

2022

UOAA Advocacy



IMPACTS AND ACHIEVEMENTS

"Our strong and solid Advocacy Committee has been consistently striving to support You. Working hard for the ostomy community, they are a powerful voice that has been heard time and again as they solidify their ongoing efforts for you locally and nationally. I am astonished at the work our Committee has achieved - going beyond what we could ever have dreamed to make a difference in your life now and in the future."

~Cheryl Ory, UOAA President

Year In Review

FROM THE DESK OF UOAA'S ADVOCACY MANAGER
JEANINE GLEBA



UOAA is the trusted national organization advocating for all people living with an ostomy or continent diversion, and those about to undergo this life-saving surgery. We strive to ensure that ostomates have access to quality ostomy care and their prescribed choice of medical prosthetic technology. Our position on issues and proposals in the healthcare arena matters. As a result of our strong relationships with medical organizations, industry partners, and supply providers, we collaborate together to make things happen for the betterment of the ostomy community.



Advocacy work comes in all shapes and sizes and doesn't necessarily happen overnight. It may take the form of raising awareness, educating others, speaking up and questioning things, persuading decision-makers, and sharing personal stories. UOAA relies on the personal anecdotes we receive from the community to ensure the ostomy patient perspective is recognized and understood. We greatly appreciate the support of all those who answer the calls to action with our legislative priorities and support our efforts such as Ostomy Awareness Day. We can't do it without you!



Lastly, UOAA gratefully acknowledges the hard work and dedication from the volunteers of the Advocacy Committee (Co-Chairs Joanna Burgess-Stocks BSN, RN, CWOCN, and Susan Mueller BSN and member Keagan Lynggard-Hysell) who give tirelessly of their personal time to help us achieve our annual goals.

Here are highlights of our advocacy work in 2022.

Federal Advocacy

- Added our support by signing several coalition letters including Healthy Futures Treatment Access, Colorectal Cancer Awareness month in March, encouraging appropriators to finalize FY23 National Institutes of Health funding increase and funding to the Agency for Healthcare Research and Quality, and coding reform for urinary catheter supply codes
- Submitted Federal Comments on the proposed 2022 CDC Clinical Practice Guideline for Prescribing Opioids; received signatory endorsements from American Society of Colon & Rectal Surgeons (ASCRS), WOCN Society, American College of Gastroenterology (ACG), Digestive Disease National Coalition (DDNC), and the Oley Foundation
- UOAA became a member of the National Quality Forum



A POSITIVE CHANGE ACCOMPLISHED!

Our steadfast advocacy efforts on access to opioids for non-pain medical conditions such as high output stomas **resulted** in the CDC changing their title to '2022 Clinical Practice Guidelines for Prescribing Opioids **for Pain**' to better reflect its content and intended use. They also added language throughout the document to emphasize that the guidelines provide voluntary clinical practice recommendations that are not intended to be inflexible standards of care or implemented as absolute limits of policy or practice for patients by clinicians, healthcare systems, or government entities **whereby protecting ostomy patient access to their prescribed treatments.**

UOAA gave visibility to policy issues impacting ostomy care and access to supplies, including:

- Submitted Federal comments to the Centers for Medicare and Medicaid Services (CMS): on ways it can improve Medicare Advantage Plans; regarding establishing a new national directory of healthcare providers & services (recommended including certified ostomy nurses and ostomy clinics); and addressing healthcare and related challenges with recommended solutions to improve ostomy care
- Continued support of DDNC public policy agenda such as the Safe Step Act including adding new Co-Sponsor Congressman Payne; served as Vice Chairperson on the Executive Committee and had UOAA representatives attending both the Spring and Fall Public Policy Forums to provide ostomy patient perspectives to elected officials
- Active supporter of the Medical Nutrition Therapy Act and attended Senate Finance and House Energy and Commerce Health subcommittee meetings

DDNC leadership team meeting with Senate and House offices in November 2022

(pictured from left to right DDNC President Dr. Bryan Green, DDNC Vice Chairperson (UOAA Advocacy Manager) Jeanine Gleba and DDNC Director of Development Dr. James DeGerome)



Ostomy Awareness



Double Baggin' It @DoubleBagginIt · Sep 29, 2022

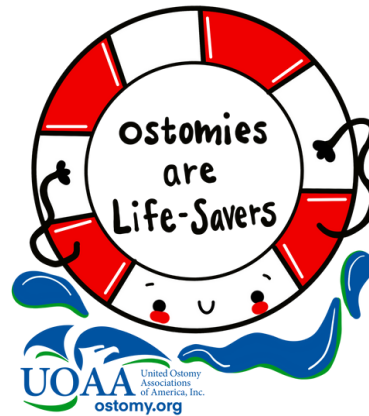
Let the [#ostomyawarenessday](#) road trip shenanigans commence! Stay tuned as Sir Poops-a-Lot brings [#ostomy](#) adventure, advocacy and awareness to [@Hersheys](#) and more! [@UOAA](#)

[#oad2022](#)

[#ostomyawareness](#) [#ostomate](#) [#hersheypa](#) [#ostomyday2022](#)



2022 OAD Champions were the duo Danielle Gulden and Joe Teeter from Double Baggin' It!



From participating in UOAA's annual Run for Resilience ostomy 5k to creative social media posts including the trend This or That - ostomy edition people across the country spread the positive message that "Ostomies Are Life-Savers"!

4,875 people visited our dedicated webpage for this special day.

Once again UOAA collaborated with many organizations including Crohn's and Colitis Foundation, Cleveland Clinic and Bladder Cancer Advocacy Network to bring the ostomy community together for special online events and podcasts.

October 1, 2022

Influential Together

- To raise awareness and improve patient education UOAA now engages with Patient Point to provide valuable content about ostomies in over 9,000 gastroenterologist (GI) doctor offices
- Partnered with the Crohn's and Colitis Foundation's Open Restroom Movement to improve access to restrooms for people living with medical conditions such as those with an ostomy
- Co-presented a webinar with the WOCN Society directed towards PA assisted living facility state association members to dispel myths on the care required for ostomates and answer FAQs
- Partnership with the CMS Medicare Learning Network (MLN) to ensure ostomy information and reminders are in their weekly newsletters sent to providers and also shared with community when applicable; this year in an effort to prevent delayed ostomy supply shipments and ensure timely physician signatures UOAA published an article with tips for providers

BIG WINS!

Ostomy supply coverage in New Jersey and Wisconsin State Medicaid Plans improves with UOAA participation in coalition efforts.

NJ added 42 ostomy product codes to the list of covered items. WI increased quantity limits from 6 to 20 per month for several extended wear products.

Increasing Advocacy Engagement

By the Numbers in 2022:



1,970 advocates in our Advocacy Network ready to take action



1,192 messages were sent to elected officials for our 5 advocacy campaigns



UOAA Office Staff included various advocacy resources such as our checklists, infographics and patient bill of rights in over 646 mailings plus included in the start-up boxes for 17 new Affiliated Support Groups and welcome mailings to 604 national members



15 proclamations for Ostomy Awareness Day across the country and 1 Congressional House Resolution introduced



Ostomates are self-advocating! 3,116 downloads of the TSA travel communication card; 2,291 people viewed the patient rights webpage with 857 downloads of the rights; and 797 downloads of the new restroom communication card

5 Upfront with Ostomies columns for the Wound Management Prevention journal

2 Phoenix magazine articles

4 ostomy.org blog posts

New Tools and Resources

EMPLOYMENT-BASED DISCRIMINATION

While many persons who have had ostomy or continent diversion surgery may not consider themselves to be disabled, they are protected under the Americans with Disabilities Act and the Rehabilitation Act of 1973 against employment-based discrimination in the workplace. When discrimination occurs, there are several steps that can be taken when an employer discriminates against (or treats someone differently) because of ostomy or continent diversion surgery or the on-going needs of a person who has had these procedures.



ARE YOU HAVING TROUBLE AT YOUR WORKPLACE ?

- Do you need a change (accommodation) at your workplace?
- Have you been treated differently because of your ostomy?
- Accommodations for persons with an ostomy or continent diversion could include an office near a restroom, waste receptacle in restroom stall, the ability to eat when and where needed, or access to a drinking fountain.

FOLLOW THESE ADVOCACY STEPS:

EDUCATE

- Tell your boss or human resources department that you are being treated differently because you have an ostomy (your employer must stop discrimination once they know about it)



NEGOTIATE

- Ask human resources or your supervisor for a change to your work environment so that you can do your job with the same conditions as your colleagues (close by bathroom, break times, facilities)



GET LEGAL HELP

If the above steps have not resulted in resolution, you may consider obtaining legal assistance or filing a formal complaint using the resources below.

- Equal Employment Opportunity Commission: 800-669-4000 www.eeoc.gov info@eeoc.gov
- Disability Legal Rights Center: 866-999-3752 <https://thedrcl.org/> drcl.org
- Disability Rights Bar Association: <http://disabilityrights-law.org/> drbalaw@syr.edu
- Local attorney who helps with disability law



BE AWARE

Time limits for legal action are very short. Do not delay in getting help.

RESTROOM ACCESS NEEDED NOW

The cardholder needs urgent restroom access to empty or change their ostomy pouch and/or catheter.

The cardholder is wearing an ostomy pouch which contains bodily waste and is carrying pouches and related supplies to manage personal hygiene.

Access to the restroom is critical for the cardholder's wellbeing and for public sanitation.

Thank you for your help and understanding.



Provided by



Restroom access self-advocacy tools including a communication card, guidelines for ostomy friendly restrooms, information on the 'I Can't Wait' app, and more

Ostomy Self-Management Checklist

DAILY POUCH EMPTYING

- ☐ Are you able to ambulate/ self-propel to the bathroom to empty your pouch?
- ☐ Are you able to adjust your clothing before and after pouch emptying?
- ☐ Are you able to empty your pouch, clean the end and reseal it?
- ☐ Do you remember to empty your pouch on a regular basis?
- ☐ Are you experiencing leaks related to your pouch emptying schedule?
- ☐ Are you able to empty your pouch at night?
- ☐ Urostomy- Can you change from daytime drainage system to nighttime drainage system?

APPLIANCE CHANGE

- ☐ Are you able to gather your supplies and change your appliance on a regular schedule and maintain a functional wear time (3-4 days)?
- ☐ Are you able to observe your peristomal skin at your appliance change to determine if the area is intact?
- ☐ If your skin is not intact at appliance change, are you able to manage minor skin problems?
- ☐ Are you able to observe your stoma at your appliance change to determine any changes and to aid in aligning the appliance over your stoma?

PROBLEM SOLVING

- ☐ Can you identify and problem solve leak problems?
- ☐ Do you know when you need to seek medical assistance and how to access this care? (Signs and symptoms of blockage, severe skin problems, dehydration, infection, constipation)

SUPPLY MANAGEMENT

- ☐ Do you maintain a list of supplies (include supplier name and contact number, product manufacturer, reference number and amount ordered monthly)? UOAA has a handy supply checklist that you can use for this purpose.
- ☐ Do you have automatic reorder set up with supplier or a system to remind you to reorder?
- ☐ Does your Primary Care Provider have an up-to-date supply list in your medical record?
- ☐ Are you able to self-advocate for supply problems?
- ☐ Are you able to store your supplies in a temperature neutral place away from excessive heat or cold?

LIFESTYLE MANAGEMENT: DIET & HYDRATION

- ☐ Ileostomy: Do you know how to maintain adequate hydration and electrolyte balance? Do you know how to avoid foods which may cause blockage?
- ☐ Urostomy: Do you maintain adequate hydration?
- ☐ Colostomy: Do you maintain adequate hydration and diet to avoid constipation?

For more ostomy resources visit UOAA's website: <https://ostomy.org>

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Tools to self-advocate for living in an assisted living facility including a self-management checklist to help ostomates understand the components of ostomy care and determine if they need assistance with any component of care. Video presentation on preparing for the future - where you live matters

Infographic on the steps to advocacy for employment-based discrimination



<https://www.ostomy.org/>

UOAA does not offer legal advice nor does it provide legal services.

Our self-advocacy tools help empower people to make a real impact in their own lives.

Ostomy Advocates Point to Research to Demand Better Patient Healthcare

ENDORSERS OF PATIENT BILL OF RIGHTS (PBOR) WHITE PAPER:



- UOAA White Paper that validates the PBOR as a guideline for best practices in quality ostomy care was published in Journal of Wound Ostomy Continence Nurses (JWOCN) as an Open Access article in May/June
- UOAA “Best in Practice Care for Ostomy Patients” research results were published in the September/October issue of the JWOCN showing patient rights are being utilized but gaps in care being provided exist such as receiving educational materials on ostomy management
- UOAA is of the opinion that access to an outpatient ostomy clinic improves quality of life. UOAA supports increasing outpatient services and ostomy clinics to fill the gap in care available to people living with ostomies in Board approved position statement

Continued to improve access to quality ostomy care and blaze a trail with the Ostomy and Continent Diversion Patient Bill of Rights (PBOR) Initiative.

PLANNING FOR NEXT YEAR



The following list, not all-inclusive, includes some of the advocacy goals and priorities we will be focusing on in 2023:

Collaborative Advocacy Efforts

- With the Digestive Disease National Coalition and Access and Care Coalition continue support of the legislative priorities for the new 118th Congress including the Safe Step Act, HELP Copays Act and Medical Nutrition Therapy Act
- With the WOCN Society continue outreach efforts to drive change in Community Care

Ostomy and Continent Diversion Patient Bill of Rights (PBOR)

- Continue outreach for utilization of the PBOR and animated series and sharing of the White Paper to drive systemic change in ostomy care

Ostomy Awareness

- Advocacy session at UOAA's national conference in Houston in August 2023
- Celebrate national Ostomy Awareness Day in the United States on October 7, 2023

Access to Care and Supplies

- Continue efforts for Phase 1 of National Quality Ostomy Care campaign which includes launching new webpages, producing a new resource with guidelines on establishing outpatient ostomy services
- Continue to advocate for access to quality ostomy care and proper coverage of ostomy supplies under Medicare/Medicaid and commercial plans

