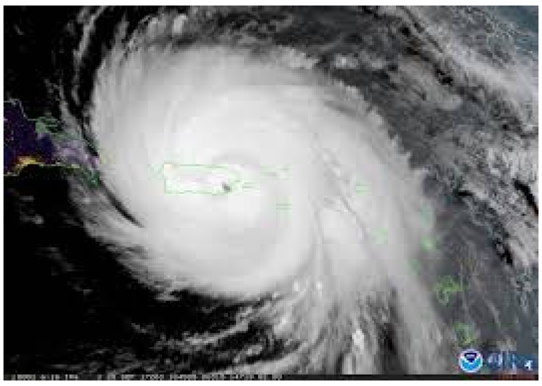
Ostomy Outlook

LETTER OF THE OSTOMY ASSOCIATION OF THE MINNEAPOLIS AREA
Volume III, Issue IX May/June 2019

Date:	**Monday, May 20, 2019**
Time:	**6:30 PM-8:00 PM**
Place:	**United Methodist Church of Peace** 6345 Xerxes Avenue South Richfield, MN 55423 612-866-0069
Program:	Puerto Rico was hit very hard by Hurricane Maria, causing destruction throughout the country. Joel Branes will talk about the shortage of ostomy supplies in this country.



Date:	**Monday, June 17, 2019**
Time:	**6:00 PM-8:00 PM**
Program:	Antless Picnic—**Note time change!** Come early. Supper of Kentucky Fried chicken, potato salad, and dessert will be on us! Bring your best joke and we can all enjoy the fun.

Presidents:	**Rich Trainer**	**952-888-7315**	**goldenstrainer@yahoo.com**
And Hospitality:	**Frank Moriarty**	**763-557-5712**	**moriartyf@earthink.net**
Secretary:	**Marilyn Carlson**	**612-741-4312**	**thunderlake@usfamily.net**
Treasurer and Membership:	**Brenda Elsagher**	**952-882-9882**	**brenda@livingandlaughing.com**
Patient Advocate:	**Dar Hafner**	**952-835-4599**	**dmhafner@yahoo.com**
Program:	**Carole Ann Barron**	**952-941-8884**	**barronski@aol.com**
ASG rep/ Editor:	**Carol Larson**	**952-934-3804**	**caroldavidlarson@aol.com**
Social Media:	**Nancy Hagfors**	**952-237-6465**	**nhagfors@gmail.com**

Mailing: Ostomy Association of the Minneapolis Area P O Box 385453, Bloomington, MN 55438-5453 The Ostomy Outlook is printed and circulated for people with Colostomies, Ileostomies, Urostomies, and alternativeprocedures, their families and other interested persons.

******If you have weather questions, please call 952-882-0154**

Our new website address is: **ostomyminneapolis**

Ostomy Association of the Minneapolis Area Membership Creed

As members of this group, it is important to be ever mindful of our many blessings: our understanding families and friends, our homes, and our way of life. Most of all, as ostomates we need to be ever mindful of the life which has been given back to us and to find the courage to face our daily challenges. Let us continue to be concerned for people who need our help, our support, and the knowledge that we have gained. Let it be our task to reach out to others and to ourselves. May we do this in a spirit of fellowship and fond regard.

New Business

A big thank you to Dr. Ann Lowry

Our last meeting was one of the best!

Sincerely, OAMA

****If you would like to suggest a future program, please contact: Carole Barron barronski@aol.com**

Brenda Elsagher Trasurer and Membership Report

Our annual membership drive took place last month and many of you have gotten back to us and we appreciate it. Thanks to you we can keep our outreach happening. We would like to acknowledge and thank the people that have given extra donations over the last couple of months. Some of those donations will benefit kids at Camp that have ostomies.

Alan Sanders
Don Heinrich
Pat Cropley
Dave Dulum
Ed Scinto
Linda Hucke
and Mike Carlson in Honor of Healing for his sister Marilyn.

****Joel Branes would like to thank all those (Plus Handi Medical) who contributed ostomy supplies to Puerto Rico and victims of last year's hurricane. Please bring your extra supplies to our meeting to be delivered to The Ostomy Association of Puerto Rico.

Thanks Again to our sponsors:

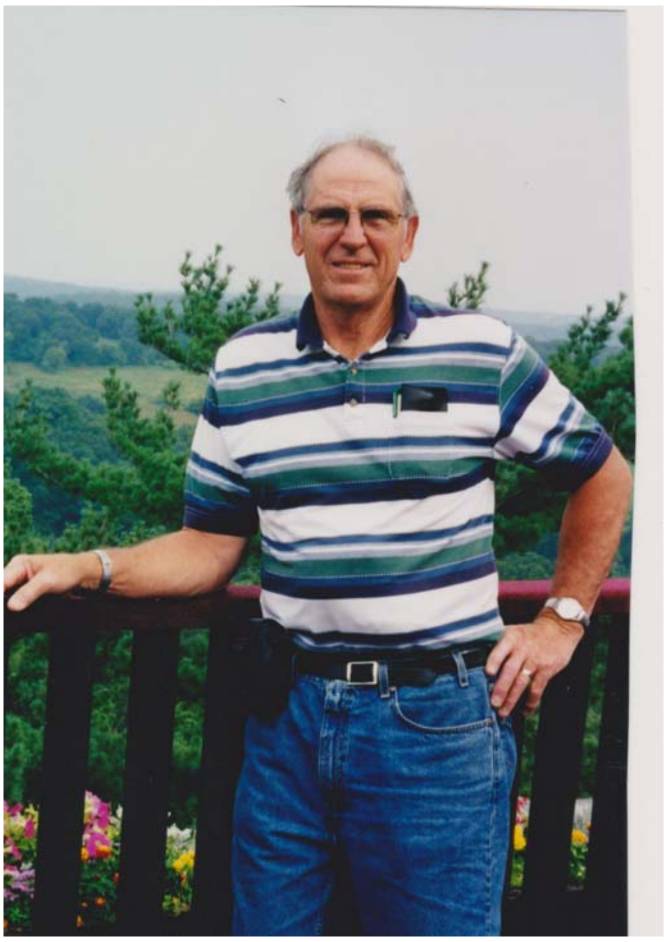
Action

There is legislation languishing on Capitol Hill called the Disability Integration Act (DIA). The DIA is bipartisan legislation that ensures people with disabilities have a federally protected right to live and receive services in their own homes or in the setting of their choosing. The DIA further secures our Constitutionally protected right to liberty by preventing disabled people from being forced into costly institutional settings by unnecessary government regulations.

The DIA assures the full integration of disabled people in the community by ensuring that people with an ostomy and other conditions are able to exercise real choice in where they wish to receive attendant services, assistance with health-related tasks such as “maintenance and use of a stable ostomy” or other services that enable a person with a disability to live in the community such as in an assisted living facility and lead an independent life.

UOAA **supports** and advocates for this landmark legislation and encourages the ostomy community to **take action here** to help us garner legislator support and pass this in 2019.

GETTING TO KNOW- CY HENNEK



FAA (Federal Aviation Agency) 35 years

U.S.A.F. Age 19

Where do I start?
Age 57, I'd been healthy 'til then.

After retiring from the FAA, in the spring of 1992, I saw blood in my stool. I went to my regular doctor and arranged for a colonoscopy check-up. He took one look and said, "You have cancer."
Within two days, I was at the St. Paul Colonoscopy Association with Dr. Gemlo.
A few days later, I was on the operation table with Dr. Gemlo in charge at Unity Hospital.
I woke up with an ileostomy because four biopsies came back positive. I needed six weeks of radiation treatments and six chemo treatments.
Soon after, they hooked me back up. After a few months, it still wasn't working right.
Dr. Gemlo said if it wasn't working by now it would never work. So, a colostomy was in order.
When he asked me when I wanted it, I said, "Would tomorrow be okay?"
It all went fine and life is good! God Bless, Cy

Patient Power –

If you have any ideas or issues you'd like us to address, please send them in to the newsletter editor or directly to us, Darlene Hafner and Anne Marie Kronick." You can reach us by emailing dmhafner@yahoo.com or amkronick@comcast.net

I DIDN'T HEED MY OWN ADVICE

This coming summer will be 16 years since I've had my colostomy. During those years, I've experienced some of the typical issues some of us might have, such as leaking, appliance problems, blockages or even a trip to the ER. But I have been very fortunate not to experience too many skin issues other than the occasional irritation and redness.

But during the last several months I ended up having a very painful, red, itchy skin issue that looked like a rash. And let me tell you, it was one stubborn rash. It first started off small but eventually after a month or so it started to spread. To make matters worse, it was half way around my stoma and extended out several inches. It was so close that I could never put anything on it because then my appliance wouldn't adhere.

Of course the right thing to do would have been to contact my stoma nurse right away but I thought I had it under control by not using extra tape, I throughly dried it every time it got wet, I avoided going swimming, and even tried different types of barriers.

When none of these methods were working I called my stoma nurse RIGHT before I was leaving town for a month. What was I thinking!? I'm suppose to follow my own advice and call as soon as I have an issue. I thought for sure I could get in to see her ASAP but then she told me, "We have a new policy now. You need to get a referral from your GI or your surgeon before I can see you. WHAT!? This was all new to me. I used to be able to call and get in right away. Thank goodness I have a very good rapport with both my GI and my surgeon. Within a few hours I was able to get a referral so I could see my WOC nurse.
She gave me some ideas but unfortunately during my month away it never got any better.

Taking advantage of technology, as soon as I returned from vacation, I took photos of the stoma and the surrounding skin and sent them to my WOC nurse. She in turn sent them to my surgeon and talked to him who eventually prescribed a steroid cream after it was determined it wasn't a fistula or active Crohn's. Advocacy in action!

Then a few hours later the pharmacy called. She told me the cream was $140 and insurance wasn't going to cover it. She said, "I'll call the surgeon back and have him prescribed one that insurance will cover." Advocacy in action again! When the pharmacist found out my surgeon had already left for the day, she found another surgeon to prescribe a different cream. Once again...she advocated for me. After it was all said and done, I picked up the cream the same day for a total of $10.44.

At the end of all this, I was so appreciative of all the professionals who rallied for me and advocated for me. From my GI giving the referral, to the WOC nurse asking the surgeon for his advice, to the pharmacist who chased down a surgeon who was still in the hospital in order to get the price down from $140 to $10. They kept up their end of the bargain and I feel like I didn't keep up mine. I should have been more proactive when I first saw the signs of the skin irritation. I should have called the WOC nurse sooner, I should have known the new policy for the referral process. I should have been more on top of things.

So as I write this article I am humbled, (and embarrassed) that I didn't heed my own advice of being proactive in my health care at the first sign of a problem. I learned my lesson, so I hope you can learn from mine. Don't wait until things get worse, consult your WOC nurse or physician sooner rather than later. It makes things a lot easier. And your body will thank you for it.

Dar

From Our President –Thank you Julie Powell

I can never fully express my gratitude to WOC nurses. They come in on their day off for us, they heal us, they teach us, they empower us, they advocate for us, they volunteer for us, they learn for us, they run our support groups, they makes us laugh and help dry our tears. That is my definition of a superhero.

As you'll read below they are also a central part of our national conference and advocacy program.

We also know many people have not had access to a nurse they deserve, which is a key reason for our Ostomy and Continent Diversion Patient Bill of Rights. Also, see below about when its best for your health to contact a WOC (wound, ostomy and continence) nurse.

We're proud of not just the nominees mentioned in this issue for UOAA's WOC Nurse of the Year, but to all the unsung and dedicated professionals out there.

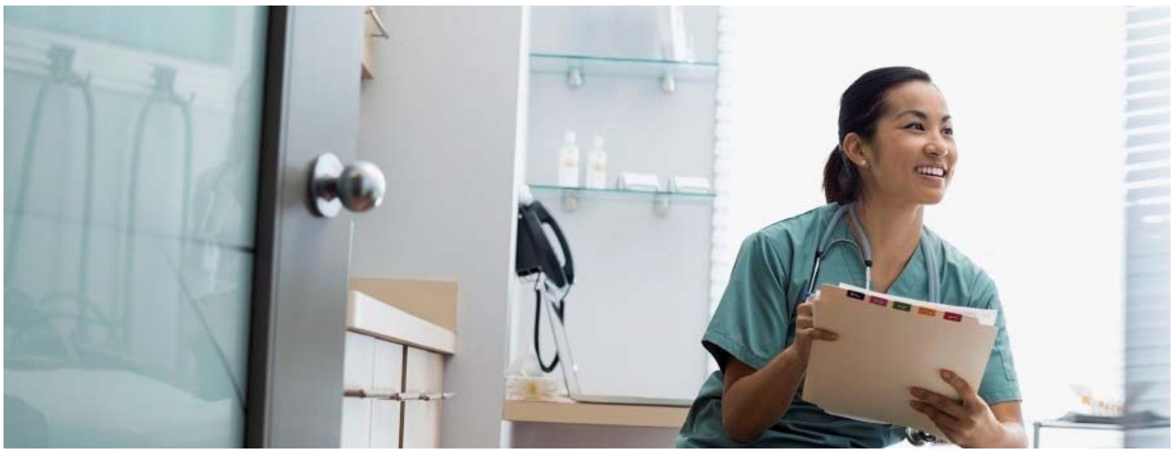
It's WOC Nurse Week (April 14-20, 2019) take the time to thank a nurse in your life.   Susan Burns

Healthy living tips

Question: Does an apple a day keep the doctor away?

Answer: Only if you aim it well enough.

When to Contact Your Stoma Care Nurse



Your stoma care nurse has the specialized training to help you care for your ostomy and address any issues that arise. These professionals are also known as “WOC” (wound, ostomy, and continence) nurses. Stoma care nurses are there to help you make a smooth transition after surgery, and can give you the training you need to care for your ostomy at home. You should consider them your “go-to” resource for ostomy care education, consultation, and troubleshooting.

In honor of WOC Nurse Week, celebrated every year in mid-April, it is important to recognize the ongoing role that stoma care nurses can play in your ostomy care.

When to Contact Your Stoma Care Nurse

Not every ostomy care challenge warrants contacting your stoma care nurse, but certain issues are causes for concern and should be assessed by a trained professional. Connect with your stoma care nurse if you notice any of the following problems.

If you have a colostomy or ileostomy, call your ostomy care nurse if you notice:

- Skin irritation
- Recurrent leaks under your pouching system or skin barrier
- Excessive bleeding of your stoma
- Blood in your stool
- A bulge in the skin around your stoma
- Persistent diarrhea
- Diarrhea with pain and/or vomiting
- A stoma that appears to be getting longer

If you have a urostomy, call your ostomy care nurse if you notice:

- Any sign of urinary tract infection
- Skin irritation
- Urine crystals on or around your stoma
- Recurrent leaks under your pouching system or skin barrier
- Warty, discolored skin around your stoma
- Excessive bleeding of your stoma
- Blood in your urine
- A bulge in the skin around your stoma
- A stoma that appears to be getting longer

Finding a Stoma Care Nurse and Showing Your SupporIf you do not have a stoma care nurse, you can search to Find a Nurse using your state or zip code on the WOCN Society website. This feature is also accessible by clicking the “Resources” icon in the **Peristomal Skin Assessment Guide for Consumers**, a free, easy-to-use, digital 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 WOC nurse.

How Hollister Secure Start Services Can Help

Hollister Secure Start services offer free customized ostomy support for as long as you need it, regardless of the brand of products you use, including help using the Peristomal Skin Assessment Guide for Consumers. Call us at **1.888.808.7456**.

Top Medical Professionals
Inspirational Stories
Free Stoma Clinic Appointments with WOC Nurses
Product Exhibit Hall with 25+ Vendors
Social Events
ASG Leader Networking
Dedicated Sessions for Caregivers and Family
Vacation Destination
Medical Marijuana/Pain Management
Sexuality

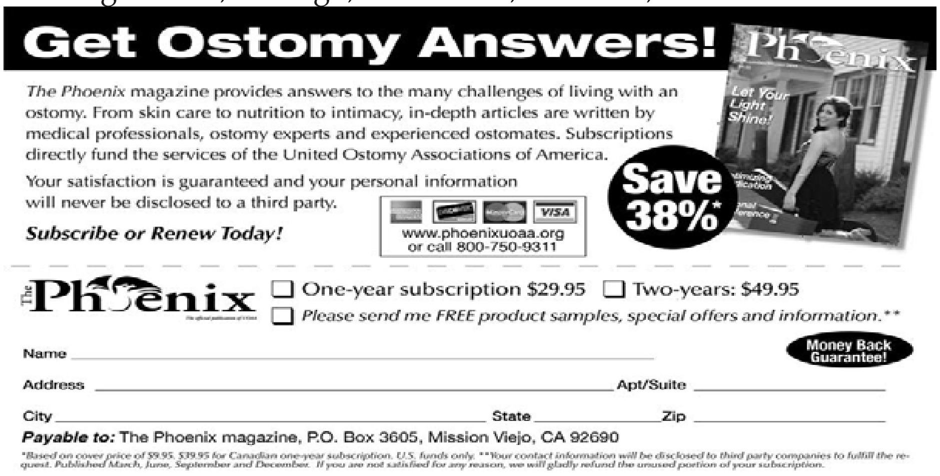
August 6-10, 2019

UOAA National Conference

Philadelphia, PA

Early Bird Pricing until 5/31/19

August 6-10, 2019 Philadelphia is home to UOAA's 7th National Conference. It's a not to be missed event for the ostomy community and your chance to connect and learn from medical experts and
people living with an ostomy from all around the country.
Gather at **Philadelphia 201 Hotel**, a great vacation destination right in the heart of this historic city (Special $159 UOAA rate available). Please join us and prepare to make new life-long friends, to laugh, shed a tear, celebrate, and learn. You've earned it.



5 Things No One Tells You About Having an Ostomy

Having a surgery that results in an ostomy is a huge, life-changing event. It can feel scary and there are so many ‘unknowns’. Asking questions, and gathering as much information as possible before your surgery will help to prepare you for your new life and routine.

Based on others who have had surgery before you, we have put together a list of ‘five things no one tells you before your ostomy’. These are 5 things many ostomates wish they had known before adapting to life as an ostomate. We hope this list helps to prepare you even more, and encourages you with moving forward into your new lifestyle and routine.

1.) You are Not Alone

You may feel like your ostomy alienates you from your world, but you are not alone in this. There are many people who have had surgery before you and there is an extensive and supportive ostomy community available to you. Your adjustment process may take time, and if you are experiencing discouragement, talking about it with someone who understands can be helpful. There are also numerous ostomy blogs and websites dedicated to sharing stories and experiences, as well as tips on living with your ostomy and how to avoid common mishaps. Once you have settled into the routine that works best for you, consider adding to these resources or reaching out to someone you may know who is struggling with their new ostomy.

2.) Your Quality of Life May Improve

Most ostomates are happy to find out that they are able to do everything they were already able to do before their surgery, and often, even more. There’s a chance that your illness leading up to your surgery was debilitating and left you with little to no control over your own life. If this was the case, having an ostomy will be a profoundly new experience in which you have more control and less limits. You will be able to check items off of your bucket list that seemed impossible before.

3.) There are Amazing Products Available to You

In the first few months to a year after your ostomy, you may take some time getting used to your appliance and how to change it out and clean the skin around your stoma. In addition to helpful information and tips online, you can also find an array of different products to help you manage your ostomy on a daily basis. It’s amazing how far science and technology have come, and companies such as Coloplast, are continuing to develop new products with you in mind.

4.) It Takes Time to Adjust - And That’s Ok

While your ostomy should not hold you back from seeing and doing new things, it also is a big adjustment and there is no timetable on how and when you do this. Be patient with yourself and take the time you need to feel confident with caring for your new stoma. Use the information that is available to you, but do so without comparing your progress with that of others. Every body is different, so don’t rush your recovery with unrealistic expectations and goals. Be kind to yourself.

5.) Diet - Most of the Same Rules Still Apply

As far as diet and exercise, they are just as important after your ostomy as they were before. If you were a healthy person before your ostomy, continue to treat your body well with what you put in it and how you use it. Keep in mind that the foods that were good and healthy for your body before your operation are still good for you. Hydration is key. It is important to drink lots of liquids with an ostomy.

When you are in the hospital, chances are you will be given a list of what foods to avoid. Eating simple and bland soft foods directly after your surgery will be easier to digest, and will help your recovery. As you heal, it’s okay to incorporate other foods into your regular diet, but it is recommended that you try them slowly and possibly even one at a time. Again, every body is different, and what affects someone else may not affect you in the same way. Keeping a journal or diary of how your body responds to different foods can be helpful.

For more information, visit www.coloplast.us

Ostomy Association Of The
Minneapolis Area
P O Box 385453
Bloomington, MN 55438-5453

ADDRESS SERVICE REQUESTED

If you **DO NOT** wish to receive this newsletter, please check here ____ and return to the ←address at left

To:

<u>Please enroll me as a new member of the Ostomy Association of the Minneapolis Area</u>

If you haven't enrolled, 2019 Annual dues are $25 and are due in March following your submittal of this form. Membership in the Ostomy Association of the Minneapolis Area includes 12 informative meetings, subscription to the "Ostomy Outlook" newsletter and an "Antless picnic" in June.

OAMA
PO Box 385453
Bloomington, MN 55438-5453

I have a: Colostomy ☐ Ileostomy ☐ Urostomy (ileal diversion) ☐ Other ☐ Non-ostomate ☐

Name:____
Street:____
City:_______________________________ State:______ ZIP: _______________ Phone: ( ) ___________

As a tax exempt Organization, all contributions and dues are tax deductible

---✂--

OSTOMY ANNIVERSARY

The Anniversary of my stoma is ____/____/____, and in order to celebrate my return to good health, I am contributing the sum of _________ or $_______ per year for my stoma.

I hereby grant permission to print my name in the Chapter Newsletter.

Name_____________________________ Years________ Amount $____________

Send this form with your check, Payable to OAMA

- ✂ - - - - - - - - -