

Ostomy Association of the Houston Area

"We help ourselves by helping others to help themselves."

We are a volunteer-based organization dedicated to providing education, information, support and advocacy for people who have had or will have intestinal or urinary diversions.

P.O. Box 25164 Houston, TX 77265-5164 www.ostomyhouston.org

Stepping Up For Ourselves and Others

By Patti Suler



Those of us in the ostomate community have found that once we adjust to our intestinal or urinary diversions, we often resume our lives with little thought to the political architecture around us. Yet we do belong to a larger community that has unique issues and needs.

An ostomate would no more leave the house for work or school without their pouching system than an amputee would leave without their artificial leg. Most permanent ostomates are amputees having had their internal organs removed or reconstructed to such a point that reversal is not an option.

Medical terms define a **prosthesis**, **prosthetic**, or **prosthetic limb** as an artificial device extension that replaces a missing body part. Our pouching systems replace the functionality of our amputated organs. Awareness of this basic fact and its broader implications is the first step in addressing ignorance and bureaucracy.

The 112th Congressional Session received House Resolution 152 introduced by Representative Leonard Lance of New Jersey's 7th District and a similar Senate Resolution 95 by Senator Richard Burr of North Carolina on March 8th of this year. Both resolutions, although differently worded, request similar attention.

H.Res. 152 text highlights (complete resolution text can be viewed via the Google search engine)

Identifying the key issues:

- Whereas following ostomy surgery, patients need specially selected medical prosthetics to manage, temporarily or permanently restore intestinal or urinary system function, reestablish activities of daily living, improve quality of life; and require access to uniquely skilled ostomy specialty nurses who recommend and customize ostomy products for patients;
- Whereas, however, ostomy products are reimbursed under the Medicare program as medical supplies and not as prosthetics;
- Whereas there is a significant inconsistency under the Medicare program between the coverage category of, and reimbursement policy for, ostomy products;

- Whereas ostomy products are prosthetic devices prescribed by health care providers and meet the definition of prosthetics under the Medicare program;
- Whereas the Federal law does not require coverage of prosthetics, including ostomy products, under the Medicaid program;
- Whereas ostomy products are customized to the clinical needs of individual patients and are not the same as other easily interchangeable medical supplies such as gauze and bandages;

Identifying the key recognitions:

 Recognizes the life-saving role of ostomy care and prosthetics in the daily lives of hundreds of thousands of people in the United States and the necessity of a specialized ostomy nurse to recommend and customize ostomy prosthesis for the individual;

(Continued on page 3)

We are a health support group, a non-profit, tax-exempt, organization of volunteers whose purpose is to provide mutual aid and education to persons who have ostomies and to their families. We are a Texas non-profit corporation. Membership fees and donations are tax deductible.

Patient Visiting and Support Services

Doctors and ET Nurses, please note:

Upon request from a doctor or nurse, a specially trained visitor will be sent to visit an ostomy patient before and/or after surgery. The visitor will be matched as nearly as possible according to sex, age, and type of ostomy. There is no charge for this service. The visitor does not give medical advice. Please contact our Visitor Coordinator, Dorothy Andrews at 713-789-4049.

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Central Group News

We welcomed 18-year-old Caleb Alford as our speaker at our July meeting. Caleb gave an enthusiastic and heartfelt presentation about the Youth Rally, held in San Diego this summer. Having attended Rally for a couple of years as a camper, this year, he was a Counselor-in-Training. Our organization was honored to help Caleb with the registration fees for the Youth Rally. Caleb showed us



Caleb Alford

pictures from the various events at the Rally and of some of the 130 attendees. He told us how important the Rally was for the campers. For many, it is the first time to meet someone with a similar circumstance. For all, it is unique and freeing to not be the odd person in the crowd. For some kids, this is their first trip away from home and their parents. It is a chance to work toward greater independence. In fact, that is a major goal of the Rally to help the kids realize that they are not limited by their physical state. The kids learn that they can do lots of things, they can have lots of fun, and they can learn to take care of themselves in many ways. The Counselors-in-Training learn how to assist the kids while allowing them the freedom to learn and grow. Caleb said that the last day is full of tears as the connections made at the Rally are life changing for some and deeply felt by all.

Caleb said that Texas was only represented by three people while Connecticut, a much smaller state, had at least twice as many. His mission is to locate other kids in Texas who would benefit from the Youth Rally experience and to urge them to attend. To that end, we add our support to Caleb's effort and will look for ways to connect with kids in the Houston area. Here is a link to the Youth Rally web site. http://www.rglly4youth.org/

In other news, the July dues statements have gone out. Please return your dues so that you can continue to receive the newsletter. In the statement letter, you will find the Kroger Neighbor to Neighbor Program customer letter. There was also a Kroger letter in the July newsletter. Please take your letter along with your Kroger card next time you shop and renew your support of the Ostomy Association. The Kroger program donated over \$1,000 to our organization this year. Thanks to all for participating.

The National Conference of the UOAA is next month, August 7–11 in Reno. If anyone is attending, we would love to hear about your experience there.

One aspect of the UOAA is advocacy for persons living with an ostomy or other related conditions. To that end, there is a resolution before members of Congress recognizing the lifesaving role of ostomy care and prosthetics for people who have an ostomy. This resolution was introduced by members of Congress from both parties. To read more about the Resolution and to

send your Congressman and Senator a letter supporting the resolution, go to https://capwiz.com/uoaa/issues.

For those who are having an ostomy reversed, or if you have accumulated extra supplies that you aren't going to use, please contact Mary or Clarice. We are getting many calls from persons with no insurance or no means to purchase supplies. If you need supplies, please contact Mary or Clarice whose numbers are on the back page of this newsletter.

September 16–17, we will be participating in the MD Anderson Network Cancer Survivor Conference. If you have extra *Phoenix* magazines or old newsletters, please bring them to the August meeting. The newsletters and magazines along with our brochure are handed out to those interested in our organization.

In August, our speaker will be Arlene Ehlers, ET. Arlene was one of the earliest certified Enterostomal Therapists. She recently moved to Texas after marrying her high school sweetheart. We welcome Arlene to our group and look forward to hearing about her experiences as an ET.

Respectfully,

Denise Parsons, President, OAHA

Northwest Group News

17 people participated in the annual ice cream social at the Northwest Group meeting in July. Members voted on the Vice President and Treasurer positions for the National UOAA. One new member was welcomed and a variety of discussion topics related to heat and wafer wear time were covered as everyone enjoyed the homemade banana ice cream provided by Gay Nell.

Attendees were solicited regarding taking over Gay Nell's coordinator position. Duties and responsibilities as well as available support options were discussed. A potential volunteer has stepped forward pending affirmation by the President. If approved, the new coordinator could start as soon as the first of the year.

Our next meeting will be a vacation roundtable—bring photos to share of where you took your stoma.

 Gay Nell Faltysek
 Tony Romeo

 281-446-0444
 281-537-0681

Disclaimer: The information contained within this newsletter is presented expressly for informational purposes only and may not be applicable to everyone. It should not be substituted for professional medical care or attention by a qualified practitioner. Always check with your doctor if you have any questions or concerns about your condition.

WOCN and ET Directory

Cindy Barefield, RN, CWOCN

(281) 425-2164

Clarice E. Kennedy, CET claricekennedy | @comcast.net

(713) 647-8029

Charlene Randall, RN, CWOCN

(713) 465-8497

Specialty Wound & Ostomy Nursing, Inc.

charlene@swoni.com

Pat Thompson RN, BSN, CWON Pat.thompson@tenethealth.com

(281) 397-2799

Catherine Walsh RN, BSN, CWON

(409) 747-3070

UTMB @ Galveston

Fax: (409) 747-3038

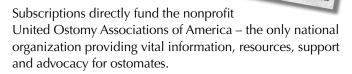
cmwalsh@utmb.edu

The United Ostomy Associations of America (UOAA) can be contacted at:

www.uoaa.org or 800-826-0826

Get Ostomy Answers!

The Phoenix is the leading national magazine for ostomates, their families and caregivers. Each issue contains 72 pages of inspiration, education and information including new products, medical advice, management techniques, personal stories and more.



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Stepping Up For Ourselves and Others

(Continued from page 1)

- 2. recognizes if a surgical procedure results in a patient needing a prosthetic that manages or restores intestinal or urinary system function—specifically the control of the elimination of the body's waste products, then such a patient should have access to individually prescribed, customized prosthetics that the health care provider believes will best meet the patient's needs;
- 3. urges that ostomy products be recognized, categorized, covered, and adequately reimbursed by Medicare in a new payment category of "prosthetic supplies" consistent with Medicare's current recognition of ostomy products as prosthetics in order to allow appropriate patient access; and
- 4. Urges the Secretary of Health and Human Services to ensure that programs, policies, and payment practices of the Department of Health and Human Services facilitate, and do not discourage, innovation of and access to medical devices that restore or improve intestinal or urinary system function of individuals in the United States with an ostomy.

Linda Aukett, the UOAA's Advocacy Chair, was contacted regarding the significance of these resolutions and how they relate to our community. She advised that "It is very important our public policy makers understand that ostomy pouches and wafers are very different in function than single-use medical supplies such as bandages."

Ms. Aukett went on to state that these key issues have needed attention for a long time. She shared that this particular set of resolutions had a strong beginning as they were introduced at the same time the Great Comebacks awards were made. Each of the award recipients had the opportunity to meet with their representatives in person while in Washington DC.

Gaining momentum, grass roots support for these items was cultivated at the annual WOCN conference in June. UOAA and Convatec presented information on the resolutions at their booths. The Convatec booth also provided computers and direct links to the Capwiz site so visitors could instantly show their support.

Additionally a 'Capwiz' easy button or widget has been added to the www.UOAA.org site under their advocacy tab. A similar widget has been placed on our www.OstomyHouston.org web site under Useful Links. This click-once button allows a person to send messages to both their Senate and House representatives. Each person will be prompted for their name, address and email information to ensure the request is routed to the proper office.

Ms. Aukett shared that every email or letter sent was important, however, in today's high tech arena, a simple sincere phone call was even more powerful as a follow-up or substitution to the email. If you don't have the resources to contact your representatives electronically, consider working with a family member who does or possibly using free computer access at the local library.

Calling Your Congressional Representatives

*Key Committee Member

If you are going to call, be prepared to provide your name, address, and ZIP code so the staff can verify you are a constituent of the Member of Congress. Reference the resolutions specifically by bill number and session number. Talk about the impact of the resolution on you and your own reason for supporting it. Recommendations are that you personalize, stay short and on target with your issue.

Our representatives are only able to respond to their constituents, people who live in their service area. To save time, please verify you are contacting the correct representative either by checking on your voter registration card (U.S. Representative or State Senator boxes). If you do not have your voter registration card handy, you can contact your local Tax Office for the same information.

Most resolutions are routed through various committees to allow for closer inspection by key members before the resolution is

Position	Title	Name	Coverage Area	Phone
Senate	Senator	John Cornyn	State	713-572-3337
Senate	Senator	Kay Hutchison	State	713-653-3456
Representative	Congressman	Ted Poe	District 2	281-446-0242
Representative	Congressman	John Culberson	District 7	713-682-8828
Representative	Congressman	Kevin Brady*	District 8	936-441-5700
Representative	Congressman	Al Green	District 9	713-383-9234
Representative	Congressman	Michael McCaul	District 10	281-255-8372
Representative	Congressman	Ron Paul	District 14	979-285-0231
Representative	Congressman	Sheila Jackson-Lee	District 18	713-655-0050
Representative	Congressman	Pete Olson*	District 22	281-486-1095
Representative	Congressman	Raymond "Gene" Green*	District 29	281-999-5879

Contact information obtained from representatives' web sites.

Additional State-Wide Committee Members:

Rep. Sam Johnson (R-3)—Ways and Means [Richardson]

Rep. Joe Barton (R-6)—Energy and Commerce [Arlington, Ennis]

Rep. Charlie Gonzalez (D-20)—Energy and Commerce [San Antonio]

Rep. Lloyd Doggett (D-25)—Ways and Means [Austin]

Rep. Michael Burgess (R-26)—Energy and Commerce [Lewisville, Ft. Worth]

forwarded on or not. Critical Committee members that will be looking at our resolutions are bolded and starred above. We have spent much of the last year talking about volunteer opportunities and ways to make a lasting difference. Let's join together and make a big difference now.

Central Group

Monthly: Third Monday Time: 7:00 p.m.

Place: American Cancer Society Building

6301 Richmond Avenue, Houston

Contact: Terry Marriott 713-668-8433

marriot@rice.edu

Meeting: August 15, 2011

Program: Guest Speaker: Arlene Ehlers, ET

(Enterostomal Therapist)

Baytown Group

Monthly: First Monday Time: 6:00 p.m.

Place: Community Room in Lobby of San Jacinto Methodist

Hospital

4401 Garth Road, Baytown

Contact: Cindy Barefield 281-420-8671

Meeting: August 1, 2011 Program: Roundtable

We encourage you to bring your spouse or significant other and members of your immediate family to our meetings.

Northwest Group

Monthly: Third Tuesday of the month

Time: 7:00 p.m.

Place: NW Medical Professional Bldg., (The Cali Bldg.)

17117 Cali Drive, Houston (This location is just off of 1960 and west of I-45. Turn north on Cali Drive from 1960. At the stop sign turn left on Judiwood and left

again to park behind the Cali Building.)

Contact: Tony Romeo 281-537-0681

sa1tmr@sbcglobal.net

Meeting: August 16, 2011

Program: Vacation Roundtable—Bring photos!

J-Pouch Group

Monthly: Third Monday Time: 7:30 p.m.

Place: American Cancer Society Building

6301 Richmond Avenue, Houston

Contact: Ron Meisinger 281-491-8220

Meeting: August 15, 2011

Monthly support and information meetings are held in three locations for member convenience.

^{*} These key members also belong to the reviewing committees. Please consider asking friends and family members from these other areas to contact their representative on behalf of this resolution.

Opportunities and Announcements

Anniversary Gift

As you celebrate the anniversary of your ostomy surgery each year, consider making a monetary gift to the Ostomy Association. Checks should be made payable to the *Ostomy Association of the Houston Area* and sent to the address shown at the right (in the box).

Use Those Shopping Cards

Kroger and Randalls return a percentage of your purchases to the Ostomy Association on a quarterly basis. For information about

shopping cards, please visit the website: http://www.ostomyhouston.org/

Memorial Fund

Donations can be made to our Memorial Fund to memorialize or honor individuals. Checks should be made payable to the *Ostomy Association of the Houston Area* and sent to the address at the top right (in the box). When sending a donation, be sure to include the name of the person being honored so that acknowledgement can be sent.

Moving?

Our newsletter is sent by bulk mail, which the Post Office will not forward even if you fill out a forwarding request. To continue receiving the newsletter after a move, contact Lorette Bauarschi, Treasurer, at 713-582-0718 or lbauarschi@sbcglobal.net or send your request to the provided address at the top right of this page.

Donation of Supplies

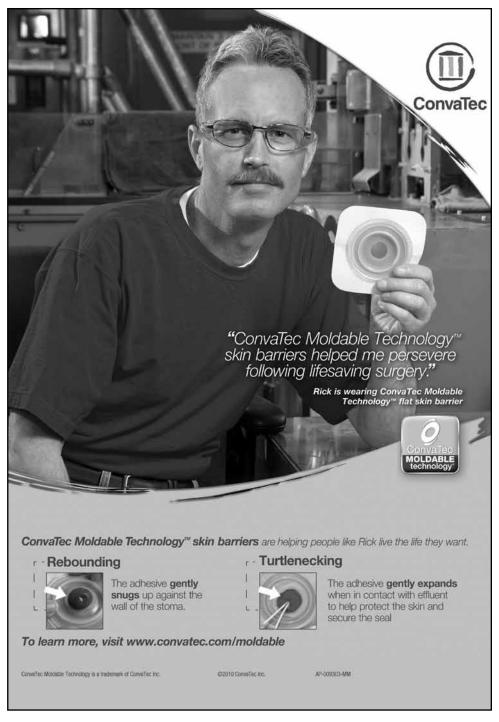
We are contacted on a regular basis by individuals who are in need of donated ostomy supplies. Consider donating ostomy supplies that you no longer use to assist your fellow ostomates in the Houston area. Please contact Mary Harle at 713-782-7864 with any questions.

Sponsorship

You can sponsor a member of our ostomy support group with a tax-deductible donation to cover the cost of their membership. Please make the check in the amount of \$25.00 payable to *Ostomy Association of the Houston Area* and send to the address at the top right.

For Anniversary Gifts, Memorial Donations, Mailing Changes, or Sponsorships, please send all correspondence to:

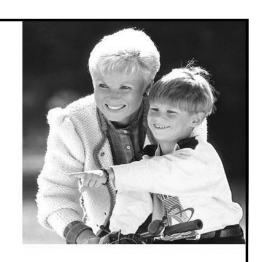
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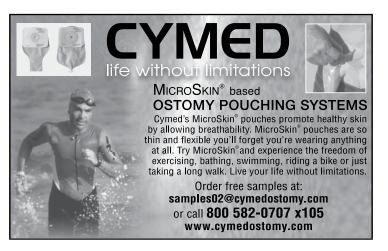




For a Free Sample or For More Information Contact Clarice Kennedy, CET (713) 647-8029 or cekennedy1@peoplepc.com

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Membership Application Membership in the Ostomy Association of the Houston Area requires one easy payment. Please complete the following form and mail as directed with payment as shown. Dues of \$25.00 per year are payable to: Ostomy Association of the Houston Area, Attention: Treasurer P. O. Box 25164, Houston, TX 77265-5164 Date: _____ Name: ______ Phone: _____ Street Address: _____ City: ______ State: _____ ZIP: _____ E-mail: _____ Surgery Date: ______ Birth Date: _____ Reason for surgery: Crohn's Ulcerative Colitis Cancer Birth Defects Other Do you speak a foreign language? □ Yes □ No Foreign language spoken: _________ Procedure or Relationship: To help us complete our records, please answer the following. *Check all that apply.* Membership benefits include: □ Colostomy □ Continent Ileostomy □ Ileostomy □ Continent Urostomy □ Urinary Diversion □ Pull-Through □ Other: □ □ Parent of Child with procedure Monthly Support/Information □ Spouse/Family Member Meetings, Social Events, □ Physician Monthly Newsletter □ Nurse □ I would like to attend meetings with the *(please circle one)*: Baytown Group Northwest Group Central Group J-Pouch Group □ I would like to become a member but cannot pay dues at this time. (*This will be kept confidential*.) I learned about the Ostomy Association from □ Other:____ □ Surgical Shop □ Website □ ET Nurse □ Physician □ Newsletter I am interested in volunteering. ☐ Yes ☐ No I have enclosed an additional \$_____ as a donation to support the association's mission of helping ostomates.





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