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https://www.facebook.com/JaxUOAA/?ref=aymt_homepage_panel

Find all the past issues of the MailBag at <http://ostomymcp.com/id6.html>

Jacksonville Contact Information:

Patti Langenbach
 (800) 741-0110
 (904) 733-8500

patti@ostomymcp.com

Support group meets the 3rd Sunday
 of each month 3 p.m.
 4836 Victor Street
 Next Meeting: **Oct 20th**

Gainesville Support Group Contact info:

JoAnne Bell at 352-284-4214
 Meets the 1st Sunday of each month
 (except Holidays)
 at Hope Lodge 2121 SW 16th St
 Gainesville, FL
 Next meeting: **Oct 6th**

Ocala Support Contact info:

Lynn Parsons 252 337-5097

www.ostomyocala.com

Meets the 2nd Sunday of each month
 (except July & Aug) at 2 p.m. at the
 Sheriff's Station 3260 SE 80th Street
 between Ocala and Belleview.
 Next Meeting: **Oct 13th**

Citrus County Support Group

Meets third Sunday of each month at
 2:00 PM in the Seven Rivers Regional
 Medical Center, 6201 N. Suncoast
 Blvd., Crystal River, FL 34428, in the
 Community Room of the Medical
 Office Building **Oct 20th**

Amelia Island Area Ostomy Support Group (904) 310-9054

Meets second Monday of each month
 at 6:30pm UF North Campus
 UF Health North 15255 Max Leggett
 Parkway Jacksonville, FL 32218
 (Meeting Room 3-4)
 Free parking
 Next Meeting: **Oct 14th**

The Villages Ostomy Support

Group We meet on the 2nd Tuesday
 evening of each month at 6:00 PM at
 (except July & August)
 Saddlebrook Recreation Center
 3010 Saddlebrook Lane
 The Villages, Florida
 Linda Manson
 tvostomy@gmail.com
 865-335-6330
 Next Meeting: **Oct 8th**

"Gutsy's FAB Gab-About: Stories of Ostomy 'Glories/Gories'!"

"Speak Out and YOUR WORDS WILL Be Heard!"

By Linda Blumberg AKA "Mrs. Lips"



Perusing the Spring 2019 US Phoenix ostomy mag, Gutsy saw this article and bravely emailed Bill Van Clief at: horses@execpc.com...here was his response:

Last month we met Bill! Here is the rest of the article. If you need the first part... visit the [ostomymcp](http://ostomymcp.com) website and look for the September 2019 issue of the MailBag. <http://ostomymcp.com/id6.html> Or call 904-733-8500 and ask for a copy to be emailed to you.

The following is reprinted with permission from The Phoenix magazine, www.phoenixuoaa.org, 800-750-9311, the official publication of the United Ostomy Associations of America.

Following Up with Surgeon Selection

Next, I prepared a short list of surgeons who perform K pouches and BCIR's and made a few phone calls. I sent abbreviated medical records to several of the most likely surgeons to see which ones would accept me for surgery, and received two rejections. I was elated when I was accepted by Dr. Ernest Rehnke at Palms of Pasadena Hospital in St Petersburg, Florida. His office sent me a packet of information about the procedure that included a list of about 300 people with BCIR's who I could contact. Other surgeons might also provide contact information for some of their patients so you could have better insight on their experience with the procedure and with the care they received from their surgeon and hospital staff. I talked with six people on Dr. Rehnke's list who provided very encouraging information and responded to my questions about the procedure and their life with it. My surgery was more involved than normal due to the presence of numerous dense adhesions resulting from my prior surgeries. Everything went very well in surgery and the 21 days of post-operative care in the hospital before being discharged home. In the five years since my surgery, I have experienced a very well-functioning BCIR and an excellent quality of life that it has provided me. In the event of future complications, I would definitely take the necessary steps to keep my pouch.

Participation with Message Boards

Having benefited so greatly from my BCIR and reading posts online of others with comparable results, I became quite active on several message boards. Two very active ones are: UOAA Discussion Board (Continent Diversions forum) and The J-Pouch Group (K-Pouch Korner forum). I related some of my experiences on message boards in my QLA presentation. It is interesting to note some of the most common topics presented in these message board posts. Topics pertaining to ostomies include: • Alternatives for failed j pouches and ileostomies • Medications and probiotics for pouchitis • Supplies – Catheters, dressings, lube, etc. • Diet & foods • Non-related medical conditions • Surgical experiences • Contact information of BCIR & K pouch surgeons • Pouch problems and complications • Follow-up medical care • Sex and intimacy • Emotional issues Many people in the audience could personally relate to my lists of "What Doctors Tell Their Patients" and "Why Doctors Do This." Unfortunately, many doctors do not know about continent ileostomies or have negative and outdated knowledge about them when advising their patients about surgical procedures appropriate for their conditions. This is why I recommend getting a second medical opinion, especially when you have concerns or doubts about what you were first told.

Reading and Posting

Two things become evident from reading numerous message board posts: (1) There is very little knowledge of continent ileostomy pouch procedures by potential patients; and (2) These message boards are rarely visited by those with well-functioning pouches (the majority of us), thus causing viewers to believe that there is a very high rate of complications and failures. Many visitors to these boards are there to obtain information for themselves and do not post responses. Although it is perfectly OK to read message board posts for information only, the board's overall success and benefit depends on people to post responses. By all means, post a response if you have something to offer or would like specific information for yourself. Here are a few guidelines for posting responses: identify the poster's concerns; feel confident that you are qualified to respond; relate your personal experiences to enhance your response; don't play doctor; be empathetic, not critical; identify your personal opinions as such; be informal; don't try to "hard sell" a procedure or treatment; follow up on your response as

appropriate; encourage “thinking outside the box.” Remember that some posts are best left unanswered. Message boards often have a way to communicate information without being publically viewed. This feature is known as “Private Messages” or “PMs.” To avoid unwanted contacts and exposure, use a PM to provide your email address or phone number to someone you want to contact you. Never post this information in open forums. Use PMs to communicate sensitive or personal information. Be informal in your communication, like you would write to a friend. Encourage the other party to talk. PMs are an excellent way to have a discussion that benefits both of you.

UOAA Discussion Board

The United Ostomy Associations of America website hosts a discussion board with 13 forums including General, Temporary Ostomies, Parents, Young Adults, Irrigation and Continent Diversions. The board is designed to be user friendly with a search feature, archived posts and a forum dedicated to helping users navigate the many posts to find the information or advice they are looking for. To post or reply to a post, users must create an account and login. As of this writing, the discussion board has hosted during the appointment or shortly afterwards. Keep all of your research findings, notes and medical records in one place for easy reference. I was really having a great time giving my presentation 218,732 posts from 6,088 members covering 24,632 topics. The board has two active moderators and commercial posting is not allowed, although there are display ads at the top of each forum. You can find the discussion board at www.uoaa.org/forum/index.php or from the “Support” header at www.ostomy.org.

Meeting with Your Doctor

A good doctor should appreciate that you have done your homework before having your appointment. This applies to your initial appointment as well as subsequent appointments with other doctors in second opinions. Make a list of your questions beforehand and don’t let the doctor leave the room until all of them are answered to your satisfaction. Consider having a spouse, relative or friend in the exam room with you in case you later have questions about what was discussed. Take notes before this audience and kept it informal by using a lapel mic and not standing behind a podium. The slides I had prepared served as a guide and eliminated the need to rely on notes. When I came close to the conclusion, I noticed my wife waving frantically to let me know that my hour was up and it was time to break for lunch. I could have easily continued talking for another hour. My message is quite clear. When faced with a significant medical decision, you are most likely to be satisfied if you identify the available options, research each one well and then select the option that you believe will be most satisfactory for you. After all, it is you who will have to live with it, possibly for a long time.

For more information about Quality Life Association, visit www.qla-ostomy.org or call 662-801-5461. Bill Van clief can be reached at horses@execpc.com.

Short-term Ostomate: A Point of View

by Katy Duggan; via Pomona Valley (Upland, CA) *News and Views*; and Chippewa Valley (WI) *Rosebud Review*

One day I was on vacation in New York and simply feeling constipated. The next day I was in a Seattle emergency room signing a consent form for a resection (surgical removal of part of my bowel) and a possible ostomy. As an RN, I took care of many a child with a colostomy and could only remember the awful skin breakdowns that many of the kids had on their abdomens. I remembered the struggles to keep the old style appliances on their fragile bodies. I was feeling scared, confused and incompetent to take care of one on my own body. My surgery resulted in no ostomy, and I was relieved. I had only a colon cancer diagnosis to deal with post-operatively.

Five days later, I found myself again faced with a consent form for emergency surgery for complications. This time there was no doubt that I would have an ostomy — an ileostomy. The surgeon assured me that it would be only for eight to ten weeks, and then it would be closed. The assurance vanished with the first visit of the oncologist. He did not want me to have a third surgery, recover from that operation, and **then** start chemotherapy.

Now my challenge was to face nine to ten months of taking care of the ostomy on my body. Even as professionally trained as I was, I had all the same fears as those who must face living a lifetime with an ostomy. I kept telling my family I just wanted to pay a nurse to come in each week to deal with the bag change and any problems. I wanted someone else to deal with “it.” I had to have help for several weeks but gradually became less “scared,” not as “confused,” more “competent” as each week passed. Although, as I write this, I am closer to the surgery date to reconnect my bowel, I have walked the road each ostomate walks. Between chemotherapy side-effects and learning new skills for managing an ileostomy, I am a stronger, more competent individual.

Your Link to Understanding Skin Health

Here's How The Peristomal Skin Assessment Guide for Consumers Can Help

Is your skin irritated or weepy under your pouching system's skin barrier? Wondering what causes it and how to resolve it? The Peristomal Skin Assessment Guide for Consumers may be able to help. It's an easy-to-use digital tool designed to help identify common skin problems through actual photographs, suggest next steps for care or management, and appropriately prompt individuals to seek advice from a Wound, Ostomy and Continence Nurse (WOCN) for additional support.

The original guide, sponsored by Hollister Incorporated, was developed for use by clinicians only. But it soon became clear that it would benefit people living with ostomies. The same development team put their heads together and created a new version for consumers.

"Up to seventy-five percent of people with ostomies may experience a peristomal skin issue but don't know it's a problem and don't seek help," states Karen Spencer, Director Global Clinical Education Ostomy, Hollister Incorporated. "So having photos of what's normal and what's not is a good idea."

Since its launch in June, more than 5,486 people have accessed the guide from across the globe - the U.S., Canada, United Kingdom, Saudi Arabia, Australia and Brazil. And the numbers are growing every day.

"Hollister believes in helping people with ostomies adjust to living life with an ostomy", says Spencer.

Start using the tool today!

Find the guide on the WOCN Society website at psag-consumer.wocn.org.



Hollister Secure Start services provide ongoing support to people living with an ostomy. We are here to help! Call us today at 1.888.808.7456.

Nothing contained herein should be considered medical advice. Medical advice can only be provided by an individual's personal doctor or medical professional.

Editor's note: This educational article is from one of our digital sponsors, Hollister Incorporated. Sponsor support helps to maintain our website www.ostomy.org and the free trusted resources of UOAA, a 501(c)(3) nonprofit organization.

It doesn't get any more beautiful than this!

By Wendy Lueder
President Broward Ostomy Association

Erik Myers' beautiful daughter Rae celebrated her bat-mitzvah February 2, 2019. Honoring her father's health challenges that included ostomy surgery, Rae decided that for her bat-mitzvah project she would make it possible for BOA's youth camper Miguel to attend his third Youth Rally Camp this July 8th through 13th at the University of Washington in Seattle by underwriting all of his expenses.

Erik said that his daughter saw his issues and was happy to make her cause sending someone near her own her age to ostomy summer camp. The Youth Rally is a summer camp that provides a non-threatening environment for kids between the ages of 11 and 17 with any sort of bowel or bladder dysfunction. The Youth Rally is designed to help campers understand that everyone has the same opportunities to achieve their goals regardless of medical or physical differences. In short, that they are not alone.

To raise money for Miguel, an ostomate, to attend Youth Rally, Rae designed a piece of art that incorporated the "World Ostomy Day" logo. Rae had the image placed on tote bags and contacted family and friends about her project, to bring awareness and to raise donations. The tote bags were provided to all that donated a certain amount to the cause.

Erik and Rae are proud to say that, to date, they have raised over \$1,526. They have even exceeded their minimum goal. Once they have a final amount, they will use the required amount to allow Miguel to attend camp. The remainder will be used to provide some level of support at the camp.

To quote Erik, "My daughter is turning 13 next year and will have her Bat Mitzvah in early February. She was looking for a cause, related to my medical issues through the years, to raise money with her Mitzvah Project. I mentioned this summer camp need, and she was very interested. My kids go to summer camp and it is the highlight of their year, and my daughter loved the idea of helping a kid with an ostomy in need. It is an honor for my daughter, and our entire family, to assist Miguel."

And from a Rally nurse volunteer, "Several times throughout the week Miguel said that he "wished he didn't have to leave this place". I think he felt like just one of the kids, a normal teenager."



Visit the Peristomal Skin Assessment Guide for Consumers
<http://psag-consumer.wocn.org/#home>



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