



Friends of Ostomates Worldwide-USA

The Mission of Friends of Ostomates Worldwide-USA, a non profit volunteer-run organization, is to provide ostomy supplies and educational materials to help ostomates in need around the world.

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Joan Loyd Glenview, IL
(Warehouse Coordinator)
Ruth Salinger Bethesda, MD
Jim Spitzer Jamaica Plain, MA
Mario Pardo Norridge, IL

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Giancarla Pozzo, ConvaTec

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TennieBee Hall, La Jolla, CA
Marilyn Spencer, Euclid, OH
Marilyn Zuckerman, Bethany Bch, DE

Web Site www.fowusa.org

E-Mail info@fowusa.org

Send Supplies to:

FOW-USA Project SHARE
4304 Regency Dr
Glenview, IL 60025-5200

NEWSLETTER

Summer/Fall 2004

Volume XIII

President's Message

Dear friends of FOW-USA,

I regret that illness kept me from attending both a Saturday afternoon warehouse meeting and the regular semi-annual Board of Directors meeting on April 25th. I especially regret that I could not be there to greet our guest, Di Bracken, Vice President of the International Ostomy Association (IOA), who participated in some of the board discussions. I am pleased to report that I am up and running again.

An informal Saturday meeting at the warehouse was devoted to discussing various aspects of the warehouse operation in an endeavor to formulate a draft of procedures. When completed, a procedures document will make it easier for future warehouse volunteers.

Many thanks to Don Binder, our Treasurer, for chairing the board meeting in my absence. Mike Cherry of Hollister sat in for industry advisor Al Maslov who had a previous business engagement.

Thank you for continuing to send your donations of supplies to our warehouse. Our volunteers have been keeping busy opening and separating the supplies to prepare them for shipment overseas to the many needy ostomates. Mario Pardo reports that he has logged in some 644 cartons of donations from 39 States!

Many of you continue to ask questions about what supplies are acceptable to send us. A list can be found on the FOW-USA web site FAQ page, at www.fowusa.org, and in our brochure. Our warehouse coordinator would like to remind you not to send used supplies, open tubes of pastes or powders, liquids, or aerosol cans. She also requests that you not send loose items, medicines, or any items that are past the expiration date. Pouches without wafers or vice versa are acceptable if they are combined and placed in a box or plastic bag so that they do not scatter. U.S. parcel post is the least expensive shipping method.

Through the efforts of Joan Loyd we have secured the services of a new export shipping company in Chicago. They promise to expedite the shipping paper work. We expect that this will speed delivery of our shipments. Despite all our efforts, we are told that a shipment to Ethiopia can be expected to take more than two months.

(continued on page 2)

(President's Message, continued from page 1)

Along with contributions of your excess ostomy supplies, your continued financial support is needed to defray our warehouse expenses and the overseas shipping costs. Thank you for helping ensure that FOW-USA can continue its mission.

I look forward to greeting some of you at the UOA conference in Louisville, Kentucky, this August.

Fred Moore



FOW-USA Shipping

H. R. (Bob) Hall

Project SHARE Shipment Database Manager

A complete report of our shipments this fiscal year (August 1, 2003, through July 31, 2004) will be presented at the FOW-USA Annual Meeting in August, along with charts showing our shipping history since 1988. The final report for the year, along with the charts, will be printed in the Winter/Spring newsletter.

At this time, we are pleased to report that there have been eight shipments so far this year, amounting to more than 10,000 pounds of supplies. Individual shipments have been made to Argentina, Bolivia (2), Ethiopia, Indonesia, Jamaica, and Uzbekistan (2). The shipment to Ethiopia was to the Addis Ababa Fistula Hospital. (See, also, page 6.)



Mail your surplus ostomy supplies to:

**FOW-USA Project
SHARE
4304 Regency Dr**



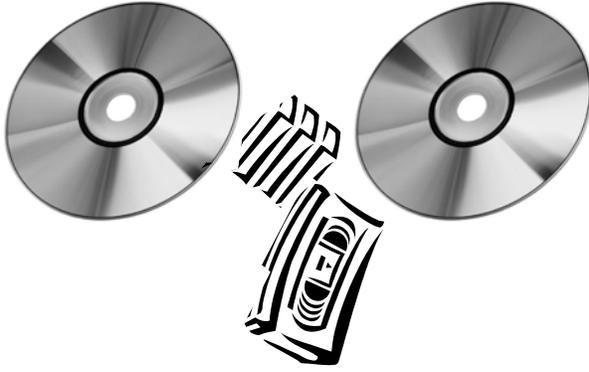
FOW-USA Annual Meeting

Join the officers and directors of FOW-USA at the annual membership meeting in Louisville, Kentucky. This year our meeting will be held on Saturday, August 7, from 9:00am to 11:15am.

Learn more about living conditions of ostomates in Bolivia, Panama, Costa Rica, Puerto Rico and Cuba, participate in a brief business meeting, and be present as the new officers are elected to serve the next two years.

The nominating committee has presented for election: President, Fred Moore, Oakland Park, FL; Vice President, Jim Spitzer, Jamaica Plain, MA; Secretary, Marilyn Mau, Park Ridge, IL; Treasurer, Mario Pardo, Norridge, IL; Membership Secretary, Ruth Salinger, Bethesda, MD.

Be sure, too, to visit us at the FOW Booth in the Exhibit Hall, where you can get literature and visit with FOW-USA directors. Learn more from them about our mission and service.



Presentations Report

Jim Spitzer

From October 2003 to April 2004, there were 8 requests for the SHARE tape, to present to local chapters. The cities making requests included Eugene, OR, Chattanooga, TN, Toledo, OH, Houston, TX, and Lewiston, ID. Some of the responses to the tape:

- ☐ “Well done video with good information”
- ☐ “Great borrowing procedure”
- ☐ “This touches the heartstrings.”

With the continuing evolution of video technology and formats, we have been reviewing the possibility of supplementing the VHS video tape offering with more updated DVD disks. Here are some comparisons of the two formats:

VHS Tapes

Advantage:

Most common format. Almost every person and organization has the equipment and ability to play VHS tapes.

Disadvantages:

Quickly becoming obsolete. All new video production is moving to DVD format.

Difficult to make copies. Copies of copies result in poorer quality rendition each time a copy is made.

Expense and inconvenience. Because there are a limited number of tape copies of the presentation, we must request that recipients mail the tapes back to FOW after the programs are completed.

DVD Disks

Advantages:

Preferred format for all new video production. (The shelves at Blockbuster are emptying of VHS tapes in favor of DVDs.)

Easy and inexpensive to make copies. The DVD disks and labels can be easily copied on a home computer. Copies have the same quality as the originals—no degradation as a result of producing copies. Copies of a DVD, including label and case, cost less than \$2 (probably less than \$1 within a year as blank DVD prices drop).

Convenience and wider distribution. Because we can make copies of the DVD cheaply and as required, we can send out DVDs without the requirement that they be returned after the presentation. The DVD stays with the recipient and can be further passed around to increase exposure to Project SHARE’s message.

Easier to edit and modify the content. Because the information on the DVD is fully digitized, the effort to edit and improve the presentation becomes more affordable and accessible than the older VHS tape productions, which require more professional studio type equipment to compose.

Disadvantages:

Not yet compatible for some persons and groups.

Although DVDs are the current and growing format for video production, VHS tapes have been around for a long time and most everybody has a VHS tape player and knows how to use it. DVDs are still early in their growth; lots of folks do not have DVD players yet.

Because there are advantages and disadvantages to both presentation formats, it would be prudent to make both types available and let the requesting person or group select which they prefer.

Because we are a small volunteer organization, we cannot personally present Project SHARE’s mission throughout the extensive network of ostomy chapters and community groups around the country. We will always depend on these prepared presentations and our companion brochures to be our ambassadors in this effort. Making the presentations more easily and widely available (and capable of being updated and improved periodically) will strongly influence the success of the organization. For any ostomate, the message of Project SHARE sells itself; getting the message out more widely and effectively is our challenge.



Supply Donors
5/16/2003-5/10/2004
 Ival Secrest,
 Membership Secretary

The list below gives the names of those individuals, chapters, suppliers, dealers, and health care agencies who have, according to our records, made one or more shipments of ostomy supplies to our collection center in Glenview, IL. Please note that most of the names have been taken from mailing return labels. We apologize for any misspelled or missing names. If you donated supplies during this period and your name does not appear in the list, please notify the Membership Secretary at FOW-USA Project SHARE, 4304 Regency Dr, Glenview, IL 60025-5200 or

membership@fowusa.org.

Thank You to all the supply donors.

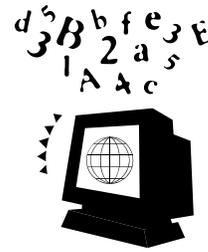
- AL** Francis Craddock
Joan D Crawford
East Alabama DME Inc
Robert L Miller
- AR** Twin Lakes Chapter
- AZ** James Azzinaro
Robert Hedge
Evelyn J Hitch
Frank R Kordas
Harold Martin
Mission Ostomy Chapt of Tucson
Gerald Shaughnessy
- CA** Jack Alexander
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Pheebee Brown
Canvasback Missions
Robert Currie
Veronica Daube
Jean Edge-Levins
Al Fogelman
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Sieglinde Glover
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Douglas Kreitz
Lois Kuechler
Lancaster CA Chapter
Jack H Leibler
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Eve Mobley
Nu-Hope Laboratories Inc
Ostomy Assn of Orange Co CA
Andy E Powers
San Diego Chapter
Henry Schach
Renee M Schoeopflin

- CO** SGV Medical Supplies
O Sharon
Marlene Sharp
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Sonoma Co CA Chapter
Mrs F Stanley
United Ostomy Association Inc
Frank Vanni
Woodley Family
- CT** Bill & Elaine Adams
- FL** Doris Adams
Apex Pharm Home Care Ctr
Bristol/New Britain Chapter
BMS ConvaTec
Fox Health Care
Judith Friedman
Marshall & Marilynn Glen
Hartford Ostomy Assn
NLCOA
So Fairfield Co CT Chapter
Cathy Sullivan
- GA** Able Medical Aids Inc
Sally Bahlman
Broward FL Ost Assn
W E Burr
C Carrol
Central Florida UOA
Barbara Cooper
Ferguson Enterprises
James Fockler
Barb Forest
Seth Grubman
Highlands Co Support Group
Robert & Connie Inman
Joan C Jones
Cy Kawalek
Joseph Kresse
Greater Orlando & Central FL Chapter
Riverside Paper Co
Chris Saretsky
Mark & Melody Sorrells
So Brevard Ostomy Assn
Frank Verdecia
- HI** Appalachian Medical Services
Sandra Conard
Billy Cruce
Georgia Med Equip & Supplies
Elizabeth R Hardage
Mrs E Jackson
Middle GA Ostomy Assn
- IA** Honolulu HI Ostomy Assn
- IL** Agri Drain
Marilyn Cech
Fifth Avenue Medical
Delores Herington
HCI Medical
Eloise Hughey
Medicap Pharmacy
Phyllis Norton
Spencer Iowa Chapter
Waterloo IA Chapter
- IN** Addis Spitzer Susman & Enders
George R Brace
L Bradley
Mr & Mrs W A Breckenridge
Mimi Celesky
R A Cole
Joan Crow
DuPage Chapter

- IN** Family Home Med Equip
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Carrie Gronau
Ed Gubman
Hollister Incorporated
Dr Robert Hurley
Fred Jacobsen
Jeannette Jenkins
N Karris
Mr & Mrs Louis Katz
Keefer Pharmacy
P Lane
Mark Drugs
Roy & Deborah Minnich
Nagel
Luis Navarro
N Suburban Chicago IL Chapt
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Rockford Ostomy Assn
The Shelk Family
Fred Shulak
Sterling IL Area Chapter
Kay Trevartheon
Helen van Poucke
The Wilkinson Family
- KS** Indianapolis Chapter
Madison Co IN Chapter
Ostomy Centre
Riverview Hospital
George M Rodgers
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- KY** Hutchinson Area Chapter
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Deborah Vaughn
- MD** William T Bonomi
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Ostomy Assn of Cape Cod
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Doris L Fern
Grayton Inc
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Irving Lipsky
Mortimer
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Shadi Reeder
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Susan Smith
Ostomy Assn of Springfield MA
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- ME** Tara Fouse
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- MI** Mac-Lin Medical Supply Co
Miller Drug
Edward H Stein
- MI** Ken Anston
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Phyllis M Bandfield
Bay de Noc MI Chapter

- MN** Binson's Hospital Supply
Borgess Medical Center
Karen Cole
Mary Decarteret
Malvin L Kotewicz
Macomb Co MI
Monroe Industrial Supply
Northern Michigan Hospital
C Priest
Sparrow Regional Medical Supply
Straits MI Area Chapter
Albert & Barbara
- MO** Albert Lea Area Ostomy Group
Diane Kemper
Mayo Foundation
The McDonoughs
Mrs D J Orpen
Elizabeth Parker
Janice M Schreck
Saint Paul MN Ostomy Assn
George Stoops
E A Sween Co
Jolene Van Horn
Willard Voight
Barb Wilczek
- MS** Dorothy Alexander
Emogene Burton
Garner/Wheatly
Lisa Hinton
Ostomy Care Center (OCC)
George Prsha
A Schlee
Bill Spieler
St Louis MO UOA
Treat
- NC** Parson's Discount Drug
- ND** Advanced Home Care
Burke Pharmacy Inc
Lisner
Margaret Wells
- NE** Williston ND Chapter
- NJ** Bryan LGH Medical Center
Peggy Christ
Omaha NE Chapter UOA
Milton Sharp
Westfield Pharmacy
- NJ** J K Alexander
Kenneth & Linda Aukett
Bergen County Ostomy Assoc.
Frances Brown
Burlington Co NJ Chapter
Barbara Byrnes
Byron Healthcare Ctrs
The Community Advocates
Marianne Cullinan
Evelyn Doyle
Essex Co Chapter
R Fahy Jr
Paula Gruccio
Martin Lonow
S Lopez
Charles McDewitt
Ruth Metz
Middlesex Co Ostomy Assn
Joseph & Carmela Morano
Ann Orenstein
Passaic Co NJ Chapter
Policastro Graphics
Shefford
Sterling Medical Service
Edward Sucorowski

- | | | | |
|-----------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | Diana Virano
Robert H Vlack
Loma Zellerkraut | | Keystone Medical Equipment
R D Kolash
Angeline Lauer
LRP Publications
Jack Marsh
Mercy Surgical Dressing Group
Wayne W Miller
Nazareth Medical Equipment
A Orenstein
Physicians Pharmacy
Punxsutawney Hospital
Reading Hospital/Medical Center
Cynthia Samuels
Doris Seldin
Brooks Slatcher
St Mary's Medical Center
Standard Medical Supply Inc
Tyree
Geza Verga
Norman D Yocom
Theodore Zernhelt Jr |
| NM | Candice Cotton
Natalie Keller | | |
| NV | Joan Crim | | |
| NY | Henry Adler
American Homecare Supply LLC
Ellie Burgess
Laura Deutsch
Barry Forman
Sylvia Friederich
Harriet Greene
Eliezer Hyman
F R Irons
Raymond La Bar
J Lawler
Mid-Hudson NY Chapter
Mark Nowak
Oneonta NY Chapter
Sandra Rosenthal
Schenectady Chapter UOA
Helen Siegal
Pearl Siegl
Anthony Snell
Snyder Pharmacy Inc
Nina Somers
Suffolk Ostomy Assn | RI | Van Guard Home Medical |
| | | SC | ANMED Home Care Services
Smith Wholesale Drug |
| | | TN | W B Johnson
Metro Medical Pharmacy
The Pouch Place
Tri-County Medical Supply |
| OH | Alpine Pottery
Mary Arnold Lang
Robert A Bacon Family
Jack Bergren
B & K Home Medical Services Inc
Cindy Boswell
Cleveland OH Ostomy Assn
Columbus Childrens Hospital
Debra Cooper
Findlay OH Area Chapter
Lynda K Frazier
c/o Shipping Manager
George Isoma
Joe Kauslick
Helen P Livingston
C R Pilcher
Portage Co OH Ostomy Group
Phyllis Rovner
Gregory Smith
St Ritas Medical Center
Steubenville OH Chapter
Sally Thompson
Louis & Rita Wray | TX | ACS Fort Worth Texas Division
Brian Arnold
Dallas TX Chapter
Houston Chapter UOA
Elizabeth Romero
Ralph Kaye-San Antonio Sun Satellite
WOC Nurses |
| | | UT | The Parthenon Company Inc
Walter C Rudolph |
| | | VA | A Mazzotta
Herbert Neiss
Northern Virginia Chapter
Kyong Pang
HME Warehouse
Mr & Mrs William G Williams |
| | | WA | Linda Bures
Choice Medical Supplies (Spokane)
Jones Pharmacy
Tacoma WA Chapter
Sharon & Jack Wood |
| OK | Stillwater-Ponce City OK Chapter | WI | American Cancer Society
Jean Boxrucker
Duluth Area Ostomy Group
Margaret Jone
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Alice M. Saben
Dick Simeth |
| OR | Black Oak Pharmacy
Douglas Co OR Chapter
Sherry Lessard
Rogue Valley Medical Ctr
Michael Sellers
Three Rivers Community Hospital
Patricia Young | WV | Sallie Pat Tackett |
| PA | Armstrong City PA Chapter
Beaver PA Chapter
Shirley Bilek
Jean Boland
H Braithwaite
Rodman Buggy
Marilyn Burnham
Jacob & Melinda Buurma
Chambersburg Ostomy Support
James Cunningham
Germantown Pharmacy
Johnstown PA Chapter | | |



Update on the FOW-USA Web Site

<http://www.fowusa.org>
H. R. (Bob) Hall, Webmaster

The FOW-USA web site is available for reference at any time. It gives the latest information on our shipments, volunteers, and addresses. Refer to it often at <http://www.fowusa.org>.

A new information ordering function has recently been added to the web site: You may order copies of our brochure, our latest newsletter, or our video program (in either VHS Tape or DVD format). Simply click on the name of the item you need on one of the yellow graphics on the site; these appear on the Home, About Us, Brochure, and Contact Us Pages. When you click on the name of the item you need, a web page with a fill-in form will appear. You need only fill in the requested information and click on the "Send" button to send an e-mail message with your request to the responsible volunteer. You will receive a confirming e-mail message immediately and an appropriate response from the volunteer later. Please be sure the information you give, in particular your phone number and e-mail address, is correct and complete, or we cannot fulfill your request. In the short time this ordering feature has been available, we have received a number of information requests, not only from the US but also from other countries around the world.

Also new on the web site is an FAQ (Frequently Asked Questions) Page. When you visit the site, take a look and get your questions answered. If you have a question that isn't answered there, you may ask it in a message to our general information e-mail address, info@fowusa.org. There are active click-points for this e-mail address on the Home Page and several other pages of the site.



Russian Recipients of FOW-USA Shipment



Letters of Appreciation

Provided by Florence Cohen

Thank you again for your kindness and generosity and for giving us once again a membership in WCET (World Council of Enterostomal Therapist). The medical publications that this provides us are so helpful in caring for the large number of very young patients in our fistula hospital. We do appreciate your continuing help.

Dr. Catherine Hamlin, Medical Director
Addis Ababa Fistula Hospital
Addis Ababa, Ethiopia

Thank you for giving us a year's membership in WCET (World Council of Enterostomal Therapy). The four medical publications we receive benefit us so much.

Dr. Naguib Einkhaily
Heliopolis, Egypt

I am in receipt of the book, *Wound, Ostomy and Continence Nursing Secrets*, containing material from 60 medical professionals. It is a wonderful book. As the Director of the Stoma Clinic in Bombay, India, I find the current information very useful. Since I run a school for enterostomal therapists for nurses from this part of the world I use the book in my teaching also. I thank FOW-USA for their interest in us.

Anjali Patwardhan, RN, ET
Director of Stoma Clinic
Director of School for Enterostomal Therapists
Tata Memorial Hospital
Bombay, India

Spreading the Word

Stuart Grossman, Vice President

When Louisville was selected for the UOA Conference, we said we would try to make it one of the best attended Conferences, EVER.

So, at this conference you will find very hospitable Conference Hosts, excellent room rates, great food at low cost, and exciting places to visit and tour.

Phyllis and I have tried to visit every UOA chapter within 250 miles of Louisville to encourage attendance at the conference. Since we are also dedicated to the cause of FOW-USA, we have used these visits to show the Project SHARE video.

Some of the groups we visited by press time for this newsletter were: Dayton, OH; Owensboro, KY; Indianapolis, IN; Nashville, TN; Murfreesboro TN; Clarksville, TN; Columbus, IN; Evansville, IN; Lexington, KY; Columbus, OH; Columbia, TN; Anderson, IN; Cincinnati, OH; and Paducah, KY.

Most Chapters we visited had never had anyone from UOA visit, nor did they know much about FOW-USA. Our trips were, we think, beneficial to the chapters, and we know they were beneficial to us as we got to meet so many ostomates.

**See you in Louisville.
Y'All come!**

JOIN UOA IN THE WINNER'S CIRCLE



42nd National Conference
United Ostomy Association, Inc.
August 4-7 • Louisville, KY

Application for Membership — Friends of Ostomates Worldwide –USA

Name _____	<u>Contribution for Annual Membership</u>	
Address _____	<input type="checkbox"/> Individual \$45	<input type="checkbox"/> Corporate \$300
City _____	<input type="checkbox"/> Family \$60	<input type="checkbox"/> Supporting \$300
State _____ Zip _____	<input type="checkbox"/> Contributing \$150	<input type="checkbox"/> Benefactor \$1000
Country _____	<input type="checkbox"/> Other	<input type="checkbox"/> Lifetime/ Memorial \$5000
Telephone (_____) _____	<input type="checkbox"/> Chapter, Group or Association—\$1 per member (\$25 minimum, \$150 maximum)	
E-mail Address _____		

All donations to FOW-USA are tax deductible.

Total Amount Enclosed \$ _____

Make checks payable to FOW-USA

Please mail to: **Donald Binder, Treasurer, 400 North June St., Los Angeles, CA 90004-1002**



Ostomates Struggle For Normal Life

According to an on-line article published on May 10, 2004, in *The Jakarta Post—The Journal of Indonesia Today*, ostomy patients in Indonesia experience many of the same fears, doubts, and concerns as those of us in the United States.

The Indonesian Ostomy Association (InOA), associated with the Indonesian Cancer Association (YKI), provides mutual aid similar to UOA Chapters. A spokesperson estimates there are approximately 500 ostomates in Jakarta alone, with around 100 new cases occurring every year. As many ostomates are not listed with InOA, nationwide numbers are not known.

The difference in care between USA ostomates and those in Indonesia becomes clearer when we read that the country does not produce ostomy pouches. The wife of one patient was quoted as saying, “It’s very difficult to find the bags, even if you have a lot of money, as they are available only in limited quantities.” An InOA member stated that Indonesian ostomates depend upon donations from countries such as the United States and Australia.

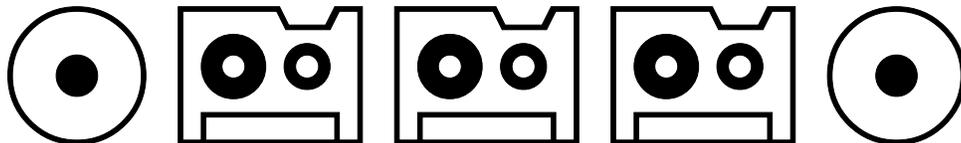
FOW-USA is pleased to be able to help these ostomates in need.

TennieBee M. Hall, Editor
8585-7 Via Mallorca
La Jolla, CA 92037-2585

Summer/Fall 2004 NEWSLETTER



Need a Chapter Meeting Program?



Project SHARE Video and DVD are Available

FOW-USA has a presentation about Project SHARE (Sending **H**elp and **R**ehabilitation **E**verywhere) in video tape and DVD formats for use by UOA chapters or other groups. The program is approximately 12 minutes long, and explains the purpose and the workings of Project SHARE. Learn more about how FOW processes ostomy supplies to ship to needy ostomates in other countries.

Send loan requests to **Jim Spitzer, 41 Morton St. #27, Jamaica Plain, MA 02130;**

phone 617-524-3955; fax 617-452-8505

or go to FOW's web site,

<http://www.fowusa.org> and click on the Tape/DVD yellow graphic on the Home page.

Please specify date wanted, a complete phone number or fax number, and where to mail the presentation. Allow at least 3 weeks lead time from the date requested. The tape is to be returned after the showing.