Vol. 2, Issue 2 November 2016

The Advocate

Greater Eastside Ostomy Support Group

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Fall/Winter Schedule

Date	Time	Speaker/Topic	Room
11/02/16	Wed 6:30—8:00 pm	Dr. Wayne Lau, MD (general surgery UW/Valley Medical Center)	Tan 119
12/11/16	Sun 4:00—7:00 pm	Winter Social & White Elephant @ Laurie Cameron's House (address will be provided to GEOSG contact list by email)	
01/04/17	Wed 6:30—8:00 pm	Vendor Fair	TBD

Annual Support Group Registration

For the last two months we have been encouraging GEOSG participants to register for the 2016/2017 year. While registration is definitely not required to attend the support group, we urge everyone to become registered members of the group.

The annual dues are $25.00. These dues go towards the group's expenses for speakers, UOAA Affiliated Support Group membership, brochures, website and to support the Supply Closet (see page 2). Your annual membership will also include a bimonthly copy of our newsletter, The Advocate.

Registration forms will be available at the support group meetings and online at www.geosg.org..

If there is a financial hardship and you are unable to pay the $25.00 dues, please fill out the registration form and an allowance will be made for this year's dues.

UOAA United Ostomy Associations of America, Inc.
AFFILIATED SUPPORT GROUP

GEOSG MEMBER STOMA "BIRTH" DATES

November	Ostomy	Years		December	Ostomy	Years
Carl Burroughs	*Ileostomy*	*34 yrs*		*Shawn Fortsyth*	*Ileostomy*	*3 yrs*
Irma Sessums	*Ileostomy*	*3 yrs*		*Brooks Russell*	*Ileostomy, Urostomy*	*2 yrs*

♥ ♥ ♥ *Supply Closet* ♥ ♥ ♥

The Ostomy Supply Closet provides supplies free of charge to anyone with an ostomy that has a need due to lack of insurance coverage or is in need of emergency supplies. The Supply Closet is dependent on donations. If you have extra, unneeded supplies, please consider donating them to the Supply Closet.

The supply closet is located at a Public Storage in Kirkland, If you have a need, or know someone who is in need, please contact Laura Vadman (lovadman@hotmail.com) to arrange a time to meet and pick up needed supplies.

#IAmResilient

Contacts

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We're on the web! www.geosg.org

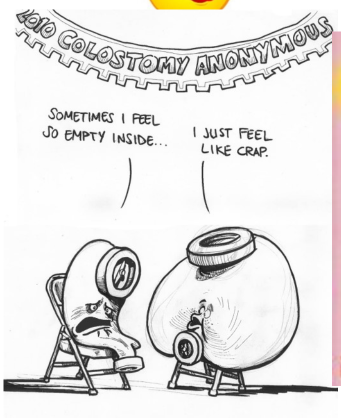
Manufacturers		
Coloplast	888-726-7872	www.us.coloplast.com
ConvaTec	800-422-8811	www.convatec.com
CyMed	800-582-0707	www.cymed-ostomy.com
Hollister	800-323-4060	www.hollister.com
Marlen	800-321-0591	www.marlenmfg.com
Nu Hope	800-899-5017	www.nu-hope.com
Organizations		
American Cancer Society	800-227-2345	www.cancer.org
Crohn's & Colitis Foundation	800-343-3637	www.ccfa.org
Friends of Ostomates Worldwide	N/A	www.fowusa.org
United Ostomy Associations of America	800-826-0826	www.ostomy.org

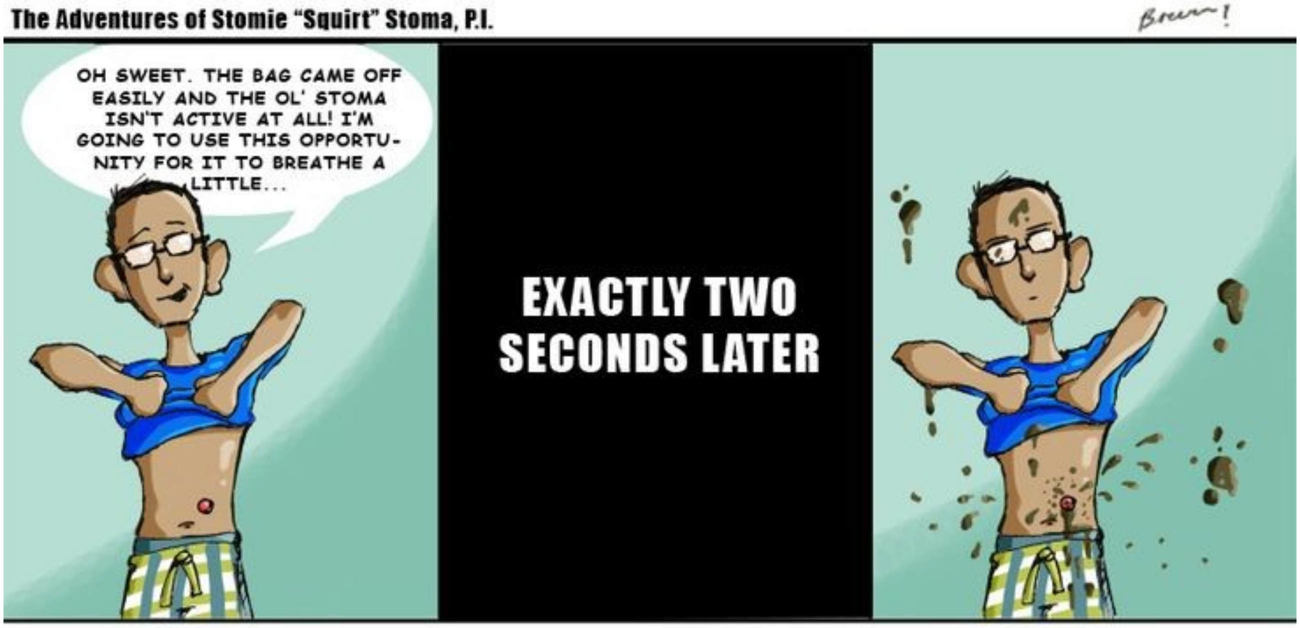
Aug 22-26, 2017 • Sixth UOAA National Conference • Hotel Irvine, Irvine CA

UOAA's Sixth National Conference will offer a variety of resources to everyone within the ostomy community. The Conference features great education, wonderful guest speakers, and most importantly—community. All are welcome to participate in this amazing event—people who are currently living with an ostomy, those who may be having surgery in the near future, as well as family members, spouses, friends, and members of the medical community. Attendees receive the support and answers they needed to adjust comfortably and to reach their ultimate goal of a "new normal" life.

GEOSG is putting together a group to attend this conference. Please let us know if you are interested in attending.

ON THE LIGHTER SIDE





Traveling with an Ostomy | Part 1 | Preparing for Your Trip

Aug 23, 2016 | Excerpts from Ostomy Care and Tips, Ostomy Life

Preparing for travel can be stressful and hectic as it is, but when you've got an ostomy there are a few extra things that you'll want to be aware of.

Whether you're travelling for work or pleasure, your ostomy shouldn't come between you and your destination. I started traveling after having my ostomy, and the experience has been positive all around. It does require some extra planning, but I'm hoping this guide will get you started in the right direction. Remember that traveling can cause anxiety to anyone (ostomy or not), so don't be afraid to ask for help if you feel lost.

Stuff to Pack

Ostomy Supplies

The Golden Rule when packing supplies is that it's always best to bring more supplies than you'd normally use in the same amount of time you plan to travel for.

Since ostomy wafers and bags don't really take up much space and they aren't heavy, I will often double or triple the amount of supplies I bring. In my case, since I tend to change my appliance every 3 days or so, I'll bring enough for a full change per day. If you are travelling to someplace that's really hot and humid, or if you plan to swim a lot, then you may want to either bring even more appliances or special supplies (like wafer extenders) to accommodate those situations which may reduce your wear time.

One thing I'd recommend to colostomates or ileostomates who normally have thicker output (like myself) is to bring a gelling agent in case you develop "travelers diarrhea," food poisoning or some other unexplained liquid output. These gelling products will help to thicken your output and keep things easier to manage.
Depending on where you are traveling, you may also want to check ahead to see if there are any local suppliers who sell ostomy products in case of an emergency.

Ostomy Accessories

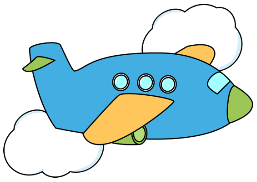
Accessories would include products like ostomy wraps, stoma guards, pouch covers, etc. These can help to conceal your appliance, keep your stoma protected, and can help **boost confidence**.

There are many accessories to consider for your trip. The type of accessories you choose to bring will depend a lot on what you plan to do, but if you like using specific accessories on a daily basis just pack those along.

Liquid supplies

Keep in mind that depending on where you are travelling to, carry-on supplies may be limited to 3.4 ounces or less per item (as per the TSA 3-1-1 rule), and fit into a 1 quart-sized sealable bag. Pack items that are in containers larger than 3.4 ounces or 100 milliliters in checked baggage.

These supplies may include:



- Liquid ostomy pouch deodorant
- Stoma paste.
- Barrier rings.
- Adhesive remover sprays (wipes should not count as liquid, but call your airline to confirm).
- Skin care cream.

Continued on next page

Traveling with an Ostomy | Part 1 | Preparing for Your Trip (Continued)

While ostomy supplies are medically necessary, and may be exempt from the 3-1-1 rule, I would strongly suggest contacting your airline or local airport authority to see if they allow those exemptions. I've contacted CATSA here in Canada, but they said it would depend on the screening person you have to decide whether any specific supply is exempt from the rule (ostomy bags and wafers are automatically exempt). Rather than risk not being able to bring all my supplies, I just pack with the assumption that no exceptions will be made. Note that if you are travelling with checked luggage you'll be able to bring larger containers. Keep only what's absolutely necessary for an appliance change in your carry-on if you decide to bring extras.

Sample Ostomy Travel Kit

While I do have a travel kit that I take around with me locally, it can certainly be trimmed down for air travel. (To see what I include in my kit go to https://www.veganostomy.ca/my-ostomy-travel-kit-march-2015/) Personally, I can get away with using adhesive remover wipes and no other extras, but that's only if I'm not having skin problems. If you require stoma paste, adhesive remover spray, and barrier rings, it can be a little more complicated. I would suggest limiting things like sunscreen, shampoo, and liquid soap (which you can easily purchase at your destination) before removing essential supplies.

My basic kit for air travel consists of:

- wafers and pouches
- pouch deodorant
- adhesive remover wipes
- gauze pads
- portable mirror (try to get one that can be positioned on a flat surface and doesn't need to be held)
- gelling products (I like the Diamonds sachets by ConvaTec)
- medical scissors (these need to comply with your airline rules; i.e. under a certain blade size, rounded tips, etc.). I would pack these with your liquids so they can be easily inspected by security.
- stoma measuring guide (if you are bringing cut to fit).
- pen or marker to trace a template on the stoma measuring guide
- wafer extenders (These may come in handy if you plan to be in the water a lot.)

If your airline allows you to bring both carry-on luggage and a "personal item", be sure to keep a few extra supplies with your personal item; this can often be a purse, briefcase, small backpack, or similarly sized item. You'll want to do this in case your carry-on luggage isn't easily accessible when you need it.

If you are traveling with both carry-on and checked luggage, I would suggest keeping supplies in both in case you get separated from your luggage. Remember, always have supplies nearby regardless of how you packed your main luggage.

Medication and Supplements

If you are travelling with medication or supplements, you should try to get a note from your doctor if possible. Since some medication (like narcotic painkillers) may require additional clearance, it's best to have supporting documents with you.

For medication which requires refrigeration, like biologics used for IBD, you may want to see which cooling methods are allowed through your airline.

I always plan to pack some Imodium Complete in case I get a bout of traveler's diarrhea. I keep the tablets in the original box so there's no confusion about what I'm bringing as I pass through security.

Continued on Page 6

Life is a gift.

Never forget to enjoy and bask in every moment you are in.

- Unknown -

Traveling with an Ostomy | Part 1 | Preparing for Your Trip (Continued from Page 5)

Snacks/Drink

Generally speaking, foods have similar restrictions as personal items. That means liquids such as orange juice, apple sauce will be subject to the 3-1-1 rule but solid foods are fine.

Here's the thing, though, if you do bring "liquid" food they'll have to share space with your liquid ostomy supplies and personal care items – you're gonna run out of space very quickly! Instead, I would suggest packing foods such as energy bars, cookies, crackers, and similar snacks in your carry-on as they are not restricted. If you'd like to keep a drink with you (and you should because travel tends to be dehydrating) you are free to purchase beverages after passing through airport security.

Personally, I love to bring Clif Bars with me because they are high calorie, taste great, don't cause me any trouble with my ostomy. They are also fortified with vitamins and minerals, which are important if you won't be eating much for a while.

Be sure that if you pack food for your flight that you keep them with you or in your "personal item" bag. If you put them in your carry-on or checked luggage you may not have access to them until after you land.

Things to Consider

Pick your seat (if you can)

Planning which seat you'll be on can be helpful when you have an ostomy because you'll likely need more access to the bathroom while on a flight and not all seats are convenient to get in and out of easily.

Pros/Cons to each seat:

Aisle:	**Window:**
Very easy access to the aisle (great if you need to use the bathroom often).	Not as easy to access the overhead compartment (if you need to).
Easy to get your meals, drinks, or whatever else from the flight attendants	Harder to access the bathroom, because you'll have to disturb the passenger(s) next to you.
Makes it easier to get up and walk around on long flights.	You won't be disturbed when another passenger needs to use the bathroom.
Easy access to the overhead bins (no need to ask other passengers to get up).	If you're afraid of heights, this might not be a good option.
You may be disturbed more if the passengers next to you need to get to the aisle.	Not as easy to get your meal, drinks, etc.
Aisle traffic may bother you (especially if you are near the bathrooms).	A bit more privacy
You don't get a very nice view	Easier to sleep in.

Obviously, if you are traveling with family or friends, some of the concerns about disturbing other passengers may not be so much of an issue. But if you travel alone, then these options should be considered.

Pre-screening

Some people may qualify for pre-screening, and the TSA has their own program that frequent travelers may want to look into. The TSA Pre program will help you move through the security checks much faster as you won't be required to remove shoes, belts, or liquids (among other things).
You can find out more about the TSA Pre program here: https://www.tsa.gov/tsa-precheck

Parts 2 & 3 will be published in upcoming newsletters.

Ostomy United Founder Gives An Inspiring Speech At Coloplast's Ostomy Day Celebration

Ostomy United Founder, Ted Vosk

Ostomy United's founder, Ted Vosk was invited to speak to hundreds who gathered at Coloplast's headquarters in Minnesota on October 1, 2016 to celebrate National Ostomy Awareness Day. The 45-minute speech was followed by an hour of questions from ostomates and guests. Quite a few people in the audience were moved to tears and others approached Ted feeling elated after hearing his inspiring words.

Here is an excerpt from Ted's speech:

The first thing that I remember feeling after waking from ostomy surgery four years ago was hopelessness. Hopeless at the prospect of living the rest of my life with a bag of poop on my belly. I cried myself to sleep at night. But I realized that I had a choice. I could live the rest of my life as if it were a prison sentence or take advantage of the second chance that my ileostomy gave me.

It's a choice a lot of people living with ostomies face. Waking from surgery to realize that part of your insides are now on the outside can be traumatizing. It's not only the loss of physical security, but there is a feeling that you are now ugly or grotesque. That's the stigma at least. And that's how many ostomates feel as they struggle to come to grips with their new reality. But it doesn't have to be that way. Each of us holds the key to living an extraordinary life with an ostomy.

I chose to take advantage of the second chance my ileostomy gave me. Since then I've completed my first Ironman triathlon, a 140-mile race consisting of a 2.4-mile swim, 112-mile bike and 26-mile run, had my first book published, my first peer reviewed paper published in a scientific journal, become an international speaker, traveled to Europe for the first time, taken part in my first case before the United States Supreme Court and founded Ostomy United (a triathlon team made up of ostomates and their friends, whose goal is to inspire and empower people living with ostomies.) Absent my ileostomy, I would have died without ever having done any of these things. So, when people ask if I like my ileostomy, honestly, not really. But I do LOVE the life my ileostomy permits me to live.

There is nothing special about me. Other ostomates have done more. There are people with ostomies who work as firefighters, policemen, trial lawyers, construction workers, models and nurses; those who surf, pilot their own planes, climb mountains, ride motorcycles, play hockey, ski and go to the beach or a ballgame with friends; and many who, like me, have better lives now than they did prior to getting an ostomy. And these individuals are no different from you or I. You can live the life that you dream of. The secret is to believe in yourself and be willing to fall and get back up as often as necessary to reach those dreams. There will be setbacks and times when you get so frustrated that you'll want to quit. But if you keep trying, you'll find that others rally to your cause, and that you have become an inspiration. Not because of what you achieve, but because of your enduring spirit in the face of adversity.

Ostomy United on Facebook

This is why I founded Ostomy United. The Team uses triathlons as a metaphor to demonstrate its motto: **There Is Nothing We Can't Do!!** There is nothing that anyone with an ostomy, nothing that YOU, can't do. To drive home the point, Ostomy United has a photo album of ostomates from around the world (on Facebook) doing all those things one living with an ostomy might want to do. And as I've searched for things that one might think that an ostomy could prevent someone from doing, I haven't found a single activity.

We only live once, and that is the only chance that we'll ever have to realize our dreams. Your ostomy is giving you another chance at that life, so you might as well live it, exactly the way that you want, without fear or regret. The strength to do so lies within you, simply take the first step, a small step… and then take another. Each of us is capable of extraordinary things, but extraordinary is not required. Simply live the life that you want to: **There Is Nothing YOU Can't Do!!**

7 Quotes From Ostomates On Acceptance (Part 2)

From acceptance, to overcoming your fears and letting go…

Having ostomy surgery can be intimidating and acceptance may be tough at first, but that doesn’t mean it can’t be one of the best things that ever happen to you. These inspiring words come directly from ostomates who made the decision to keep moving forward.

From Karin Miller, creator of Newbie Ostomy…
An ostomy only limits your life as much as you let it. If you live in fear of trying new things, you won’t ever know if you’re capable of them. Having ostomy surgery is scary, but a beautiful life can exist beyond your surgery if you let it.

From Matthew Mewhorter, artist and creator of Cancer Owl…
We can be basket-cases sometimes…passionate one moment and a blubbering mess the next. But that’s because we’re hit all at once with the kind of perspectives that takes a normal human being a lifetime to achieve, if they’re lucky. So yeah, we’re kind of awesome like that.

From Amy Oestreicher, writer and performer of “Gutless & Grateful“…
Instead of loathing the ostomy bag, I decided to make friends with it. I realized that my colostomy is a beautiful thing, and has enabled me to do all the things I’ve been able to accomplish over the years. It is my uniqueness.

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

These ostomates and others have been down that rocky road, but we picked ourselves up, dusted ourselves off and began doing the work in order to live the best life possible. No matter how hard life gets, don’t give up, push through.

◆ ◆ ◆

Kidney Stones and the Ileostomate

By Jill Conwell, RNET, Corpus Christi, TX

Kidney stones are fairly common medical problems. They occur in about 5 percent of the population. They are more common in men with a sedentary lifestyle and in families with a history of kidney stones. The average age of first occurrence is about 40, but they can occur at any age. For ulcerative colitis patients, the incidence of developing kidney stones is about double that of the rest of the population. For ileostomates, the incidence is 20 times greater.

There are two basic types of kidney stones; uric acid and calcium. Both may occur in ileostomates since the underlying cause is dehydration. Uric acid stones are more frequent. One reason for this is the chronic loss of electrolytes, producing acid urine. The stones may vary in size and shape, some being as small as grains of sand, while others entirely fill the renal pelvis. They also vary in color, texture and composition.

Symptoms during the passage of a kidney stone include bleeding due to irritation, cramping, abdominal pain, vomiting and frequent cessation of ileostomy flow. When ileostomy flow stops, distinguishing between an obstruction versus a kidney stone may be difficult since the symptoms are similar. Treatment of most kidney stones is symptomatic and in most cases the stone passes spontaneously through the urinary tract. Medication for the spasms is usually administered. The urine should be strained in order to collect the stone for analysis. Once the composition of the stone is determined, steps should be taken to prevent recurrence of an attack. The physician will prescribe medication or dietary modifications depending on the type of stone. The best preventative measure is to drink plenty of fluids (8 glasses) every day. If the urine appears to be concentrated, increase fluids and use a sport drink that is rich in electrolytes to replace losses.

11 Thoughts Everyone Has When They Have An Ostomy

by Hattie Gladwell

There's a number of things that go through your head when you have an ostomy, some good, some bad… some you just never expected to have at all! I rounded up a few other ostomates to see which thoughts had most stood out to them since having an ostomy.

1. **"Will my bag look big in this?"** Every piece of clothing you try on is accompanied with the thought.. will my bag look big in this? i.e. does it look like I have a whoopie cushion hiding under this dress? Or am I good?
2. **"Will my partner still find me attractive?"** A lot of feelings hit you after ostomy surgery. You can begin questioning yourself, your appearance, how others may see you. But anyone that see's you for anything but YOU is not worth it. And you know what, your partner, or the person you fall for, is probably more focused on the fact that they're lucky enough to still have you there with them.
3. **"Do I just do it? DO I EAT THE POPCORN?"** If you don't have an ostomy, you may not know that you are pretty much warned to stay away from popcorn. This is because it can cause a blockage in the stoma. BUT, you always want what you can't have… and being told not to do something makes you want to do it ten times more!
4. **"My bag better not fart in this exam!"** Or any other important event for that matter.. especially when the room is filled with empty silences. Annoyingly, gas is one thing you have no control over… it happens when it wants to… you have to accept that!
5. **"Do you think they can tell?"** Going out in public amongst people who have no idea about your ostomy (and why should they) can be a little daunting, because you can be curious as to whether it is noticeable under the clothing you're wearing. (But who cares if it is!)
6. **"Do they really go like that?"** You can become so accustomed to your ostomy bag that you literally forget how other people go to the toilet. I know when I see my boyfriend heading into the bathroom and sitting in there for half an hour I'm left thinking… what the hell is he doing?! It only takes a minute!
7. **"I'll never be able to go on a sun holiday again and wear a bikini!"** You spend time planning all different kinds of holidays avoiding the ones where you may have to wear a bikini, until you remember… who am I trying to please?
8. **"To bathe or not to bathe… Will my bag float away?"** There's always that wonder of whether you can still take an hour long bath with netflix by your side. It's the best part of anyones week for sure. But can you still do it??? Will the bag stay stuck in hot water? The answer is yes. So get back in the tub!
9. **"I didn't know I could produce that much wind!"** Most mornings you awake with a helium balloon on your stomach – if you haven't woken up 3 times already to empty it during the night. I guess it stops you sleeping in though! (Sometimes)
10. **"Am I the only one?"** Ostomy surgery can be very lonely, especially if you choose not to talk to anyone. about it. And sometimes, this can be the case because you feel like you're the only one dealing with it. But, there are many people out there in the same situation, and so to answer that thought – no, you are most definitely NOT alone.
11. **"I'm never eating that again."** This seems to be quite a frequent thought. Although I never stick to it because I'm basically obese at heart. Food after ostomy surgery is all about trial and error. Some things work with your new digestive system… some things don't. But some things just… really don't.

11 Thoughts cont'd

And just one more, that a lot of people tend to think, no matter how long it takes them to think it…

"Thank you… you saved my life."

Personal Stories of Healing & Hope

We need your stories. What lead up to your ostomy surgery? How have you handled the difficulties that are inevitable when recovering from your surgery? What are your special "tricks of the trade"? Do you have any funny stories to tell? Have you travelled with your ostomy? Do you have any pictures to share with the group? Would you rather write up your story anonymously? We're looking to inspire, comfort, encourage and possibly even entertain those who have new ostomies and those who may be facing ostomy surgery.

One story for every newsletter would be fantastic. If you are willing to share, please submit your written story to Laurie at lauriecmrn@gmail.com. This is a wonderful opportunity to not only feel empowered by your own journey, but to also assist those who are just starting down the path.

Transportation
Security
Administration

What to Expect

Disability Branch, Office of Civil Rights & Liberties, Ombudsman, and Traveler Engagement

Colorectal Awareness: Ostomies (Colostomy, Ileostomy, Urostomy)

TSA Pre✓®	Standard Screening
Travelers eligible for TSA Pre✓®: o Present your boarding pass and government-issued ID to the TSA travel document checker; o The TSA travel document checker will scan your boarding pass barcode; o Proceed to the **TSA Pre✓®** line. **At the beginning of screening:** o Inform the TSA officer about your disability or medical condition. o Inform the TSA officer if you have a medical device such as an ostomy pouch. o Oversized medically-necessary liquids should be removed. These liquids are permitted through security checkpoints after undergoing x-ray or inspection screening. Medically-necessary items may include lotions, creams, cleaning agents, disinfectants, and other ostomy-related equipment and supplies. o Inform the TSA officer of any sensitive area where pain or medical complications could happen if touched.	**Travelers not eligible for TSA Pre✓®:** o Present your boarding pass and government-issued ID to the TSA travel document checker; o The TSA travel document checker will scan your boarding pass barcode; o Proceed to the standard screening line. **At the beginning of screening:** o Inform the TSA officer about your disability or medical condition. o Inform the TSA officer if you have a medical device such as an ostomy pouch. o Oversized medically-necessary liquids should be removed. Medically-necessary items may include lotions, creams, cleaning agents, disinfectants, and other ostomy-related equipment and supplies. o Inform the TSA officer of any sensitive area where pain or medical complications could happen if touched.