and felt dissatisfied with his job. Taking a cue from an older cousin, he wanted to test his limits and hit the trail before life became too complicated. This was the biggest adventure of his life until this point, and it was sure to build character.

Henry did not have any formal physical training prior to the hike, except walking in his hometown of Northville, Michigan a few nights each week. Nothing could prepare him for the thousands of miles that lay ahead.

### How Did Henry’s Mom Feel About This Idea?

Henry’s mom Ali, and his father Fritz, raised him to live his life as normally as possible, which contributed to his adventurous nature. But initially, this hike felt just a little too risky. Ali equates her parenting philosophy to that of a “mother duck.” On top of the water she always remains calm so as to not alarm the kids, but below the water she works ferociously to ensure their safety. Although Henry is an adult, she wanted to be sure he planned this trip carefully.

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To enhance the system of care for people with hemophilia and its related complications, including HIV and Hepatitis C disease, by assuring the lowest possible price for the full range of blood products (clotting factor concentrates), HIV related therapies and other medications available to treat their disease; to provide access to these medications for those who have inadequate insurance coverage; to support the comprehensive hemophilia treatment centers in treating and educating consumers and their families so they may become knowledgeable and proactive in managing their own care; to fund research to find a cure.

### Mission Statement



# Living and Thriving: What an Adventure! Meet Henry Quitmeyer

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## What Type of Planning did Henry do Before Setting Out on His Journey?

Henry's backpack was roughly 55 pounds and packed with "lots of ramen noodles, instant mashed potatoes, and oatmeal." Other survival items included a sleeping bag, stove, tent, knife and, of course, factor. But long before packing his bags, careful plans were set in place.

- Henry notified his HTC medical team of his expedition well in advance of the trip to allow for safety considerations.
- His HTC nurse helped plan the trip and had emergency letters written, just in case.
- Ali wrote out contact information for every treatment center along the trail.
- Cascade organized factor shipments to Post Offices along the trail. Henry hiked or hitched a ride into towns to re-stock as needed.
- He had contact by a solar charged phone at all times. Henry's parents followed his journey on a map pinned to their kitchen wall. As Henry checked in, they would record his progress and the date.



## How did Henry Handle the Bleeds on His Trip?

The first two weeks were pretty rough. Henry treated every day for left ankle and knee bleeds. Out in the woods, he came up with creative ways to slow a bleed, once using an old cardboard beer case filled with ice to ease a bleeding ankle.

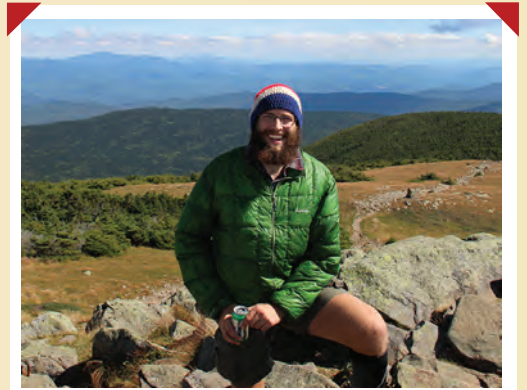
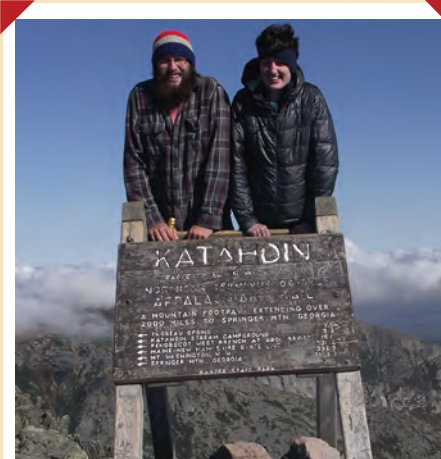
Henry could not keep his factor at recommended temperature and knew that its effectiveness might be compromised. As someone with mild hemophilia, he understands that he may have had an easier time with bleeding than someone with a more severe form.



## Difficulties Henry Encountered on the Trail

As the weather grew warm, Henry sent home his sleeping bag and other supplies to ease the weight of his pack. However, he didn't expect the unusually cold nights that time of year. At this low point, Henry considered coming home. His parents strongly encouraged him to keep on target and finish his goal. Ali was now fully rallying behind her son, and realized the importance of reaching his dream.

In the end, Henry met his challenge. To stay warm, he heated larger rocks in the fire to sleep with at night. He also filled the tent with leaves to act as a barrier to the cold. With parent's encouragement, Henry kept on his path.



## What was the Best Part of Henry's Trip?

The best, and most unexpected, part of the trip was meeting his future wife, Julie. They met on the trail in Tennessee, and by Maine, Henry knew she was "the one." They plan to marry in 2018.

Henry was also heartened by the random acts of kindness from strangers along the trail. Citizens in the area would leave gifts for the hikers along the way, that they called "Trail Magic." It might be a cooler of beer, a bag of apples, or, if they were lucky, a church b-b-q on the trailside. These thoughtful acts and "getting back to basics" for 6 full months had changed him.



## While Traveling Be Prepared for All Possibilities!

- 1 Let your HTC medical team know you will be traveling out-of-state or country in order to set up an appropriate plan.
- 2 Review with them the number of doses you will need while on your vacation and, if necessary, contact Cascade well before your trip to ensure timely delivery of your meds.  
**Keep in Mind:** Extra doses may require more approval time from your insurance company.
- 3 Familiarize yourself with your insurance plan rules regarding out-of-state travel, or particularly when traveling internationally. Be sure to carry your current insurance information with you at all times.
- 4 Ask your nurse to supply you with an **Emergency Department Letter** explaining your disorder and how to treat. The HTC writes many of these letters and may also call an HTC near your vacation destination, if necessary. As applicable, have all letters written in English or in the language of the country you are visiting.



### Planning Ahead for Unexpected Occurrences will Help You Relax and Enjoy Your Trip

- 5 Review a list of treatment centers in the state/s or countries that you will be visiting to determine availability of adult and/or pediatric care centers in the area. Remember some HTCs only treat adults or pediatric patients.  
**Visit:** [hemophilia.org](http://hemophilia.org) for a complete list of U.S. treatment centers and [wfh.org](http://wfh.org) for centers outside of the U.S.
- 6 If flying, carry all factor products, medications and supplies (in their original containers) along with the treatment center letters in your carry-on to ensure they arrive with you at your destination and maintain their required temperature. Place them in a clear plastic bag for ease during screening.  
**Visit:** your airline's website for more information and requirements, or [tsa.gov/travel/special-procedures](http://tsa.gov/travel/special-procedures).
- 7 Don't forget to wear your up-to-date medical ID bracelet at all times.

### And Have Fun!

## What Impact did this Trip have on Henry and His Mom?

Ali feels that this trip was a life-changer. She can see Henry has changed and has become more mature. But she too has changed. Although she will always watch out for Henry, she feels a sense of confidence in his ability to care for himself. Ali and her husband Fritz "couldn't be more proud."

As for Henry, his advice is, "Don't let hemophilia hold you back in life." He feels this extraordinary trip is only the beginning. We look forward to hearing about Henry's next great adventure!

## Henry's Mom, Ali, Offers Advice to Other Parents



- ✓ Nurture the development of your kids' "voice" as early as you can. Encourage them to talk with the doctor and express their opinions and interests.
- ✓ Encourage exploration which allows them to enjoy their childhood, within reason. (Ali and the HTC decided that wrestling was not for Henry).
- ✓ Be a "DUCK" parent in front of your kids. Remain calm on the surface while paddling under water to make things happen. Try to not let your kids see you panic.
- ✓ Don't treat your child with a bleeding disorder differently than your other kids. Give them appropriate discipline and enforce some rules.
- ✓ Involve your children in their own care. (This extends to siblings, as well, who may someday have children with hemophilia, and will need to know how to parent a child with the condition). Include them, as age appropriate, in their own health care decisions.
- ✓ And finally, give them the space and support to be their own responsible, independent individuals.