

Navigating School with HCU

A College Experience

By Ben Lewis

For nearly everyone who does it, heading off to college (or, for those of you abroad, university) brings a mix of emotions. Yes, there is a lot of excitement, but that comes with some degree of worry and likely a healthy dose of stress. That is understandable, as it is a big change, particularly for freshmen. For many, the experience represents the first time that they are on their own, away from family and long-standing friends. These young adults must take on a new, higher level of responsibility and independence. For anyone, it can be one of the bigger challenges they have faced to that point. For those of us who live with HCU, and our families, the worry, stress, and the challenge associated with transitioning to college – and, really, true adulthood – is only amplified. We must navigate all the same changes as our peers with the added ‘bonus’ of independently managing our disorder through complexities such as entirely new schedules, meal plans, social situations, and more. It can be tough! Although, take some comfort in the fact that you are a lot less likely to gain the ‘freshman fifteen’ when on diet. Kidding aside, I would like to take this opportunity to share a bit about my experience as someone with HCU who attended college and was able – with a little trial and error – to achieve success in managing my disorder along the way. Hopefully, in doing so, others with HCU who are off to college will be able to see the same level of success.

The success I experienced in navigating college with HCU was due in no small part to a couple of steps that I took before I ever stepped foot on campus. The first step was to factor in my disorder and dietary needs when evaluating schools. For me, it was important to visit each of the schools I was considering whenever possible so that I could tour the dining halls and meet with dining staff to better understand how they would accommodate my needs. Ultimately, those accommodations were an important part of my decision as to which school to attend. For me, it appeared (key word; more on why later) that Rensselaer Polytechnic Institute (RPI) in Troy, NY fit best with my criteria across not only my dietary needs, but also academics, campus life, career prospects, and other important factors. Once I had decided on attending RPI, I took that second important step that I thought would set me up for success, which was to meet with one of the coordinators for the school’s dining services. For my freshman year, the plan we made was for me to access and prepare my own low protein foods from an area dedicated to people with various dietary needs, as well as, access the normal dining options available to all students. We also planned for my formula to be delivered to the campus post office on a monthly basis. Having taken these steps, it appeared to my family and I that I was heading into my freshman year with all the arrangements necessary to manage my HCU, stay on diet, and keep up with formula.

As it turns out, those plans were not as solid as we thought. Freshman year was, well, essentially a failure when it came to having all the arrangements needed to manage my disorder effectively. Taking time to prepare my own low protein foods meant my new friends were often done eating by the time I sat down to join them, and I would not say DIY meal prep left me with a wide variety of tasty or healthy options. After some time, I just about gave up on the low protein foods and cobbled together meals from what I could find among the options available to all students. On top of that, the three heavy boxes of formula (HCU Coolers) I needed each month were being delivered to a building that was over a quarter mile from my dorm room. Every four weeks, I had to trek up to the campus post office, borrow a

hand truck, and wheel the three heavy boxes halfway across campus back to my room. It. Was. A. Pain. The steps I took before going to school were important. However, I discovered during freshman year that the arrangements made were not as 'user friendly' as I had thought and HCU was an additional burden over the course of that year. Heading into sophomore year, it was time to go back to the drawing board.

After that freshman year failure, my parents and I requested a meeting with the dining staff and shared a simple sentiment: that really did not work, so fix it. That may seem a little harsh, but remember that you pay a lot of money to go to college (cost of attendance at RPI for 2020-2021: \$75,824... crazy, I know) and everyone deserves to get a satisfactory experience in exchange for that enormous cost. The dining staff heard us loud and clear, and we completely changed the plan for sophomore year. First, they tasked one of the lead chefs, Jason, in the dining hall nearest to my dorm with cooking for me. Yes, I was essentially assigned my own personal chef. Second, we arranged to have my formula delivered to that same dining hall, which was only a short walk from my dorm – a much shorter distance than the quarter mile to the post office. Having sorted all that out, I then sat down with Jason and we talked through my dietary restrictions and my preferences. That was incredibly important to the success of the new arrangements because I was able to educate him on all of the dos and don'ts of the diet, which, as we all know, are not always easy to understand at first. During our conversation, there was one more thing I did that led to success: I choose to give up some of my picky eating habits to allow Jason more flexibility to cook up tasty and healthy food. I knew that he was already taking on a big challenge in having to find low protein foods and I wanted to be as flexible as possible within those boundaries to set him up for success. Our efforts, and complaints paid off. Jason found his groove and he, and then another chef named Chris, prepared some great meals for the remaining three years I spent at RPI. And I had a much easier time keeping a supply of formula available with deliveries coming closer to my home away from home. With the new arrangements, HCU was no longer a drag on my college experience. In fact, working with Jason and Chris was an enjoyable part of my time at RPI, and it was even a bonus for others too. Jason and Chris were excited to have the opportunity to do some creative cooking with limited ingredients and there were even some perks for my friends, as the two chefs were able to access fresh fruits and other rare treats not normally available to students. There was one time Chris 'borrowed' some pricey mushrooms that had been reserved for a private VIP donor dinner to use in one of my meals and another instance where Jason honored a request from one of my good friends, Deborah, and delivered her some fresh strawberries. Experiences like these meant that accommodating HCU went from a major burden to a major highlight as part of my college experience.

I know my story above contains a lot of info! Let me summarize some of the aspects of my experience that are, hopefully, helpful for any readers who they themselves are about to go off to college:

- **Do** consider your disorder and dietary needs when looking at schools. Dining is an important part of the college experience, and you will see greater success across the board if you account for that.
- **Don't** forget to make arrangements for your formula, betaine, and other necessary medications. And remember that college life can be busy, and schedules can be hectic, so think carefully about how easy it will be for you to access those things on-demand and amid an ever-changing schedule.
- **Don't** be afraid to push the school and dining staff to think 'outside the box' in order to meet your needs. You're paying a large sum to have a great college experience, and they should support that.

- **Do** what you can to turn HCU into a positive part of your college experience. It can be! It can take some effort and planning, but make sure you're setup for success and enjoy your time at school!



Here's the last meal that Chris prepared for me before I graduated! I miss benefiting from his cooking skills!