

# Intestinal Rehabilitation Programs and Resources



Navigating the Journey



# SBSEF

*Short Bowel Syndrome Foundation*

[www.shortbowelfoundation.org](http://www.shortbowelfoundation.org)

## Medical Advice Disclaimer

The Short Bowel Syndrome Foundation (SBSF) is committed to providing educational resources, support, and advocacy for the community we serve. The information we provide is intended solely for educational purposes. It should not be used for self-diagnosis or to make medical decisions without first consulting with your healthcare provider. Please note that SBSF does not provide medical advice. If you have any health-related questions or concerns, we strongly encourage you to reach out to your healthcare provider.



## Understanding Intestinal Rehab

Intestinal Rehabilitation is a specialized medical approach designed to restore and enhance the function of the intestines, particularly for individuals with Short Bowel Syndrome who struggle with nutrient absorption and digestion.

These programs offer numerous benefits by combining medicines, surgery, and nutrition strategies to improve nutrient absorption, significantly enhancing the gastrointestinal tract's function.

As a result, patients can reduce or even eliminate their dependence on intravenous (parenteral) nutrition.

Additionally, these programs provide comprehensive care through an integrated, interdisciplinary team of specialists, ensuring personalized and continuous treatment.

This approach not only improves patients' overall health and quality of life by allowing them to enjoy a more normal diet but also includes extensive education on nutritional needs, medication management, and recognizing symptoms that require medical attention.



# Key Components of Intestinal Rehabilitation:



**Dietary Adjustments:** Tailoring the diet to include foods and liquids that are more easily absorbed by the remaining functional parts of the intestine.



**Medications:** Prescribing medications to enhance the digestive and absorptive functions of the intestines.



**Surgical Interventions:** In some cases, surgery may be necessary to improve the structure and function of the intestines.

The primary goal of intestinal rehabilitation is to help patients reduce or eliminate their dependence on intravenous nutrition (total parenteral nutrition or TPN) and improve their overall quality of life.



# Conditions That May Require Intestinal Rehabilitation

**Short Bowel Syndrome:** When a significant portion of the small intestine is missing or has been surgically removed, making it difficult to absorb nutrients from food.

**Gastroschisis:** A birth defect where a baby's intestines develop outside the body. Surgery is needed to place the intestines back inside, but sometimes the intestines fail, requiring nutritional support.

**Necrotizing Enterocolitis:** A serious condition in premature infants where tissue in the intestines becomes inflamed, damaged, or dies.

**Intestinal Atresia:** A congenital condition where part of the intestine is absent or closed.

**Intestinal Pseudo-Obstruction:** A rare motility disorder where the intestines do not contract normally, causing symptoms similar to a blockage.

**Hirschsprung's Disease:** A condition affecting the large intestine, causing problems with passing stool.

**Congenital Enteropathies:** Inherited disorders that affect the intestines from birth, leading to malabsorption and feeding difficulties.

**Intestinal Failure:** When the intestines cannot sustain adequate nutrition and growth, often requiring total parenteral nutrition (TPN) or an intestinal transplant.

These conditions often require a multidisciplinary approach, including dietary management, medications, and sometimes surgical interventions, to improve intestinal function and patient outcomes.

## Who is on the Team?

An intestinal rehabilitation team is typically composed of a multidisciplinary group of healthcare professionals who work together to provide comprehensive care for patients with intestinal failure. This collaborative approach ensures that all aspects of a patient's health and well-being are addressed, leading to better outcomes and improved quality of life.

The team usually includes:

- **Gastroenterologists:** Specialists in digestive system disorders who oversee the medical management of intestinal failure.
- **Surgeons:** Perform necessary surgical interventions to improve intestinal function.
- **Nurses and Nurse Practitioners:** Provide day-to-day care, patient education, and support.
- **Dietitians/Nutritionists:** Develop and monitor specialized nutrition plans tailored to the patient's needs.
- **Psychologists:** Offer mental health support to help patients cope with the stress and lifestyle changes associated with intestinal failure.
- **Social Workers:** Assist with coordinating care, providing resources, and offering emotional support to patients and their families.
- **Occupational Therapists:** Help patients develop skills to manage daily activities and improve their quality of life.

## Success Rates with Intestinal Rehab

### **Weaning Off Parenteral Nutrition (TPN)**

Many programs have successfully weaned patients off Total Parenteral Nutrition (TPN), which is a significant achievement. This process involves gradually transitioning patients to enteral nutrition (feeding through the gastrointestinal tract) or oral feeding. The goal is to achieve nutritional autonomy, meaning the patient no longer relies on TPN for their nutritional needs. This transition can significantly improve the patient's quality of life and reduce the risk of complications associated with long-term TPN use, such as liver disease and infections.

### **Survival Rates**

The survival rates for patients undergoing intestinal rehabilitation and transplantation have improved significantly over the years. For instance, one-year survival rates for intestinal transplants are now above 90% at experienced centers. Long-term survival rates have also seen improvements, with five-year survival rates around 61% and ten-year survival rates around 42%. These improvements are largely due to advancements in surgical techniques and immunosuppressive therapies.

### **Quality of Life Improvements**

Intestinal rehabilitation programs aim to enhance the quality of life for patients with intestinal failure. Achieving nutritional autonomy is a major goal, but these programs also focus on reducing complications and hospitalizations. Patients who successfully transition off TPN often experience significant improvements in their overall health and well-being. Additionally, those who undergo intestinal transplantation and achieve long-term survival report better quality of life, including improved physical and emotional health.

### **Comprehensive Care**

Successful intestinal rehabilitation and transplantation programs often involve a multidisciplinary approach. This includes a team of specialists such as gastroenterologists, surgeons, dietitians, and psychologists working together to provide comprehensive care. This coordinated approach ensures that all aspects of the patient's health are addressed, leading to better outcomes.

## Common Challenges

**Nutrient Absorption:** Patients often struggle with absorbing sufficient nutrients, leading to malnutrition and nutrient deficiencies.

**Fluid and Electrolyte Imbalance:** Maintaining the right balance of fluids and electrolytes can be difficult, especially for those with short bowel syndrome.

**Diarrhea:** Frequent diarrhea is a common issue, which can further complicate nutrient absorption and hydration.

**Infections:** Patients who rely on parenteral nutrition (PN) are at risk of catheter-related infections.

**Liver Complications:** Long-term use of PN can lead to liver problems, including liver failure.

**Psychological Impact:** The stress and lifestyle changes associated with managing intestinal failure can affect mental well-being.

These challenges require a multidisciplinary approach, including dietary management, medical therapies, and sometimes surgical interventions, to improve patient outcomes and quality of life.





# Top Intestinal Rehabilitation Programs in the United States

These programs are renowned for their expertise and comprehensive care, leading to positive outcomes for many patients.

**Nebraska Medicine:** Offers a comprehensive program for both pediatric and adult patients. Approximately 40% of patients remain off total parenteral nutrition (TPN) after intensive treatment, and another 40% significantly reduce their need for intravenous feedings.

**Mount Sinai Hospital:** Located in New York City, this program provides comprehensive care for patients with complex intestinal failure. Many patients have been successfully weaned off TPN.

**Cleveland Clinic:** Home to one of the largest and most comprehensive programs globally, with an overall patient survival rate close to 70% for intestinal transplants.

**UPMC (University of Pittsburgh Medical Center):** A leader in transplantation and rehabilitation services for intestinal failure, consistently meeting or exceeding national averages.

**Boston Children's Hospital:** Their Center for Advanced Intestinal Rehabilitation (CAIR) is one of the largest and most experienced programs for children with intestinal failure.

**Stanford Children's Health:** The Intestinal Rehabilitation Program at Lucile Packard Children's Hospital offers a comprehensive approach to treating children with intestinal failure, focusing on both medical and surgical management.

**UCLA Intestinal Rehabilitation Program (IRP):** Provides comprehensive care for both pediatric and adult patients with intestinal failure and short bowel syndrome, including nutritional management, medical therapies, and surgical options.

**Seattle Children's Hospital:** The only program of its kind in the Pacific Northwest and one of the few in the United States. The program uses the latest treatments to help children with intestinal failure, aiming to restore intestinal function and reduce the need for intestine transplants.

## States with Intestinal Rehab Programs

Alabama

California

Colorado

District of Columbia

Florida

Illinois

Indiana

Iowa

Massachusetts

Minnesota

Missouri

Nebraska

New York

Ohio

Oklahoma

Oregon

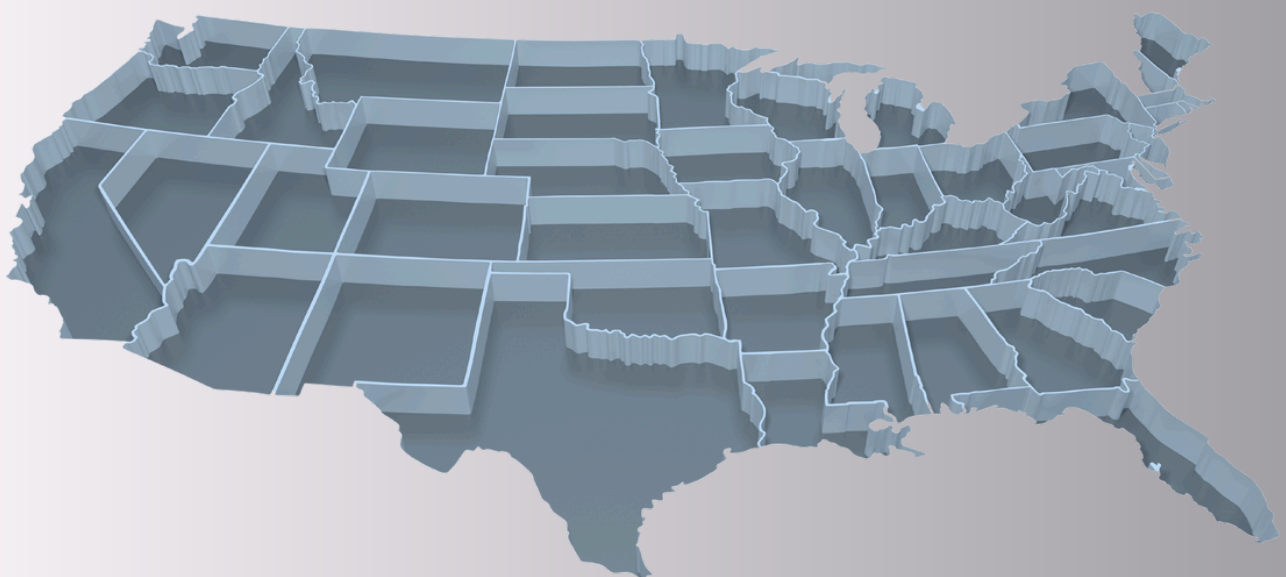
Pennsylvania

South Carolina

Texas

Washington

Wisconsin



# Contact SBSF



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