June 2011



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

# Ostomy Association of the Houston Area

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

# Take Steps Walk

The weather was perfect, the skies were blue and the temperature and humidity were both low. 14 people came together and formed a team to represent the Ostomy Association of the Houston Area in the annual Take Steps for Crohn's and Colitis fundraiser. Assisted by additional support walkers, the team was successful in completing the walk and raising nearly \$3,000.00 dollars for the cause.

OAHA Team Member Roster from the CC Take Steps Site:

Dorothy Andrews Paul Batchelder Sr. Lorette Bauarschi Ron Cerreta Laura Beth Jackson Ian Keith Shawn Keith Terry Marriott Deborah Mazzola Marian Newman Tom Ryan Patti Suler Anne Swanson Patricia Thompson Edgar Wood



Laura Beth Jackson and granddaughter Sophia Valentina Ceron

Support walkers: Tom Andrews, Gladys Wood, Scott Jackson, Sophia Valentina Ceron, Rosalie Johnson, Michelle Johnson, Bob Swanson, and Kristen Johnson.

Top fundraisers were Paul Batchelder Sr., Anne Swanson, and Ron Cerreta. If you see one of these people, shake their hand. Their combined contributions made up over 53% of the overall amount.

The Take Steps event was held at Discovery Green in downtown Houston on Saturday, May 14th.



# **Youth Rally**

The Youth Rally is a camp for kids aged 11-17 years with urinary or bowel diversions. Kids travel from all over the United States to participate in activities with the support of counselors and nurses.



Caleb Alford

Caleb Alford from Channelview is one such youth. He originally started out as a camper and this year he is going back as a counselor trainee. "I have Bladder Exstrophy. I go to a camp every summer in July that is for kids ages 11–17 with bladder or

(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**

On Monday May 16th, the Central Group of the Ostomy Association of the Houston Area had 19 in attendance at their meeting.

We started out with an announcement by Dorothy Andrews that a long time Ostomy Association member and ET, Anita Price, who was with the Houston Group in the 1970s and 1980s had died. Dorothy donated the book written by Anita about ileostomies to our library. Then we had our election for Board of Directors and all the nominees were voted in by acclamation:

**Terry Marriott** is nominated for a new 3-year term as a board member, his Presidency is term-limited and will end this June.

**Lorette Bauarschi** is nominated for a new 3-year term as a board member, her Treasurer position is term-limited and ends June 2012.

**Jenrose Foshee** is nominated for a new 3-year term as a board member to replace Dale Whittington, whose term expires this June.

**Suzanne Hill** is nominated to complete the remaining 2 years of a 3-year term for Anne Mueller, who has resigned from the Board.

Colleen Reeves, RN, WOCN who is a nurse at MD Anderson Hospital and has also acted as a counselor at Youth Rally Camp for kids with ostomies and related physical problems gave a presentation on Colorectal Cancer, the causes, treatment, and if not prevention, at least early diagnosis for successful treatment. She told us about the various types of colon cancer and the various stages 0 through 4 that colon polyps or tumors go through as they grow in the wall of your colon and become more dangerous. She told us that only 5–10% of polyps will become cancerous within 20 years, but that can vary from person to person and some people have a genetic predisposition to having colon cancer. She also told us about the High Risk Gastrointestinal Cancer Genetics Clinic that they now have at the M. D. Anderson Cancer Center that can counsel families that may have some hereditary cancer predisposition syndrome, such as, Lynch syndrome/HNPCC, or Familial Adenomatous Polyposis (FAP), MYH-associated Polyposis, Hereditary diffuse gastric cancer, or the somewhat more rare Peutz-Jeghers syndrome, and the Juvenile Polyposis syndrome. The counseling that is done can tell a cancer patient's family members who don't have cancer how often and what types of checkups that would be best for them, and especially how often they should have a full colonoscopy. Most people (for those of us that still have a colon) are considered to need to have a colonoscopy every 5 years after the age of 50. For those considered at high risk this may be changed to as often as once a year starting at the age of forty or even younger.

Our Newsletter Editor, Patti was the OAHA team captain for the CCFA Take Steps walkathon that took place on Saturday May 14. We had 15 walkers plus Laura Beth's granddaughter in a stroller.

The website where you can sign up to donate for one of the walkers is (and you can still make donations for 3 or 4 months after the actual walk): http://www.cctokesteps.org (Select "find a walker" and then enter Patti Suler or Ostomy Association of the Houston Area)

Our June meeting for the Central Group will be on Monday, June 20th and we will be having a Roundtable Discussion on whatever topic that you may have a concern about. Hope to see you all on June 20th.



Paul Batchelder (team top fundraiser) and Patti Suler, CC Take Steps Team Captain

#### **Terry Marriott**

President, Ostomy Association of the Houston Area

#### **Northwest Group News**

A dozen people gathered to hear Physical Therapist Christy Bizzell speak about ostomates and exercising. Ms. Bizzell is a twenty-five year physical therapist, who holds a CFMT certification. The Functional Manual Physical Therapy discipline addresses the whole body and not just the injured area.

Up until just a few years ago, Ms. Bizzell had never worked with an ostomate except one colostomate. However, things changed when her friend and business partner underwent ostomy surgery. Right away Ms. Bizzell noted the lack of physical support and information from the hospital and staff for managing the fresh abdominal incision and ostomy area. She shared how she observed that patients were not even taught the basics of getting up out of bed, careful movement or basic strengthening strategies for recovery.

Ms. Bizzell acknowledged that all ostomies are hernias based on the nature of the surgery and she added that most ostomates will eventually experience an additional abdominal hernia. She discussed ways through exercise and core strengthening whereby hernia susceptibility can be delayed via proper muscular reinforcement.

There are many similarities between a cesarean section and ostomy abdominal incisions. Based on this factor, Ms. Bizzell offered one exercise program from the post partum care group and one from an ostomy support site. Both exercise programs are easily downloaded from the Internet and easy to follow. Each program should be carefully applied by building up strength over time and with repetition based on an individual's physical condition and recovery level. As always, consult your physician before beginning any new workout routine.

http://www.iasupport.org/factsheets\_home.aspx

[Click on the link for Ostomate Exercises]

http://exercise.about.com/library/blpostpartumabs1.htm

After Ms. Bizzell's presentation, we voted unanimously to elect all Board of Director nominees. Refreshments were provided by Suzanne H. and Carol J. Next month's speaker will be Polly Johnson from Convatec. Ms. Johnson will be presenting a program on summertime and the ostomate.

**Gay Nell Faltysek Tony Romeo** 281-446-0444 281-537-0681

#### **Baytown Group News**

Dr Boutros Kahla joined the group to present "Stomas—How to Live with Your Stoma, Maintaining a Healthy Stoma and Avoiding Hernias". Dr Kahla reminded the group that stoma is a surgically created opening that can be made almost anywhere on the body. Features of stomas include red color which indicates a good healthy blood supply, moist to the touch, they can bleed easily, and they have no feeling and no sphincter (voluntary control).

The opening for the output should come from the center of the stoma to allow for better drainage. If the stoma opening is below or at skin level, output is more likely to leak under the barrier. After surgery, the stoma can change size and shape over time and often continues to shrink. This can take days, weeks and sometimes even months. It's a good idea to routinely measure the stoma for the correct opening in the skin barrier until final size is achieved.

Parastomal hernia is one of the problems that can occur on the abdomen related to the stoma. Parastomal hernia:

- Is a protrusion of intestine through abdominal muscles around the stoma, and is seen as a bulge under the skin around the stoma.
- Can occur reasonably frequently, as the muscles around the stoma have been 'surgically weakened.' Muscles which normally provide support are deliberately incised open to allow the formation of the stoma, and they are often weaker.
- Sometimes supported with a wide belt or binder and sometimes needs surgical correction if it has progressed too far and is causing issues.
- A type of incisional hernia that occurs at the site of the stoma or immediately adjacent to the stoma.
- In literature review, occurrence in 1.8 to 28.3 percent of patients with end ileostomies, 0 to 6.2 percent with loop ileostomies, 4.0 to 48.1 percent with end colostomies, and 0 to 30.8 percent with loop colostomies. (Lower rates for loop ostomies are related to the temporary nature of most of these stomas and the short duration of follow-up.) Most occur within the first two years from construction, and studies with longer follow-up have reported higher rates.
- **Prevention is better than curing.** Everyone should take care to protect their abdomen. The surgery required to make a

stoma can weaken muscles so it pays to be extra careful when doing any form of lifting or exercise.

- Guard against the development of a stoma hernia with gentle abdominal exercises such as sit-ups and walking.
- Avoid heavy lifting and straining. Use a wheeled trolley to help move heavier items or get someone to help you.
- Weight management—stay within an appropriate weight range.

In June, we will have information about the new home medical equipment program that has opened at Walgreens pharmacy. We hope you will join us.

#### Cindy Barefield, RN, WOCN

281-425-2164

#### Youth Rally (Continued from page 1)

bowel disorders including things like an ostomy. Many kids at the camp have ostomies. It is a great camp that helps kids living with bladder or bowel disorders gain self esteem as well as a feeling of being normal in a way. When I go to Rally I feel normal and I am not afraid to hide my catheter every time I have to use the restroom. It is a great environment for kids with these types of things to share their story of how they deal with living with an ostomy or how they live with Bladder Exstrophy. I graduated last year and will be returning as a counselor in training this year." Caleb will also be speaking later this summer at the Central Group.

This year's Rally will be held in San Diego. Youth Rally supports about 2 of every 3 campers in full or part but costs have been rising. OAHA is donating the registration fees for Caleb this year. You can learn more about Youth Rally or make a donation at www.rolly4youth.org.

# OAHA Donation Supports WOCN Education

A gift of \$1,000 to the WOCN's Cycling for Scholarships' fund was made recently on behalf of the OAHA organization. After consideration, the Board of Directors thought it was important to encourage the education of ostomy nurses, especially since MD Anderson closed its school. This is another example of how your membership dues are used to further knowledge and education.

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 (713) 647-8029

cekennedy1@peoplepc.com

Charlene Randall, RN, CWOCN (713) 465-8497

Specialty Wound & Ostomy Nursing, Inc.

charlene@swoni.com

Pat Thompson BSN, RN, CWOCN (281) 397-2799

Pat.thompson@tenethealth.com

Catherine Walsh RN, BSN, CWOCN (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

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Name

Address Apt/Suite

#### **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: June 20, 2011

Program: Roundtable Discussion

#### **Baytown Group**

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

Place: Community Room in Lobby of San Jacinto Methodist

4401 Garth Road, Baytown Cindy Barefield 281-420-8671

Meeting: June 6, 2011

Contact:

Program: We will have information about the new home

medical equipment program that has opened at

Walgreens pharmacy.

#### **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

Meetina: June 21, 2011

Program: Guest Speaker: Polly Johnson from Convatec will

be presenting a program on summertime and the

ostomate.

## 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: June 20, 2011

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

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

### **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**

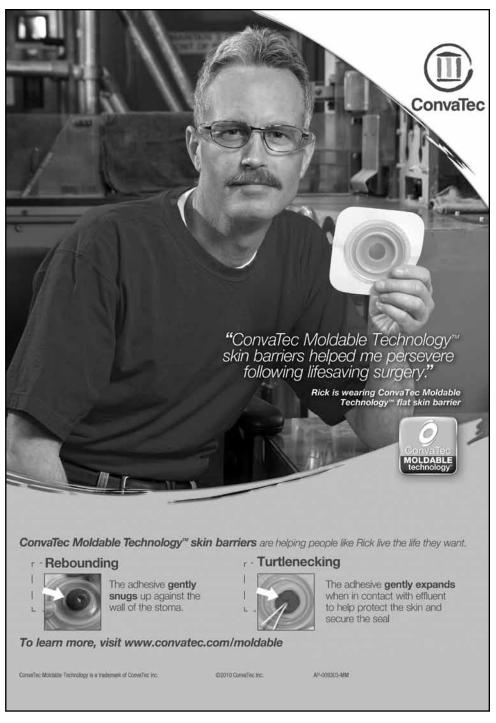
We are contacted on a regular basis by individuals who are in need of donated ostomy supplies. Consider donating ostomy supplies that you no longer use to assist your fellow ostomates in the Houston area. Please contact Mary Harle at 713-782-7864 with any questions.

#### **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:

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



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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 record  Colostomy Ileostomy Urinary Diversion Other:	□ Continent Ileostomy □ Continent Urostomy □ Pull-Through	□ Parent of Child with procedure	Membership benefits include: Monthly Support/Information Meetings, Social Events, Monthly Newsletter		
□ I would like to attend meetings with the <i>(please circle one)</i> :					
Central Group	Baytown Group	Northwest Group J-Pouc	h 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  □ ET Nurse □ Physician □ Newsletter □ Surgical Shop □ Website □ Other:					
I am interested in volunteering. $\Box$ Yes $\Box$ No					
I have enclosed an additional \$.	I have enclosed an additional \$ as a donation to support the association's mission of helping ostomates.				





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