

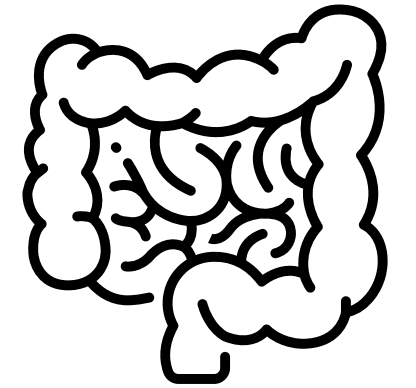
Intestinal Transplant First Appointment Questions and Checklist

The first appointment with your child's intestinal transplant team may feel overwhelming. This guide provides a starting point of information to share with the care team about your child and questions you may want to ask the team during the appointment.

Information To Tell The Care Team

Cause

- Tell the care team the cause of the short bowel syndrome or intestinal failure, if your child has already been diagnosed.
- If your child has not been diagnosed, provide a reason for referral to the care team.



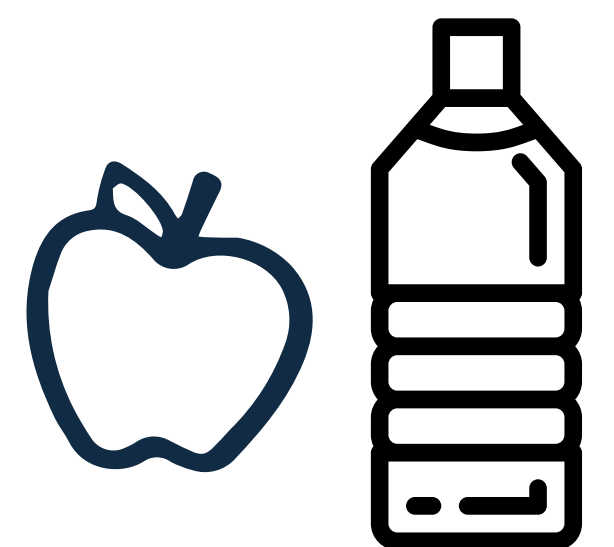
Medical History

- Provide the care team with a detailed review of surgical procedures and any related complications.
- Review of hospitalizations, including the reason for the stay, how long, what was done, and where it was.
- When you started noticing signs and symptoms of your child's gastrointestinal condition. (i.e. from birth, not meeting growth milestones)
- History of your child's height and weight.
- Immunization record.
- Any medications your child has been given.
- Known allergies, including medication, food, and environmental.



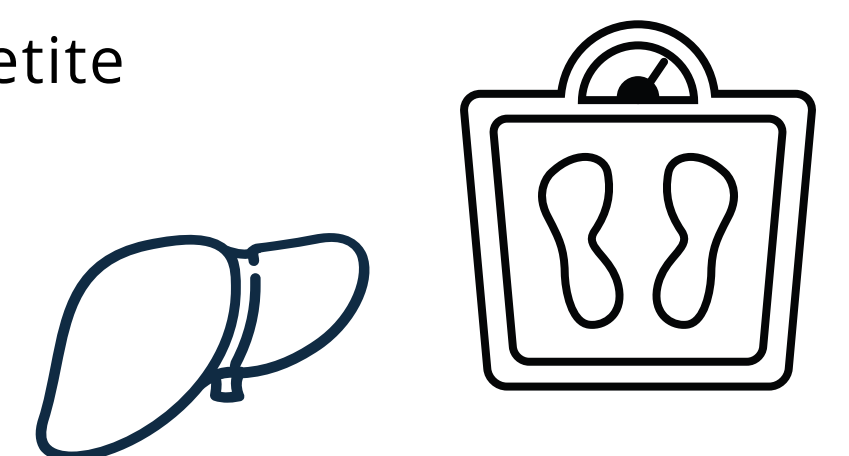
Hydration and Nutrition

- Hydration and nutritional needs of your child.
- State if they are on parenteral nutrition (PN), intravenous (IV) hydration, or enteral nutrition (tube feeds).
- Does your child eat anything by mouth?
- Weight and growth history- is your child following the growth curve for their age group?



Bowel and Liver Function

- Questions related to bowel function: Diarrhea, nausea, recurrent vomiting or spitting-up, bloating, appetite
- Questions related to malabsorption: Diarrhea, poor growth, inability to gain weight (failure to thrive), fatigue
- Signs of liver dysfunction: yellowing of the skin (jaundice) or fluid in belly (ascites)



Central Lines

- The number of central lines your child has had and the type of each line (i.e Hickman®, Broviac®, Port-a-Cath, Single or Double Lumen).
- Reasons why your child's central line was changed (i.e. blood clot, infection).
- If there was an infection, the type of organism caused the infection (fungus, bacteria).
 - Indicate if a hospitalization, IV antibiotics, mechanical ventilation, were needed.
- Your child's current central line (i.e Hickman®, Broviac®, Port-a-Cath, Single or Double Lumen).



Questions to Ask The Care Team

What are my child's choices other than transplant?

What are the risks and benefits of transplant for my child?

What does the evaluation process include?

How long do most patients with my child's blood and organ type wait at this center for an intestinal transplant?

How long has this center been doing intestinal transplant?

How many intestinal transplants does this center perform each year?

Questions to Ask The Care Team

Is my child allowed to be listed at more than one transplant center (e.g. multiple listing)?

What are the organ and patient survival rates for intestinal transplant at this center and how does that compare with the survival rates of the rest of the country?

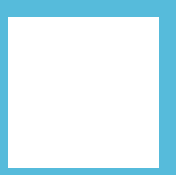
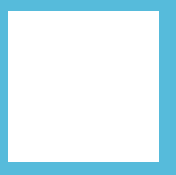
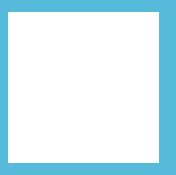
Do we have to relocate to the area before my child's transplant while on the waitlist?

How long will we have to stay in the hospital and the area after my child's transplant?

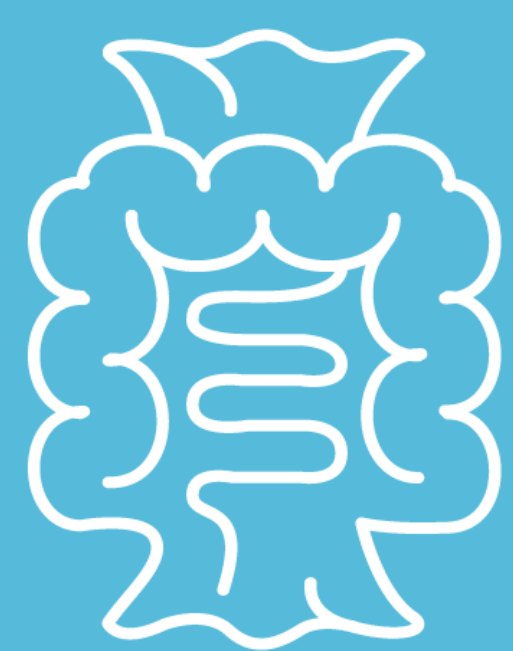
What are the costs should we expect associated with transplant and what financial assistance is offered?

What are the expected outcomes of my child's transplant? (i.e. wean from PN, tube feeds, eat orally)

Your Questions to Ask The Care Team



Additional Notes or Questions:



Transplant
UNWRAPPED

www.transplantunwrapped.org

www.transplantunwrappedkids.org

Disclaimer: This booklet is not intended to be used as medical advice or to diagnose, treat, cure or prevent any disease, nor should it be used for therapeutic purposes or as a substitute for a health professional's advice. Transplant Unwrapped does not accept any liability for any injury, loss or damage incurred by use of or reliance on the information presented.