

2025

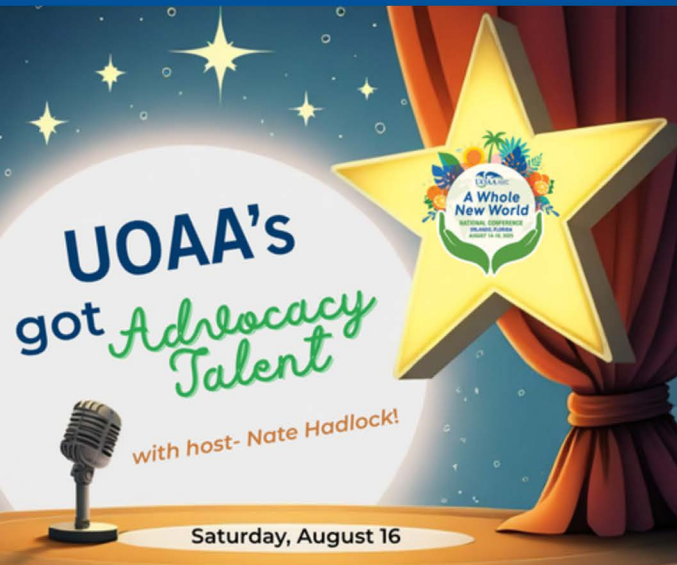
UOAA Advocacy



IMPACTS AND ACHIEVEMENTS

Year In Review

FROM THE DESK OF UOAA'S DIRECTOR OF ADVOCACY
JEANINE GLEBA



Throughout 2025, advocacy was a key force shaping UOAA's work and impact within the ostomy and continent diversion communities. UOAA rose to meet emerging challenges, amplifying the voices of ostomy patients at the federal and state levels. Through persistent advocacy, we achieved meaningful victories—ending discriminatory swimming pool policies and safeguarding access to the essential supplies our community depends on.

As a result of our strong relationships with other like-minded patient organizations, medical societies, coalitions, industry partners, and supply providers, we collaborate together to make things happen for the enhancement of our community.

Thank you to all of our affiliated support group leaders who shared our advocacy efforts with their members and rallied them to take action! Thank you to all of the advocates who responded to our calls for action over the past year whether by contacting your elected officials or sharing your personal stories with us! Thank you to UOAA's Patient Advisory Board for their valuable support!

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 Rebecca Mceylea MSN, RN, CWOCN) who give tirelessly of their personal time to help us achieve our annual goals.

These highlights showcase the real-world impact of our advocacy work and some of these efforts will continue in 2026.

Federal & National Advocacy

Prevented Non-Coverage of Supplies for Temporary Ostomies Under Medicare

In March CMS released important language changes to the Ostomy Policy Article (A52487) and the Urological Supplies Policy Article (A52521) which stated that supplies for temporary intestinal or urinary diversions would no longer be covered. UOAA, with the WOCN Society, took swift action and submitted a formal joint letter of concern to the CMS Director for Coverage and Analysis urging them to withdraw these changes. By April 1, we received a response from CMS where they clarified that the updated language does not represent a change in coverage policy. They also amended the policy language to prevent further confusion among providers ensuring coverage of supplies for temporary ostomies.



PROTECTED ACCESS TO EXTENDED WEAR PRODUCTS AT A NATIONAL SUPPLIER!

In early 2025, UOAA was contacted regarding an access issue. Customer service representatives at a national supplier were informing customers with a colostomy that “Medicare issued a new rule in August 2024,” which the supplier had implemented in its internal system, limiting individuals with colostomies to coverage of standard-wear skin barriers. Under this new change, coverage of extended-wear barriers required special provider medical documentation. However, CMS did not issue any amendments, updates, or new regulations to the ostomy supply Local Coverage Determinations (LCDs) in 2024. No Medicare policy change occurred in August 2024. Under Traditional (Original) Medicare, there is no eligibility requirement restricting colostomy patients’ access to extended-wear skin barriers.

UOAA worked directly with the company’s leadership to correct this misinterpretation of Medicare policy. As a result, the company has discontinued the improper requirement for extended-wear barrier justification in patients’ medical records, restoring appropriate access for individuals with colostomies.

UOAA Led the Patient Advocacy Effort to Oppose Ostomy Supplies Inclusion in the Medicare Competitive Bidding Program

Our top priority in 2025 became clear on June 30, 2025, when CMS released a proposed rule (CMS-1828-P) that could significantly restrict access to ostomy and urological supplies and the suppliers who provide them. The proposal would reclassify these supplies as “medical equipment items” to include them in the Competitive Bidding Program, despite their current legal protections and exclusion from bidding. UOAA strongly opposed this proposal. At the end of 2025 CMS released the Final Rule in the Federal Register. Despite all of the opposition from industry, supply providers, medical societies, and patient advocacy organizations, this rule specifies that ostomy, tracheostomy, and urological supplies are medical equipment items mandated for inclusion under the DMEPOS CBP by section 1847(a)(2)(A) of the Act. *This was not the ruling we had hoped for.*

Prior to the final ruling UOAA took the following actions:

- Submission of national organization's [Federal Comments](#) stressing our opposition
- Spearheaded an effort to submit additional [Federal Comments](#) from a group of non-profit organizations. In total, **48 groups** from across the country signed-on including several UOAA Affiliated Support Groups, which was a very strong showing of support
- Launched a new [web page](#) on [ostomy.org](#) dedicated to this top advocacy priority
- Became a member of the [ITEM Coalition](#)
- Partnered with AAHomecare on their Consumer Engagement Toolkit
- Elevated the patient voice, by collecting many compelling testimonials from impacted patients for advocacy materials and updated our [#MyAccessMatters portal](#) on the website for ongoing story collection
- Created an action alert for our Take Action Center and called upon our grassroots Advocacy Network and many others to submit individual federal comments before the August 29th deadline to ensure the patient perspective was understood and recognized in this decision-making at CMS
- Invited to attend a Day on the Hill meeting in August with key health committee Representatives in the House. Myself and one of the Advocacy Committee Co-Chairs, Joanna Burgess-Stocks, went to DC to participate in these meetings. We were able to represent the voice of the patient and the voice of the ostomy nurse, by showing supplies and giving hands-on visuals to demonstrate how ostomy products are crucial and needed for quality of life and that one size does not fit all. We also attended many subsequent virtual Congressional meetings with lobbyists and the Spina Bifida Association



Competitive Bidding Program Efforts continued



- Created another action alert in September calling on grassroots advocates to contact their Representatives to share their ostomy stories and request that their Representatives sign a Congressional letter led by Reps. Neal Dunn (R-FL) and Greg Murphy (R-NC)—both urologists—urging CMS and OMB to withdraw the proposal. The final [letter](#), sent on October 9, 2025, was signed by **26 Members of Congress**
- Developed a social media campaign and designed graphics for patients to post on social media with the hashtags #MyAccessMatters and #CompetitiveBidding.
- Successfully hosted its first-ever Patient Voices on the Hill Day on October 8th through the sponsorship of the manufacturer, Convatec. We had advocates from across the country—strategically chosen from districts and states with influential lawmakers on health policy—travel to Washington, D.C. to protect access to ostomy and urological supplies. Read about the day and see photos in this [blog](#).
- Mailed final [letter](#) to Dr. Oz at CMS and Director Vought at OMB



State Advocacy

Directing the Effort for Passage of State Legislation in MA

In early 2025 Massachusetts Representative Rob Conslavo introduced legislation entitled “An Act to Increase Access to Healthcare for Ostomy Patients”. Its official bill number is [H. 4162](#).

This bill was posted for a public hearing in September. UOAA submitted written testimony in support of the bill and UOAA Executive Director, Christine Ryan, joined several patient and clinician advocates to testify in-person.

UOAA also led the planning and coordination of another successful State House event to educate elected officials and raise awareness of the new bill.

We have an action alert in our [Action Center](#) for MA residents to help us gain more sponsors of the bill. We will continue to advocate for passage of this bill in 2026.



Global Impact

- UOAA was contacted by the founder and director of the IBD Patient Support Foundation in the country of India asking if UOAA would send a letter to support ostomates in India because their government does not recognize ostomy as a legal disability. In our statement we urged the Government of India to legally recognize ostomates as persons with disabilities so that people with an ostomy are protected from discrimination. We hope that one day individuals all over the world will have rights and protections if they have an ostomy.
- In 2025 UOAA became a member of the Hidden Disabilities Sunflower program and partnered with them for World Ostomy Day. We have a dedicated [web page](#) on their website and we helped them develop ostomy-related content for their [website](#). UOAA advocates also participated in a [special podcast](#) for World Ostomy Day. Their organization also created a new poster to raise awareness about ostomies that their clients can download.



UOAA is also a member of the Global Colon Cancer Association. We are listed in their [directory](#) for people to find us and the [services/support](#) we provide to the ostomy community.

Increasing Advocacy Engagement By the Numbers in 2025:



1500+ new advocates in Advocacy Network



2236 messages were submitted to the federal government portal from our action center in opposition of the CMS proposal to include ostomy and urological supplies in the competitive bidding program. *The greatest engagement UOAA has ever had on a campaign!*



100,000+ people were reached on social media for UOAA's Facebook/Instagram Competitive Bidding posts



26 proclamations for World Ostomy Day



30 Congressional meetings advocates attended in Washington, DC for UOAA's Patient Hill Day

2 new "Who's Raising Ostomy Awareness?" stories

1 Scholarship awarded at UOAA's National Conference to Erin Young for ostomy nursing certification

1 Mighty Advocate Award presented at UOAA's National Conference to Stanley Cooper

New Tools and Resources

Continent Diversion Self-Management Checklist

For Internal Pouch/Reservoirs that Have a Stoma that is Catheterized

DAILY INTERNAL POUCH EMPTYING

- Are you able to get to the bathroom to empty your internal pouch?
- Are you able to adjust your clothing before and after emptying?
- Are you able to insert the catheter and empty regularly?
- Are you able to determine when irrigation of your internal pouch is needed and perform irrigation?

STOMA AND SKIN CARE

- Are you able to observe your stoma and peristomal skin to identify skin problems?
- Are you able to determine what type of dressing is needed to best protect your stoma and peristomal skin?
- Can you manage minor skin problems?
- Do you have a doctor or nurse you can contact if you have serious skin issues?

PROBLEM SOLVING

- Can you identify and problem solve issues with intubation and/or leaking?
- Do you have supplies ready and are comfortable with placing your internal pouch to continuous intubation if needed?
- Do you know how to prevent, treat or seek medical attention for any of the following: blockage, difficulty with self-intubation, and dehydration?
- Have you maintained contact with a health care provider familiar with continent diversions?

SUPPLY MANAGEMENT

- Do you regularly inspect and replace catheters?
- Do you keep a current list of your supplies and supplier contact information?
- Does your medical provider have an up-to-date supply list in your medical record?
- Can you contact your supplier to fix any problems with your supply orders?

LIFESTYLE MANAGEMENT: DIET & HYDRATION

- Continent Bowel Diversion: Do you know how to regulate diet and hydration to maintain stool consistency, avoid blockage and dehydration?
- Continent Urinary Diversion: Do you drink enough fluids every day?
- Do you wear or carry a medical ID that tells others you need to empty your pouch with a catheter, if you can't speak or respond?

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

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Aging with an Ostomy or Continent Diversion

This an ongoing cause that is important to UOAA.

We want our community to be prepared for the future as they age with an ostomy or continent diversion.

In 2025 we revamped our dedicated webpage for this initiative, created a self-management checklist for the continent diversion community, in particular those with an internal reservoir with a stoma that needs to be catheterized and hosted a special Ostomy Academy webinar. You can check out the new and improved [web page](#) to download the resources or watch the webinar.

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

New in 2025!

Planting Seeds for Future Ostomy Nurses!



As part of UOAA's ongoing efforts to advocate for more ostomy nurses and increase ostomy education with medical professionals, UOAA spearheaded a new initiative entitled "Back to Your Nursing Roots".

With our partner, the WOCN Society®, we are recruiting nurses with an ostomy certification and participants have begun to "return to their roots" (nursing school alma mater) to raise awareness, reduce ostomy stigma, "plant seeds" for future certified ostomy nurses, and encourage more time added in the curriculum for ostomy education. Four nurses completed the program and we now have 80 registrants.



Launched an Educational Game for Children!

UOAA's Advocacy Committee developed an interactive web-based game for the pediatric population "Revving Up with an Ostomy" designed to educate and empower young children about ostomy care. If you haven't seen it, you can check it out [here!](#)



PLANNING FOR NEXT YEAR



The following list, **not all-inclusive**, includes some of the advocacy goals and priorities we will be focusing on in 2026:

Collaborative Advocacy Efforts

- With key stakeholders UOAA will continue to advocate against the CMS ruling to include ostomy and urological supplies in the Competitive Bidding Program with a multi-prong approach including both government affairs and public affairs campaigns. Stay abreast [here](#). In addition to the advocacy efforts, UOAA will be creating resources to educate and prepare the ostomy community should this continue to move forward including a FAQs resource, patient advocate training, and a webinar to explain what it means to the community
- With the Digestive Disease National Coalition continue support of the legislative priorities for the new 119th Congress including the Safe Step Act, HELP Copays Act and Medical Nutrition Therapy Act
- With the WOCN Society continue to promote the “Back to Nursing Roots” campaign

Access to Care and Supplies

- Continue efforts for the Non-Medical Switching of Ostomy Supplies [campaign](#) to prevent this barrier to supplies and ensure the collaborative decision-making between patients and medical professionals remains intact
- Continue promotion of the rebranded Ostomy and Continent Diversion Patient Bill of Rights ([PBOR](#)) to drive systemic change in ostomy care and improve patient outcomes across the United States

Ostomy Awareness

- Celebrate national Ostomy Awareness Day in the United States on October 3, 2026

To learn more about all of our public policy priorities visit this [web page](#).

