



April 2013

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
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www.ostomyhouston.org

Appreciation for the Affordable Care Act

By Jennifer C. Jaff, Esquire, the founder and executive director of Advocacy for Patients with Chronic Illness, Inc. Her op-ed dated March 22, 2012.

Ostomy News Editor's Note: Whether or not you support the Affordable Care Act, it is important to understand how it would affect the chronically ill. This article was written before the Supreme Court's decision upholding the ACA.

—*Courtesy of the Ostomy News of North San Diego County.*

If you don't have a chronic illness, you don't really get it. You can't. Chronic illness is different from illnesses that kill you and illnesses from which you recover. If you have a chronic illness, it never ends. Although there are thousands of chronic illnesses, there are several characteristics that are common among us:

- Chronic illnesses are largely invisible. We're not in wheelchairs (well, not most of us) and, as a general rule, we don't look sick, at least not all the time.
- We are in pain much, if not all, of the time. Joints ache. Muscles strain. Lying flat on a bed, there is throbbing. 24/7. Pain.
- We experience a fatigue that those without chronic illness can't really imagine. It's not sleepiness. Indeed, sleep does little

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.

to alleviate it. I call it Chronic Illness Fatigue. It's beyond bone tired. It's overwhelming and looks a lot like depression but it's not a mental illness; it's a real symptom of all chronic illness.

And none of us—not one—can purchase individual insurance in most states. Not for any amount of money. We are shunned, like lepers. We are the castoffs. We are second class citizens. And so we get sicker, until the cost of our care falls to the government when we land in a hospital, or until we have no alternative but bankruptcy. The sicker we get, the harder it is for us to hold onto our jobs, and whatever insurance we get through our employers. Without insurance, when our disease flares, we lose everything.

The Affordable Care Act would change that. Starting on January 1, 2014, insurers no longer would be allowed to turn applicants down on the grounds that they have a pre-existing condition.

This is the most important civil rights victory for people with chronic illnesses—ever.

The individual mandate is so closely tied to universal guaranteed issue insurance that the Justice Department has conceded in its brief to the Supreme Court that, if the individual mandate is struck down, so, too, must the guaranteed issue provisions be eliminated. Equal treatment of people with chronic illnesses will be lost—and that will happen as the result of a conversation about the individual mandate, without even an acknowledgement of what loss means to those of us with chronic illnesses.

I will never forget the day when President Obama signed the Affordable Care act, March 23, 2010. I watched, with tears streaming down my cheeks. That was the day when my civil rights as a person with a chronic illness were first recognized by the

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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.

Central Group News

We celebrated the 57th Anniversary of the Ostomy Association of the Houston Area. For 57 years, ostomates in the Houston area have supported one another in this all volunteer group. That is an amazing record and shows that there is still a need for experienced ostomates to share their practical tips for caring for the ostomy and for demonstrating that life can be good with an ostomy.

A great example of accomplishing new goals after ileostomy surgery, is Kathleen Duplessis, our speaker this month. Kathleen suffered with ulcerative colitis and Crohn's disease for several years before her surgery. Kathleen had been a runner before her illness and surgery, but after recovering and starting to run again, decided to challenge herself by attempting to qualify for the Boston Marathon. If you have never trained for an event like that, it takes months of running shorter distances and gradually increasing your endurance. Running in the Houston heat presented challenges as some wafers just melt from body heat. Kathleen found that Coloplast wafers work well for her. Kathleen entered a qualifying marathon where she exceeded the minimum time necessary in her age class to enter the Boston race. Generally, Race Day in Boston is cool and very pleasant running conditions. In 2012, Boston had unseasonably high temperatures, so Kathleen had some advantage having trained in Houston. She completed the race. However, she had over compensated for the heat by drinking too much water and developed a problem after the race. Moving forward, Kathleen is running and placing in her age group with better times than she had before surgery. Kathleen and her husband travel to Africa frequently as part of his photo safari business. Kathleen enjoys traveling and has not had any ostomy issues while traveling in remote areas. She does recommend carrying Xifaxan (rifaximin) which is an antibiotic that fights bacterial infection only in the intestines. Xifaxan is used to treat travelers' diarrhea caused by E. coli. Most people get this infection by eating food or drinking fluids that have been contaminated with the bacteria. She has also found, like many of us, that chewing well and drinking water keeps her system working well. We enjoyed Kathleen's baby animal photos and many of us are ready to sign up for a safari.

Linda Aukett, a key person in the UOAA national organization, died this month. More information from her memorial is located on page 3 of this newsletter.

You can help the Crohn's & Colitis Foundation of America (CCFA) by participating in one of our nationwide fundraising walks. Patti Suler is heading up a team so please contact her to join the walk. Donations are welcome to support our team as well.

I have an update from Clarice Kennedy, ET. She is still recovering from the severe illness that overcame her last year. She is getting better and is at home with her daughter while getting rehab and regaining her strength. She isn't up to seeing patients yet, but sends her love to the group as she thinks of us often.

The speaker for the April 15 OAHA meeting will be David B. Engler, MD, FACAAl, FAAAAI, from The Allergy Clinic,

whose topic will be seasonal allergies and how to control those symptoms.

Best regards,
Denise Parsons, President, OAHA
713-824-8841

Baytown Group News

In March, we scheduled time for Roundtable—"Friends helping Friends." Our group, though small, had a great time sharing ideas on managing their ostomy care. We know from research that the adjustment to life after an ostomy comes with time and lots of support. A study by Jenks, et al. in 1995 found that it takes 6-12 months to adapt and become comfortable with having an ostomy. A study by Richbourg et al., in 2007 involved 43 ostomates who were asked about **difficulties after discharge**. The findings are listed here:

- 88% had at least one problem after discharge
- Average number of problems per ostomate = 3.6
- Peristomal skin irritation = 76%
- Pouch leakage = 62%
- Odor = 59%
- Reduction in enjoyable activities = 54%
- Depression or anxiety = 55% females, 50% males
- Bulge around stoma = 53%

Ostomates were asked **who they sought for help**. Here were the responses:

- Primarily nurses when related to stoma and management
- Medical doctor
- Ostomy support group
- Customer service representative of ostomy manufacturer
- Insurance case manager
- **20% Nobody**

I like the comments that Brenda Elsagher, colorectal cancer survivor, comedian, speaker and passionate blogger for C3life.com posted recently, "Even though information is plentiful these days, there's just something refreshing about face to face contact especially if a few laughs are associated with it." We like to think that's what our support group offers. Support with a few good laughs.

April is a great time to join us. Laura Weldon, Exercise Physiologist will present, "Exercise that's Smarter, Not Harder". Hope to see you on April 1 at 6 p.m.

Cindy Barefield, RN, CWOCN, 281-428-3033



The **United Ostomy Associations of America (UOAA)**
can be contacted at:
www.uoaa.org or **800-826-0826**

Northwest Group News

Nick Sprague with Coloplast presented a comprehensive program covering all the products offered by Coloplast including their latest innovations to approximately a dozen attendees. We had some new mates in the group and they were able to see all the options available in the closed, open, single and two piece pouching systems. Nick also shared the no-sting accessory line of silicon based products. Everyone was very interested to go through a second edition Home Skill Kit for new ostomates. It comes with step by step photos and training material that includes a DVD.

Next month's program is Positive Thinking...It's Good For You! Paul Batchelder will be presenting a program on the power of positive thinking. We will explore not only how to stay positive, but also why it is so important. "People are just about as happy as they make up their minds to be." —Abraham Lincoln

The topic fits right in with the recent series that ran in the OAHA Newsletter "Minding the Maturing Mind". Get ready for a lively evening!

Craig Cooper
281-948-6883

Tony Romeo
281-537-0681

Visitor Training—May 11, 2013 Northwest Group Site

On May 11, 2013, OAHA Ostomates will get a second chance to take the Visitor Training at the Northwest Group site located in the NW Medical Professional Bldg., The Cali Bldg., 17117 Cali Drive, Houston. This location is just off of FM 1960 and west of I-45. This training provides extensive information about ostomies and all the side issues. It is a chance to get to know your fellow mates outside of a meeting arena. Training lasts approximately 6 hours and will be held on Saturday, May 11. Please RSVP with Patti Suler at 281-352-2566 before May 1, to ensure enough training materials are available.

CCFA Take Steps

<http://online.ccfa.org/goto/OAHA>

By Patti Suler, Team Captain

Come join Tom Ryan, Dorothy Andrews, Terry Marriott, Shawn Keith and myself for the upcoming CCFA Take Steps fundraiser on April 27, 2013, at Discovery Green. This is an optimum opportunity to make a big difference with a little bit of time investment. The walk itself can be accomplished in as little as 30 minutes. The food, entertainment and fellowship are a bonus. Absolutely cannot walk with us? Please consider a donation.

Contact Patti Suler at 281-352-2566 or pattiksuler@aol.com.



Appreciation for the Affordable Care Act

(continued from page 1)

United States. That was the day when I first saw the glimmer of equality on the horizon.

January 1, 2014. For two years now, I have been telling people with chronic illnesses to just hang in until then. We find them a free clinic or free prescription drugs, a patchwork quilt of health care until 2014. Hold on. The end is near. You will be fine once we get to 2014. Every time I say it, I feel a tightness in my chest. What if the Affordable Care Act doesn't make it to 2014?

Let's be clear about what's at stake in the Supreme Court case: Nothing less than the equal treatment of many millions of Americans with chronic illness. If we lose this now...well, it's just unthinkable.

Ms. Jaff passed away last September at the age of 55 from complications of Crohn's disease. She was a leading advocate for people with chronic illnesses.

OAHA Editor's note: Texas is one of a few states that offers a high risk individual insurance pool with current rates that can be as high as two times the market value for people with uninsurable medical conditions such as cancer, Crohn's, ulcerative colitis, stroke, heart attack and many others.

Linda Aukett

December 12, 1943–March 1, 2013

"A Life Well Lived"

Courtesy of the Ostomy Outlook, Ostomy Association of North Central Oklahoma

It is with great sorrow that we announce the passing of our dear friend Linda Aukett. Linda came from a family that believed in service to others and when she joined her first ostomy support group she was immediately drawn into the mission of the United Ostomy Association. She began as the local chapter's newsletter editor and progressed into more influential roles.

In the years since Linda's first ostomy support group meeting she held many positions on the local and national level. From 1992–1994, Linda served as the president of the former UOA and when that organization closed its doors in 2005, she and her husband Ken founded the United Ostomy Associations of America. Since its inception, Linda served as the Advocacy Chair for the UOAA. In this role, Linda touched countless lives with her tireless crusade as the voice of ostomates on every level of government, making sure that we could pass through airport security with dignity and that our ostomy supplies will continue to be paid for by our insurance companies.

(Continued on page 4)

Linda Auckett (continued from page 3)

In addition to Linda's work with the former UOA and the UOAA she served as a counselor for Youth Rally for 20 years. In this role she touched many lives that will carry on her legacy of caring and support for many years to come.

We all thank Linda for her tireless efforts in the service of ostomates everywhere and we will all miss her but we should look at her as an example for how to live our lives.

To help the UOAA continue Linda's legacy, you can contribute in her name by going to the UOAA (www.UOAA.org) donation page; click "Donate Now Directly" and select ADVOCACY as the fund designation.

Respectfully, Management Board of Directors, UOAA

Local OAHA Upcoming Elections

Denise Parsons, Marian Newman, and Suzanne Hill have been nominated to serve on the Board of Directors. Nominee(s) will be voted on at the May OAHA meetings.

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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Central Group

Monthly: Third Monday
Time: 7:00 p.m.
Place: American Cancer Society Building
 6301 Richmond Avenue, Houston
Contact: Denise Parsons 713-824-8841
 rockynme2@aol.com
Meeting: April 15, 2013
Program: Guest Speaker: **David B. Engler, MD, FACAII, FAAAAI**, from The Allergy Clinic

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 281-428-3033
Meeting: April 1, 2013
Program: **Guest Speaker: Laura Weldon**, Exercise Physiologist, will present "Exercise That's Smarter, Not Harder"

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: April 16, 2013
Program: **Guest Speaker: Paul Batchelder** will present, "Positive Thinking...It's Good For You!"

J-Pouch Group

Monthly: Third Monday
Time: 7:00 p.m. or by Appointment
Place: American Cancer Society Building
 6301 Richmond Avenue, Houston
Contact: Ron Cerreta 832-439-1311
 Ron Meisinger 281-491-8220
Meeting: April 15, 2013

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

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 Treasurer at the address shown below.

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 below. 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 Ron Cerreta, Treasurer, at 832-439-1311 or texasronc@aol.com or send your request to the provided address below.

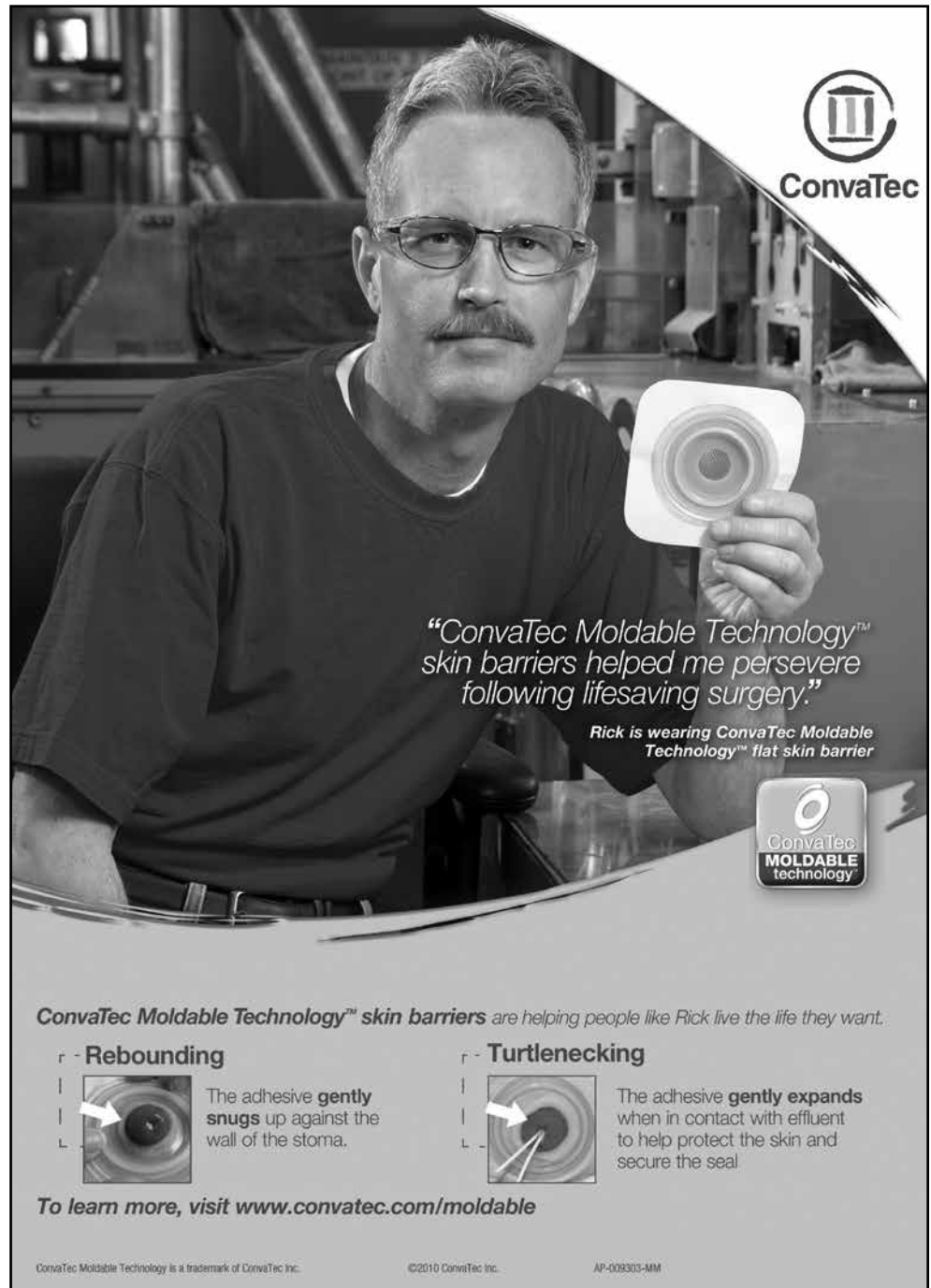
Donation of Supplies

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.

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

Ostomy Association of the Houston Area
Attn: Ron Cerreta, Treasurer
P. O. Box 25164
Houston, TX 77265-5164

(When sending a donation, be sure to include the name of the person being honored so that appropriate acknowledgement can be sent.)



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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/>

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

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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.**

- | | | |
|--|--|---|
| <input type="checkbox"/> Colostomy | <input type="checkbox"/> Continent Ileostomy | <input type="checkbox"/> Parent of Child with procedure |
| <input type="checkbox"/> Ileostomy | <input type="checkbox"/> Continent Urostomy | <input type="checkbox"/> Spouse/Family Member |
| <input type="checkbox"/> Urinary Diversion | <input type="checkbox"/> Pull-Through | <input type="checkbox"/> Physician |
| <input type="checkbox"/> Other: _____ | | <input type="checkbox"/> Nurse |

☐ I would like to attend meetings with the (**please circle one**):

Central Group Baytown Group Northwest 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

☐ WOC nurse ☐ Physician ☐ Newsletter ☐ Surgical Shop ☐ Website ☐ Other: _____

I am interested in volunteering. ☐ Yes ☐ No

I have enclosed an additional \$_____ as a donation to support the association's mission of helping ostomates.

*Membership benefits include:
Monthly Support/Information
Meetings, Social Events,
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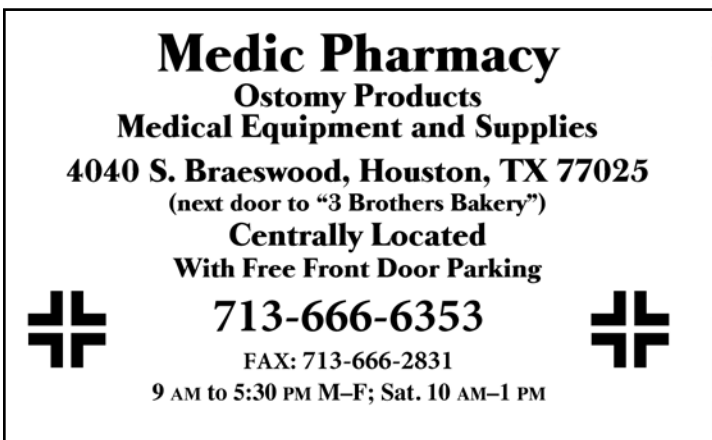


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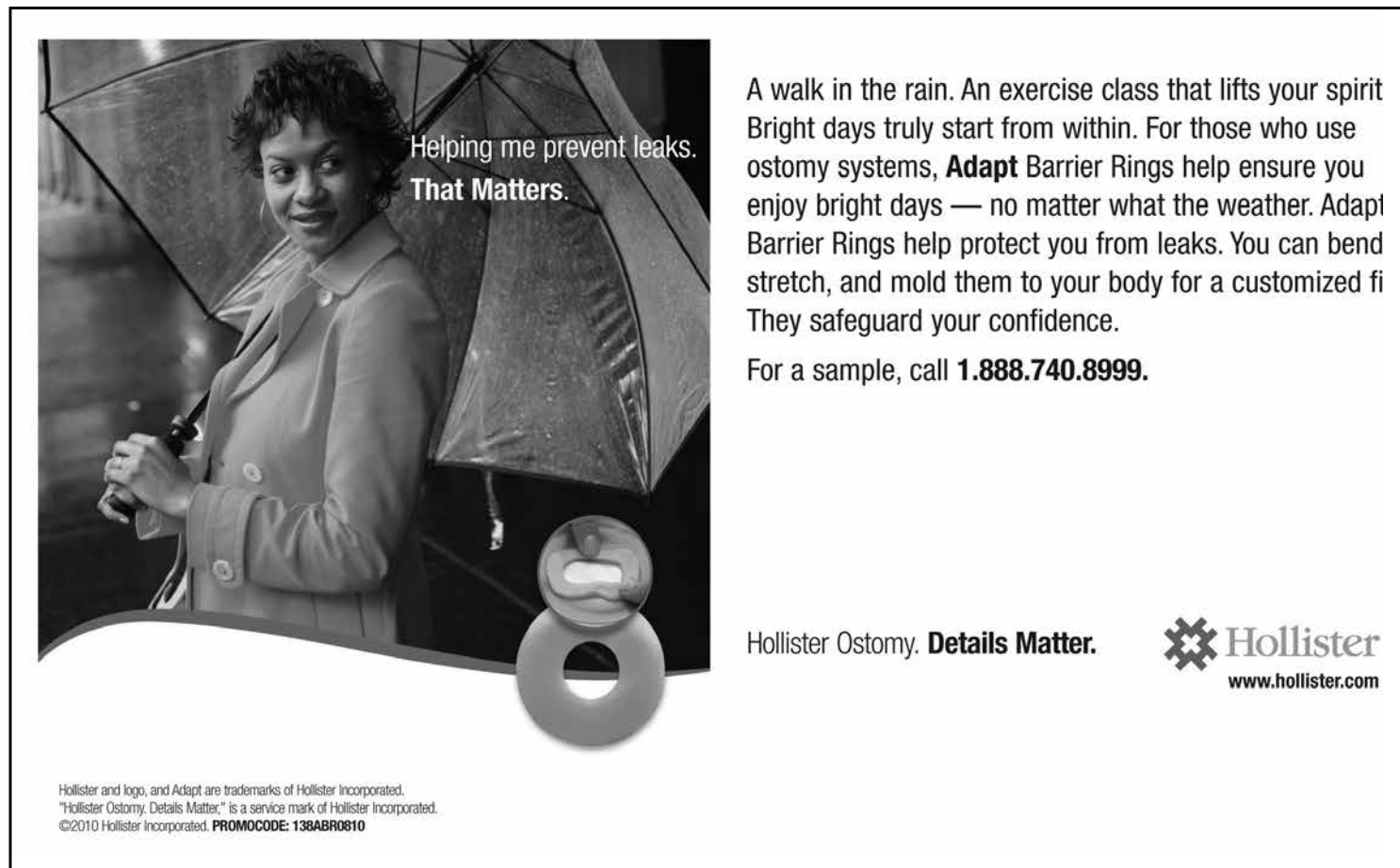


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