Welcome to today’s webinar...

Hemophilia and School Success: Navigating the System

Presented by: Joby S. Robinson, PhD
Hemophilia and School Success: Navigating the System

Joby S. Robinson, Ph.D.
OBJECTIVES

✓ Tips for Successful Advocacy
✓ Laws that support your child
✓ Resiliency
QUESTION?

What age is your child?
Children with Chronic Health Conditions are more at risk for adjustment difficulties

• Academics
• Emotional
• Behavior
• Social relationships
Possibly At Risk Due to:

- Increased absences
- Pain and anxiety
- Impaired stamina
- Fatigue
- Side effects from treatment such as mobility issues and other physical limitations
Educating School Personnel About Hemophilia (1)

• Visit your HTC so they can help you provide information to your school

• Meet at start of every school year with key school personnel (administrators, school nurse, teachers, PE instructors, school counselors, and social workers)

• Provide overview of diagnosis, treatment plan, emergency contacts, medical reports, educational materials, and current contact information
Educating School Personnel About Hemophilia (2)

• Encourage discussion and questions and work collaboratively to find common ground if disagreements arise

• Think outside of the box – Be creative!

• Involve your child as much as possible

• School nurses are required to have individual health plans for students with medical conditions

• Be positive

• Be aware of the Family and Medical Leave Act (FMLA)
QUESTION?

Have you set up a school meeting yet?

What service(s) do you want for your child this year?
Summary of What School Staff Need to Know

• Basic facts about hemophilia
• Severity of bleeds
• Caring for bleeds with factor
• Treating a bleed with R.I.C.E.
• School attendance
• How hemophilia has affected my child’s school experience
• Participating in PE
Fitness in School

• Discuss how exercise and PE class are essential for maintaining strong muscles and healthy joints with school personnel
• Consult with your clinician on what sports and activities are safe and when your child should participate after recovery periods
• Understand the appropriate use of safety equipment
School Attendance

• Regular school attendance is expected

• Be prepared with a plan for bleeds that may occur during the school day

• Stay on top of any missed school assignments

• Seek further help from the school in the form of tutoring if your child’s school work falls behind
Homebound

Each state has its own procedural guidelines to ensure that teaching is offered to students who have an acute or chronic medical condition that prevents them from attending classes at school.

There are two types of homebound services:

• **Intermittent Homebound**: This service is for when a child has infrequent, unexpected school absences; it is arranged at the beginning of the school year prior to an absence

• **Regular Homebound**: This service is for when a child is absent for a set number of days rather than intermittently; it is arranged when a child is absent
Responsibilities of the Student (1)

- Attend school regularly
- Become comfortable communicating needs to teachers and other school personnel
- Report bleeding episodes immediately
Responsibilities of the Student (2)

• Be responsible for handing in all assignments, such as homework or makeup work, unless there is a prior arrangement.

• Responsibilities typically transition from the parents to the child as he grows older.
Responsibilities of the School Staff (1)

• Respect the student’s privacy and confidentiality

• Understand and comply with the student’s healthcare plan

• Monitor student’s progress in school and report any changes in academic performance or any areas of adjustment (behavioral, social, emotional)
Responsibilities of the School Staff (2)

- Maintain open communication with parents
- Train necessary school staff on hemophilia
- Understand the school’s legal responsibilities and comply with agreed-upon accommodations
Challenges (1)

• Disagreements between parents and school staff on what services should be provided

• Plan is agreed upon but not implemented, or not being followed consistently by all staff members
Challenges (2)

• Homebound (HB) instruction is delayed or services are delivered inconsistently or ineffectively (eg, poor communication between HB teacher and regular teacher responsible for directing HB teacher)

• Continued poor performance in school and/or adjustment difficulties
How would you rate your school experiences with getting health care plans and classroom accommodations for your child?
FOUR LAWS

- Individualized Health Care Plan
- Rehabilitation Act of 1973 (Section 504)
- Individuals with Disabilities Education Act (IDEA)
- Americans with Disability Act (ADA)
Individualized Health Care Plan (IHCP/IHP)$^1$

- A state statute that requires a plan that lays out specific instructions on child’s healthcare needs

- Plan provides school staff with specific instructions on your child’s healthcare needs, including having an emergency plan and any necessary training needed by school staff
Individualized Health Care Plan (IHCP/IHP)\textsuperscript{1}

• In most cases, the school nurse is responsible for writing the plan with the parents and sharing it with all members of the school staff who are assigned to your child

• IHCP/IHP can stand alone or be included with a Section 504 plan or IDEA
How to Develop an IHCP

• Ask your HTC to document specific health needs within the school environment prior to your meeting with the school nurse

• Document other necessary procedures:
  – Services needed
  – Emergency protocol
  – Pain management protocol
  – School staff training
  – Implementation date
  – Periodic review dates
How to Develop an IHCP

• Set up a meeting with your school to discuss the plan; invite all necessary parties, including teachers, counselors, social workers, administrators & HTC staff
The Rehabilitation Act of 1973 (Section 504)

- A civil rights law that states a person cannot be discriminated against because of gender, race, culture, or disability
- Any program or service that receives federal financial support must comply with Section 504
- Disability is broadly defined and includes students with special healthcare needs
- In order to be eligible, the Section 504 team must establish that the disability (e.g., hemophilia) substantially limits at least one or more major life activities (e.g., learning)

*References are available at the end of the presentation.*
Examples of Section 504 Accommodations

• Flexibility in completing missed assignments and tests due to medical absences
• Notes of missed lectures
• Additional time to make up tests
• Accommodations in PE instruction

These accommodations are examples and are not an exclusive list.
Section 504: Who is eligible?

- Child who has a physical or mental impairment that substantially limits at least one major life activity.

- Major life activities: walking, seeing, hearing, speaking, breathing, learning, reading, writing, performing math calculations, working, caring for oneself, and performing manual tasks.
504 Accommodations: Other Examples

- Extra set of books for home-use
- Modified Physical Education
- 2-min. early dismissal for class changes
- Rolling backpack and top-row locker
- Extra time for assignments, if absent
- Tutoring
- Behavior Management
Individuals With Disabilities Education Act (IDEA)³

• Provides special education services with direct, specialized instruction according to an individualized educational plan (IEP) designed to meet the child’s unique needs (for students ages 3-21)
Individuals With Disabilities Education Act (IDEA)$^3$

- IDEA covers 13 disability categories, including “Other Health Impaired” (i.e., hemophilia)
- To be eligible to receive special education service, the child’s hemophilia condition must be determined to adversely affect his educational performance
IDEA Disability Categories

- Deafness
- Deaf-blindness
- Hearing impairment
- Mental retardation
- Multiple disabilities
- Orthopedic impairment
- **Other health impairment**
- Serious emotional disturbance
- Specific learning disability
- Speech or language impairment
- Traumatic brain injury
- Visual impairment, including blindness
Other Health Impaired (OHI)

- Having limited vitality or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness to the educational environment, that is due to chronic or acute health problems, such as...ADHD, hemophilia...that adversely affects a child’s educational performance.
Special Education: Delivery Models

• **Intinerant**: The special education consults with regular teacher or works with child in the regular classroom.

• **Resource**: Child spends 1-3 hours/day with special education teacher.

• **Self contained**: Child spends all day in a special education class.
## Summary: 504 vs. IDEA

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<th>504</th>
<th>IDEA</th>
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<tr>
<td>Civil Rights Law</td>
<td>Special Education Law</td>
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<td>Provides modifications to regular education</td>
<td>Provides special education services</td>
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<td>Does not require a written plan, but often has one</td>
<td>Requires a plan (IEP) with evaluation &amp; annual goals</td>
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The Americans With Disabilities Act (ADA) of 1990 is a civil rights law that prohibits discrimination on the basis of disability in employment, public services, and public accommodations.
Americans With Disabilities Act (ADA)

• Many postsecondary schools have an Office of Services for Students With Disabilities that serves as a liaison between students and faculty and can advocate for reasonable accommodations. If not, the school is required by law to have an ADA/Section 504 coordinator.
Americans With Disabilities Act (ADA)

• Regarding employment, any business with 15 or more employees falls under ADA law and must provide an equal opportunity to qualified individuals; the law restricts employers from asking applicants about health conditions before a job offer.
Maurice

Maurice is in 4\textsuperscript{th} grade. He has severe hemophila (Factor VIII deficiency). He also has some mild problems with attention and low motivation to complete his school work. He has been absent from school a lot, and his homebound instruction has been inconsistent.
QUESTION?

What recommendations would you suggest for Maurice?

--Environmental
--Instructional
--Behavioral/Social
--Academic
Jamie

Jamie is in 12th grade. He has severe hemophilia A. His parents are divorced and he lives with his dad. He has recently been hospitalized for gastrointestinal bleeding. He had dozens of needle pokes in just a few days and it caused him a lot of pain and distress. Jamie has missed a lot of school this year and is in danger of failing English. He hates to read. His dad wants him to go to college but he hasn’t done any of the applications as he’s not sure if he wants to go to college---he’s thinking of dropping out.
QUESTION?

What recommendations would you suggest for Jamie?

--Environmental
--Instructional
--Behavioral/Social
--Academic
Making Sure Your Child Is Ready for Independence

The path to independence begins from the moment your child is born. The more he learns to take care of himself, the greater his chances for success and independence.
How would you or your child answer these questions?

- I consistently and promptly identify bleeds
- I self-infuse at home and away
- I inventory and order my supply of factor
- I maintain my infusion supplies
- I complete a log after each infusion
- I make and keep clinic appointments or call to reschedule
- I come prepared to my HTC with a list of questions
- I communicate concerns and questions directly with all medical staff
- I do home exercises as instructed by my physical therapist
- I follow the advice of my doctors and nurses
Growing Up

• Encouraging independence is part of growing up. Fostering opportunities to learn at the appropriate stages can help a child mature into an independent, self-sufficient adult

• As your child progresses through school, it’s important for him to seek career options that match his interests and talents but also enable him to manage his physical and healthcare needs
Growing Up

• Emphasize continued education, whether in a vocational, community, or 4-year school, to help your child reach his potential

• Preparation for advanced education starts early
  – Parents must prepare by helping their child progress toward an independent lifestyle
  – Students must prepare by attending school regularly, getting good grades, and participating in extracurricular activities
Leaving Your Hometown

- If you are going away to school, you should consider the following:
  - Have you notified your current HTC?
  - Is there an HTC nearby your new location?
  - Where is the local emergency department?
  - Are there criteria for you staying on your parents’ health insurance policy?
  - Does your factor need to be shipped to a new address?
  - Understand rules and regulations for storing factor/pain medication
  - Have you contacted services for disabilities or the ADA/Section 504 coordinator at college?
Resilience

- Children with chronic health conditions are at greater risk for adjustment disabilities.
- Educate school staff about hemophilia and possible impact on social/emotional development as well as the physical impact.
- Encourage your child to talk with you, teachers, and other trusted adults about health-related stressors.
- Obtain professional support (school counselors, social workers, psychologists) for your child if he is having difficulty coping.
- Planning is essential during times of transition.
Strengths of Youth With Chronic Health Conditions

- Greater development of empathy and altruism
- Mature coping with pain and disappointment
- Increased determination and resiliency in the face of challenges
THANK YOU FOR JOINING US!

Our next webinar:
Tuesday, Oct. 15th
“Building Strong Families”
Presented by: David Robinson, PhD
September 27 – 29, 2013
Learn more at: www.hemophiliafed.org