September/October 2019

Ostomy Outlook

LETTER	OF THE OSTOMY ASSOCIATION OF THE	MINNEAPOLIS AREA	
	Volume IV, Issue IX	September/October 2019	
Date:	Monday, September 16, 2019		
Time:	6:30 PM-8:00 PM		
Place:	United Methodist Church of Peace 6345 Xerxes Avenue South Richfield, MN 55423 612-866-0069		
Program:	Darcy Helder from Coloplast will be our speaker. Come hear about the new BodyFIT technology in the Sensura Mio® Convex Flip, designed for outward areas around the stoma, as well as our new Brava ® Ostomy Support Belt. See more information in "New Business." Page 2		
Date:	Monday, October 21,2019		
Time:	6:30 PM-8:00 PM		
Program:	Josh is a C-130H Instructor Pilot and has served over 19 years in the United States Air Force. He was diagnosed with Ulcerative Colitis in November 2017 at the age of 37 and one year later I was cured from UC and my ileostomy became permanent. See article "Getting to Know Josh."		
	"Getting to Know Josh."		

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55438-5453 The Ostomy Outlook is printed and circulated for people with Colostomies, Ileostomies, Urostomies, and alternative procedures, their families and other interested persons

.****If you have weather questions, please call 952-882-0154 Our new website address is: <u>ostomyminneapolis.org</u>

Ostomy Association of the Minneapolis Area Membership Creed

As members of this group, it is important to be ever mindful of our many blessings: our understanding families and friends, our homes, and our way of life. Most of all, as ostomates we need to be ever mindful of the life which has been given back to us and to find the courage to face our daily challenges. Let us continue to be concerned for people who need our help, our support, and the knowledge that we have gained. Let it be our task to reach out to others and to ourselves. May we do this in a spirit of fellowship and fond regard..

New Business



Darcy Helder has been with Coloplast for 24 years and is the current Ostomy Territory Manager. She worked in Mankato, MN in the skin and wound side of the business but developed a passion for the ostomy business when her grandmother had a colostomy. Recognizing that Coloplast Ostomy products and services can really make an impact in people's lives, she became the Territory Manager for Minnesota and the Dakotas for the last 15 years. Come hear about the new BodyFIT technology in the Sensura Mio® Convex Flip, designed for outward areas around the stoma, as well as our new Brava ® Ostomy Support Belt. We want to make sure there is a Mio for EveryBody! She will also show the newer Mio Pediatrics/Baby pouches and updates to the CARE wellness Program. If you'd like to enroll for the Education and support in the Care program, please call 877-858-2656 and speak with Krista or any of the CARE advisors. **If you would like to suggest a future program, please contact: Carole Barron <u>barronski</u> @aol.com

Brenda Elsagher Treasurer and Membership Report

I want to thank all of our sponsors for their continued support and a special thanks to all our members as well. Currently we have 110 members with about 20% lapsed in membership. I usually send out the membership letters in April and then remove anyone from the list that has not responded in two years. We also send out our electronic newsletter to 118 nurses every other month. We have inquiries over the phone about eight times a month and on our website at least six times a month with new memberships or information requested.

When our beloved member, Anne Marie Kronick recently died, her family requested that donations be sent to our chapter. Through friends and family of Anne Marie, we received \$1220.00. Thank you all for your generosity in such a time of sadness. Anne Marie was our membership chair for many years along with being a patient advocate with Dar Hafner. Thanks Dar, in keeping in good contact with the family to aid in this process.

I thank the members who acknowledge their stoma anniversaries with extra donations. Some celebrate birthdays and others are more than generous at member renewal time. We are self-sustaining as a non-profit which aids in continuing to reach out to the new person adjusting to life with an ostomy. An important part of that is our face to face meetings where newly diagnosed recent new ostomates can get questions answered by the people who know what it's like. This was a gift to me 24 years ago when I came in and it still is today. Thank you for your part in keeping us engaged for others. Written by Brenda Elsagher.

Thanks Again to our sponsors: Minnesota Gastroenterology. 612-871-1145 www.mngastro.com

We appreciate your support-



M I N N E S O T A GASTROENTEROLOGY, P.A.

Premier Gastroenterology Care

Action: OSTOMY AWARENESS DAY

This year's ostomy community events from UOAA are not over yet. It was an amazing time of camaraderie and fun in Philadelphia at our 7th National Conference, but I know many of you have not had the opportunity to experience the feeling of being with others who understand what you have gone through.

Gather with the community and celebrate Ostomy Awareness Day on October 5, 2019. Also, you don't have to be a runner to come out to support the resilience of our community at the Run for Resilience Ostomy 5k, The donations raised from the 5k events helps to support the critical resources UOAA provides to those who have or will have ostomy surgery, and the advocacy work we are doing on behalf of the ostomy community. Remember, over 300 Affiliated Support and Information Groups around the country are here for you anytime. Your donations to the 5ks support the critical resources and advocacy of UOAA.

visit **https://www.ostomy.org** to write a proclamation request or a letter to the editor, join the fun on social media, and much, much more. See below.



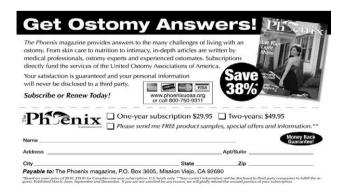
- HOME
- OSTOMY INFORMATION
- SUPPORT
- ADVOCACY
- WHO WE ARE
- LATEST
- EVENTS
- DONATE
- SEARCH

Events Events, Ostomy 5k Events, UOAA Events

Virtual Run for Resilience Ostomy 5K

Join the Nationwide Run For Resilience Virtual Ostomy 5k at Your Favorite Place to Walk/Run/Roll this Ostomy Awareness Day: October 5, 2019

If you are interested in participating in the Run for Resilience Ostomy 5k but are unable to physically attend the <u>live events</u> in AL, AZ, ID, MI, NC, NJ, PA, TN or WA, you can still sign-up and participate in your own virtual 5k walk/run/roll on October 5, 2019 or on a date convenient for you! You can also support the cause by donating or fundraising on behalf of UOAA.



GETTING TO KNOW JOSHUA NELSON



Born and raised in Minnesota, I call Otsego my home. My wife, Natalie, is a Special Education evaluator in the Elk River school district and we have two beautiful girls, Brinley (9) and Brenna (5). I'm a C-130H Instructor Pilot and I've served over 19 years in the United States Air Force. I was diagnosed with Ulcerative Colitis in November 2017 at the age of 37 and one year later I was cured from UC and my ileostomy became permanent.

Ulcerative Colitis came at me out of nowhere. No family history of this disease and definitely outside of the generalized age ranges. To this day I've only been given medical theories regarding why. Initially, I did pretty well on basic mesalamine medications. I had my second colonoscopy in January 2018 indicating treatment was going well and although slight inflammation still existed my colon was continuing to heal. I felt confident my treatment was working because life was back to normal and I had no indications/symptoms of UC thinking that I was in remission, wrong. Once the summer 2018 arrived I battled with a constant flare that I couldn't get over. I tried everything to include, internet cures/remedies, restricting/changing diets, gut biome health, food sensitivity testing, and anything that could help keep my UC in remission because constant calling to a local GI helpline was not working. Biologic treatments were discussed and I was prescribed Humira because the maximum prednisone and mesalamine dosages were no longer working. In October 2018, at this point, I've never had anything so debilitating in my life and I wasn't the same. I was concerned about my career, my ability to earn income, provide for my family, be a good husband/father, and not be a prisoner in my own home. Thankfully my wife was adamant we look elsewhere and get a second opinion because the treatment and care I was receiving at the time was not acceptable considering what I was going through. I was evaluated at the Mayo Clinic following a four day consultation. This is the first time I heard the term Inflammatory Bowel Disease specialist! My previous health care provider made no mention of them at all! They confirmed my UC diagnosis following my third colonoscopy, and added azathioprine to aid with Humira. I hit rock bottom towards the end of October 2018 and this started my 24 day deployment to the University of Minnesota Medical Center returning home on 18 November 2018, without my colon! While in-patient, I met daily with floor care teams, IBD specialists, and my colorectal surgeon. We had multiple plans and multiple courses of action. My fourth colonoscopy confirmed my body was not able to reach therapeutic levels required to keep UC in remission following two biologic trials.

After numerous blood tests and not responding to medications it was determine to remove my colon on 12 November 2018. After my first surgery I decided to keep my ileostomy permanent because I honestly wanted nothing to do with the risk of inflammation again! My final surgery was completed in February 2019. Since, I've been cured from Ulcerative Colitis no longer requiring any medications, thinking about an unannounced flare, or require any special diet. The biggest learning moment for me was being my own health advocate. I learned not all healthcare providers or hospitals are created equal. Certain diseases require specialized care and don't be afraid to seek second opinions and ask questions! Although I'm fighting to keep my job as an Air Force pilot, at the end of the day, I'm freed from the clutches of Ulcerative Colitis. I'm no longer bound by the nearest bathroom, medications, special diets, or wondering if and when the next flare will arrive. I'm healthy and living my life to the fullest, I have my life back and there is nothing that will get in my way!



President's LETTER

It was a wonderful meeting. Alexisis was such a good speaker and was inspirational to us all. Our membership is growing. See you in September!

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Patient Power -

If you have any ideas or issues you'd like us to address, please send them in to the newsletter editor or directly to me, Darlene Hafner. You can reach us by emailing dmhafner@yahoo.com.



2019 Get Your Rear in Gear & Tour de Tush - T C

Sunday, September 22, 2019Veterans Park Bottom of Form

Select A Team:

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- Team Captains
- Fundraising
- Volunteer
- FAQs
- Matching Gifts

Event Details

Get Your Rear in Gear and Tour de Tush - Twin Cities DATE: Sunday, September 22, 2019 LOCATION: Veterans Memorial Park, Bandshell 636 East 66th St., Richfield, MN 55423 FEES: Through September 16 at midnight 5K run/walk, 25 mile bike ride, 1.7 mile walk Adult: \$35 Youth (12 and under): \$20 Kids' Fun Run (10 and under): \$20

Survivors FREE REGISTRATION - Email Stacy

Race Day Adult: \$40 Youth (12 and under): \$20 Kids' Fun Run (10 and under): \$20

Please note: We do our best to ensure everyone gets a shirt but to be guaranteed one please register by September 1. Fees are non-refundable and race bibs are non-

transferable

Online Registration closes Saturday, September 21 at midnight

Packet Pick Up: Local Roots 817 66th St E. Richfield, MN 55423

BECOME A VOLUNTEER Schedule

7:30 a.m. - Registration

8:20 a.m. - Opening Ceremony and Team Awards
8:50 a.m. - Kids' Fun Run
9:00 a.m. - Bike Ride - This is a recreational ride, NOT a race
9:05 a.m. - 5K Timed Run, 5K Walk and 1.7 Mile walk around Legion Lake in Veterans Park
9:50 a.m. - Post Race Finisher awards Join us after the event at Local Roots.

A race village has moved from the pavilion to the bandshell. It will featuring a kids fun run, food, entertainment including kids activities, music and more will anchor both courses.

Veterans Park has plenty of grassy areas for participants to relax and hang out and for families to play during the before, during and after the race.

DIRECTIONS & PARKING:

This year race village will be at the Veterans Park bandshell. The bandshell is on the south side of the park, on 66th Street. There is some parking at the Richfield Ice Arena and limited parking at the back of the Richfield Legion. There is also plenty of street parking around the park.

Please consider carpooling, biking, or taking the bus.

COURSE MAPS:

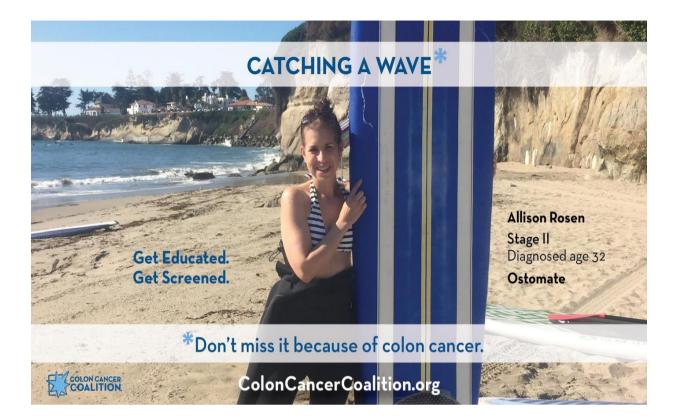
<u>Kids Fun Run Route (.35 mi)</u> - 10 and under - Kids Fun Run participants receive a medal upon finishing!

<u>5K route</u> - The 5K will stay in Veterans Memorial Park to enjoy the beauty and wilderness of this park.

The **1.7 mile course** is the outer loop of the 5K. It will start with the 5K and then finish at the 5K water stop at the bandshell.

<u>25 Mile bike ride</u> (pdf version) (Ride with GPS) - This ride will take you from Richfield into Minneapolis and back. It is an open course so please obey the rules of the road. Rest Stop at East River . Helmets are required.

September/October 2019





Ostomy Association Of The Minneapolis Area P O Box 385453 Bloomington, MN 55438-5453 If you **DO NOT** wish to receive this newsletter, please check here _____ and return to the \leftarrow address at left

ADDRESS SERVICE REQUESTED

To:

Please enroll me as a new member of the	e Ostomy Asso	ociation of th	he Minneapolis Area						
If you haven't enrolled, 2019 Annual dues are \$25 and are due in March following your submittal of this form.									
Membership in the Ostomy Association of the Minneapolis Area includes 12 informative meetings, subscription to the "Ostomy Outlook" newsletter and an "Antless picnic" in June.									
									OAMA
PO Box 385453									
Bloomington, MN 55438-5453									
I have a: Colostomy 🗆 Ileostomy 🗆 Urostomy (ileal diversion) 🗆 Other 🗆 Non-ostomate 🗆									
Name:									
Street:									
City:	State:	ZIP:	Phone: ()						
As a tax exempt Orga	anization, all con	tributions and	dues are tax deductible						
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OSTOMY ANNIVERSARY	,								
The Anniversary of my stoma is/, and in order to celebrate my return to good health, I an									
contributing the sum of	of	or \$	_ per year for my stoma.						
I hereby grant permission to print my name in the Chapter Newsletter.									
Name		Years	Amount \$						
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