

The Picture Frame

A publication of the
Ostomy Association of Greater Orlando

May/June 2017
Circulation 500

Affiliated Support Group



www.ostomyassociationofgreaterorlando.com

MEETING ANNOUNCEMENTS

Saturday, May 20, 2017 @ 10:30 AM

Please welcome Tracie Haney, Yoga Instructor and ostomate. Tracie will tell us how she began yoga after surgery and now after two children! She will show us how to get started practicing Yoga.



Saturday, June 17, 2017, 12:30 PM

June Luncheon @ Nonno's Italian Restaurant

1140 E. Altamonte Drive, #1018
Altamonte Springs, FL 32701
Phone: 407.260.8900

(Shopping Center with Party City)

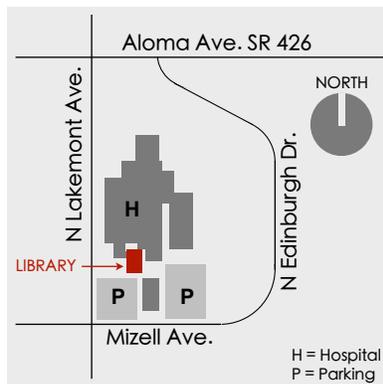
Please RSVP to Shelley at 407.929.3668 or
shelleydittmer@gmail.com. Mary 407.960.4323.

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

Evelyn Vihlen, Treasurer
418 Tulane Drive, Altamonte Springs, FL 32714
407-862-6567

If not interested in receiving the Newsletter please call or write Evelyn Vihlen

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.

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IT'S THAT TIME OF THE YEAR AGAIN

The Ostomy Association of Greater Orlando cannot continue its programs without your support. Through your membership and contributions we are able to support those facing ostomy surgery and those with ostomies through our meetings, Mentor/Visitation Program, Gift Room, and Youth Rally sponsorship.

Membership Application and Renewal Form on Page 3.
Thank You for your support.



Premier Online Version

Get instant access to *The Phoenix* magazine by ordering the Premier Online Version. Read the magazine through any web browser on your computer, iPad, or any other device where you can browse the Internet. Annual Premier Online Edition subscription is \$19.95. Annual print subscription is \$29.95. See ad and on Page 8.

What's going on at OAGO ?

PRESIDENT'S MESSAGE

Hello to all my friends!

I had another President's message all ready to send, but just this morning I received a note from our sister Ostomate, Tracie Haney. As some of you know, her little baby Amelia needs a **heart transplant**. She is not so lucky as to be able to have surgery to correct the heart defect. But what you may not understand is that the same rules affecting Amelia and a heart transplant also will have an effect on all of us.

We all have "Preexisting conditions". Below I have reprinted the notice that I received today from UOAA.

Please read carefully. It concerns all.

Yesterday, the House of Representatives narrowly passed the American Health Care Act (AHCA) by a vote of 217-213.

The bill in its' current form will be devastating for all of UOAA's constituents as the legislation weakens basic patient protections, reduces cost sharing subsidies to low-income individuals, and gives states the opportunity to apply for waivers from the Affordable Care Act's Essential Health Benefits and "community rating" requirements. Without the key protection of "community rating" for people with pre-existing conditions, insurers can go back to charging exorbitant premiums to people based on their health, which could put coverage out of reach for many. Although a last-minute addition of \$8 billion more in funding for people with pre-existing conditions was added, many experts doubt whether that will be close to enough funding.

In addition, the Congressional Budget Office has not issued an official score for the revised AHCA measure, so the impact on premium costs, coverage options, and number of Americans covered is still being developed.

Now what? The bill has been referred to the Senate where the measure is expected to undergo a major overhaul. Senate Republicans are saying that they will write their own bill.

In a statement released after the bill passed, Maine (where UOAA is located) Senator Susan Collins stated, "This is an extremely important debate with significant implications for millions of Americans. We need to spend the time necessary to get this right and work to achieve the goal expanding access to healthcare that is truly affordable and accessible."

Our advocacy efforts to ensure access to quality affordable healthcare is protected for all persons living with an ostomy or continent diversion are just beginning. As provisions of a Senate version become available and action is required from our constituents we will alert you for your ongoing support. There is much work to be done.

**Sincerely,
Jeanine Gleba
UOAA Advocacy Manager**

***See you at the next meeting,
Shelley Dittmer, President***

**"Work for a cause, not for applause.
Live your life to express, not to impress,
don't strive to make your presence noticed,**

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.

NOTE:

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): _____

PLEASE FILL IN THE APPROPRIATE BLANKS BELOW. Information will be kept CONFIDENTIAL.

Type of diversion(s) - Circle all that apply or check None.

Ileostomy Colostomy Urostomy Ileoanal Reservoir/J-Pouch Continent Ostomy

Other: _____ Date of Surgery: _____ None: _____

Relationship to Ostomate: Self Spouse Family Member Parent Other: _____

Dues and Donations: (Please note that 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.

_____ Enclosed is an additional donation to support the annual Youth Rally.

_____ Enclosed is an additional donation to support our ostomy supply GIFT ROOM.
Our Gift Room provides ostomy supplies for those without insurance in the greater Orlando area.

_____ Total Amount Enclosed

Please make checks payable to the **OAGO**.

Bring this form and payment to our next meeting, or mail to:

Evelyn Vihlen, Treasurer
418 Tulane Drive
Altamonte Springs, FL 32714 - 4024

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Happy Birthday
to those born in
May & June!!!

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Sometimes I
need expert
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Wound, Ostomy, Continence
Department



601 East Rollins Street
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Helpful Hints for Swimming

UOAA Update July 2015

Summer is here and you know what that means. More family trips to the beaches, lakes, pools, etc. Swimming is a great way to have fun, exercise and cool off. Having an ostomy should not stop you from relaxing in the water, going for a swim or enjoying other water sports. However, here are a few precautions you might want to take:

- Don't change your pouch immediately before getting into the water, allow a few hours for it to set.
- Picture frame the faceplate by applying micropore (pink, waterproof) tape around the edges to provide a waterproof seal. This will ensure that the faceplate adheres to the skin.
- Wear a soft panty girdle (or pantyhose with the legs cut off) under a bathing suit if you feel it is needed to give extra security and support for the pouch.
- If you will be in a spa, jacuzzi or hot tub beware as hot water destroys the pouches ability to contain odor. Also, you will probably not get as much wear time as usual.
- Ladies, choose a swimsuit with a skirt and a "busy" pattern. This will effectively cover up the vulnerable spot. Boxer swim shorts work well for men.
- Remember to drink lots of water. Sweating cools the skin, but moisture must be replaced.

Pain You Should Never Ignore

By Dr. Mallika Marshal

Pain is your body's way of telling you something is wrong, and failure to address it could lead to serious problems.

Chest/Shoulder Pain. It could mean that you're having heart problems. Sometimes it's a pain in the chest, sometimes in the left arm, shoulder, neck, or jaw. However, many people who've had heart problems say it's not really a pain, but a pressure or discomfort. Now there are other things that can cause pain in the chest such as acid reflux, inflammation of the chest wall muscles, or inflammation of the lining of the lungs. But the thing we really worry about and want to rule out is a heart attack. So if you develop these symptoms, especially if you have risk factors for heart disease or are over 40, you need to contact your doctor right away or call 911.

Pain in the mid-back. If you experience pain in your back or between your shoulder blades, it's most likely caused by arthritis. But pain in this area, especially if it's severe or sudden can indicate an aortic dissection in which blood actually gets trapped in a tear of the main artery in the body, the aorta. This can be life-threatening. It more commonly occurs in people with high blood pressure or people with a history of heart disease, so if you're concerned, call your doctor right away.

Abdominal pain. We all get the occasional bad stomach ache but what we are talking about here is sharp pain that that hurts so much that it takes your breath away. This kind of pain could signal appendicitis or a ruptured appendix which is a very serious condition that needs to be treated right away. Severe abdominal pain could also signal problems with your gallbladder, pancreas, or even an ulcer.

Calf pain. Whenever we hear someone complain of calf pain, we worry about a blood clot or deep venous thrombosis in the leg. These clots affect about 2 million Americans every year and can be life-threatening...if the clot breaks off and travels to the lungs.

People most at risk are those with cancer, pregnant women, people who have had recent leg surgery, bed-ridden patients, and people who have been on long plane flights. So if you have pain in your calf, especially if there's redness and swelling and no recent injury or muscle strain, you need to call your doctor right away.

Feet or leg pain. Burning in the feet or legs could be a sign that you have peripheral neuropathy or nerve damage. One of the most common causes is diabetes which we all know is a very serious condition. And the sad fact about diabetes is that many people who have it don't even know they do. So a burning sensation in the feet could be the first indication. Other causes of nerve damage could be injury, inflammatory conditions such as Lupus, or vitamin deficiencies. So talk to your doctor.



6th National Conference
Tues-Sat, Aug. 25-29, 2015, Hilton Garden Inn, Tallahassee

You're Invited to UOAA's National Conference!

- Education Sessions
- Motivational Talks
- Stoma Clinic
- Product Exhibit Hall
- Special Events
- ASG Leadership Academy
- Vacation Destination



Visit www.ostomy.org for Registration, Programs, and Hotel Information.

Stomal Prolapses

By Diane Kasner, RN, MS, ET, Baltimore, MD
UOAA UPDATE 6/2014

Prolapse is a relatively frequent stomal complication (affects up to 14 percent of all ostomates) defined as the excessive protruding of the bowel out of the abdomen. The piece of bowel that protrudes may often be as long as six inches in length, up to three inches wide easily.

If your stoma prolapses, you should remove your pouch, so that the bowel has space without being constricted. Apply a cool compress. If this is the first time you have prolapsed, call your physician or WOCN nurse immediately. If you cannot get in touch with a WOCN and especially if your drainage has stopped, it would be wise to go to the emergency room at your local hospital. If your stoma has prolapsed before, you may have been taught by the physician to "reduce" your stoma and you should try to do so.



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EAST ORLANDO 7975 Lake Underhill Rd, Ste 310, Orlando, FL 32822
ALTAMONTE SPRINGS 616 E. Altamonte Dr, Ste 120, Altamonte Springs, FL 32701
DR PHILLIPS 7301 Stonerock Cir, Ste 1, Orlando, FL 32819

I took skiing lessons last year, but by the time I learned to stand up I couldn't sit down.

From "DOWNTIME" by Ron Dentinger, Comedian and Banquet Speaker www.banquetspeaker.com

Are You Having Trouble Sleeping as You Grow Older?

UOAA Update July 2015

How much sleep do older people need? Most of us need about eight hours of sleep at night to feel fully alert when we're awake. Many things can get in the way of sleeping well or sleeping long enough. As we get older, we might have more trouble sleeping.

What sleep changes are coming in elderly people? People 65 and older may have trouble falling asleep when they go to bed at night. They might not stay asleep all night. They might wake up very early in the morning and not be able to go back to sleep.

These problems can make older people very sleepy in the daytime. The sleep-wake cycle changes as we get older, so we might get sleepy earlier in the evening and wake up earlier in the morning.

What causes sleep problems? Several things cause sleep problems. By the time we're in our 60s and 70s, our sleep-wake cycle doesn't seem to work as well. Some lifestyle habits (like drinking alcohol, caffeinated drinks, or smoking) can give us sleep problems.

Sleep problems may even be caused by illness, when pain keeps us from sleeping, or by medicines that keep us awake. People of all ages might have these sleep disorders: sleep apnea, restless legs syndrome and periodic limb movement disorder.

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"Behind every great man is a woman rolling her eyes."

Jim Carrey

OUT PATIENT OSTOMY CLINICS IN CENTRAL FLORIDA

The Ostomy Association of Greater Orlando frequently receives calls from individuals who are dealing with skin and product issues. Below is information on outpatient ostomy clinics.

Orlando Health Wound Healing Center

Services Provided:

Comprehensive ostomy and fistula care are offered, as well as pre-operative stoma site marking and teaching. Donations of ostomy supplies are welcomed as we see many indigent and homeless individuals.

Location:

Orlando Regional Medical Center
Orlando Wound Healing Center - Ostomy Clinic
55 West Gore Street, Annex Building, First Floor
Orlando FL 32806

Location Note: The Orlando Wound Healing Center is located just west of Main Lane at the intersection of West Gore Street and Kuhl Avenues. The entrance door to clinic is under the drive through canopy.

Ostomy Clinic Phone: 321-841-5469 FAX: 321-841-7470

Requirements: Appointment and doctor's script/order required, along with demographic sheet, last progress note.

Insurance: Most insurances accepted. Medicare and secondary insurance accepted.

Principal Staff:

Sally Matson, RN BSN MS CWOCN.
Karen Durigan, Nursing Operations Manager.

Central Florida Wound and Skin Consultants

Services Provided:

- NP-C/WOCN specialists provides ostomy evaluation and refitting to homebound or ALF patients in their homes.
- We are a **mobile** ostomy, wound and lymphedema medical practice caring for Medicare patients only.
- Our medical practice also specializes in customized hernia support options.
- Preoperative education and stoma marking.
- Postoperative education on stoma management including pouching system selection and education on self-care.
- Assistance with appliance fittings, pouching system failures, peristomal skin loss, ulcers, and rashes.
- Management of complex, high output fistulas.
- Services also offered at Assisted Living Facilities in Orange and Seminole County.

Phone and Fax: 407-359-6426

Requirements: No doctor's script/order required.

Insurance: We are Medicare providers and do not accept HMO or PPOs. We bill direct to Medicare and secondary insurances. Self pay rates: \$175.00 for initial visit, \$75.00 for additional visits. We accept payment by cash or check.

Principal Staff:

Tabassum Merchant MS, WOCN, MSN, NP-C
Debbie Moulavi CWON, MSN, NP-C
Collaborating Physician: Rita Laracuente, MD

About Tabassum Merchant and Debbie Moulavi:

Board certified nurse practitioners with a speciality in wound and skin disorders. Additional training through WOCN Program at Emory University. We are also known as NP/ET/WOCN specialist. Able to write prescriptions and provide a medical service for the treatment of ostomy related disorders.

Out Patient Ostomy Clinics in Central Florida continued

DAYTONA

Florida Hospital Memorial Medical Center

Location:

Center for Wound Healing and Hyperbaric Medicine
Florida Hospital Memorial Medical Center
Center for Wound Healing
301 Memorial Medical Parkway
Daytona Beach, FL 32117

Ostomy Clinic Phone: 386-231-3615

Appointment and doctor's script/order required.

Insurance: Most insurances accepted. This facility is a Medicare assigned provider and accepts Medicare Secondary insurances.

PALM BAY

Health First Outpatient Wound Center/Ostomy Clinic

Appointments on Wednesday's only.

To schedule an appointment: 321-434-6100.

Appointment and doctor's script/order required.

OAGO GIFT ROOM

The Gift Room is stocked with donated unused ostomy supplies that we collect and provide, free of charge, to fellow ostomates who are uninsured or underinsured. This service is run solely by the **Ostomy Association of Greater Orlando, Inc.** on a volunteer basis under Gift Room Director Evelyn Vihlen. For information call 407-862-6567.

OSTO GROUP

This not-for-profit organization provides free ostomy supplies to those without insurance. Your only cost is shipping and handling. Call 877-678-6690 or visit their website at www.ostogroup.org.

FRIENDS OF OSTOMATES WORLDWIDE - USA

UOAA Update November 2014

The modern ostomy supplies we take for granted in the U.S. and other developed countries may be unavailable or too costly in many areas around the world. People resort to plastic bags, rags, and duct tape, resulting in poor skin, odor, no jobs, and no school. Since 1968, the Friends of Ostomates Worldwide-USA (FOW-USA) has collected new supplies from U.S. individuals and groups and sent them overseas where needed. From Afghanistan and Cameroon to Zambia and Zimbabwe, to over 70 countries, our shipments have made a difference. You can too, with supplies and financial donations: FOW-USA, 4018 Bishop Lane, Louisville, KY 40218. Phone: 502-909-6669 Website: www.fowusa.org

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To report abuse, neglect, or exploitation call 1-800-962-2873

What Food Should I Eat While Healing From Ileostomy Surgery?

Author: Sarianne H. Madsen, Registered Dietitian (RD)

Source: LIVESTRONG.COM, a proud licensing partner of the LIVESTRONG Foundation.

Featured on OstomyConnection.com

Recommended Foods To Eat While Healing From Ileostomy Surgery

An ileostomy is a surgical opening, or stoma, created to bypass the large intestine by attaching the end of the small intestine, or ileum, to the abdominal wall. As food makes its way down the digestive tract, it is excreted through this opening into a pouch rather than continuing on to the large intestine. Ileostomy nutrition therapy can vary depending on individual tolerances, and it includes an array of well-tolerated foods.

In the Short Term (Up to Six Weeks Post-Surgery)

Immediately after surgery, the recommended diet is clear liquids — broth, apple juice, tea — with a progression to a solid, low-fiber diet. You should try solid foods one at a time to assess for tolerance and to avoid any food that may potentially cause odor, gas, diarrhea or a blockage. If a particular food causes gastrointestinal symptoms, stop eating it and try it again a couple of weeks later.

Recommended Foods While Healing

Well-cooked and seedless vegetables such as cooked carrots or squash, strained vegetable juice, and lettuce will help you avoid blockages as you heal.

Fruits with minimal fiber like avocados, soft melons and canned fruits (except pineapple), pulp-free juices except prune juice, applesauce, ripe bananas, and oranges and grapefruits without the membrane should also give you fewer problems than high-fiber foods.

You should generally be able to tolerate foods made with refined grains such as white bread, white rice, crackers, pasta and rolls. Milk products are also acceptable to eat while healing. If you experience discomfort after eating them, you can try lactose-free versions instead.

Chicken, fish, pork and beef prepared without extra fat, along with smooth nut butters and eggs, are excellent sources of protein while healing. Fish, eggs and nut butters may cause odors, and you should try them in small amounts at first. Introduce fats slowly, as they may cause some discomfort.

In the Long Term

Patients are usually able to return to a normal diet within two to six weeks after surgery. Foods such as asparagus, broccoli, Brussels sprouts, cabbage, cauliflower, garlic, onions, eggs, fish, dried beans and peas, peanuts, and carbonated beverages may cause odor or gas in some individuals.

Drinking out of straws, eating too quickly and chewing gum can also increase gas. Foods such as kefir, yogurt, parsley, cranberry juice and buttermilk may help to reduce odors.

To reduce risk of blockages, eat foods such as corn, popcorn, raw cabbage, coleslaw, celery, dried fruit, coconut, unpeeled apples, grapes and nuts in small quantities and chew them thoroughly.

High-fat foods, fried foods, grape and prune juice, spicy foods, and foods with added sugar could potentially cause diarrhea in some individuals.

Eating small frequent meals and having your largest meal during the day can help lessen stool output at night. Foods such as bananas, applesauce, cheese, smooth peanut butter, pasta, potatoes, tapioca and rice may help to thicken stool.

Countering Deficiencies

To prevent dehydration, aim for eight to ten cups of liquid per day. In times of high diarrhea output, you may require extra potassium from tomato and orange juice, bananas, avocados and potatoes. If you need extra sodium during these times, you can get it from canned soups and broth and lunch meat.

An ileostomy decreases the absorptive surface area of the ileum and can potentially cause vitamin and mineral deficiencies in some individuals.

Consult your doctor or registered dietitian to help identify the need for increased potassium and sodium, along with any other nutrition-related deficiencies that may require additional supplementation.

Source: OstomyConnection.com, A Hub for Ostomates. Reprinted with permission.

We thank our OAGO members and those named or anonymous below who gave additional support to our programs in 2017.

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Renee Mueller, MD FASCRS FACS

Wound Ostomy and Continence Nurses

Florida Hospital
Sloan Bartlett, MSN RN CWOCN
407.303.5600 Extension 110-9271

Florida Hospital: Winter Park Memorial Hospital
Terry Barton, BSN RN CWOCN
407.646.7523

Orlando Regional Medical Center
Orlando Wound Healing Center
Donna Sellers, BSN RN CWON
321.841.5469

THE PHOENIX, UOAA's MAGAZINE

Also available as an online version for \$19.95/year.

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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.ostomyassociationofgreaterorlando.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/>

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*