Yukon-Kuskokwim HEALTH CORPORATION

Congenital Sucrase-Isomaltase Deficiency (CSID) Resource

Congenital Sucrase-Isomaltase Deficiency (CSID)

- This condition leads to an inability to digest sucrose (table sugar).
- Signs/symptoms:
  - Watery diarrhea after food containing sucrose
  - Abdominal pain/distension
  - Malnutrition, poor growth, FTT
- The condition is seen in Alaska Native people but is often under-diagnosed because patients unknowingly manage it with a traditional diet.

If you are considering this diagnosis, please consult a pediatrician. There are many more resources in the Pediatrics Folder on the vault, including sucrose content of medications and formulas.

CSID suspected

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- Consult a YKHC pediatrician.
- Consult the **ANMC CSID Guideline** for details on testing.

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- After CSID has been confirmed, treat with sacrosidase enzyme replacement (Sucraid). Sucraid is not covered by Medicaid, so there are many necessary steps.
- To obtain Sucraid:
  1. Go to: **Sucraid.com → How to Order**.
  2. Click Physician Prescription Form.
  3. Fill out the information in the form with CSID as the diagnosis with 11 refills. (Must fill out this form annually.)
  4. Fax this form to the number at the top.
  5. Instruct family to fill out HIPAA form, found **here**. This is the form to get the Sucraid for free via the financial assistance program.
  6. Fax this form to the number at the top.
  7. Get a reliable phone number for the family and tell them they must answer their phone when the company calls. They will need to give more information over the phone.
  8. Call the company to confirm everything has been arranged: 1-833-800-0122.

This guideline is designed for the general use of most patients but may need to be adapted to meet the special needs of a specific patient as determined by the medical practitioner.
Approved by Clinical Guideline Committee 6/1/23.
Click **here** to see the supplemental resources for this guideline.
If comments about this guideline, please contact Leslie_Herrmann@ykhc.org.