

## Resources for Families of K-12 Students with Idiopathic Hypersomnia

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### COUNSELING RESOURCES

- **Chai Lifeline**  
<http://www.chailifeline.org>  
Chai Lifeline's programs and services meet the unique emotional, social, and financial needs of families living with serious pediatric illness or loss.
- **Society for Behavioral Sleep Medicine**  
[www.behavioralsleep.org](http://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](mailto:Kathryn@behavioralsleep.org)  
**Phone: 859-312-8880**

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### LEGAL RESOURCES

- **Children's Rights Litigation**  
<https://apps.americanbar.org/litigation/committees/childrights/directory-legal-clinics.html>  
The American Bar Association provides a directory of firms that handle children's rights.

- **Office for Civil Rights, Department of Education**  
<https://www2.ed.gov/about/offices/list/ocr/docs/hq5269.html>  
*"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."*
- **U.S. Department of Education (DOE)**
  - <https://www2.ed.gov/policy/landing.jhtml>  
This link provides an overview of policy documents for the Every Student Succeeds Act (ESSA), with links to Civil Rights, FERPA, IDEA, and WIOA websites.
  - <https://www2.ed.gov/policy/rights/guid/ocr/disability.html>  
This link provides an overview of disability discrimination laws, regulations, resources, and STEM resources.
- **Pro Bono Services**  
[https://www.americanbar.org/content/aba/groups/legal\\_services/flh-home.html](https://www.americanbar.org/content/aba/groups/legal_services/flh-home.html)  
FindLegalHelp.org is a public service by the American Bar Association for sources of help for people who qualify as low-income.
- **Hire a Lawyer**  
[https://www.americanbar.org/content/aba/groups/legal\\_services/flh-home/flh-hire-a-lawyer.html](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 with 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 your child and family. Some offer legal services, while others offer services through medical-legal partnerships. The following is a sample list of the clinics providing services to children with educational and/or medical needs.
  - **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](http://www.americanbar.org/groups/probono_public_service/resources/directory_of_law_school_public_interest_pro_bono_programs/definitions/pi_pi_clinics.html)
  - **Boston College Law School - Juvenile Rights Advocacy Project Clinic**  
[https://www.americanbar.org/groups/probono\\_public\\_service/resources/directory\\_of\\_law\\_school\\_public\\_interest\\_pro\\_bono\\_programs/directory/ld9.html](https://www.americanbar.org/groups/probono_public_service/resources/directory_of_law_school_public_interest_pro_bono_programs/directory/ld9.html)  
"Delinquency, post-disposition administrative advocacy, **special education**, personal injury, status offenses, child abuse and neglect, and public benefits. In addition, students work as guardians-ad-litem for girls in the status offender system."

- **Columbia University - Law - Adolescent Representation Clinic**  
[https://www.americanbar.org/groups/probono\\_public\\_service/resources/directory\\_of\\_law\\_school\\_public\\_interest\\_pro\\_bono\\_programs/directory/ld27.html](https://www.americanbar.org/groups/probono_public_service/resources/directory_of_law_school_public_interest_pro_bono_programs/directory/ld27.html)  
"housing and homelessness prevention; teen parenting; health and health benefits; income and support benefits; **education**, tuition, and financial aid benefits; financial planning; **civil rights** including LGBTQ issues; job training and career planning; and domestic violence"
- **Florida State University - College of Law - Children's advocacy clinic**  
[https://www.americanbar.org/groups/probono\\_public\\_service/resources/directory\\_of\\_law\\_school\\_public\\_interest\\_pro\\_bono\\_programs/directory/ld36.html](https://www.americanbar.org/groups/probono_public_service/resources/directory_of_law_school_public_interest_pro_bono_programs/directory/ld36.html)  
"Represents children in foster care, juvenile delinquency, health care, **special education, disability, social security** and criminal law cases...The Health Care Access Project (HCAP) advocates for two groups of children: fragile children (children on life support) and developmentally delayed children (mainly cerebral palsy, autism, and mental retardation). The goal of the project is to provide these two groups of children with the services they are legally entitled to so that they can remain integrated in their communities."
- **Illinois Institute of Technology: Chicago-Kent College of Law - Health & Disability Law Clinic**  
[https://www.americanbar.org/groups/probono\\_public\\_service/resources/directory\\_of\\_law\\_school\\_public\\_interest\\_pro\\_bono\\_programs/directory/ld23.html](https://www.americanbar.org/groups/probono_public_service/resources/directory_of_law_school_public_interest_pro_bono_programs/directory/ld23.html)  
"The clinic represents adults and children with various medical impairments, including diabetes and autism, in cases that typically involve issues such as: **disability discrimination in schools; discrimination in employment;** vaccine-related injuries; **Social Security disability benefits;** and benefit denials by private insurance companies."
- **Rutgers Law School**  
[https://www.americanbar.org/groups/probono\\_public\\_service/resources/directory\\_of\\_law\\_school\\_public\\_interest\\_pro\\_bono\\_programs/directory/ld90.html](https://www.americanbar.org/groups/probono_public_service/resources/directory_of_law_school_public_interest_pro_bono_programs/directory/ld90.html)
  - **Child and Family Advocacy Clinic**  
This clinic handles child abuse and neglect, public benefits, **education**, immigration, medical, and mental health issues.
  - **Child Advocacy Clinic**  
This clinic handles children at risk and living in poverty - child abuse, trauma, and **disability**.
- **University of Michigan**  
[https://www.americanbar.org/groups/probono\\_public\\_service/resources/directory\\_of\\_law\\_school\\_public\\_interest\\_pro\\_bono\\_programs/directory/ld65.html](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)"

- **University of Pennsylvania Law School - Interdisciplinary Child Advocacy Clinic**  
[https://www.americanbar.org/groups/probono\\_public\\_service/resources/directory\\_of\\_law\\_school\\_public\\_interest\\_pro\\_bono\\_programs/directory/ld86.html](https://www.americanbar.org/groups/probono_public_service/resources/directory_of_law_school_public_interest_pro_bono_programs/directory/ld86.html)  
"ICAC brings together law, social work, **medicine** and mental health to advocate across disciplines for vulnerable adolescents"
- **Wake Forest University School of Law - Child Advocacy Clinic**  
[https://www.americanbar.org/groups/probono\\_public\\_service/resources/directory\\_of\\_law\\_school\\_public\\_interest\\_pro\\_bono\\_programs/directory/ld123.html](https://www.americanbar.org/groups/probono_public_service/resources/directory_of_law_school_public_interest_pro_bono_programs/directory/ld123.html)  
Custody, domestic violence, **education**
- **Willamette University Law - Child and Family Advocacy Clinic**  
[https://www.americanbar.org/groups/probono\\_public\\_service/resources/directory\\_of\\_law\\_school\\_public\\_interest\\_pro\\_bono\\_programs/directory/ld130.html](https://www.americanbar.org/groups/probono_public_service/resources/directory_of_law_school_public_interest_pro_bono_programs/directory/ld130.html)  
"adoptions, guardianships, dissolutions, child custody and parenting time, paternity, **education advocacy cases**, impact litigation, and law reform."
- **University of Virginia School of Law - Child Advocacy Clinic**  
[https://www.americanbar.org/groups/probono\\_public\\_service/resources/directory\\_of\\_law\\_school\\_public\\_interest\\_pro\\_bono\\_programs/directory/ld122.html](https://www.americanbar.org/groups/probono_public_service/resources/directory_of_law_school_public_interest_pro_bono_programs/directory/ld122.html)  
"Though most of the legal work will involve the representation of clients in the juvenile justice system or children **being denied legally mandated educational opportunities**, students may also represent children in cases involving immigration, services for incarcerated children, mental health and developmental disabilities law..."

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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](http://www.kennedykrieger.org/kki_misc.jsp?pid=5761)
- **NPR: Gap Watch: How Schools Treat Students with Physical Disabilities vs. Emotional Disabilities (June 2015)**  
<http://stateofopportunity.michiganradio.org/post/gap-watch-how-schools-treat-students-physical-disabilities-vs-emotional-disabilities>
- **NPR: When the Doctor's Prescription Is a Lawyer (May 2015)**  
<http://stateofopportunity.michiganradio.org/post/when-doctors-prescription-lawyer>
- **Law Quadrangle Notes: Doctor's Orders: Call Your Lawyer (Spring 2015)**  
<http://quadrangle.law.umich.edu/spring2015/features/doctors-orders-call-your-lawyer/>

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## **SAFETY MEASURES**

There are two sources of medical safety measures to consider: the medical practitioner at your child's school and medical alert options, which now include *medical alerts available on many smartphone lock screens*, in addition to *traditional alert bracelets or wallet cards*.

- **School Nurse**  
The school nurse should be kept current with your child's medications and the symptoms that are evident in school and at home. In addition, the school nurse should be informed of all changes in medications or dosing as well as changes in symptoms. You want to consider giving the school nurse permission to be in contact with your child's treating physician as needed. The nurse should also be kept informed of the clinical information and resources available through the Hypersomnia Foundation and other relevant information, including stories written by students of their experiences living with idiopathic hypersomnia (***Teens Talk:*** <http://www.hypersomniafoundation.org/wp-content/uploads/Teens-Talk.pdf>).

- **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/](http://www.oley.org/)

- **Safety Products | Families and Adults/Resource Library | Autism Speaks**

- <https://www.autismspeaks.org/family-services/resource-library/safety-products>

- **RARE Toolkits: Taking Control: Gaining Independence as a Young Adult with a Rare Disease**

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

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## **SOCIAL RESOURCES**

There are several sources of social support available to families with children with idiopathic hypersomnia.

- **The Hypersomnia Foundation**

- [www.hypersomniafoundation.org](http://www.hypersomniafoundation.org)

- Annual events are held that bring together those with idiopathic hypersomnia, their supporters, members of the Board of Directors, 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](http://www.atlantahypersomniasupport.com) OR
- [https://www.facebook.com/HypersomniaAlliance/?hc\\_ref=ARRs5UJIKdZxSE-jyRhoIWFneczzFfQWGVIBjqDZ638d\\_PwpKJi5EcrRoRdKM3kSuE](https://www.facebook.com/HypersomniaAlliance/?hc_ref=ARRs5UJIKdZxSE-jyRhoIWFneczzFfQWGVIBjqDZ638d_PwpKJi5EcrRoRdKM3kSuE)

- **Good Days, Bad Days: Magazine for Children with Chronic Illness**

<http://www.gooddaysbaddays.net>

This resource is identified by the Oley Foundation ([www.oley.org](http://www.oley.org)) and is an online magazine.

- **Camps**

- **Center for Courageous Kids**

[www.courageouskids.org](http://www.courageouskids.org)

This camp is located in central Kentucky and offers free camp weeks during the summer for children and free camp weekends for families and children in the spring and fall. Each of the weeks is designated for a particular diagnosis. Although there is no week or weekend dedicated to idiopathic hypersomnia, children with IH can apply and once the Center's medical team approves their application, the child can be placed on a wait list.

**The following camp resources are identified on the Oley.org website and may or may not be appropriate to your child's needs beyond IH.**

- **Camps & Scholarships**

<http://oley.org/?page=CampsScholarshipsDat>

- **CCFA Camp Oasis**

<http://www.crohnscolitisfoundation.org/get-involved/camp-oasis/>

- **Challenge Air for Kids and Friends**

<http://www.challengeair.com>

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Approved by Hypersomnia Foundation Board of Directors and former college students with IH

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