

The New Outlook

Summer 2020

ALL IN PERSON
MEETINGS AND EVENTS
ARE ON HOLD

July 21 Virtual Meeting



As everyone is very aware meetings in hospitals have been suspended indefinitely. We have not been particularly enthusiastic about having virtual meetings, preferring much needed social interactions and perhaps being a bit too optimistic that in-person meetings could resume soon. But as this drags on we must yield to inevitability. Therefore, we will plan a virtual meeting for July 21.



We are planning a virtual meeting for Tuesday, July 21. Please watch your emails for details and instructions to participate.

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

Remember, newsletters are now quarterly. Make sure we have your current email address to receive monthly meeting and event reminders. Our member list is private, never shared or sold. To request the electronic newsletter, email uoachicago@comcast.net or sign up on our website's home page.

OAGC is a 501(c)(3) non-profit, run entirely by volunteers. We depend mostly on donations to fund this newsletter and our website. Thank you all so much for your support!

www.uoachicago.org



www.ostomy.org

Ostomy Association of Greater Chicago (OAGC)

Established 1975

President

Judy Svoboda uoachicago@comcast.net 847-942-3809

Vice President/Program Director

Nancy Cassai cassainancy@gmail.com 847-767-1447

Treasurer

Tim Traznik ttrazpargolf@gmail.com 630-736-1889

Secretary

Patricia Johnson hereandnow@wowway.com 224-523-0509

Visiting Chairperson

Peggy Bassrawi, RN pbassrawi@gmail.com 847-602-0184

Chapter WOCNs

Madelene Grimm madelene_grimm@yahoo.com

Bernie auf dem Graben-Bailie henny311@yahoo.com

Hospitality

Sandy Czurylo

Wound Ostomy Continence Nurses (WOCN)

Julianne Ciaglia 773-990-8498

Presence Resurrection Medical Center

Ana M. Boden 773-296-7095

Advocate Illinois Masonic Medical Center

Swedish Covenant Hospital 773-878-8200

Teri Coha 773-880-8198

Lurie Children's Hospital

Jan Colwell, Maria De Ocampo, 773-702-9371 & 2851

Michele Kaplon-Jones

University of Chicago

Laura Crawford 312-942-5031

Rush University Medical Center

Casey Mulle 847-657-5963

Glenbrook Hospital

Cheryl Isberto 847-933-6091

Skokie Hospital

Highland Park 847-926-5806

Agnes Brugger 847-570-2417

Evanston Hospital

Connie Kelly, Mary Kirby 312-926-6421

Northwestern Memorial Hospital 312-695-6868

Carol Stanley 708-660-5956

Rush Oak Park Hospital

Kathy Krenz 815-338-2500

Centegra-Northern Illinois Medical

Marina Makovetskaia 847-723-8815

Lutheran General Hospital

Elizabeth Perry, Colleen Rohrbacher 847-618-3215

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

Barb Sadler 630-933-6562

Central DuPage Hospital

Nanci Stark 708-216-8554

(Mary Clare Hogan-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

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 847-618-3215, Elizabeth Perry eperry@nch.org

Southwest Suburban Chicago, Evergreen Park

3rd Monday at 6:30pm, Little Company of Mary Hospital, 2800 W. 95th St., Evergreen Park - Rm 1702. Contact Nancy Olesky 708-499-4043, nanook60@sbcglobal.net or swscost@gmail.com

Sherman Hospital, Elgin

2nd Wednesday of month at 2 pm. Lower level Conference B. Contact Morgan Coconate morgan.coconate@advocatehealth.com 224.783.1349, or Tom Wright, tomwright122@att.net

DuPage County, Downers Grove

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

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

Grundy County, Morris IL

Monthly Meetings 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.

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

2nd Wednesday 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

Rush University Medical Center, Chicago

Professional Building 1725 W. Harrison St. Suite 1138 - Conference Room. Parking for main garage will be validated. 1st Thursday of month, 5:30p.m. Contact Rachel Hendee, rachel_hendee@rush.edu

Hazel Crest, IL South Suburban Hospital

17800 South Kedzie Avenue, SSUB-CONF-RM Dining Room 1. Lower level adjacent to the cafeteria. 4th Saturday 10am to Noon. Free Parking. Contact Herb at 708-510-7479

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

Wellness House, Hinsdale

Kay & Mike Birck Home of Hope 131 North County Line Road Ostomy Networking Group for Cancer Survivors Quarterly 7:00pm Contact Karie Milewski-Carlson, 630.654.5114 or kmcarlson@wellnesshouse.org

Here and Now

with Patricia Johnson

A Covid-19 Wedding

There has been so much bad news lately that I thought I would write about something joyful, a wedding. If you have been reading my columns you know that our daughter was engaged. The date set for the wedding was June 20, 2020.

As we watched the days, weeks and months slip by we really did not know what was going to happen. The whole wedding was planned, the church, the venue for the reception, the caterer, the music and flowers, and The Dress. Hilary's dress did come before covid stopped brides from getting their dresses. She even had a couple of fittings. We waited and hoped. In April they moved the reception to August of 2021. Then, as some things began to open in Chicago, she was able to get her dress and they got their marriage license. It was Monday, June 15 that Hilary called to say the wedding was on! They would be getting married at Our Lady of Mont Carmel on June 20, 2020! They had met with the priest and planned the ceremony. It was going to be small with family and close friends all wearing masks.

A friend and I made lovely masks for the women in the bridal party, and I ordered masks for the men. Everyone else brought their own. There were people from the parish there to direct us. It was weird walking down the aisle with Dale wearing a mask. Hilary on her father's arm was radiant as she walked down the aisle. The Mass was simple and beautiful. Everyone in the two families had a part in the ceremony. It was really lovely, the bride and groom surrounded by their closest family and friends, all socially distanced and wearing masks. Covid couldn't stop the joy and love in that church on Saturday.

After the ceremony we went to a restaurant where there was a place set aside for us. We had to wear masks while walking or standing but not while sitting. People stayed in their seats and talked. There were none of the wedding rituals we have all come to expect, no speeches, no cake cutting, there was no cake, or throwing the bouquet. The sun shone and people rejoiced that Hilary and Michael were now married.

Oh yes, because this is for the ostomy newsletter, I want to say that my stoma did not act out. No loud noises and the pouch did not fill up with air making me look strange. All in all, a lovely day.

Life is good

Editor's note: We are all happy for Pat and Dale and wish much happiness for Hilary and Michael!



Inspired
by you

Living life to the fullest. You've never been one to let life slow you down. Every challenge is met with the confidence that comes from knowing life is all about the journey. And that confidence is an inspiration to us every day at Hollister.

For more than 50 years, we've been delivering customer-inspired innovations that have helped make life more rewarding and dignified for those who use our products. Because for us, there's nothing more inspiring than seeing people like you getting back to doing what you love.

Hollister Ostomy. **Details Matter.**



The Hollister logo is a trademark of Hollister Incorporated.
"Hollister Ostomy, Details Matter" is a service mark of Hollister Incorporated.
©2014 Hollister Incorporated. 922479-114

Tips for Coping in a Crisis

Hollister Secure Start Newsletter

Living through a crisis is hard for anyone, but there is an extra layer of concern for people with ostomies. Hollister sat down with two influential people in the ostomy community to find out how they cope during challenging times.

Amber Wallace is the creator of the Ostomy Diaries YouTube channel and social media platforms, and **Dr. Paul Wischmeyer, MD** is a critical care, perioperative, and nutrition physician at Duke University School of Medicine in Durham, North Carolina. Both Amber and Paul live with an ostomy.



Q: How can people with ostomies stay healthy both physically and emotionally when facing a crisis?

Amber: The best way to take care of your emotional health is to take care of your physical health. Continue to take your supplements. Stick to a schedule and make checklists. During a difficult time, I do the same things at the same time every day and that helps. It's also important to get enough rest and exercise, even if you have to find a routine online. Grief and anxiety can manifest physically if you don't put those things into practice.

Paul: I agree with taking the proper supplements. Some of us with ostomies absorb vitamins differently, so it's important to consult your doctor before starting a regimen. Exercise is also very important. As a senior in college, I was doing research with a doctor at Mayo Clinic. One day he said, "Paul, you're getting soft and look a little out of shape – do you want to keep getting sick? You should start running and taking better care of yourself." I had never had anyone say that before and was motivated (and a little miffed) so I started running and ran almost every day for a year. And when that same doctor performed my tenth surgery to remove my failed ileal pouch, it took only four hours instead of eight. Afterwards he said, "Your abdomen looked like you never had surgery – your adhesions were gone! Whatever you did in the last year, you should definitely keep it up!" I haven't stopped running and exercising since.

Q: What can we do to stay healthy if we have to travel during a health crisis?

Amber: It's important to keep a change of ostomy supplies on your person when travelling and make sure to stay hydrated. We all have leak stories. One time I was hiking in the Great Smoky Mountains and my pouch fell off. I had to change it in a porta potty! And, of course, I use hand sanitizer constantly, especially on my phone.

Paul: I've had leaks on planes and have had to run to the washroom with it pouring down my leg. Never a dull moment with an ostomy some days! I keep supplies in a small kit. I also always wear an ostomy belt, which helps keep my pouch secure. When my wife and I travel now we wear masks and bleach wipe everything we have to touch.

Q: Where should people turn when having a really bad day?

Amber: Stay connected with nature and focus on things that are beautiful. Take a moment and be still. Keep grounded and turn to your faith. It's OK to cry and let those emotions out. Recognize it, feel it, and embrace it. There's a myth that if you ignore depression it will go away. You have to deal with it before you can move ahead. Last year after my wedding I was feeling down and didn't know why. I was too ashamed to tell anyone. So I decided to speak to my doctor. He ran some tests and it turned out that my vitamin levels were out of whack. Never be ashamed to talk to your doctor, that's what they're trained in.

Paul: Well, as I shared before, exercise has been a true lifesaver for me. When I'm down I also often turn to my family. Being vulnerable is hard especially when you're sick. I often have trouble loving myself with a body that could turn on me and threaten my life at any moment. Just a few years ago, I was sick again and needed three surgeries and a prolonged hospital stay (almost a month). My wife slept every night at my bedside in the hospital. Through that I realized that perhaps I am loveable no matter what. When feeling depressed, another resource I often use is to connect to the ostomy community on Instagram and other social media. I've seen so many people get support from others all over the world. It's definitely healing to share your story...and to hear others and know you are not alone.

Q: A crisis can present problems with participating in milestone events, such as graduations and funerals. How can people still stay connected?

Amber: If it's a death, you can honor them by the way you live your life and stay positive. That's how you can keep their memory alive. If it's a graduation or birthday, plan something with the person or people when you're feeling better or the crisis is over. Connection is so important. Check in with people, even your happy friends. You never know what they're going through. Gratefulness works too, I write down one thing I'm grateful for each day and put it in a jar.

Paul: I agree about gratefulness. In our family, we play a game every night called "3 GOOD THINGS" where we all go around and name three good things that happened each day. At our hospital we are spending conscious time thanking people for the little things they do. Getting out of your head and thanking someone else is so essential and therapeutic. It's so important especially if you're down. Gratitude is as rewarding to yourself as it is to the one you're thanking.

Q: What's the best way to help a loved one cope with an emotional crisis?

Paul: Don't talk, just listen. A subtle touch on the hand can mean so much. Open body language, walking all the way into a patient's room and sitting down and making eye contact shows that you are present with them. I teach residents to sit down at eye level with their patients, and never cross their arms. I sit low in the hospital and ICU rooms all the time so I can get at eye level with my patients!

Amber: Even if they don't feel like talking, let them know you're there if they want to. Talk about something positive to help get their mind off of what's going on. And I agree about touch. I was rushed to the hospital in an ambulance and had lost a lot of blood. They couldn't get an IV started and the doctor stopped and held my hand. A nurse said, "Doctor, what are you doing?" And she said, "Right now holding her hand is most important."

Q: How can people with ostomies balance staying informed with protecting their mental health?

Amber: Find a credible source and follow the medical professionals. I always cite where I get my information in the Ostomy Diaries. Limit your exposure to the media. You have to take time to focus on something else; don't let a crisis captivate your thoughts. I only check the news in the morning and evening.

Paul: I stay informed in many ways, through podcasts and scientific sources. We as physicians and healthcare providers most often communicate and debate new data and ideas via Twitter. We share the things that are relevant to patients and cite our sources. I also learn so much from the ostomy community on social media. In fact, I've learned more in the last year as a physician about my ostomy from the people who live with an ostomy than I learned in 35 years with my own ostomy and more than 25 years in my medical practice.

Golfing with a Stoma and Outdoor Sports

Hytape.com



Golfing and outdoor activities with a stoma can be tricky, but with the preparation and care can be very enjoyable. To frame the capabilities and abilities of those with a stoma we look to former PGA Champion Al Geiberger. Prior to his surgery in 1980 Al had won 15 PGA events, it was then that while participating at the Gerald Ford Invitational golf tournament, he had to leave the tournament in order to have an emergency surgery to address a perforated colon resulting in an ostomy. Al feared that his days on the tour were over. During his recovery he was introduced to NFL placekicker Rolf Benirschke. Rolf's story is extraordinary. Rolf was the first professional athlete to wear an ostomy appliance while playing. Early in his career he was struck with ulcerative colitis and nearly died after surgeries in 1979, but then returned the next season to continue his

record-setting career for seven more years. After Al and Rolf met, Al decided to return to competitive golf and won an additional 14 times on the PGA and Champion's tour with top ten finishes throughout.

Those are both very inspirational stories that highlight the fact that an ostomy or illiostomy should not stop you from getting out and either continuing to pursue your passion, or trying something new.

Golfing with an Ostomy

Exercise is extremely important both physically and mentally when you have an ostomy. Walking, swinging the club, and fresh air is very healthy.

We also know that there are limitations and that no two patient conditions are the same, however, be aware that because a golf swing requires a lot of torque, playing golf could require adding extra security to your ostomy appliance. The added security should conform to your body, be sweat-proof, and allow for movement. There are belts on the market that help to secure your ostomy appliance, but may not keep the wafer edge affixed to your skin.

Tips, Techniques, and Added Security for Your Ostomy

- Plan your pre-round meal accordingly. Understand your body and how certain foods affect you.
- Don't try and play 18 holes your first time out. Go slow, ride in a cart and play 9 holes to test your strength, flexibility, and abdominal muscles
- Based on your experience choose the support and wafer securement that suites your swing and extent of play.
- Empty your pouch before you get out on the course.
- Ensure your wafer has been on for at least an hour prior to getting wet or beginning any activity that will cause you to perspire.

Some items you may consider bringing:

- Odor eliminator drops
- Hand sanitizing gel
- Ostomy wafers that are trimmed to your specific needs
- Extra ostomy pouch
- Disposable towels
- Waterproof tape or pre-cut strips for bordering the wafer
- Ziplock bag for disposing of items
- Fruit juice or an electrolyte rich drink
- A change of cloths in case of a leak
- Secure Your Ostomy During Golf

Men's health: Prevent the top threats

Many of the leading causes of death among men can be prevented. Here's what you need to know to live a longer, healthier life.

By Mayo Clinic Staff

Do you know the greatest threats to men's health? The list is surprisingly short. The top causes of death among adult men in the U.S. are heart disease, cancer, unintentional injuries, chronic lower respiratory disease and stroke, according to the Centers for Disease Control and Prevention. The good news is that making a few lifestyle changes can significantly lower your risk of these common killers.



Start by looking at your lifestyle

Take charge of your health by making better lifestyle choices. For example:

- **Don't smoke.** If you smoke or use other tobacco products, ask your doctor to help you quit. Avoid exposure to secondhand smoke, air pollution and chemicals, such as those in the workplace.
- **Eat a healthy diet.** Choose vegetables, fruits, whole grains, high-fiber foods and lean sources of protein, such as fish. Limit foods high in saturated fat and sodium.
- **Maintain a healthy weight.** Losing excess pounds — and keeping them off — can lower your risk of heart disease as well as various types of cancer.
- **Get moving.** Exercise can help you control your weight, lower your risk of heart disease and stroke and possibly lower your risk of certain types of cancer? Choose activities you enjoy, such as tennis, basketball or brisk walking. All physical activity benefits your health.
- **Limit alcohol.** If you choose to drink alcohol, do so only in moderation. That means up to two drinks a day for men age 65 and younger and one drink a day for men older than age 65. Examples of one drink include 12 fluid ounces (355 milliliters) of beer, 5 fluid ounces (148 milliliters) of wine or 1.5 fluid ounces (44 milliliters) of standard 80-proof liquor. The risk of various types of cancer, such as liver cancer, appears to increase with the amount of alcohol you drink and the length of time you've been drinking regularly. Too much alcohol can also raise your blood pressure.
- **Manage stress.** If you feel constantly on edge or under pressure, your lifestyle habits may suffer — and so might your immune system. Take steps to reduce stress — or learn to deal with stress in healthy ways.

Stop avoiding the doctor!

Don't wait to visit the doctor until something is seriously wrong. Your doctor can be your best ally for preventing health problems. Follow your doctor's treatment recommendations if you have health issues, such as high cholesterol, high blood pressure or diabetes. Also, ask your doctor about when you should have cancer screenings, immunizations and other health evaluations.

The bottom line

Understanding health risks is one thing. Taking action to reduce your risks is another. Start by making healthy lifestyle choices. The impact might be greater than you'll ever know.

Kindred Box

As seen on kindredbox.org

Our Story – Christine Kim, Founder

This mission started with a question.

What can I do to help people in America who cannot afford ostomy supplies?

The answer was simple and came loud and clear.

Collect as many donations as possible and get these supplies into the hands of people who need them.

You may be wondering . . . What is an ostomy?

If you're not familiar with the word *ostomy*, it's a medical term used to generalize three main types of surgery; colostomy, ileostomy, and urostomy. People need these operations for many different reasons; including cancer, diverticulitis, inflammatory bowel disease, injury, Hirschsprung's disease, and more. After ostomy surgery is performed, a person must wear a pouching system (i.e. ostomy supplies) to collect waste that exits the body through an opening on the abdomen called a stoma.

You might also be wondering . . . Why do some ostomates go without supplies?

The problem in America is certainly not access. There are literally thousands of medical suppliers available to choose from. The issue is affordability. Some people in the United States do not have health insurance. Some have insurance but ostomy supplies are not covered, or the amount allowed is limited, or a high deductible must be met before coverage is granted. These people are forced to pay out-of-pocket for medical essentials they can't live without. This expense can add up to hundreds of dollars every single month, for some thousands.

There is absolutely a need for Kindred Box and I've known this for a very long time, mainly because I was someone who used to pay out-of-pocket for my own supplies. In 1994, at age 21, I underwent permanent ileostomy surgery because of Crohn's disease. In my late 20's, paying for my own supplies was a heavy financial burden. I'll never forget that feeling of desperately needing help. So when I read messages like this, it motivates me to take action and do something.

"I have baggies and tape. I guess that's how it'll have to be until my insurance gets figured out. Depression is hitting me hard."

–Jessica, New York

Thankfully there are many ostomates with excess supplies who want to donate. Also, people who have reversal surgery and no longer need ostomy supplies donate their extras. Caring nurses donate. Families of loved ones who passed away donate. All this generosity is why Kindred Box exists. *Kindred* meaning alike, connected, similar in kind. As in... we are in this together!

I understand this initiative doesn't solve the big problems. But until we can get more States to pass laws that require all major commercial medical insurance policies to cover the provision of ostomy supplies (like New York did in 2014 and Maryland in 2015), this is how we will pay-it-forward.

When you see firsthand the impact receiving supplies has on the life of another, it's the best feeling in the world.

"The ostomy supplies from Kindred Box helped us recover what was lost from Hurricane Harvey. It gave us peace of mind and was one less thing to worry about while trying to rebuild our lives and continue with my father's cancer treatment. We truly appreciate your help in our greatest time of need."

– Pia C., Texas

I'm calling for change because people with an ostomy deserve access to affordable medical essentials they need and expert care they deserve to live their best life, no matter the circumstance.

My sincere appreciation goes out to you, for simply taking the time to read our mission and consider a donation. Each day, it amazes me to witness the kindness of others. We are so grateful. Please spread the word so we can make a bigger impact!

Our Mission

Kindred Box is a 501(c)(3) organization dedicated to improving the lives of people with ostomies. We believe that every person living with an ostomy deserves affordable medical supplies, regardless of circumstance.

Our programs assist uninsured Americans who find it difficult to afford these necessary supplies. Our goal is to connect ostomates to the support and care they need and deserve.

We are on a mission to raise awareness, promote understanding, create solutions, and encourage others to donate ostomy supplies.

More Than A Box is our motto because we not only want to give people the essentials needed to live with an ostomy, we want them to know that we are all in this together.

“Giving someone supplies to make it through one day matters.”

– Christine Kim, founder

~ ~ ~ ~ ~



The following is an excerpt from the Summer Issue of America's leading ostomy publication, The Phoenix magazine. Subscriptions directly support the work of UOAA.

Blood in the Pouch

I occasionally see blood in my colostomy pouch. It is usually only a small amount and then resolves by itself. Is this normal?

O.C.

Dear O.C.,

The end of the bowel was not designed to be exposed to the outside world. In addition, contact with a pouching system along with intestinal contents results in trauma to the bowel. So, it is very common for ostomates to occasionally see small amounts of blood

from their stoma. If the amount remains small and you are not anemic, there should not be a problem. I would discuss this when you see your physician and possibly get a complete blood count (CBC) during your next visit. Your body can usually replace small losses, but you could take a multivitamin with iron to help replace any blood products you have lost.

Ask the Colorectal Surgeon is a regular column in The Phoenix magazine, the official publication of UOAA. Dr. Beck and other medical professionals answer ostomy questions in each 80-page issue of America's leading ostomy publication.



David E. Beck, MD, FACS, FASCRS
Professor of Clinical Surgery
Colon and Rectal Surgery
Vanderbilt University
Nashville, TN

The 80-page Summer issue of The Phoenix magazine provides answers to the many questions and challenges of living with an ostomy. The leading ostomy publication in America features articles written by ostomy experts, medical professionals and ostomates that inform, educate and inspire.

Visit www.phoenixuoaa.org or call 800-750-9311 to get your ostomy answers now.

No Stopping Now

*Adventurous urostomate travels the world
after bladder surgery*

By R. S Elvey

When Erik Bayer was told he would need surgery for the lump in his bladder his only question was: "Can I still go on my African Safari next month?" Having dealt with Type One diabetes for 45 years he was not going to let bladder cancer interfere with his love of traveling and skiing in his retirement years.

At the beginning of his employment in 1969 with an American food manufacturer, Erik was diagnosed as a Type One diabetic. He had that "Why Me Moment?" but quickly decided that he would not let a medical condition define who he was or what he would do with his life. With that in mind, he began a 38-year successful career with a national corporation and with his wife, Cathy, raised two children.

In 2010 he was at his endocrinologist's office in what had become a 41 year ritual of semi-annual blood tests and daily insulin injections. His doctor told Erik he was very concerned about his raising PSA, prostate-specific antigen, numbers, often an indicator of prostate cancer. In 2011 the PSA numbers were still increasing and Erik was referred to a urologist for follow up. Again he was told that they would wait and monitor his numbers. However, his PSA numbers continued to rise and in 2012 it was decided to treat his prostate. He elected to have radioactive seeds placed into the prostate. After scanning the prostate it was decided that this treatment was not effective as they had also found a lump in his bladder. His doctor then recommended Intravesical BCG, the injection of Bacillus Calmette-Guerin, a biologic response modifier, to kill the cancer cells in the bladder. This very painful procedure would be performed once a week for six weeks. Four months later a new lump was found in Erik's bladder and the intravesical immunotherapy was performed again for another six weeks. But the lumps continued to grow larger and biopsies confirmed the cancer.

Two surgeries were completed in 2013 to remove the growths from his bladder but these surgeries proved unsuccessful. His doctors then recommended removing his entire bladder and prostate. But after all the treatments and surgeries Erik was fearful of the next step his doctors were recommending. During all these treatments and surgeries Erik had been suffering constantly with painful and uncontrollable urinations. He wanted a second opinion and made an appointment with the Mayo Clinic in Rochester, Minnesota.

In late June of 2014 Erik checked into to the Mayo Clinic on a Wednesday for what he described as the most thorough and exhaustive set of tests he had ever been through. Two days later the Mayo physicians discussed the results of their tests. They informed Erik that instead of one problem there was two. They agreed that the bladder and prostate needed to be removed but there was a more immediate concern. The tests showed a cancerous spot where the ureter for the left kidney met with the bladder. If left untreated it would cause kidney failure. They recommended immediate surgery that following Tuesday to resolve this problem. Bladder and prostate removal would have to wait. When he asked his Mayo surgeons if he could go on his African Safari the next month, the answer was a resounding, "No".

On the first Tuesday in July a stent was placed in his ureter solving that problem. At the end of July the Mayo surgeons performed a second surgery to remove Erik's bladder and prostate and create a stoma.

Mark Drug Medical Supply

548 W Dundee Rd, Wheeling IL 60090 847-537-8500

The Ostomy Store

**We are local and have the largest inventory
in the Chicago area**

Come in and visit . . . See what is new

Manufacturers

ConvaTec
Hollister
Coloplast
Marlen
NuHope
Cymed



847-537-8500
1-800-479-MARK
FAX 847-537-9430

Accessories

Adhesive Removers
Skin Prep
Deodorants
Belts
Undergarments
Pouch Covers

**We bill direct to
Medicare-Medicaid
and Private Insurance**

Alan@markdrugmedicalsupply.com

Before the surgeries at Mayo, Erik and Cathy had planned to see all seven continents and also travel extensively throughout the U S. They purchased a four-wheel drive RV that came in very handy as they traveled back and forth to Rochester. Prior to Erik's cancer they had traveled to China and Japan with a travel and tour group. However, just like in 1969 when he had become a Type One diabetic, he once again said, "Why Me?" And again, Erik made the decision to not let a medical condition like a stoma define who he was or what he could do. As he recovered from two surgeries he began to plan his foreign and domestic travel. It was time to get up and go.

But first he joined a local UOAA support group and consulted with an ostomy nurse. He began to learn about the daily maintenance of a urostomy and the required products. Additionally, he was able to meet with fellow ostomates. Though he was very adept at giving himself insulin injections and wearing a glucose monitor, maintenance of a urostomy was a new experience requiring a very different skill set. He also had his questions answered about travel with an ostomy.

The surgeons had said no overseas traveling in 2014, so Erik, feeling confident with his new ostomy, packed up the RV, and with Cathy traveled over 33,000 miles in America. Their plan was to travel to national parks, presidential museums and libraries, and for Erik to continue with his love for alpine skiing. Also by traveling by RV within the U S, Erik became more familiar with life with a urostomy.



In August, 2015, Erik and Cathy set out on a three week African Safari vacation that took them through South Africa, Botswana, Zambia and Zimbabwe. They returned home the first week of September and three weeks later went on an adventure tour of Australia and New Zealand. Taking a break from international travel, 2016 found Erik in a new RV, attending weddings and visiting eight states. But in 2017 the travel bug bit again with trips to Hawaii, Peru, Ecuador, the Galapagos Islands, Iceland and Greenland.

Erik has become very experienced at changing and emptying his pouch under all circumstances. When asked what was his most unusual urostomy travel experience was he said, "I was on the Amazon River in the rear of a canoe with other passengers and a guide. I suddenly realized I needed to empty my pouch. By sign and gesture I let the guide know what I needed to do. He nodded to me and began to point up river at the birds and monkeys. My fellow passengers all turned their attention to where the guide pointed. I quickly gained access to my pouch and directed the valve over the side of the canoe. After emptying I secured my pouch and clothing. The guide glanced back at me and resumed his regular narrative."

This article originally appeared in The Phoenix Fall 2017 magazine.

Both the subject, Erik Bayer, and the author, Ray Elvey, are proud members of the Support Group in Arlington Heights and the Ostomy Association of Greater Chicago.

"The purpose of life is to live it, to taste experience to the utmost, to reach out eagerly and without fear for newer and richer experiences."

Eleanor Roosevelt



Life isn't about finding yourself. Life is about creating yourself.

- George Bernard Shaw



Did you know...

Your body is about 60% water. Lose even 1.5% of that H₂O—the tipping point for mild dehydration—and your mood, energy levels, and cognitive function all drop, according to research from the University of Connecticut. And while there are obvious reasons you can end up dehydrated—a sunny day, exercise, or not drinking enough in general—other triggers are less obvious. Surprising causes of dehydration can include diabetes, stress, low-carb diets, alcohol, and medications, both prescription and over the counter.

A wise man should consider that health is the greatest of human blessings, and learn how by his own thought to derive benefit from his illnesses.

-Hippocrates

► A very special thank you to everyone who donates to our association! Our largest expenses, the cost of this newsletter, our website and security for our website are 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!

Krispy Kreme are giving away a free face shield with every 12 doughnuts 👍 it even carries the warning "contains nuts" 😂😂😂



Laughter is,
and will always be,
the best form of therapy.

IMPORTANT: 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, WOC Nurse, licensed pharmacist or other health care professional.

Summer of Love Becomes Four Seasons of Care

By R. S. Elvey

In the summer of 1967, thousands of young people descended on San Francisco's Haight-Asbury neighborhood in what would be described as the "Summer of Love". They brought with them a youthful idealism about ending the war in Viet Nam, saving the environment, promoting social equality and not trusting anyone over 30. But as Malcolm Kaines writing on the website, Medium, notes, "For all that generation's interest in social justice - equality for blacks, women, migrant workers, Vietnamese peasants, and others - the flower children of the 1960's nevertheless vocally maintained (as many apparently still do) one vestige of plain bigotry: ageism." Fast forward to current times and that youthful generation of the 1960s is now the largest demographic of over 65 year olds and other seniors needing assisted living, nursing homes and in-home care. The U S Census Bureau confirms this growth and estimates that, "Starting in 2030, when all boomers will be older than 65, older Americans will make up 21 percent of the population, up from 15 percent today. By 2050, nearly one in four Americans will be 65 years and older, the number of 85-plus will triple, and the country will add a half million centenarians." With advancing age, many of the 1960's flower children have to face the need for a care focused lifestyle. Suddenly they and their loved ones need to understand the difference between assisted living and nursing homes. What are they finding?

The first thing a senior finds is that care has many different names. It is necessary to understand the differences between assisted living and nursing homes. This is not an easy task as there is not just one main difference. Also a senior must assess their own personal care needs and physical condition versus the senior care marketplace. In addition, a senior must review and understand the myriad requirements of Medicare and Medicaid reimbursement for different kinds of care. Then with input from family and friends make a decision: Assisted Living or a Nursing Home. Let's take a look at Assisted Living Facilities.

You can't miss them when you watch television: smiling seniors dancing, playing golf, eating ice cream with the grandkids, in slickly made commercials for Assisted Living Facilities ("ALFs"). They go by many names such as: Assisted Care, Residential Care, Supportive Housing, Supported Living, and Adult Foster Care (facilities with no more than four residents). But over the past two decades ALFs have gone through many changes. When they first began they offered a humane alternative to nursing homes for those who could not live on their own. But now this multi-billion dollar industry finds itself caring for the seriously ill elderly, and many suffering with dementia. An ALF typically provides a place where a resident can live semi-independently with varying levels of help with day-to-day activities. ALFs are regulated by each individual state. Nursing homes are federally regulated. This means ALFs receive little outside monitoring. The states either dictate the services that must be provided or let the facilities decide what to offer. And when it comes to staffing the facilities, for the most part, ALFs can do as they please. In many states an AFL administrator only needs a high school diploma and in other states an ALF is not required to have even one licensed nurse on staff. When it comes to the number of staff on duty, again in most states, the facility can do as it pleases. The staffing levels can range from one staffer on duty for every 15 residents during the day and one per 25 residents at night. "In California, by contrast, facilities housing as many as 200 seniors need no more than two workers on the night shift. Neither of them is required to have any medical training. And one of them is allowed to be asleep." According to A. C. Thompson and Jonathan Jones, propublica.org.

In senior living facilities healthcare providers, doctors and support staff suffer from the same ageism bias as the rest of the population. Many studies have noted that healthcare professionals do not receive enough training in geriatrics to care for the elderly. "Of the 204,000 physical therapists nationwide, only 2,133 hold a geriatric specialization. The lack of interest is common across health professions. Less than 1 per cent of registered nurses are certified in geriatrics and 37 percent of geriatric medicine fellowship training slots go unfilled." Margaret Danilovich, Northwestern University Feinberg School of Medicine.

While there are many differences on how each state regulates ALFs, they all agree on one thing – all facilities can refuse admission to anyone whose needs cannot be met by the facility. Facilities are evaluating applicants based on a blanket policy as opposed to a case-by-case basis based on an individual's need. Two examples of how this policy can go very wrong are found in cases of persons using wheelchairs or an ostomy for daily life activities. In New York many ALFs use a blanket policy of no persons with wheelchairs in their facilities. And if a current resident begins to use a wheelchair that resident may be evicted. This has resulted in a lawsuit brought by the Fair Housing Justice Center. The suit claims that four New York ALF facilities, using state regulations, discriminate against current residents and potential residents in violation of Federal Law. The problem here is outdated state regulations.

Every year over a 100,000 people have lifesaving ostomy surgery and nearly 1,000,000 persons, “ostomates”, are living with an ostomy. “An ostomy changes the way urine or stool exits the body as a result of a surgical procedure. Bodily waste is rerouted from its usual path because of malfunctioning parts of the urinary or digestive system. An ostomy can be temporary or permanent.” United Ostomy Associations of America. Many persons with an ostomy can self-care but many ALFs deny them admittance. In fact some states such as New Mexico, Wyoming, California, South Dakota and Rhode Island include the word ostomy in their regulations to prohibit admittance to ALFs in their states. Again, a blanket policy does not make determinations based on case-by-case evaluations but on out-of-date state regulations. It also would seem to violate Federal discrimination laws. When elderly ostomates, who can self-care, are refused entry to an AFL facility, their only option is a Long Term Care Facility or a Nursing Home. This alternative choice is much more expensive and may be unnecessary.

Nursing homes, unlike ALFs, are regulated by the Federal Government and they are reviewed on the Medicare website. Additionally, ratings of nursing homes are provided annually by U. S. News and World Report, www.health.usnews.com/best-nursing-homes. Nursing homes do not advertise on television. As a matter of fact the only time you see them on TV is in ads for elder abuse attorneys and catastrophic events news reports. The stereotypical view of nursing homes is a place where people go to die. Nursing Homes are also called: Long Term Care, Extended Care, Rest Home, Care Home and Intermediate Care Home. They are more medically orientated. They provide for residents who cannot live independently and require 24 hour care due to physical or mental conditions and age.

When a person finds themselves in a nursing home it is because they have severe medical problems and are unable to take care of themselves. Often the decision to enter a nursing home is very stressful and made during a time of medical emergency. There is little time for evaluation or consideration of costs.

The majority of nursing homes participate in the Medicare and Medicaid programs. The Kaiser Family Foundation noted that in 2015 62% of nursing home residents were paid for by Medicaid. Medicare coverage will pay for only the first month at a nursing home.

Quality of care is a constant criticism of nursing homes or as Lori Emetanka, executive director of the National Consumer Voice for Quality Long-Term Care states, “Whenever you see a concern or problem in a nursing home, you can generally trace it back to inadequate staffing standards.” However, meeting the challenge of adequate staffing is difficult. Students in health care provider training programs often view nursing homes as less prestigious and unrewarding places to work.”

As long as staffing problems, conflicting state and federal regulations exist in the nursing home and ALF industry, the selection of an appropriate care facility is difficult. **But there are ALFs and nursing homes that do provide a care focused quality of life.** In Illinois the state's regulations for assisted living facilities do not mention ostomies. When considering an Illinois ALF you have to ask the specific question, “Are you able to assist me with my ostomy?” By employing due diligence in advance of need; The Summer of Love generation's transition to continuing care does not have to turn into a winter of discontent.