



Everyone's path is different, and the life changes (transitions) you need to prepare for are based on the specific path you're on. For those that are interested and able to pursue secondary education through college, it's important to be aware of the support that's available to you, and what you need to do to access it.

All public and private colleges that receive federal funding **must provide equal access** to education for students with disabilities and cannot discriminate against people with disabilities.¹ Common challenges with XLH, such as hearing problems or difficulty walking far distances, would be covered under these laws. Some key things to remember are:

- If you had an Individualized Education Plan (IEPs) in high school, it does not apply in college; however, your **504 plan** does if the college receives federal money.
- Students are responsible for locating the disabilities office, identifying themselves, requesting accommodations, and providing any required documentation (like a 504). The school is not required to help **unless you ask**.
- Typically, the student is responsible for **requesting accommodations each year**.² An accommodation for XLH might be having more time to get across campus for class or permission to make up assignments missed during an absence due to a hospitalization or required medical appointment.

If you haven't communicated about your condition and documented or requested accommodations ahead of time, your professors aren't required to make exceptions later. Determine exactly what you may need, and when you make the request try to be as specific as possible.

UNDERSTANDING FERPA (FAMILY EDUCATIONAL RIGHTS AND PRIVACY ACT)



This law gives parents certain rights regarding disclosure of their children's educational records. It's important to note that these rights transfer from the parent to the student after the student turns 18. Therefore, colleges must have a student's permission to release any of their information, including health information, to their parents.

<https://www2.ed.gov/policy/gen/guid/fpco/ferpa/index.html>

Also, keep in mind that you'll be juggling class, personal, and medication schedules. Use some of the resources in this toolkit to help you with self-care and to make sure you stay on track with your disease management plan.

"When I went to college, no one was telling me to take my medication anymore so I wasn't as adherent as I should have been."

ENTERING THE WORKFORCE



Many people choose to enter the workforce after high school rather than go to college. Resources like state-based Vocational Rehabilitation Agencies can help individuals with disabilities find and secure employment through a variety of support services. Once you enter a job or career, reference the **Navigating the Workplace** section of this toolkit for important information about communication with employers and co-workers about XLH.

RESOURCE

Find more information about secondary education and the workplace in the Global Genes toolkit:
Optimizing Your Potential as a Young Adult with a Rare Disease
globalgenes.org/wp-content/uploads/2015/06/GG_toolkit_Taking-Control-2_web.pdf



Jason, living
with XLH

REFERENCES

1. What are a public or private college-university's responsibilities to students with disabilities? ADA National Network; 2019. <https://adata.org/faq/what-are-public-or-private-college-universities-responsibilities-students-disabilities>. Accessed December 8, 2019.
2. Student disability accommodation policy. Maryland Institute College of Art; 2019. <https://www.mica.edu/mica-dna/policies/disability-accommodation-policies/student-disability-accommodation-policy/>. Accessed December 8, 2019.