

SPECIAL FEATURE: FITNESS AND HCU

How to Hike (with HCU)

By Benjamin Lewis

In many ways, living with a rare disease like Homocystinuria (HCU) is like hiking in the mountains. Both have high points and low points along a journey, and you are more likely to see success and enjoyment in both with planning and preparation. In my experience, it is also the case that the former should not hold you back from pursuing the latter. In other words, I and others with HCU are as able as anyone to set out on our own adventures, whether that be to points over a dozen miles into the woods of New Hampshire (NH), 6,288 feet above sea level at the top of Mount Washington, or the top of the Franconia Ridge in a -60-degree (Fahrenheit) windchill in the middle of winter. Over many years exploring the White Mountains of NH and other wild places, those are all situations I have found myself in and HCU and all of the considerations that come with it have not been a blocker. Therefore, drawing upon my experience over many hundreds of miles trekked and at least 60 or so high peaks climbs, I would like to offer others in the community a bit of advice on how to be a hiker, climber, or mountaineer with HCU. I think you will find that – spoiler alert – nearly all my advice applies to anyone who wants to hit the trail or climb a peak because, of the key steps to take to ensure your safety and enjoyment, none of them are all that different if you have HCU.

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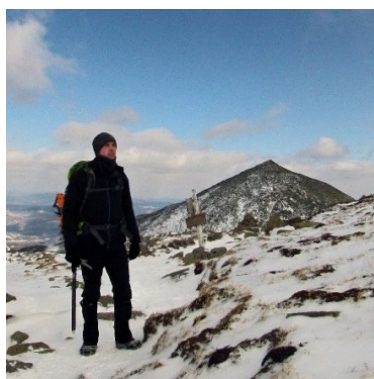
1. Set a goal! While you are more than welcome to pick any single trail or scenic mountain top and go through the rest of the steps, I highly encourage you to set a goal that goes beyond just one trip into the woods. For me, my love of hiking and mountaineering really got going after I set my sights on the Appalachian Mountain Club (AMC) Four Thousand Footer Club list of 48 peaks in NH. Not only did the list motivate me to keep getting out there, but it also forced me to try new trails and peaks I would have never otherwise visited. In northeastern United States, AMC and others offer many lists and achievements that you can choose to be your goal and other outdoors-oriented organizations around the world do the same. So set a goal and get outside!
2. Plan your outing! Regardless of whether you have picked a single hike to get your outdoor adventuring started, or a more extensive objective that will mean many miles are in your future, I highly recommend you do your homework before hitting the trail. A poorly planned trek may turn out to be miserable or even dangerous if you are caught in bad weather, get lost, or find yourself dealing with more than you bargained for. Using guidebooks, online blogs, and other resources, I always plan my route, check the weather and trail conditions, and estimate the hike time for my outing before I leave home. If you are venturing into an area with high peaks and/or areas above tree line where you will be exposed to the elements, take extra precautions and note your best ‘bug out’ or escape routes, triple check the weather in the 24 hours leading up to your hike – including, if available, a higher summits forecast, and know how much daylight you will have versus your arrival time and hike time. You will not regret doing this homework.
3. Prepare you and your gear! This is another step that may make or break your experience regardless of whether it is your first climb or you have been bagging peaks for years. Never leave home ill-prepared even if the outing is expected to be short. The best advice I can give is to listen to the experts and pack at least the “10 Essentials” for every hike. I always have some form of each essential system – a map, headlamp, sunblock, first aid kit, knife, fire-starting items, a form of emergency shelter, extra

food, extra water or a filter, and extra weather-appropriate clothes. I often like to hike solo and/or in the winter, and I take gear prep even more seriously in those cases. I will usually add a personal locator beacon (PLB), more first aid and clothing, as well as specialized equipment for winter mountaineering such as micro-spikes and an ice axe. In some cases, this gear is chosen to mitigate the risks of something going wrong, or to help respond more effectively if there is an issue. For the most part, I am thinking about situations anyone could encounter when selecting my gear, but certainly packing a pouch or two of HCU formula or having available medical care instructions for first responders are good practices with HCU in the picture. This line of thinking also extends to what I consume before a hike and then during. I always aim to have my formula before I set out to take advantage of the energy it contains, and I pick cereal bars, sports drinks, snacks, and sandwiches that are low protein but have some nutrition to give me a boost out on the trail. That preparation helps ensure I have the energy to make it through even the most taxing 20+ mile hikes, as well as essential equipment to deal with the unexpected!

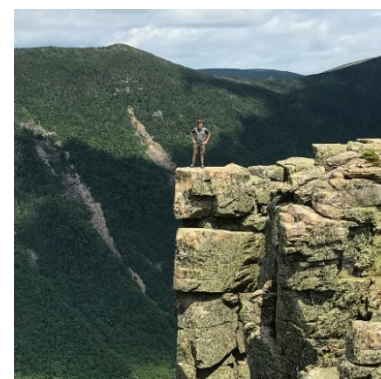
4. Have fun adventures! The last step is the easiest - get out there and experience the fresh air, scenic views, and exciting trails near you! The long and short of it is that HCU has not held me back from doing that here in New England and beyond. The key steps to ensure a safe and enjoyable hiking or mountaineering trip are the same for virtually everyone. Yes, having HCU means you may benefit from drinking formula before you hit the trail, or that you may find yourself eating pretzels instead of the traditional trail mix as you take in the views from a high peak (you can always pick at a friend's trail mix - I suggest M&Ms over raisins any day). However, I can assure you that if you are going to focus on anything in advance of a hike or climb, I suggest it be the planning and preparation that will make for a successful trip and not HCU. Get out there, seek out those high points, and discover your own adventures. I hope to see you on the summit!



At the "finish line" of my WM4K



At a trail crossing near Mt. Adams



On the outcropping of Bondcliff

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