Understanding CSID

A simple guide to a rare digestive condition

What is CSID?

Congenital Sucrase-Isomaltase Deficiency (CSID) is a genetic digestive condition that affects the body’s ability to break down certain sugars and starches.

People with CSID have reduced or absent activity of an enzyme called sucrase-isomaltase in their small intestine. This enzyme helps break down sucrose, a type of sugar found in table sugar and naturally in many fruits and vegetables, as well as certain components of starch. When these carbohydrates aren’t properly digested, they can cause uncomfortable digestive symptoms.

Common symptoms

• Abdominal pain or cramping

• Bloating and gas

• Diarrhea or loose stools

• Nausea

• Poor weight gain or growth difficulties in some young children

Symptoms and food tolerances vary widely. Not everyone experiences the same symptoms or severity.

Why awareness matters

CSID symptoms can resemble those of other digestive conditions, which may contribute to missed or delayed diagnosis. Understanding the condition can help families ask informed questions and seek appropriate specialist care.

Rare doesn’t mean insignificant.

Understanding CSID

Diagnosis, management & everyday life

How is CSID diagnosed?

A gastroenterologist may use testing of digestive enzyme activity from a small-intestinal biopsy, genetic testing for changes in the SI gene, or certain specialized breath tests. No single test is appropriate for every person, and a negative genetic test does not necessarily rule out CSID.

How is CSID managed?

Management is individualized and may include adjustments to sucrose and starch intake, guidance from a registered dietitian familiar with CSID, and prescription sacrosidase (Sucraid) to help digest sucrose. Sacrosidase does not replace the enzymes needed to digest starch. Food tolerances and treatment needs differ from person to person.

Living with CSID

CSID can affect everyday decisions about meals, snacks, restaurants, celebrations, travel, and managing symptoms. For children, school meals, classroom treats, field trips, and access to prescribed medication may require advance planning and individualized support.

DID YOU KNOW?

Not everyone with CSID is lactose intolerant! CSID affects digestion of sucrose and certain starches, while lactose intolerance involves a different enzyme called lactase. Some people have both conditions, but not everyone with CSID needs to avoid lactose.

Every experience is different. Every voice matters.

Connecting families. Inspiring change.

Medical disclaimer: This resource is for general education and awareness, not medical advice. It has not yet undergone professional medical review. Consult a qualified healthcare professional about diagnosis, dietary changes, medications, and individual treatment needs.