

Affiliated
with...



SHORT CIRCUIT

Cedar Rapids / Iowa City Area Ostomy Support Group #171, Inc. — an affiliate of UOAA, Inc.
Our 51st Year! Serving Ostomates of Eastern Iowa since 1972 www.iowaostomy.org September 2023

Welcome!

The Cedar Rapids / Iowa City Area Ostomy Support Group is dedicated to providing information, advocacy and service to our members and their caregivers. We also include the intestinal and urinary diversion community at large.

Who is U.O.A.A.

The United Ostomy Associations of America is a 501(c)(3) non-profit organization. The UOAA serves to unify and strengthen ostomy support groups in America.

UOAA services include:

- Advocacy
- Non-profit Status
- Conferences
- ThePhoenix magazine
- Toll-free Help and Referral Line
- Special Interest Groups
- Ostomy Community Liaison

For more information, contact the UOAA at 800-826-0826 or visit their website www.ostomy.org.

From the Coordinator:

Hello everyone!

Our first IN PERSON meeting in years was super successful in my opinion. We had 2 couples that included 'educated' ostomates, we had 4 new ostomates (a couple with support people) and 1 came knowing she is getting an ostomy in September. Several of them plan to be back with us in September as well at that meeting.

At the August meeting I thought we would have to find another place to meet in person because the University had already said we could not be in person. That has changed!! We will be at the Iowa River Landing/ University of Iowa off I80 (exit 242). They are working on that exit so leave yourself time - you may need to work around construction getting off the interstate.

I was able to share a few things from conference but I do have quite a bit more to bring and show for the September meeting as well. Those that weren't there probably do not know I came back with COVID. I was unable to collect myself and all the stuff I brought back to have ready for the meeting. So not only will we hear from the kids and their time at camp - but I will have more information on new things on the market as well.

I want to just thank you all again for your support in me going to the conference. Even though COVID was just 1 of the hurdles we encountered - the 3 days I had at the conference were so worth it. Can't wait to see you at the September meeting!

Best Regards,

Gina Carlile



Our local chapter

We meet regularly to share experiences, provide mutual support and learn about the latest products and information for ostomy, urostomy, and intestinal diversions.

Meetings are held at area hospitals, and involve informal round-table discussions on topics of interest. All of our meetings will have a question and answer session with one of the local WOC nurses. Meetings can include potential new product demonstrations, guest speakers, and insurance company speakers. Families and friends of ostomy and intestinal diversion patients are always welcome to attend.

For more information about the local chapter, contact us at 319-775-0175, online at www.iowaostomy.org, or find us on Facebook at Cedar Rapids/Iowa City Area Ostomy Support Group.

Need a Wound/Ostomy Continence Nurse (WOCN)?

St. Luke's Hospital
Cedar Rapids, IA
Ostomy Clinic
319-368-5582

Mercy Medical Center
Cedar Rapids, IA
Healing Center
319-398-6400

Regional Medical Center
Manchester, IA
Wound Clinic
563-927-7511

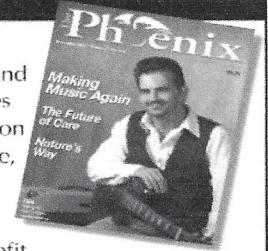
University of Iowa
Iowa City, IA
Nurse Line
319-356-7994

Mercy Hospital
Iowa City, IA
Wound Center
319-339-3967

Buchanan County
Health Center
Independence, IA
Wound Clinic
319-332-0999

Get Ostomy Answers!

The Phoenix is the leading national magazine for ostomates, their families and caregivers. Each issue contains 72 pages of inspiration, education and information including new products, medical advice, management techniques, personal stories and more.



Subscriptions directly fund the nonprofit United Ostomy Associations of America – the only national organization providing vital information, resources, support and advocacy for ostomates.

The Phoenix

ORDER FORM

Money Back Guarantee!

One-year subscription \$29.95 Two-years for \$49.95

Payable to: The Phoenix magazine, P.O. Box 3605, Mission Viejo, CA 92690

Name _____

Address _____

Apt/Suite _____

City _____

State _____

Zip _____

11/11 5015/20

The **SHORT CIRCUIT** is the official newsletter of the Cedar Rapids/Iowa City Area Ostomy Support Group #171, and is published 7 times per year.

MEMBERSHIP is open to ostomates along with their families, friends and caregivers. Dues are \$10 per year and include an email subscription to the **SHORT CIRCUIT** newsletter. Copies are also available free on our website at www.iowaostomy.org.

Don't have email? To subscribe to the printed edition of the newsletter there is an additional \$10 charge per year (to cover the costs of printing and mailing).

Membership dues and print subscription fees are collected on the honor system. If you are reading this newsletter you are considered a member even if you are not able to attend meetings. Your membership fee is tax deductible and will help support educational activities for ostomates in eastern Iowa. Send membership dues and printed subscription fees to Vicki Kee, P.O. Box 5227, Coralville, IA 52241

iGive.com You Shop. Your Charity Gets Money. For Free.™

Home Search Stores/Web My Stores Stats Cause Tell a Friend Settings All Stores Promote Your Cause Logout

Welcome back Gina! You've raised \$39.29 YOU'RE SUPPORTING (CAUSE): CEDAR RAPIDS/IOWA CITY AREA OSTOMY SUPPORT GROUP

Remember to save your favorite stores! You and all iGive members have collectively raised \$10,137,195.10

\$5 New Member Shopping Bonus!
Recruit friends to support Cedar Rapids/Iowa City Area Ostomy Support Group, when they join today and make their first purchase within 30 days they'll earn a \$5 bonus!

Search for iGive Stores

Are you an online shopper? Consider creating an account with iGive.com and setting up to link to the support group. For your computer browser, you can then download the iGive button located at the bottom of the website. Then every time you're at a store supported by iGive you'll be alerted that a donation will be made to the support group. Prefer mobile apps? Also at the bottom of the webpage there is a mobile app option to be able to download as well.

Officers of the Cedar Rapids / Iowa City Area Ostomy Support Group

Gina Carlile, Support Group Coordinator

Vicki Kee, Treasurer

Newsletter Editor

PO Box 5227

New Ostomate Support Visitor

Coralville, IA 52241



Upcoming Meeting Info

Thursday, September 14, 2023

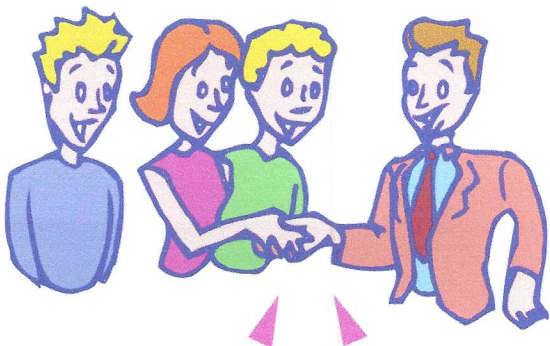
IN PERSON Support Group Meeting @ 6:30pm
University Iowa - Iowa River Landing
TOPIC: Kids from Camp

Thursday, October 19, 2023

Support Group Meeting @ 6:30 pm
UnityPoint Health - St Luke's Campus - Cedar Rapids
Room 163 Behind Gift Shop

2024 Meetings Coming Soon

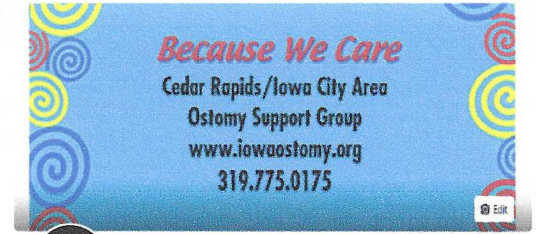
Meeting cancellations — If it becomes necessary to cancel a support group meeting due to weather conditions, the information will be posted on our website: www.iowaostomy.org. If you receive the Short Circuit via email, you will also receive an email notice of cancellations. If you suspect a meeting will be canceled because of inclement weather but don't have access to email, just give the group number 319-775-0175 a call to find out the status of the meeting.



Zoom Meeting Info

TBD:

Let me know if you would like the zoom link open and I will create a meeting



Cedar Rapids/Iowa City Area
Ostomy Support Group

Edit Contact us

FIND US ON FACEBOOK

ABOVE IS FB page to like (friends can see you like this)
<https://www.facebook.com/iowaostomy>

BELOW IS FB group managed by me (Gina - and as a private group nobody will see you're a member or anything you post)

<https://www.facebook.com/groups/EasternIowaOstomySupportGroup>



Eastern Iowa Ostomy Support
Group

Private group · 64 members

Ostomy 101 Mobile App

Free on IOS & Android Devices - scan barcode for app

- Ostomy Surgeries Explained
- Clinician led Ostomy Education Videos in English & Spanish for Adult & Pediatric
- Free New Patient Classes
- Telemedicine Appointments with a Certified Ostomy Nurse (WOCN)
- Ostomy Lifestyle Videos, Blogs & Podcasts
- Free Manufacturer Samples & Coupons
- Ostomy Pouches & Accessories
- Free Recovery Programs
- Free Virtual Support Groups, Classes & Events
- More!



CELIA'S STORY: FEELING AT HOME WITH SHORT BOWEL SYNDROME

Article by Takeda via UOAA Website

Since short bowel syndrome is not something most people talk about every day, I am excited that we have a month to bring awareness to it. As someone living with short bowel syndrome (SBS) and an ostomy, I have learned to be grateful for the technologies and doctors who have helped keep me alive through my surgeries and infections. And I am proud of myself for developing the self-reliance to find ways to make my life easier.

People with ostomies come from all stages of life, and we all have different stories to tell. But we also share some common experiences—and we can learn from each other. I have an ostomy because of SBS, a rare digestive disorder that many people may not know much about. If you asked me about my memories of my SBS diagnosis, I couldn't answer that because I don't remember it. My SBS diagnosis happened right after I was born. Fortunately, my doctors quickly ran tests and diagnosed me with Hirschsprung's disease, a condition at birth where certain nerves are missing from parts of the intestine. I immediately had surgery to remove my colon and half of my small intestine, which led to my SBS diagnosis and having an ostomy.



My parents, who were graduate students at the time, were as ready as they could be to bring home a baby, but I think they had prepared for the predictable, everyday challenges of having a "normal" baby, not for me. After my surgery, I spent about one month in the NICU, where the nurses instructed my parents on how to care for me.

When my parents brought me home, they raised me to never feel different and didn't see my condition as something to hold me back: they wanted me to be independent, which I am! My health condition has been just a part of who I am. I grew up getting hooked up to IV nutrition, a form of parenteral support or PS, every night. It was such a part of my routine that I didn't know any different. SBS was just part of my life.

From a very early age, I learned how to take care of myself because that's what parents teach their children. If I hadn't had SBS, they would have potty-trained me. Instead, they taught me how to drain my ostomy. Their attitude was, This is going to be difficult, but she has to do this. So, we would work on the steps together. Just like other kids learning to make it to the toilet, I learned how to change my ostomy so that I would be ready for school.

Starting preschool was an adventure. How many schools are equipped to care for a kid with an ostomy? Wildly enough, the director of the preschool was an older woman who had friends with ostomies, so she was familiar with my needs! It's a great example that, despite age differences, we can connect through our ostomy knowledge and help each other out. Eventually, the preschool teachers and director trained the staff at my elementary school when it was time for me to start my education.

As I was growing up, all my friends knew that I had a health condition. I also think I was lucky in that, while I was technically very sick in the beginning, the doctors were able to address it early on. That meant that even though I had a rare digestive disorder, I was actually not a very sick child. Plus, I just didn't have that concept of shame. For show-and-tell, I'd pull up my shirt to show everyone my line for my parenteral nutrition. And they'd all be like, "Cool! There's some weird plastic thing hanging out! Moving on..." No one cared.

Then, when I was in middle school, we moved from California to the East Coast. For the first time ever, I had to share my condition with others—in a student population hundreds of times larger than the tiny magnet school I'd left behind. Plus, my health condition started flaring up for the first time. I missed the first day of school due to my first-ever line infection. At that point, I hadn't really processed what my medical condition meant for my life.

So, I was dealing with complex new health issues while trying to pretend I was "normal." I got through middle and high school through sheer determination. While I enjoyed my time at school, I often felt like an outsider—like I couldn't tell people about my true self. I shrank into myself and let fear cause me to lose who I really was. I realized, for example, that the type of shirt "everyone was wearing" would show my line. If I wore the "in" jeans, which were low-waisted, my ostomy bag popped out. I was already not like everybody else just by my clothes alone. Add in missing a lot of school due to hospitalizations and infections, and people would recognize me as "the girl that's gone all the time." I let go of hobbies, friends, talents, and dreams just to blend in.

These days, more than two decades after my SBS diagnosis, I don't worry about blending in so much. Instead, I am clear about my needs, and I've figured out what works for me. It doesn't matter if my jeans are on trend—feeling good and confident in my own skin and my own life matters most. From my clothing choices to creating an ostomy station in my bathroom that's both functional and cozy, I have learned to set up the things I need to feel comfortable and happy. This also means that when something is stressful or hard, like if the bag breaks in the middle of the night, I already have a bag ready on my nightstand so that I can deal with the issue. I try to think through what might happen when I am clear-eyed and calm so that when difficulties arise (which, in my experience, they have), I can focus on fixing the problem.

I've been managing my ostomy on my own since high school, and even when I'm in the hospital or being visited by nurses at home, I take charge of changing my bag. Sometimes the nurses are curious to see how a patient does it independently. I think that as they watch me, they pick up tips and strategies to show their patients different—but still medically acceptable—ways of managing their bags at home.

CELIA'S STORY: FEELING AT HOME WITH SHORT BOWEL SYNDROME (Cont)

I've been managing my ostomy on my own since high school, and even when I'm in the hospital or being visited by nurses at home, I take charge of changing my bag. Sometimes the nurses are curious to see how a patient does it independently. I think that as they watch me, they pick up tips and strategies to show their patients different—but still medically acceptable—ways of managing their bags at home. We (or our caregivers) learn the correct procedures in the hospital, and we all find ways to adapt to SBS.

Thankfully, hospitals and homes are two separate things. So when I bring my SBS home with me, I try to be a good host and make it cozy and comfortable.

In recognition of Short Bowel Syndrome Awareness Month (August), I would like to encourage my fellow SBS patients and their caregivers to stand up and become their own best advocates. As I said, people with ostomies come from all stages of life, and while every patient is unique, we are all in this together.

NOTE: I know there are many in our group with SBS. At conference I learned about a medication being used called Gattex. Website found here: https://www.gattex.com/?utm_medium=email&utm_source=US-TED-1333&utm_id=EM230803140301

Fashion model poses with her ostomy bags to inspire other cancer survivors

via Ostomy 101/CBS news article from 2019

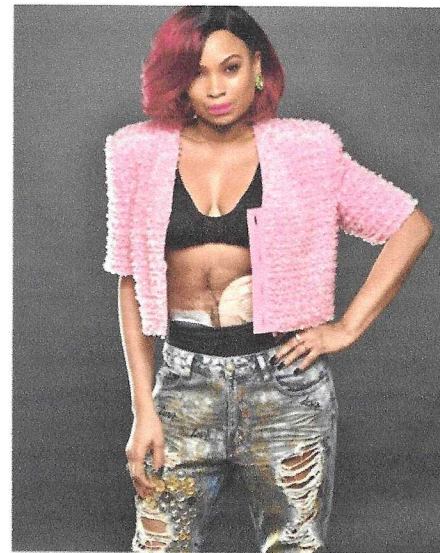
Growing up with ostomy bags in Baltimore, Maryland, fashion model Jearlean Taylor wasn't sure she would be able to pursue her dreams. Now, she's on a mission to inspire others to embrace what makes them different.

At only 3 years old, Taylor was diagnosed with a rare vaginal cancer called Rhabdomyosarcoma, which doctors didn't expect her to survive. After chemotherapy, radiation and several surgeries, Taylor was cancer-free, but left with two permanent ostomy bags — colostomy and urostomy, which aid her bladder and bowel functions — for the rest of her life.

Taylor found it difficult to accept her ostomy bags during her adolescence. She struggled with self-pity, depression and low self-esteem. "I found it hard, embarrassing and painful to be considered 'different,'" Taylor told CBS News. She was teased in school, though she said she "could not blame the kids for what they did not understand."

"I remember that embarrassing moment in middle school when my bag burst on the school bus, the entire bus smelled awful," said Taylor. "That day, I could have ripped those bags off me."

Taylor was discovered by a modeling scout at a local mall. She had never considered modeling before, and was initially worried she could never be successful with her ostomy bags. However, modeling gave her the self confidence to embrace her bags, rather than hide them. "It allowed me to not be afraid of following my passions," Taylor said. "I was able to take the focus off of my bags and concentrate on my talent as a model."



Since then, the 51-year-old has been featured in over 30 magazines, as well as various newspapers, billboards and runway shows. Her goal is to have a positive impact on the ostomy community through her modeling, motivational speaking and personal memoir. "I used to say, 'Why me? Why cancer? Why ostomy bags?' I thank God every day because he is showing me 'why not me?'"

According to the United Ostomy Associations of America, between 725,000 and 1 million Americans are living with an ostomy, and 100,000 ostomy surgeries are performed annually in the U.S.

"My desire is to show others, especially in the ostomy community we can be, do and live," Taylor said. "We don't have to be defined by our circumstances. I encourage others to live your life on purpose ... with a purpose ... for a purpose."

Check out her store: <https://xmade4u.tuosystems.com/stores/ostomystylzz>



Importance of Hydration

via: Ostomy Association of Greater Chicago: New Outlook Newsletter

Regular physical activity and healthy diets are important for healthy aging. However, the body's basic need for water is often overlooked, resulting in dehydration. Hydration is the replacement of body fluids lost through sweating, exhaling, and eliminating waste. On average, the body loses and needs to replace about 2-3 quarts of water daily.

Luckily, many foods we eat are composed mostly of water. Foods with high water content include greens and most fruits and vegetables. Caffeinated beverages (soft drinks, tea and coffee) count, in part, toward our daily fluid intake. Though they do not dehydrate you, they can promote increased urination and should not be the primary nonfood source of liquids during your day. The best sources of hydration are water and drinks that are primarily water (sport replacement drinks, herbal teas, lemon water and vegetable broth).

The role of water in the human body:

We can last up to six weeks without food, but only one week without water. Here are some other ways water impacts our health:

- Carries nutrients and oxygen to all cells in the body.
- Helps convert food into energy
- Lubricates joints.
- Regulates body temperature.
- Protects and cushions vital organs.
- Moistens oxygen for breathing.
- Is essential for our senses to work properly.
- Is the main property of blood, which carries nutrients to cells and carries waste out of the body.
- Is one of the six nutrients essential for life (water, fat, carbohydrates, protein, vitamins and minerals).
- Kidneys and liver need extra water to process medicines.
- Our bodies need water to balance fiber intake.

Increasing fluid intake: To meet your body's needs, and prevent frequent urination problems, drink regularly throughout the day, rather than several big gulps at once. Fluids are more easily absorbed when they are cooler, about 40-60 degrees. Drink 1-2 cups of fluid 30 minutes before exercising and $\frac{1}{2}$ cup-1 cup fluid every 25 minutes while you exercise. Within two hours after exercising, drink enough water to replace fluid lost during workout (for example, 2 cups for each pound lost)

Drink before you get thirsty. Thirst is a sign that your body is already dehydrated. Keep drinking regularly throughout the day even after your thirst is quenched.

Webinar from Coloplast (same date/time as our support group meeting):

https://www.bigmarker.com/coloplast-corp1/Developing-a-good-body-image-with-an-ostomy-Tips-for-females?utm_bmcr_source=LocalSupportGroups

The image is a promotional banner for a webinar. It features two women in the foreground, one in a black top and one in a patterned top, smiling and talking. The background is a blurred image of a clothing store with mannequins. The text is overlaid on the image. At the top, it says 'Developing a good body image with an ostomy: tips for women'. Below that, it says 'Thu, Sep 14, 2023 - 6:00 PM | Central Time (US & Canada) (GMT -5:00) | Add to calendar'. In the center, there is a countdown timer showing '10 days 04 hours 01 minutes 07 seconds'. At the bottom, there is a blue button that says 'REGISTER'.

Looking for information on ostomy products or ostomy related organizations? Contact information below

Major Manufacturers

Manufacturers are the companies that make each type of ostomy supply. Most have an ostomy nurse on staff to answer your questions about products. Call or go to their website for free samples!

Coloplast	888-726-7872	www.coloplast.us
ConvaTec	800-422-8811	www.convatec.com
CyMed	800-582-0707	www.cymed-ostomy.com
Hollister	888-808-7456	www.hollister.com/us
Marlen	800-321-0591	(via Edgepark)
Marlen	216-292-7060	www.marlenmfg.com (directly)
Nu Hope	800-899-5017	www.nu-hope.com

Suppliers

They will send a free catalog featuring many brands of ostomy supplies. Suppliers stock all type of supplies from each manufacturer. This is a great way to compare different manufacturer's products!

AOS Medical Supply	800-858-5858	www.mmsmedical.com/aos
Byram Healthcare	877-902-9726	www.byramhealthcare.com
Duke Medical Supply	888-678-6692	www.dukemedicalsupply.com
Edgepark Medical	800-321-0591	www.edgepark.com
Liberty Medical	888-844-2651	www.libertymedical.com/ostomy
SGV Medical	800-395-6099	www.sgvmedical.com

Organizations

Great resources outside of our local chapter for ostomy related questions.

American Cancer Society	800-227-2345	www.cancer.org
Crohn's & Colitis Foundation	800-343-3637	www.ccfa.org
Friends of Ostomates Worldwide-USA	Donate unused supplies	www.fowusa.org
Osto Group - free product for the uninsured	877-678-6690	www.ostogroup.org
United Ostomy Associations of America	800-826-0826	www.ostomy.org
Wound, Ostomy and Continence Nurses Society	800-224-9626	www.wocn.org