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eNewsletter Q4 2019

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FEATURE STORY



"People don't care if you have an ostomy...they're going to judge you for who you are."

-David Rudzin
Past President of UOAA

Just Jump In

A Life Dedicated to Ostomy Support & Service

Past Treasurer and National President of United Ostomy Association (UOA), 65-year old David Rudzin of Northbrook, Illinois spends every free moment advocating for ostomy support for others near and far. You'd never guess that he refused to psychologically deal with his own ileostomy for 17 years.

Diagnosed with Ulcerative Colitis at 18 months old, David was the youngest person treated at the time for the disease at the University of Chicago Medical Center by renowned Gastroenterologist, J.B. Kirsner. After David experienced a flare-up between freshman and sophomore years of college, Dr. Kirsner suggested that he have ileostomy surgery.

"He told me I was like a son to him, since he knew me my whole life," says David. "Dr. Kirsner assured me I'd be fine after surgery and I trusted him."

Turns out he was right. At 18 years old, David's body healed quickly, but he was overcome with insecurity and sought ostomy support. He compared himself to television character, The Six Million Dollar Man, who, after an accident, was rebuilt with bionic strength.

"I was rebuilt, too, but not like he was," explains David. "I considered myself a freak of nature and warned my college roommates not to tell a soul about my ostomy."



FEATURE STORY

Just Jump In

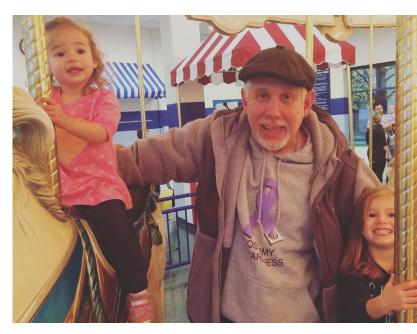
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After graduating from college, David became a successful financial analyst and got married. It wasn't until he had children that his insecurity started to lift.

When his children asked about his pouching appliance, he simply explained its purpose, and they accepted it without further question. One day the kids even begged him to jump into the pool with them.

"I had avoided swimming after surgery, and just had to conquer my fear for my kids," says David. "So I jumped in and the only thing that happened was I got wet!"

At age 35, this experience gave him the courage to attend his first ostomy support group meeting.



"I had issues...and I wanted to help people avoid those same problems." - David Rudzin

"I said to myself, if I'm old enough to be president of the United States, I'm old enough to get over this—so I went," David notes.

To his surprise, David ended up finding ostomy support throughout the community, got himself involved, and later became president of the Greater Chicagoland Chapter of UOA. Then, in 1999, he attended his first United Ostomy Associations of America (UOAA) national conference in Reno and made lifelong friends.

"I began talking to people and they started flocking to me in ostomy support groups and at conferences. I had issues in the past and I wanted to help people avoid those same problems," says David.

As a passionate political advocate, David held national offices in the UOA and later, as it became the United Ostomy Associations of America (UOAA), from 1999 to 2015. Whether serving as treasurer or president he always gave it his all. A test to his leadership came in 2013 when news hit about violent street gang activity called "bagging" in the Cincinnati area, and a police program intended to deter gang activity that put the ostomy community in a negative light. In this



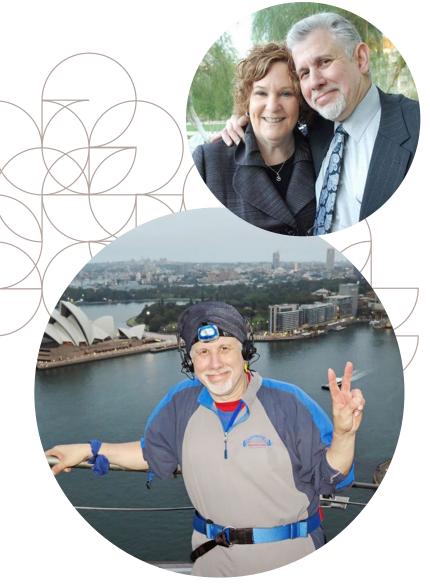


Above: David enjoys spending time with both his grandchildren, his now adult children (center), and wife Barbara (bottom).

FEATURE STORY

Just Jump In

(continued)



Above: David and wife Barbara remain active in the ostomy community.

Below: A trip to Australia shows just how full life can be with an ostomy.

unfortunate practice, attackers intentionally wound others in the intestines to require emergency ostomy surgery. The Cincinnati police commissioner was quoted making a disparaging comment about people with ostomies.

"Boy, oh boy, did he mess with the wrong group of people," says David.

He rallied people with ostomies from all over the world to bombard the Cincinnati Police Department with Facebook posts and emails expressing their disdain for this stigmatized attitude about ostomies. Four days later, the police commissioner contacted David asking what he wanted in exchange for ceasing this overwhelming show of ostomy support. Finally, as demanded, David received a written apology sent directly to the UOAA National Conference in Jacksonville, Florida, which he proudly read on stage.

David continues to jump into anything and everything related to ostomy support and ostomy support groups. He and his second wife, Barbara, former Director of the Crohn's and Colitis Foundation of America, plan to move to Arizona where he envisions working with the nursing community to help eliminate the stigma surrounding ostomy surgery. And don't be surprised if you see David on the UOAA board of directors' ballot again!

In the meantime, David continues to use his many years of experience to counsel others with ostomies. "Look, I've been where you are, and just know that people don't care that you have an ostomy. As long as you're a decent person and are kind to them, they're going to judge you for who you are," explains David. "I didn't know that at 18 and I wish I had."



David Rudzin is a Financial Analyst and the former Treasurer and National President of the United Ostomy Associations of America. When not counseling others with ostomies, he enjoys sports, especially Chicago Blackhawks games, travel and getting together with family and friends. He and his wife Barbara live in Northbrook, Illinois, and hope to relocate to Arizona within the next couple of years. They have five sons ranging in age from 25 to 34 years old and three grandkids.

Financial Disclosure: David Rudzin received compensation from Hollister Incorporated for his contribution to this eNewsletter.

NEWS FROM HOLLISTER INCORPORATED

Hollister Secure Start Services Corner

Meet the smile behind the voice

Our team is passionate about helping Hollister Secure Start services members over the phone or by email. If you have a question about your ostomy, we're here to help. Get to know these members of our team!



Edgar



Title: Customer Care Representative

Serving you since: July 2019

What is your favorite part of the holiday season? My favorite part of the holiday season is spending time with my friends and family.

What are your favorite holiday traditions? Every holiday season, my dad makes our favorite hot chicken soup. We look forward to it every year and it makes us feel "at home."

To whom do you turn for support and advice? I have two particular friends that I admire as individuals, along with their commitment to their careers and family values. I turn to them for advice.



Mary



Title: Consumer Service Advisor

Serving you since: August 2002

What is your favorite part of the holiday season? I enjoy spending time with my family and cooking for them during the holiday season

What are your favorite holiday traditions? I love to bake for my family. The house always smells so good!

To whom do you turn for support and advice? I turn to my husband for support and advice.



Taylor



Title: Consumer Service Advisor

Serving you since: June 2016

What is your favorite part of the holiday season? My favorite parts of the holiday season are getting together with my friends and family and enjoying all of the beautiful decorations.

What are your favorite holiday traditions? My family always takes a day to go to the Richardson Corn Maze during the fall. We get everyone together, rent a fire pit and spend the day doing the maze and eating apple cider donuts.

To whom do you turn for support and advice? I turn to my dad for support and advice. He is my biggest supporter and best friend.



NEWS FROM HOLLISTER INCORPORATED

Supporting Your Skin Health

Empower your skin health savvy with this tool from the Wound, Ostomy and Continence Nurses Society™ (WOCN®), Sponsored by Hollister Incorporated

The Peristomal Skin Assessment Guide for Consumers is a free, easy-to-use, web-based tool designed to help teens and adults living with an ostomy identify common skin problems, provide next steps for care or management, and prompt when it is appropriate to seek support from a healthcare professional.

The guide was developed by a team of wound, ostomy, and continence nurses from the U.S. and Canada who had previously devised a similar format for clinicians who provide ostomy care. To help create the consumer version, Christine Kim, founder of Ostomy Connection and Kindred Box (see related article on page 10), joined the project to offer her perspective of living with an ileostomy. She is a consumer advocate who interacts with the ostomy community through her websites and social media.

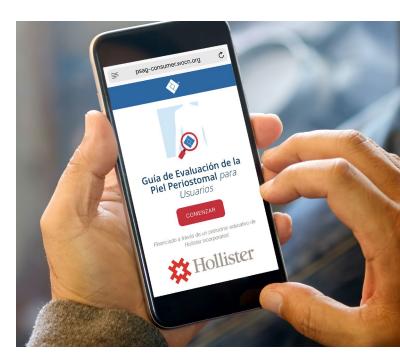
The Peristomal Skin Assessment Guide for Consumers:

- Helps identify main categories of peristomal skin conditions
 - ✓ Name and definition
 - ✓ Steps to manage condition
 - ✓ Steps to help prevent in future
 - ✓ When to seek professional care
- Identifies referral-level conditions
- Includes many and easy-to-follow tips, instructions, images, videos
- Links to other resources, including access to services, and ostomy products

Margaret Goldberg, MSN, RN, CWOCN, and a member of the Guide Development Team, recently led a demonstration session at the 2019 UOAA National Conference in Philadelphia. "As a WOC nurse as well as living with an ostomy myself, it was great to have so many people engaged in learning how to better evaluate and understand their peristomal skin health," Margaret notes. "During the demo, one of our attendees was visibly excited that the PSAG pinpointed a skin issue she had experienced but had not been identified for over a year. I'm delighted that she and others like her may find the help they need by using this guide."

Always looking to reach more people, the Peristomal Skin Assessment Guide for Consumers is now available in Spanish. "We are thrilled to now provide this essential tool in both an English and a Spanish version," said WOCN Society President Stephanie Yates, MSN, RN, ANP-BC, CWOCN. "With the addition of the Spanish language version of the Peristomal Skin Assessment for Consumers, we are looking forward to expanding our reach and empowering a larger audience of consumers to take control of their skin health by providing them with tools, additional comfort and support to increase their quality of life."

Visit **psag.wocn.org** to access the English or Spanish language versions of the Peristomal Skin Assessment Guide for Consumers, or the guide for clinicians.



The Peristomal Skin Assessment Guide is now available in both English and Spanish

The Peristomal Skin Assessment Guide for Consumers and the Peristomal Skin Assessment Guide for Clinicians were funded through educational grants from Hollister Incorporated.

ASK THE EXPERT

5 Healthy Ways to Relieve Ostomy Surgery Anxiety for Caregivers

Learn from nurse and caregiver herself, Kerri Consigli, on how to take care of your loved one, while still taking care of yourself.

By Kerri Consigli, BSN, RN, CWOCN

My husband Adam and I met on Match.com, and on our first date he discovered that I was an ostomy nurse and I discovered that he had an ileostomy. We hit it off immediately. Then, six months into our relationship, Adam had a routine visit with the physician who performed his ostomy surgery. He learned that he was going to need another abdominal surgery involving relocation of his stoma.

After a successful operation, he recovered better than I ever thought he would. But, let me tell you that before, during and after his surgery I was a mess! I guess you could call it "surgery anxiety." I had finally found the love of my life, and now all the "what-ifs" were running through my mind, and it ultimately left me anxious, depressed, and scared.

Sound familiar? That's the tip of the iceberg of emotions that we, as caregivers, often feel when a loved one needs surgery. My experience left me asking an important question: What about support for the caregivers? I'm an ostomy nurse, so the ostomy itself wasn't a source of stress for me. However, I recognize that this can certainly come as a challenge for many family caregivers.

My experience has taught me that part of my assessment as an ostomy nurse is to check in with who I like to call the "loved one's other half" or the caregiver. You are what makes your other half whole (see what I did there? Ha hal).

Bottom line: You matter, too! You, as a caregiver, are as much a part of the process as the person being cared for. You aren't the one being operated on, but you are certainly going through that surgery anxiety. And, trust me, that doesn't stop even after the surgery is over.



ASK THE EXPERT

Tips for Caregivers

(continued)

Looking back on my experience with my husband's ileostomy, it shed some light on why I wasn't coping well with his surgery. Self-care didn't exist for me. I was so focused on making sure that he was okay that I forgot about caring for myself. As a result, I admittedly became a weepy, irritable, anxious monster. My physical and emotional defenses were down, and it was affecting my day-to-day life.

Everyone copes differently, but what matters most is that self-care becomes a priority and that you accept that it's not being selfish. It's survival. You must make sure that you maintain your health and well-being, in order to be available for your loved one.

I came up with 5 tips, while seemingly basic, that are vital to your survival in the process from pre-op to post-op ostomy surgery and beyond:



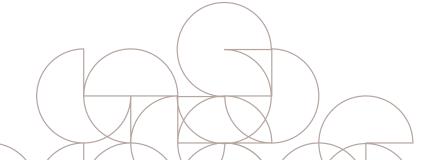
1 Sleep

- Get your 8 hours. I know that when I am sleep-deprived, I am useless.
- Take a nap if you want and don't feel the least bit guilty.
- During the post-op period, go home and sleep at night. The nurses and doctors will take good care of your "special patient."
- Rest is important. You need to be bright-eyed and clear-headed the next day so you can start the recovery process alongside the person with an ostomy.



2 Eat

- Avoid a typical "stressed-out" diet of comfort foods, sweets, and junk food.
- Maintain a well-balanced diet of fruits and veggies, complex carbs, and lean protein.
- Drink plenty of water.
- It's okay to leave your loved one's bedside to grab a bite to eat.
- Head to the cafeteria, bring food in, or go home and make yourself a healthy meal.
- Eating and hydrating properly will fuel your brain and body so you can be physically and mentally available for your loved one.



ASK THE EXPERT

Tips for Caregivers

(continued)



3 Exercise

- Keep up with your regular exercise routine.
 This is the time to release those endorphins.
- A brisk walk around the hospital will get your muscles moving and your blood flowing.
- Any type of physical activity will help keep you alert and less stressful.



5 Talk or laugh it out

- Express your feelings with your loved one.
 Have a good cry if that's what you need.
- Call that person in your life who can make you laugh.
- Watch a funny movie or TV show. A few good belly laughs always feel amazing!
- Family caregivers can become overwhelmed. Talk it out with other family members or a close friend.
- Do not worry or suffer in silence. Look for a shoulder to lean on.



4 Educate Yourself

- During the pre-op phase, prepare yourself for an educational session with an ostomy nurse.
- Visit reputable websites for information.
 United Ostomy Associations of America
 (www.ostomy.org) is very helpful. You can even search for a local UOAA support group by visiting www.ostomy.org/support-group-finder/
- Avoid online negativity and misinformation.
- During post-op, be there with your loved one to receive valuable information and instructions from the ostomy nurse.
- Take notes, ask questions about stoma, ileostomy bag, or anything that comes to mind. Remember, no question is ever too frivolous to ask.
- Knowledge is power.

Yes, surgery is stressful both for the patient and the caregiver. And having an ostomy creates a major life change for both people in a relationship. You need to just keep in mind that you are the most important person for your loved one, and because you are so important, you must remember not to lose yourself in the whole process. Simply put, take good care of you.

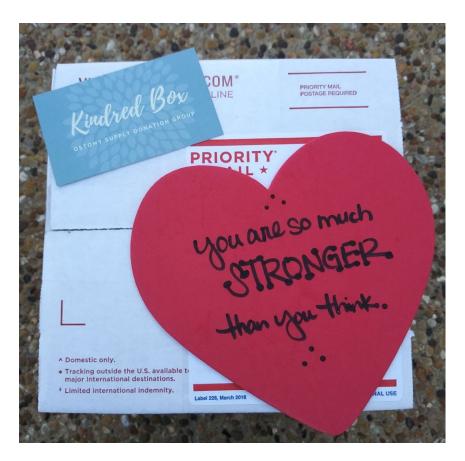


Kerri Consigli is a certified Wound, Ostomy, and Continence Nurse Specialist (CWOCN) at Milford (MA) Regional Medical Center. Ostomies are a constant in her life, as husband Adam has an ileostomy. She balances her time being a wife and mother with making a difference for ostomy patients in her community.

COMMUNITY SPOTLIGHT

Kindred Box has a heart for those in need

A program supporting those in challenging circumstances with free ostomy supplies



"Many are fortunate to have excess supplies, yet others don't have any. Making this connection is very important to our mission."

-christine Kim

Kindred Box is a nonprofit organization in the United States dedicated to improving the lives of people with ostomies. Since 2017, they've been collecting donations for programs that provide free ostomy supplies to U.S. military veterans and for disaster relief assistance.

They also offer low-cost ostomy supplies to those who are faced with challenging circumstances such as living in a low-income household or being uninsured.

"Many are fortunate to have excess supplies, yet others don't have any. Making this connection is very important to our mission," noted Christine Kim, the founder of Kindred Box. "When we first started out, we were sending supplies to a few dozen people. Just two years later that number grew significantly—by word of mouth."

Christine indicated that Kindred Box has over 200 people on their list who request supplies on a regular basis, and she expects that number to double in 2020.

You may be surprised to learn that some people in America with an ostomy do not have proper medical supplies. And you may be thinking: Why don't they have supplies? What do they use? Christine has connected with many people who are struggling to pay out-of-pocket for ostomy supplies, including Jessica from New York who was down to only one pouch because she was waiting on her insurance to approve an order from a supplier.



COMMUNITY SPOTLIGHT

Kindred Box

(continued)

"If help didn't come fast, Jessica said that baggies and tape was how she'd get by," Christine said. "She couldn't afford the expense of paying retail for ostomy supplies and said depression was hitting her hard."

Unfortunately, Jessica's situation is more common than you might think. Waiting weeks, even months, for insurance approval is the main reason for a short-term need of ostomy supplies, but there are other reasons which are long-term or lifelong:

- Some return home from the hospital with the shocking news that ostomy supplies are not covered by their health insurance.
- Some with health insurance say their deductibles for durable medical supplies are very high or the coverage limits are very low.
- Some do not have health insurance.
- Some have been through a natural disaster and lose everything, including their ostomy supplies.

Christina from Virginia contacted Kindred Box after her son Zachary had ileostomy surgery because of Crohn's disease. They'd been using samples from the manufacturers but when those ran out, she couldn't afford to pay out-of-pocket for his supplies. Not only were they drowning in medical debt, but when Christina's husband lost his job, the family lost their insurance.

Thankfully, she came across Kindred Box and reached out for help. About a week later the box arrived and Christina shared her gratitude on their Facebook page: "My son was down to his last bag and we so needed these ostomy supplies for him. Thank you so much. One less stress to worry about."

Christine credits the kindness of many for the reason Kindred Box has been able to help so many people year after year. "We would simply not exist today if it weren't for people who generously donated to help those in need," she said. There's even a page on their website devoted to "thank you" notes from recipients who have received donated supplies from Kindred Box.



For example, "I'm a U.S. Air Force veteran in need of colostomy supplies. It means the world to me that people who don't even know me donate to Kindred Box so these ostomy supplies can be sent to me. I am so thankful!" – Kelly E.

Kindred Box gives people living with an ostomy a new lease on life. With the option of affordable ostomy supplies, they can leave the house, they can work, they can simply get back to living. More importantly, they can find a little joy knowing that someone cares.

To learn more about Kindred Box, visit **kindredbox.org**.

Facebook:

www.facebook.com/kindredboxorg/

Donation page:

donorbox.org/kindred-box

NEWS FROM HOLLISTER

Together, we made a difference

Dear Hollister Secure Start Services Members,

Another year has come to pass, and we couldn't be prouder of how we were able to join *together* in support of the ostomy community. We have gone "ALL IN" throughout 2019 in so many ways – from speaking to you one-on-one whenever you have needed our assistance, to meeting you at community events such as Youth Rally, the annual United Ostomy Associations of America (UOAA) conference, and Run for Resilience Ostomy 5K events all over the country.

Together, we helped to raise ostomy awareness to a new level and brought related conditions such as Inflammatory Bowel Disease and cancer to the forefront, with personal stories of courage and perseverance that remind us all that ostomy surgery can often be a "life-saver." We only share a glimpse of that in these eNewsletters, but it's really the day-to-day involvement that matters most.

Thank you for letting us be a part of your journey and for the humbling and inspiring testimonies you've shared with us, including:

"You were very understanding and gave me back my life."

"You answered every question with such confidence. That really, really helped in the MOST difficult time of my life."

"If I was closer, I would give all of you a hug from each of my patients that you have assisted over the years – and, yes, it would run in the hundreds!"

One of our core principles at Hollister Incorporated is *Dignity of the Person*. As such, we hold one's quality of life in the utmost regard. This supports our mission to make life more rewarding and dignified for the people who use our products and services. We are eager to learn and find additional ways to serve you. With that said, we look forward to bringing you new and helpful innovations in the coming year. So, stay tuned for more.

We wish all of you and your families a very safe, happy, and healthy holiday season! See you in 2020!

Best Wishes,



Brian Luedtke

Senior Vice President, Global Marketing, Hollister Incorporated



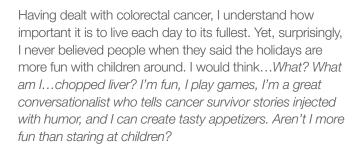




WHAT'S SO FUNNY?

Bring On the Eggnog or Maybe a Small Child

Brenda knows children make the holidays special



My own kids were amusing, but they also had to be disciplined, fed, clothed, taught things, and not believed when they said they were going to a certain place. Check and recheck, a lot of work... and yet they were the best things we ever made. They filled a void in my life I never knew I had until they were born. And then at the holidays we could relax a little because they were safely in Grandpa and Grandma's house and they would run off giggling with their cousins and have a blast.

Here they are again...the holidays...bring on the eggnog and iced sugar cookies and let's get this party started!

Our kids are older now and they are fun, witty—more than cutesy at this point. But then something changed. We had a grandchild. At first, she was just beautiful to look at and she didn't change the holidays too much because we just passed her around and sighed in contentment.

She is 22 months this holiday season. She's a little sassy in her mannerisms, she knows she's cute...because what do we do with her now? We stare at her, play with her on the floor (after much effort getting up and down, of course) and



generally smile nonstop as we play peek-a-boo with whatever is handy to hide behind...a blanket, a pillow, the dog.

Everything she does is adorable. When she comes to my house we dump a basket of old toys on the living room floor and watch in fascination as she picks up and plays with them or brings them to us to play with too. Of course she is brilliant, funny, and fast, and we are moving into that scary period when she can navigate faster than me...and when language begins. She is developing the level of skill where the communication is simple and purely honest. Can't wait for that!

And as I write this, we are waiting for her baby brother to arrive. Two of those lovely creatures to watch, to change the holidays from games, eggnog, and delicious food to pure entertainment by little ones: a new kind of fun that requires very little but the wonderment and joy of the presence of small children.

So, do you think at this moment I am grateful for a life-saving ostomy that changed me from being a patient to a cancer survivor? You bet. My kids were three and five years old when I was diagnosed with colorectal cancer. They have grown up to be lovely adults always knowing that their mom has a colostomy. And now my grandchildren will know too. Does that matter to any of them? NO. They are grateful I am around for another holiday where we stare at these magnificent children, sigh in contentment, and love each other. I am grateful too.



Brenda Elsagher is a national keynote speaker, author and comedian. She has been living well with a colostomy since 1995. Check her funny books out: **livingandlaughing.com**.

Financial Disclosure: Brenda Elsagher received compensation from Hollister Incorporated for her contribution to this eNewsletter.

EVENT UPDATES

Find an event near you

Get involved to make a difference



Colon Cancer Coalition Get Your Rear in Gear

Walk, run or ride in the largest colon cancer-focused event series in the country. Get Your Rear in Gear Run/Walk and Tour de Tush Bike Ride are sponsored by The Colon Cancer Coalition, a nationally recognized partner in the fight against colon cancer. Participants are invited to add a personalized sign to the "Blue Mile" to honor those diagnosed with cancer, remember loved ones and celebrate the important people in their lives. Find one of 45 national events at **coloncancercoalition.org** or create your own local event!



Crohn's & Colitis Foundation

Take Steps for Crohn's & Colitis™

Take Steps walks offer a wonderful way for family and friends to empower and inspire each other, and help connect with the greater IBD community. These walk events are filled with live music, food, kids' entertainment and educational activities. Take Steps is a nationwide event in more than 100 communities across the United States. Find one near you! Register at **cctakesteps.org**.



ALL AGES • NATIONWIDE

Crohn's & Colitis Foundation

spin4 crohn's & colitis cures

spin4 crohn's & colitis cures is an indoor cycling relay to find cures for the 1 in every 200 Americans living with inflammatory bowel diseases. You and up to three team members reserve a stationary bike and pedal with a purpose during this two-hour, high-energy fundraising event! This #partyonabike is taking place across the country – find an event near you! crohnscolitisfoundation.org.



Youth Rally

Youth Rally 2020

More than 30 years after its inception, the Youth Rally remains a community for young people to meet others who live with similar medical conditions. Lasting friendships are formed in an atmosphere that promotes self-confidence and independence. Applications will be available January 2020. Learn more at **youthrally.org**.

NEWS FROM HOLLISTER

Free Personalized Support – Now Online



Get Started Now

As a member of Hollister Secure Start services, our NEW and IMPROVED website is exactly what you need to access support connections, product information, and educational resources that will help you live the life you want to live, regardless of the brand of ostomy or continence products you use.

Once you create an account or log in, you'll be able to:

- View articles and videos based on your personal preferences
- Track product sample shipments
- Stay informed about upcoming events throughout the ostomy community

And, you'll also have access to a personal Hollister Secure Start Consumer Service Advisor, as well as educational resources in our exclusive Ostomy Care and Continence Care Learning Centers.

To create an account, update your information, or simply explore all the ways we can support you, go to **securestartservices.com**.

Hollister Secure Start services are free of charge, and there is no obligation to purchase anything to receive them. Hollister Incorporated reserves the right to change Hollister Secure Start services at any time.

Share Your Story

It's a great way to inspire others

Your ostomy experience is as unique as you are. We'd love to hear all about it, and your story might just inspire someone else.

Have you...

- Trained for a sporting event?
- Volunteered to support others with ostomies?
- Taken up a new hobby or art form?

Please share your unique experience with us. We might just profile you in an upcoming eNewsletter!



Submit your story today at securestartnewsletter@hollister.com

Hollister Secure Start Services

eNewsletter

Resources

Hollister Secure Start Services

1.888.808.7456 www.securestartservices.com Hollister Facebook Page

United Ostomy Associations of America, Inc. (UOAA)

1.800.826.0826 info@uoaa.org www.ostomy.org

Crohn's & Colitis Foundation

1.800.932.2423 www.crohnscolitisfoundation.org

Colon Cancer Coalition (CCC)

952.378.1237 www.coloncancercoalition.org

Bladder Cancer Advocacy Network (BCAN)

888.901.2226 www.bcan.org

Friends of Ostomates Worldwide-USA

www.fowusa.org

Youth Rally

www.youthrally.org

Run For Resilience

www.ostomy5k.org

Shadow Buddies Foundation

www.shadowbuddies.org

Girls With Guts

www.girlswithguts.org





It's Personal

We are proud to offer dedicated support for each and every ostomy and continence care patient along the continuum of care. Hollister Secure Start services provide a lifetime of personalized support.



Hollister Incorporated

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Nothing contained herein should be considered medical advice. Medical advice can only be provided by an individual's personal doctor or medical professional.

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