

The Twenty-Five Years of Project SHARE 1985-2010

By Lou Wray

In the early 1950's ostomy surgery was in its infancy. Pioneer surgeons grasped hold of this developing life-saving technology and began to gather information and techniques specializing in colostomy, ileostomy and urinary diversion surgeries. The performance of such surgeries expanded significantly by the 1960's but one essential element was still lacking. That missing link was in the rehabilitation of the ostomate following surgery and their problems in trying to return to a normal productive lifestyle. In those early days, educational materials and ostomy appliances were scarce which led to many new concerns such as diet, odor control, social acceptance, leakage and often, total despair.

While ostomy surgeries expanded, medical professionals became increasingly proficient while the post-operative rehabilitation of the patients progressed very little. Fortunately, a nucleus of medical professionals and ostomates assembled in Cleveland, Ohio in 1962 and organized the United Ostomy Association (UOA). The UOA mission was to organize self-helping local ostomy chapters throughout the United States and Canada to exchange ostomy management ideas and educational materials. The pre-op and post-op visits to new ostomy patients became a distinguished trademark of UOA's outreach. By 1980, UOA had grown to a membership of over 60,000 and had organized over 600 local chapters in the US and Canada.

As doctors, nurses, and medical professionals traveled abroad, especially to developing third world countries, they returned home with pathetic stories of the horrible conditions endured by patients following ostomy surgery. In the very early 1980's several UOA chapters and individual members began soliciting for and gathering ostomy supplies and sending them to places known to be in great need such as Mexico and Colombia. This trickle of supplies by pioneers Gary Ponti, Chuck Beadle, and Maria Siegl soon grew so rapidly that requests for aid exceeded all expectations. Visionaries such as Archie Vinitsky, past UOA president and a founder and first president of the International Ostomy Association (IOA), began to urge UOA leaders and equipment manufacturers to recognize the terrible plight faced by ostomates abroad and to share our wealth with less fortunate ostomates worldwide. Canada had already been collecting and shipping supplies led by Al Porter of Hamilton and Maria Siegl of Toronto. Their collection center was located in an elementary school building in Hamilton, Ontario.

In 1980, the IOA, a coalition of some 30 nations, applied for a new charitable corporation status in the state of New York to be named the Friends of the International Ostomy Association, Inc. (FIOA). The stated purpose of FIOA was "to seek dues and donations to support the work of the IOA in promoting the health and rehabilitation of ostomates." IRS assigned FIOA the Employer Identification Number 04-2733846.

Then on June 9, 1981, two former UOA Presidents, Ed Ward and Lou Raffio, applied to the Internal Revenue Service for Recognition of Exemption under section 501(c)(3) of the Internal Revenue Code. FIOA later received recognition and approval of tax-exemption from IRS. The IOA Board of Directors had set up a program to help ostomates world-wide and named it Project SHARE (Sending Help and Rehabilitation Everywhere). However, with neither IOA nor UOA having funds to support Project SHARE, the FIOA was formed as a fund-raising non-profit

organization to allow donors tax exemption for donations of products and monetary contributions.

Product donations and membership dues were limited between 1983 and 1986 and shipments abroad were limited until sufficient funds were raised to pay for shipping expenses. Since IOA declined direct client involvement with Project SHARE, the entire program was virtually absorbed totally by the USA and Canada.

Then, in 1981, the USA and Canada established Friends of Ostomates Worldwide (FOW) and pledged to actively carry out and expand the SHARE project successfully. Both the US and Canada then decided in 1985 to incorporate in their own countries to comply with tax exemption statutes in each nation. Thus was born Friends of Ostomates Worldwide-USA (FOW-USA) and Friends of Ostomates Worldwide-Canada (FOWC).

At IOA's 10th Anniversary conference in August 1985 and UOA's annual conference held consecutively in Anaheim, CA, leaders of both organizations met informally to discuss worldwide ostomy matters. Interest and concern continued to mount that foreign aid was greatly needed. Then at UOA's Toronto conference in 1986, several past UOA presidents were invited to a special meeting to discuss more active involvement with FIOA(US). It was agreed that the establishment of a collection center and a volunteer group to pack supplies was priority number one. Soon after the conference, Maria Siegl succeeded in contacting Steve Lutz of the Cleveland Ostomy Association and learning of his willingness to provide space in his machine shop located in North Ridgeville, Ohio.

The period 1985 through 1987 was largely involved with organizing and planning FOW-USA's Project SHARE. The drafting of by-laws, incorporating as a non-profit tax exempt organization in Ohio and fund-raising and publicizing the SHARE program were necessary to launch our real mission. It was decided to enlist volunteers from northern Ohio UOA chapters to meet the collection site needs.

Steve's machine shop was cramped, noisy, and limited in size, but nonetheless gave us a foothold and an address we could call home. The response to our appeals for clean unused appliances was over-whelming and we soon ran out of space. Again, Steve helped us by moving his business to an Elyria, Ohio site providing more room for further growth and expansion. We collected and shipped from Elyria for several years before relocating once again to a smaller warehouse in North Ridgeville, Ohio.

Lou and Rita Wray began searching for a possible warehouse in the Akron, Ohio area which might be more central to packers and highway transportation. They succeeded in acquiring a large secure site in Akron, possessing all of the facilities hoped for plus being offered free of charge. This warehouse was located adjacent to the Goodyear Rubber Co.'s huge dirigible hangar. The logistics company's site even furnished free trash disposal, heat and electricity as well as loading docks and personnel to accept incoming supplies and assisting outgoing shipments 6 days a week. As was the case with Steve Lutz, we continued to be blessed with minimal expenses incurred by Project SHARE. The packing crew of five consisted of the Wrays, Marilyn Spencer (RNET), John Snyder of Finley, Ohio, and Bob Taylor, a non-ostomate

friend of Lou and Rita's. Marilyn was instrumental in streamlining our packing procedures as well as being our shipping coordinator studying requests for supplies from abroad and arranging responsible reception in the countries to whom we shipped. We have been very careful to make sure our donated products were protected from foreign black markets by dealing only with trusted medical recipients in overseas distribution of our shipments.

The number of countries served and the tonnage of supplies shipped grew by leaps and bounds. For example, in the period from July 1989 to January 1992, over 15 tons were shipped to 17 different countries at a cost of \$30,000 (about \$1.00 per pound). FOW-USA solicited financial donations as well as product donations and our membership grew to nearly 300 by 1993.

The International Association of Enterostomal Therapists (IAET) has always been most supportive of Project SHARE. The greatest donors of ostomy supplies have come from UOA chapters, hospitals, pharmacies, manufacturers and individuals. Ostomy manufacturers have helped in many ways such as Hollister, Inc. supplying all shipping cartons free of charge. About 95% of FOW-USA's income is dedicated to shipping costs.

FOW-USA is managed by an elected Board of Directors which meets twice annually with everyone paying their own expenses. The Board also holds an annual open membership meeting at UOA's annual conference each year. FOW-USA always exhibits and promotes Project SHARE at UOA conferences.

In 2001, we were notified that our warehouse in Akron was needed by the local owners to accommodate their growing business. Thus began a search for a new warehouse location. Appeals were made to UOA chapters and members seeking their help. Fortunately, the North Suburban Chapter located in the Chicago suburb of Glenview, IL volunteered to offer their services. An active chapter leader and a SHARE supporter, Joan Loyd, agreed to expedite the transition from Akron to Glenview and did a wonderful job.

The new quarters were smaller yet very clean and suitable to accommodate the continuation of SHARE. The large UOA chapter also offered a greater number of volunteer workers to handle packing and shipping. About this time, Canada had chosen to become FOW-Canada and expanded its SHARE program with three Canadian collection and shipping sites. Thus the outreach from North America continued to grow.

Not only had SHARE's quantities skyrocketed but the quality of our shipments also greatly improved. For example, we included a variety of items such as manuals, films, Ostomy Quarterlies, tapes, bandages, and even disposable cameras asking recipients to send us pictures of their received shipment. We also made sure that pouches and flanges matched by type and size. We also catered to the specific needs for the destinations we were packing for, as an example, some countries perform little or no urinary diversions so we would not include any urostomy supplies to them. Some nations have a history of larger or smaller stoma size, so we would try to pack sizes appropriate to their needs. If shipments were arranged for hot equatorial destinations, we were careful in sending stomahesives. Thus quality as well as quantity have become a trademark in the Project SHARE program.

Rental costs for our Glenview site along with a shrinking number of sorting and packing volunteers caused FOW-USA to once again look for a new location to call home. This search was culminated when Louisville, Kentucky under the leadership of Stuart Grossman volunteered to maintain and expand our mission. We have again been fortunate to continue our outreach into the future. Congratulations to Louisville for the fine job they are doing.

We realize that an occasional delivery of ostomy products to any one country is only “a drop in the bucket” but we believe that many additional benefits have resulted. It has encouraged the establishment of ostomy self-help groups in recipient nations, has broadened ostomy literature distribution, has led to training of ostomy therapy nurses and in several instances has led to the manufacture of ostomy supplies in their own country. The success of Project SHARE has also encouraged the growth of similar programs in Europe, Asia, and South America.

And thus we look forward to the next 25 years to the continuation and growth of SHARE. Hopefully, the requests for our assistance may diminish slightly as national become more familiar with helping themselves with improved education and products. After all, we in America and Canada were in similar straits just a few years ago and today are in a position to share our good fortune with others worldwide. The FOW-USA Board of Directors deeply appreciates all of the volunteers who have contributed so much in our brief 25 year program. The monetary donors, the product donors, the packers, the manufacturers, the ET's, the local UOA chapters have all been instrumental in our growth. You should all feel proud of your humane outreach to less fortunate ostomates throughout the world.