

Short Bowel Syndrome: Where to find support, information, and community

Short Bowel Syndrome (SBS) can be challenging, potentially impacting many aspects of your life. But with the right expertise and support, it is entirely possible to live a full and productive life with SBS.

On the following pages, you'll find a summary of the services offered by various patient groups, as well as useful resources that can help you navigate the SBS journey and connect with those who understand and share your experiences.



This resource is focused on adult SBS.

Editorial content is retained by the Authors.

Development of this resource was funded by Ironwood Pharmaceuticals.

About SBS

SBS occurs due to insufficient working intestine, as a result of surgery or injury, making it difficult to absorb necessary nutrients and fluids. In some cases, it might require artificial nutrition, such as intravenous (IV) nutrition and/or IV hydration. This is known as parenteral support or total parenteral nutrition (TPN). SBS is different for every individual.

Symptoms of SBS can include diarrhea, weight loss, dehydration, malnutrition, electrolyte loss, fatigue, nausea, cramping, pain, and loss of appetite. Many patients also experience depression and anxiety. Sometimes, SBS can result in feelings of isolation and stigma.

It's good to be aware of these symptoms so that you and your healthcare team can take action to help you feel better.

As a rare and complex condition that requires a great deal of management, it can be hard to find people who understand SBS and its impact. Connecting with peers and organizations who have first-hand experience of SBS can make a real difference to how you feel about the condition. They know what the journey involves and can help you find expert care, advocate for yourself, and get through the tough times.

SBS Facts:

- Usually follows surgery to remove large parts of the small intestine.
- Some people with SBS have an ostomy.
- Symptoms can include: Diarrhea, weight loss, dehydration, fatigue and pain.
- SBS has many causes, including: Inflammatory Bowel Disease (IBD), cancer, sudden twisting of the small bowel (volvulus), damage to the bowel's blood flow (ischemia), complication of weight loss surgery and traumatic injury to the abdomen.
- In certain cases, SBS is caused by a condition from birth.



Learning to advocate for yourself is about being heard, understood, and well cared for without feeling dismissed.

-Lori Plung, SBS and IBD patient and advocate




Contents

■
Featured US
Patient Groups

■
Featured European
Patient Groups



Patient Groups



The list of patient groups provided here is not exhaustive. A number of other groups are available in the US and Europe, so it's a good idea to speak with your healthcare team about any support groups local to you. You can also find patient information from Intestinal Rehabilitation and Transplant Centers, many of which have excellent resources on their websites.

/

/ FEATURED US PATIENT GROUPS

Featured US Patient Groups



As of February 2024 some of the featured US patient groups* have received educational grants and sponsorships from Ironwood Pharmaceuticals.

Color of Gastrointestinal Illnesses (COGI)

COGI is a nonprofit on a mission to improve the quality of life for Black, Indigenous and people of color who are affected by IBD (inflammatory bowel disease), digestive diseases, and associated chronic illnesses, through community, research, education, and advocacy. In addition to providing information on digestive diseases and chronic illnesses, COGI offers community events, support programs, and an ambassador program to engage patients and healthcare professionals in raising awareness about chronic illnesses within their communities and among their social networks.

Community

Black, indigenous and people of color with IBD, digestive diseases and associated chronic illnesses.

Links

[Homepage >](#)



Crohn's & Colitis Foundation

The Crohn's & Colitis Foundation is a non-profit organization dedicated to finding cures for Crohn's disease and ulcerative colitis, and improving the quality of life of children and adults affected by these diseases. As well as funding research, it provides a network of experts, resources, and support groups to help people living with inflammatory bowel diseases (IBD) to live their best life. Through its IBD Help Center, it provides live support in 170 different languages, including advice on accessing and funding care. It also offers a directory of IBD care specialists in the US, and a wide range of online education and resources, including information specific to SBS and on surgical resection.

Community

Adult and pediatric patients living with inflammatory bowel disease and their caregivers, healthcare professionals and clinical research scientists.

Links

[Homepage >](#)

[Surgical resection factsheet >](#)

[Short bowel syndrome and Crohn's disease >](#)

[IBD help center >](#)



Girls with Guts

Girls with Guts is a non-profit organization with the mission to support and empower women with inflammatory bowel disease (Crohn's disease and ulcerative colitis) and/or ostomies through the building of sisterhood and self-esteem. With a community of 8,000 people, the group aims to establish a national support network that helps to ensure that no woman will ever feel isolated by their disease. Through online resources and live events, it helps strengthen the network to bring patients, doctors, and thought leaders together to advocate for IBD issues, while spreading awareness. The group holds annual retreats, provides post-operative care packs and infusion kits, and hosts online resources including a patient information blog on SBS led by Jenny, Girls with Guts' Director of Communications who lives with SBS. She received very little information about SBS in the period before and following her surgery, leaving her to find her own specialist care team.

Community

Women with inflammatory bowel disease and/or ostomy.

Links

[Homepage >](#)[SBS blog >](#)The logo for Girls with Guts features the word "Girls" in a blue, rounded font with three dots above the 'i'. The word "with" is in a smaller, black, lowercase font. The word "Guts" is in a blue, rounded font with three dots above the 'i'. The entire logo is set against a light gray background.

the gutsy perspective

the gutsy perspective is an initiative driven by and for the SBS/intestinal failure (IF) community. Set up by community stakeholders (SBS parents and an SBS patient) with backgrounds in the social sciences, public health, and epidemiology. Its goal is to close the gap between the SBS/IF community's lived experiences and research that ultimately affects its members. A main focus is expanding the narrative around quality of life with SBS/IF for patients and families through research and systematic storytelling, by documenting what life is like for children with SBS/IF, how families adjust and navigate life, and how adults with SBS/IF describe their experiences. In partnership with clinicians, and through engagement with the SBS/IF community, the gutsy perspective group has developed the first and only existing quality of life questionnaire for pediatric SBS/IF. Research findings and ways to engage are made available to patients, families, and clinicians at conferences and via publications, the website, and social media.

Community

Pediatric patients with SBS/IF and their families, adults with SBS/IF since childhood.

Links

[Homepage >](#)

[Publications & presentations >](#)



the gutsy perspective

International Foundation for Gastrointestinal Disorders (IFFGD)

IFFGD is an education and research organization, dedicated to providing information, assistance and support to people affected by gastrointestinal (GI) disorders. It funds a wide range of research projects, and publishes a variety of training presentations which are shared via the IFFGD YouTube and social media channels. The Foundation provides online factsheets and educational resources on a wide range of GI disorders including SBS, written by physicians and made available online. IFFGD trains patients and family members on how to advocate for themselves and others, while bringing them together with health care providers and researchers to share their experiences at congressional offices in Washington.

Community

Adult and pediatric patients with GI disorders and their caregivers, HCPs, investigators, regulators, employers and industry partners.

Links

[Homepage >](#)

[SBS resource page >](#)

[Dietician directory >](#)



iffgd

National Organization for Rare Disorders (NORD®)

The National Organization for Rare Disorders (NORD®) is a national non-profit organization, dedicated to improving the health and well-being of people with rare diseases by driving advances in care, research, and policy. As well as providing factsheets and a helpful video animation giving a detailed explanation of SBS, it also offers a premium copay assistance program for patients with SBS, as well as caregiver aid and resources.

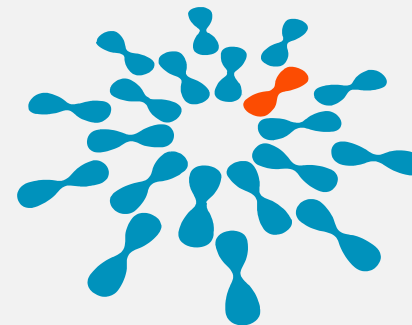
Community

Patients with rare diseases and their caregivers, clinicians and researchers, other advocacy groups.

Links

[Homepage >](#)

[SBS resource page and animation >](#)



NORD®

National Organization
for Rare Disorders

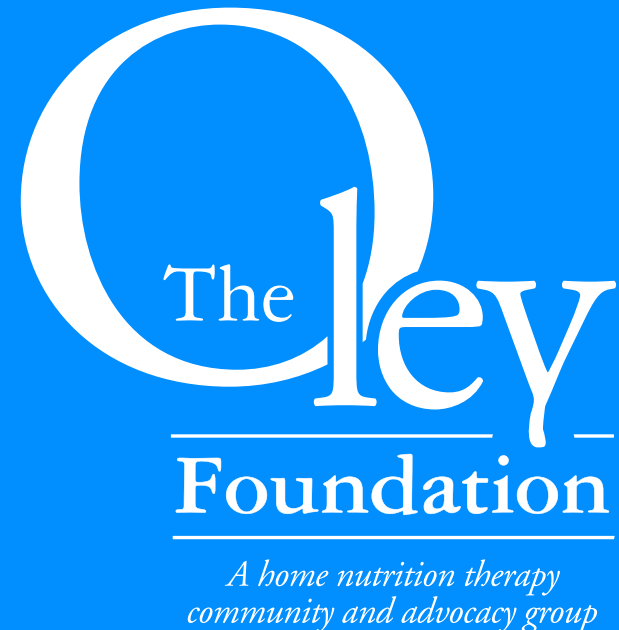
The Oley Foundation

If you or someone you know needs home nutrition therapy, the Oley Foundation is here to help. The Oley Foundation is a national, non-profit home nutrition therapy advocacy group dedicated to the unique needs of the home nutrition support community. Through their four pillars of advocacy, education, community, and innovation, Oley supports over 30,000 consumers, care partners, and healthcare professionals. The national grassroots ambassador network of patient and caregiver volunteers offers outreach and support locally, while its Community Connections program allows members to access virtual quality of life tools and support from home. In addition, Oley offers online resources, SBS webinars and virtual meetings, and an annual national conference each summer for consumers and care partners to connect with leading nutrition and bowel health experts and each other. Join the Oley community today, and let us help you live your best life.

Community

Adult and pediatric patients on nutrition support and their caregivers, HCPs and industry partners.

Links

[Homepage >](#)[SBS resource page >](#)[Consumer support page >](#)

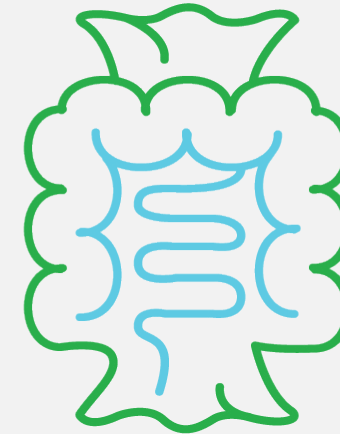
Transplant Unwrapped

Transplant Unwrapped aims to ensure every patient, caregiver, and member of the intestinal disease community feels well-educated and supported throughout their journey with intestinal failure, intestinal rehabilitation, and intestinal and multivisceral transplantation. It offers a wide range of online and downloadable resources on intestinal disease, including patient and caregiver videos, tailored information on adult and pediatric SBS, and a directory of intestinal rehabilitation and transplantation centers in the US. It also hosts regular webinars, some focused on SBS, and virtual support sessions for patients and their caregivers. Established by Kayla Pfab after living with IF and receiving an intestinal transplant, the group continues to be run by volunteers whose goal is to support those living with serious intestinal disease.

Community

Adult and pediatric IF, intestinal rehabilitation, and intestinal and multivisceral transplantation patients and their caregivers.

Links

[Homepage >](#)[SBS resource page >](#)

Transplant UNWRAPPED

United Ostomy Associations of America Inc. (UOAA)

UOAA supports, empowers, and advocates for people who have had or who will have ostomy or continent diversion surgery. Its mission is to promote quality of life through information, support, advocacy, and collaboration. UOAA provides educational resources for ostomates, their caregivers and medical professionals, and connects people to affiliated ostomy support groups across the country. UOAA has a national advocacy network and provides tools and resources to help patients advocate for themselves. The organization also offers access to a virtual ostomy nurse, an online discussion board and detailed information on living with an ostomy, including SBS-specific information and patient stories.

Community

Adults and children with an ostomy or continent diversion.

Links

[Homepage >](#)

[SBS resource page >](#)

[SBS patient blog >](#)



Featured European Patient Groups

The provision of healthcare for people with SBS is different in every country, so national organizations tend to work collaboratively with clinical experts to develop support and resources relevant to their local communities. A variety of organizations work to support people with SBS on a national level across Europe, so it's a good idea to check for your local group and ask your healthcare team about relevant organizations in your area.

The following groups are particularly active in ensuring patients are heard by European clinicians and policymakers:



Other groups in Europe include:

- Hello TPN, **Belgium** >
- HPN Foreningen, **Denmark** >
- Nupa, **Spain** >
- Un filo per la vita, **Italy** >



Appetite for Life

Appetite for Life Association (Stowarzyszenie 'Apetyt na Życie') is a Polish organization that supports, empowers and integrates patients who suffer from digestive system diseases, particularly those dependent on enteral and parenteral nutrition. Through numerous education activities, the group raises awareness about SBS, IF and medical nutrition to improve patients' health literacy in this area, and help them to gain access to innovative medication and therapies. Appetite for Life also aims to improve patients' quality of life and prove that living with artificial nutritional support does not have to exclude people from living a normal life. Based on its patient advocacy experience, the group was involved in the creation process of national and European health policies, such as the development of the European Health Parliament's recommendations on Healthy Economies.

Community

Patients in any country living with digestive system diseases and inflammatory bowel disease and their caregivers, policy makers and those working to support patients with these diseases.

Links

[Homepage >](#)





La Vie par un Fil

La Vie par un Fil, or Life by a Thread, is a national association for children and adults receiving parenteral and enteral nutrition at home. The association aims to overcome isolation, encourage collaboration, and facilitate connections with the medical profession, as well as promoting integration and formalizing good practices in parenteral and enteral nutrition. It offers a range of detailed booklets and guides, accredited by the Société Francophone Nutrition Clinique et Métabolisme (SFNCM), including a therapeutic patient education app, downloadable free of charge on IOS and Android, and the 'Mon Suivi - La Vie par un Fil', for people on parenteral and enteral nutrition, which has been developed in partnership with the medical profession. As well as annual national meetings for patients and their families, it also provides a directory of parenteral nutrition centers for children and adults.

Community

Adult and pediatric patients requiring artificial nutrition at home.

Links

[Homepage >](#)

[Directory of parenteral nutrition at home centers >](#)

[Mon Suivi-La Vie par un Fil app >](#)

La Vie par un Fil

Association pour enfants et adultes en nutrition parentérale et entérale à domicile



UNITED KINGDOM

PINNT: Support and advocacy for people living with home artificial nutrition

PINNT is a UK-based charity with a 35-year history of supporting adult and pediatric patients adapting to life on home artificial nutrition. It provides support via local and regional groups and ambassadors, online forums and a range of resources aimed at assisting people to live with their condition and treatment. This includes information specific to SBS/IF, a comprehensive guide to living with artificial nutrition written by patients, for patients, and a telephone and email helpline. In 2023, it launched a new resource for healthcare professionals, aimed at ensuring they can meet the promises made to patients regarding the care they should expect to receive. PINNT has an extensive network to advocate for products, services and healthcare which can enhance the quality of life for those on home artificial nutrition.

Community

Patients (adults and children), and carers on home artificial nutrition.

Links

[Homepage >](#)

[Patient resources >](#)

[Request a Living with Artificial Nutrition guide >](#)



PINNT

A SUPPORT GROUP FOR PEOPLE
RECEIVING ARTIFICIAL NUTRITION

/

/

/ CZECH REPUBLIC



CZECH REPUBLIC

Život bez střeva, z.s.

Život bez střeva, or Life Without an Intestine, is a Czech patient group, founded in 2008 by a group of adult patients, parents of pediatric patients, and doctors. Its aim is to inform and educate the general public and help patients who have been diagnosed with complex bowel diseases - most of whom are dependent on parenteral (intravenous) nutrition. A key focus for the group is to improve patients' quality of life as much as possible and to involve them in a normal way of life. The group also collaborates with the Health Ministry and health insurance companies to ensure that individuals relying on parenteral nutrition are legally entitled to benefits, based directly on their diagnosis. The majority of members are SBS patients, and as well as providing detailed information specific to the condition, parenteral nutrition, medications and ostomy, the group also provides an advisor to help patients access the support they need.

Community

Adult and pediatric patients with complex bowel conditions and their caregivers.

Links

[Homepage >](#)[SBS information >](#)

Social Media Communities

Peer to peer online support can be a resource in your journey as you see fit. Here is a list of Facebook groups attended and recommended by our author group. Some groups cover a specific underlying cause and SBS.

[AAGF* Short Bowel Group >](#)

[Central Line Travelers >](#)

[Intestinal Malrotation Foundation Group >](#)

[Intestinal and Multivisceral Transplant Support Group >](#)

[Living Life on Total Parenteral Nutrition >](#)

[Grupo de soporte Intestino Corto >](#)

[SAIA** IBDesis Community >](#)

[SBS Foundation \(adult patients\) >](#)

[Short Gut Syndrome Families' Support Group >](#)

[Total Parenteral Nutrition Group >](#)

[Transplant Unwrapped Support: Short Bowel & Intestinal Rehab and Transplant >](#)



These groups are separate to the social media pages, respective groups and resources of the organizations listed above. It is common for Facebook groups to be administered by patients and/or caregivers who are personally affected by short bowel syndrome and intestinal failure. Please do not replace feedback received in a group with medical guidance from a clinician, but rather consider including it as one source of information in your arsenal of knowledge. When joining a group, please do familiarize yourself with group rules, group posts, guidelines on who is allowed to become a member, and the administrator.

Other Useful Resources

[American College of Gastroenterology: Guide to diet and SBS >](#)

[American Gastroenterological Society: SBS resources >](#)

[European Society for Clinical Nutrition and Metabolism \(ESPEN\): Clinical nutrition in chronic intestinal failure >](#)

[European Society for Clinical Nutrition and Metabolism \(ESPEN\): Guideline on chronic intestinal failure in adults - Update 2023 >](#)

[GastroGirl: Homepage >](#)

[GI Society/Canadian Society of Intestinal Research: SBS factsheet >](#)

[National Institutes of Health \(NIH\): SBS Factsheet >](#)



Authors

Beth Gore

PhD, Executive Director, Oley Foundation
and parent of child with intestinal failure*

Bethany Johnson

*SBS Patient Expert and Board Member,
Transplant Unwrapped**

Swapna Kakani

*MPH, SBS Patient Expert, Rare Disease
Advocate, and Co-Founder/Researcher,
the gutsy perspective*

Carolyn Wheatley

Chair, PINNT and IF Patient Expert

Lori Plung

SBS and IBD Patient Expert

Ceciel T. Rooker

*President, International Foundation
for Gastrointestinal Disorders (IFFGD*)*

Marek Lichota

*SBS and IBD Patient Expert
President, Stowarzyszenie
"Apetyt na Życie"*

Laurie Reyen

*Clinical Nurse Specialist
(formerly UCLA)*

Maria Karimbakas

*RD, CNSC, Optum Intestinal
Rehab Program Manager,
Optum Infusion Pharmacy*

Monika Malíčková

*SBS Patient Expert, Vice
President, Život bez střeva z.s.*

Marion Winkler

*PhD, RD, LDN, CNSC, Surgical
Nutrition Specialist, Department of
Surgery and Independent Nutrition
Consultant, Rhode Island, USA*



the gutsy perspective



Transplant
UNWRAPPED



Život bez střeva

This resource is compiled by a collaborative group of patients, community organization leads and medical professionals who are working together to improve SBS education and awareness. Authors are compensated as advisory members of an SBS educational taskforce convened and funded by Ironwood Pharmaceuticals.

Several Authors are affiliated with patient groups featured in this resource. An asterisk * indicates if their affiliated organization has received an educational grant or sponsorship from Ironwood Pharmaceuticals.

**Editorial content of this SBS community resource is retained by the Authors.
Funding support for its development comes from Ironwood Pharmaceuticals.**

