Macomb County Ostomy Officers

<table>
<thead>
<tr>
<th>Position</th>
<th>Name</th>
<th>Phone Number</th>
</tr>
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<tbody>
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<tr>
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</tr>
<tr>
<td>CWOCN Nurses</td>
<td>See Inside Newsletter</td>
<td></td>
</tr>
<tr>
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<td><a href="http://www.ostomysupport-macomb.org">www.ostomysupport-macomb.org</a></td>
<td>(877) 849-2076</td>
</tr>
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Metro Detroit Officers

<table>
<thead>
<tr>
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<th>Phone Number</th>
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<tr>
<td>CWOCN Nurses</td>
<td>See Inside</td>
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Mission: To provide support, information, and assistance to anyone dealing with an ostomy, diversion or continent surgery.

Meeting Times and Locations: See page 3:

CALENDER OF EVENTS

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
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<tbody>
<tr>
<td>June 5, 2016</td>
<td>Annette Caruso, Convatec Supply Rep</td>
</tr>
<tr>
<td>July and August, 2016</td>
<td>No Meetings</td>
</tr>
<tr>
<td>September 11, 2016</td>
<td>To Be Determined</td>
</tr>
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Editor’s Corner

A new look and format for our newsletter!

It was mentioned in the last issue that we were going to redesign some of the newsletter and asked for suggestions for a new title. We have decided to use the New Horizons name, since it accurately describes our newfound lifestyle, and also goes along with the Phoenix logo, (rising from the ashes). We checked the sample newsletters given on the ostomy.com website and some of the other newsletters around the country and gleaned ideas from them. We are excited about the changes, and hope you like them too. This is our first attempt; there may be other changes within the letter as we go along, until we get it the way we want.

I am open to suggestions or comments, or let me know if you find an article that you think would be suitable for our newsletter. Email me at ostomyinfo@yahoo.com or call me at (586) 576-0117. Carol Wheatley
BULLETIN

STOMA

Stoma is a Nonprofit Organization that out sources donated ostomy supplies free of charge every three months to ostomates that are uninsured, underinsured, has no income, low or/ and hardship.

Stoma outsource supplies such as, Colostomy, Ileostomy and Urostomy Pouches as well as barrier strips and paste.

Please be mindful that these are donated supplies and we may not have what you want but I am sure we have what you need “Pouches”.

Goal: No Ostomate Pouch-less
"We do accept both unused supplies monetary donations"

Office: 248-277-0369
18121 E. 8 Mile Rd
Eastpointe, MI 48021

See Facebook or Twitter? Become a friend of the UOAA on Facebook and interact with thousands of other ostomates. Go to Facebook.com/UOAAinc. Or follow them on twitter. Get update, links to photos or articles, and much more. Go to Twitter.com/UOAA

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Fax (844) 273-2422
Email: customer.service@global-bus-systems.com

None of this technology means anything without our commitment to old fashioned customer service standards such as:

- Our customers come first and are always right
- Treating every customer as our only customer
- Buses arriving 15 to 30 minutes early so there is no worry
- Buses not leaving field trip sites
- Respectful and courteous drivers, without exceptions!

“GREAT PEOPLE PROVIDING GREAT SERVICE!”

Thanks in advance for your commitment:

Darrin L. Williams
Founder. CEO

Local Hospital Based Support Group

McLaren Macomb Ostomy Support  Quarterly meetings in Jan., April, July and October.
Place: McLaren Mt. Clemens Hospital, 1000 Harrington Blvd. Mt. Clemens, MI 48043. (586) 493-1760.
Registration is required. Call for details.

This newsletter is printed quarterly
Spring, Summer, Fall, and Winter
Issued in February, May, August, and November

Advertising yearly rates:
Whole page  $400.00
Half page  $300.00
1/4 page  $200.00
1/8 page  $100.00

Mission : To provide information, peer support, and assistance to our members, their family and care givers, or anyone dealing with an ostomy, diversion or continent surgery.

Disclaimer: The articles and information contained in this newsletter are expressly for informational purposes and may not be applicable to everyone. Always check with your doctor or CWOC Nurse if you have any questions or concerns about your condition and what is best for you.

In Memorium  We were sorry to hear of the passing of Macomb County member.

Howard Kaplan
National Affiliation

United Ostomy Associations of America, Inc. (UOAA), with IRS 501c3 Charity status.

Contact information:
http://www.ostomy.org/
(800) 826-0826
Twitter.com/UOAA and Facebook.com/UOAAinc.

Visitation Program

If you have recently had or are considering ostomy surgery, we can arrange for you to talk with a trained ostomy visitor who is living successfully with their ostomy.

Call Toll Free, 24/7: (877) 849-2076 or email: ostomyinfo@yahoo.com

We do not offer medical advice nor do we actively assist in physical care of the stoma

MACOMB CHAPTER CHATTER

A lot has happened with our group since the last issue as you will see in this article.

Our March speaker was Tom Fortis from Entrust Ostomy Care, a newer ostomy supply company. The highlight of his presentation was that the products contain “fortaguard”, effective in preventing itch and odor. and they also have a built in natural hydrocolloid base, (hydrogen peroxide) to help prevent yeast and promotes healing. The fortaguard is in barriers, rings and pastes. You may call 855-550-2600, or go online at www.fortismp.com to request free samples.

Also on March 26 we held our first Annual 5k fundraiser walk. See separate article on this elsewhere in this newsletter.

Field trip

The April meeting was held in conjunction with the Metro Detroit Group. Dr. John Webber M.D., a top general surgeon from Detroit Medical Center, wanted to speak to both of our groups at the same time. So we met with them at Beaumont Botsford Hospital on the second Sunday, April 10th.

Many did not want to drive that far, so Sarah of S.T.O.M.A. arranged transportation, provided by Mr. Darrin Williams. His company name is Global Bus Systems (GBS), see his ad on p. 2. His is a local business that transports our local community school children. We want to thank him for graciously giving us a wonderful rate on transportation to and from the support group meeting. Continued on page 5

Metro Detroit Ostomy Support Group

MEETING LOCATIONS:

We meet at St. Mary Mercy Hospital on the odd numbered months: Jan., March, May, Sept. and Nov.
Beaumont/Botsford meetings are on the even months: Feb., April, and Oct. We do not meet in June, July, August or Dec.

Meetings will be held the second Sunday of each month at 1:30 PM, unless indicated. Everyone is welcome! You do not need to be a member to attend. Please note some meeting time or location changes

In case of weather advisories, meetings will be cancelled. Call Dennis or Marge to verify.

St Mary Mercy Hospital
36475 5 Mile Road Livonia, MI 48154
734-655-4800
Classroom #1, Women’s Birthing Center
1st floor, South Entrance off Levan Road
(South of Emergency Room Entrance

Beaumont/Botsford
28050 Grand River
Farmington Hills, MI 48338
248-471-8000
Administration and Education Center
Building at right of Main Hospital

METRO DETROIT CHAPTER CHATTER

In spite of bad weather, we’ve had pretty good attendance. Five new ostomates have come. For older ostomates, remember how worried you were about everything connected with ostomies. Please come as often as you can to reassure the newbies that life goes on after an ostomy and that life is good. Much of how we adapt depends on being positive and seeing positive role models.

We need volunteers to help the chapter. Dennis, Marge, Cheryl and Larry can’t do everything. Areas where we need help are: Finding and/or contacting speakers; writing thank you notes to speakers; writing a short Chapter Chatter 4 times a year; greeters at the meetings; maintaining membership files on the computer; folding and getting newsletters ready for mailing 4 times a year; answering the toll free number. If you think you can help in any way, please let one of the officers know.

Have a safe summer. Take time to smell the roses and enjoy life.
Proud Sponsor of Macomb County Ostomy Association

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www.jandbmedical.com
We are affiliated support groups of the United Ostomy Association of America (UOAA)

Macomb Chapter Chatter cont. from page 3

We all agreed afterward that the trip was well worth it. He has operated on several of our members and they compare him to Dr. House, (on the TV show). He is a very experienced surgeon; knowledgeable and straightforward, and even though he specializes in bariatric surgery, he has performed many ostomy and even rare ostomy related surgeries.

The May meeting was a bit of a disappointment, in that we had planned small group discussions, but did not have enough people attending to do so. I think since the meeting was on May 1, and only 3 weeks after the Beaumont trip, that it just slipped up on some of us. But it still turned out good; we had a general discussion, question and answer time, and those who had walked in March and/or went to the April meeting commented on their impressions on that.

PRESIDENT’S MESSAGE

I am having very mixed emotions as I make the announcement that after 17 years of holding office, the last 10 years as president, I am stepping down. I am getting older and need to relinquish some of these responsibilities. So I am “passing the baton” on to a very capable (and younger) president, Sarah Mays. She has already proven her leadership qualities in the foundation of Stoma, inc., collecting and redistributing donated ostomy supplies. She is dedicated to the cause of supporting and helping ostomates, and is bringing some fresh, new approaches to doing that. She was the organizer of the 5K walk, and arranged the meeting with Dr. Webber, who performed her surgery. So I know the group will be left in good hands with all of the officers, current and new, that we have. However, I am not going away! I am staying on as the newsletter editor, a job I truly enjoy, and also as the visitor coordinator, until we can get someone else to take that job. I will still attend most meetings and be around to cheer on the new officers. Ostomates are special people, survivors, and I am proud to be one!

Colon Cancer Fundraiser 5K Walk

March is colon cancer awareness month, so on March 26, 2016, we held our first annual 5K fundraiser walk to raise awareness of colon cancer and to urge people to make sure they follow up on their colonoscopies. Colon cancer is one of the easiest cancers to cure when detected early.

The event was held on Belle Isle in Detroit. Unfortunately the weather did not cooperate with us and it was 35 degrees but felt colder, being surrounded by water. The Saturday before and the one after were nice days, but March is unpredictable, still sixty people showed up and others made donations. We barely broke even, but valuable experience was gained from this first walk. Next year we will advertise sooner, and pick a location that is not on the water. Also we will ask for people, if they can, to create teams of 5 or more people to walk with them.

Giving credit where credit is due, DJ detail and Window Tint in Eastpointe, MI. donated the big sign that was used to direct walkers. J’s Silkscreen also made our shirts; as they offered us tax exempt pricing….and free shirts for the volunteers. We raised approximately 1,200.00 dollars, which only paid for the price of the needed essentials for the walk, such as: 800.00 to Belle Isle, 90.00 for the porta potty, and 352.00 for the insurance policy for the walk, and other expenses which that S.T.O.M.A. sponsored themselves.

We would like to give a personal Thank you for their support to Laura Hendrick and her family for their donation made to the walk. as well as to Ms. Samia of Mary Kay, Mrs. Tina and her family, Mr. Ken Dandridge from Change Me Inc. and last but not least let us thank the young ladies from Destine for Greatness for coming out and supporting our walk, and many others that may have donated.

Members, let us keep in mind that this walk will be sponsored by S.T.O.M.A. every year on the last Saturday of the month of March. Even tough our support groups assist with the most important aspect of the walk by volunteering, there is still a need for financial support to help bring this awareness to our community. Therefore, if you know of any businesses and/or individuals that would love to donate and help sponsor this cause, please pass along the S.T.O.M.A. information.

Thank you for your support, Mrs. Sarah Valentine-Mays – President and founder of S.T.O.M.A.inc.

Participants in the 5K Walk. From left to right: Sarah Mays, Carol Wheatley, Suzanne Fleet, Wayne Wheatley, Pam Wade
Colon Cancer Fundraiser 5k Walk

Some of our members who participated on Belle Isle in the 5K walk

A CAREFREE VACATION

tips from here and there

Concerned about traveling with an ostomy?
Follow these tips for peace of mind.
Pack extras. Pack twice the amount of supplies that you would normally use during the time period that you’ll be traveling. Changes in activity, climate, and diet may mean you’ll have to change your pouch more often.

Consider using a Closed-end Pouch if you have a colostomy. It works well for many travelers with a colostomy, but is only suitable for short term wear for ileostomates, due to the more liquid output and more often need to be emptied.

Know where to go for supplies. Find out where to get supplies while you’re on vacation in case you do run out. You can call your supplier to ask about suppliers near your vacation spot.

To swim or not
If you enjoyed swimming before your ostomy, you can enjoy it now. Some people worry that their pouch will become loose in the water. Others are concerned about the visibility of their pouch. But with the swimwear and ostomy products that are available today, you can swim in the pool worry free. You can use waterproof tape, available where you purchase your other ostomy products, and “window-frame” the tape around your barrier for added security.

To minimize any bulges, choose a swimsuit with a pattern or print. Women may want to wear a skirted bathing suit that fits a little more loosely.

You will probably be the only person in the pool who knows, or can tell, that you have an ostomy. If you use a pouch with a filter, be sure to use a filter cover before going in the pool.

Abdominal Changes to an Ostomy

By Arthur Clarke, CWOCN  Edited by B. Brewer, UOAA UPDATE 2011

When you had your ostomy surgery, the surgeon was allowed (according to your personal physiology) only so much moveable bowel in the construction of your stoma. Once that piece of bowel was pulled through your abdominal wall, it was tacked down on the inside of the abdominal wall and on the outside of the skin. That length will remain constant throughout your life; therefore, if the wall of your abdomen thickens; (i.e. with fatty tissue), the length of the bowel used for your stoma will not be changed to accommodate your increased girth.

One result caused from the fixed length of bowel which forms the stoma as the abdominal wall thickens, is that when you sit or stand, the changed position causes the abdominal wall to shift forward and down. The stoma segment prevents the peristomal skin from shifting as much as the rest of the abdomen. The limited movement results in a skin well around the stoma when you sit or stand. Skin adjacent to the stoma becomes quite mobile being pulled down and then flattened by your changing positions. This may cause problems with your pouching system adhering well or springing leaks.

Consider these two solutions:

1) Adjust your weight to return your abdomen to its shape at surgery. This would include exercises to firm your body as well.

2) Another common solution is to change to a convex pouching system. I have found that a skin barrier with a convex surface, which—pushes the skin back, and holds it stable, relative to the stoma, works much better than the highly flexible flat barriers. Your ostomy nurse can help you with these issues.

This newsletter sponsored and printed courtesy of:

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email: info@worldmedicalrelief.org

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Certified Wound Ostomy Continence Nurses (CWOCN)

If you need assistance in an area not listed, you can find WOC Nurses at 888-224-9626 (888-224-wocn) or wocn.org. At the bottom of the screen, click on “Patient Care and Information.” Then click in the right hand column, “Find a WOC Nurse in my Area.” You can also speak to a WOCN or ET Nurse by calling customer service at Hollister at 800-323-4060 or Convatec at 800-422-8811 or Coloplast 800-533-0464. You can speak to a nurse 24/7 at AARP Nurse Health Line about any subject at 888-543-5630. The uoaa.org is a fabulous web site, and don’t forget ostomysupport-macomb.org.

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Kathleen Herman, MS, RN, ANP-BC, CWOCN
313-745-1846
kglover@dmc.org
Acid Reflux Drugs May Cause Dementia and Neuropathy

Dr. Brent Hunter, Chiropractic Physician
excerpted from www.wellnessachiever.net

New research, published in The Journal of the American Medical Association (JAMA), showed that certain acid reflux drugs are "significantly associated" with vitamin B12 deficiency. In turn, vitamin B12 deficiency causes serious health consequences including anemia, osteoporosis, depression, memory loss, dementia, neuropathy and cardiovascular disease.

If you have acid reflux, you need to understand what is causing it. Find the cause and correct the cause. Simply popping pills to block the natural production of stomach acid has proven to only cause even more serious health conditions. Acid reflux drugs, like Nexium, have long been known to cause some very serious side effects. Among them are problems such as anemia, heart problems, hypertension, osteoporosis and further digestive problems including irritable bowel syndrome (IBS). In fact, drugs used to treat acid reflux do not treat the condition itself but only the symptoms. They are not designed to correct the cause of the problem. As a result, the problem continues to worsen over the years. Drug treatment is continued and the drug side effects continue to worsen as well.

This new research showed that people taking certain acid reflux drugs are far more likely to suffer from vitamin B12 deficiency. The study implicated proton pump inhibitors (PPIs) – Nexium, Prevacid and Prilosec – and histamine 2 receptor antagonists (H2RAs) – Pepcid, Tagamet and Zantac. Proton pump inhibitors proved to be the worst.

The study's senior author, Dr. Douglas Corley, stated that patients should not stop taking the drugs but should get their B12 levels checked. If your levels are deficient, then presumably, you should treat that as another symptom as well. All the while, the underlying causes are left unaddressed. Vitamin B12 deficiency cannot be corrected unless the cause of the deficiency is addressed. In this case, the cause may be your acid reflux pill.

Why Do You Have Stomach Acid?

You have acid in your stomach for a reason. The cells that line your stomach produce it. In fact, your stomach is specifically designed with a layer of cells that protect it from the otherwise damaging effects of the acid. This stomach acid is required by your body for:

- proper digestion of food, especially carbohydrates
- Absorption of nutrients (such as vitamin B12)
- Killing harmful bacteria and limiting bacterial overgrowth

Without this acid in your stomach, you cannot properly digest carbohydrates or effectively absorb certain nutrients. Blocking this acid production also allows for overgrowth of bacteria and opens the door for H. pylori infections.

Simply having the stomach acid is not the problem. In fact, most people suffering from acid reflux actually have too little stomach acid rather than too much. The problem is when the acid leaks (refluxes) into the esophagus. Your esophagus does not have the protective lining that your stomach has. When stomach acid gets into the esophagus, the burning pain of acid reflux results.

Your body has a very strong valve - called the Lower Esophageal Sphincter (LES) between the stomach and esophagus that is designed to prevent the reflux of acid. The cause of the acid reflux is a dysfunctioning LES muscle which allows the acid to reflux into the esophagus. The acid is just in the wrong place. Lowering acid levels or blocking its production does not fix the problem. As a result, the acid reflux continues and you are prescribed acid blocking drugs for the rest of your life.

You may benefit from natural digestive enzyme supplements as well. Without proper levels of stomach acid, the pH is too high to stimulate the release of these enzymes naturally. These supplements can help provide your body with the support it needs to break down carbohydrates and proteins more effectively.

Thanks to James Clark for finding this article. To read the complete article, go to:
Acid Reflux Drugs May Cause Dementia and Neuropathy
We are affiliated support groups of the United Ostomy Association of America (UOAA)

Vitamin B-12 Replacement Therapy
By Bob Baumel, Ostomy Association of North Central Oklahoma

Vitamin B-12 is, under normal conditions, absorbed in only a small section of the terminal small intestine (ileum), raising the possibility of B-12 deficiency if that section of ileum has been removed surgically or damaged by disease. People who may have lost that portion of ileum include some ileostomates, people who had a failed J-pouch or Kock pouch, and some people with urinary diversions (especially continent urinary diversions) made using the terminal ileum. A condition such as Crohn's disease may have damaged the terminal ileum, even if it hasn't been removed surgically.

Vitamin B-12 is necessary for many metabolic processes including development of red blood cells, and also maintains normal functioning of the nervous system. Deficiency causes anemia (reduced oxygen carrying capacity of the blood resulting in fatigue) and can also cause nervous system damage. It's worth noting that folic acid (another B vitamin) can correct the anemia caused by vitamin B-12 deficiency but will not correct the nerve damage caused by B-12 deficiency. So it's important to get enough vitamin B-12.

If you think you are at risk for vitamin B-12 deficiency, you can ask your doctor to check your serum (blood) B-12 level. This test can be added easily to routine blood testing. If your ability to absorb vitamin B-12 by the normal pathway involving the terminal ileum has been impaired, you can supplement the vitamin by three basic methods:

**By injection:** This method bypasses the normal gastrointestinal process of B-12 absorption by inserting it into the body by intramuscular or subcutaneous injection. In cases of serious B-12 deficiency, this method should be used first in order to build up the B-12 level as rapidly as possible; then, the patient may switch to one of the other methods if desired. B-12 injections may be self-administered in the same way that diabetic patients can give themselves insulin shots. Maintenance therapy may require only one B-12 injection per month.

**Nasally:** This method also bypasses the normal gastrointestinal absorption process, as vitamin B-12 can be absorbed through nasal mucous membranes. The nasal form of B-12 was developed first as a nasally applied gel and later a true nasal spray (brand name Nascobal®). This product is marketed by the company Par Specialty Pharmaceuticals, who promotes it as the only FDA approved form of vitamin B-12 besides the injectable form (Note: FDA approval isn't relevant to oral B-12, discussed below, because the FDA doesn't regulate oral vitamin sales). Nasal B-12 can be effective but, because one company has sole rights to distribute it in the U.S., it can be an expensive way to get your vitamin B-12. Orally: Until recently, doctors believed that B-12 taken orally was useless to people who lack the normal absorption mechanism involving the terminal ileum. That opinion has changed, however, as research has revealed that even in such people, when a large dose of vitamin B-12 is taken orally, a small fraction (typically around 1%) gets absorbed by passive diffusion through the gut. Therefore, you may absorb an adequate amount of B-12 by taking a big enough oral dose—a typical recommended dosage is 1000 micrograms per day. Vitamin B-12 tablets in large sizes of 1000 micrograms or more are available inexpensively without a prescription and are also quite safe (there is no known toxicity to vitamin B-12, even in considerably larger dosages, and even in people with normal ability to absorb the vitamin). Oral B-12 can thus be a safe, easy and effective way to get the vitamin. It may not work, however, in people with a severely shortened intestine (short bowel syndrome), who may therefore have to use one of the first two methods listed above.

**Notes on Oral Forms of Vitamin B-12**
Many of the available oral preparations of vitamin B-12 in sizes of 1000 micrograms or more are marketed as either "sublingual" or "time release." The time release versions should definitely be avoided. Considering the small fraction of vitamin B-12 that gets absorbed (in people who lack the normal pathway for B-12 absorption), delaying that absorption further makes no sense. The sublingual versions do "work," although there's no evidence that this vitamin can be absorbed through membranes under the tongue, so the "sublingual" form is basically a gimmick. Effectiveness of oral B-12 depends only on the dosage. So you can just buy the lowest cost version available at the desired dosage (whether a "sublingual" form or regular tablets), as long as it isn't a time release preparation.

From Eric Polsinelli, creator of Vegan Ostomy...
I've learned that the only limitations I have are the ones I set for myself, and while an ostomy might come with some new challenges, my stoma won't stop me from doing what I want to do (don't let yours stop you!).
Medicare and Ostomy Supply Prices
By Julie Powell, WOCN

In the United States, 120,000+ people undergo ostomy surgery every year. The leading causes for ostomy surgery include cancer, trauma, birth defects and inflammatory bowel diseases. Ostomies can be permanent or temporary. No matter the cause, having an ostomy is a life altering experience. Learning to care for the ostomy can be a daunting task. The transition is eased if ostomy supplies are available and covered by insurance.

Medicare is health insurance for people who are 65, people under 65 with certain disabilities, and all people with end-stage renal disease. Medicare has two parts. Part A is the Hospital Insurance. Part B is the Medical Insurance. In Medicare Part B, ostomy supplies are covered under Durable Medical Goods. Medicare determines the allowable fee for supplies. A yearly deductible is paid by the Beneficiary. After the deductible is paid, Medicare Part B will cover 80% of the supplies and the Beneficiary is responsible for the remaining 20%.

Medicare determines what supplies are covered and has set utilization guidelines for those supplies. For example, a one piece drainable pouch for a fecal stoma has an allowable amount of 20 pouches per month. A physician order is required in the following circumstances. 1) The first time an order is placed for supplies. 2) When a yearly order is placed. 3) When an order is placed for an increase in the number of supplies, accompanied by medical justification for the additional supplies. 4) When there is a change in the type of supplies, and if both closed and drainable pouches are utilized.

Private insurance companies often use these Medicare guidelines as a template to determine what will be covered under their policies. However, in the past some private insurers would cover the cost of the ostomy surgery but not the supplies. Under the Affordable Care Act and the individual State Health Care Exchanges it remains to be seen if ostomy supplies will be covered and if covered at what level.
MEMBERSHIP APPLICATION
YOU MAY JOIN EITHER GROUP
Annual Dues - $15.00

1. Macomb County Michigan Ostomy Association: Send check payable to MCMOA, along with application to:
   Suzanne Fleet, 31630 McNamee, Fraser, MI 48026 or

2. Ostomy Association of Metro Detroit: Send check payable to Metro Detroit, along with application to:
   Larry Harris, 3220 Mimosa Dr., Commerce Twp., MI 48390

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Note: All Information Remains Confidential