



LIVE AND LEARN

Fall 2004

President's Message

A UROSTOMY EXPERIENCE TO SHARE
By: Becky Redmond, Via: Belleville, Regina Ostomy News

Hello Members and Friends,

Another annual conference has come and gone, and again it was a great experience. Several members were able to attend this conference and in this issue you will hear from them and they will give you insight on their trip to Louisville. My take is that UOA is making lives better for ostomates through the networks, chapters and the website, and I am happy that I am part of the local and national organization. The exhibit hall gave us the insight on the newest products, and the seminars that I attended were very informative. I had a special moment this year when I met a member of the Rolla, MO satellite chapter, with a urostomy. This member was having several problems, and really needed guidance. She was able to attend a seminar that was led by a urostomate of 42 years as well a WOC nurse. The Rolla member was thrilled with all the information and tips that she was given, her whole outlook took a much more positive turn. We had a young adult conference in Louisville concurrent with the annual conference, with a great turnout, and some of the campers from the Youth Rally attended. Great to see young people, the future of UOA come together and work with our national association.

We have a busy fall ahead of us, good programs at our meetings, a visitor training with Betsy Naeger in October, and a holiday party in December. We will be launching the new dues billing system this winter. Bill Lawson will be explaining this new system at the meetings and in the Live and Learn. We are working with the national office to make this transition as smooth as possible.

Hope to see you at the upcoming meetings, see you soon,

Susan Burns
President

I have been reading articles on your site for a couple of years. I had an

unusual and frightening experience concerning my urostomy last week that I thought might be of interest to your readers. I have had my stoma for four years now and have had no complications or problems. For the past six months, I had noticed that the skin around my stoma was white and irritated. I tried several different things to clear it up, changing different brands of flanges, changing the flanges more often, drinking more water and cranberry juice, and using different powders but nothing seemed to clear it up. I knew I should get in to see the doctor, but with starting a new job this summer, I couldn't afford to take time off. So I just put up with it, hoping that once I had enough time saved up at work, I could get in for an appointment. Last Thursday, while at work, I went to empty my pouch and it was full of bright red blood. I noticed two small blood clots. This really got my attention and I went directly to the phone and called the doctor who had performed my surgery four years ago. The nurse said she would get hold of him and have him call me back at work. Meanwhile, I continued to work. I started drinking a lot of water and drank a bottle of cranberry juice, thinking this would clear things up. After lunch in the early afternoon, I again went in to empty my pouch and this time, it was not only full of bright, red blood but so full of huge blood clots that my pouch wouldn't even drain! I was so scared that I went immediately to the phone and told the nurse that I had an emergency situation and needed to talk to the doctor. I ended up at the emergency room and had a urologist come in to look at it. When I took off the pouch, the blood had coagulated so thick, the doctor couldn't see the stoma. He peeled off the flange and blood was spurting from a severed artery next to the stoma. He said that because the skin around the stoma had such severe erosion, it caused the breakdown by the artery and it broke loose. He had to put in several stitches to close the artery. I had lost quite a bit of blood, but not enough to keep me in the hospital, so I was released and went home. I was told my urine would clear up by later that evening, which it did. It took several days for me to get over the panic of what had happened. Because of this ordeal, I made an appointment with an ostomy nurse. She told me that she recommends people with urostomies wear a convex flange. It keeps the urine from pooling around the stoma area. And, she showed me how to use Stomahesive Powder and paste on the white, moist areas surrounding my stoma. I have also scheduled an appointment with my doctor to have him check what the emergency room urologist did. I

was told that in 25 years of practice, this was only the second time he had seen this happen.

HERBS AND THE INTESTINE

Via: Cheers & Tears, & Greater Cincinnati Chapter & Re-Route

Herbs have long been proclaimed nature's remedy for many of our maladies. The fact is that 40% of all prescribed drugs are based on chemicals from plants. The following are a few examples:

*The juice of Aloe leaves is very helpful in caring for the skin around the stoma.

*Bay leaves, added to slow cooking foods are said to "tone" the digestive tract. They also relieve cramps and expel wind from the stomach and bowels.

*Cayenne is claimed to have such benefits as easing congestion, warming your feet, and aiding digestion.

*Dill is an old remedy for stomach ulcers, probably because of its calming effect. But it will also reduce flatulence when used as a seasoning.

*Garlic has long been proclaimed to be an aid to the immune system and effective against colds, flue and bronchitis. It, also strengthens the digestive system and helps in gastro-intestinal disorders. It works better raw than cooked.

*Parsley is nature's finest deodorant. It is a breath freshener but also reduces odor in the stool. Chew a couple of sprigs of parsley, especially after eating Garlic.

*Thyme in tea is proclaimed to be a cold remedy assist.

DON'T SWEAT IT!

By: Christine Newberry, RN, WOCN, Cymed

Via: The Greater Cincinnati Chapter & Re-Route

Does sweating cause you pouching problems? If you work or live in a warm environment, if you are an athlete or just prone to sweating, you may have problems keeping your pouch barrier on.

Here are three approaches to solving your problem:

Sweat less! Some antiperspirants can be used underneath an ostomy barrier. Many antiperspirants dry after application and leave little residue that would affect the adherence of a pouch. C.C. a cyclist in Maryland, uses Tussy 5-day Antiperspirant that is sold in packets. Mitchum and Crystal, among others, have been used successfully by ostomates to diminish perspiration. Do your own research and find one that works for you.

Increase Adhesion! If your barrier is floating off, consider increasing the quantity of adhesive. SKIN TAC has recently been produced in a new wipe-on form. This is a thin, clear adhesive that is easily removed with alcohol; Torbot manufactures it. Hollister makes a medical adhesive spray. And for the truly needy, there are paint-on adhesives that, though more cumbersome, can make a dramatic difference in adherence. Two of these are NuHope Adhesive and Skin Bond by Smith and Nephew. All of these

products are available at most ostomy product dealers.

Try a Breathable Barrier. The MicroSkin adhesive barrier on all Cymed pouches is moisture-vapor permeable and allows perspiration to flow through the barrier rather than being trapped beneath it. John Dermengian recently wore a Cymed pouch through the grueling Iron-Man Triathlon. His pouch held up through 16 hours of extreme physical exertion and lasted a total of 6 days.

SOME OF THE BEST BASIC OSTOMY HINTS

Via: The Right Connection, San Diego & Re-Route

Don't believe as if having an ostomy makes you less of a person or some freak of nature. There are lots of us and most of us are glad to be alive. Build a support system of people to answer questions when you have a problem. Consider our ETs and your officers who are listed in this newsletter. Don't play the dangerous game of making your appliance fail by over taping or putting off a change. There aren't any prizes given for the longest wear time except accidents. Don't wait until you see the bottom of your supply box before ordering more. Always count on delays in shipping, holidays, etc. when calculating what is needed. Zip-lock sandwich bags are useful and odor-proof for disposal of used ostomy pouches. Don't get hung up on odors. There are some great sprays and some internal deodorants...Remember— everybody creates some odors in the bathroom. Don't feel you are an exception. Hydration and electrolyte balance is of vital importance. Be sure to drink enough fluids to maintain good hydration, ileostomates especially. Read and learn all you can about ostomies. You never know when you may find an opportunity to educate someone about the life-saving surgery that has extended so many lives. Learn to be matter of fact about this and never embarrassed. Few folks get out of this life without some medical problems and unpleasant situations with which to cope.

You may be amazed at how people will admire your adaptability and courage. In the beginning after surgery, almost everyone experiences some depression. If you fit into this category, you are certainly not alone. But it need not be a lasting condition. Try something as simple as walking...long walks. If the depression seems to linger, don't be afraid or ashamed to seek help. There is help out there! The bottom line is— We are alive! In other times, in other countries, we might not be. Medicine and techniques today have given us an opportunity to experience this second chance. It is certainly an opportunity worth accepting and exploring. The most important part of you as a human being has not changed.

**United Ostomy Association's Annual Youth Rally
University of San Diego, California
July 10 - 14, 2004**

My Trip to San Diego by: Treyvionne D. Norman

In San Diego, California, at 6:37 p.m. Jackie and her friend, Nate, and I soon landed at the airport. Then we went to our bus and got checked into our rooms. I had ideas like going to swim, taking pictures, making friends, and having a lot of fun.

I learned that other people had an ostomy, colostomy, or an appendectomy like me. I also learned how to deal with certain problems related to my unique situations.

During camp I had fun at Ocean Beach getting on rides, swimming in the ocean, buying food and souvenirs. It was an exciting and pleasant experiment for me. I am looking forward to Colorado next year. I am so glad I was able to attend and this trip has blessed my life and family.

Dear U.O.A.S.L,

Thank-you for the great time I had at camp. It was awesome. We did a Family Feud, a talent show and went to Mission Bay Beach. My favorite part was the beach. I thought it was neat to be with fellow ostomates.

Thanks again, **Nate Scheller**, Eureka, Missouri

My first UOA Camp by Lindsey Mahler

This was my first experience going to camp far from home. I remember how nervous I was when my parents dropped me off at San Diego State University. As I began to meet the counselors and other campers, my nervousness went away and the fun began. I remember my counselor Christine, my friends Gina, Matt and Amy. I had so much fun doing Karaoke. I love to sing. The day we spent at the amusement park and the beach was a blast. I also enjoyed the dance. Knowing that I'm not the only person with an ostomy really made me happy and helped my self-esteem. I'm really looking forward to Boulder, Colorado next year. Thank you United Ostomy Association for making this summer the best summer ever.

Come meet and hear our kids at the Holiday Party in December

**United Ostomy Association's Annual Youth Rally
University of Colorado in Boulder, Colorado.
Saturday, July 9 through Wednesday, July 13, 2005.**

For information, please call
Mary Beth Akers, UOASL, Youth Chair 314-522-8523.



Lindsay,
Mary Beth,
Jackie, Nate,
and Trey
at Rally

Reflections on Conference and Rally ...by Mary Beth Akers

I always enjoy attending the conference. I am in a position in life where I feel I can attend any of the age groups at the conference. I have worked at the Youth Rally, so feel comfortable with the kids, I had my ileostomy as a young adult, so feel comfortable with the Young Adult Network, and I have been around a loooooong time, so feel comfortable

with the old timers. It is a pleasure to see that those of us who keep coming back find a reason to be there, just as it is wonderful to see the light of recognition in a new attendee as they see others like them.

The Rally is just the same. There are some kids who have been coming to Rally for 6 or even 7 years and are so sad that they are graduating and can't come the following year. What they get from Rally is so powerful and meaningful in their daily lives, they can't get enough. The ones who are there for the first time, many have never met anyone who has been through what they have. They feel alone. That is why the Rally's motto, "You Are Not Alone," is so real. Everyone there, from the youngest camper to the most seasoned counselor or nurse, is of benefit to someone else and benefits from someone else.

It is a very worthwhile trip to bring together people from all over the country and beyond to be with people they can relate to in a different way than in their daily living at home. I am so fortunate to be able to be a part of both events – Conference and Rally.

2004 UOA CONFERENCE REFLECTIONS

Let me begin by introducing myself. My name is **LeeAnn Barcus**, I am 32 with an ileostomy due to Crohns disease.

My story begins 13 years ago, soon to be 14 years, at age 18. Diagnosed with Crohns disease while in nursing school after an 87 lb weight loss in a very short tie. Upon diagnosis, I began a fight for life in which I have fought for years alone and without support of others who "truly know".

March 6, 2004 added to the loneliness and feeling of isolation. That date was the date of the surgery I had avoided at all cost for years. It was also the start to a final phase of what I felt was total isolation. I truly believed it was the final nail in the coffin and I would never be "normal" again.

In June of this year I attended my first meeting and met some wonderful people. I was approached and asked to represent St.Louis' Young Adults at the national conference. My thoughts were "why me, I hate myself, I hate my ileo, I am not the right person to represent anyone." With encouragement from others I decided I would do it, but with great reservation and doubt in the outcome.

Upon arrival in Louisville, Kentucky, I was quite skeptical and critical. I doubted these people could do or say anything to change my outlook on life, and most of all, how I felt about ME. I began the conference in the very back of the room and making no eye contact with anyone. I felt like I did not belong there and almost packed up and left for home. People came

out of the woodwork and were saying they felt the same ways I was feeling. I began to think I was wrong to think I was alone. These people, old, young, and in between knew my life. They had been there and were sharing it with others.

I began speaking up and asking questions I could never get a straight answer on before. I began to realize I was not alone, my feelings and frustrations were not irrational. I attended a number of sessions and wished I could have gone to many more. "Reimbursement" helped me to realize I did not have to fight the insurance alone, like I had been fighting for years. "Motivation and self-esteem" made me realize that I am normal and my feelings are valid and again, I was not alone. The social held by Convatec brought about a time where people acknowledged my feelings and still accepted me as a person, a normal person, which I have not felt in years.

At the exhibit hall visiting with all the distributors as well as manufacturers was encouraging. It let me know that they care. All went above and beyond to help with issues pertaining to my ileo as well as acceptance issues. Not once did they make me feel like they were doing whatever it took to get rid of me. Again, they cared and they accepted and acknowledged my need to fit in and be accepted for me not pushed away due to my ileo. During the short bowel session, I learned ways I could try to improve things no doctor has been able to. I found things to try that were not "another pill". There were ET nurses there to assist with problems and give advice. Convatec provided an unimaginable amount of help not just to me but to all who needed it.

Living with an ileostomy and sexuality were probably the best sessions for me. I learned that everyone young and old have issues similar to mine and have had their ostomy for years. Again, I left feeling "normal" and less like I was losing my slight grip with sanity. I came out of those sessions with the realization of "I have to live with it, I don't have to like it, but I am alive" if others are grossed out by it or me, I need to take a deep breath rather than be insulted and say "their loss." That one I will probably work on for the rest of my life, but I will be alive to work on it. And for that, I can only say "thank you" to my ileostomy.

And so I am going to end this with a big thank you first, to my children for without them I would not be where I am today. Also, a big thank you to all who made me feel human for what, I realize, is the first time in years. In the closing sessions, I commented that "I came to the conference feeling like an ugly troll and am going home feeling like a human being." I know now, I am not alone, I am not ugly, and most of all, I am not irrational and my feelings matter. There is a family out there,

though not blood relation, who understands the ups, the downs, and the in-betweens. That is something I have looked for for many years and it took what I thought was the end to find the beginning. I leave these final words of appreciation, they say it better than I can:

I am not a perfect person, but I continue learning.
I just want you to know, I found a reason for me,
a reason to be who I used to be, a reason to start over new,
and that reason is YOU.

Thank You all more than you know.

A First Timer's Impressions

By Martha Weaver

Never having attended a conference before, I had no pre-conceived notions or expectations, so reflecting on my 4+ days at the 42nd Annual UOA Conference in Louisville, KY, I have nothing but good memories!

There's a world of information out there for us ostomates and a world of educated, friendly people eager to answer your questions (or if they can't, they'll tell you who can).

One thing I love about being a part of this organization is the overriding sense of humor. Where else can you discuss your bowels (if you have any) and feel completely comfortable? No subject is taboo! Most of the rest of the world is so uptight about their bathroom habits, and that's okay I guess) but when it's the worst part of your day, in fact it's the worst part of your life, finding others who understand, have or have had similar experiences, and can still find humor in it, that's very comforting in itself! I for one know laughter has helped me through the many years of health problems which started with Day 1.

There were sessions with a speaker usually followed with a question and answer period for almost every conceivable problem. There were very talented speakers who convinced us there were no hurdles in life we can't overcome.

I felt the Louisville Chapter did a very good job hosting the conference, and they were all very pleasant and helpful. The hospitality room was very inviting, the coffee pot was always full as was the water and lemonade containers. The Galt House is beautiful, our suite of rooms gorgeous and although the on-going construction a little inconvenient at times, no big deal! The banquets were great and the food outstanding! The tour of Louisville was nice, I particularly enjoyed seeing Churchill Downs. We also toured the Louisville Pottery Factory and saw a movie on the Kentucky Derby at the IMAX Theater. I had never been there before but Louisville is a lovely city.

The RN's were amazing and so knowledgeable. I took advantage of the Stoma Clinic where I had a private consultation with a WOC (ET) Nurse, and was welcomed even though I hadn't made an appointment.

All in all, it was a busy, productive week and I'm very happy I attended. I learned a lot. I would advise everyone to participate in at least one conference --- who knows, you could learn something that could improve your quality of life considerably and at the very least you will meet some very nice people and have a great time!

And More Thoughts

by Doris Smithson

Imagine being with 600 Happy people-men, women, and children of all sized and ages who have been through ostomy surgery, that was the UOA Convention 2004 in Louisville, KY. It was great meeting so many people nationally and internationally from Hawaii-Canada-Bolivia-Egypt-Australia- and so on.

There were so many interesting sessions, not all could be attended. The most interesting to my that I learned the most was given by a dietician and was "Fat Is Not Where It's At." The subject covered health and tips for weight control and pouch security. Also the good and bad fats were discussed. Almonds are my favorite snack but I was told my limit is only 5 per day!!

I really enjoyed the boat trip up and down the Ohio River along with a nice dinner buffet. And yes, there were even FIREWORKS from the river to make it all complete on Saturday night. The city had pretty painted horses on every street corner and even between in honor of the Kentucky Derby. All told, it was a great time!!



A portion of our St. Louis contingent at the Ice Cream Social:
Martha Weaver, Mary Beth Akers, Kate Lobstein, LeAnn Barcus, Hank Thill
Doris Smithson, Bill Lawson, Susan Burns, and Jackie Lawson

MORE CONFERENCE REFLECTIONS

AND.... From Hank Thill

The keynote speaker, Stanley Frager was great! His hilarious approach to having an ostomy had the audience in stitches. His presentation was a good way to start the conference on an upward note.

At the Hollister booth I met and visited with Brenda Elsagher who has authored "If The Battle Is Over, Why Am I Still In Uniform? A while ago, after reading her book, I sent her a letter expressing how much I enjoyed her humorous account of dealing with her ostomy and many serious medical problems. She remembered my letter, and thanked me for my comments.

I particularly enjoyed Dr. David Beck's session "When Something Goes Bump In The Gut" This colorectal surgeon is a great platform speaker, who explains complex medical conditions in layman's language.

Of course, the Convatec dinner/dance party and the Hollister ice social were hits with everyone. Both were well done.

Ah... Moments Bruce R. DuMont ☺

For several years now, I've spent a week's vacation to attend the annual UOA conference, and sometimes ask myself if I'm wasting my Money and vacation time. However, every year I learn some valuable tips on managing my life with an Ileostomy a little better than before. Every year I have a barrel of fun visiting with the many friends I've made over the years, and dancing at the big evening parties. Every year I've visited a city and taken an extra day or two to see some sights and parts of this great country that I wouldn't otherwise taken the time to see.

This year I had a special mission starting out, but didn't have success in learning what I had intended, so now it's back to surfing the web for that info.

One of the great things about the UOA is people helping other people. This year's "Ah moment" came to me during the regional meeting. I considered which regional meeting I should attend. Should it be the East, since I am currently living mostly in Maryland, or the Mid-west since I'm a member of the St. Louis Chapter, or the west coast, since I still have my Condo there and hope to retire there in a few years.

I finally decided to attend the Eastern regional meeting, and found my Ah moment when I heard the plight of an ostomate in need of help, who lived in an area where the chapter had shut down. As it turned out, Sheri had emergency colectomy along with some small bowel, last November,

and at least 5 more surgeries since, including one in early July, and really needed another ileostomate to help her along her road to recovering her life. She lives with her husband and two sons, only about three miles (as a crow flies) from where I'm working, and her husband works on the other side of the Naval Air Station where I've been working for over a year. I have spoken with her once since I've been back, and she seems much less stressed about her situation, and has scheduled for a rectomectomy on Aug. 30th. She is studying nursing, and hoping to become an ET/WOCN in this area. My 'Ah' moment gave me a whole new purpose for being at this year's conference, and one I was glad to have.

AND.... From Bill Lawson

I attended my first UOA National Conference in 1990 and if my memory serves me, this is probably the eighth one that I've had the privilege to attend. Every time, I come back with new information that I feel is beneficial not only to me personally, but to our local chapter. Not only do I come away with new information but also a new fire and desire to apply and share new ideas with our local UOA Board and members. The trick is to keep that fire alive and get other people ignited. I was amazed at the energy that the Teens, the Young Adults, the Parents of Ostomy Children and the 30+ brought to the Conference. Each group had their own platform tailored to their needs for their age.

Ron Titlebaum, UOA President, said that one of his goals this year is to make "Ostomy" a household word. I intend to help toward that goal. I have a tendency when, in a casual conversation, I could talk about my Ostomy but I refer to a Health Group of which I am a member. I am now making a special effort to say Ostomy, explain what it is and that I have one, and how it saved my life.

Another impressionable moment was at the closing session with Keynote Speaker, John M. Dermengian, a Hawaii-based Ironman triathlete and four-year ileostomate. He talked about friendships he has made along the way in various athletic events and how competing has improved his daily life. He asked us, "What do they call the man who finishes last in the Ironman race? ... An Ironman." So we are all in the race of life together and we are all winners as long as we keep trying and working together. He closed by saying, "Anything is possible and with the right tools you can do anything."

More Thoughts by Kate Lobstein., age 20

For most people, getting an ostomy is most definitely not something they want- it's something that's thrust upon them, something they are forced to accept. Not me. I didn't just want it, I begged for it.

After years of being sick with ulcerative colitis and then miserable and barely able to leave my house with a j-pouch, I told my doctors I was done. No more drugs, no trying to surgically correct the j-pouch, no second opinions. I couldn't take it anymore and I was not going to waste any more of my youth being sick and miserable if I had a choice in the matter... and I did have a choice. I chose my ostomy. I'd had a temporary ostomy before, I knew what I was getting into. I never went through an acceptance process with it. After my surgery, I named my stoma "Buddy" and proclaimed my love for him when I ate at a restaurant for the first time in years. I finally had my life back. Everything was going to go back to normal. My ostomy was never an issue to me. I was thrilled that now I could finally be a healthy, happy college student.

Except it didn't happen that way. Throughout my illness, I made the mistake of equating health with happiness and normalcy. I truly believed that when I was finally healthy, I'd forget the last few years of my life and my universe would suddenly revert to the way it was before I knew what ulcerative colitis was. I thought I'd just get over it and move on. Obviously, that doesn't really happen. I spent a year beating myself up for not being "normal." I hated college. I hated the other 19-year-olds and wrote most of them off as being immature and self-centered. Mostly though, I hated myself. I was frustrated that I couldn't just forget the last few years of my life and the fact that I had an ostomy, like they had no effect on me. In my mind, they shouldn't have had an effect... after all, it was over now, right? Life should be normal again, shouldn't it?

The amazing, wonderful people at the conference changed my perspective completely. I met people my age who'd had ostomies for ten years, some who'd had ostomies their entire lives... and here they were at an ostomy convention. Even after living with an ostomy for so long, they still had issues with it, still needed to talk about it, and still enjoyed the friendship of others in the same position. I finally realized that it's never going to go away. I realized that it doesn't matter how old you are, how long you've had your ostomy, or how well you accept it. We all need the support and friendship of those who share the same feelings and daily challenges. I realized that, for what I've been through, I am normal after all. When the UOA and Young Adults Network welcomed me into their family, it literally changed my life. What they have done for me means more than words can express and I am eternally grateful. This is a family I know I will be a part of for the rest of my life.

**Holiday party invite on
Print Artist in greeting cards**

UOASL MEETING SCHEDULE
for remainder of 2004

October 4 Christian Hospital NE
7:00 pm Morin Hansen MD, Colorectal Specialist
Update on Inflammatory Bowel Disease

**Visitor Training Workshop will be held:
Thursday October 14, 6 to 9 pm at St. John's,
For more info call Betsy Naeger at 314-725-4544.**

November 1 St. Luke's Hospital West, Institute of Health Education
2:00 pm Robin Beckerly, Rep. Sterling Medical Services
Update on Ostomy Supplies

December 6 St. Luke's Hospital West, Lower Atrium
6:30 pm HOLIDAY MEETING Please RSVP

Rolla Satellite News

Several members will be attending the National Conference.

For meeting dates, times, and place, contact:

Retta Sutterfield RN CNS CWOCN

Phelps County Regional Medical Center

Rolla, MO 65401

retta_s@hotmail.com

Any articles welcome for consideration:

personal experiences, health, obituaries, find a pen pal, etc.

Publication Deadline: November 25, 2004

Send articles to: Mary Beth Akers

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