



# OSTOMY NEWS NOTES



**PROMOTING OSTOMY ADVOCACY IN THE PHILIPPINES**

OSTOMY NEWS NOTES PHILIPPINES QUARTERLY PUBLICATION

ISSUE # 2 - VOLUME III APRIL - JUNE 2011

1ST ASPOA  
REGIONAL  
CONFERENCE

DAVAO  
OSTOMY  
ASSOCIATION

UOAA RENO  
CONFERENCE  
NEWS

20 / 40  
FOCUS GROUP

IN REMEMBRANCE  
OF DATO JOHN CARDOSA

NATIONAL FEDERATION OF  
OSTOMATES OF THE PHILIPPINES, INC





# Mailbox



*Got something to say about the newsletter or ostomy care in the Philippines in general? Write in and tell us! Email us at [ostomynewsnotes@gmail.com](mailto:ostomynewsnotes@gmail.com) to share your views and comments with your fellow readers.*

## ULCERATIVE COLITIS FLARE UPS VS. REMISSION

Letter 1:

I was taking three Asacol of 400mg each daily. I've been in remission since 2009 up until now. I quit taking Asacol all together at that time. About three months later and having changed doctors, I was told not to quit Asacol as it acts as a protective drug to remain in remission. I chose at that time to take one 400mg tab daily, and have done so since, without any problem, and remain in remission. However, you know what's one person's cure for UC isn't for another.

Letter 2:

It's interesting to know how GI doctors differ on what is "right" to do. My GI wants to take me off it completely then I'll mention just staying on just one pill or going back to one or three a day if I start to flare after being off. Thank you again!

Letter 3:

When I was in a long remission, I was able to taper down on Colazal from the maximum dose. I am getting into remission now with Cimzia and will probably start tapering Apriso after my next GI appointment next month.

Hello, I had a GI appointment and the doctor thinks that since 6mp is working so well, it did the trick and I am getting myself back in remission. I can now try tapering off Asacol. I'm on nine pills a day so will go to six pills a day for a few months then three pills a day for another few months.

Has anyone tried this and NOT gone into a flare? I really don't need another flare again....

## CONSTIPATION

HI,  
I grew up with IBS and in my early 40s was diagnosed with UC. I haven't dealt with constipation since the diagnosis. I'm on 2000mg of Pentasa daily. I don't have any

active UC. These past couple weeks though I've dealt with constipation and it's been so severe, that it has doubled me over in pain. I've used OTC pills and when it was horrible, took a glass of prune juice that had me going to the bathroom the rest of the night. Not to mention gas build-up until it finally got completely out of my system. I'm starting to wonder if the Pentasa dose is too high, as I was on 500mg 3x daily until a few years back, when we switched to one dose per day. The it started that there was far more success with 2000mg daily, then with 1500mg, so my doctor went with that dose. I haven't had any issues until lately, which is why I'm thinking its the dose of Pentasa. Has anyone else dealt with this?

Answer:

Are you eating any fibre? It is critically important to get enough fibre in your diet. If you must use a laxative use a non-stimulant one like lactulose. Don't let it go too long. The Pentasa is keeping you symptom free.

## IN REMEMBRANCE OF DATO JOHN DAVID CARDOSA

Dato John Cardosa passed away in the morning of October 6, 2011 due to lingering illness. He is survived by his wife and children.

The story of Dato John David Cardosa goes a long way as he has touched a lot of people's lives merely by the energy and passion in the way he has lived life and witnessing to it.

He reveals that he had made a vow in the year 1972 when he was given a death sentence by his doctors then. It was then that he made a vow to serve his fellowmen for as long as he is able to do. It inspires everyone to know that he has been faithful in his promise to our Lord and Master who have actually gifted him with 38 years more of a well lived life.

When Dato John was still alive, he would say "every additional day I am alive is a bonus, it is the reason for me to serve Him through my fellow ostomates and cancer survivors."

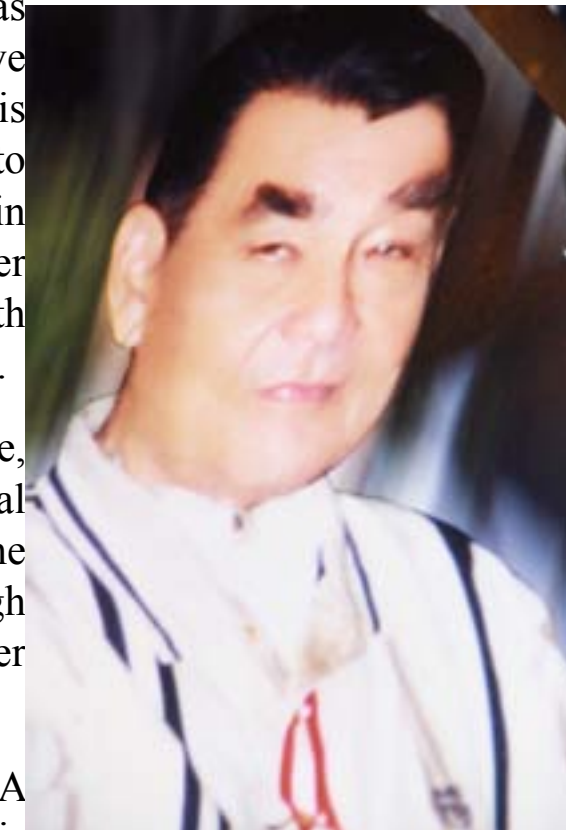
Dato John was a long time AOA President for 3 year term in his own right. In 1998, the then President Tahir of Malaysia, was unable to travel to IOA Executive Meeting due to illness. Dato John

was deputized to attend in his stead. He was first elected as AOA President in his own right in 1999 and served for 3 years up to 2002 during the Manila AOA Conference. At the House of Delegates Meeting in Manila, Dato John proposed Dr. Harikesh Buch of Mumbai as the AOA President for the term of office 2002 to 2005, but Dr. Buch refused to accept this position unless Dato John remained on the AOA Council as Secretary and Treasurer. He had to agree to those terms and Dr. Buch, was elected the AOA President, while John Cardosa served as Secretary and Treasurer of the AOA. In 2005, at the Bangkok AOA Conference, he was again voted in as President of the AOA. So in actual fact, Dato John has served for 3 terms.

He would have not served for these long if not for the charisma, the smile and the love he had

for people.

Rest in peace our dear friend Dato John David Cardosa.





## Davao Ostomy Association

Bob Hewson

An Australian, living with his Filipino wife and two children in Catalunan Grande Davao City, went to Australia for an operation [urostomy] to remove his cancerous bladder. On his return to the Philippines, he found there were two others in his area in similar situations [colostomy] but unable to afford their appliances. One of these was his neighbor of over three years, Mae. While he and his wife known her well, they had not known about her situation until then. After reading about the Australia Fund and their activities, he contacted them on their behalf of these people, to check the possibility of supplying at least some product.

On hearing about these two people, the Australia fund chairman, Mr. Gerald Barry decided he would do what he could on this occasion, although he would be unable to assist full time without a stoma association in Davao. He organized product through his resources and subsequently supplied a large quantity of appliances that would be able to assist what has now become three people for about three months. Appliances in the Philippines are relatively cheap but the cost is about the same as the daily wage of those that are lucky enough to have employment, and the unemployment in this area is very high. He also offered suggestions as to founding a stoma association in Davao so that donated appliances could continue to be supplied on an ongoing basis.



Estela Arnaiz had been using a home made two piece product. Her flange was a plastic coffee lid with a hole, taped over her stoma and a plastic bag tapped to that. This in no way was effective in reducing the odor which was obvious to those that were near to her. Angela Diligencia did not use of a plastic coffee lid but also used plastic shopping bags directly tapped to side for most of her 22 years. Mae Manigos was only able to purchase small quantities of product and therefore she needed to keep cleaning and reusing the same appliance over and over again.

There was also a gentleman in the area that had recently received a colostomy, but unfortunately, he passed away shortly after his operation due to infections, possibly due to not having adequate appliances.

While the donated product has brought smiles to these three faces, the supplies will only last a few months. The suggestions of Mr. Gerald Barry's are now being implemented and they are now trying to organize a stoma association in Davao in order that the Australia Fund will be able to supply product to these and other needy people in Davao for a long time to come.

These three people would like to express, through this article, their overwhelming thanks to all that have assisted in getting this product to them, with a special thanks to Mr. Gerald Barry, the chairman of the Australia fund.

## Ostomates in Focus

*Mae Manigos has had a long run with her problems, it started in England in 2000 when she had a total hysterectomy due to an ovarian cyst and during the operation they found Cancer in her large bowl and gave her a reversible stoma. After 3 years of chemo then some radiation therapy she stopped all treatment and returned to the Philippines with her husband [she thought, to die]. In May 2006 they found more cancer in her small intestine and removed it to make her fifth operation for cancer. He husband died later that same year. Her doctor told her in August last year that she now has diabetes and she also may have cancer in her bladder, if it needs to be removed it will make her a dual ostomate. Since her English husband's death she has found it very hard with little income from her part time work. She has now left work due to illness and can not afford to purchase her necessary needs.*



*Mae, delighted with her donation*



*Estela's face tells the whole story*

*Estela Arnaiz, 49 was diagnosed with an ovarian cyst in 2006 but could not afford the operation. In March this year she had sever abdominal pain and received emergency surgery to remove her two ovaries along with a 6cm cyst.*

*While they were operating they found her intestines were stuck together (her description) and she was given her colostomy.*

*Estela, along with her husband own and run a Sari Sari store [very small general convenience shop] where*

*the daily turnover would be well under 500 PHP about US\$10 and the take home very much less.*

*Her supplies will take her a long way from her home made two piece appliance of a plastic coffee lid with a hole for her stoma, tapped to her belly. She offered a native [live] chicken as her appreciation for the donation. Her husband is even more happy with her new situation as the appliances have an odor filter built in, something not standard on a plastic shopping bag, her old collection device.*





Lions for Stoma Care ( LFSC ) project is an initiative of Lions Clubs of Modena Wiligelmo & district 108Tb, Italy. It was started in 1999 by Prof. Carlo Pezcoller, a Colorectal Surgeon from Polyclinic & University Medical School Hospital of Modena.

Under this project, doctors from many countries of Asia & South America are invited to Modena, Italy & are trained in different aspect of Stoma Care by Prof. Carlo Pezcoller & his team & members of International Travelling Teaching Team ( ITTT). With the help of these doctors from different countries, ITTT then organises short course of 5-7 days of training in different aspect of Stoma Care in their countries & where possible helps them to establish an Ostomy Association as well & supports them to grow.

ITTT consists of Prof. Carlo Pezcoller, a Colorectal Surgeon from Modena , Italy; Dr. Harikesh Buch, Surgeon , an Ostomate as well as Past President IOA from Mumbai, India; Dr. (Mrs.) Silvia Ebalginelli, Surgeon from Italy; Dr. Fernando J. Soria, Colorectal Surgeon, from Cordoba, Argentina, Dr. Jorge Medina Gutierrez, Colorectal Surgeon, from Asuncion, Paraguay; Dr. Hugo Heredia, Colorectal Surgeon, from Santa Cruz, Bolivia ; Mrs. Louise Forest Lalande, ET & President WCET, from Montreal, Canada; Mrs. Rosine Van den Bulck, ET & President ECET, from Bruxelles, Belgium; Mrs. Beatriz Reynoso, ET, from Cordoba, Argentina; Ms Di Bracken, IPP, IOA, from Toronto, Canada and our beloved friend Dato John Cardosa who passed away last year .

#### Training in June 2011:

From June 6th to June 10th 2011, a training course was organized by Prof. Carlo Pezcoller and his Team of Dott. Afshin Heyari, Dr Silvia Ebalginelli, Dr. Castagnetti ,Dr Roberto Aloesio, Mr Fernando Vitale Mr De Salvo, Mr Carmine Marra (ET) along with Dr Harikesh Buch,

Surgeon & IPP IOA, Mumbai, India & Mrs Louise Forest Lalande, WCET President from Montreal, Canada ( members of ITTT ) in “Nuovo Ospedale Civile S. Agostino – Estense”, Modena, Italy with financial support by Lions Club of Modena Wiligelmo & district 108Tb, Italy.

Dr. Jose Victor Rodriguez Mendoza, from San Salvador, El Salvador; Dr. Srinivas Chunduri, from Bangalore, India; Dr. Roxas Manuel Francisco from Manila, Philippines Dr. Moldavan Cosmin, from Bucarest , Romania were invited & trained in various aspect of Stoma Care.

This training included Anatomy & Physiology of G.I & G.U. Tract, Indication of ostomy surgery, Stoma marking, Pathology of various diseases , Complications of Stoma & its management, Creating a good stoma, Establishing a new Stoma Clinic, Methods of managing various types of stoma including Irrigation, Visitor Training, What is IOA , What is WCET, Collaborations of health Care Professionals & Ostomy Associations, Ostomy products, Clinical aspects of ostomy management, Nutrition for Ostomates, Psychosocial & sexual aspect of Ostomy patients & Establishing & sustaining new Ostomy Associations etc.

#### My Personal Thoughts

The trip to Italy was very moving and special for me. More than just a stoma course, it made me more insightful and understanding about the deep concerns of ostomates and the intricacies of ostomy care. The members of the Lions Club Modena welcomed us with such hospitality and warmth, filling our already busy schedule with daily culinary and cultural tours around Modena. It was my first time in Italy, so I got to truly appreciate it's rich history and culture at a very intimate level - much more than if I had gone on the regular tourist beat. I will always be grateful to Lions Modena, Carlo Pezcoller, and Hari Busch for giving me such a wonderful experience. I hope to repay this by being a staunch and leading advocate for stoma care in my country, the Philippines.

By: Dr. Ramy Roxas

President: Philippine Society of Colon and Rectal Surgery



Dr. Ramy Roxas and fellow surgeons during the training for ostomy care in Modena Italy.



## National Federation of Ostomates of the Philippines, Inc.

In support and partnership with the Department of Health, we have started organizing the National Federation of ostomy associations all over the Philippines. The Secretary of Health Dr. Enrique Ona has been supportive of this advocacy in order to empower support groups and associations all over the country. Different government hospitals from Manila and from the provinces coming from the north and south of the Philippines have signified their interest to be affiliated with the National Federation.

#### Mission:

Help ostomates understand their problem and have the knowledge to take care of themselves; getting confidence by adapting to their current situation and returning to normal life; creating opportunities for mutual support among support groups and fellow ostomates all over the country

#### Vision:

Empower Filipino Ostomates to live a quality of life and promote this advocacy through effective and efficient ostomy support care groups

#### Activities of the National Federation:

1. Hospital and home visits
2. Stoma Clinic and Hospital Ward referrals
3. Orientation Program for new members
4. Social and Recreational Programs
5. Stoma Care Workshops
6. Drop-in and Inquiry Services
7. Interest Class
8. Volunteer Training
9. Counselling and Case Management

*The NFOP, Inc is calling on graphic artists, illustrators, design students, and design experts to join its logo design contest on the theme, “Empowering Ostomy Health Care in the Philippines.”*

*The logo design contest is open to all Filipinos. The entry must be able to illustrate the theme, as well as the slogan, “Every Ostomate is a living example of a quality of life.” The theme and slogan articulates NFOP’s commitment towards empowering ostomates back in society. Email your entries to: [ostomynewsnotes@gmail.com](mailto:ostomynewsnotes@gmail.com) - Deadline May 15, 2012*





## The 1st ASPOA Regional Conference, Tehran, Iran

The 1st ASPOA conference was a successful meeting where the delegates present experienced the hospitality of our Iranian hosts. There were 7 countries namely Australia, Hong Kong, Iran, Japan, Korea, New Zealand and the Philippines that took part in the event. During the House of Delegates meeting, the following were elected as the new set of officers for the Asia South Pacific Ostomy Association.

President – Mr. Barry Maughan  
Vice President – Dr Harikesh Buch  
Treasurer – Mr. Richard McNair  
Secretary – Mr. Ronaldo Lora



## Our Visit to the Iranian Ostomy Society in Tehran, October 2011

Astrid Graham

Our trip to Iran was a very pleasant surprise. Many people we know were worried that we were going and quoted negative stories to us. We had a wonderful time and no problems. Our visa was only for 7 days (I had missed reading this!), but our stay and airline ticket was scheduled for 10 days. So we had to go to the Police and Immigration Office in Tehran to get an extension. There were paperworks involved and sitting around, but the extension was issued without any problem. Special thanks to Maryam for all her help.

We went to Tehran at the invitation of the Iranian Ostomy Society's President to take part in the 1st Asian South Pacific Ostomy Association (ASPOA) Conference. The Iranian people were great, the conference was a super success, food was plenty and weather could not have been better, no rain. We met people we have known for years and others for the first time. All the people were very nice. The conference had many interesting topics and we attended most of them. i.e. Type of ostomy & their indications, Correct construction of an ostomy, Enterostomal care, Ostomy sitting & discharge planning, Complications of intestinal ostomy, Non surgical management of ostomy complications, Genetic in rectal cancer, Fecal diversion, Stoma & nutrition, The effect of ostomy on sexual relationship, Ostomy managing products & accessories in Iran, Rectum & colon irrigation, Urostomy & nephrostomy, Gastrostomy: indications & care, Surgeon & Enterostomal collaboration with ostomates, Welfare policies for ostomates, Techniques in sphincter preservation, Rectal cancer and ostomy, Surgical management of ostomy complications, Appendicostomy, Ostomy in paediatrics etc.



go



*Dr. Vafai showing one of the presents Doug and I brought from Canada*

The idea for the Iranian Ostomy Society (charity) was formed in 2001 by Dr. Mohammad Vafai, veteran Iranian surgeon and current President of the Society. I started to help Iran with ostomy supplies two years later as no other country was able to help. It was not easy but I did have success. The society has an ostomy house that is out of this world. Three levels with an outside courtyard in back.

There is a basement where ostomy supplies are stored on shelves. I was able to recognize some of my writing on the boxes. I was honoured when they told me that the storage room will be named and dedicated to me. The street level floor is for ostomates to receive help. It has an office, a large comfortable sitting area and a room with two beds (divided by curtain) where a nurse provides help. Patients receive daily medical care and attention to their problems. Also, Ostomy bags are given out by the nurses of the Society. There are about 30,000+ Ostomy patients in Iran comprising of; 70% Colostomy 20% Ileostomy and 10% Urostomy – of which 3,500 are members of the Iranian Ostomy Society.

Each Society Member has a small picture glued into a large membership book. Color coding shows what type of ostomy and a black dot is added when the member is deceased. There is a huge filing cabinet with color coded files, one for each member. The house has lots of space and is a well organized operation. This house was donated by a very rich man who died. The Society is very grateful and lucky having such a beautiful house.



## EDITORIAL



The year 2011 went by so fast that there were a lot of blessings to be thankful for in the promotion of ostomy advocacy in the Philippines.

Finally, I have touched base with the secretary of the Department of Health of the Philippines in order to further the quality of life for ostomates.

There were definitely struggles but the results were beneficial reaching out to new ostomates from far flung provinces who preferred not to expose themselves but now has the confidence to live a little more confident and trusting that life with an ostomy bag is a chance for second life. There are support groups sprouting in pilot government hospitals but the problems is sustaining the work since surgeons have to give their time apart from their official time of work and they do not have that luxury. There is also a scarcity for wound care and ostomy nurses who could be a big help to assist new ostomates that may have a lot of questions and problems. In the meantime, ostomates can act as visitors to help bridge this gap.

I thank the Friends of Ostomates - USA who has been instrumental in sending 1 pallet of ostomy

appliances. I also received from Mr. Richard McNair from the Federation of New Zealand Ostomy Societies Inc 2 boxes of ostomy appliances that were distributed to the Philippine Ostomy Association and another to the newly formed support group of the Wound and Ostomy Care Clinic of the National Kidney Institute.

We look forward to a busy year of 2012 focusing on ostomates who are far from the city and living in provinces as the Philippines is a geographically made up of 7,107 islands.

Happy New Year to All.

Ronaldo - Editor



The 20/40 Focus Group Desk is a structured set-up of young volunteer ostomates coming from the countries and regions of Asia. They establish themselves as a satellite group with its own rules and regulations that is in constant communication with the 20/40 Focus Asian representative. The desk will fall under the umbrella of the present ostomy association of the particular country. The reason behind forming a satellite desk is decentralization. It can propose activities other than the set guidelines proposed by the 20/40 Asian representative. In this way, the activities are acted upon and implemented according to one's cultural inclinations and background. **LET US HELP YOUNG OSTOMATES BUILD FOCUS**



Visit [ostomyasiasouthpacific.org](http://ostomyasiasouthpacific.org)

The official website of the  
Asia South Pacific Ostomy Association



Cover Page:

The Ostomy News Notes presents ostomates from Tehran Iran during the 1st ASPOA Regional Conference. The women in the photo are ostomates and volunteers who helps the Iranian Ostomy Society in all its endeavors.

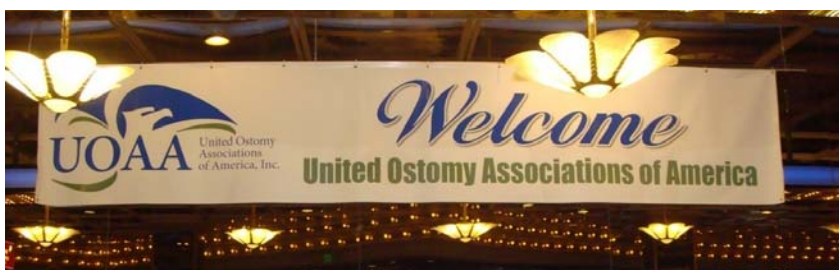
The regional conference was a huge success experiencing first hand Iranian hospitality where Iran will play a pivotal role in bridging ostomates in the middle east in the Asia South Pacific and like wise in Europe.

# Bag on Wheels

Newsletter for ostomates who are paraplegics  
Philippine Edition

August 2011 Issue  
Volume 1, Issue 1

## Cashing in at the RENO UOAA Conference



The casino slots of JA Nugget hotel were brimming with a lot of people cashing in several bucks of money from the winnings they made. They sure were very lucky.

I had my own brand of cashing in at the hotel – it was winning new friends: meeting fellow ostomates was a lot of fun, meeting a fantastic biker who toured different states, a mountain climber who conquered Mt. Everest, an iconic fashion model and a book writer who talked about sexuality and

even autographed her book for me. I met long time friends from previous conferences who have been real and loving people both to me and my wife. Lastly, I cashed in on learning a lot of insights which was truly an eye opener.

I believe I hit the jackpot without even playing at the casino.

*(The activities lined up each day were very informative and helpful for a first timer like me. Congratulations to the organizers of Reno Conference).*



***“I hit the jackpot without even playing at the casino”***

## United Ostomy Association of America holds Reno Conference

The UOAA Conference of 2011 was held at the “Biggest Little City” in the world – Reno Nevada. The theme for the conference was “Seize the Opportunity.” This is very much similar to what Robin

Williams of the movie Deads Poets Society would say “Carpe Diem.”

There were several sessions lined up and events that were organized in order to maximize such opportunity.

This is my first time to join

this kind of event and I truly grabbed the opportunity to choose what sessions will be most useful for me.

It has not concluded yet but I can say what a success it would be!

### Inside this issue:

Editorial 1

UOAA Reno Conference

Fashion Show Night sponsored by Hollister and C3Life

2

NuHope Fun Run

Snippets of Bag on Wheels

### Conference Highlights:

- First Timers Orientation
- Fashion Show Night
- Ostomysecrets no more
- Annual Fun Run

## Fashion Show Night

The fashion show night was a blast. It was sponsored by Hollister and C3Life modeled by ostomates themselves.

There was a long modeling ramp placed and elevated inside the middle of the auditorium. The lights of the entire auditorium were switched off setting a fun filled mood to start the evening.

The show began with the comic Brenda Elsagher as

host of the show doing an uncanny shuffle upon her introduction. She walked down the ramp to the delight of the audience.

The real part of the show came when ostomates started coming out from the backstage modeling clothes from lingerie, to bathing suits, and different clothes wear. Loud applause were heard when Jamie walked down the ramp with a beautiful gown to the respect and love of all.



*Cowboy outfit with models Bob Baker and Janet Paquet (Photo by RSL)*

## Nu Hope Fun Run

It was 6:30 am in the morning that participants came in trickles at the main lobby of the hotel until a large number appeared prior to the holding of the annual fun run sponsored by Nu Hope

I made an early registration and did some stretches on my wheelchair. I made sure I had my dependable leather gloves on to have a good grip on my chair.

Then it all started.

As much as I wanted to speed off and lead the pack, I gave the opportunity for others to go ahead.

We covered a stretch of probably around 4 km circling the JA Nugget hotel. I am use to this kind of distance but not in a mode of speeding off with people jogging in fast pace. It was a tiring run and I have to say

that my shoulders did hurt. Luckily, my wheelchair was well oiled prior to going to the conference.

I am happy to say that I was one of the early finishers and received a free t-shirt as a souvenir for the event. If ever such activity and opportunity arises again, I will not think twice of joining and doing it all over again.

Congratulations to all.

## Snippets of Bag on Wheels

Ostomates who are paraplegics have twice the care to think of about with regards maintaining a healthy attitude and a quality of life.

In this conference, I was not the only with Bag on Wheels, there were a couple of

participants who were also struggling like me trying to make the best out of life in spite of these challenges.

The theme was surely opportune to seize the day. I continually take it one day at a time knowing that life's challenges come here and

there. I hoped I have brought some inspiration to others that life just moves on. I will continue to reach out to others and be a symbol of strength. A fellow ostomate sums it all well in his speech in the first day of the conference "if I was able to help even just one ostomate, then it already means a lot for me."

Happy Wheeling to all.

*"If this was able to help even one ostomate, then it already means a lot for me" Bob Baker*

