

Zespół krótkiego jelita

gdzie znajdę dodatkowe informacje i grupy wsparcia.

Zespół krótkiego jelita (z ang. Short Bowel Syndrome - SBS) dla wielu pacjentów z tym problemem medycznym może stanowić prawdziwe wyzwanie i wpływać na wiele aspektów codziennego życia. Jednocześnie dostęp do stosownej wiedzy i wsparcia umożliwi prowadzenie satysfakcjonującego i pełnego energii życia z SBS.

Mamy nadzieję, że ten materiał pozwoli Ci zdobyć dodatkową wiedzę na temat różnych grup pacjentów działających w obszarze SBS, wraz z zakresem oferowanego wsparcia oraz zasobami edukacyjnymi, które pomogą Ci w codziennym funkcjonowaniu z SBS. Pomogą one także w nawiązaniu kontaktu z osobami, które doskonale rozumieją Twoje położenie i są otwarte na wymianę doświadczeń związanych z chorobą.

W ramach współpracy pacjentów, opiekunów, liderów organizacji pacjenckich i lekarzy działających w obszarze edukacji i podnoszenia świadomości, dążymy do tego, by właściwie zaadresować potrzeby osób z SBS i dać im poczucie zrozumienia.

Wspólnie pragniemy sprawić, by pacjenci i ich opiekunowie mieli dostęp do wiarygodnej, merytorycznej wiedzy i wsparcia, którego potrzebują. Mamy nadzieję, że dzięki temu z właściwie wyposażeni, będą oni mogli stawić czoła wyzwaniom SBS. Ważne jest dla nas, by

wszyscy cierpiący na SBS wiedzieli, że nie są sami ze swoim problemem.



O Zespole Krótkiego Jelita

Zespół Krótkiego Jelita (SBS) to rzadkie schorzenie, które wiąże się z niewydolnością jelit. Najczęściej jest wynikiem operacji lub urazu dużego odcinka przewodu pokarmowego, przez co ograniczone jest wchłanianie niezbędnych składników odżywczych i płynów. W niektórych przypadkach może wymagać sztucznego odżywiania (np. dożylnego)

Dożylny sposób podaży składników odżywczych odbywa się w formie częściowego lub całkowitego żywienia pozajelitowego (z ang. Total Parenteral Nutrition).

Objawy SBS mogą obejmować wyniszczającą biegunkę, utratę masy ciała, odwodnienie, niedożywienie, utratę elektrolitów, zmęczenie, nudności, skurcze, przewlekły ból i utratę apetytu. Wielu pacjentów doświadcza także depresji i lęku.

Czasami SBS może skutkować również poczuciem izolacji w wymiarze społecznym.

Ze względu na rzadkość i złożoność tego schorzenia, wymaga ono intensywnego leczenia w specjalistycznych ośrodkach referencyjnych, przez interdyscyplinarne zespoły medyczne, doświadczone w opiece nad pacjentami z niewydolnością przewodu pokarmowego.

Kontakt z innymi chorymi i organizacjami, które mają bezpośrednie doświadczenie z SBS może w realny sposób zmienić Twoje samopoczucie i sposób funkcjonowania w kontekście codziennego życia z chorobą. W ramach udzielanego wsparcia mogą pomóc Ci znaleźć specjalistyczną opiekę i przetrwać różne trudne momenty.

FAKTY O SBS:

Zwykle następuje w wyniku resekcji (usunięcia) dużych odcinków jelita cienkiego. Dodatkowo część osób z SBS ma stomię. Objawy mogą obejmować: biegunkę, utratę wagi, odwodnienie, zmęczenie i ból.

SBS ma różne przyczyny, do których możemy zaliczyć: nieswoiste zapalenie jelit (z ang. Inflammatory Bowel Disease IBD), nowotwory, nagły skręt jelit, ostre niedokrwienie jelit (martwica jelit), operacje i mechaniczny uraz brzucha. W niektórych przypadkach SBS jest spowodowane chorobą występującą od urodzenia.

”

Życie z rzadką chorobą jest trudne i dlatego tak ważne jest znalezienie innych – kogoś, kto zmagają się z podobnym problemem; grupy wsparcia, na której można się oprzeć. Szkoda, że nie wiedziałam o tym, że nie jestem sama, na początku mojej drogi z SBS. W grupie siła, bo razem mamy głos. Razem nie czujemy się rzadkością.

– Swapna Kapkani, pacjentka SBS i ambasadorka chorób rzadkich

”

”

Akceptacja choroby, polega na byciu wysłuchanym, zrozumianym i otoczonym dobrą opieką lub bez poczucia izolacji.

– Lori Plung, pacjentka i ambasadorka SBS i IBD

”

Zawartość

01

GRUPY
PACJENTÓW

02

MEDIA
SPOŁECZNOŚCIOWE

03

INNE PRZYDATNE
ZASOBY

04

O AUTORACH





GRUPY PACJENTÓW



Wyróżnione grupy pacjentów z USA.



Wyróżnione grupy pacjentów z Europy

Podana tutaj lista grup pacjentów i organizacji nie jest wyczerpująca. W USA i Europie dostępnych jest wiele innych grup i organizacji pacjenckich, dlatego dobrym pomysłem jest porozmawianie ze swoim zespołem medycznym na temat lokalnych grup wsparcia.



/

/ FEATURED US PATIENT GROUPS

Wyróżnione Grupy Pacjentów z USA



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 small blue 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 small blue dots above the 'i'.

Girls with Guts

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.

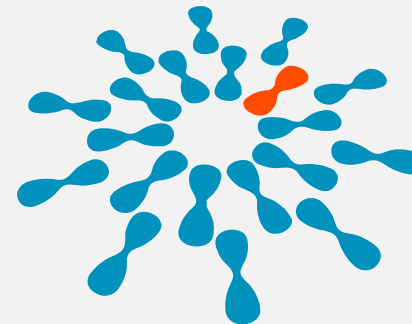
Community

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 >](#)



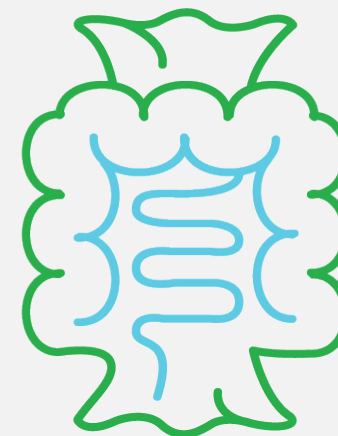
Transplant Unwrapped

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 >](#)



Wyróżnione Organizacje Pacjentów z Europy



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 >](#)



/

/

/ FRANCE



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 >](#)

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



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 >](#)

Media społecznościowe

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.

Inne przydatne zasoby

[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 >](#)



O Autorach

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.**

