

The Roadrunner



Newsletter of the Ostomy Association of Albuquerque, NM

Next Meeting

Sunday, February 4, 2018

1 PM

Executive Board Meeting, Aspen Room (Open to All)

2 PM

Support Group Meeting, Aspen Room

Support Group Updates and Events

*Please mark your calendar

Our regular meeting for April this year falls on April 1, which is Easter Sunday 2018. OAA did not want you to have a conflict between our April meeting and sharing the holiday with your family and friends, so with Presbyterian Kaseman's permission we have moved the meeting to Sunday April 8th. The time is still 2 P.M. and the meeting place will be the Aspen Room as usual.

I hope all of you enjoyed the Fiesta Luncheon January 7, at Pelican's Restaurant, as much as I did. It is always such a special day at the beginning of the New Year, to get together with our group and just relax over delicious food and share a couple of hours with friends who we only talk to at meetings where our focus is how to help each other with our mutual challenges. Those of you who were unable to attend please put our "Fiesta Luncheon" on your calendar for 2019, we missed you.

Volume 52 Issue 1

February 2018

Upcoming Meetings:

- February 4, 2018 (quarterly)
- March 4, 2018
- April 8, 2018 * (Second Sunday)
- May 6, 2018 (quarterly)

Meetings are at 2 PM
in Aspen room
at Kaseman Hospital
unless otherwise stated.

Inside this issue:

"President's Message"

"A Tale of 2 Hospitals"	3
"2 Hospitals cont."	4
"ABQ, Your Care"	5
"Allergic? How to tell"	6
Resources	7
Membership Forms	8
All About OAA	9
Contact Us	10





PRESIDENT'S COMMENTS

By Brian Leen, President OAA, NM

We are starting a discussion within the Board as to whether we should drop our dues and instead use donations to come up with the money we need. We heard about this from a briefing by one of our sister groups at the last UOAA National convention. What are the advantages of doing this? First, there is no question that everything a person gives to us is a "donation" and is deductible from taxes. Second, there are a certain number of people who do not join because they look at dues as a quid pro quo and do not feel that they gain a benefit commensurate with the dues or they simply cannot afford them, Third, we lose people who just don't happen to show up when we are collecting dues and get dropped from the rolls. Fourth, the groups said those who do donate, give more than the amount that we can ask as dues. The argument against changing will be provided in the May issue of the Roadrunner but generally seems to say everyone should bear an equal financial load. In my mind, the financial support is the least important thing that our members provide. Time and empathy and support for newcomers struggling to adjust to an Ostomy are, to me, far more important. Or taking time to assist us on projects working with outside agencies, internal tasks like maintaining a website or Facebook page. Perhaps filling one of the board positions like secretary, treasure, or membership chairman. To me, it

is just not a financial calculation. Yes, we do need some money and if we move to a commercially provided website we may need more. But I believe we can raise what we need through donations from members during regular pledge drives that are separated from the annual Fiesta.

So where do we go from here? We will have discussions at the board meeting, beginning in February and, if it is decided to proceed, would probably present it to the membership for a vote in the fall, early enough for us to adjust prior to beginning the 2019 dues collection campaign. I will support whatever the final decision is and we can make either work. The bottom line is that we need to be an organization that reaches out to Ostomates in need and at the same time provides a venue



that is useful and satisfying to long time members and Ostomates and thus helps to retain members.







(Or Make Sure Your Doctors Participate!) by Sharon Householder, Pittsburgh Ostomy Society, Nov 2017

An article on www.medscape.com by Norra MacReady states "A primary care physician (PCP)'s prior knowledge of a patient has a significant effect on outcomes when that patient is hospitalized." It goes on to say that "care by a PCP who had previously seen the individual as an outpatient was associated with a greater chance of being discharged home and a lower 30-day mortality compared with care delivered by a hospitalist or generalist who had never met the patient before. These findings can be especially important for patients with multiple illnesses and those who require a complex level of care."

None of us ever want to go into the hospital. However, if you are like me, you have multiple issues that have nothing to do with your ostomy. I decided to write this after my last inpatient stay to encourage you to plan ahead 'just in case.).

I have had doctors that I loved and doctors that I didn't care for through the years, but I obviously settled on those that I trusted and who treated me well. Unfortunately, I never gave thought to what hospital they were affiliated with, or to what hospital I would want to go to in an emergency – and then it happened!

It happened that I had a problem with my continent ileostomy so I went to the nearest ER. I ended up having emergency surgery and a 3 week hospital stay. Unfortunately, not one of my regular doctors practiced there so they were not allowed to come in and treat me. My treatment was now at the mercy of Hospitalists. (A hospitalist is a doctor who only treats patients

while in the hospital. There is no continuity of care once you leave.) Not having a doctor who knows your history, understands your unique needs, is aware of past treatments that worked or didn't work, or who you have a relationship with is problematic. I spent most of every day trying to make the staff understand about my ileostomy, how it was cared for, why a specific treatment wasn't going to work, etc. For instance, those of us with ileostomies cannot take extended release meds because they don't stay in our system long enough, but I was constantly given 12 hour tablets which wore off in 4-5 hours. There were other examples – I was in the ICU 3 times, twice because my secondary conditions were not being optimally treated. It was not a pleasant experience overall.

When I finally got home, I decided that the hospital I just left was where I would want to return in the future due to its location. So, I had to search for a new PCP, Endocrinologist, Gastroenterologist, etc. that could practice in that institution. I'll admit it wasn't something I was looking forward to but it was necessary. I first went online on my insurance carrier's website to find out which doctors in my area had privileges in my designated hospital and then made appointments to meet them. It took time, but I now have a team of doctors who know my medical history and who can attend to me if I am admitted. I am in the process of developing those deep relationships that I had previously.

Fast forward to a few weeks ago. I once again was admitted into that same hospital via the emergency room. This time, the doctors who came in were familiar with

(Continued on page 4)





A Tale of Two Hospital Visits (Or Make Sure Your Doctors Participate!) by Sharon Householder, Pittsburgh Ostomy Society, Nov 2017

(Continued from page 3)

me and had all my medical information. They quickly admitted me rather than keeping me in the observation unit or sending me home. The endocrinologist knew how to treat my Adrenal Insufficiency correctly – with no errors. My PCP quickly revised some of the medicines that the nurses were giving me to make sure I could digest them properly and brought in additional specialists based on my immediate needs

My PCP coordinated all my care, and on my last day there, even came in with all 4 doctors who were treating my symptoms to discuss what follow up was needed, made sure appointments were scheduled, and confirmed that I had scripts for medication and the follow up labs I was going to need once I went home. It worked like a 'well-oiled machine.' Overall, a much better experience!

So, why did I share this story? I want to encourage you all to make plans for the unexpected. We never know when it will happen, but we know it will.

What should I do?

Determine which doctors you want to care for you both when you are doing well and when you are not doing well.

Find out in which hospital your preferred providers have privileges to practice.

Make a decision on what hospital you want to use based on location, quality of the facility, and/or where your providers are allowed to practice. Let your family and friends know this is where you prefer to go in an emergency.

Make adjustments in your lineup of doctors according to your decision. You may want to keep a physician who does not practice in your preferred hospital even though they won't be available during your stay. They can be contacted by the staff if needed.

Other preparations that I found are helpful: Keep a list of all prescriptions, over the counter medicines, diagnosis, recent treatments, surgeries, physicians, etc. handy. It will make things much easier when you aren't feeling well and are asked a 'million' questions.

Have an 'emergency bag' ready to grab that contains your ostomy supplies and a few personal items (comb, toothbrush, etc.) and let your family or friends know where to find it in case you have to stay overnight.

Finally, if you have a Living Will/Five Wishes, etc., send a copy to the hospital and each of your preferred doctors so they have it on file if it is ever needed. I hope you never need any of this information, but it's better to be ready in an emergency situation than to have it happen and you are unprepared.







Sue Mueller BSN, RN, CWOCN-colostomate

Within the Albuquerque community there are three basic healthcare systems for medical/surgical hospital care: Presbyterian (Presbyterian Hospital, Presbyterian Rust Medical Center and Presbyterian Kaseman Hospital), Lovelace (Lovelace Medical Center, Lovelace Women's Hospital, Lovelace Westside), University of New Mexico (UNM Hospital, UNM Sandoval Regional Medical Center). There are physician groups linked to each hospital system and independent groups which may have hospital privileges in more than one hospital. Lovelace has practice agreements with the UNMH system but Presbyterian has arrangements that are limited to needs that cannot be treated in their system. In the article "A Tale of Two Hospital Visits" Sharon Householder speaks of her PCP coordinating her care. I don't believe there are any PCP's that practice in the hospitals in Albuquerque so we do not have the option of a PCP coordinating hospital care. Specialists who practice in the community may practice in the hospitals as consults to the main team of "Hospitalists" and Intensivists (ICU specialists). Specialists in the community could include endocrinologists, surgeons, infectious disease physicians.

Communication is a constant challenge in healthcare and we should do whatever we can to promote the exchange of information. If all your treating physicians are within the same system it facilitates communication. Just as you make sure that all your healthcare providers are covered by your insurance make sure that all are in the same healthcare systems.

Maintain a list of your prescription medications and supplements and the specialists involved in your care. Maintain a list of your ostomy supplies with the manufacturer and manufacturer reference numbers. Healthcare facilities are not required to provide you

with the exact supplies that you normally use, that would require an immense and costly inventory but they should be able to offer supplies in the appropriate category (ex. one piece and two piece pouches, urostomy specific pouches). If you have determined that the pouch combination that you utilize could not bear substitution then I would bring my supplies to the hospital. In the event that you are too ill to communicate make sure your designated advocate has your lists. Every time you go to the hospital have a COPY of your advanced directives with you, even if you submitted a copy the very last time you went to the hospital.

Be prepared to give a brief medical history, including allergies and noteworthy specifics of your care needs. Despite the fact that you have been admitted to the hospital numerous times you cannot assume that your doctor knows your history. Its probably best to assume that none of your healthcare providers knows anything about ostomies so you will need to mention for example that as an ileostomate you normally don't take laxatives or extended release or long acting medications, that you require a special diet.

Don't leave your medical care to chance-









ALLERGIC?? HOW TO TELL FOR SURE

Stillwater Ponca City (OK) Ostomy Outlook, June 2001 via Winnipeg Inside/Out, Nov/Dec 2016

Many times I hear that people are allergic to adhesive tape, or paper tape, skin prep, or any number of different products that are used in ostomy care. Allergies can occur with any product; they can occur with the first use of a product or after years without problems. Most people never have an allergic reaction, but a few are plagued with multiple sensitivities. However, many things assumed to be an "allergic" reaction may be another problem. It is important to know whether or not you are truly allergic to a product, because eliminating products reduces your options. Believing you are allergic may cause you not to try a pouch that might be perfect for you. Allergic reactions are usually severe and cause blisters and/or weeping skin wherever the pouch touches.

Two situations are frequently labeled as allergic by mistake:

First, if a skin sealant wipe is used, it needs to dry completely to allow the solvents to evaporate. If the pouch is applied while the solvents are still on the skin, sore skin can easily occur. Since the solvents can't evaporate through the skin barrier as they can through the paper tape collar, this will look like an allergy to the skin barrier.

Second, each time you remove a pouch, the adhesive takes with it the top layer of dead skin cells. However, if you are removing a pouch frequently, cells can be removed faster than they are replaced. This is called "tape stripping." Everyone's skin reacts differently to having tape removed. But it's important to be gentle and not remove a pouch more frequently or quicker than necessary. Skin that is stripped will be sore in some spots and not in others. Sometimes skin around the stoma becomes fragile and strips easily, and a pouch and tape with very gentle adhesive must be found.

To check whether you are really allergic, take a small piece of skin barrier or tape and place it on the other side of your abdomen or, with the help of someone else, on your back. After 48 hours, take it off and see whether you are reacting. (If pain, itching or blistering occurs, take it off immediately.) If it's an allergy, you will react. If you have a history of allergies, test this way before trying on a new pouching system. It's better to have a patch of sore skin on your back than around the stoma, where you need a good seal.

If you develop an allergy to a product you have used for a long time, you can call the manufacturer and find out if they have made changes in the manufacturing process. Calls from users are sometimes their first notice that the new improvements aren't working.







Medical and Support Group Resources

New Mexico Ostomy Support Groups:

<u>Albuquerque</u>: Ostomy Association of Albuquerque meets monthly in Albuquerque, NM. For current info call voice-

mail: (505) 830-2135

Email: oa.albuquerque@gmail.com

<u>Albuquerque</u>: VA Ostomy Support Group for military veterans. Meets at the VA Hospital, Albuquerque, NM.
For current info call ostomy nurse at VA Medical Hospital

voicemail: (505) 265-1711, Ext. 5171

<u>Las Cruces</u>: Ostomy Support Group of Southern NM. Meets in Las Cruces, NM. For current info call ostomy nurse at Memorial Medical Center voicemail: (575) 640-5242 or (575) 521-5038

Other Hospital Contacts in Albuquerque, NM (not having a support group):

Lovelace Medical Center Ostomy Nurses:

(505) 727-8250

Presbyterian Main Hospital Ostomy Nurses:

(505) 841-1251

Presbyterian Outpatient Wound Care Clinic:

(505) 823-8870

University Medical Center Hospital Ostomy Nurses:

(505) 272 9098

Manufacturer Resources

Coloplast Ostomy Supply Manufacturer:

Local Representative: new one coming

Phone and email unknown

Coloplast Care Program

1-(877) 858-2656

ConvaTec Ostomy Supply Manufacturer:

Local Representative: Tim Canning

Phone unknown <u>Tim.Canning@convatec.com</u>

CYMED Ostomy Supply Manufacturer: (Microskin pro-

ducts) Local Representative: none

<u>www.cymedostomy.com</u> 1 (800) 582 0707

For samples: <u>samples@cymedostomy.com</u>

EDGEPARK Medical Supplies:

www.edgepark.com 1-888-394-5375

Hollister Ostomy Supply Manufacturer:

Local Representative: Leslie Sisk

Email, leslie.sisk@hollister.com

1 (405) 819 – 5635

Cust. Svc: Richard Wysocki 1 (888) 808 7456

Marlen Ostomy Supply Manufacturer: www.marlenmfg.com

1 (216) 292 7060

Nu-Hope Ostomy Supply Manufacturer:

1 (800) 899 5017 www.nu-hope.com

Stomacur Ostomy Supply Manufacturer: www.forlife.info

TORBOT Ostomy Supply Manufacturer: 1 (800) 545 4254

www.torbot.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 financilly 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. DATE OF BIRTH: NAME: STREET ADDRESS: STATE: ZIP: CITY:__ 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 [] Physican [] Nurse [] Other__ Year of Surgery; ____ Reason for Surgery: [] Crohn's [] Ulcerative Colitus [] Cancer [] Birth Defects I have enclosed an additional \$_____ as a donation to support the ongoing work of the OAA

Join United
Ostomy
Association
of America

Save the Date

The next UOAA National Conference will be held in 2019.



UOAA's Mission

UOAA is an association of affiliated, nonprofit, 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

Website: www.ostomy.org

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. Subscribe Today! PESCENIX Start or Renew One-year: \$29.95 Two-years: \$49.95 Payable to: The Phoenix magazine, P.O. Box 3605, Mission Viejo, CA 92690 Name Address Apt/Sulte Gity State Zip * Based on \$9.95 cover price. Canadian subscriptions: \$35 one-year, \$60 two-year, U.S. funds only.





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505-856-0203

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505-249-7770

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703-261-3920

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505-242-2173

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Gerry Copeland: 505-856-6045

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(donations & supplies)

Eunice Hoeft

Call ahead; 505-889-9705

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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 Aspen Conference Room at Presbyterian Kaseman Hospital. 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 at 1 PM prior to the Quarterly meetings (Feb, May, Aug, and Nov.) in the Aspen Room. Everyone is welcome to attend and participate.

<u>Directions</u>: Address: Kaseman Hospital, 8300 Constitution Pl., NE; Albuquerque, NM. Kaseman Hospital is one block North of I-40 and Wyoming Blvd. Then it is about one block West of Wyoming on Constitution. Drive to West end of parking lot and enter the Emergency Room entrance. Take an immediate left, go through double doors and find Aspen room on the right side.

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. They have 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

P.O. Box 525

Kennebunk, ME 04043-0525

1-800-826-0826

Web: www.ostomy.org

Find them on Facebook and Twitter.

Please do not delay.

Postmaster: Contains Dated Material.

P.O. Box 35598
Albuquerque, NM 87176

Ostomy Association of Albuquerque







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

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Thanks to the American Cancer Society for Printing and Postage!