Understanding CSID at School

A practical introduction for school nurses, teachers & administrators

What is CSID?

Congenital Sucrase-Isomaltase Deficiency (CSID) is a genetic digestive condition that affects the breakdown of sucrose (a sugar found in many foods) and certain components of starch. Symptoms and food tolerances vary from student to student.

What might a student experience?

• Abdominal pain or cramping, bloating, gas, nausea, or diarrhea.

• Symptoms that may interfere with concentration, attendance, or participation.

• A need to access the restroom promptly or visit the school nurse.

Symptoms can fluctuate. A student may appear well at one moment and feel unwell later.

Meals, snacks & celebrations

• Follow the student's individualized food plan provided by the family and healthcare team; do not assume the same restrictions apply to every student with CSID.

• Coordinate ahead of time for school meals, classroom treats, parties, and field trips.

• Avoid pressuring a student to eat foods outside their plan. Offer an inclusive alternative when possible.

Medication and enzyme access

Some students are prescribed sacrosidase (Sucraid), an enzyme replacement used with foods or drinks containing sucrose. It does not treat starch digestion. A student may need access to prescribed medication around meals and snacks according to their individual medical orders and school policy.

Important: School staff should follow written orders, the student's healthcare plan, and district medication procedures. Do not change a dose, timing, food plan, or storage instructions based on this guide.

Supporting a Student with CSID

Everyday planning, accommodations & communication

Build an individualized school plan

Families, school nurses, and educators can work together to document supports. Depending on the student's needs and eligibility, these may be addressed through a health plan, Section 504 plan, or other school process.

• Prompt, discreet restroom access without unnecessary delay.

• A clear plan for symptoms, nurse visits, and contacting a caregiver when needed.

• Access to safe food, water, and prescribed medication at appropriate times.

• Advance notice of food-centered activities, field trips, and schedule changes.

• Reasonable flexibility for symptom-related absences, missed work, or participation, as individually appropriate.

What helps students feel included?

Keep health information private, avoid drawing attention to a student's dietary needs, and offer participation options that do not depend on eating a particular food. Ask the student and family what works best.

Questions for a family-school conversation

• What foods, snacks, or supplies should be available at school?

• What are the student's medication orders and who is authorized to assist?

• What symptoms should staff watch for, and what response does the family recommend?

• How should teachers plan for birthdays, parties, field trips, and substitute staff?

Did you know? Not everyone with CSID is lactose intolerant. Some students also have difficulty digesting lactose, but dairy restrictions should never be assumed solely because of a CSID diagnosis.

Connecting families. Inspiring change.

Medical disclaimer: This resource is for general education and awareness only, not medical or legal advice. It has not yet undergone professional medical review. Follow the student's individualized medical orders, school policies, and applicable requirements; consult qualified healthcare professionals for treatment decisions.