



The Roadrunner



Newsletter of the
Ostomy Association of Albuquerque, NM

Next Meeting

Support Group Updates and Events

Recent Events

February and April we had general support group meetings.

In the March meeting nurse, Barbara D'Amore, explained some of the various intestinal and urinary surgical diversions including continent types.

Many members were enlightened about the fact that continent types existed. Since we sometimes mention that patients are offered perhaps a "J"-Pouch option, Barbara explained what that means in terms of surgery and good and bad expected and possible outcomes.

It is good to see increasing attendance at our in-person meetings! Thank you to all of you who so regularly give of your time to come and support others. This allows us to meet people and help with needs of more ostomates. Now we can once again invite speakers to our meetings. Yayyy!

Upcoming Events

May 1- Speaker - Kourtney Kropp from Seating and Mobility. Being located in Albuquerque, they carry ostomy products from the major ostomy manufacturers. They can provide distribution of the products that you wish to order. In addition, Kourtney can provide understanding and updates of questions you may have about insurances and allowables, etc. Please come and welcome Kourtney!

June 5- general support group meeting.

July 10- general support group meeting.

Note: this is an irregular date due to the July 4th holiday.

As always pay attention to emails as events and speakers may be added.



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Upcoming Meetings:

Cherry Hills Library

- May 1, 2022

Cherry Hills Library

- June 5, 2022

Cherry Hills Library

- July 10, 2022

Cherry Hills Library

- August 7, 2022

Meetings start at 2 p.m. and end approximately at 3 p.m.



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PRESIDENT'S Message
by Brian Leen, President OAA, NM

Well, it is clearly time to get back to work! We have recently started our outreach work again. Barbara D'Amore is leading the outreach committee. Members of the committee will be visiting the various Medical clinics and centers to drop off brochures and let them know we are here. We have established great contact with Era Tzamaloukas, the nurse who is setting up the UNM Hospital Ostomy Clinic. One of our members, Nurse Haley Wills is making contact with her fellow nurses at Lovelace and we are Re-energizing our long time connection with Presbyterian. In future phases, we will reach out to the Cancer treatment clinics, and outlying and independent doctors and clinics. In our final phase we will reach out to the Rehab Facilities and Home Care Providers.

In addition, we will be looking toward reestablishing our visitor training sessions. Getting our Visitor training program which has the ability to respond to individuals that ask to speak to people who are living with the type of ostomy operation they are about to have or have been advised to have. In the past these programs around the country were able to assist medical personal to explain the day to day of living with an ostomy. Over the years medical professionals became hesitant to offer this assistance due to the fear of being in violation of the HIPAA rules by sharing the contact information of the patient. It is now becoming understood that if the patient is offered the information and agrees to have a visitor there is no violation of HIPAA involved. However, a different approach is to work with the medical community to make certain that new or potential ostomates are aware of our existence and how to contact us. It is obviously their choice whether they do so.

For the present we will continue to meet on the first Sunday of each month (with a few exceptions for major holidays) at the Cherry Hills Library. If You have never been to a meeting; we would love to see see if it is for you. Or take the easy approach and just drop in at one of our monthly meetings and check it out. I believe you will find it very helpful to listen to other ostimates talk about their operations and the wonderful days they spend feeling good about their often life saving operations.

Brian Leen

Albuquerque International Balloon Fiesta

October 1st through the 9th, 2022.

This year we celebrate the 50th annual Balloon event in Albuquerque.

Ben Palmer

Roadrunner Editor





Parenteral Support in Patients with Short Bowel Syndrome

UOAA April 2022

People living with Short Bowel Syndrome (SBS) often face challenges related to nutrient absorption. SBS can prevent the body from absorbing enough nutrients needed from food and drink through the intestines. In cases like this, Parenteral Support (PS) is a lifesaving option. PS delivers fluids and/or nutrition intravenously (IV).

PS may be relied on periodically or routinely required for extended periods during the recovery process of the intestine after an injury or surgical resection. Despite the intestine's ability to recover and adapt, the process can take years. In some patients, the intestine may never fully adapt or recover, and those patients may require PS indefinitely.

Possible Complications of PS

While PS plays a vital role in patients with SBS, complications are possible.

Some of the possible complications associated with long-term use of PS can include:

- Intestinal failure-associated liver disease (IFALD)
- Kidney diseases
- Sepsis or catheter-related infections
- Hyperglycemia (high blood sugar)
- Fluid overload
- Bone disease

To find out more about the possible complications of long-term use of PS, visit: [LifeWithSBS.com](https://www.lifewithsbs.com)

Beyond the medical challenges that patients with SBS face, people relying on PS may also be impacted by the burden of SBS-related hospitalizations. One study showed that the overall mean length of stay for SBS-related hospitalizations was more than two weeks with an average hospital cost in excess of \$34,000. This strain—along with the disruption of day-to-day activities—can place undue stress on patients, families, and caregivers.

How to reduce possible complications of PS

PS provides much-needed nutrition for people living with SBS. Preventive measures and planning may help mitigate possible complications associated with long-term use of PS. Some ways to reduce possible complications of PS include:

- **Hydration:** Staying properly hydrated is an important part of SBS management. Patients should consume small, frequent drinks of oral rehydration solutions and avoid drinks like fruit juices and sports drinks, which can contain high amounts of sugar.
- **Hygiene:** Careful hygiene can help minimize the likelihood of infections. Simple actions like washing hands and keeping the insertion site clean can help reduce the risk of infection.
- **Treatment plan:** The long-term treatment plan should support intestine function by reducing dependency on daily PS. Encouraging oral diet whenever possible can help reduce the number of hours per day or days per week of PS. Patients should always work with their healthcare team to create a treatment plan that fits their individual needs. To identify goals and learn about the steps you and your healthcare team can take to manage SBS, visit: [SBSplan.com](https://www.sbsplan.com)

Palliative Care and Differing Types of Pain

From the Broward Beacon

Dr. Miransky explained that he is a palliative physician who takes care of people who have symptoms as opposed to pain. Anesthesiologists take care of people with pain by sticking needles into the appropriate areas to provide nerve blocks. Dr. Miransky explained that although he does work in the hospice field by being medical director of two programs, that only encompasses ten percent of his work. Palliative care focuses on two things: improving quality of life while enhancing ability to continue functioning. A palliative doctor does manage the pain but also the sequelae associated with pain, pain management, or medical treatment. Each person is different requiring a different “recipe” for symptom management. The “right tool” or medication is needed for the “right job” or symptom. Nociceptive pain is at the tissue level in the bone, stomach, or muscle and is experienced as an ache, throb, stabbing or crushing feeling. Neuropathic pain is a burning, electric, shooting, numbing symptom and this involves the nervous system. The World Health Organization in the 1980’s made an analysis and produced policies on how to manage pain. They suggested that for mild pain to use Tylenol or Ibuprofen also known as NSAIDS (non-steroidal anti-inflammatory drugs). However, Tylenol is toxic to the liver and Ibuprofen is toxic to the kidneys if taken in excess. They suggested Codeine, Vicodin, and Percocet for moderate pain, morphine for severe pain. Anytime opioids are required to manage the pain, there needs to be a discussion with the prescribing physician to include concerns regarding abuse potential. Dr. Miransky explained terminology that is often unclear to the lay person. 1) Addiction to a drug means you like the way it makes you feel and you use it despite any harm it may cause. In other words, you are using the substance for a purpose other than for which it was prescribed. The chances of this happening is much smaller over the age of 25 years. 2) Dependence means your body has gotten used to a substance and if you stop taking it, you experience a withdrawal phenomenon which includes physiological changes. The most common example is headaches when stopping caffeine. 3) Tolerance means you need to take more of a substance to get the same amount of symptom relief. Dr. Miransky stated that Ostomates have unique pain patterns. There is more of a burning sensation at the site which is neuropathic. Of course, this also could mean it is time to change your pouch. People who have stents in place often get colicky spasm type pain. There are older medications which were developed for other purposes which are especially effective for burning nerve pain such as anticonvulsants. These however, may affect one’s ability to concentrate. These drugs are Neurontin or gabapentin, and Lyrica. Antidepressants are Pamelor and Elavil. Cymbalta and Effexor are also good for the neuropathic pain. Pain medication is classified in context to the opium poppy. Morphine and Tylenol with codeine are the closest to the natural poppy. Partial synthetics are originally from the poppy but are manipulated in the lab. These include hydrocodone, oxycodone, and Dilaudid. There is another group of medication made only in the labs and never seen in nature. These are Fentanyl and Methadone for which a prescribing doctor needs specialized training as not understanding the prolonged half life differences in this medication can be fatal. NSAIDS go to the site of pain first but opioids go to the spine first and cut off signals going to the brain. Concurrently, this is the same key-lock system that is in the gastrointestinal tract which is why constipation becomes an issue. To relieve this side effect, Senna (up to eight per day) and docusate are the only effective medications because they turn the bowel “back on”. Stool softeners will not be effective on their own. Prunes, figs, and dates also may work because they irritate the bowel. It was also mentioned that ileostomy blockages can often be resolved with grape juice. Some stimulants may cause cramping. Other information re: medication is that short acting drugs dissolve mostly within the stomach in about thirty minutes. These last up to four hours. Sustained release drugs dissolve more slowly and are not as effective for ileostomates. It takes one to two hours for the medication to take effect and lasts usually about twelve hours. There is also a type of medication referred to as immediate release long acting. Any medication with this explanation should be effective for everyone. If you have rapid gastric emptying take pills without food so that they have a chance to absorb.



Colitis Ninja

On April 15th, 2014, I had my colon removed and began living my life with an ostomy for three months. Beginning life with an ostomy is not easy... and to those ostomates out there, you guys rock. So many of them are out there fighting the stigma and helping others every day. They even helped me on multiple occasions.

Though I only got to know the ornery Peeves the Stoma for three months before the takedown surgery for my j-pouch, I learned to appreciate him. Despite the fact that he once leaked into my lemon-sized abscess wound.

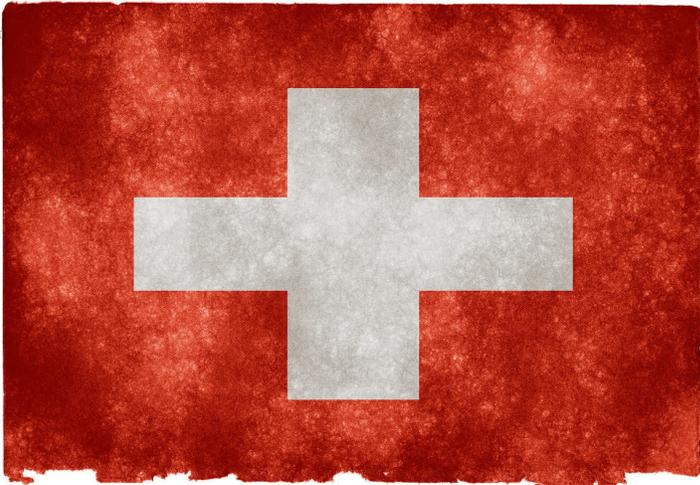
I kind of look back on that time fondly because I know that without my ostomy, I would not have met the amazing people I know today. During that time in my life strong bonds were built between complete strangers like nothing else I've experienced. I will treasure my life with an ostomy for that reason. I am humbled and grateful for every single one of them.

After living with Peeves for three months, I have realized three things:

- 1) If I ever have to go back to life with an ostomy, I definitely could. Though it isn't ideal to live without a colon, it's sure as heck better than living with a DISEASED colon.
- 2) If I ever have to go back to life with an ostomy, I know that I have the support (aka FRIENDS) I need. In the internet age, we have so many resources at our fingertips (The Stolen Colon, Vegan Ostomy, Journaling IBD, The Front Butt YouTuber, Empowering Patients and so many more I'm sure I've forgotten to mention – sorry guys, you know who you are!).
- 3) Having an ostomy does not make me ugly, smelly or disgusting. Living with an ostomy gave me my life back. And there's definitely something to be said about that. <http://colitisninja.com/2015/10/3-things-my-ostomy-gave-me/>

* * * * *

“ What’s the best thing about living in Switzerland? I don’t know, but the flag is a big plus.”





You Have Adjusted to Your Ostomy When...

From North Central Oklahoma *Ostomy Outlook*

- You stop spending all of your spare time in the bathroom waiting for your stoma to work so you can empty the pouch right away.
- You can move about freely, without holding your appliance as though it might fall off any minute.
- You make that first trip to the mailbox without taking along your ostomy supplies.
- You stop grabbing your abdomen when the grocery clerk asks if you need help to the car with your bag.
- You go out for the evening and realize too late that you left your emergency kit at home.
- You begin to think how lucky you are to be alive instead of how unlucky you are to have an ostomy.
- You attend the monthly support group meetings with an expectation of learning more about your ostomy rather than staying at home worrying about it all.

Ostomy Supply Resources — for low-cost options

Local Resources: The Ostomy Association of Albuquerque (OAA) maintains a supply closet of donated supplies at no cost to people who need them. Since the supplies are donated the available supplies vary. These supplies are helpful to people who have emergency needs, or who want to trial a different product and are flexible. It is not a good source to fill regular long term needs. To make an appointment and get directions contact the OAA by voicemail or email.

Manufacturer's Assistance Programs: All the major manufacturers sponsor programs for people without insurance coverage. They vary in the amount and length of time they offer assistance and you must complete a form to qualify.

Convatec 800-422-8811

Coloplast 877-781-2656

Hollister 800-323-4060

National Groups (Provide supplies but require shipping and handling costs)

Osto Group 877-678-6690

Ostomy 211 ostomysupplies.ostomy211.org (emergency supplies, donation requested)

Kindred Box- Resource on Facebook, kindredbox.org

Lower Cost Options

Best Buy Ostomy Supplies 866-940-4555

Mercy Supply Collaborative 888-637-2912

Ostomy4less 877-678-6694

Parthenon Ostomy Supplies 800-453-8898

Stomabags: 855-828-1444



Support Group and Medical Resources

New Mexico Ostomy Support Groups:

- ◆ Albuquerque: Ostomy Association of Albuquerque meets monthly in Albuquerque, NM.
For current info call voicemail: (505) 830-2135
Email: oa.albuquerque@gmail.com
Website: ostomyalbuquerque.com
- ◆ Albuquerque: VA Ostomy Support Group for military veterans. Meets at the VA Hospital, Albuquerque, NM. For current info call ostomy nurse at VA Medical Center Hospital voicemail: (505) 265-1711, Ext. 5171 or 5232 or 4411
- ◆ Las Cruces: Ostomy Support Group of Southern NM. Meets in Las Cruces, NM. For current info call ostomy nurse at wound care center: (575) -532-4399 or Rebecca Kroll, ostomy nurse, at C: 575-649-8249

Ostomy Care in Albuquerque, NM

- ◆ Lovelace Medical Center Ostomy Nurses:
(505) 727-8250
- ◆ Lovelace Medical Group—General Surgery — Ostomy Outpatient Clinic— Savanna Noel
(505) 727-7096
- ◆ Presbyterian Main Hospital Ostomy Nurses:
(505) 841-1251
- ◆ Presbyterian Outpatient Wound and Ostomy Care Clinic: (505) 823-8870
- ◆ UNM Hospital Inpatient Ostomy Nurses:
(505) 272-9098
- ◆ UNM Outpatient Ostomy Clinic M-F need referral sent to Fax (505) 935-1191
ph: (505) 272-2336
- ◆ Veteran’s Administration Hospital Ostomy Nurses:
(505) 265-1711 Ext: 5232 or 5171 or 4411

Manufacturer Resources:

- ◆ Coloplast Ostomy Supply Manufacturer:
(855) 385-3991 Web: www.coloplast.us
- ◆ ConvaTec Ostomy Supply Manufacturer:
(800) 422-8811
Web: www.convatec.com/ostomy
- ◆ Cymed Ostomy Supply Manufacturer:
(800) 582-0707 W: www.cymed.ostomy.com
- ◆ Hollister Ostomy Supply Manufacturer:
(888) 808-7456 Web: www.hollister.com
- ◆ Marlen Ostomy Supply Manufacturer:
(216) 292-7060 Web: www.marlenmfg.com
- ◆ Nu-Hope Labs Ostomy Supply Manufacturer:
(800) 899-5017 Web: www.nu-hope.com

Local Supply Resources:

- ◆ HME: (Home Medical Equipment) 2 Locations:
611 Osuna Rd. NE Albuquerque, NM
10801 Golf Course Rd., NW Albuquerque, NM
Web: www.hmespecialists.com
Cust. Svc. for both locations: (505) 888-6500
Toll free: (866) 690-6500
- ◆ Phillip’s Pharmacy: carry some ConvaTec supplies for over-the-counter (OTC) purchase
5510 Lomas Blvd NE Albuquerque, NM 87110
Cust Svc.: (505)-265-6868
- ◆ National Seating and Mobility: (formerly Sandia Surgical, Inc.) carry Coloplast, ConvaTec, and Hollister supplies for ongoing orders or OTC purchases
4431 Anaheim Ave. NE, Ste. A, Albuquerque, NM
Cust Svc.: (505) 883-2817 Toll free: (800) 753-1589
FAX : (505) 355 6691 Web: www.nsm-seating.com

Join Our Albuquerque Ostomy Support Group

OSTOMY ASSOCIATION OF ALBUQUERQUE MEMBER APPLICATION

The Ostomy Association of Albuquerque (OAA) is a member of the national American Ostomy Association. This allows us to have access to all the latest ostomy information available for our use. The OAA annual membership fee is \$20.00 and can be paid by check or cash. If being paid by check, make the check payable to Ostomy Assn. Of Albuquerque. Your payment can be mailed to OAA, PO Box 35598, Albuquerque, NM 87176-35598 or at any monthly meeting. If you are financially unable to pay this fee, please call 505-275-2470 and leave a message with your name and telephone number and someone will contact you. Please complete the form below as best as you can and all information will be used for our records and be kept confidential.

NAME: _____ DATE OF BIRTH: _____

STREET ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

E-MAIL: _____ PHONE NUMBER: _____

OCCUPATION (If retired, enter former occupation): _____

HOBBIES: _____

CHECK ALL THAT APPLY:

Colostomy Ileostomy Urinary Diversion Continent Ileostomy Continent Urostomy Pull-Through
 Parent with Child Procedure Spouse/Family Member Physician Nurse Other _____

Year of Surgery: _____ Reason for Surgery: Crohn's Ulcerative Colitis Cancer Birth Defects

I have enclosed an additional \$ _____ as a donation to support the ongoing work of the OAA

Join United Ostomy Association

UOAA's Mission

UOAA is an association of affiliated, non-profit, support groups who are committed to the improvement of the quality of life of people who have, or will have, an intestinal or urinary diversion.

- It is dedicated to the provision of information, advocacy and service to, and for, its affiliated support groups, their members and the intestinal/urinary diversion community at large.
- It is organized to grow and develop while remaining independent and financially viable.

Membership in UOAA is open to any non-profit ostomy support group that meets UOAA's affiliation requirements. UOAA has an IRS Group 501(c)(3) charity status that its affiliated support groups can use.

1-800-826-0826

Save the Date and Start Your Vacation Fund!



Get Ostomy Answers!

The Phoenix is the leading national magazine for ostomates, their families and caregivers. Subscriptions directly fund the nonprofit United Ostomy Assoc. of America – the only national organization providing vital information, resources, support and advocacy for ostomates.

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Note* there is a less expensive e-version available.



Officers and Chairpersons of OAA Chapter

President: Brian Leen

505-856-0203

Vice President: Ben Palmer

505-828-0936

Treasurer: Barbara Regan

703-261-3920

Secretary: Vacant (interim)

Voicemail and Visitation Coordinator:

Brian Leen, 505-856-0203

Telephone Reminder: (volunteer?)

Ostomy Supply Closet:

(donations & supplies closet)

Eunice Hoeft

Call ahead; 505-889-9705

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damorebd@aol.com

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Marjorie Abbott 505-263-5301

sweetscat2008@gmail.com



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About Us

Ostomy Association of Albuquerque (OAA) is organized to support people with ostomies and their caregivers in the New Mexico region. OAA publishes *The Roadrunner* newsletter quarterly to inform and update its members.

Membership is \$20.00 a year and includes the Roadrunner newsletter and monthly informative meetings. This money is used for promotional purposes and expenses of the OAA. Although chapter membership is encouraged, anyone with financial hardship, should see the Treasurer or President for help in this matter. No one is denied based on ability to pay.

Meetings are monthly at 2:00 PM in the meeting room of the Cherry Hills Library 6901 Barstow St NE 87111. Meetings are usually held on the first Sunday of every month. Since there are occasional changes due to holidays, please refer to *The Roadrunner*

for information or call the association's voicemail.

Executive Board Meetings are held the 3rd Thursday of each month at 7p.m. on Zoom. All members are welcome contact Brian Leen at least one day prior to the meeting for log in information

Affiliation: Ostomy Association of Albuquerque (OAA) functions as a chapter affiliate of the national organization supporting people with ostomies-- the United Ostomy Association of America (UOAA).

The UOAA holds biennial national conferences. They publish the wonderfully informative *Phoenix* magazine four times a year. There is a subscription cost for this publication. UOAA has a great website with all kinds of information available for free. Much of it is available in any language on earth!

Contact Information:

United Ostomy Association of America (UOAA)

P.O. Box 525

Kennebunk, ME 04043-0525

1-800-826-0826

Web: www.ostomy.org

Find them on Facebook and Twitter.



Postmaster: Contains Dated Material.
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P.O. Box 35598
Albuquerque, NM 87176

Ostomy Association of Albuquerque



Helping each other to live well and do the things we love!

How to Keep in Touch with Us

Contact us: For info please call voicemail 505-830-2135 or Email us at oa.albuquerque@gmail.com

Unsubscribe or Change to Mailing Address or Email: For any of these changes, please notify the sender by return Email. If your change concerns mailed copies, please call person in charge of mailing or send back cover page with your address and changes requested to return address. Thank You.

Supplies: If you have new and unused supplies you no longer need, please bring them to a support group meeting to be given to those who need them.

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