



# In His Shoes (or Hiking Boots): William's epic solo adventure to help fellow hemophilia patients in need

Wednesday, March 31, 2021



When it comes to making the world a better place for people living with hemophilia—a rare disease characterized by inadequate blood clotting—William Addison doesn't just talk the talk.<sup>1,2</sup>

And he doesn't just walk the walk, either.

William hiked the Appalachian Trail—all 2,200 miles of it—to raise funds for a charity dedicated to improving care for people with hemophilia and other bleeding disorders in developing countries. He completed the solo trek in about half the average time, all while managing his own hemophilia.

That's no easy feat, considering the disease currently has no cure and requires caution to avoid injuries that may result in traumatic bleeds. Not to mention the need for regular infusions of prophylactic factor medication to prevent spontaneous bleeds. In preparation for the hike, William worked with his healthcare providers to understand how much of his medication he would need to keep with him.

"I like to think that the only difference between me – a hiker with hemophilia – and another hiker without hemophilia is, I'm just carrying maybe a pound more medication on my back. Managing hemophilia when I was hiking was really interesting for me to see. I did not really expect my body to perform the way it did," said William, a 16-year-old Eagle Scout from Maine and 4th generation individual with severe hemophilia A. "If I wasn't completely independent before my four-month-long backpacking trip, I am now. I was the only one out there at times – thousands of miles away from my parents. So, I was the only one who could infuse myself."

William approached planning for his trip with the same fervor as he did completing it. Well in advance of his first day hitting the trails, he worked directly with his healthcare providers to determine a modified treatment regimen and strategically mapped out how and when he would receive treatment supplies along the 2,200-mile trail. Just like his hike, there were no shortcuts taken when discussing the risks and potential challenges he could face – helping William be as prepared as he could be for the path ahead.

William is grateful he can access the care and medications he needs and recognizes that many people around the world aren't so lucky. To challenge that disparity, William set up his hike as a fundraiser for a program that donates factor medication to patients in developing countries. To date, William has raised over \$27,000 (more than twelve times his initial goal of \$2,200).

From his global philanthropic efforts to his commitment to building awareness closer to home, it's safe to assume William will continue to grow as an advocate for the bleeding disorders community near and far: leading the way to build understanding and empathy for those bravely navigating the stresses and day-to-day impact of these conditions—from bump to bruise, cut to climb.

You can learn more about hemophilia and how to raise awareness for the bleeding disorders community.

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#### References:

National Organization for Rare Disorders. Hemophilia B. <https://rarediseases.org/rare->

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Originally published, Wednesday, March 31, 2021