

Galactosemia School Guide

Education and Tools for Key Milestones in Your Child's Galactosemia Journey

Galactosemia is a rare metabolic condition that can be overwhelming for child and parent alike, especially when it comes to navigating educational milestones. Because they may experience developmental stages and the education process differently than their peers, children with Galactosemia may need more support in school. Here are some tips from parents of children living with Galactosemia that may help you prepare your child for their journey from preschool to high school and beyond.

Considerations



Preschool

- Look into your state's special education process
- Contact an [Early Intervention Program](#). Information can be obtained from your pediatrician or your state's Department of Education
- Join local [parental advocacy groups](#) to get support in the educational space

Check [here](#) for more information about caring for your child at this milestone.



Primary School

- Determine if your child needs formal special education plans for their needs, such as [The IEP: Individualized Education Program](#) and [504: Special Access Program](#)
- Familiarize yourself with the food services list at your child's school or school district and develop a safe foods list
- Gather all necessary materials to create an Introduction Package that you can provide to the school regarding your child's Galactosemia. (Consider materials like the [Galactosemia diet instructions](#), IEP/504 Plan, or any information you feel would be beneficial)
- Schedule an introductory meeting with the school to discuss your child's Introduction Package, and arrange follow-up chats
- Tap into advocacy groups for additional support in navigating the school system
- Empower your child to talk to friends, teachers, and school staff about their diet and condition

Check [here](#) for more information about caring for your child at this milestone.



Transition to Middle School, High School, and Beyond

- Schedule an introductory meeting with the school to walk them through the materials mentioned previously
- Continue to empower your child to talk about their condition in new situations
- Give your child parameters to begin selecting safe foods on their own
- Begin planning for occupational or educational transitions after high school
 - Consider starting in their early teens and including your child in the process

Check [here](#) for more information about caring for your child at this milestone.

Change in Treatment Plan, New Life Adjustments, or Start of New School Year

For other life changes like starting new treatment plans, programs, or school years, or starting at a new school, update your child's Introduction Package as needed, and schedule introductory meetings with new staff.