

Education Essentials for Students with Idiopathic Hypersomnia

**June 4, 2017
Boston, MA**

**Mary A. King, EdD
Member, Board of Directors
Hypersomnia Foundation**

The Backstory

- **It All Began in Atlanta** (2015 HF Conference)
 - Compelling question:
What can be done to make a difference in the lives of those affected by this diagnosis?
 - Conversations, feedback, & comments >>> Identified challenges & needs of students

- **Takeaways**

- *Unmet educational needs across grade levels for*

INFORMATION, DIRECTION, & SUPPORT

- **Responses**

- K-12 initiative
 - Higher Education initiative

- **Results**

- *Education Essentials for Students with Idiopathic Hypersomnia*



Education Essentials for Students with IH

- **17 Education Essentials Guides**
K-12 Directory of Guides Higher Ed Directory of Guides

INFORMATION, DIRECTION & SUPPORT

- **All Guides vetted by Board of Directors, Education Legal Counsel, and Medical Advisory Board** (medically-related content)

Contents of Guides

- **Considerations** for when requesting accommodations/academic adjustments
- **Guidance** for physicians working with students with IH
- **Information** about academic and non-academic resources
- **Direction and support** from those who have “been there, done that!”



EE K-12

- **SEEDS & DEVELOPMENT: 2015-17**

- **504s, IEPs, & AT sessions at 2015/Atlanta Conference**
- **4-part series in SN** *Crash Course: Public School Accommodations for Children with Hypersomnia*, authored by Kate Pece, MEd, IEC)
- **Volunteers** (students, parents, physicians) contributed to guides' contents
- **Results: K-12 Directory of Guides**; 8 guides, all derived from volunteers' work

- **SAMPLE GUIDE: *Guide to Requesting Accommodations for K-12 Students with IH***

- **FRONT END** Statement: *Standard Characteristics of Idiopathic Hypersomnia*
- **BACK END** Signatures: Parent(s), Student, Physician
- **BODY** **Statement of Impact on Learning*
**Checklist of Potential Accommodations & AT*
- **SOURCE:** Team of veteran SpEd teachers; Point Person: Kate Pece, MEd



EE Higher Ed

- **SEEDS & DEVELOPMENT: 2015-17**

- **Higher Ed Conversations Project:** Goal: useful academic adjustments
 - **Exploratory Interviews(28):** Students & families; faculty, admins, & disability service providers
 - **Approach:** Qualitative Design & Analysis, Narrative Inquiry, Points of Saturation
 - **Guiding Inquiry:** *What worked? What didn't work? What did you need and didn't have?*

- **Results:**

Higher Ed Directory of Guides: 9 Guides, 6 derived from *Higher Ed Conversations Project*

- **SAMPLE GUIDE: *Guide to Requesting Academic Adjustments for College Students with Idiopathic***

Hypersomnia (Counterpart to K-12 sample guide; see previous slide)

- **FRONT END Statement: *Standard Characteristics of Idiopathic Hypersomnia***
- **BACK END Signatures: Student & Physician**
- **BODY: *Checklist of Potential Academic Adjustments***
- **ACADEMIC REVIEW TEAM:** 4 disability services experts vetted the *Checklist of Academic Adjustments*; a patient expert who graduated college with honors and sought services through the ADA office on campus
 - Collaborators: Colombia-Greene, CC (SUNY), Kingsborough CC (CUNY), Minnesota State U, Mankato, and Smith College



Student Guide to Thinking about Academic Adjustments

Information, Direction, & Support

- **Focus:** Student-centered; *what they think they will need* and *why they will need them*
- **Direction & Support to:**
 - Become familiar with their challenges
 - Identify appropriate services for those challenges
 - Understand *why* the student needs those services
- **Expectations on campus:**
Know needs *before* entering college and be able to *discuss* what would benefit them
- **Challenges:** Often recently diagnosed with IH; trying to **understand, live, and cope** with their symptoms & treatment *while* learning how to live away from home *and* succeed in college AND not knowing what services are available through offices providing disability services
- **Primary Source:** Gail Glass-Malley, MEd, LMHC, Kingsborough CC (CUNY)

Common Experiences

•Idiosyncratic Nature of Symptoms

- Changes occur, students react; may not know what to expect that day, next day
- Dealing with expectations at school/on campus as they live with an invisible/hidden disability, experience changes in their EDS, symptoms, & medications, and create a social life

•Effects of an Invisible Disability

- Perception*: a “lazy student” who needs sleep
- Reality*: IH symptoms include loss of focus/sleepiness/sleeping in class and related activities

•“Elephant in the Room” Issues

- Attendance**: Absences, tardiness, dismissals
- Participation**: *Expectation*: Visibly/actively engaged in class
Reality: Unfocussed/sleepy in class and in outside-of-class activities
- Assignments**: *Expectation*: Meet deadlines and handle the volume of assignments
Reality: Needs extended time to meet deadlines and struggles to handle

the volume of

work

•Subjective Experiences

- “Not feeling understood”– by teachers/professors and physicians
- “No one knows what the diagnosis is”



Moving Forward

- **Work as a Team**
 - Collaborative stance, working *with*
- **Become Informed about IH**
 - Understand the *diagnosis* and recognize the *symptoms*
 - Realize how student is *affected* by the symptoms
 - Understand how symptoms affect the ability to function in educational setting
- **Advocate!**
 - Know the IH resources and share them with education & medical personnel
- **Be Knowledgeable about the Accommodations/AA Process**
 - Know the *challenges* the student will likely experience and *why*
 - Know and understand *services* the school/campus can provide
 - Know the services the student *needs*



What You Should Know: *K-12*

- **Realities**

- K-12 is about *Student Success*
- Parents must request their student be evaluated for accommodations

- **Productive Responses**

- *If denied an evaluation or denied accommodations, seek a second opinion outside the school system*
 - Parent Advocacy Groups
 - Office of Civil Rights
 - Personal Advocate
 - Legal consultation



What You Should Know: *Higher Education*

Realities

- **Higher Education --- about *student access*, not *student success***
 - Access to programs & services
- **Idiopathic Hypersomnia--- an invisible/hidden disability**
 - **Multiple professors** each semester vs. K-12 teachers who know the student
 - ***Seeing is believing*** sometimes rears its head



What You Should Know: *Higher Education*

Wise Choices: Best Productive Response

•Institutional Flexibility

•Examples:

- *Grades of Incomplete *Medical Withdrawals *Flexible, without penalty
- *Course Reduction *Retroactive Medical Withdrawals Attendance, Participation, & Course withdrawal policies *Part-time status *Semesters “off” without penalty

•A Good Fit with the Academic Major

- Issue: Right to choice of academic major *and* as academic major student can “live with”
- Highly engaging classes:
 - Experiential learning (Internships, course practica, Co-op Learning, Service-learning)
 - Student-centered or applied learning, group discussions, role-playing, field-based classes
- Flexibility within structure of academic major:
 - Incomplete Grades, semesters off, taking courses out of sequence, classes on-line

•Advocacy Stance

- Issue: Students working/dealing with professors
- Liaison Role vs. Advocacy Role by staff in the office providing disability services



The Invisible Disability

Invisible or “hidden” disabilities:

- Include symptoms such as debilitating fatigue and cognitive dysfunction
- Not always obvious to the onlooker
- Can limit daily activities with mild to severe challenges
- Can vary from person to person.

“People have such high expectations of folks like you [with invisible disabilities], like, ‘come on, get your act together,’ but they have such low expectations of folks like me in wheelchairs, as though it’s expected that we can’t do much.” (Joni Eareckson)

Source: www.invisibledisabilities.org



K-12 Directory of Guides

Information, Direction, & Support

- *Considerations When Requesting K-12 Accommodations*
- *Assistive Technology in K-12: A Walk on the Tech Side*
- *K-12 Student Success: Physicians Can Make an Important Difference*
- *Guide to Requesting Accommodations for K-12 Students with IH*
- *K-12 Academic Resources Guide*
- *Tips for Parents of K-12 Students with Idiopathic Hypersomnia*
- *Teens Talk*
- *Resources for Families of K-12 Students with Idiopathic Hypersomnia*



Higher Ed Directory of Guides

Information, Direction, & Support

- ***Student Guide to Thinking about Academic Adjustments***
- ***College Student Access: Physicians Can Make an Important Difference***
- ***Requesting Academic Adjustments for College Students with IH***
- ***Guide to Academic Resources for College Students with IH***
- ***Advice from College Administrators, Faculty, and Disability Service Providers***
- ***Tips for College Students with Idiopathic Hypersomnia***
- ***In Their Own Voices***
- ***Tips for Supporters of College Students with Idiopathic Hypersomnia***
- ***Resources for College Students with IH and Their Supporters***



Thank You!

Education Essentials

- **Karen Ammons**, Point Person, *Tips for Parents of K-12 Students with Idiopathic Hypersomnia*.
- **Catherine Carlson**, Director of the Office of Accessibility Services, Columbia-Greene CC (SUNY); Member, Accommodations Review Team.
- **Fiona Cousland, JD**, Associate, in collaboration with Brenda Bliss, JD, Partner, Riker Danzig, Scherer, Hyland, & Perretti; provides advisement and review of *Education Essentials* program materials.
- **Rev. Tom & Karla Fast**, provided outreach to community professionals.
- **Julie Flygare, JD**, Founder, Project Sleep; provided permission to adapt content from her chapter "Succeeding in School and in the Workplace with Narcolepsy" in Goswami, Thorpy, & Pandi-Perumal, (Eds.), *Narcolepsy: A Clinical Guide (2nd ed.)* (2016) to the needs of the *Education Essentials for Students with Idiopathic Hypersomnia* guides.
- **Dwight E. Giles, Jr., PhD**, Professor Emeritus, University of Massachusetts, Boston; provided peer consultation for qualitative designs, analyses, and interpretations throughout the *Higher Ed Conversations Project* and the *Tips for Parents of K-12 Students with Idiopathic Hypersomnia* guide.



Thank You!

Education Essentials

- **Jessamine Griewahn-Okita, BA**, College Intern, Summer, 2016. *Education Essentials* program.
- **Diana Kimmel**, Co-founder, Hypersomnia Alliance; provided access to pool of potential participants for the *Higher Ed Conversations Project*.
- **Jeannette Landrie, MEd**, Learning Specialist, Office of Disability Services, Smith College; Point Person and Member, Higher Education Accommodations Review Team.
- **Shannon Lavey, MS, OTR**, Student Service Coordinator, Assistive Technology Resource Center, Colorado State University; provided consultation re assistive technology at the college level.
- **Shonda Lyons-Golden, EdS**, Assistive Technology Specialist; co-presented assistive technology, session, 2015 Atlanta Conference, and Primary Source, *AT in K-12: A Walk on the Tech Side*.
- **Gail Glass-Malley, MEd, LMHC**, Student Psychological Counselor, Access-Ability Services, Kingsborough CC, (CUNY); Primary Source, *Student Guide to Thinking About Academic Adjustments*; Member, Higher Education Accommodations Review Team.



Thank You!

Education Essentials

- **Elise Newkirk**, Chancellor's Office, SUNY Albany, facilitated access to disability services providers in the SUNY and CUNY systems.
- **Kate Pece, MEd**, Independent Educational Consultant; session presenter, 2015 HF Conference; author, four-part series *Crash Course: Public School Accommodations for Children with Hypersomnia (SN)*; Special Education Point Person, K-12 Accommodations Review Team
- **Olivia Robbins, BA**, Student Representative, Higher Education Accommodations Review Team; Graduate Volunteer & HF Consultant, 2016/17; Graduate Intern, Summer 2017, *Education Essentials* program
- **Julie Snow, MS,LSW**, Director, Accessibility Resources and ADA Compliance, Minnesota State University Mankato; Member, Accommodations Review Team.
- **Robert Steinbaum, JD**, Associate Dean for Advancement, Rutgers Law School; provided access to legal services for *Education Essentials* program.
- **Gigi Whiteside, EdS**, Assistive Technology Specialist; co-presented assistive technology session, Atlanta 2015 Conference, and Primary Source, *Assistive Technology in K-12: A Walk on the Tech Side*.



Thank You!

Education Essentials

The Hypersomnia Foundation is indebted to those who contributed to:

- ***The K-12 Accommodations Review Team***
- ***The Higher Ed Conversations Project***
- ***The Higher Education Accommodations Review Team***
- ***The Tips for Parents of K-12 Students with IH and Teens Talk***
- ***In Their Own Voices***



Disclaimer:
Educational Essentials for Students with IH

The documents listed in the K-12 Directory of Guides and in the Higher Ed Directory of Guides are provided for informational and educational purposes only. They are not intended as a substitute for the advice or guidance of professionals or the policies of school districts, campuses, or offices that provide services to those with disabilities in K-12 or higher education.

