



PEDIATRIC OSTOMY RESOURCES

OSTOMY CARE

American College of Surgeons (ACS) -

<https://www.facs.org/education/patient-education/skills-programs/ostomy-program/pediatric-ostomy>

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

ImproveCareNow – Ostomy Toolkit

<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 -

<https://www.youtube.com/watch?v=eLmFXLy4wa0>

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)

<http://awesomeostomy.com/awesome-ollie-teddy-bear>

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

Provides educational and motivational Gastronomer 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 – Buttony Bear Project

<http://www.breakawayfoundation.org.uk/buttony-bear>

Tubie Friends – Taking the fear out of feeding tubes – one Tubie Friend™ at a time...

<http://www.tubiefriends.com/index.php/products>

ADDITIONAL OSTOMY RESOURCES are available through Manufacturers. Visit <https://www.ostomy.org/ostomy-healthcare-resources/> to learn more.

SUPPORT

United Ostomy Associations of America (UOAA) –

www.ostomy.org

Offers an online Parents Discussion Board to easily connect and share questions and concerns with parents of 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.

Pull-thru Network - <http://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.

Facebook Page—"Parents of Kids with Ostomies"

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

<https://www.aboutkidsgi.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.

Megacystis Microcolon Intestinal Hypoperistalsis Syndrome (MMIHS) - <http://www.mmihs.org/>

This website is dedicated to increasing awareness of MMIHS and providing support and resources for those affected by it.

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

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

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

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

CLOTHING

Etsy - www.etsy.com—Pediatric pouch covers and more are available through this website.

Miracle Snappies – <http://www.facebook.com/miraclesnappies>

Adaptive, custom-made snappy clothing for your child's medical special needs.