

Ostomy Outlook



NEWSLETTER OF THE OSTOMY ASSOCIATION OF THE MINNEAPOLIS AREA

Volume XX, Issue VI, Sept/Oct 2009

| | | |
|-----------------|---|---|
| Date: | Monday, Sept 21, 2009 |  |
| Time: | "6:30 PM" | |
| Place: | United Methodist Church of Peace 6345 Xerxes Avenue South | |
| Program: | Rockin' and Rollin' in New Orleans News of the UOAA conference from Your Jazzy members | |
| Date: | Monday, Oct. 19, 2009 |  |
| Time: | "6:30 PM" | |
| Place: | United Methodist Church of Peace 6345 Xerxes Avenue South | |
| Program: | RAP Session with Julie Powell | |

Mailing Address; 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 alternative procedures, their families and other interested Persons.

Consult your physician before using any product or procedure published in this newsletter

| | | | |
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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
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If you know any members who are hospitalized or ill, Please call Patsy Murphy 952-831-1371, so a card can be sent.

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.

The Presidents’ Corner



Hi! We are your new leadership for the coming year. I’m Marilyn Carlson and I have had a colostomy for 22 years, I started coming to our meetings shortly after having surgery and have been involved ever since. I have had many jobs in the OAMA over the years.

And I’m Anne Marie Kronick. I’ve had an ileostomy for almost 8 years. I first came to the OAMA meetings about a year after my surgery but felt odd and uncomfortable. I came back once or twice during the following year and couldn’t quite get into it. Finally I came to a meeting where we were having a rap session and I found the camaraderie, humor, and friendliness so wonderful and inviting that I finally felt I had found somewhere I could belong – and learn a lot at the same time.

We just returned from New Orleans for the 2nd Annual United Ostomy Association of America conference. Our chapter was well represented. There were nine members and spouses that attended. The weather was hot but the sessions were great. There was Ask the DR, Ask the WOCN Nurse, panel discussions with other ostomates, information sessions about keeping our organization interesting, and inviting to new people as well as long-time members, and of course there was the session that featured our past presidents Carol and Brenda, “How To Have Fun Meetings.” Needless to say, they were a roaring success. Brenda was also featured at the Exhibition Hall signing her book “Bedpan Banter” and emceed a great Fashion Show.

We have an exciting year planned including Rap sessions, nutritionist, panel discussion, Colon Rectal Month, and of course the Antless Picnic. See you on Monday, September 21st. Please come at 6:30 for discussion before the meeting. Marilyn Carlson and Anne Marie Kronick

GETTING TO KNOW ME!

Marlee Kivens 2009



On June, 1971 was born with Spina Bifida Myleomengocele. I attended school in the St. Louis Park School District in Minnesota. My family and I are long-time members of Adath Jeshurun, a conservative synagogue in Minnetonka, Minnesota. I think having a Bat Mitzvah in 1984, having a sweet 16 party and being confirmed in 1987 were the highlights of my childhood. Finding a job on my own without my parents help was another step. There were others as I was growing up. For example, getting a driver's license at the age of 16 was a powerful experience and another highlight of my life, graduating from high school and Talmud Torah in 1989 was an exciting time and very emotional for me.

I accomplished things many thought I wouldn't be able to do because of my disability. I felt like my own advocate at times growing up. I graduated UMD with a Women's' Studies major and a double minor in Sociology and Philosophy in 1994. In 1997 I moved out of my parent's house into my own condo and started to live an independent life. This was the first sign of empowerment as an adult for me.

When I returned home I assumed the role of Vice President of my father's company, Minneapolis Granite & Marble Co. until May of 2003. I decided I needed a new direction in my life. In 2003 I joined Bet Shalom Reform Congregation in Minnetonka, Minnesota and became the Administrative Assistant to the Executive Director of the synagogue until June of 2009.

In November 2004, I became an ostomate for the 2nd time. As an infant I had a urinary diversion but had it reversed before I went off to college in the summer of 1989. This time I had colostomy surgery. I was at my wits end after a year trying all sorts of medication and treatments to stop incontinent issues due to my Spina Bifida. It was a long surgical recovery because I wasn't taught proper ways to take care of the ostomy and I kept having supply issues. Roxie King-Smith, a family friend that had gone through the surgery years before, put me in contact with the Minneapolis chapter of the Ostomy Association and two great WOCN nurses through University of MN/Fairview Southdale Hospital. I am currently President Elect of the chapter. I am probably one of the youngest people in the group but I am sure I will make an impact.

On July 20, 2009 I was hired as the Office Manager of a charter school called Nova Classical Academy in St.

Paul, MN. Nova means new, and it offers parents “a classical education for a new century.” At Nova Classical Academy staff, parents, and students share a unity of purpose and consider themselves members of a community of learners. They believe, with the late Mortimer Adler, that a complete education is the work of a lifetime and that the K-12 years are only the beginning of a lifelong educational journey.

After years of struggling to find my place and voice in the Jewish community, I have finally found it. I am a vocal part of Aduth Jeshurun’s Inclusion Committee and am currently serving as committee chair. I am the happiest and the most peaceful I have ever been. As a Jewish female with a disability, I finally feel the joy, powerful spirit and the strengthened inner-self I had while attending UMD classes. While at UMD I helped form a student run group for people with disabilities called Access for All. I felt I needed to connect with others that had a variety of disabilities. That is why I have created Empowering Jews with Disabilities. I needed to fill a void. Jews with disabilities seem to be hidden throughout the Twin Cities. It isn’t easy to meet people, let alone people with disabilities.

This site is a way to get information, connect, talk openly about anything and everything, and be respectful towards different opinions and ways of life. To empower ourselves as Jewish people with disabilities is one of the most rewarding and greatest self esteem builders I can think of. There will be open forums posed and message boards created for all types of issues, questions, thoughts, comments. A chat room will be open so someone can go in and meet, talk, and make history. This website is new and ground-breaking. I am very excited to see where this evolves and I can’t wait to meet new people and re-connect with people from my past.

Please check out my website:

Empowering Jews with Disabilities

www.empoweringjewishwithdisabilities.org

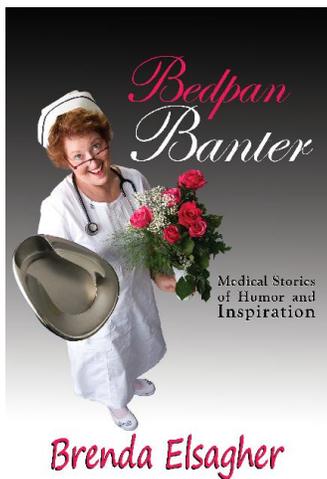
Please take the Attitudes, Questions & Beliefs Survey on my website and let your voice be heard!

Marlene Kivens, Founder

Brenda’s Done It Again!

Review of Brenda Elsagher’s book, *Bedpan Banter*

From Secure Start Book Club



Some things are universal. Like birth and death, illness and hospital stays are two experiences that deeply connect us on a human level. No matter who we are or what background we come from, the same apprehension and fear around these events seize us to the very core.

In *Bedpan Banter*, Elsagher shows us how our stories about these experiences can create bonds of friendship, compassion and hope that can never be broken. Brenda, a survivor of colorectal cancer, comedian and motivational speaker gathers over 110 stories from published writers, doctors, nurses, patients and caregivers she met on her travels. Some are funny, some gut-wrenchingly sad, and others are rainbow-after-the-storm inspirational. But all are Unforgettable.

Unlike her other two books that focus solely on the ostomy experience, *Bedpan Banter* spans the spectrum of medical adventures from childbirth, accidents and breast exams to near death experiences and caring for aging parents. Of course there are a generous sprinkling of ostomy-related stories as well like one from a man whose clip fell off of his pouch as he ran on the treadmill sending the contents flying all over the room. Or one from the woman who avoided long lines at the ladies’ room by emptying her urostomy pouch in a men’s room urinal. And of course out-of-the-mouth-of-babes stories of children’s reactions to ostomy pouches.

Brenda prefaces each chapter with a story of her own related to the topic, proving that if we think about it we all have something to say when it comes to anything. That's the beauty of sharing stories, and *Bedpan Banter*. This book would make a great gift or to keep on hand to share with anyone and everyone dealing with being human. To order Brenda's book, go to www.livingandlaughing.com.



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Yet another prime target for aspirin: colon cancer

Last update: August 12, 2009 - 12:05 AM

CHICAGO - Score another win for the humble aspirin. A study suggests that colon cancer patients who took the dirt-cheap wonder drug reduced their risk of death from the disease by nearly 30 percent. Aspirin already is recommended for preventing heart attacks and strokes, along with its traditional use for relief of minor aches and pains. Its merit in colon cancer prevention has been tempered by its side effects, bleeding from irritation of the stomach or intestines. The new study suggests patients who already have colon cancer may benefit from taking aspirin along with surgery and chemotherapy.

"The paper is absolutely incredible," said Dr. Alfred Neugut of Columbia University Medical Center who has done similar research. In an accompanying editorial, Neugut wrote that the study "comes as close as it can to offering patients a way to help themselves." This is certainly something patients would want to discuss with their doctors," said Dr. Andrew Chan of Harvard Medical School in Boston, who led the study, which appears in today's Journal of the American Medical Association.

It's too early for an across-the-board recommendation, however, both Chan and Neugut said. The results should be confirmed in an experiment where patients would be randomly assigned to take aspirin or a dummy pill. A study based in Singapore that's now recruiting patients may verify aspirin's benefit. Chan's study was observational, meaning researchers merely observed what patients were already doing, such as taking aspirin regularly for headaches. It's possible that factors other than aspirin accounted for the difference

in cancer deaths. Colorectal cancer is the second leading cause of cancer death in the United States after lung cancer. The National Cancer Institute estimates that nearly 50,000 Americans will die from it this year.

For Patient Power contact Darlene Hafner and 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

Next month we will be having a rap session with Julie Powell. Please give us a call or email us as to what subjects you would like Julie to address. Even though so many of us are "pros" there is always new information we can find helpful. Here's a simple tip from the latest update of the Ostomy Outlook of North Central Oklahoma: **"Push the Skin-Don't Pull the Tape."**

Damaging the skin around a stoma (or anywhere else) is asking for infection. Don't peel your pouch away from your body. Take hold of an edge of the adhesive sections of tape and push the skin away from the tape. Some more hints from Sharon Williams RNET in a UPAA update 2/2008:

"Keep Your Ostomy Management Simple." Do not use extra cement, skin-care products etc, unless absolutely necessary. Plain water is still the best cleaning agent around the stoma. Realistically, not everyone may be able to achieve a seven-day leak-free wearing time.

"Write Medicine" has tips from a UOAA update also on 2/2008:

If you're suffering from chronic pain or illness, pen and paper will help. A recent issue of the *Journal of the American Medical Association* reported that patients who wrote about stressful experiences in their lives felt their symptoms decrease. This unique study adds support to a growing body of literature documenting writing's health benefits.

Healthy subjects have shown positive changes in blood pressure and a greater sense of well-being after writing exercises.



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We wonder if the same benefits could be documented after one of our meetings! Certainly joining a support group can add pleasure to our lives as well as diminishing bad side effects. Last year, the **"Get Your Rear in Gear"** 5k walk, run, and kids' fun run brought out thousands of people to support survivors of colorectal cancer and their families

Did you know? Ostomy surgery is performed on 70,000 people in the United States annually. Of these surgeries approximately 60% are temporary, lasting from three to six months. The primary reasons for ostomy surgery include colon cancer, inflammatory bowel diseases such as ulcerative colitis and Crohn's disease, bladder cancer, trauma and birth abnormalities. Ostomy patients range in age from newborns to seniors in their 90's. There are 650,000 people in the United States who have an ostomy.

The UOAA has the nation's most comprehensive website: www.uoaa.org and is a non-profit, volunteer managed organization that provides a national network for the local support groups in the United States.

In 2005, **Thanks to Ken and Linda Aukett**, the UOAA survived on a limited budget made possible through electronic communication and a nine person Management Board of Directors, made up of people living throughout the United States. Their objective is to eliminate the stigma and misinformation surrounding this lifesaving surgery through public awareness.

The Phoenix
The official publication of UOAA

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.



Half of each subscription funds the nonprofit UOAA. Subscribe Today!

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Annual dues are \$15 and are due by January. 1st. Membership in the *Ostomy Association of the Minneapolis Area* and a subscription to the *Ostomy Outlook Newsletter*

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Annual dues are \$15 and are 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
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I have a: Colostomy Ileostomy Urostomy (ileal diversion) Other Non-ostomate

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