

Transitioning to College with Hypophosphatasia

A Guide for Teens on Strensiq®



Congratulations on making the decision to attend college! As a student with hypophosphatasia (HPP) on STRENSIQ®, it's essential to plan and prepare for the transition to college. Read through our comprehensive checklist to help you navigate the process.

Before You Start Your College Search



It's important to understand the resources available to you if you need help or to assist you in planning for your college experience. Here are a few **key terms** that will help you know what to ask for:

- **Accessibility Department:** Most schools have **Accessibility Departments** that are there to help connect you with existing programs or create a plan for your needs. Schools have different names for these departments, so be sure to ask during a tour or look on the school website to find out the right terminology. Some schools use the following terms to describe this department:
 - Accessibility Services
 - Disability Services
 - Student Accessibility Services
- **TIP:** Go to the school website and type keywords such as “**accessibility**” or “**disability accommodations**” in the search bar to find the name of the department at that particular school. Every school has a different name for these departments, which can be confusing! Keeping a notebook can be helpful.
- **Accommodations:** Think about what you need to be successful in school. Maybe you need extra room in a dorm for your refrigerator. Or maybe stairs are challenging and a first floor dorm room might make things easier. These special student needs are referred to as **accommodations** or plans to help students be successful.

Understand Your Needs: Discuss and list out your personal, mobility and/or educational needs with your parent/guardian and high school counselor/case manager. When you are further into the process, you can have a clear understanding of what to ask the Accessibility Department. If a school cannot adequately meet your needs or provide sufficient support, this can help you narrow down your list of potential colleges to apply to.

IEP or 504: If you were on an Individualized Education Program (IEP) or a 504 Plan during high school, gather your paperwork about your current accommodations to discuss what was working or not working with the Accessibility Department.

What are my needs?

Schools have many different programs and services in place for students and faculty with a variety of disabilities and medical conditions. Here are some accommodation ideas to be on the lookout for during your college search

- **Assess Campus Accessibility:** Look at the terrain. Is it hilly? Is it in an area that gets a lot of snow and ice? Evaluate the campus's accessibility, including wheelchair ramps, elevators, and accessible restrooms. Do you have any concerns?
- **Are there EMTs on staff?** Do they have the ability to administer an EpiPen (if appropriate).
- **Transportation Options:** Research transportation options, including campus shuttles, ride-sharing services, and parking accommodations. Consider if walking to class is possible, or will you need mobility assistance.



STUDENT TIP

I figured I would just do my injections in the bathroom, but then I learned that it's not sanitary or recommended to do. I also learned that I should not lay syringes, vials, or other injection supplies directly onto a dirty surface (like a bathroom or dorm room counter). I'm not the best at cleaning but I always clean the surface by my desk where I do my injections with bleach wipes so it stays germ free.

- Confirm if the school allows students to have a car on campus and if there are accommodations for medical purposes. (For example, will you need a car to transport medication from the mailroom to your dorm?)
- Are you comfortable doing injections in front of a roommate? If not, consider asking if a single room is an option. Some patients with HPP have opted to ask for accommodations for single rooms, while others have wanted to have the social experience of having a roommate. It's important to weigh the pros and cons of each to decide what is best for you.
- **Medication Support, Delivery, and Storage:** The delivery of refrigerated medication poses its own logistical challenges on a college campus. Ask questions about how the school can accommodate medication shipments, including via mailroom or health center. Other questions include:
 - Does the campus allow more than one fridge per dorm room?
 - Determine if the school provides assistance with injections, EMTs on staff and access to a health center with a generator.
 - Is it easy to transport a large box from the mailroom to a dorm room? Can the mailroom accommodate a large box (mailrooms can be very small at some campuses).
 - Does the Health Center have the means to store refrigerated medication during a power outage?
 - Does the campus have a sharps disposal program?
- **Sharps Disposal:** Explore options for sharps disposal, including a sharps container or other vessel.



Are you wondering what to do with your disposed-of sharps while away at school? If your school doesn't have a disposal option, Alexion has contracted with Stericycle to mail sharps containers to patients to support the disposal of hazardous waste (including used needles and syringes). Contact **PANTHERx Rare** for more information.

BEFORE SCHOOL CHECK LIST:

- Understand the Accessibility Department and key terms
- Write a list of your needs
- Locate your IEP or 504

College Tour Time? Bring This List of Considerations:



Here are a few tips from students to help you make the most of your college visit:

- Inquire about the tour itself. Is it a walking tour? Many tours require a significant amount of walking, covering a lot of terrain.
- Consider attending an Open House. Typically various department heads are represented and you can get questions about accommodations and accessibility answered at that time.
- Gather your questions for your tour guide.
 - Where is the health center and what are the hours?
 - Are freshman dorms close to the main campus where classes will be?
 - Where is the dining hall? Is there a dining hall in some of the dorms?
 - Are freshmen allowed to have cars?
 - How do students get to class? (Larger campuses may have buses/shuttles. Some students use bikes/scooters, etc.)
 - Ask the tour guide or Admissions Department for the contact information of someone from the Department of Accessibility.

You Know Where You Want To Apply. Now...



Narrow Down Your List of Schools

Once you have all of the information and have decided that you are interested in applying to a school, email the Accessibility Department to determine whether the school can meet your medical needs and assist you with any of your accommodations.

- Contact the Accessibility Department while school is in session to discuss support options and determine eligibility for services.
- Set up a call or an in-person meeting, or send an email inquiring about your list of needs.
- Determine if you and your family are comfortable with the school and its ability to meet your needs.



You Applied! Were Accepted! Decided To Enroll!

Congrats! Now... Before School Starts

Before you pack your bags, there are still a few steps to take to ensure you have covered all your bases before you head to school. Remember the Accessibility Department? If you haven't reached out to them yet, *now is the time!*



Contact Accessibility Department

- Notify Them:** Let them know you are enrolling and to finalize accommodations requests. Share necessary documentation, including your high school IEP/504, medical records needed to support your medical diagnosis.
- Communicate:** Discuss how to communicate with professors and Resident Advisor (RA) about your HPP and any necessary accommodations, if necessary.
- Refrigerator and Medication Storage:** Some schools do not allow more than one refrigerator in a room. You may need to obtain an accommodation to allow you to bring your own medical refrigerator.

STUDENT TIP

I told my roommate all about my HPP so she understood why I had my own refrigerator and why I might need privacy in the room when doing my injections. I was happy that I was able to have a roommate who understood my medical needs.

Set Up Your Injection Plan

- Medication Reminders:** Get a calendar or download the myHPP app for medication reminders.
- Sharps Disposal and Needle Risks:** Ensure you know how to properly dispose of sharps bins once they are full.
- Determine Medication Storage:** If you're bringing your own refrigerator, be sure to include it on your packing list!
- Roommate Communication:** Every person has different preferences about what to share about themselves and their HPP journeys. Soft Bones has a variety of resources to help you with this. At the very least, explain the importance of maintaining proper medication temperature and storage, especially if you share a refrigerator.

STUDENT TIP

I used the Soft Bones myHPP app on my phone to remind me when to do my injections. It was great!

STUDENT TIP

I asked for the manager of the mailroom and got his contact information. It was helpful to have a go-to person who knew what to look out for when I was receiving my medication. He would reach out and let me know when the shipment arrived!

Are you wondering how to return the cooler and packaging your Strensiq[®] comes in? **PANTHERx Rare** Pharmacy will recycle the coolers they ship the Strensiq[®] medication in through an automated return process via FedEx. Contact **PANTHERx Rare** for more information and instructions on how to opt into the program.

Plan for Medication Delivery

College students can arrange to get their medications in different ways. In some cases, parents receive shipments and drop them off with their students at college. Other students receive medication shipments directly from PANTHERx (the pharmacy that delivers STRENSIQ) at their college campuses. Either way, it's important to have a plan and decide ahead of time how you will ensure you have your medication.

- **Roles and Responsibilities:** Who will be responsible for ordering new shipments of medication? It's important to know how to contact PANTHERx pharmacy to order new medication and have the phone number handy in case you need it. When ordering medication, it's important to order additional supplies (for example, alcohol swabs, syringes, bandaids, etc.). In addition, be sure to have a plan about who will report any issues with injections or other side effects to PANTHERx, OneSource, or your doctor.
- **EpiPen:** Some patients who are on Strensiq carry an EpiPen. Make sure you are comfortable and aware of how to use it and when to use it.
- **Medication Shipments:** Talk to the mailroom (or the health center) about receiving refrigerated medication and who can help you understand any specific shipping or handling instructions before you arrange your shipment to the school. Determine how medication shipments will be received.
- **Sharps Disposal:** Explore options for sharps disposal in your dorm, including a sharps container or other vessel. Ask the school where you can safely dispose of sharps containers that are full. In addition, PANTHERx has a mail-in sharps disposal program as well that you might want to look into.

Medication Delivery Checklist:

- _____ will work with the pharmacy PANTHERx to arrange medication delivery.
- I have determined how I will receive my medication shipment at school.
- I know what supplies are available and who to talk to if I need additional supplies.
- I know how to properly dispose of my sharps bin/needles.

STUDENT TIP *I forgot to bring a sharps disposal with me. So be sure to add that to your packing list.*

Additional Tips

It's important to "expect the unexpected." Some scenarios can (and will) occur that you might not have planned for. Here are a few other tips from college students to help you plan.

- **Explain HPP to Professors:** Discuss HPP with your professors and establish a communication plan for missing class due to HPP.
- **Plan for Power Outages:** Confirm if the health center has a generator and if they do, ask if your medication can be stored in the health center refrigerator in the event of a power outage.
- **Communicate:** Think about how much information you would like to share with your roommate. In some cases, it may be important for your roommate to know about your HPP. For example, if they want to store pizza in your medicine refrigerator, it will be essential for them to understand the importance of maintaining a consistent temperature. Or if you need privacy while injecting, communicating about your needs will be imperative to a successful living arrangement.
- **Disposal of Strensiq Packaging Materials:** If you have ever opened up a shipment of Strensiq, you know that there is a lot of packaging that needs to be properly disposed of.
- **PANTHERx** - 855-726-8479
- **OneSource** - 888-765-4747

STUDENT TIP

I didn't share much about my HPP until I got to know my roommate better. Now she knows that I like to do my injections when I'm alone and she also knows that I could need an EpiPen.

STUDENT TIP

Because of my HPP, carrying the large box to and from my dorm room was not possible. So instead of doing this, I instead opened up my package in the mailroom, removed the medication and supplies, and sealed up the remaining package, sending it right back to PANTHERx as part of its recycling program. This allowed me to only have to transport the small box of medication to the dorm room without having to carry the large box across campus, and then back again. If you have a longer walk, you could transport the cooler as well, but it was close enough that I didn't have to do that.

Before College

College Tour

Narrow Down

After Enrollment

Additional Tips

Notes

Before College

College Tour

Narrow Down

After Enrollment

Additional Tips

Notes



**A special thanks to our Teen
Advisory Council, Morgan S.
and Cannon S. for sharing
their experiences and for their
contributions to this resource**

December 2024