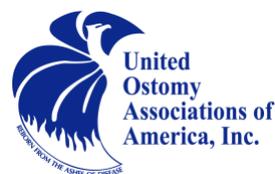


Ostomy Outlook



NEWSLETTER OF THE OSTOMY ASSOCIATION OF THE MINNEAPOLIS AREA

Volume XXII, Issue VIII, Jan/Feb 2010

Date:	Monday, January 18, 2010	
Time:	"6:30 PM"	
Place:	United Methodist Church of Peace 6345 Xerxes Avenue South	
Program:	Short video from the UOAA Ostomy conference, "Living With An Ostomy." Discussion to follow. Happy New Year!!!!	
Date:	Feb. 15, 2010	<p>Happy Valentine's Day!</p> 
Time:	"6:30 PM"	
Place:	United Methodist Church of Peace 6345 Xerxes Avenue South	
Program:	Dr. Tom Schmidt, the force behind the Patient Council from Park Nicollet/Methodist Hospital, will talk about Patient Advocacy Issues.	
<p>Mailing Address; Ostomy Association of the Minneapolis Area P O Box 385453, Bloomington, MN 55438-5453</p> <p>The Ostomy Outlook is printed and circulated for people with Colostomies, Ileostomies, Urostomies and alternative procedures, their families and other interested Persons.</p> <p>Consult your physician before using any product or procedure published in this newsletter</p>		

President	Marilyn Carlson	952-941-9148	thunderlake@usfamily.net
	Anne Marie Kronick	612-236-4899	amkronick@comcast.net
President Elect	Marlee Kivens	952-931-0862	kiven002@umn.edu
Secretary:	Mike Carlson	952-948-5170	pcarlson49@yahoo.com
Treasurer:	Donald Heinrich	651-631-4978	donh17023@hotmail.com
Newsletter Editor:	Carol Larson	952-934-3804	caroldavidlarson@aol.com
Membership:	Gary Brooks		gab-tom@charter.net
Hospitality:	Frank Moriarity	763-577-5907	moriartyf@earthinknet
Past Presidents:	Brenda Elsagher	952-882 9882	brenda@livingandlaughing.com
	Carol Larson	952-934-3804	caroldavidlarson@aol.com Fran &
ET Nurse CWOCN:	Julie Powell	952-924-5086	jpowell1@fairview.org
UOAA Web Site:			www.uoaa.org

Remember: Bring your Ostomy supplies you no longer use to the meeting, or call any board member to arrange pickup or ship those supplies to

FOW-USA
1500 Arlington Avenue
Louisville, KY 40206-3177

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.



PRESIDENT'S CORNER

We hope you all had a great holiday and also hope that each and every one of you has a very healthy and prosperous new year.

What a wonderful year we have had so far. We have had record attendance at each of the three meetings that we have held and hope to continue this trend.

At our last meeting Mary Benhardus, from Handi Medical, spoke on Medicare reimbursement and other issues related to ostomy supplies and equipment.

There are some volunteer opportunities available. The first one is our Visitation Chairman. Our current chair, Anita Summers is moving to the warmer climate of Tucson, Arizona this summer and we would like someone ready to take her place when she leaves. If you're interested in serving in this position, please send us an email to the address in the newsletter, or speak to us at the next meeting so we can explain more about the duties of this position. As Anita will tell you, it's a very rewarding one.

We are also in need of a Co-President elect to partner with Marlee Kivens for 2010-2011 year. It is really helpful for the Presidents Elect to spend the year prior to serving learning from the current acting presidents. That's been our tradition and we can personally say it's a really smart one. We will be having our elections in June, so now's the time to step forward and have the chance to get your feet wet and find out just how much fun this job is. We can also say from personal experience how much easier and more fun it is having another person you can lean on for ideas and help. Everyone has their own talents to bring to a job and this is definitely a case where one plus one adds up to more than two.

In January we will be watching a film made by UOAA called "Living with an Ostomy". It premiered at the national conference in New Orleans and was really well received. Telling the stories of real people who 'live with ostomies' in their own words, it gives the world a view into their lives and also into our lives. We'll have a discussion after the film to share our reactions. Who knows, we might ask the UOAA to send a copy to the producers of "Grey's Anatomy." See you in January.

Marilyn and Anne Marie

GETTING TO KNOW ME!

Gary Brooks has volunteered to be this year's membership chair.

***If any of you have an email address, please send it to him: gab-tom@charter.net

Funny... growing up in NY I never would have imagined the health decisions I would be faced with years later. Most of my life I have had some sort of intestinal/digestive issues. It all came to a head this past June when I started losing a lot of blood.

As my health worsened, my stress level rose. In addition to the physical struggles I was experiencing, I watched a friend pass as I stood by his bed. As I dealt with his death, I was making plans to move my mother from a nursing home to my house. The next week, when I was finalizing the plans, she was taken from me as well. My job was changing but I continued to keep everything hidden from friends and coworkers. One day however, after feeling so ill, I decided to see a doctor who did tests to assess if I had colon cancer, ulcerative colitis, or Crohn's disease.

Determining it was ulcerative colitis, they gave me drug after drug but nothing helped. The symptoms only got worse. I was up every hour rushing to the bathroom getting sick from both ends.

As the days passed, I became so weak, and in so much pain that I went immediately to the ER where I was admitted right away. I was in the hospital for one week before surgery just to get me rehydrated. After a blood transfusion, they prepared to remove my colon. Off to surgery I went. I later found out they also removed my appendix due to appendicitis. I literally became half the person I was just the day before. After another blood transfusion, I was discharged from the hospital two weeks later. I was not only 50 pounds lighter, I now was an ostomate... a term I never knew, but now has become a part of me.

Patient Power contact Darlene Hafner and Anne Marie Kronick

□ **LETTER TO DIRECTOR OF GRAY'S ANATOMY**

November 14th, 2009

To: The Executive Producers of **Grey's Anatomy**

Shonda Rhimes, Betsy Beers, Mark Gordon, Rob Corn, Krista Vernoff, Mark Wilding

The Prospect Studios

ABC Television Center (West)

4151 Prospect Ave

Los Angeles, CA 90027

As a person with a colostomy, I would like to comment on the episode of **Grey's Anatomy** that aired in Minneapolis, MN on Thursday Sept. 24th, 2009. Season 6, Episode 2. After managing Crohn's Disease for over 40 years and having numerous bowel resections, I ended up with a permanent colostomy in 2003 due to surgeon error when she punctured my intestine. It was discovered too late before my kidneys starting shutting down and an emergency colostomy was performed to save my life.

I was frustrated, disappointed and alarmed during that episode, when confronted with surgery, the patient, who has a bowel infection asks, "What is the worst possible thing that could happen to me?" And Cristina responds, "You'd end up with a colostomy bag." The patient starts to cry and responds "No, no ... no poo bag for me! My Grand Dad had one of those! I won't do it!"

Later on in the show, Cristina is reprimanded by Dr. Bailey, Dr. Bailey says "Well, thank you very much for threatening my patient with a colostomy and talking her out a life saving operation." She retorts back, "What was I supposed to say? How am I supposed to sugar coat a colostomy?" Once again, words like "threatening" and "sugar coating a colostomy" makes having a colostomy a negative image.

I do give you credit for the exchange of words further into the episode where Dr. Bailey says to Dr Yang, something to the effect of it was a fragile situation and the patient needed time to accept it.

This short conversation sparked my anger and the catalyst for this letter. The writers of the show obviously gave no thought what so ever to the thousands of people who have colostomies.

We are not all “old Grandpas” like depicted in the patient’s comment. We are mothers, spouses, children, young, old, sisters, brothers, co-workers and employers. We have survived colon cancer, Crohn’s disease, colitis, inflammatory bowel disease, bowel resections, anal cancer, ileitis, trauma and birth defects. It was disheartening to have the patient ask, “What the worst possible thing that could happen to me?” and to have the answer be “a colostomy”. The WORST thing that could happen is that the patient could have died. I sat in front of the TV thinking.....what about all the viewers out there that may be scheduled for an ostomy due to cancer or others that have suffered years of inflammatory bowel disease that have finally decided to have the surgery and then to hear that it “is the worst thing that could happen.”

I understand that Grey’s Anatomy is just a TV series. But as successful as it is, and the number of viewers it can have an impact on, I would have thought you would have taken the opportunity to have Cristina say, “A colostomy will save your life. It may take some adjusting to, but you can have a long and healthy life with it.” But, instead, the writers portrayed it as something negative and undesirable.

We, as ostomates are trying so hard to erase the stigma that goes with it and that episode certainly didn’t help. I’m sure you are aware, in real life, that ostomies have saved 1000’s of people’s lives who are now leading productive, healthy and successful lives.

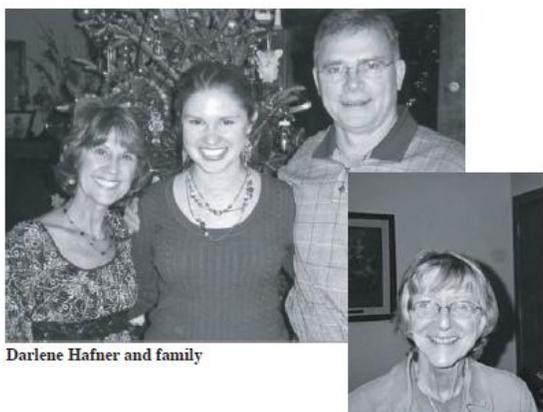
As a patient who endured a surgeon’s error and must live the rest of my life with a colostomy I would encourage your writers to think twice about what is written and to reflect whether anything in the script will have an impact on a certain group of people. After my surgery I turned my anger into being pro-active and being involved in something positive. I am a patient advocate and I speak not only for myself but for others about this episode. I do hope it will make a difference in how you write and how you view a colostomy...that it is NOT the worst thing that can happen to you! None of us really wanted one, but it became a necessity for some people who have had years of enduring pain and/or cancer. If a person had an artificial limb or a hearing aid, or a wheelchair other people would freely accept that, but when it comes to such a personal part of a person’s bodily function such as an ostomy, it is more difficult to accept and to talk about. I am trying to increase awareness of having a colostomy and not being ashamed of it. Your episode made me feel ashamed again. But it should really be the writers of **Grey’s Anatomy** that should feel ashamed of how you made some of your viewers feel.

Sincerely,

Darlene Hafner and the Minneapolis Chapter of the United Ostomy Associations of America.

(We will be sending the Executive Producers of “Grey’s Anatomy” a copy of this newsletter.)

PATIENT ADVOCATES



Darlene Hafner and family

Anne Marie Kronick

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

Just heard that Austin Hummel’s wife passed away. Look for the obituary notices in January for details. Our thoughts and prayers go with you, Austin.

A Letter from Marlee Kivens:

We are requesting your email address so that we may electronically send you the newsletter. It saves on costs! Sending the newsletter to a printer and through bulk mail is very expensive to do and it is not environmentally friendly. More and more of our association members have email addresses and it is an easier and more cost efficient way to communicate. Members would get information quicker than if it was mailed out, as it takes a lot of time to run home addresses and send them to the post office. For the people that do not have the internet or email we will still send out the newsletter first class rates. Please send your email address to Marlee Kivens at kiven002@umn.edu

We are trying to set up a new website because technology is the way to go for promoting our organization. Many of our association members gain the information they need/want by surfing the internet. We would gain a lot of new members by creating a user friendly, cost effective website. People from all over Minnesota, and nationwide could connect on a deeper level, whether it is for support or just to meet another ostomate to share information with.

What is inspirational to many about our group is that it is expanding, and we need room to grow. With email use and a website we can go leaps and bounds, and gain the information on meetings, contact information, current articles, connect with other ostomates, and share experiences with each other and the people that love ostomates.

Please consider giving a donation to the Ostomy Association to create a new website for our organization. We realize with the financial crisis upon us it may be difficult but it doesn't have to be a big donation. Any amount would be appreciated.

A NEW YEAR ... TO EXERCISE

UOAA UPDATE 12/09

Was exercise at the top of your New Year's Resolution List, only to be replaced with a set of excuses a week later? Well, let's see what those excuses may be:

* **I DON'T HAVE TIME:** One less cup of coffee in the morning and a few more minutes in your busy day taken from other less beneficial activities will add up! Say to yourself, "I'm worth 30 minutes a day!"

* **BORING, BORING:** Exercise is not a dirty word or a second job without pay! Find something you enjoy and you just might stay with it.

* **TOO TIRED:** Studies have proven that exercise revs up the bloodstream which produces energy. A brisk walk in the cool of the evening will relax and revive you—it may even add to romance!

* **TOO OLD:** Oh, Please!! Have you seen Sophia Loren lately? She may have been born beautiful but staying there is no gift. But don't have unrealistic expectations; just go at your own pace. You just might inspire some youth in your life to want to find out how you do it.

* **NOT ENOUGH SPACE:** All you need is enough room to lie down—but avoid drafts which may cause muscle cramps. Or better yet, go walking outdoors. That will use all your muscles and you get fresh air to boot!

* **TOO EXPENSIVE:** You don't need fashionable regalia and the high-priced equipment. If you plan on walking, a good, but not necessarily really expensive, pair of shoes is all that is required.

**Exercise. Exercise. Exercise. It remains the single most potent anti-aging medication known to humankind.—Gail Sheehy
from Robert d. Ramsey's book,
Well Said, Well Spoken. 2001, Corwin Press Inc.**

NINE REASONS FOR OSTOMY POUCH LEAKAGE

UOAA UPDATE 12/09

Poor Adherence to Peristomal Skin – Make sure that your peristomal skin is “bone dry” before applying your pouch. Hold a warm hand over the pouch and stoma for 30-60 seconds after application to warm it and assure a good initial seal.

Wrong Size Pouch Opening – If the size of your stoma has changed (due to postoperative shrinkage or change in body weight) and you have not remeasured and adapted the opening accordingly, undermining of the wafer and leakage may be the result.

Folds or Creases – If folds or creases develop in the skin and leakage always occurs along the crease, wafer pieces or ostomy paste can be used to build up the area. Consult your WOCN nurse for proper methods.

Peristomal Skin Irritation – Pouches will not stick well to irritated skin. So practice meticulous skin care in order to avoid irritated or denuded skin. If any of these problems develop, consult your WOCN nurse or physician at once so that the problem can be nipped in the bud.

Improper Pouch Angle – If the pouch does not hang vertically, the weight of its contents can exert an uneven, twisting pull on the wafer. Ostomates must find an optimal angle for their own individual body configurations.

Too Infrequent Emptying – Pouches should be emptied before they become half full. If they are allowed to overfill, weight of the effluent may break the seal and cause leakage.

Extremely High Temperatures – Wafer melt out may cause leakage in warm weather. Try more frequent pouch changes or change wafer material.

Pouch Wear and Tear – Disposable wafers do wear out. If you are stretching your wearing time, leakage may be due to the wafer wearing out. Change your pouching system more frequently.

Improperly Stored Appliances or Aging Materials – Store your ostomy supplies in a cool dry place; humidity may affect your pouch adhesive. Also, pouches won't store forever. Ask your vendor what the shelf life is for your supplies and keep some extra pouches on hand.

As always, consult your WOCN nurse if the problem persists!



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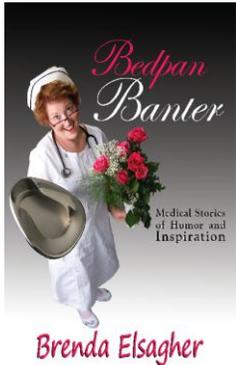
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OSTOMY ASSOCIATION of the MINNEAPOLIS AREA

Annual dues are \$25 and were due by January. 1st. Membership in the *Ostomy Association of the Minneapolis Area* and a subscription to the *Ostomy Outlook Newsletter*

SEND TO: **Ostomy Association of the Minneapolis Area**
P O Box 385453
Bloomington, MN 55438-5453

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Please enroll me as a new member of the Ostomy Association of the Minneapolis Area

Annual dues are \$25 and were due by January 1st following your submittal of this form. Membership in the Ostomy Association of the Minneapolis Area includes 8 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

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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 \$ _____

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