# Ostomy Association of Greater Chicago

# The New Outlook

October/November/December 2018



#### **UPCOMING TUESDAY MEETINGS**

October 16, 7:30 pm (November, No Meeting) December 18, 7:00 pm

GLENBROOK HOSPITAL

2100 Pfingsten Rd, Glenview, IL Conference Rooms C & D, 1st Floor

#### July's Meeting (our 478th)

Stephanie Brenner, LCSW, presented "Surviving the Challenges of an Ostomy" from a psychological point of view. We discussed the many different reactions we all had to learning of, and undergoing ostomy surgery. Ms. Brenner is accepting patients at her practice Chronic Illness Psychotherapy.

#### September's Meeting (our 479th)

Wow, what a night! Two new (Pre-op) attendees researching ostomy surgery asked a myriad of questions, revealing extremely informative answers from our knowledgeable group. We hope they left a little more confident (or at least less terrified!) of the decision they are making.

Attending your first meeting? There are always supportive ostomy veterans to chat with you.

Remember, newsletters are now quarterly. Make sure we have your current email address to receive monthly meeting reminders.

www.uoachicago.org

On October 16 we're presenting "The Age of Ostomy". An ostomy can be a challenge at any age, but imagine being a child, teen or young adult. We'll hear about this experience as well as information on Youth Rally from Bret Cromer. See page 3. Katie and Sheryl will also contribute. Open discussion after.

December 18 is our annual Holiday Party! We eat, we sing, we celebrate and we laugh...a lot! Bring a dish to share. We will again have Portillos, so appetizers, salads, side dishes, chips, soft drinks, desserts...all good ideas. Party begins at 7:00 pm; we'll set up at 6:30.

To request the electronic newsletter, email uoachicago@comcast.net



www.ostomy.org

#### Ostomy Association of Greater Chicago (OAGC)

Established 1975

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Hospitality

Sandy Czurylo

#### **Wound Ostomy Continence Nurses (WOCN)**

wound Ostomy Continence	e Nurses (WOCN)
Julianne Ciaglia	773-990-8498
Presence Resurrection Medical Center	
Ana M. Boden	773-296-7095
Advocate Illinois Masonic Medical Center	
Nancy Chaiken	773-878-8200
Swedish Covenant Hospital	
Teri Coha	773-880-8198
Lurie Children's Hospital	
Jan Colwell, Maria De Ocampo,	773-702-9371 & 2851
Michele Kaplon-Jones	
University of Chicago	
Laura Crawford	312-942-5031
Rush University Medical Center	
Casey Mulle	847-657-5963
Glenbrook Hospital	
Cheryl Isberto	
Skokie Hospital	847-933-6091
Highland Park	847-926-5806
Agnes Brugger	847-570-2417
Evanston Hospital	
Connie Kelly, Mary Kirby	312-926-6421
Karen Blum	312-695-6868
Northwestern Memorial Hospital	
Kathy Krenz	815-338-2500
Centegra-Northern Illinois Medical	
Marina Makovetskaia	847-723-8815
Lutheran General Hospital	
Carol Stanley	847-618-3125
Northwest Community Hospital	
Nancy Olsen, Mary Rohan	708-229-6060
Little Company of Mary Hospital	
Kathy Garcia, Jola Papiez	708-684-3294
Advocate Christ Medical Center	
Sandy Fahmy	847-316-6106
Saint Francis Hospital	
Nancy Spillo	847-493-4922
Presence Home Care	(20,022,6762
Colleen Drolshagen, Jean Heer, Barb Stadler	630-933-6562
Central DuPage Hospital	500 016 0551
Kathy Thiesse, Nanci Stark	708-216-8554
(Ginger Lewis-Urology only 708-216-5112)	
Loyola University Medical Center	700 245 2020
Alyce Barnicle (available on as needed basis of	only) 708-245-2920
LaGrange Hospital	210 200 5020 210 002 0500
Sarah Greich	219-309-5939 or 219-983-8780
Porter Regional Hospital & Ostomy Clinic	Valparaiso, Indiana

# National UOAA Virtual Groups

Continent Diversion Network: Lynne Kramer	215-637-2409
Familial Adenomatous Polyposis (FAP) Foundation: Travis Bray	334-740-8657
Friends of Ostomates Worldwide - USA: Jan Colwell	773-702-9371
GLO Network: Fred Shulak	773-286-4005
Ostomy 2-1-1: Debi K Fox	405-243-8001
Pull-thru Network: Lori Parker	309-262-0786
Quality Life Association: Judy Schmidt	352-394-4912
Thirty Plus: Kelli Strittman	410-622-8563
·	

#### Additional area support groups:

#### Northwest Community Hospital, Arlington Heights

2nd Thurs at 1:00 pm every other month. Feb, Apr, Jun, Aug, Oct, Dec in The Learning Center, Level B1 of the Busse Center Contact Carol Stanley 847-618-3215, cstanley@nch.org

#### Southwest Suburban Chicago, Evergreen Park

3rd Monday at 6:30pm, Little Company of Mary Hospital, 2800 W. 95th St., Evergreen Park - Rm 1702. Contact Nancy Olesky 708-499-4043, nanook60@sbcglobal.net or swscost@gmail.com

#### Sherman Hospital, Elgin

2nd Wednesday of month at 2 pm. Lower level Conference B. Contact Morgan Coconate <a href="mailto:morgan.coconate@advocatehealth.com">morgan.coconate@advocatehealth.com</a> 224.783.1349, or Tom Wright, tomwright122@att.net

#### DuPage County, Downers Grove

The fourth Wednesday at 7:00pm, Good Samaritan Hospital, in the Red and Black Oak Rooms by the cafeteria. Contact Bret Cromer 630-479-3101, bret.cromer@sbcglobal.net

#### Aurora

The second Tuesday at 7:00pm, Provena Mercy Center. Contact John Balint 630-898-4049, <a href="mailto:balint.john@yahoo.com">balint.john@yahoo.com</a>

#### Will County, Kankakee IL

2:00 p.m. the last Saturday of Feb, Apr, Aug and Oct in the Riverside Medical Center Board Room, next to the cafeteria. Also a June picnic and December holiday party. Charlie Grotevant 815-252-1551, <a href="mailto:charliegrtvnt@gmail.com">charliegrtvnt@gmail.com</a>

#### Grundy County, Morris IL

Monthly Meetings at 11:00 AM, the 3rd Saturday at Grundy Administration Bldg., 1320 Union St., Morris, IL. Contact Judy Morey at 815-592-5717 or Kelly Hitt at 815-941-6818.

#### Lake County Illinois

Hollister in Libertyville, 10:00am the 3rd Saturday, every other month. Jan, March, May, July, Sept, Nov. Contact Barb Canter 847-394-1586, barb1234@sbcglobal.net

#### Lovola University Health System, Maywood

2nd Wednesday month at 7:15 in the Cardinal Bernadine Cancer Center 2nd floor Auditorium A. Contact Robin Handibode 708-205-6664 or Nanci Stark, WOCN 708-216-8554, <a href="mailto:nhstark@lumc.edu">nhstark@lumc.edu</a>

#### Rush University Medical Center, Chicago

Professional Building 1725 W. Harrison St. Suite 1138 - Conference Room. Parking for main garage will be validated. 1st Tuesday of month, 6:30p.m. Contact Rachel Hendee, rachel hendee@rush.edu

#### Hazel Crest, IL South Suburban Hospital

17800 South Kedzie Avenue, SSUB-CONF-RM Dining Room 1. Lower level adjacent to the cafeteria. 4th Saturday 10am to Noon. Free Parking. Contact Herb at 708-510-7479

#### Valparaiso, Indiana

Porter Regional Hospital, 1<sup>st</sup> floor Community Room. 6:30 pm the 4<sup>th</sup> Thurs., Jan – Oct. Contact Sarah Greich 219-309-5939, Sarah.Greich@porterhealth.com

#### Wellness House, Hinsdale

Kay & Mike Birck Home of Hope 131 North County Line Road Ostomy Networking Group for Cancer Survivors 4th Mondays Contact Karie Milewski-Carlson, 630.654.5114 or kmcarlson@wellnesshouse.org

#### Here and Now

with Patricia Johnson

I don't know if I should admit this but in May I celebrated my 65th birthday. We all have them, birthdays, because of a small red stoma.

We have in life other "birth" days. A stoma birthday. The birth days of our children. The day we are told we are cancer free. We rejoice because we are given these times to mark and celebrate.

For my birthday, to mark this milestone, I had my ears pierced. Granted that my birthday was in May and I got my ears pierced in July, two months later. But the idea was born in May. I have always been a slow start.

My daughter went with me. Because of medical experiences I did not like the idea of going to Clair's and having a sales person shoot a gun into my earlobe. Instead we went to a tattoo parlor. Yes, you read that right, a tattoo parlor. I have never been in a tattoo parlor before but this one was very nice, more like a jewelry store. And everything was clean. He used needles, no gun.

So there you have it. A 65-year-old woman and her 30-year-old daughter walk into a tattoo parlor... sounds like the beginning of a bad joke. But we did.

This whole thing started because of a conversation with a lady who owns a jewelry shop and seeing so many cute earrings while shopping one day with my daughter. It all just sort of evolved. I did not wake on May 5th and say 'I am 65 and I think I will have my ears pierced.'

So, it is a done deed. I did think briefly, very briefly, while in the tattoo parlor of getting a small tattoo around my stoma that says "poop happens here". But I didn't.

All of this to say that although we have come through a lot we can celebrate. We are on our way. There will be many more "birth" days to celebrate. Pat yourself on the back and celebrate yourself today. Where there is life there will be something to celebrate.

And have a great day because.....

Life is Good!



Living life to the fullest. You've never been one to let life slow you down. Every challenge is met with the confidence that comes from knowing life is all about the journey. And that confidence is an inspiration to us every day at Hollister.

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Each year, the **Youth Rally** host kids and teens living with conditions of the bowel and bladder at a college



campus for a 5-night one of a kind camp experience that promotes independence, self-esteem, learning, friendship, and FUN!

You will not want to miss the inspiring stories of the amazing tweens and teens attending this camp where these kids get to be KIDS!

As part of our "Age of Ostomy" meeting, **Bret Cromer** gives us a glimpse into the camp experience.

Bret was diagnosed with Crohn's in the summer before senior year of high school. Ostomy surgery 90 days later and back to high school, onto college, building a career and



family alongside a beautiful wife. Living and thriving with an ostomy came with the support of family and friends, a local support group and getting involved with the Youth Rally. Know that no matter where you are on your ostomy journey, you are not alone.

# Get Ostomy Answers

The 96-page Fall issue of *The Phoenix magazine* provides answers to the many questions and

challenges of living with an ostomy. The leading ostomy publication in America features articles written by ostomy experts, medical professionals and ostomates that inform, educate and inspire.



#### Fall Issue Highlights

Male Sexual Function After Ostomy Surgery The effects of surgery and treatment options available By Cliff Kalibjian

Concealers and Covers Five products are put to a real-life test By Cliff Kalibjian

Dietary Considerations What to eat and what to avoid after ostomy surgery By Sharon Osgood BSN, RN, CWOCN

Rebuilding Core Strength Safely regain and improve abdominal strength By Trish Massart, RHN, CPT

Ostomy Accessories Understanding when to use an extra product for a perfect pouch seal By Maggie Bork, RN, BSN, CWOCN

<u>The Phoenix</u> is the official publication of UOAA. From odor control to intimacy to skin care, the leading ostomy publication has in-depth articles that inform, educate and inspire.

Visit <u>www.phoenixuoaa.org</u> or call 800-750-9311 to get your ostomy answers now!

# Ostomy ~ The New Normal

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# Back to School with an Ostomy



For many parents, the hardest part of your child having ostomy surgery is feeling fearful or anxious about your child's day-to-day needs in the weeks and

months following surgery.

If you are a parent or the caregiver of a student with an ostomy, here are some tips that may help reduce anxiety about returning to school following ostomy surgery.

Schedule a meeting with the school nurse, also teachers, administrators. Use this time to educate those that will be in communication with your child daily on what ostomy surgery entails and how your child's needs may have changed since last attending school.

Diet, Nutrition and Hydration. If dietary needs have changed, it is a good idea to investigate what sorts of nutritional options are available at school or know if you will need to pack meals and snacks. You may need special permission for your student to carry a water bottle with them throughout the day to stay hydrated. Ensure that your child has permission to use the restroom whenever needed. If they are

restricted, they will not be likely to drink as much as necessary to stay hydrated.

Ask to tour the restrooms. Check out the privacy offered by stalls, sink layout, and proximity to classrooms. You may determine that a staff restroom or another non-student restroom may be more comfortable for pouch emptying or changes. If so, establish permissions in advance for your child to use these restrooms as needed. Most schools have a private restroom at the nurse's station and extra supplies can be kept there as well. Closed ended pouches may be more convenient.

Create an emergency change pack and leave it in the nurse's office. Be sure to include all the supplies needed for 2-3 full pouch changes including pouch and wafers, bathing wipes, necessary accessories, and a change of clothes. Even if your child can empty or change their pouch themselves, consider training a school nurse to assist if needed. If there is not a school nurse available, have a contact list on hand who can quickly get to the school to help.

Teenage drivers shouldn't leave supplies in their cars. Teenagers may prefer to leave supplies in his or her locker or backpack. Remind your teen not to leave extra supplies in the car to avoid temperature extremes affecting supplies.

If you are testing new supplies out, do so on a weekend or over breaks versus during the school week.

Confirm with the student's physician what types of activity are appropriate after surgery. Resuming activity following surgery is encouraged, but full contact sports like football and wrestling may require a slightly longer recovery window following surgery. Please consult with your physician before resuming any activity or exercise. Ask if during PE they will be changing clothes in a shared locker room and see if accommodations can be made.

No need to buy a new wardrobe. Consider Ostomysecrets® wraps and undergarments paired with their favorite wardrobe items to increase confidence. People living with an ostomy can wear almost everything they wore before surgery. Learn more about how Ostomysecrets® products work.

Over communicate what to expect before returning to school. Whether talking with teachers with your student, communicating about needs will help make your child have a smooth return to school.

Discuss with your child how to handle inquiries from classmates. Although classmates do not need to know about your child's ostomy it is good to discuss with your child how to handle instances should a classmate ask. You may consider opaque pouches in case a shirt rides up. Your child will feel more comfortable practicing responses with you at home. Always remind your child that an ostomy is nothing to be ashamed of.

Be respectful of your child's wishes as to who is informed of his or her ostomy. Some children may only want minimal staff to know about their ostomy.

This article originally appeared on meplus.convatec.com

#### HOW I DID IT:

I told my teenage friends about Crohn's disease and ileostomy surgery.



True friends will be there for you no matter what.

By Sophie via OstomyConnection.com

To set the scene:

You're hanging out with a friend. All she seems to be saying is, "Why have you been missing so much school?"

You feel bad she doesn't know you've been sick and really wants to make an attempt to explain.

Finally, you decide to tell your friend.

You take a deep breath and begin...

"In 2010, when I was 6-years-old, I was diagnosed with Crohn's disease and had to have ileostomy surgery in 2012." Now that I'm 13, I've learned a thing or two about telling people about my illness and ostomy. When I was younger it was easier to tell my friends because I wasn't as worried that they would judge me. It's fine to tell your friends when you're older, but the conversation might go one of two ways:

Your friends will likely be fine with it and like you for who you are inside, or

They can feel awkward and your friendship won't be as strong.

To help the conversation go well, here are some tips on how to tell friends about your ostomy.

- **1. Be Prepared.** I usually go to websites like The Great Bowel Movement, Crohn's & Colitis Foundation or United Ostomy Associations of America. These organizations have a lot of great information where I get ideas on how to explain IBD and ostomies. I don't plan out word for word what I say, but I think it's a good idea to know as much about your illness and ostomy as possible, just in case your friend starts asking questions. You should only share things about your illness when you feel comfortable.
- 2. Make Sure You Have Their Trust. Some of my friends have been there with me from the beginning and already know about my illness. But if you've only known your friend a short time, it might be best to hold off so you can establish some trust. One time I had a pen pal, and I wrote to her a letter about Crohn's disease and my ileostomy. That helped me by putting my thoughts on paper. Don't feel like you're lying to your friends when you don't share things about your condition, or feel bad that you're hiding something if they ever ask, "What's your biggest secret?" A fellow ostomate told me there's a difference between keeping things secret and being private. It's your choice whether you want to talk openly about your ostomy or not.
- 3. Be Confident. You might feel like you don't have confidence because you think your friends might feel disappointed and betrayed that don't know about your ostomy. As I got older, I was actually less confident in telling my friends. I would try to start a conversation, but wouldn't have enough confidence to finish. Sometimes I get upset and nervous that it won't go well. One way to feel confident is by simply telling yourself that bad reactions won't happen. I've had many successful conversations and I'm still friends with the people I've told. Every now and then I need an extra boost of confidence before telling someone.

#### 4. It's All About How You Talk To Your Friend

First, I make a promise with them that they won't tell anybody else. I don't want my friends telling their friends, especially if those kids don't really know enough about IBD or ostomies to understand. Then, I explain the surgery in a way that young kids understand. For example, instead of saying "my colon was inflamed," I will say something like, "my large

intestine was swollen." Both mean basically the same thing, just different wording.

5. Humor Helps. It's good to add some humor to your conversation so your friends know that having an ostomy is not all serious. The noises stomas make can be funny, so if your conversation gets awkward, sometimes the best thing is laughter. Humor helps me talk about my illness and cope with it. Your sense of humor also helps bring back some joy into your life. My life with an ostomy and Crohn's disease has changed me in ways I could not have imagined. I've learned more about my disease and how to handle it. I also feel more confident with things that I used to be afraid of (like needles). Having an ostomy might be weird at first, but then it becomes second nature. It can be the most horrible thing in the world OR it can be the most awesomest, coolest thing ever... it's all about how you think. I personally like the second option, even though ostomy life has its challenges. I get frustrated having leaks or checking my bag a lot before going swimming, but that's ok. I hope this helps kids with an ostomy feel like they're not alone and that there are other young ostomates going through similar things.

This article was originally published on OstomyConnection.com.

Happy Halloween!



# Stress, Depression and the Holidays: Tips for Coping

By Mayo Clinic Staff

Stress and depression can ruin your holidays and hurt your health. Being realistic, planning ahead and seeking support can help ward off stress and depression.

The holiday season often brings unwelcome guests — stress and depression. And it's no wonder. The holidays present a dizzying array of demands — parties, shopping, baking, cleaning and entertaining, to name just a few.

But with some practical tips, you can minimize the stress that accompanies the holidays. You may even end up enjoying the holidays more than you thought you would.

#### Tips to prevent holiday stress and depression

When stress is at its peak, it's hard to stop and regroup. Try to prevent stress and depression in the first place, especially if the holidays have taken an emotional toll on you in the past.

Acknowledge your feelings. If someone close to you has recently died or you can't be with loved ones, realize that it's normal to feel sadness and grief. It's OK to take time to cry or express your feelings. You can't force yourself to be happy just because it's the holiday season.

**Reach out.** If you feel lonely or isolated, seek out community, religious or other social events. They can offer support and companionship. Volunteering your time to help others also is a good way to lift your spirits and broaden your friendships.

Be realistic. The holidays don't have to be perfect or just like last year. As families change and grow, traditions and rituals often change as well. Choose a few to hold on to, and be open to creating new ones. For example, if your adult children can't come to your house, find new ways to celebrate together, such as sharing pictures, emails or videos.

Set aside differences. Try to accept family members and friends as they are, even if they don't live up to all of your expectations. Set aside grievances until a more appropriate time for discussion. And be understanding if others get upset or distressed when something goes awry. Chances are they're feeling the effects of holiday stress and depression, too.

**Stick to a budget.** Before you go gift and food shopping, decide how much money you can afford to spend. Then stick to your budget. Don't try to buy happiness with an avalanche of gifts.

Try these alternatives:

Donate to a charity in someone's name.

Give homemade gifts.

Start a family gift exchange.

**Plan ahead.** Set aside specific days for shopping, baking, visiting friends and other activities. Plan your menus and then make your shopping list. That'll help prevent last-minute scrambling to buy forgotten ingredients. And make sure to line up help for party prep and cleanup.

Learn to say no. Saying yes when you should say no can leave you feeling resentful and overwhelmed. Friends and colleagues will understand if you can't participate in every project or activity. If it's not possible to say no when your boss asks you to work overtime, try to remove something else from your agenda to make up for the lost time.

Don't abandon healthy habits. Don't let the holidays become a free-for-all. Overindulgence only adds to your stress and guilt.

#### Try these suggestions:

Have a healthy snack before holiday parties so that you don't go overboard on sweets, cheese or drinks.

Get plenty of sleep.

Incorporate regular physical activity into each day. **Take a breather.** Make some time for yourself. Spending just 15 minutes alone, without distractions, may refresh you enough to handle everything you need to do. Find something that reduces stress by clearing your mind, slowing your breathing and restoring inner calm.

Some options may include:

Taking a walk at night and stargazing.

Listening to soothing music.

Getting a massage.

Reading a book.

Seek professional help if you need it. Despite your best efforts, you may find yourself feeling persistently sad or anxious, plagued by physical complaints, unable to sleep, irritable and hopeless, and unable to face routine chores. If these feelings last for a while, talk to your doctor or a mental health professional.

#### Take control of the holidays

Don't let the holidays become something you dread. Instead, take steps to prevent the stress and depression that can descend during the holidays. Learn to recognize your holiday triggers, such as financial pressures or personal demands, so you can combat them before they lead to a meltdown. With a little planning and some positive thinking, you can find peace and joy during the holidays.

# Inclusive Campaign by Lingerie Retailer Puts Ostomy in the Spotlight

By Ed Pfueller, UOAA

This feels like a moment. For many in the ostomy community seeing that someone with an ostomy has been included as a model, ostomy pouch showing, in a large national retail website was groundbreaking. The viral #AerieREAL campaign a smiling ostomate alongside other body positive models living with an insulin pump, wheelchair, crutches and conditions such as fibromyalgia and cancer. The brand has long highlighted "real, authentic and unretouched

women." You can find the photos scattered over their

product pages.



The model, Gaylyn Henderson, has been sharing her infectious positivity with the ostomy community for years including in a past Ostomy Awareness Day Video produced by UOAA. Her website Gutless and Glamorous chronicles her life speaking out in support of

ostomy and IBD awareness. She was selected for the campaign after submitting a video for an open call for models. Gaylyn has since become a face of the campaign in mainstream media outlets such as People, CNN, Fox News and Today.

She told Today Style "Having the support of an influential brand like American Eagle to promote positive ostomy awareness has already changed lives, and I know this because of the feedback I am seeing and receiving," "To have this opportunity is surreal! For Aerie to give me this opportunity, I'm beyond grateful and thankful they would give someone like me a shot."

# The outpouring of support this mom received for her Hirschsprung's baby left her speechless

When the ostomy community bands together, there's nothing we can't accomplish.

By R.S. Elvey, OAGC Member, OstomyConnection.com Contributor

Within the first 24 hours after the birth of her second child, Bridgett Demick received some worrisome news from doctors. Hudson, her newborn son, was not passing stool. When there was no stool on the second day, Bridgett found herself in an ambulance with Hudson being transferred from their local hospital to Children's Hospital of Michigan in Detroit. At Children's many tests were performed, including exploratory surgery which revealed that his small intestine was twisted – a bowel obstruction that was handled laparoscopically. After the surgery, doctors felt his condition was resolved but Hudson was still pulling away when Bridgett fed him. He had to be put on intravenous feeding (TNP), a method of getting nutrition into the body through the veins. Next, doctors performed a full rectal biopsy which revealed that Hudson had Hirschsprung's disease.

The Mayo Clinic states Hirschsprung's (HIRSH-sproongz) is a rare condition present at birth as a result of missing nerve cells in the muscles of the baby's colon. There are fewer than 200,000 US cases per year, affecting approximately 1 in 6,500 newborns. Its name originates from the Danish physician who first defined it. The disease is classified into four types: short segment, long segment, ultrashort segment and total colonic. Of the estimated 200,000 cases annually, only 7.5% are classified as total colonic Hirschsprung's disease or TCHD.

Hudson's diagnosis was total colonic. At just two weeks old, ileostomy surgery was needed to bypass the affected part of his colon so he could become stronger and ready for the next step in his treatment plan — a stoma reversal and straight pull-through procedure. The doctors told Bridgett they felt this could take place within six months, however, after waiting twenty months little Hudson was still not medically ready for the next step. His surgery has been put on hold until he stops expelling clear liquid and thrives.

For the past year, Hudson has struggled wearing an ostomy pouch because of the placement of his stoma and skin irritation. Bridgett says, "I was changing his

pouch six to eight times a day. We've tried so many brands and products, but they all caused his skin to blister." Unable to connect with a local ostomy nurse, she turned to a private Facebook support group for advice. There she learned that other infant ostomates experienced the same skin problems as Hudson. Instead of using an ostomy system, some parents were recommending the "double diaper method" and skin protectant products. Bridgett started using two diapers on Hudson, one for his normal diaper and the other is wrapped around his waist to cover the stoma. Growing up in the Midwest, hard work and perseverance are rooted in the Demick family. Bridgett kept her job as an Accounting Clerk because of the insurance and her husband quit working to give their child 24-hour care. Between losing an income and gaining medical expenses, it's put an enormous strain both mentally and financially on the family. "Our insurance covers so little product and we use so much to protect his skin. The cost of buying retail ostomy supplies is so expensive," she said. Although the past few years have been a struggle, they still remain hopeful.



"He is a very happy little boy. All he has known is a life in and out of the hospital. I just want him to have every opportunity in life." — Bridgett Demick

Unfortunately, in America, there are too many patients that need ostomy supplies and cannot afford them (even with insurance). For this very reason, the founder of OC created an ostomy supply charity group called Kindred Box as part of our commitment to pay-it-forward. Many ostomates have excess products to donate and others don't have any. Making this connection is very important to our mission.

When Bridgett reached out for help, she didn't realize the generosity of our community. Ostomates from around the world donated their own supplies: stoma powders, adhesive sprays, wipes, and skin barrier creams were mailed to her home in Michigan. Diapers were sent through Amazon. We connected her with Corstrata, a telemedicine wound and ostomy company. CEO, Katherine Piette, had one of her WOC Nurses contact Bridgett since Hudson had never been seen by a certified ostomy nurse. They were able to address her needs for accessing lower cost products through medical suppliers like The Parthenon Company, and identify regional resources for ongoing access to care. When the ostomy community bands together, there's nothing we can't accomplish.

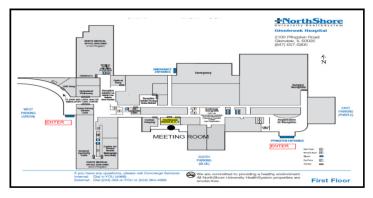
Hudson has been through more in the past 36 months than most people will endure in a lifetime. Hirschsprung's disease has changed this family in a way they never expected. Most of all, Bridgett hopes that her son's story will inspire others: "Whenever I seem to lose faith, it's the kindness of strangers that lifts me back up. It leaves me speechless. My precious baby, when I look at him I see strength and determination. He is my brave warrior! Thank you all for taking care of me, so I can take care of him."

This article was originally published on OstomyConnection.com.

## **OAGC** General Meetings

Glenbrook Hospital, 2100 Pfingsten Rd, Glenview, in the first floor Conference Rooms C-D.

There is abundant free parking including many handicapped spaces directly in front of the hospital. An information desk is just inside the Hospital's Pfingsten side Entrance. Upon entering, take the hallway to the left.



**Glenbrook Hospital** is bordered by Pfingsten Rd east, Hospital Dr. south and Landwehr Rd. west.

From I-294 take Willow Rd exit east to Landwehr Rd south. From Waukegan (43) take Lake or Willow west to Pfingsten. The parking lot entrance is on Hospital Dr.

We exist to support you, You support us so we exist.

#### What is Crusting?

Edited by Madelene Grimm, CWON

The key to successful ostomy pouch wear time is directly related to the placement of the stoma barrier on a clean, dry, mostly hair-free peristomal skin. The stoma barriers/wafers are designed to melt into the irregularities of the abdominal skin. There are times when this dry skin becomes raw and weeping (denuded) and under these conditions, the wear time will decrease and often becomes unpredictable. We need at this point to make an artificial dry peristomal pouching surface.

First, we need to determine the cause of the skin irritation, discontinue the irritation, and make a temporary patch to fix the skin until the skin can heal. This artificial patching process is called *crusting*. We make a dry crusty patch over the moist denuded skin and create the dry pouching surface we need for reliable wear time.

# Here is the crusting procedure which helps support the healing of the irritated or raw peristomal skin:

- 1. Clean the peristomal skin with water (avoid soap) and pat the area dry.
- 2. Sprinkle skin barrier powder onto the denuded skin.
- 3. Allow the powder to adhere to the moist skin.
- 4. Dust excess powder from the skin using a gauze pad or soft tissue. I actually like to use a clean, and no longer used make up brush designed for face powder application. Once this brush is used for ostomy use, retire it from your make-up application (please). The powder should stick only to the raw area and should be removed from dry, intact skin.
- 5. Using a blotting or dabbing motion, apply the polymer skin barrier over the powdered area, or lightly spray the area if you're using a polymer skip barrier spray. This polymer skip barrier spray. This polymer skip barrier spray.



polymer skin barrier spray. This polymer product is what we now refer to as the skin prep or skin barrier. The older barrier wipes had an alcohol base and happily the new polymer has removed that irritation.

6. Allow the area to dry for a few seconds; a whitish crust will appear. You can test for dryness of the crust by gently brushing your finger over it. It should feel rough but dry.

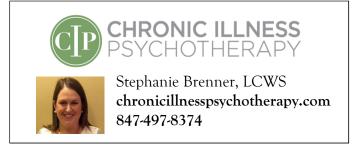
- 7. Repeat steps 2 through 6 two to four times as needed to achieve a crust.
- 8. Apply a pouching system over the crusted area. Stop using the crusting procedure when the skin has healed and is no longer moist to the touch.

The crusting process may shorten the wear time of your pouching system, but, the stoma barrier will be adhering to the crust and not the painful denuded skin. Once the skin is healed return to your original pouching process monitoring for whatever condition caused the denuded skin. Crusting is an intervention not intended to be an ongoing process.

Should healing not take place, and the denuded skin continue – seek out the assistance of your Ostomy Nurse



We don't know them all, but we owe them all.



#### Vitamin C: An essential nutrient....

Vitamin C is a water-soluble vitamin that supports normal growth and development, and helps your body absorb iron. Because your body doesn't produce or store vitamin C, it's important to include vitamin C in your diet. For most people, an orange or a cup of strawberries, chopped red pepper, or broccoli provides enough vitamin C for the day.

# Ostomy Association of Greater Chicago

Confidential Membership Application

We invite you to join our association. You are especially welcome if you have an ostomy, are preparing for surgery, are a healthcare professional and/or have a loved one who has had surgery. We are a completely volunteer-operated ostomy support group. Our mission is to support, educate and advocate for people with ostomies.

Name							
Address							
City			State_		_Zip		
E-mail				Phone			
Type of Ostomy:	Colostomy	lleostomy	Urostomy	Continent Proced	dure		
Date of surgery			Age Group	<21 21–35 35–50	51–65	66–80	>08
Donation enclosed \$	S		(optional)				

Attend one of our general meetings. There are always friendly people to talk with you. You may even want to participate in our association's leadership. We always need talented people to share in our good work. Membership is free (our funds come primarily through donations). Please mail this application to

Judy Svoboda, President 605 Chatham Circle, Algonquin, IL 60102

A very special thank you to everyone who donates to our association! Our largest expenses, the cost of printing and mailing this newsletter, and security for our website are continually increasing and is only made possible through the generous donations of our members.

To make a tax deductible donation, please make check payable to Ostomy Association of Greater Chicago or OAGC and bring to a meeting, or send to

> Tim Traznik Treasurer/OAGC 40 Fallstone Drive Streamwood, IL 60107

Donations can also be made online using a credit card: www.uoachicago.org/donations

Without you, we don't exist!





The information contained in this newsletter and on our website, is intended for educational/informational purposes only, and is not a substitute for the medical advice or care of a doctor, surgeon, WOCN, licensed pharmacist or other health care professional.

# Know Your Pouching System (Appliance) Checklist

Patient Date of Birth: _ Allergy Alert:	# £	Supplier Contact Information: Supplier Order #:	rmation: Order #:	
Pouching System:	Brand	Pouch:	Wafer/Barrier/Flange:	Accessory Products:
,	Manufacturer:	Product #	Product #	☐ Skin Barrier Seals/Rings
One-Piece		Size:	Quantity:	Adhesive Remover
☐ Two-Piece	<ul><li>Coloplast</li></ul>	Quantity:	☐ Pre-cut	Wipes or Spray
	<ul><li>Convatec</li></ul>		Size:	<ul> <li>Barrier Wipes or Spray</li> </ul>
Stoma	☐ Cymed/Micros	Pouch Features:	☐ Cut-to-fit	<ul><li>Barrier Strips</li></ul>
Information:	kin	Color:	Size:	<ul><li>Deodorizer</li></ul>
Size:	☐ Hollister	☐ Transparent	☐ Moldable	<ul><li>Paste (Tube or Strip)</li></ul>
	☐ Marlen	☐ Opaque	Size:	□ Таре
Ostomy Type:	☐ Nu-Hope			☐ Powder
<ul><li>Colostomy</li></ul>	Other:	Closure/Outlet:	☐ Flat	<ul><li>Support Belt</li></ul>
<ul><li>lleostomy</li></ul>		<ul> <li>Drainable (velcro or</li> </ul>	☐ Convex:	<ul> <li>Overnight Drainage Bag</li> </ul>
<ul><li>Urostomy</li></ul>		clip)	Soft/Flexible	Overnight High Output
Other:		☐ Closed-end	Light	Pouch
		☐ Tap Bottom	Deep	Irrigation Supplies
				☐ Other:
		Gas Management:	Two-Piece:	
		Integrated Filter	<ul> <li>Adhesive Coupling</li> </ul>	
		☐ No Filter	<ul> <li>Mechanical Coupling</li> </ul>	

