

2021

UOAA Advocacy



IMPACTS AND ACHIEVEMENTS

"Our Advocacy Program is watching out for you. I'm continually amazed at how much they accomplish year after year and how they have elevated UOAA's voice on issues of national importance to us all. With your continued support, we expect more great things in 2022."

~Jim Murray, UOAA President

Year In Review

FROM THE DESK OF UOAA'S ADVOCACY MANAGER
JEANINE GLEBA



UOAA is the leading organization advocating for the approximate 725,000 to one million people living with an ostomy or continent diversion, and those about to undergo this life-saving surgery. We now have over 1200 advocates in the Advocacy Network. Additionally, in 2021 there have been thousands of downloads of our self-advocacy resources such as our TSA Communication Card and over 10,000 visits to our advocacy webpages such as our Swimming with an Ostomy webpage.

We've become the trusted resource to address public policies that may create barriers to patients' access to quality ostomy care and prosthetic ostomy pouching supplies. As a result of our continued work to foster relationships with medical organizations, industry partners, supply providers, and key decision makers we hold an important seat at the table in many ostomy policy discussions.

UOAA would like to gratefully acknowledge the contributions of the Advocacy Committee (Co-Chairs Joanna Burgess-Stocks BSN, RN, CWOCN, Susan Mueller BSN, RN, CWOCN, and member Keagan Lynggard-Hysell) in helping us achieve our 2021 goals.

UOAA also recognizes the voice of ostomates can be a powerful tool in improving quality of care and patient satisfaction. As a result, this year we formed a Patient Advisory Board which serves as an important sounding board for the organization from the patient perspective.

Here are highlights of our advocacy work in 2021.

Federal Advocacy

- Voiced concerns at CMS public hearings on current coding for irrigation sleeves and supported application for new codes, which resulted in CMS decision to approve new codes to differentiate disposable ostomy irrigation sleeves from reusable ostomy irrigation sleeves with appropriate respective monthly allowable limits (effective 1/1/22)
- Submitted letter of support to CMS for proper reimbursement of new codes
- Submitted letters of support to CMS to increase quantity limits for extended wear products in state Medicaid plans with very low monthly limits (OH - 5/mo, WI - 6/mo) and will monitor these efforts in 2022
- Continued support of DDNC public policy agenda including the Safe Step Act; served as Secretary 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
- Served as an active supporter of WOCN Society efforts for CMS coverage of fistula supplies



Our steadfast two-year advocacy efforts on appropriate coverage and coding resulted in meaningful policy changes and removing barriers for colostomy irrigation at CMS.

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

- Contributed to and endorsed the White Paper with American Association of Home Care and other stakeholders to protect access to ostomy supplies and services to improve health outcomes in a home-based setting
- Submitted Federal comments with recommendations for the Home Community Based Services Access Act of 2021
- Spoke out against non-medical switching (aka product substitution) of ostomy supplies with legislators during the virtual 2021 DDNC Spring Public Policy Forum and garnered the support of the Access and Care Coalition to join the cause to prevent this practice by providers of medical supplies
- Signed several coalition letters including urging Congress to a) triple funding over three years for the CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP); b) provide funding (\$46.4 billion) for the National Institute of Health and research in the 2022 budget; and c) encourage the HELP committee to include medications access in emergencies in any pandemic preparedness legislation
- UOAA Medical Advisory Board updated our position statement on the use of opioids for non-pain treatments for medical conditions such as high output stomas for some people living with an ostomy

**NJ Advocates with Senator
Cory Booker's staff**



"Advocacy is important to me because it empowers me to educate and influence those in positions to make changes in healthcare in the country that will not only positively affect me, but all patients."

~UOAA Advocate Mollie Tinnin, CSP, CHST

Ostomy Awareness



**NJ advocate with proclamation
declaring World Ostomy Day**

World Ostomy Day

Oct. 2 2021



2021 was the 10th celebration of World Ostomy Day, and on October 2nd thousands of people raised ostomy awareness and helped citizens of the United States recognize that health is a human right and that ostomates are entitled to quality ostomy health care. The theme was "Ostomates' Rights are Human Rights - anytime and anywhere."

**Over 7,000 people visited
our dedicated webpage
for this special day.**

UOAA collaborated with many organizations including Crohn's and Colitis Foundation, Girls with Guts, WOCN Society and partners such as Byram Healthcare, Coloplast, ConvaTec, and Hollister to bring the global ostomy community together for special online events.

UOAA played a central role uniting people around the world for a common cause and to increase public acceptance and understanding of "ostomy".

Influential Together

- Partnered with Fight Colorectal Cancer and contributed an article about eating with an ostomy to their Beyond Blue magazine
- Co-hosted a webinar with Health Advocacy Summit for young adults with a J-Pouch and produced a poster on the topic
- Continued advancement of our joint advocacy priority with the WOCN Society to drive change in Community Care (i.e., admittance and retention of residents with an ostomy in assisted living facilities) including but not limited to mailing our FAQs to every State Association in the US to educate their members and dispel ostomy myths. We learned many states welcome ostomates and others have requested education to encourage facilities to expand services

Recruited members to UOAA's Medical Advisory Board



**American Society of
Colon and Rectal
Surgeons**



**American College of
Surgeons**



**American
Gastroenterology
Association**

Achieved our goal to continue to foster stronger relationships with existing partners, build new alliances and increase ostomy care education.

Wrote a Wound Management Prevention journal article with the Wound Ostomy Continence Nurses Certification Board (WOCNCB) to inspire more nurses to get certified in ostomy care.

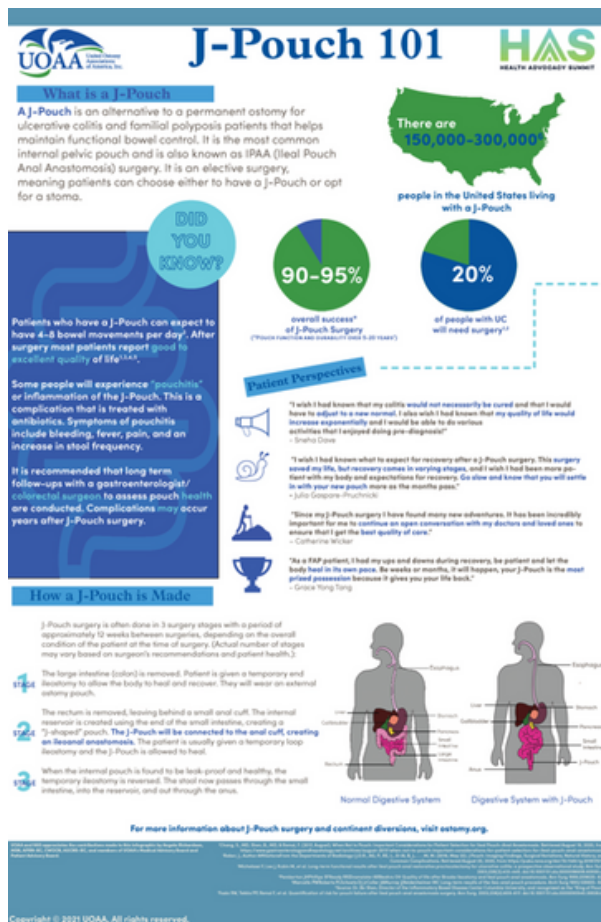


Established a scholarship program to help offset education expenses for a nurse to become a Certified Ostomy Care Nurse (COCN)® which will increase access to nurses knowledgeable in ostomy care. In collaboration with the WOCNCB they will provide a complimentary application exam fee (value \$395) to the scholarship winner

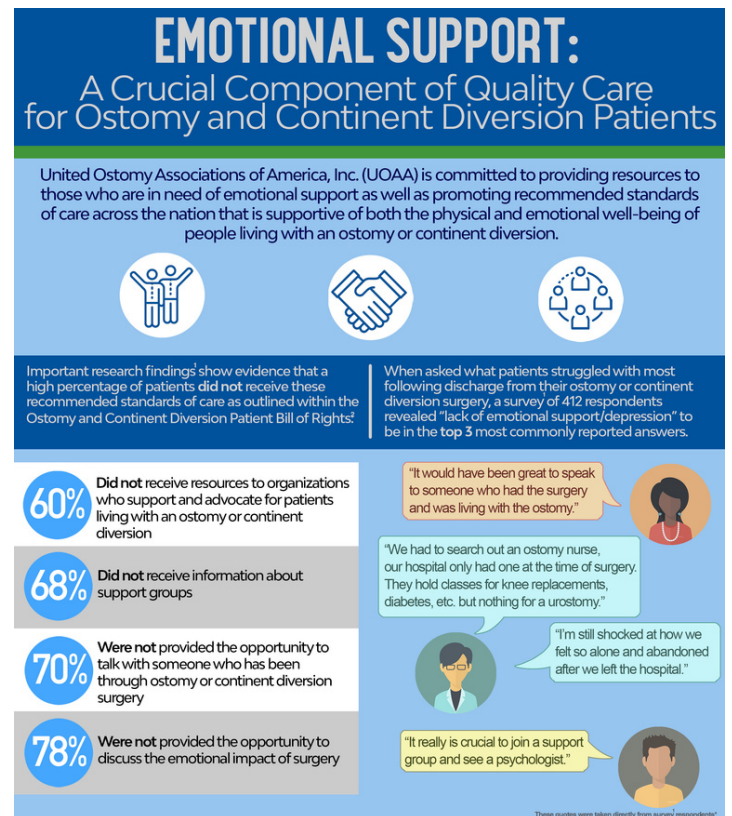
Published six articles in UOAA's Upfront with Ostomies column for the Wound Management Prevention medical journal to educate medical clinicians from the patient perspective.

Tools and Resources

- Revised the “Know Your Ostomy Supplies Checklist”
- Updated UOAA’s Employment-Based Discrimination resource
- Created two new infographics:



J-Pouch infographic poster to raise awareness about this type of continent diversion to treat patients with ulcerative colitis and familial polyposis



Infographic with research results showing how crucial emotional support is for quality ostomy care

Produced new and revised tools and resources to make a real impact.

Quality Ostomy Care

OSTOMY AND CONTINENT DIVERSION PATIENT BILL OF RIGHTS:

Research Validation of Standards of Care



- Published an important White Paper that validates the best practices recommended in the PBOR for quality ostomy care
- Produced and launched a new animated series in collaboration with Better Health to explain ostomy rights which is helping to make the topic of ostomy rights accessible to all
- 19 organizations and industry partners endorsed the newly revised PBOR including new endorsements from the American Society of Colon and Rectal Surgeons and the American College of Gastroenterology and the International Foundation for Gastrointestinal Disorders

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

2022 UOAA Advocacy Goals and Priorities

UOAA is the leading organization advocating for the 725,000 to 1,000,000 people living with an ostomy or continent diversion in the United States as well as the approximate 100,000 new patients facing ostomy surgery annually. The following list, not all-inclusive, includes some of the advocacy work we will be doing in 2022:

Collaborative Advocacy Efforts

- With the Digestive Disease National Coalition and Access and Care Coalition continue support of the legislative priorities for the 117th Congress including the Safe Step Act
- With the WOCN Society continue outreach efforts to drive change in Community Care (i.e., admittance and retention of residents with an ostomy in assisted living facilities). These outreach plans could include creating an educational webinar designed for state associations to share with their members about ostomy care as well as the Society potentially having a volunteer network of WOC nurses to help educate facilities about ostomy care

Ostomy and Continent Diversion Patient Bill of Rights (PBOR)

- Work with CMS's Person and Family Engagement Group as they "put patients first" to recognize and highlight the best in practice standards of care in the PBOR to achieve positive patient health outcomes in ostomy care
- Continue outreach for utilization of the PBOR and animated series, and add more endorsers to PBOR and White Paper

Ostomy Awareness

- Celebrate National Ostomy Awareness Day in the United States on October 1, 2022.

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 on how to speak up and forming a roundtable of stakeholders
- Continue to advocate for proper coverage of ostomy supplies under Medicare/Medicaid

