Ostomy Association of Greater Chicago

The New Outlook

September 2014



NEXT MEETING Wednesday, September 17, 7:30 pm

Lutheran General Hospital 1775 Dempster St., Park Ridge, IL Special Functions Dining Room 10th Floor

Last Months' Meeting (our 442nd)

We thoroughly enjoyed a gentle fitness work-out with special guest Personal Trainer Ben Rudzin. Emphasizing strength training using our own body weight, Ben guided us through basic exercises (many while seated) working individual muscles and muscle groups. It was amazing how intense these simple movements felt in each muscle. And we can do this at the office, or while reading or watching TV! We learned strengthening our abdominal muscles may also help to lower the risk of hernias. Additionally, Ben demonstrated proper posture and balance, and discussed the importance of maintaining muscle mass as we age.

Afterward, many of us realized we were very out of shape! We then transitioned into a spontaneous rap session, with assistance from WOCNs Karen Blum and Mary McCarthy. We were very fortunate to have these two incredibly knowledgeable nurses join us.

Don't forget to let us know if your physical address or email address has changed. Our member list is private, never shared or sold. Our next meeting, September 17, will feature prominent Gastroenterologist Dr. Eugene Yen, Northshore University Health System.

Attending your first meeting? Simply park in the underground garage, enter the Parkside Center and take Elevator B to the 10th floor, then hallway to the right. There are always supportive ostomy veterans to chat with you.

We're going GREEN! Paper is so 20th century! Thanks to everyone who volunteered to receive this newsletter via email. If you have Internet access, you can 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 safe sender's list.



www.ostomy.org

Ostomy Association of Greater Chicago (OAGC)

Established 1975

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Wound Ostomy Continence Nurses (WOCN)

Bernie auf dem Graben	773-774-8000
Resurrection Hospital	552 050 0200
Nancy Chaiken	773-878-8200
Swedish Covenant Hospital	772 000 0100
Teri Coha	773-880-8198
Lurie Children's Hospital	772 702 0271 0 2051
Jan Colwell, Maria De Ocampo,	773-702-9371 & 2851
Michele Kaplon-Jones	
University of Chicago Jennifer Dore	047 570 2417
	847-570-2417
Evanston Hospital	212 042 7000
Karen Blum	312-942-7088
Rush University Surgeons	212 042 5021
Robert Maurer, Laura Crawford	312-942-5031
Rush University Medical Center	047 022 6001
Madelene Grimm	847-933-6091
Skokie Hospital-Glenbrook Hospital	
North Shore University Health System	212 026 6421
Connie Kelly, Mary Kirby	312-926-6421
Northwestern Memorial Hospital	015 220 2500
Kathy Krenz & Gail Meyers	815-338-2500
Centegra-Northern Illinois Medical	0.47. 722. 001.7
Marina Makovetskaia	847-723-8815
Lutheran General Hospital	0.47 (10 2125
Diane Zeek, Carol Stanley	847-618-3125
Northwest Community Hospital	700 220 (0(0
Nancy Olsen, Mary Rohan	708-229-6060
Little Company of Mary Hospital	700 (04 2204
Kathy Garcia, Jola Papiez Advocate Christ Medical Center	708-684-3294
	947 216 6106
Sandy Fahmy	847-316-6106
Saint Francis Hospital	847-493-4922
Nancy Spillo Presence Home Care	047-493-4922
	630-933-6562
Colleen Drolshagen, Becky Strilko, Barb Stadler	030-933-0302
Central DuPage Hospital	
© 1	708-216-8554
Kathy Thiesse, Nancy Stark	/06-210-6334
(Ginger Lewis-Urology only 708-216-5112) Loyola University Medical Center	
Alyce Barnicle (available on as needed basis only)	708-245-2920
LaGrange Hospital	100-243-2920
LaGrange Hospitat	

National UOAA Virtual Networks

Pull Thru Network: Lori Parker	309-262 6786
UOAA Teen Network: Jude Ebbinghaus	860-445-8224
GLO Network: Fred Shulak	773-286-4005
YODAA: Esten Gose	206-919-6478
Teen Network: Jude Ebbinghaus	860-445-8224
Thirty Plus: Kathy DiPonio	586-219-1876
Continent Diversion Network: Lynne Kramer	215-637-2409
FOW-USA: Jan Colwell	773-702-9371

2014 Meeting Dates at Lutheran General Hospital

September 17- Dr. Eugene Yen, Gastroenterologist October 15-

November 8- Midwest Regional Ostomy Education Conference in Arlington Heights

December 10- Annual Holiday Gala

More area support groups:

Northwest Community Hospital

Arlington Heights. Oct. 9, Dec. 11, at 1:00pm, level B1 of the Busse Center. Contact Diane Zeek 847-618-3215, dzeek@nch.org

Southwest Suburban Chicago

The third Monday at 7:30pm, Little Company of Mary Hospital, Evergreen Park. Contact 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.com

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

Charlie Grotevant 815-842-3710 charliegrtvnt@gmail.com

Lake County Illinois

Hollister in Libertyville, 10:00am the 3rd Saturday, every other month. Meetings are in January, March, May, July, September and November. Contact Barb Canter 847-394-1586 barb 1234@sbcglobal.net

Here & Now with Patricia Johnson

Let there be such oneness between you, that when one cries the other tastes salt.

Author Unknown

At a recent ostomy meeting Judy said, "We have all been through a lot." And she was so right; we <u>have</u> been through a lot. That verbal acknowledgement was a balm to my spirit.

I think our families, spouses, friends, and significant others who have stood by and watched have been through a lot also. Maybe more.

I say this because while we were the center of attention by doctors, nurses, and technicians, they could do nothing but watch. And it must have been painful for them. To see someone you love struggle or in pain and not fix it must be very frustrating.

These dear people have taken us to appointments, held us when we hurt, dried our tears, and encouraged us to keep going. Our achievements, healing, and victories great and small, are theirs too. We must not discredit their trial. It was just as difficult as ours.

Because of these people in our lives who love us and who have stood by us we are blessed.

Life is good.



United Ostomy Associations of America, Inc. • www.ostomy.org

THE UNITED OSTOMY ASSOCIATIONS OF AMERICA (UOAA) is declaring that on October 4, 2014, UOAA is acknowledging ostomy and continent diversion surgery. The day will be recognized as Ostomy Awareness Day 2014 – Live, Learn, Share.



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Our mission by celebrating this special day is an effort to help patients LIVE a normal life following surgery, to help the medical community LEARN about the needs of ostomy patients, and to SHARE our stories to raise awareness about ostomies throughout the United States.

Those of us who LIVE with an ostomy have an opportunity to SHARE our stories so that other patients, medical professionals and the general public can LEARN about living with an ostomy. Building AWARENESS begins with you, and together we can make a difference in the ostomy community.

Susan Burns President/UOAA

Chemotherapy and Your Ostomy

Edited by B. Brewer UOAA Update 08/2014

If you are taking chemotherapy, you should be aware of many chemo agents that affect the body differently. Below are listed basic side effects of chemo that an ostomy patient should be aware of.

Stomatitis - Is an inflammation that can develop anywhere in the gastrointestinal tract. It may appear as white ulcers in your mouth, on your stoma or elsewhere in your GI tract. You must be very careful in caring for your stoma, using care in gentle removal of the pouch and barrier, and using plain tap water to cleanse the stoma.

Dermatitis - Is an inflammation of the skin. Skin reactions are worse when you are on chemo; therefore, if leakage occurs, change your pouching system as soon as possible. Again cleanse your skin with tap water only, making sure to get it clean. You will want to look for areas of increased redness, weeping areas, or a red rash that may have a white head on it. If the skin is open, or you identify a rash, see your doctor or ostomy nurse.

Diarrhea - Can be a severe side effect for the ostomy patient, especially the ileostomate. It is necessary for the ostomate to keep track of the amount of fluid he/she is able to drink versus what is expelled.

Dehydration - Is a big risk, as well as losing two of the body's minerals-sodium and potassium. If a colostomate develops diarrhea, discontinue irrigations (if you normally irrigate). You will want to eat foods that slow the bowel down, such as bananas, rice, applesauce, tapioca, or yogurt. You should notify your doctor if diarrhea occurs. He or she may prescribe some medications to slow bowel activity.

Constipation - On the opposite end of the spectrum, some agents can cause constipation. If this occurs, see your doctor. He or she may want to give you a laxative or stool softener. Remember to increase your fluid and fiber intake if you are constipated. Chemotherapy can be taxing on you. Nutrition and rest are essential. Do your routine stoma care when you are well rested.

People often go to another room to get something and when they get there, they stand there wondering what they came for.

This is NOT a memory problem; it is nature's way of making people do more exercise.



Skin Care
WOCN Society via Shield Healthcare

People who manage ostomies pay special attention to the stoma site and surrounding skin. It's very common to be concerned about irritation caused by exposure to stool or urine. With this in mind, the Wound, Ostomy Continence Nurses Society (WOCN) developed a Basic Ostomy Skin Guide to address typical questions. The guide is designed to help ostomates use products correctly, protect the skin, and gently clean and care for the stoma and surrounding skin. Here are WOCN's answers to the most commonly asked questions about stoma cleaning and care.

• To clean the skin around your stoma, all you really need to use is warm water and a washcloth (or good quality paper towels). The use of gauze or gloves is not usually necessary.

- For those that prefer to use soap to clean around the stoma, it's best to use a very mild soap. Avoid using soaps and cleansers with oils, perfumes or deodorants since these can sometimes cause skin problems or prevent your skin barrier from sticking.
- Rinse the soap off the skin around your stoma very well because the residue may keep your skin barrier from sticking and may also cause skin irritation.
- If you are using a skin paste, it may be easier to remove the paste before you wet the area.
 Some people may use adhesive remover. Do not worry if a little bit of paste is left on your skin.

- Always dry your skin well before putting on your new pouching system.
- Do not use alcohol or any other harsh chemicals to clean your skin or stoma. They may irritate your skin.
- Do not use baby wipes or towelettes that contain lanolin or other oils, as these can interfere with the skin barrier adhesive and may irritate your skin.
- Unless recommended, do not apply powders or creams to the skin around your stoma because they can keep your skin barrier from sticking.
- Sometimes you may see a small amount of blood on your cloth. The stoma tissue contains small blood vessels and may bleed a small amount when cleaned. Any bleeding that does not stop should be reported to your health care provider. The stoma has no nerve endings, so you are not able to feel if you are rubbing too hard. For this reason, use a gentle touch when cleaning around the stoma and do not scrub.
- The basic rule that applies is not to use too many products on the skin. Do not use adhesive remover if you have skin that tears very easily. If you do use adhesive remover, always wash well with water and mild soap to remove the oily coating on the skin. Then rinse the skin well with water and dry completely.

If you have a new ostomy, it's recommended that you measure your stoma once a week for the first six to eight weeks after your ostomy surgery. Your stoma shrinks while it's healing and you'll make sure the opening in the skin barrier is the right size for your stoma. Remeasure your stoma if you experience irritation between the stoma and skin barrier wafer. Should you experience painful skin problems or severe irritation around the stoma, please contact your health care provide or WOC Nurse.

You Can Hide Your Ostomy

Mayo Clinic Ostomy Care

To you, the ostomy bag attached to you is very obvious. When you look in the mirror, you notice the bag under your clothes. You might think every

gurgle and noise coming from your stoma is loud and heard by everyone in the room.

Most people won't notice your ostomy unless you tell them about it. As you get used to your ostomy, you'll figure out tips and tricks to keep the bag concealed and the noises to a minimum. Here are some ideas to get you started:

- Empty your ostomy bag when it gets to be one-third full. That way it won't bulge under your clothes.
- Work with your ostomy nurse to find the ostomy pouching system that works best for you.
- If you're worried about the odor when emptying your ostomy bag, ask your ostomy nurse or visit your medical supply store for pouch deodorants or air sprays to minimize odor.

Ask a close friend or loved one whose opinion you trust whether your ostomy bag is visible under your clothes or if the sounds your ostomy makes are as loud as you think they are. Everyone's body makes noises and produces odors from time to time. While it can be embarrassing, don't let a fear of what could go wrong keep you from going about your day.

Simple, Yet Profound Words From a Five-Year Old

By Kathy Ward, Admin. Asst.-UOAA

When my granddaughter was five, she had many problems with her digestive system. Her surgeon placed a stoma over her stomach so that a feeding tube could be inserted.

One day, she looked at me and said, "Grandma, did you name your stoma?"

I replied, "Yes, I did. I call it Rose, because it looks like a flower to me. Did you name yours?"

"Yes," she said. "But I named mine Jack."

Thinking this was an odd name for a little girl to name her stoma, I had to ask, "Why did you name it Jack?"

Her response, "Because Jack is the name of the lifeguard at the beach and my stoma saved my life."

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Ostomy ~ The New Normal

Tips

University of Pittsburgh Medical Center

When to call the doctor.

If you have any of the following symptoms:

- Purple, black, or white stoma
- Severe cramps lasting more than 6 hours
- Severe watery discharge from the stoma lasting more than 6 hours
- No output from the colostomy for 3 days
- Excessive bleeding from your stoma
- Swelling of your stoma to more than 1/2inch larger than usual
- Pulling inward of your stoma below skin level
- Severe skin irritation or deep ulcers
- Bulging or other changes in your abdomen

When to call your ostomy nurse.

If any of the following occurs:

- Frequent leaking of your pouching system
- Change in size or appearance of your stoma, causing discomfort or problems with your pouch
- Skin rash or rawness
- Weight gain or loss that causes problems with your pouch

Daily Exercise for the Non-Athlete

Vancouver Ostomy Highlife

A recent medical association report stated that "proper weight control and physical fitness cannot be attained by dieting alone. Many people who are engaged in sedentary occupations do not realize that calories can be burned by the hundreds just by engaging in strenuous activities that do not require physical exercise."

Here is a tongue-in-cheek guide to calorie burning activities that can be conducted right in your workplace, as well as the number of calories per hour they consume.

Activity	Calories Consumed
Beating around the bush	60
Jumping to conclusions	75
Climbing the walls	150
Swallowing your pride	20
Passing the buck	50
Throwing your weight around	100-400
Pushing your luck	100
Making mountains out of mo	lehills 600
Wading through paperwork	100
Juggling deadlines	120
Balancing the books	60
Running around in circles	250
Bending over backwards	50
Opening a can of worms	60
Tooting your own horn	100
Reinventing the wheel	150

Great opportunities to help others seldom come, but small ones surround us every day.

Sally Koch

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Acidic Urine and its Importance for Urostomates

Ostomy Nutrition and More by Allen & Price via West Texas Group UOAA Update

Urine odor from the urostomy pouch indicates possible infection. More often this is due to stale alkaline urine residue (or poor hygiene), although some medications or foods will produce odor in the urine. Acidic urine tends to keep bacteria down, thereby reducing the incidence of infection, and decreases urine.

In chemistry, "pH" defines the degree of acidity or alkalinity of a substance. When food you eat is burned in the body, it yields a mineral residue called "ash". This ash can be either acidic or basic (alkaline) in reaction, depending on whether the food burned contains mostly acidic or basic ions. The reaction of urine can be definitely changed by foods. Most fruits and vegetables actually produce an alkalinized ash and tend to alkaline the urine. Meats and cereals will usually produce an acidic ash that will acidify urine.

By taking Vitamin C (ascorbic acid), one can acidify urine pH. The normal dosage is 20 mg four times daily. Do not take the total daily amount all at once. Several doses a day gives the best result. High alkaline urine may cause stoma stenosis or the narrowing of the stoma opening, often caused by bacteria in alkaline urine. High alkaline may also cause blockage of urine and subsequent ureteral and kidney damage. Persons with urostomies should maintain acid urine with a pH of 5.5 to 5.0. This range can be determined by dipping nitracine (litmus) paper into a drop of fresh (not from the pouch) urine that has come directly from the stoma. Never take a urine sample from urostomy pouch. Stale urine is almost always alkaline.

FOW Save the Date!

Friends of Ostomates Worldwide is holding a fundraiser Sunday, October 26th from 2 – 5pm at The Painted Penguin family activity center in the Fox Valley Mall, Aurora, IL. There will be painting, takehome artwork, refreshments, raffle prizes and a silent auction. Money raised is used to send ostomy supply donations to needy people all over the world. For advanced information call 847-764-0891.



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Why You May Need a Health Advocate

by: Carolyn M. Clancy, M.D., AHRQ, from: AARP Bulletin, July 23, 2010

Imagine your doctor has just given you a serious diagnosis or told you she was concerned about the results of your medical test. You might understandably be frightened.

Listening carefully to your doctor and asking questions about a diagnosis or test results can help you get better care. But here's the problem: Just when you should be paying close attention to what your doctor is saying, you may be stunned by the news you've received.

That's when having a health or patient advocate can help.

A health advocate can be a family member, friend, trusted coworker, or a hired professional who accompanies you to your appointments and asks questions, writes down information, and speaks up for you so you can better understand your illness and get the care you need.

Research shows that quality health care requires taking an active role in decisions about your care. If you're facing a difficult medical decision, it's a good

idea to bring someone with you who can help focus on your care when you're not fully up to it

As a doctor and a patient, I've seen how valuable it is to have "another set of ears and eyes" in the exam room. Having an advocate at medical appointments or during a hospital stay can ensure that you get the information you need to manage your health.

Health advocates can:

- Ask questions or voice concerns to your doctor for you.
- Compile or update your medicine list.
- Remember your medication regimen and help you follow treatment instructions, including asking questions about your followup care.
- Help arrange transportation.
- Research treatment options, procedures, doctors, and hospitals.
- File paperwork or assist with insurance matters.
- Ask the "what's next" questions, such as, "If this test is negative what does it mean? If it's positive, will more tests be needed?"

Of course, many encounters with the medical system are routine and don't require the help of a patient advocate. But there are instances when an advocate can be valuable. For example, if you've had a series of tests and you're concerned the results may reveal a diagnosis such as cancer, you might want to bring an advocate with you to hear and discuss the results.



A true friend reaches for your hand and touches your heart.

-Author Unknown

MIDWEST REGIONAL OSTOMY EDUCATION CONFERENCE Presented by OAGC and Hollister

Saturday, November 8, 2014 The Double Tree Hotel

75 W. Algonquin Road, Arlington Heights, IL 60005 Arlington Heights Rd exit off I-90

Join us for this one-day Ostomy Educational Conference filled with information for and about ostomies.

Sponsors: Hollister, OA Greater Chicago, OA Aurora, Mark Drug Medical Supply, Stoma Guard

Medical Advisor:

Bruce A. Orkin, MD Vice Chair for Academic Affairs, Department of General Surgery Chief, Section of Colon and Rectal Surgery Rush University Medical Center

Speakers:

Dr. Bruce Orkin, Colon and Rectal Surgeon Dr. Tiffany Taft, Psychologist Dr. Renjie Chang, OB-GYN Stephanie Horgan, Clinical Social Worker Jan Colwell, APN, CWOCN Karen Blum, APN, CWOCN Madelene Grimm, CWOCN Kesuri Sethurama, Physical Therapist Brenda Elsagher, Author I Want to Buy a Bowel Urologist TBA Pharmacist TBA Dietician TBA Ally Bain, Law Student, drafted Restroom Access Law (Ally's Law) Susan Burns, President UOAA Sessions for family/spouses

Stoma Clinic:

Organized by Diane Zeek, NP, CWOCN

You will need to bring an appliance change. Information on making appointments will be provided closer to the event and via email to all registered attendees.

Schedule:

8:00am - Registration/Continental Breakfast

8:00am - 4:00pm - Vendor Fair

9:00am - 5:00pm - Sessions with lunch break

9:00am - 3:00pm - Stoma Clinic

6:00pm - Casual Hawaiian Pa'ina (party) with Pu Pu's (pun intended)

Vendor Fair Exhibitors: Hollister, Convatec, Coloplast, Mark Drug Medical, Edgepark Medical, Northwest Community Hospital, MPM Medical, ABBVIE, Shield Healthcare, Oak Park Behavioral Medicine, Stomastifler, Nascent, Byram Healthcare, Stoma Guard, Safe n Simple, FOW, Youth Rally, and more.

Our website www.uoacchiccago.org/events is continually updated as Speakers and Vendors are confirmed.

If any attendee wants to stay over night, in addition to the Double Tree, there are a variety of price options; a Courtyard, a Red Roof Inn and a Motel 6 on Algonquin Rd, and a Holiday Inn Express, Wingate Inn and Jameson Inn on Arlington Heights Rd.

MIDWEST REGIONAL OSTOMY EDUCATION CONFERENCE

Saturday November 8, 2014 Arlington Heights, Illinois

REGISTRATION

NAME				
ADDRESS				
EMAIL				
TYPE OF SUR	GERY (check what you have o	or will have)		
□ Colostomy □ Ileostomy □Urost	omy 🗖 J-Pouch 🗖 Continent	Urostomy [1 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	
2		\$20	Turkey	Beef
3		\$20	Turkey	Beef
4		\$20	Turkey	Beef
	Children under 12			
1 2			Turkey Turkey	Beef Beef
Total: Adults (12+)	Children(<12)	Total Cos	t \$	
Will you attend the evening social event. There is no additional charge, but we check sessions that would interest you provide the provided Physical Therapist provided Psychology. Skin Hernia Intimacy Associated Psychology. Please note – you are not regist purposes only.	e need a count for catering. Du: □Colo-rectal Surgeon logist (patient) □ Psychologist (the Nurse (panel of WOCNs)	□Urologist (family/care □ Meet othe	egiver) 🗖 Die r spouses/care	etician egivers
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Ostor	my Association of Greater Chicag	go		
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Or register online: www.uoacl	nicago.org/events			

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.

Address								
City			State_		_Zip			
E-mail				Phone				
Type of Ostomy:	Colostomy	lleostomy	Urostomy	Continent Proced	dure			
Date of surgery			_ Age Group	<21 22–36 37–50	51–65	66–80	>08	
•	•			ople to talk with you. ed people to share ir		•		hip is

Judy Svoboda, President 605 Chatham Circle, Algonquin, IL 60102 Or sign up online at: www.uoachicago.org/membership

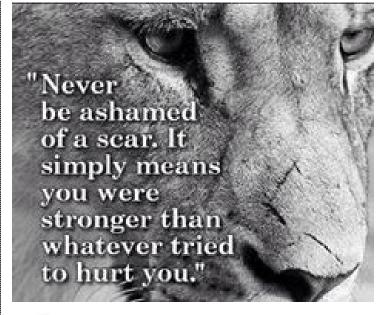
▶ A very special thank you to everyone who donates to our association. Our largest expense, the cost of printing and mailing this newsletter, is continually increasing and is only made possible through the generous donations of our members.

free (our funds come primarily through donations). Please mail this application to

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/





September is Gynecologic Cancer Awareness Month

Every seven minutes in the U.S. a woman will receive a gynecologic cancer diagnosis, totaling nearly 95,000 new cases and 28,500 deaths each year.

The information contained in this newsletter and on our website is intended for educational 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 514 Knox St. Wilmette, IL 60091

Return Service Requested



We invite you to attend our general meetings. 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).