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WORKSHOP

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# Urea Cycle Disorders

*IMPACT ON DAILY LIVES, LEARNING PROCESSES  
AND EDUCATIONAL CHALLENGES*



Urea cycle disorders pose unique challenges in education, necessitating innovative approaches. Exploring these challenges equips parents to advocate effectively and collaborate with schools for their child's success.

**PRESENTER**  
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# Introduction

## WHAT IS A UCD?

Urea cycle disorders (UCDs) are a group of rare genetic conditions characterized by the body's inability to effectively remove ammonia from the bloodstream. Normally, the urea cycle converts ammonia, a byproduct of protein metabolism, into urea, which is then excreted in urine. In individuals with UCDs, this process is disrupted, leading to the accumulation of ammonia and associated toxic effects.

## SYMPTOMS

Symptoms can vary based on the specific type and severity of the disorder but may include:

- • Lethargy or unusual sleepiness
- • Poor feeding or appetite
- • Vomiting
- • Behavioral changes or irritability
- • Disorientation or confusion
- • In severe cases, seizures, coma, and potentially life-threatening complications

# Impact on Daily Lives and Learning Processes

Children with UCDs often require careful dietary management to limit ammonia production. They may also need to take medications and supplements to support the removal of ammonia from their bodies. The cognitive and physical impact of high ammonia levels can affect a child's daily functioning and learning processes.

For instance:

- Frequent hospitalizations and medical appointments can lead to absences from school.
- Dietary restrictions and the need for medication can disrupt routine school activities and social interactions.
- Neurocognitive deficits associated with high ammonia levels can result in learning difficulties, requiring individualized educational strategies and support.

# Educational Challenges

Addressing these challenges effectively requires a collaborative approach involving educators, healthcare providers, and families to ensure that children with UCDs receive the accommodations and support they need to thrive academically and socially.



# Educational Challenges

- • Frequent Absences: Regular medical appointments and potential hospitalizations can result in significant school absences, affecting academic continuity and social interactions.
- • Dietary Management: The need for special diets and potential feeding issues can complicate school meal times and participation in certain school activities.
- • Learning Difficulties: Neurocognitive issues stemming from UCDs can lead to challenges in memory, attention, processing speed, and executive functioning, necessitating specialized instructional strategies and accommodations.
- • Fatigue and Endurance Issues: Children may experience fatigue, impacting their ability to participate in a full school day or in extracurricular activities.
- • Social and Emotional Needs: The complexities of managing a chronic condition can affect a child's self-esteem, social skills, and emotional well-being, requiring supportive interventions.

# The History and Evolution of Special Education and the IDEA

## Timeline of Special Education and the IDEA

### Early 20th Century:

Special education begins to emerge as a separate form of education, with classes and schools dedicated to students with disabilities. However, many children are still excluded from public education.

### 1954 - Brown v. Board of Education:

A landmark Supreme Court case that, while not about special education directly, set a crucial precedent for inclusion by ruling that separate is not equal, laying the groundwork for later special education legislation.

### 1972 - Pennsylvania Association for Retarded Children (PARC) v. Commonwealth of Pennsylvania:

A significant case where the court ruled that students with intellectual disabilities are entitled to a free public education.

### 1973 - Section 504 of the Rehabilitation Act:

Prohibits discrimination based on disability in any program receiving federal financial assistance, setting the stage for further legal protections in education.

### 1975 - Education for All Handicapped Children Act (EHA):

Later known as the Individuals with Disabilities Education Act (IDEA). It mandates a free appropriate public education (FAPE) for children with disabilities and ensures special education and related services.

### 1982 - Board of Education of the Hendrick Hudson Central School District v. Rowley:

The first Supreme Court case interpreting the EHA, clarifying the level of services to be afforded to students with disabilities.

### 1990 - The EHA is renamed the Individuals with Disabilities Education Act (IDEA):

Emphasizes special education and individualized instruction. Introduces transition services and assistive technology.

### 1997 - IDEA Amendments:

Strengthened the role of parents, required general education teachers to be on the IEP team, and promoted inclusion in the regular classroom.

### 2001 - No Child Left Behind Act (NCLB):

Although not specifically a special education law, NCLB affected special education by emphasizing accountability and requiring schools to show educational progress for all students, including those with disabilities.

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## Timeline of Special Education and the IDEA

### 2004 - IDEA Reauthorization:

Emphasized aligning IDEA with NCLB, required special education teachers to be highly qualified, and introduced provisions to reduce disproportionality and address discipline.

### Fun Fact:

The IDEA was initially called the Education for All Handicapped Children Act and was enacted to ensure that children with disabilities had the opportunity to receive a free appropriate public education. This groundbreaking legislation fundamentally transformed special education, guaranteeing access and rights that were previously denied to many children with disabilities.

# The 6 Pillars of the IDEA

## FREE APPROPRIATE PUBLIC EDUCATION (FAPE)

Children with UCDs are entitled to receive specific educational accommodations, therapies, and services tailored to their unique medical and learning needs, ensuring they can access their education meaningfully.

## APPROPRIATE EVALUATION

Evaluations for children with UCDs may include assessments of their cognitive functioning, learning abilities, and physical health to develop a comprehensive understanding of their educational and medical needs.

## INDIVIDUALIZED EDUCATION PROGRAM (IEP)

The IEP for a child with UCD should include specialized instruction methods, dietary considerations, emergency medical plans, and accommodations for absences related to medical appointments or treatments.

## LEAST RESTRICTIVE ENVIRONMENT (LRE)

Students with UCDs should have the opportunity to participate in general education classrooms and activities, with necessary supports and accommodations, ensuring they are not isolated due to their condition.

## PARENT AND STUDENT PARTICIPATION

Parents of children with UCDs should actively collaborate in the IEP process, providing insights into their child's health needs and advocating for appropriate accommodations and services.

## PROCEDURAL SAFEGUARDS

Parents of children with UCDs should be aware of their rights to review educational records, participate in meetings, and understand the procedures for dispute resolution, ensuring their child's needs are properly addressed.



# How to Be an Effective Parent Advocate and When to Hire an Advocate?



To practice advocacy skills in a supportive, realistic setting, helping parents feel more confident in their ability to advocate for their child's educational needs.

# Recognizing the Need for a Special Education Advocate

# Tips for Effective Advocacy

Unresolved Disputes with the School

Need for Specialized Knowledge

Complexity of Your Child's Needs

Lack of Progress

Stay Organized

Effective Communication

Understand Your Child's Rights

Stay Informed & Build a Support Network

# Resources and Support

## State and Federal Resources

- **Office of Special Education Programs (OSEP):** OSEP is dedicated to improving results for infants, toddlers, children, and youth with disabilities ages birth through 21 by providing leadership and financial support to assist states and local districts.
- **Center for Parent Information and Resources (CPIR):** CPIR serves as a central resource of information and products to the community of Parent Training Information (PTI) Centers and the Community Parent Resource Centers (CPRCs), so they can focus their efforts on serving families of children with disabilities.
- **Wrightslaw:** A leading website about special education law and advocacy, offering a wealth of information about special education law, education law, and advocacy for children with disabilities.
- **Understood.org:** Provides resources, guidance, and support for parents of children with learning and attention issues.

## Support Groups and Online Forums

- **National Urea Cycle Disorders Foundation (NUCDF):** Connects families, provides education, and supports research. A great platform for sharing experiences and advice.
- **RareConnect (Urea Cycle Disorders Community):** Offers a safe, easy-to-use platform where the UCD community can connect, share experiences, and find support.
- **Facebook Groups and Online Forums:** Search for Urea Cycle Disorder groups on social media platforms like Facebook. These groups offer community support and a platform to share experiences and advice.

# A Story of Resilience and Achievement

- “Andres, an 18 year-old with a urea cycle disorder, faced significant learning challenges and frequent hospitalizations during his school years. However, with a well-coordinated support system involving his parents, school, medical team, and a special education advocate, Andres received the necessary accommodations and medical care. His IEP included provisions for a flexible school schedule, dietary management within the school, and training for school staff on managing potential medical emergencies. Over time, Andres’s academic performance improved remarkably. He not only caught up with his peers academically but also became an active participant in specialized programs like Culinary Arts, proving that with the right support and advocacy, children with urea cycle disorders can thrive in school and beyond.”



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*Together we can  
make a  
difference!*

THANK YOU !



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