

#9 Resources for College Students with Idiopathic Hypersomnia and Their Supporters

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ACADEMICALLY-RELATED RESOURCES

- **Best Colleges for Students with Disabilities**
<https://www.ahead.org/students-parents/parents>
The Association on Higher Education and Disability (AHEAD) is highly regarded for its commitment to full participation of persons with disabilities in post-secondary education. AHEAD works collaboratively with regional Offices of Civil Rights under the Department of Education. This link addresses several issues that have to do with determining best colleges for students with disabilities.
- **College Resources for Students with Disabilities**
www.oley.org
Support, advocacy, and assistive technology to facilitate the transition to college.
- **Department of Education (DOE)**
Resources Related to Postsecondary Education for People with Disabilities
<http://project10.info/DetailPage.php?MainPageID=202&PageCategory=Postsecondary%20Education&PageSubCategory>
This site provides resources to foundational information for people with disabilities, their educators and their families.
- **National Center for College Students with Disabilities (NCCSD)**
<http://www.nccsdonline.org/>
This federally funded national center is associated with AHEAD and is a one of a kind resource for college students with all types of disabilities, chronic health conditions,

or mental or emotional illnesses. It provides information for supporters, parents, faculty, and others working with college students.

“Free information and a good ‘first stop’ available at NCCSD Clearinghouse [<http://www.nccsdclearinghouse.org>]. Contact us directly with any specific questions. [<http://www.nccsdonline.org/contact-us.html>]”

- **“Testing Out” of Classes**

- **Overview of CLEP, DSST/DANTES “Testing Out” Programs**

- www.dantes.doded.mil/service-members/ta-alternatives/clep-dsst.html

- This site describes the most commonly known “testing out” examination programs.

- **College Board’s College-Level Examination Program (CLEP)**

- CLEP – Get College Credit With What You Already Know

- <https://clep.collegeboard.org/>

- A trusted credit-by-examination program (33 examinations) sponsored by the College Board allows students to “test out” of classes by demonstrating content mastery. CLEP policies vary: not all colleges accept them; some colleges accept credit for a few exams; others accept credit for all of the examinations. Typically, equivalent course credit is granted for passing a CLEP examination

- **DANTES Subject Standardized Test Program (DSST)**

- <https://www.prometric.com/en-us/clients/dsst/Pages/landing.aspx>

- This is a form of prior-learning assessment based on standardized, college-granting exams and is maintained by Prometric. The exams (38 over six subject areas: Business, Humanities, Math, Physical Science, Social Sciences, and Technology) allow college credit-for-experience at the upper and introductory levels. Passing scores are accepted at more than 2000 colleges for college credit. See www.getcollegecredit.com for more information.

- Note:** The American Council on Education (ACE) has evaluated and recommended college credit for the DSSTs. View their recommended minimum scores here:

- <http://www2.acenet.edu/credit/?fuseaction=browse.getOrganizationDetail&FI>

- [CE=300162](http://www2.acenet.edu/credit/?fuseaction=browse.getOrganizationDetail&FI). Policies differ across colleges as to which test scores are accepted, the number of credits awarded, and the designated academic categories for those credits. The exams are funded for active-duty military and are available as well to adult learners, homeschooled students, and military veterans.

- (Source:** Bridgewater State University website / www.bridgew.edu)

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COUNSELING/CRISIS SUPPORT RESOURCES

- **National Center for College Students with Disabilities (NCCSD)**
<http://www.nccsdclearinghouse.org/crisis-resources.html>
In addition to the resources described in the entry above, NCCSD provides a “**list of crisis resources**, with tips for students who have disabilities...”
- **Society for Behavioral Sleep Medicine**
www.behavioralsleep.org
This organization of behavioral sleep medicine professionals includes therapists, and the Society will provide a list of their members in your geographic area with whom you can contract for counseling services.

Contact Person: Kathryn Hansen, Executive Director
Kathryn@behavioralsleep.org
Phone: 859-312-8880

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LEGAL RESOURCES

- **Students’ Rights**
 - **American Bar Association**
<https://apps.americanbar.org/litigation/committees/childrights/directory-legal-clinics.html>
 - **Office of Civil Rights, Department of Education (OCR DOE)**
<https://www2.ed.gov/about/offices/list/ocr/index.htm>
“The mission of the Office for Civil Rights is to ensure equal access to education and to promote educational excellence throughout the nation through vigorous enforcement of civil rights... The Office of Civil Rights (OCR) enforces federal civil rights and laws that prohibit discrimination in programs or activities that receive federal financial assistance from the Department of Education (DOE).”
- **Pro Bono Services**
https://www.americanbar.org/content/aba/groups/legal_services/flh-home.html
www.FindLegalHelp.org is a public service provided by the American Bar Association to help people with low-income.
- **Hire a Lawyer**
https://www.americanbar.org/content/aba/groups/legal_services/flh-home/flh-hire-a-lawyer.html

Hire a Lawyer is a public service by the American Bar Association, which provides unbiased referrals to affordable lawyers.

- **Law School Clinics**

There are clinics affiliated with law schools across the United States, in which law students provide services of public interest that could be useful to you. Some offer legal services; others offer services through medical-legal partnerships. The following are examples of such clinics:

- **University of Michigan**

- https://www.americanbar.org/groups/probono_public_service/resources/directory_of_law_school_public_interest_pro_bono_programs/directory/ld65.html

- Pediatric Advocacy Clinic** specializes in issues that impact the health of patients, such as: "Public benefits (food stamps, FIA/cash assistance, childcare benefits, Medicaid, SSI); **Education (denial of special education services, disciplinary issues, expulsion); Housing (Section 8, HUD, eviction, poor housing conditions, utility problems); Family law (domestic violence, child custody, child support orders, guardianship)"**

- **For a list of law school clinics in your part of the country, go to:**

- http://www.americanbar.org/groups/probono_public_service/resources/directory_of_law_school_public_interest_pro_bono_programs/definitions/pi_pi_clinics.html

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MEDICAL-LEGAL PARTNERSHIP RESOURCES

Medical-legal partnerships often are based in hospitals and other health care institutions and work with attorneys.

Source for the following resources:

University of Michigan Law School Pediatric Advocacy Clinic

<https://www.law.umich.edu/clinical/pediatricadvocacyclinic/Pages/FAQs.aspx>

- **National Center for Medical-Legal Partnership**
<http://www.medical-legalpartnership.org/>
- **Health Law Partnership**
<http://www.healthlawpartnership.org/>
- **Legal Health**
<http://www.legalhealth.org/>
- **Project Heal at Kennedy Krieger Institute**
http://www.kennedykrieger.org/kki_misc.jsp?pid=5761

- **Gap Watch: How Schools Treat Students with Physical Disabilities vs. Emotional Disabilities (NPR, June 2015)**
<http://stateofopportunity.michiganradio.org/post/gap-watch-how-schools-treat-students-physical-disabilities-vs-emotional-disabilities>
- **When the Doctor's Prescription Is a Lawyer (NPR, May 2015)**
<http://stateofopportunity.michiganradio.org/post/when-doctors-prescription-lawyer>
- **Notes: Doctor's Orders: Call Your Lawyer (Law Quadrangle, Spring 2015)**
<http://quadrangle.law.umich.edu/spring2015/features/doctors-orders-call-your-lawyer/>

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SAFETY MEASURES

There are two potential sources of medical safety measures for use on campus: the medical practitioner on your campus and medical alert options, which now include medical alerts available on many smartphone lock screens, in addition to traditional alert bracelets or wallet cards.

- **Campus Health Services/Infirmary:** At the same time that you submit your documentation paperwork to the disability services office, you also may want to do the same and meet with staff in the health services office/infirmary, informing them of and providing information about your diagnosis, your symptoms, and how they may affect your life on campus. On some campuses, this office coordinates closely with the office providing disability services, whereas on other campuses, they may work together but are not necessarily under the oversight of the same administrators. If you decide to include health services in your campus network of services, then you will want to update them about your medications and dosing changes as well as changes in your symptoms, as you would do with disability service providers when symptoms change (so adjustments in your accommodations can be discussed). With your permission, the health services office can inform both first responders and campus police of your medical issues in the event you need their services and are not able to convey information about your diagnosis and medications; that office may also be able to inform the Disability Service Provider and the offices of the Deans about the medical bases of your symptoms and needs.
- **Medical Alerts**
The Hypersomnia Foundation hopes to develop a medical identification card specific to idiopathic hypersomnia. Keep updated via *SomnusNooze* (subscribe here: <http://hypersomniafoundation.us3.list-manage1.com/subscribe?u=2635095b8af0b21724c402489&id=4ff40246e3>). Below is a current option to consider.

- **Smartphone Options**
<http://www.nydailynews.com/news/world/10-apps-save-life-case-emergency-article-1.2438105>
“**Smartphones** now let you create a **Medical** ID that can be accessed from the Emergency Call screen. ... To view a person's **Medical** ID in an emergency, go to their **lock screen**, tap on...”
- You may find useful resources on the three (3) websites below, beyond what the link brings you to directly. The first two websites are for specific populations of patients outside of the hypersomnias, and the third site has many resources intended for varied populations of patients with “rare” diseases.
 - **Oley Foundation**
www.oley.org/
 - **Safety Products | Families and Adults/Resource Library | Autism Speaks**
<https://www.autismspeaks.org/family-services/resource-library/safety-products>

Taking Control: Gaining Independence as a Young Adult with a Rare Disease (RARE Toolkit)

<https://globalgenes.org/toolkits/transitioning/resource-guide/>

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SOCIAL RESOURCES

There are several sources of social support available to college students with idiopathic hypersomnia and their supporters.

- **The Hypersomnia Foundation**
www.hypersomniafoundation.org
Annual events are held, which bring together those with idiopathic hypersomnia, their supporters, members of the Board of Directors, and physicians and researchers, including members of the Foundation’s Medical and Scientific Advisory Boards. These events include research updates and sessions focusing on the needs of those with the diagnosis of IH, as well as social gatherings. Some of these events are live-streamed and free.
- **Online Communities**
 - **Hypersomnia Alliance**
A group of people dedicated to supporting those living with a hypersomnia by increasing awareness through local and online support groups and offering support retreats. Its mantra "We can only grow in strength as we support each

other" grew out of years of witnessing the power of what happens when those with idiopathic hypersomnia, narcolepsy type 1, narcolepsy type 2, and their supporters come together and realize that "You are not alone."

- www.atlantahypersomniasupport.com OR
- https://www.facebook.com/HypersomniaAlliance/?hc_ref=ARRs5UJIKdZxSE-jyRhoIWFneczzFfQWGVlBjqDZ638d_PwpKJij5EcrRoRdKM3kSuE

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SOCIAL SECURITY

Source of links below: Oley Foundation (www.oley.org)

- Social Security Administration
<https://www.ssa.gov>
- Social Security Work Site
<https://www.ssa.gov/work/>
- State-by-State Insurance Information
(NORD's resource guide for state insurance marketplace information)
<https://rarediseases.org/for-patients-and-families/information-resources/state-health-insurance-information/>
- Students with Disabilities: Preparing for Postsecondary Education
<https://www2.ed.gov/about/offices/list/ocr/transition.html>
- The Social Security and Disability Resource Center
<http://www.ssdrc.com>
- Special Savings Account for Families of Disabled Persons
<https://www.wsj.com/articles/a-new-savings-plan-for-the-disabled-1420939307>

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VOCATIONAL RESOURCES

- **State Rehabilitation Offices**
<http://www.fda.gov/downloads/AboutFDA/WorkingatFDA/UCM277757.pdf>
There are off-campus services that can help the college student with idiopathic hypersomnia. Because IH is a recognized disability, your state vocational rehabilitation services office may arrange for a vocational counselor and provides **supportive services through all levels of schooling and into career paths**, including some services not provided on campus under ADA law. For example,

campuses are not required to provide personal coaches or personal aides, but vocational rehabilitation offices may provide such services. The link above provides a list of your state's rehabilitation offices where you can find information to learn about, explore, and request services for the student.

- **Employment Legal Support**

- **Office of Disability Employment Policy**

- U.S. Department of Labor -- ODEP - Office of Disability Employment

- <https://www.dol.gov/odep/resources/jan.htm>

- “The Office of Disability Employment Policy (ODEP) is the only non-regulatory federal agency that promotes policies and coordinates with employers and all levels of government to increase workplace success for people with disabilities... Its mission is to influence policies and practices that increase the number of employment opportunities for people with disabilities... It promotes fair and high quality work-life environments and breaks down barriers to fair and diverse workplaces and narrow income inequality... and sponsors policy development and technical assistance resources. One of these is the Job Accommodation Network (JAN) [<https://www.dol.gov/cgi-bin/leave-dol.asp?exiturl=http://AskJAN.org/&exitTitle=http://AskJAN.org>] — the leading source of free, expert and confidential guidance on workplace accommodations and disability employment issues.” (See below separate JAN entry for more information.

- **The American Bar Association's Section of Labor and Employment Law, pro bono committee** put together these web resources:

- https://www.americanbar.org/groups/labor_law/resources/pro_bono_work/probono_resources.html

- There is a page identifying pro bono programs in every state:

- <https://apps.americanbar.org/legalservices/probono/directory.html#>

- For example, here is the page for Massachusetts. Note the type of pro bono programs included on the list:

- <https://apps.americanbar.org/legalservices/probono/directory/massachusetts.html>

- **Workplace Fairness** is a non-profit employee rights organization

- <https://www.workplacefairness.org/>

- This website has free information about traditional workers' job rights and employment issues (e.g., hiring, firing, discrimination, wage issues, harassment) across 50 states.

- <https://www.workplacefairness.org/board>

- **Job Accommodations Network**

- <https://askjan.org/links/atoz.htm>

This website is full of substantial and varied “free, expert, and confidential guidance on workplace accommodations and disability employment issues.”

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HEALTH CARE INSURANCE INFORMATION

- **Affordable Care Act:** “The current Affordable Care Act requires plans and issuers that offer dependent child **coverage** to make the **coverage** available until a child reaches the **age** of **26**. Both married and unmarried children qualify for this **coverage**. This rule applies to all plans in the individual market and to all employer plans.”

The following link is to the Department of Labor Employee Security Administration website, where there is information about the “Young Adults and the Affordable Care Act: Protecting Young Adults.”

<https://www.dol.gov/agencies/ebsa/about-ebsa/our-activities/.../young-adult-and-aca>

- **Continued Health Care Coverage:**
If the student with IH will not have health care insurance beyond the age of 26 due to reasons related directly to the diagnosis of idiopathic hypersomnia (e.g., unable to work or find work, employed without health care coverage, or otherwise unable to support themselves), the parent and young adult may be eligible to request continued health care coverage under the parent’s plan. The office of the health insurance commission in your state or jurisdiction may extend health care coverage in some instances from 1-5 years. You can locate that office by searching online or by contacting your healthcare insurance company or the office of the insurance commissioner for your state or jurisdiction.
http://www.naic.org/state_web_map.htm

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Former College Students with IH
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