Galactosemia

Understanding Galactosemia

Hillary Goldfarb, MA, Emerson College
Dr. Susan Waisbren, PhD,
Children's Hospital Boston

Teaching Strategies

What is Galactosemia?

Galactosemia is a metabolic disorder of carbohydrate metabolism. Galactose is found in many foods, particularly dairy products. Children with galactosemia do not have the enzyme to convert galactose into glucose for energy. They must adhere to a dairy-free diet. They may have difficulties with communication, comprehension of new concepts, and sensory-motor integration skills.

How can I help this student?

Children with galactosemia need to experience high levels of success. Providing praise and positive feedback is motivating for these individuals. Speak slowly and try to break complicated materials down into smaller more achievable segments. Provide note packets of the lessons planned for the week and allow students to highlight notes instead of writing them out. Augment reading with pictures or sign language and change the pitch of your voice when communicating abstract concepts.

What works best?

Establish an open line of communication with the parents and the child. It is important to make dietary accommodations for special activities or celebrations, so the child does not feel left out. Providing an outline for each assignment and specific goals is helpful. Help the child stay organized. Provide subject folders for assignments and extra one-on-one instruction time. Try to maintain a similar classroom schedule and structure, so the child becomes comfortable with the sequence of events.

Classroom Management

Available Technology

Classroom computers equipped with adaptive learning software have lead to academic improvements in children with learning delays. With this software, lesson plans and documents can be uploaded and modified based on the individual student's needs. Students with galactosemia have difficulties communicating, writing, and comprehending. The program allows the student to hear through headphones what they are writing/typing.

Dietary Accomodations

The diet can be a challenge in the classroom, especially if there are special occasions or activities where treats are supplied. It is important to inform the parent and the student in advance when these special treats will be in class. Encourage the student to bring in a container of safe treats. If the parents are aware of the celebration they can make accommodations and provide alternatives.

Special Services

The No Child Left Behind Act and the Individuals with Disabilities Education Act (IDEA) provide children with learning delays and disabilities with special education services. Children with galactosemia are eligible for these services. An Individualized Education Plan (IEP) can be developed based on the particular needs of children with galactosemia. Suggestions provided in the companion booklet Understanding Galactosemia: Resources for Educators provides strategies and techniques for adaptive learning.

Additional Resources

On the Web

www.galactosemia.org

http://newenglandconsortium.org

http://www.nbpts.org

http://www.dshs.state.tx.us/newborn/teachgal.shtm

http://www.tufts.edu/~hgoldf01/home.html

Thank You

Parents of Galactosemic Children Inc.
New England Genetics Collaborative
US Health Resources and Services Administration
Parents and Participants

Next Steps

Children are unique individuals with different learning styles and progressions. Some tactics and techniques may work better than others. Be patient and learn from them as they learn from you.