MEETING ANNOUNCEMENTS

Saturday, May 19, 2018 @ 10:30 AM
Please welcome Theresa Pineda, RN, CWOCN from Florida Hospital Wound and Ostomy Clinic. The meeting is in the 1st Floor Library Room.

Saturday, June 16, 2018 Luncheon at Noon
Boston's Fish House
6860 Aloma Avenue
Winter Park, FL 32792
(Aloma Square Shopping Center)
Please RSVP to Shelley at 407.929.3668 or shelleydittmer@gmail.com

MEETING INFORMATION:
Our fellowship meetings offer an exchange of valuable information offered by our speakers, members, and guests. All are welcome, especially supporting family and friends. Coffee is provided and donated treats are always welcome.

MEETING LOCATION:
Winter Park Memorial Hospital Library, 200 N Lakemont Ave. The Library is adjacent to the parking lot and has large black letters “LIBRARY” above the entrance.

If you are not a member, please join us. Our low annual dues of $20.00 are not mandatory, but allow us to continue our programs to help others. Donations to the Ostomy Association of Greater Orlando, Inc. are tax deductible.

FOR MEMBERSHIP INFORMATION PLEASE CONTACT
Shelley Dittmer 407.929.3668
Evelyn Vihlen 407-862-6567
If you are not interested in receiving the Newsletter please call or email us at ostomyorlando@aol.com

DO YOU HAVE INTERNET ACCESS?
If you have internet access you can help reduce our costs by electing to receive the newsletter via email. Please call Shelley at 407.929.3668 or email us at ostomyorlando@aol.com. Thank You.

PLEASE DONATE YOUR UNUSED OSTOMY SUPPLIES
If you have unused supplies please bring them to our meetings or call Evelyn Vihlen at 407.862.6567 or Jack Vreeland at 407.415.8855. Donated supplies are given free of charge to those without insurance.
What’s going on at OAGO?

PRESIDENT’S MESSAGE

Happy Spring everyone!
This is my farewell message to all my “Peeps.” I am not leaving town right now; only my office as your President.

There are many capable hands to carry on. So I hope you will join me in welcoming Erica Michaels as our new President. I formally nominate her. We can vote on this at the meeting to make it official!

We also need other officers. Here is the slate as I see it.

Erica Michaels - President
_________ - 1st Vice President. (Your name can be here)
_________ - 2nd Vice President. (Your name can be here)
Patrick Rodgers - Treasurer.
_________ - Secretary. (Your name can be here)
Shelley Dittmer - Immediate Past President. (Not an official office)
_________ - Sargent at Arms. To make sure the meeting room is prepared. (Your name can be here)

Now we need others as well.
Board members - This really does not take lots of time to be a board member. We just need your ideas.
Visitor Chairman - Organize visitations. (We are working on training)

I have to say I have loved meeting all of you. I just need a break from leadership. There is so much fulfillment in seeing a person go from pure distress about this new life to getting out an accomplishing things that they never thought would be possible again.

As the saying goes “Many hands make light work” Join the team and add you special talents! I know they are many!
I love you all! Shelley Dittmer, retiring president

2018 YOUTH RALLY

The 2018 Youth Rally will take place July 16th - 21st in Boulder, CO. The mission of the Youth Rally is to provide an environment for adolescents living with conditions of the bowel and bladder that encourages self-confidence and independent living. There is still time to make a donation by going to www.youthrally.org and clicking “DONATE” in the left-hand column of their home page.

MEMBERSHIP APPLICATION & RENEWAL FORM

Membership in the Ostomy Association of Greater Orlando, Inc. is open to persons with all types of intestinal and urinary diversions, as well as supporting family, friends, organizations, and businesses. This form may be used for both new memberships and renewals.
Renewals are due on January 1 of each year. Thank you for your support.

PLEASE PRINT
Name: ___________________________ Date: ____________
Address: __________________________________________ City: __________________________
State: ______ Zip: ______ Phone: __________________________ Alternate Phone: ____________
Email Address: __________________________ Date of Birth (optional): ____________

Type of diversion(s) - Circle all that apply or check None. Information will be kept CONFIDENTIAL.
Ileostomy Colostomy Urostomy Ileoanal Reservoir/J-Pouch Continent Ostomy Other: ____________ Date of Surgery: ____________ None: __

Dues and Donations (Donations are tax deductible)
$20.00 Enclosed are my dues for membership in the Ostomy Association of Greater Orlando, Inc.
_________ Enclosed is an additional donation to support all of our ongoing programs.

Please make checks payable to the OAGO. Bring this form and payment to our next meeting, or mail to:
Patrick Rodgers, Treasurer
309 E Citrus Street
Altamonte Springs, FL 32701

“The best way to find yourself is to lose yourself in the service to others.” Mahatma Gandhi
A new concept of continent ileostomy by OstomyCure AS aims to dramatically change the patients’ quality of life.

In 1947, a young lieutenant-colonel was discharged from the Royal Army Medical Corps to become a lecturer in Surgery at The University of Birmingham and worked at Queen Elizabeth Hospital England—he would spend the next 16 years there. In July, 1952 he published a paper about the care and complications of ileostomies. As part of the text, he described a procedure that would turn the end of the ileum inside out and suture the mucosa to the skin. It was Dr. Bryan Brooke who created that technique—a stoma that protruded but was inverted.

As Doreen Harris recalls, “I had my ileostomy in 1947 and was one of only four or five people in the world who had the surgery. Very little was known about the effect of it on the body and certainly no one knew how to deal with it. In those days, surgeons refused to operate because appliances were useless. We were allowed to perforate and I had holes all over my abdomen through which there was a constant flow of feces.” Doreen would work with Dr. Brooke and others in founding IA®, the Ileostomy and Internal Pouch Support Group, and organizing the first support groups in England. The IA®, now in its 62nd year, is one of the oldest ileostomy and internal pouch support groups in the world.

As we enter the 66th year of the Brooke Procedure, another possible paradigm in surgical treatment is in the offering, and once again it is coming from across the pond. In Oslo, Norway a company called OstomyCure AS, has developed a revolutionary solution for ileostomy patients. The Transcutaneous Implant Evacuation System, TIES® System, promises a life without skin barriers and pouches.

Instead of conventional stoma surgery in which the intestine is extended a few centimeters outside the abdomen wall, a small tube of titanium is implanted into the abdomen where the intestine and soft tissue grow into it. The implant then becomes an extension of the intestine and sticks out a few millimeters on the outside of the abdomen where it is sealed with a lid that the patient can open to drain whenever necessary. The lid quite simply functions as a stopper. The new solution (implant and lid) aims to make life easier, more comfortable and increase the quality of life for many patients. OstomyCure AS site states, “the TIES® implant is designed for life-long use and will dramatically reduce skin problems as the device only needs to be cleaned with tap water and no disinfectants or glue will be used.”

Dr. Benedict Broennimann, CEO of OstomyCure AS, says: “The new implant integrates well in the body. There were no infections or rejections. The first patient went well and the implant is working great with the lid. The patients went back to work, to do sport and even going to the swimming pool. The implant has been CE marked in June 2016 and will be distributed in selected markets.”

The direction of the TIES® System is to provide an ileostomate with a non-adhesive appliance that decreases the occurrence of skin and leakage problems. TIES® implant has received the European Union’s CE Mark, meaning it has met their safety requirements for medical devices. Clinical trials began in 2009 and are scheduled to begin again in April, 2018 with follow-up through 2019. These trials will take place in Sweden and England. "We know that TIES Solution is a safe concept for ileostomy patients. What we would like to establish is a scientific base which will prove our product claims in a small number of clinical centers” says Dr. Broennimann. OstomyCure AS plans to be in the United States and Canada in 24 to 36 months. Only time will tell if these trials lead to the next paradigm in the treatment of bowel diseases.


Sign up for our weekly newsletter at ostomyconnection.com and never miss a post.

“Lettin’ the cat outta the bag is a whole lot easier’n puttin’ it back.” Will Rogers
9 Interesting Facts About President Dwight D. Eisenhower

The last one is the most interesting, obviously.

OC EDITORS, February 19, 2018, featured on OstomyConnection.com

Here are nine things you might not know about the 34th President of the United States.

1. He was born on October 14, 1890 in Denison, Texas. On the Texas Historical Commission it says that Eisenhower was the first U.S. President born in Texas, and he was the only one of David and Ida Eisenhower’s seven children born in Texas.

2. He had an appendectomy in 1923. According to some sources, after having several episodes of right lower quadrant pain beginning a year earlier, an examination showed that Eisenhower had "chronic catarrhal appendicitis."

3. He was the first President who held a televised news conference. The Baltimore Sun wrote that millions of American TV viewers tuned to watch 28 minutes and 25 seconds of footage from the history-making broadcast in 1955.

4. He was a U.S. Army Five-Star General. Nine Americans have been promoted to five-star rank. On December 20, 1944, Dwight D. Eisenhower was one of them.

5. He was the first President to ride in a helicopter. History.com says that on July 12, 1957, Eisenhower became the first President to ride in a two-passenger Bell H-13J helicopter to Camp David.

6. He had a sudden heart attack in September, 1955. The White House facts state that during a vacation in Colorado, President Eisenhower suffered a heart attack and was rushed to Denver’s Fitzsimmons Army Hospital. He remained in the hospital for nearly seven weeks.

7. He signed the Federal-Aid Highway Act of 1956, creating what is now known as the interstate highway system. President Eisenhower considered it one of the most important achievements of his two terms in office, and historians agree.

8. He was diagnosed with Crohn’s disease. It was documented that President Eisenhower had episodic lower abdominal pain for 33 years after his appendectomy. UTHealth states on May 10, 1956, six months before the election, a small bowel series led to the diagnosis of Crohn’s.

9. He had ileostomy surgery in 1956. HealthLeader magazine writes that President Eisenhower had ileostomy surgery on June 9, 1956 — less than a month after the Crohn’s diagnosis. He recovered remarkably well, and began conducting official business again five days after the surgery.

"Every gun that is made, every warship launched, every rocket fired, signifies in the final sense a theft from those who hunger and are not fed, those who are cold and are not clothed."

– Dwight D. Eisenhower
Operator: “Please deposit ten, seventy-five.
Caller: “But I said I wanted the charges reversed.”
Operator: “Fine! Deposit seventy-five, ten.”

From “Down Time” by Ron Dentinger, Comedian; Books by Ron Dentinger available on amazon.com and other book retailers.

Quality of Care Resource at the Centers for Medicare and Medicaid Services (CMS)
By Jeanine Gleba, UOAA Advocacy Manager; via UOAA Newsletter, March 2018 and UOAA blog post; and featured on North Central Oklahoma Ostomy Outlook newsletter.

The overall goal of the UOAA Patient Bill of Rights (PBOR) initiative (www.ostomy.org/bill-of-rights/) is to ensure high quality of care for people who had or will have ostomy or continent diversion surgery. To accomplish this, it’s important that patients and families actively participate in patient health care.

According to CMS an integral part of the U.S. Department of Health and Human Services’ (HHS) National Quality Strategy is the CMS Quality Improvement Organization (QIO) Program. It is one of the largest federal programs dedicated to improving health quality at the community level.

Under the QIO program there are two Beneficiary and Family Centered Care-QIOs (BFCC-QIOs) who help Medicare beneficiaries and their families exercise their right to high-quality healthcare. The two BFCC-QIOs are KEPRO and Livanta and they serve all fifty states. BFCC-QIO services are free-of-charge to Medicare beneficiaries.

Depending on where you live (Locate your BFCC-QIO at qioprogram.org/locate-your-qio) they are available to help Medicare beneficiaries and their families or caregivers with questions or concerns such as:

- Am I ready to be discharged from the hospital?
- Should I be receiving needed skilled services such as physical therapy, occupational therapy, from a home health agency, skilled nursing facility, or comprehensive outpatient rehabilitation facility? (Care from a certified ostomy nurse is a skilled service.)
- I’m concerned about the quality of care I received from my hospital, doctor, nurse or others.

Examples of quality of care concerns that pertain to our PBOR include but are not limited to:

- Experiencing a change in condition that was not treated (such as skin infection around stoma)
- Receiving inadequate discharge instructions (such as inadequate individual instruction in ostomy care, including the demonstration of emptying and changing pouch or no instruction on how to order ostomy supplies when you leave the hospital)

*Why should Medicare Beneficiaries contact their BFCC-QIO with concerns?*

First, BFCC-QIOs can help when you have a concern about the quality of the medical care you are receiving from a healthcare facility (e.g. hospital, nursing home, or home health agency) or professional. You can also file a formal Medicare complaint through your BFCC-QIO.

Furthermore, according to CMS, when Medicare beneficiaries share their concerns with their BFCC-QIO, they help identify how the health care system can better meet the needs of other patients. Beneficiary experiences, both good and bad, give the QIO Program the perspective to identify opportunities for improvement, develop solutions that address the real needs of patients, and inspire action by health professionals. This is what we are working towards achieving with our PBOR initiative. This is a resource to help the UOAA community make this happen.

Last, Medicare beneficiaries have the right to file an appeal through their BFCC-QIO, if they disagree with a health care provider’s decision to discharge them from the hospital or discontinue services, or when they have a concern about the quality of the medical care they received from a health care professional or facility.

Continued on Page 7...
Care for one...that’s Love. Care for hundreds...that’s Nursing.
The New Ostomy.org Website is Now Live!
from UOAA Newsletter, March 2018, and featured on North Central Oklahoma Ostomy Outlook newsletter.

Get the trusted ostomy and continent diversion resources of UOAA in a new way.

*Get Educated *Be an Advocate *Feel Supported

From Our President

After lots of hard work from our team we are excited to announce the launch of our new ostomy.org website! Discover our extensive ostomy information and guides, peer-support group information, events, advocacy program, personal stories, blogs, product and supply information and much more – all in a new mobile and user-friendly website.

Enjoy and share the news of this great resource!

Susan Burns
Visit our website at ostomy.org

Quality of Care Resource at the Centers for Medicare and Medicaid Services (CMS)
...Continued from Page 5

*When and who should Medicare Beneficiaries contact?

A Medicare beneficiary can call 1-800-MEDICARE or your Local State Health Insurance Assistance Program (SHIP: www.shiptacenter.org) if he or she:

- Has general questions about Medicare coverage;
- Needs clarification on how to enroll in Medicare;
- Wishes to discuss billing issues.

A beneficiary can contact their BFCC-QIO if he or she:

- Needs to discuss the quality of care received;
- Wants to file a formal quality of care complaint; or
- Needs help to understand his or her Medicare rights.

While BFCC-QIOS are the primary point of contact for Medicare beneficiaries and their families, when necessary, quality of care complaints can also still be made by calling 1-800-MEDICARE.

For those interested in learning more about what to do if you have a concern about the care you received while on Medicare, please refer to the CMS FAQs page at: qioprogram.org/sites/default/files/FAQs_for_Medicare_Beneficiaries.pdf

Be involved in your healthcare and, if you are a Medicare beneficiary, take advantage of this resource to self-advocate and ensure a better outcome for yourself.

* Source qioprogram.org

COLOSTOMY BOWEL CONTROL

Edited by B. Brewer, UOAA 1/2011

Patients with a right-sided colostomy do not have as much remaining colon as those with a left-sided colostomy. Because of this, there is usually too little colon left to absorb enough water to make a solid stool. This type cannot be controlled by irrigation, but instead behaves very much like an ileostomy with a fairly continuous discharge. The left-sided colostomy is often described as a dry colostomy because it discharges formed stool. One has the choice of attempting to manage this type either by trained control or irrigation control.

Only one-third of the people who attempt to train themselves to control the colostomy without irrigation are successful in doing so. This type of training relies very heavily on diet and medication to achieve regularity. Many physicians in this country feel that control is more easily and satisfactorily achieved by irrigation. However, there are some patients who cannot achieve irrigation because they have an irritable bowel. This problem has nothing to do with the colostomy. It is just part of some people's makeup. Some people, even before they have their colostomy, may have very irregular bowel habits. They retain these habits after the colostomy is performed, so that regular irrigation does not assure them of regularity.

When this condition exists, the physician will sometimes suggest that the patient dispense with irrigation since it will not produce the desired regular pattern, and the person may become frustrated trying to achieve this. In this case, once again the colostomy is treated much like an ileostomy with the wearing of a pouching system all of the time.

If we're not meant to have midnight snacks, why is there a light in the fridge?
ABOUT US: The Ostomy Association of Greater Orlando, Inc. is an IRS 501(c)(3) tax-exempt charitable corporation in the State of Florida with “umbrella” status under our parent company, United Ostomy Associations of America, Inc. We are an all volunteer support group dedicated to assisting people who have or will have intestinal or urinary tract diversions by providing emotional support, family support, educational services, advocacy, and promoting the services of this organization to the public and professional communities.

IMPORTANT NOTICE
Articles and information printed in this newsletter are not necessarily endorsed by the Ostomy Association of Greater Orlando, Inc. and may not be applicable to everyone. Please consult your doctor or WOC Nurse for medical advice that best suits your specific situation.

POPULAR OSTOMY RELATED WEBSITES

**www.ostomy.org**
United Ostomy Associations of America (800-826-0826) is an association of Affiliated Support Groups. UOAA serves people with ostomies and other intestinal and urinary diversions through its affiliated support groups. UOAA is a member of the International Ostomy Association. Their website has a large discussion board with over 10,000 topics posted by ostomates. Individuals can join UOAA simply by joining the Ostomy Association of Greater Orlando.

**www.ostomyassocationofgreaterorlando.com**
Our website contains information on our support group including meeting calendar, directions to our meetings, new member application, useful links, list of ostomy suppliers, helpful articles, and much more.

**ostomyconnection.com**
OstomyConnection is an online resource to find the very best support, events, products, and advice for the ostomy community. We help ostomates stay connected to the stories and topics that affect our daily lives.

**www.Ostomy.Inspire.com**
The Inspire Ostomy Support Group is a great way to meet and connect with a community of people who understand what you’re going through. ConvaTec partnered with Inspire to create this social network where people with ostomies can gain emotional and informational support.

**www.c3life.com**
A website dedicated to helping people with ostomies live their lives to the fullest. Supported by Hollister Inc., c3life.com is part of Hollister’s mission to help make life more rewarding and dignified for those with ostomies.

**www.meetanostomate.com**
Provides a free collection of real-life tips and tricks from ostomates.

**www.ostomyland.com**
Has provided ostomy support since 1998, including interactive support, chat, blogs, lifestyle guidance, lists of ostomy product manufacturers, and ostomy undergarment and accessory manufacturers.

**http://uncoverostomy.org**
Uncover Ostomy is an entirely online awareness campaign sparking positive conversation about ostomies. Spokesperson and Founder, Jessica Grossman shares positive stories, thought provoking images, and ways for you to spark this conversation.

**http://weneedideas.ca**
IDEAS, Intestinal Disease Education and Awareness Society.

**www.google.com**
Type “youtube” in the google search box, then type “ostomy” in the youtube search box. All the audio/visual guidance you could ever want.

**http://www.veganostomy.ca**
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**http://www.meetanostomate.com**
Find the latest ostomy product reviews, friendly how-to’s and support. Including topics about Crohn's, Ulcerative Colitis, and living a vegan lifestyle.

**THE OSTOMATES PRAYER**
Oh Lord, as we have been reborn, let us multiply our good fortune and share it with those ostomates who do not know how good the life you have given us can be. Let us vow in the years ahead to renew the work of our group, as you have renewed our lives. We thank you for our lives, for the mutual support of each other, and for the chance you have given us to help others. Amen.

Via the Clermont County Chapter, the Batavia OH Chapter, and Indianapolis IN Chapter