



PEDIATRIC OSTOMY RESOURCES

OSTOMY CARE

American College of Surgeons (ACS) -

[Pediatric Colostomy/Ileostomy \(facs.org\)](https://www.facs.org/pediatric-colostomy/)

[Pediatric Urostomy \(facs.org\)](https://www.facs.org/pediatric-urostomy/)

Offers a Pediatric Ostomy Home Skills Kit including Colostomy/Ileostomy and Urostomy videos, a Home Care Booklet and more.

ImproveCareNow – Ostomy Toolkit

[Ostomy Toolkit - ImproveCareNow](https://www.improvecarenow.org/ostomy-toolkit/)

The Ostomy Toolkit was created by the ImproveCareNow Patient Advisory Council's Advocacy Taskforce in collaboration with the whole ICN Community. The toolkit is designed for and by pediatric patients who have had, or are having, ostomy surgery (resting or permanent ostomy). It includes tips, tricks and personal stories about school, travel, supplies, playing sports, clothing choices, and how to tell friends.

Ostomy at Home - YouTube -

[Ostomy at Home - YouTube](https://www.youtube.com/watch?v=JmKdKdKdKdK)

Published on Dec 9, 2015—Uploaded by Intermountain Healthcare

Experts at Primary Children's Hospital created this video to help parents and families care for a child's ostomy at home. This video will teach you about normal digestion, types of ostomies, ostomy pouches and how to empty them, how to change an ostomy pouch, skin care with ostomies, daily care tips, eating to stay healthy, and problems that may occur with an ostomy.

COMFORT & EDUCATIONAL TOYS

Awesome Ollie Teddy Bear and Story Book

Inspiring, Educating and Empowering Children (and Adults)

[Ostomy teddy bear | Awesome Ostomy](https://www.awesomeollie.com/)

International Children's Ostomy Educational Foundation (ICOEF American) -

Provides educational and motivational Gastronomaut puppets. For details send a message to

<https://www.facebook.com/ICOEFUSA/> (website forthcoming)

Shadow Buddies Foundation - <https://shadowbuddies.org>

Offering seriously ill or medically challenged children the companionship of a friend "just like me."

The Breakaway Foundation – UK wide charity offering support to children with bladder and/or bowel diversions/dysfunction and their families—<https://www.breakawayfoundation.org.uk>

Tubie Friends – Taking the fear out of feeding tubes – one Tubie Friend™ at a time—<https://tubiefriends.com>

ADDITIONAL OSTOMY RESOURCES are available through UOAA. Visit <https://www.ostomy.org/find-an-ostomy-nurse/> for more information.

SUPPORT

United Ostomy Associations of America (UOAA) –

<https://www.ostomy.org>

Offers an online Parents Discussion Board and several Pediatric Support Groups across the country to easily connect and share questions and concerns for parents and children with ostomies or continent diversions. Has created the Pediatric Ostomy Patient Bill of Rights, a tool to empower parents/legal guardians to advocate for their children during all phases of care. Offers educational resources including the New Ostomy Patient Guide, which provides valuable information and answers from medical professionals to many basic questions.

Pull-thru Network - <https://www.pullthrunetwork.org>

Provides information, education, support and advocacy for families, children, teens and adults who are living with the challenges of congenital anorectal, colorectal or urogenital disorders.

Association for the Bladder Exstrophy Community

(A-BE-C) - <https://www.bladderexstrophy.com>

Works to ensure that all who are affected by bladder exstrophy have the opportunity to realize their greatest life purpose and potential.

International Foundation for Functional Gastrointestinal Disorders (IFFGD)...About Kids GI

<https://www.aboutkidsqi.org>

Works with patients, families, physicians, nurses, practitioners, investigators, regulators, employers, and others to broaden understanding about GI disorders, support or encourage research, and improve digestive health in adults and children.

Oley Foundation - <https://oley.org>

Strives to enrich the lives of those living with home intravenous nutrition and tube feeding through education, advocacy, and networking.

Youth Rally - <https://www.youthrally.org>

Provides an environment for adolescents living with conditions of the bowel and bladder that encourages self-confidence and independent living.

CLOTHING

BumBibs - <https://bumbibs.com>— offers a unique Ostomy Wrap with an adjustable waistband and absorbent core to help with ostomy care for infants and children.

Etsy - www.etsy.com—Pediatric pouch covers and more.

AdaptableSnapables - <https://facebook.com/adaptablesnapables/> - created by a tubie mom & nurse, provides top quality adapted clothing for gtubes, jtube and ostomies.