



Understanding Galactosemia: Resources for Educators

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About 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.**
- **One in 60,000 children are diagnosed with classic galactosemia in the United States. It is typically diagnosed within the first few weeks of life and the child must be put on a strict diet to prevent severe complications such as cataracts, sepsis, multi-organ failure, and even death.**
- **Maintaining this strict dairy-free diet is the only available treatment at this time. Research suggests that despite strict dietary adherence developmental, speech, and motor delays can develop as early as pre-school age and continue into adulthood.**

**Student
Card**

Name:

Condition: *Galactosemia*

Key Points

- Maintain a strict dairy-free diet
- Use pictures when possible
- Praise/Positive feedback
- Provide a word bank if applicable
- Distribute lesson plan note packet a week prior to lesson
- One-on-one instruction if possible
- When communicating different concepts, change the pitch of your voice or facial expression
- Use preparatory teaching: Inform students when their turn is coming up
- Present material in a slow sequential framework
- Maintain a similar classroom structure/schedule

Notes

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- Parents of Galactosemic Children Inc.
- Parents and Participants

Characteristics of Galactosemia

In your classroom, you may observe some or all of the following characteristics:

- **Difficulty communicating:** rambles incoherently and erratically, but assumes being understood (speech apraxia)
- **Difficulty comprehending:** Stares blankly; abstract concepts and opposites are not understood
- **Poor motor planning/processing**
- **Poor sensory-motor integration**
- **Struggles holding a pen and writing**
- **Becomes easily frustrated**
- **Difficulty remembering**
- **Lacks energy**
- **Impulsivity**
- **Wants to please and participate**
- **Motivated by praise**

Challenges

Galactosemia does not present the same in all children. Many have varying degrees of symptoms, and some do not display difficulties.

Speaking with parents about their child's galactosemia is often a challenge. They want their child to be like other children. Try and be sensitive

to this issue and convey a sense of normalcy, reminding them that learning is an individualized process.

Parents also experience their child's frustration and can also feel frustrated themselves. In order to keep remedies consistent, ask parents what they have observed at home and what strategies they use.

Work collaboratively on reinforcing successful strategies in the classroom as well as at home.

Additional Resources

Support groups for parents of children with galactosemia. To learn more about these groups visit these sites on the Web:

- Resources for parents from the Parents of Galactosemic Children Inc.
www.galactosemia.org

- Dietary guidelines and substitutions for parents with galactosemic children
<https://home.comcast.net/~tfcozzo/food/recipes.htm>

- Information regarding curricula modifications and adaptations for learning challenges associated with galactosemia :
<http://www.nbpts.org>

For further education, research, and communication about galactosemia :
<http://www.tufts.edu/~hgoldf01/home.html>
<http://newenglandconsortium.org>
<http://www.dshs.state.tx.us/newborn/teachgal.shtm>

Therapies

Therapies including physical , speech, and occupational have been shown to increase the child's motor planning, processing, and integration skills.

Some recommendations from therapists include:

- **Breathing:** Advise the child to take a deep breath if speech is erratic
- **Tracing:** Allow the child to trace letters repeatedly
- **Repetition:** repeat exercises several times to enhance muscle memory
- **Functional Training:** practice exercises that mimic everyday movements
- **Modeling:** place the children next to peers so that they can model behavior
- **Sensory Table:** use of sensory table to work with different mediums

Successful Strategies

*Tried and true tactics and techniques.
Ten Teaching “P”ractices*

Communication

- **Pace:** break topics down slowly
- **Pitch:** change the tone of your voice when describing opposite concepts
- **Pictures:** use a visual aids, pictures, or sign language when possible
- **Praise:** provide positive feedback
- **Patience:** maintain patience

Lesson Planning

- **Packets:** provide note packets for the week and distribute them prior to lessons
- **Peers/Partners:** place students next to peers or assign partners so they can emulate their behavior.
- **Prioritize:** provide subject folders for assignments and an outline of expectations/goals
- **Prompt:** tell the students when their turn is coming up

Classroom Environment

The classroom environment can also affect the child's progress.

- **Structure:** maintain a similar classroom structure and schedule
- **Sequence:** transition subject topics in the same pattern each day

- **Instruction:** one-on-one instruction with significant repetition is very helpful

- *Look for patterns/behaviors in the classroom that can be reinforced in the home*

Have an open communication policy with parents, other clinicians and educational professionals

Technologies

There are many new innovations that can be utilized in the classroom to help children with galactosemia progress along with other general education students.

Kurzweil Educational Systems, Inc :

- A computer system created for those with learning delays that adapts lesson plans based on the student's needs.

- Documents can be scanned into the program and modified for the particular delay or difficulty. Students have the ability to hear what they write via headphones and can work on the same assignment as general education students simultaneously.

Student Name:

Notes:

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Dietary Restrictions: **Avoid**

- All Milk products
- Foods that contain milk products
- Butter, Cheese, Yogurt
- Whey, casein, and curds

Key Teaching Tips:

- Speak Slowly
- Augment reading with pictures/sign language
- Break down difficult concepts into smaller achievable segments
- Maintain a similar classroom structure and subject transition sequence
- Use voice inflection (pitch/tone) when communicating opposite concepts
- Give lesson note packets in advance
- Provide individual subject folders