Juvenile Huntington’s Disease (JHD): Educational Options
National Conference
June 6, 2009
Phoenix, Arizona

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Presenters’ Disclosures
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The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose or list
Learning Objectives

• Parents will learn essential educational options for children with JHD
• Parents will learn the importance of team decision-making with school staff
• Parents will learn about accommodations available for support in school settings
School Environment Outcomes

A safe place that:

• Supports learning and social interactions with peers
• Supports independence to the degree possible
• Provides educational and related services and interventions as needed
Successful Support Framework

• Clearly identify the types of supports your child needs in educational settings
• Educate staff on JHD and how it affects your child in particular
• Develop formal plans for staff to follow to ensure safety and needed supports
• Build a strong working relationship with school staff at all levels
• Maintain two-way communication
Team Decisions Determine Support to be Provided

- Options require meeting eligibility criteria
- Evaluations or assessments of existing reports, prior history and current functioning are reviewed against criteria
- Some additional assessments may be needed to determine “educational needs”
- Documentation and important records presented help justify educational needs
Options for Support at School

- Section 504 Plan for “reasonable accommodations” in educational settings
- Special Education and/or related services with an Individualized Education Plan (IEP) for modifications to curriculum
- Behavior Intervention Plan
- Health Plan for Chronically Ill provision
- School Health Plan or Emergency Plan
Section 504 Plan

• Request a Section 504 evaluation
• Evaluation with statement of a disability that “substantially limits life activities” (e.g. learning)
• 504 meeting with relevant school staff
• Develop a 504 Plan listing “reasonable accommodations” in school settings
• Give copy of 504 Plan to ALL staff expected to implement it
Example Accommodations

- Reduced homework assignments
- Extend time for completing tests
- Shortened school day
- Behavior Intervention Plan (with Positive Behavioral Supports)
- Assistive Technology (low tech-high tech) to access general education curriculum
- Designate safe haven for “cooling off”
- Organizational planner and checklists
- Emergency Health Plan (e.g. for seizures)
Special Education

- Evaluation to determine eligibility (e.g. Other Health Impairment, Learning Disability, or Emotional Disability)
- Development of an Individualized Education Program (IEP) by a team
- Modifications to general education curriculum
- Specialized instruction and/or related services in Least Restrictive Environment
Parental Rights in Special Education

- Schools give Prior Written Notice for major changes before implementing
- Parents can disagree – recommend putting requests for appeals in writing
- Decisions are to be made by the team, including parents
- Formal due process procedures are followed through the chain of command
Continuum of Placement Options

- General Education Classroom
- Resource Classroom
- Self-Contained Classroom
- Special Public School
- Private Day School
- Private Residential School
- Homebound or Hospitalized Placement
Related Services to Consider

• Speech Pathology
• Occupational Therapy (fine motor skills)
• Physical Therapy (gross motor skills)
• Counseling
• Adaptive P.E.
• Specialized Transportation
• Behavioral Interventionist
• Assistive Technology
Primary Elements in IEPs

• Present Level of Academic Achievement and Functional Performance
• Considerations of Special Factors (behavior, communication, assistive technology, etc.)
• Goals tied to needs and state standards
• Services and Related Services to be provided
• Supports for School Personnel (e.g. training)
• Accommodations in general classroom
Chronically Ill Provisions (in AZ)

- Medical certification from a physician that child will not be able to attend school for at least 3 school months (60 school days)
- Written plan outlining how school assignments will be given/submitted
- Statement of how school grades and school credit will be determined
- Responsibilities of school and parent
- Revise at end of timeline if needed
Emergency Plan or Health Plan

- Diagnosis and physical status
- Current levels of functioning
- Medications and dosage
- Management instructions
- Physician’s contact information
- Preferred hospital or urgent care facility
- Directions for transportation in emergencies
The Individual Child or Youth

• The physical and educational needs vary depending on the progression of their disease.
• Child/youth needs to be assessed regularly and results need to be shared with school staff.
• Encourage friendships and facilitate positive social skills in all arenas
• Staff orientation to JHD can increase compassion, patience, and extra support
Things to Consider...

- Not every school has a school nurse (R.N.)
- Include the school nurse or health assistant in IEP or 504 planning
- School counselors can provide strong support as well as a “safe haven”
- Orient staff on known symptoms of JHD so they can observe and report any changes (e.g. choking, seizures, aggressiveness)
- Be sure cafeteria staff, bus drivers, and playground attendants are informed as appropriate
Resources

• NICHCY (National Information Center for children & Youth with Disabilities) www.nichcy.org
• PACER CENTER www.pacer.org
• Technical Assistance ALLIANCE for Parent Centers www.taalliance.org
• Families and Advocates Partnership for Education www.fape.org
Resources

• The Huntington’s Disease Association (HDA) Juvenile Huntington's Disease - Information for Schools (The HDA is a UK registered charity)
  http://www.hda.org.uk/juvenile/schools.html

• The Family Guide Series: Juvenile Huntington’s Disease
  Huntington’s Disease Society of America
Resources

• To Find Your State Title V Program: Health Resources and Services Administration (HRSA), Maternal & Child Health Bureau (MCHB)
  http://www.mchb.hrsa.gov/programs/default.htm

• Family Voices http://www.familyvoices.org/