

The New Outlook

June 2016



NEXT MEETING

TUESDAY, June 21

7:30 pm

GLENBROOK HOSPITAL

2100 Pfingsten Rd, Glenview, IL

Conference Rooms C & D, 1st Floor

Last Months' Meeting (our 458th)

Our May meeting was well attended and interesting. Judy opened the meeting by talking about the November 5th Regional Education Conference and encouraging everyone to save the date. You can read more about this event on page 9.

Our guest speaker was Aimee Jaremowicz, Registered Dietician with Shield Healthcare. She reviewed with us nutrition tips for ostomates, such as eating slowly, chewing thoroughly, and having small frequent meals and snacks. Aimee emphasized the importance of drinking liquids to prevent dehydration, especially as the weather gets warmer. She gave us several pieces of information to read and reference when a question arises.

After Aimee's presentation we openly discussed the effects various foods have on our ostomies, then continued with additional topics of interest, and as usual, it was quite energetic. **We are always happy to answer questions of our new members.**

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Be sure to notify us if your physical or email address changes so you don't miss an issue or important announcement.

www.uoachicago.org

Our next meeting, June 21, will feature our Summer Solstice Picnic (without ants!) Our special guest is Hedy Holleran presenting Hollister products and services.

Attending your first meeting? There are always supportive ostomy veterans to chat with you.

Thanks to everyone who voluntarily receives this newsletter via email. If you have Internet access, please **save us money** by joining our electronic distribution list. To try the electronic version, send e-mail request to: uoachicago@comcast.net

Be sure to add us to your address book or safe sender's list, and **check your email inbox.**

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www.ostomy.org

Ostomy Association of Greater Chicago (OAGC)

Established 1975

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Karen Blum 312-695-6868

Northwestern Memorial Hospital

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Lutheran General Hospital

Carol Stanley 847-618-3125

Northwest Community Hospital

Nancy Olsen, Mary Rohan 708-229-6060

Little Company of Mary Hospital

Kathy Garcia, Jola Papiez 708-684-3294

Advocate Christ Medical Center

Sandy Fahmy 847-316-6106

Saint Francis Hospital

Nancy Spillo 847-493-4922

Presence Home Care

Colleen Drolshagen, Jean Heer, Barb Stadler 630-933-6562

Central DuPage Hospital

Kathy Thiesse, Nanci Stark 708-216-8554

(Ginger Lewis-Urology only 708-216-5112)

Loyola University Medical Center

Alyce Barnicle (available on as needed basis only) 708-245-2920

LaGrange Hospital

Sarah Grcich 219-309-5939 or 219-983-8780

Porter Regional Hospital & Ostomy Clinic

Valparaiso, Indiana

National UOAA Virtual Groups

Continent Diversion Network: Lynne Kramer 215-637-2409

Familial Adenomatous Polyposis (FAP) Foundation: Travis Bray 334-740-8657

Friends of Ostomates Worldwide - USA: Jan Colwell 773-702-9371

GLO Network: Fred Shulak 773-286-4005

Ostomy 2-1-1: Debi K Fox 405-243-8001

Pull-thru Network: Lori Parker 309-262-0786

Quality Life Association: Judy Schmidt 352-394-4912

Thirty Plus: Kelli Strittman 410-622-8563

Upcoming 2016 Meetings at Glenbrook Hospital

TUESDAY, June 21 – Hedy Holleran, Hollister

TUESDAY, July 19 – Robert Evans, Coloplast

August – No Meeting

Additional area support groups:

Northwest Community Hospital

Arlington Heights. 2nd Thurs at 1:00 pm every other month. Feb, Apr, Jun, Aug, Oct, Dec in The Learning Center, Level B1 of the Busse Center Contact Carol Stanley 847-618-3215, cstanley@nch.org

Rush University Medical Center, Chicago

The first Thursday every month starting Feb 4, 2016 in the Prof. Bldg, Suite 1138 Conf Room. Contact Kathleen Hudson 312-942-7088, Kathleen_Hudson@rush.edu

Southwest Suburban Chicago, Evergreen Park

The third Monday at 6:30pm, Little Company of Mary Hospital. Contact Nancy Olesky 708-499-4043 or Edna Wooding 773-253-3726, swscost@gmail.com

Sherman Hospital, Elgin

The second Wednesday of each month at 2 pm. Lower level Conference B. Contact Heather LaCoco 224-783-2458, Heather.Lacoco@Advocatehealth.com or Tom Wright, tomwright122@att.net

DuPage County

The fourth Wednesday at 7:00pm, Good Samaritan Hospital, Downer's Grove in the Red and Black Oak Rooms by the cafeteria. Contact Bret Cromer 630-479-3101, bret.cromer@sbcglobal.net

Aurora

The second Tuesday at 7:00pm, Provena Mercy Center. Contact John Balint 630-898-4049, balint.john@yahoo.com

Will County, Kankakee IL

2:00 p.m. the last Saturday of Feb, Apr, Aug and Oct in the Riverside Medical Center Board Room, next to the cafeteria. Also a June picnic and December holiday party. Charlie Grotevant 815-252-1551, charliegrtvnt@gmail.com

Lake County Illinois

Hollister in Libertyville, 10:00am the 3rd Saturday, every other month. Jan, March, May, July, Sept, Nov. Contact Barb Canter 847-394-1586, barb1234@sbcglobal.net

Loyola University Health System, Maywood

The 2nd Wednesday of the month at 7:15 in the Cardinal Bernadine Cancer Center 2nd floor Auditorium A. Contact Robin Handibode 708-205-6664 or Nanci Stark, WOCN 708-216-8554, nhstark@lumc.edu

Valparaiso, Indiana

Porter Regional Hospital, 1st floor Community Room. 6:30 pm the 4th Thurs., Jan – Oct. Contact Sarah Grcich 219-309-5939, Sarah.Grcich@porterhealth.com

Here and Now

with Patricia Johnson

I found myself thinking recently about all the food items we are afraid to eat. Stringy vegetables like celery and asparagus. Raw vegetables, fruits, nuts. What one person can eat another cannot. Some eat mushrooms without a problem, I stay away from them. Cheese gives gas, but I love cheese and eat it anyway.

My husband eats a lot of nuts. They are always around, in the house, in the car, I can't get away from them. So I started eating them.

Pecans, roasted, unsalted cashews, walnuts, almonds, and sunflower seeds.



And I really enjoy them. However, no matter how much I chew they come through gritty and in little pieces.

In February I asked the surgeon about it. I was told that even though they don't break down completely the nutritional value is still absorbed.

I decided to try nut butter. Dale and I went to the Fisher's Outlet Store on Randall Road and we made nut butter with almonds and cashews. (It was very easy you put the almonds in the grinder and out comes the butter.) That was it, just 100% ground up nuts.

I then made cashew butter cookies and almond butter cookies. The cashew cookies were a little bland, if I make them again I'll add a little cinnamon. I added some almond extract to the almond batter. They turned out great! So there you have it, a way to eat nuts without worrying about how they will come through your pouch.

Life is good

(Oh, and by the way, if you come to the June meeting you can try the fruits of my labor. I may even have the recipes typed out.)

Ostomy ~ The New Normal



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WELCOME!

Grundy County Ostomy Support Group

Monthly Meetings are held at 11:00 AM, the 3rd Saturday at Grundy Administration Bldg., 1320 Union St., Morris, IL.

Contact Judy Morey at 815-592-5717 or Kelly Hitt at 815-941-6818.



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Coping With Chronic Pain

by Lynn Wolfson, Broward Ostomy Association

(BOA) Editor's Note: Lynn was born with Hirschsprung's Disease which severely affects the digestive system and has had over 30 surgeries since she was 4 years old. At this time, she has her seventh ostomy, a gastric tube for stomach venting since she is unable to vomit, a Jejunal tube for feeding due to severe motility issues, difficulty breaking down of foods and malabsorption of nutrients. In addition, she has a neurogenic bladder and needs to catheterize two to three times a day. Lynn enjoys traveling the world with her family.

Chronic pain is something that most people with digestive diseases live with on a daily basis. Learning to cope with this pain and to live a productive and meaningful life can be a tremendous challenge.

However, with the appropriate support, attitude, exercise and diversions it can be managed. However, this is not easy to learn and is very individualized.

It is very important that a person with chronic pain surround themselves with people that are positive and supportive. These people are the ones that you

want to see on a regular basis. This may include family, friends, book clubs, card groups, synagogue or church groups or any other group that meets on a regular basis. Talk to these people and get to know them. Listen to their challenges and give creative positive solutions. I find that when I am helping another individual, I forget about my own ailments for the moment. I put my feet in their shoes and look at life with a whole new perspective.

Attitude is another important characteristic. Unfortunately, for most of us, this chronic pain is here to stay. Accept it. Try to understand the difference from chronic pain and acute pain. Make a list of the things you have done in the past that have helped. I keep this list on my phone. My list includes venting my gastric bag, catheterizing, lying down, pushing my hernia back in place, making sure my ostomy is outputting a sufficient amount, stop eating, and feeling for any hardness in my abdomen. If I find that my output is very low or I feel a hardness in my abdomen, I know to call the doctor.

I find exercising on a regular basis keeps me healthy and happy. For me, I swim 30 laps three to five times a week at the YMCA. I also walk around my neighborhood. Perhaps there are other exercises which you are capable of doing and can enjoy.

Lastly are diversions. For me, I enjoy knitting hats. I find by keeping my hands moving and my mind focused on my hands, it helps me to endure the pain. I consider knitting turning the negative energy of pain into positive of energy of giving a hat to someone in need. Perhaps others would enjoy doing a puzzle or building a model or painting or needle pointing. I also find playing scrabble or Words With Friends on the computer another diversion.

It took me a while to figure out what works for me. Try to learn what causes your pain or when your pain is at its worst. I find I am pain after eating or standing or sitting too long. Once I realized that, I adjusted what I was doing. Coping with chronic pain is a challenge. However, once I gained control and understood my pain, I found I started to enjoy life.

We have all been given the gift of life. However, no one's gift was free of flaws. Accept our strengths and use them to create a meaningful and productive life.

(BOA) Editor's Recommended Reading: Unfortunately I am experiencing chronic adhesion pain and thus asked Lynn to write the above article. A book that

has significantly helped me is entitled *The Pain Survival Guide, How to Reclaim Your Life* by Dennis C. Turk, PhD and Frits Winter, PhD. The book covers the theme of becoming your own pain management expert with sections on activity levels, rest and pacing; relaxation; fatigue; relationships; thoughts and feelings. A good read and published by the American Psychological Association.

Lynn's on TV!

Lynn Wolfson was interviewed on NBC Channel 6 (South Florida) in a spot entitled *Clear The Shelters: Meet Lynn and Zev*. Roxanne Vargas reports on the roles service dogs play in the day to day lives of their owners and introduced viewers to Zev, a service dog who is helping his owner (Lynn) live a normal and productive life. Lynn openly discusses her ostomy and how Zev, the wonder dog, helps her out. Thanks Lynn. We're so proud of you!

To view the interview go to:

<http://www.nbcmiami.com/on-air/as-seen-on/Clear-The-Shelters-Meet-Lynn-and-Zev-Miami-321765771.html>



Having an Ostomy during Cancer Treatment

Livestrong Foundation

Some cancer survivors with an ostomy require other cancer therapies along with the ostomy surgery. Here are some issues to consider:

- **Chemotherapy:** A survivor may realize that assistance is needed to care for the ostomy if he or she feels sick or tired after

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chemotherapy. Some medications may have side effects that affect the ostomy. Let your health care practitioner examine your ostomy during follow-up visits. Take an extra pouch so you can remove yours for the examination. Stop irrigations when you have diarrhea, if you have a colostomy.

- **Radiation:** Radiation is an integral part of cancer treatment for many survivors. If the ostomy is in the marked field of radiation, you may have to remove your pouch for each treatment. Carry a spare pouch with you for all medical visits because the office may not have a pouch that fits your ostomy. Radiation may cause skin changes around your ostomy. Make your radiotherapy health care team aware of any changes with your ostomy or your skin. If diarrhea occurs during radiation therapy and you have a colostomy or an ileostomy, alert your nurse. Take your supplies with you to the hospital or clinic. Inform health care providers that you have an ostomy and let them know about your care methods.

The bodily changes like this can affect body image. Remember that your value as a person has not changed because of an ostomy. People will be unaware of it unless you tell them. You can live a normal and fulfilling life. Your health care team can answer your questions and help you adjust.

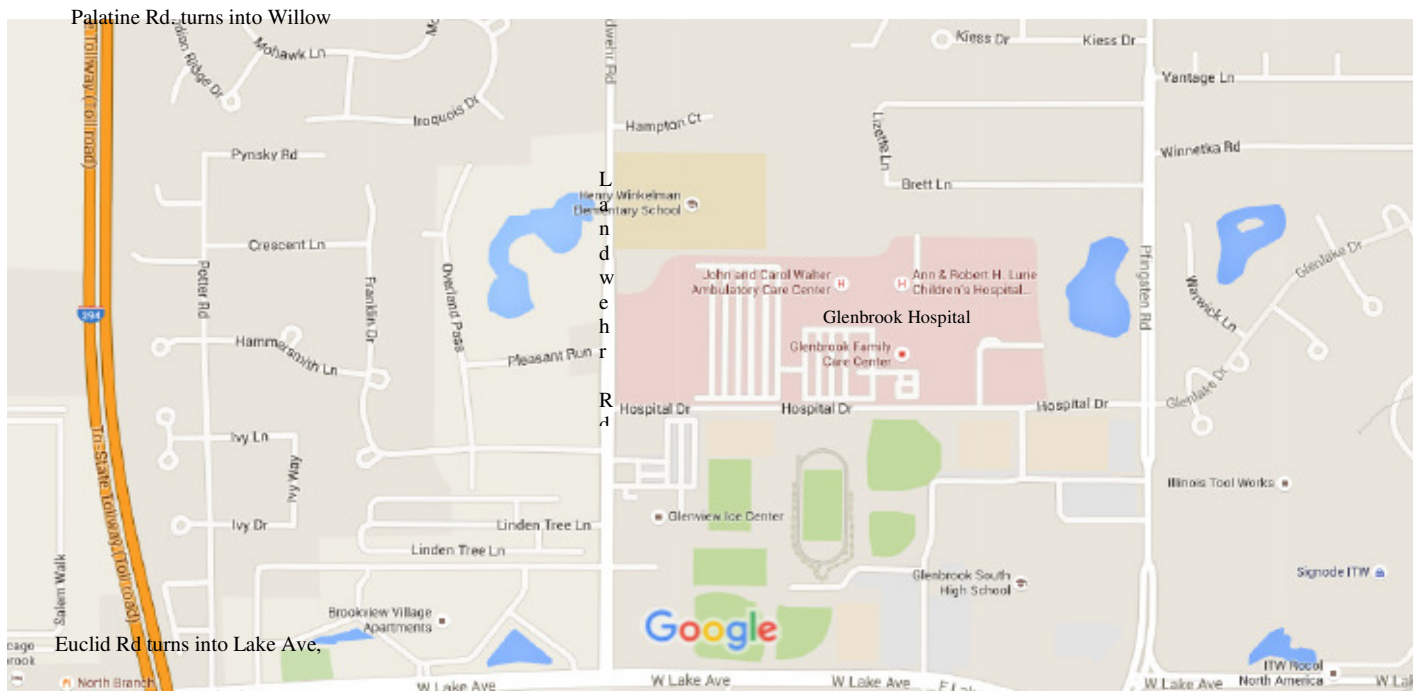
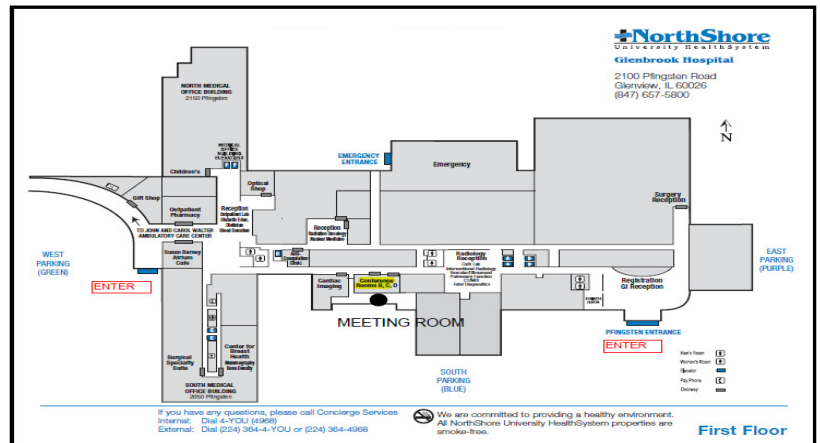
New Beginnings....

OAGC general meetings are now at Glenbrook Hospital, in the first floor Conference Rooms C-D.

There is abundant free parking including many handicapped spaces directly in front of the hospital. An information desk is just inside the Hospital's Pfingston Entrance. Upon entering, take the hallway to the left.

*We exist to support you,
you support us so we exist.*

Glenbrook Hospital is approximately 4 miles north of Lutheran General. It is bordered by Pfingston Rd east, Hospital Dr. south and Landwehr Rd. west. From I-294 take Willow Rd exit east to Landwehr Rd south. From I-94 take Willow Rd. exit west to Pfingston Rd. south. From Waukegan (43) take Lake or Willow west to Pfingston. The parking lot entrance is on Hospital Dr.



If you have a suggestion for a meeting or know someone you would like to invite to speak, contact Nancy Cassai, Vice President/Program Director at cassainancy@gmail.com



My Emergency Ostomy Kit

by Fred Shulak

When I read this article (May, 2016) I thought to myself, gee - I don't have a kit. I've had my ostomy for so long and I never carry a kit, but it's a good idea. You never know when you will need one.

I remembered that I have two leather male bags that I thought would be a good place to have a kit. I recalled they were in the trunk of my car so I went and got them. I had to decide which of the two would be the best receptacle so I opened each one to see what was in them and would you believe... one of them contained items that I would need in the case of an emergency.

I figured this kit had been in my trunk for approximately 6 years. I decided to throw everything out and start with "fresh" supplies and I now have a new emergency ostomy kit...if only I could remember that I have one.

Many many years ago I made an emergency ostomy kit and put that in my car and ultimately forgot about it. When I discovered it, I also put in fresh supplies. However, because I was going to be at home for several days, I decided to use the face plate/ flange to see if it was still good...after all it had been in the trunk of my car for ten years. What do you know... I used it and it functioned without a problem.



When would be a good time to be happy?

NOW!

Did you know....

The FDA recently proposed that food labels include a daily value for added sugars, not to exceed 10% of the calories we consume. Sugar is not only the familiar refined white crystals. It's also unprocessed carbohydrate found naturally in sucrose (sugar beets and sugar cane), fructose (fruits and honey) and lactose (milk and yogurt).

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M6236N 10.15

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 marked 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.

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When to Call for Help

US National Library of Medicine

Call your doctor or nurse if:

- Your stoma is swollen and is more than a half inch larger than normal.
- Your stoma is pulling in, below the skin level.
- Your stoma is bleeding more than normal.
- Your stoma has turned purple, black, or white.
- Your stoma is leaking often or draining fluid.
- Your stoma does not seem to fit as well as it did before.
- You have to change the appliance once every day or two.
- You have a discharge from the stoma that smells bad.
- You have any signs of being dehydrated. Some signs are dry mouth, urinating less often, and feeling lightheaded or weak.
- You have diarrhea that is not going away.

If the skin around your stoma:

- Pulls back
- Is red or raw
- Has a rash
- Is dry
- Hurts or burns
- Swells or pushes out
- Bleeds
- Itches
- Has white, gray, brown, or dark red bumps on it
- Has bumps around a hair follicle that are filled with pus
- Has sores with uneven edges

Also call if you:

- Have less output than usual in your pouch
- Have a fever
- Experience any pain
- Have any questions or concerns about your stoma or skin



Happy
Father's
Day!

June 19

*Have a Great Day...
with on Ostomy!*

OSTOMY EDUCATION CONFERENCE

Presented by OAGC and Hollister

Saturday, November 5, 2016

The Double Tree Hotel
75 W. Algonquin Road
Arlington Heights Rd exit off I-90
Arlington Heights, IL

Mark your calendar for this one day regional education conference filled with information for and about ostomies, focusing on both medical and lifestyle issues.

Additional sponsorship provided by **Coloplast**, MPM Medical, Convatec, Shield Healthcare

Times:

8:00am – Check in/Continental Breakfast
8:00am – 4:00pm – Vendor Fair
9:00am – 5:00pm – Sessions/Boxed lunch
9:00am – 4:00pm – Stoma Clinic
5:00pm – Casual Evening Social

Sessions planned:

Colorectal Surgery, Urology, Psychology, Physical Therapy, Nutrition, Stoma/Skin, Lifestyle and Caregiver/Spouse

Stoma Clinic:

Organized by CWOCN Carol Stanley and staffed by area WOCNs. You will need to bring an appliance change. Information on making appointments will be provided to registrants closer to the event.

Vendor Fair:

Features Manufacturers, Distributors and Healthcare Providers, as well as patient Education and Support information.

Parking is free. Details will be posted and continually updated on our website. Please pre-register by using form on the next page or online registration will begin soon.

*The best memories are the ones
that you try to explain,
but in the end you just say,
YOU HAD TO BE THERE!*

REGIONAL OSTOMY EDUCATION CONFERENCE

Saturday November 5, 2016 Arlington Heights, Illinois

REGISTRATION

NAME _____

ADDRESS _____

EMAIL _____

TYPE OF SURGERY (check what you have or will have)

☐ Colostomy ☐ Ileostomy ☐ Urostomy ☐ J-Pouch ☐ Continent Urostomy ☐ Other _____

Are you a member of a support group? _____ Name of group _____

Name of Attendees (for badge)	Relationship	Cost	Box lunch choice (circle one)
1. _____	Self	\$25	Turkey Beef Veg
2. _____	Spouse	\$20	Turkey Beef Veg
3. _____	Family/Friend	\$20	Turkey Beef Veg
4. _____	Family/Friend	\$20	Turkey Beef Veg

Children under 12 (no charge)

1. _____	Patient	Family/Friend	n/c	Turkey	Beef	Veg
2. _____	Patient	Family/Friend	n/c	Turkey	Beef	Veg

Total: Adults (12+) _____ Children(<12) _____ Total Cost \$ _____

Will you attend the evening social event? Please circle: **YES** **NO**

There is no additional charge, but we need a count for catering.

Check sessions that would interest you: ☐ Colo-rectal Surgeon ☐ Urologist ☐ Dietician ☐ Skin
☐ Physical Therapist ☐ Psychologist (patient) ☐ Psychologist (family/caregiver) ☐ Ask the Doctor
☐ Ask the Nurse ☐ Lifestyle ☐ Meet other spouses/caregivers ☐ Re-imburement Ins/Medicare
Other _____

>Please note – you are not registered for any specific sessions. This information is for scheduling purposes only.

Please send this form with check payable to:

Ostomy Association of Greater Chicago

c/o Judy Svoboda/President

605 Chatham Circle

Algonquin, IL 60102

Or register online beginning in late June. www.uoachicago.org

Ostomy Association of Greater Chicago

Confidential Membership Application

We invite you to join our association. You are especially welcome if you have an ostomy, are preparing for surgery, are a healthcare professional and/or have a loved one who has had surgery. We are a completely volunteer-operated ostomy support group. Our mission is to support, educate and advocate for people with ostomies.

Name _____

Address _____

City _____ State _____ Zip _____

E-mail _____ Phone _____

Type of Ostomy: Colostomy Ileostomy Urostomy Continent Procedure

Date of surgery _____ Age Group <21 22–36 37–50 51–65 66–80 80<

Donation enclosed \$ _____ (optional)

Attend one of our general meetings. There are always friendly people to talk with you. You may even want to participate in our association's leadership. We always need talented people to share in our good work. Membership is free (our funds come primarily through donations). Please mail this application to

Judy Svoboda, President
605 Chatham Circle, Algonquin, IL 60102

► A very special thank you to everyone who donates to our association. Our largest expense, the cost of printing and mailing this newsletter, is continually increasing and is only made possible through the generous donations of our members.

To make a tax-deductible donation, please make check payable to Ostomy Association of Greater Chicago or OAGC and bring to a meeting, or send to

Tim Traznik
Treasurer/OAGC
40 Fallstone Drive
Streamwood, IL 60107

Donations can also be made online using a credit card: www.uoachicago.org/donations

Without you we don't exist!

YEAH! SUMMER



The information contained in this newsletter and on our website is intended for educational/informational purposes only, and is not a substitute for the medical advice or care of a doctor, surgeon, WOCN, licensed pharmacist or other health care professional.

The New Outlook
267 Noble Circle
Vernon Hills, IL 60061



We invite you to attend our general meetings at Glenbrook Hospital. Relatives, friends, doctors, and nurses, as well as our members—any interested people—are invited and welcome. Our association has a team of trained volunteer listeners available to discuss the concerns of patients. Healthcare professionals and families are urged to use this free benefit. When you know of a patient who would like to talk to a person who has been there and done that, please call the visiting chairperson (see page 2).