IN THIS ISSUE...

12th World Congress and Invitation WCET 2006.................................4
Purpose of IOA and Charter of Ostomates’ Rights...............................5
WOD 2006.........................................................................................6
President’s Message...........................................................................7
From The Editorial Desk ....................................................................7
Helping Ostomates ………...Vladimír Kleinwächter - IOA Vice President.....8
Complication Free Stoma Surgery........................................................9
Hollister WOD photo contest.............................................................9
Regional President’s Reports followed by Member Country Reports……10, 12 - 40
20/40 Activities Around The World....................................................40 - 42
Ostomate Stories..............................................................................42 - 47

Index to Advertisers
Coloplast......................................................................................inside front cover
Convatec......................................................................................11
Dansac..............................................................................................15
Kontiba..............................................................................................21
Marlen...............................................................................................25
Hollister.........................................................................................back cover

To advertise, please contact Mr. Ian Settlemire
Settlemire Media
advertising@ostomyinternational.org
Ph/Fax 949-600-7296

The Ostomy International cover design and the 12th World Congress logo were designed and donated by Don Sieburg, owner of Studio DSC (don@studiodsc.com) in Gulf Breeze, Florida USA. Don is a professional photographer and graphic designer specializing in commercial product photography and company advertising programs.

Published once a year (January) by the International Ostomy Association. Sent to member associations, surgeons, doctors, nurses, Enterostomal Therapists, ostomy equipment manufacturers/suppliers, patron members and other interested persons and organizations. The International Ostomy Association is a non-profit, non-governmental, non-political and non-religious neutral organization, entirely based on volunteer services.

Disclaimer:
• The opinions expressed by authors are their own and not necessarily those of the Editor, the Editorial Board or Advisors, the Association, and none of the above accepts responsibility for the accuracy of the statements appearing herein.
• Please consult your doctor or ET before following any method published in this Yearbook.
• The international Ostomy Association makes no representation concerning the accuracy of advertisement contained herein and disclaims all liability relating hereto.
• We reserve the right to edit material.
• Articles may be reprinted by member associations provided an acknowledgement is given.

Please Note: All reports and articles should be received no later than December 1st each year
Plan now to join ostomates from all over the world at the International Ostomy Association 12th World Congress in 2007.

The International Ostomy Association invites you to “Live Life to the Full”

Meet ostomates from all over the world. Learn from others and share your experiences. Discover how IOA is working to improve the lives of ostomates around the globe. Participate in meetings and seminars. Have fun under the tropical sun of beautiful Puerto Rico.

16th Biennial Congress of The World Council of Enterostomal Therapists
2-6 July, 2006
Hong Kong Convention and Exhibition Centre

A New Horizon of Transcultural Care

Keynote Speakers: Ms. Dorothy DOUGHTY • Ms. Rosine VAN DEN BULCK • Dr. Elizabeth AYELLO • Dr. Keryln CARVILLE • Ms. Elizabeth ENGLISH

Topics

❖ Advances in ET Nursing, Stoma Care – Past, Present and Future
❖ Wound Management – Multi-dimensional Approach
❖ Urinary and Fecal Incontinence – A Global View
❖ Empowerment of our Future

Deadline for Early Bird Registration: 31st March 2006

enquiry:
tel: (852) 2559 9973
fax: (852) 2547 9528
e-mail: info@wcet2006.com.hk

www.WCET2006.com.hk
The purpose of the International Ostomy Association is to provide an association in the form of a world council for the benefit of ostomates, run by ostomates, and in full interests of all ostomates, with the co-operation of outside help when required, and to represent the viewpoint of ostomates on the international level. The association is organized to encourage the highest possible standards of surgery, medical attention, and patient after-care, and to assist member associations to help rehabilitate ostomates, thereby enabling them to achieve the quality of life they seek in all its aspects.

The Aims of the International Ostomy Association are:
- To provide information and management guidelines to its Member Associations.
- To help to form new Ostomy Associations.
- To represent worldwide the interests of all ostomates and those with related surgeries by advocating on all ostomy related matters and policies.

The primary Objectives of the International Ostomy Association are:
- To provide and distribute information to its Member Associations by:
  - Collecting and evaluating written information and experiences.
  - Publishing the "Ostomy International" journal and "IOA Today".
  - Publishing other advisory information and news material.
  - Organizing meetings and congresses.
- To initiate and support the formation of new Ostomy Associations by developing guidelines for founding and maintaining an ostomy group providing mentorship for new groups.
- To advocate for the rights of ostomates and those with related surgeries by:
  - Maintaining an awareness of issues that are impacting, or could influence, the quality of life and initiating Policies and activities to address these issues.
  - Coordinating and supporting all efforts to develop, establish and provide basic standards in ostomy care and rehabilitation.
  - Co-operating with medical and nursing associations, government health administrations and other allied organizations.
  - Promoting co-operation among the professional and manufacturing community who contribute to the advancement of the quality of life.

Charter Of Ostomates Rights

This Charter of Ostomates Rights presents the special needs of this particular group and the care they require. They have to receive the information and care which will enable them to live a self-determined and independent life and to participate in all decision making processes.

It is the declared objective of the International Ostomy Association that this CHARTER shall be realised in all Countries of the World.

The Ostomate shall:
- Receive pre-operative counselling to ensure that they are fully aware of the benefits of the operation and the essential facts about living with a stoma.
- Have a well-constructed stoma placed at an appropriate site, and with full and proper consideration to the comfort of the patient.
- Receive experienced and professional medical support, stoma nursing care and psychosocial support in the pre-operative and post-operative period both in hospital and in their community.
- Receive support and information for the benefit of the family, personal carers and friends to increase their understanding of the condition and adjustments which are necessary for achieving a satisfactory standard of life with a stoma.
- Receive full and impartial information about all relevant supplies and products available in their country.
- Have unrestricted access to a variety of affordable ostomy products.
- Be given information about their National Ostomy Association and the services and support which can be provided.
- Be protected against all forms of discrimination.

ISSUED BY THE IOA HOUSE OF DELEGATES, September 2004
...Living Life to the Full...

The Aim of World Ostomy Day is to improve the Rehabilitation of Ostomates worldwide by bringing to the attention of the public and the global community.

The Life situation of Ostomates / The contributions of the Ostomy Associations and Ostomy Professionals / The value of the multidisciplinary approach

World Ostomy Day is now only 7 months away. All countries have been asked by their Regional Presidents and their Assistant Co-ordinators to appoint a Country Co-ordinator. Their names are listed below and are your first point of contact.

COLOPLAST MERIT AWARD

Our sponsoring partner, Coloplast have put their link on our website. They are generously supporting this important day with three regional prizes of US $4000. Europe, the combined Americas, and the South Pacific and Asian regions are the groupings and all countries will be encouraged to enter the Coloplast Award. Each regional group will be awarded a first prize of US $2500 first prize and a second prize of US $1500. Each participant in the award will receive a Special Certificate for their efforts.

You will be given guidelines and criteria to help you in making an entry later.

Coloplast will produce 5,000 World Ostomy Day Pins which will be distributed to each region.

COUNTRIES PARTICIPATION ON OCTOBER 7TH 2006

On October 6th we will lead into World Ostomy Day with an e-mail chain starting in New Zealand and ending probably in Canada. All participating countries will be encouraged to send messages to the next country in the link telling a little of how they are meeting the challenge of World Ostomy day.

We expect that each country will participate in many ways to fulfil the aims listed under our theme Living Life to the Full. Already several countries have indicated their commitment to taking part.

The aim is to promote Ostomy activities world wide. Living Life to the Full is our theme and I am sure you will find many ways to demonstrate this in your own countries. Many will be simple inexpensive activities to publicise our cause. In some countries demonstration and publicity may be the key to achieving our theme.

Key to the success of this day will be the advance planning that is carried out. It will be a challenge but one I know you can meet. Sharing your ideas through your country and region will ensure a wide range of activities will be planned.

My suggestion is to collect a record of your activities (this may be the Country Co-ordinator and their team) so that after October 7, 2006 you can choose to enter the Coloplast Award.

The main purpose of the award is to share the ideas and activities you have carried out to promote World Ostomy Day. The ideas from the regional winners will be put into a presentation that will be available for countries to share after the 12th Congress in Puerto Rico.

Our aim is for all member countries to participate in WOD October 7 2006 and I look forward to this challenge of working with you to achieve this in the months ahead.

Barry Maughan  World Ostomy Day Co-ordinator

Regional Contacts

<table>
<thead>
<tr>
<th>ALADO</th>
<th>Candida Carvalheira - Regional President Alexander Machaca - Bolivia - Assistant Co-ordinator</th>
</tr>
</thead>
<tbody>
<tr>
<td>AOA</td>
<td>Harikesh Buch - Regional President Katherine Tang - Hong Kong - Assistant Co-ordinator</td>
</tr>
<tr>
<td>EOA</td>
<td>Arne Holte - Regional President Henning Granslev - Denmark - Assistant Coordinator</td>
</tr>
<tr>
<td>NACAOA</td>
<td>Linda Aukett - Regional President</td>
</tr>
<tr>
<td>SPOA</td>
<td>Barry Maughan - Regional President Gerry Barry - Australia - Assistant Co-ordinator SPOA and IOA</td>
</tr>
</tbody>
</table>
IOA President’s Report

APRIL 1 – DECEMBER 30, 2005

Hello to all my friends in IOA.

The year 2005 has brought many difficulties for so many people around the world. Natural disasters have created havoc and we have watched helplessly and in horror as vicious hurricanes battered islands of the Caribbean, coastal areas of the USA and inundated the city of New Orleans. Then in the autumn came the massive earthquake in Pakistan and India.

This series of dreadful events has brought loss and suffering to so many people including ostomates. We in IOA have offered our assistance appalled at our lack of ability to be able to help. We all want to help our fellow ostomates but we find ourselves paralyzed by not knowing what to do.

As I mentioned in my message in IOA Today, what these disasters have taught me is that contact has to be made with local associations if a disaster strikes and this can be done by the Regional Presidents. Any groups on the outskirts of any disaster can be on watch and encouraged to let the Regional President know when help is needed for fellow ostomates but this is not always that easy in developing countries. FOW USA was very active in working with IOA in helping ostomates affected by Hurricane Katrina in the USA. Our problem was in locating ostomates who needed help. We have had little contact with Pakistan following the earthquake there but we remain on watch in case we are asked to provide help for ostomates. We have Arne Holte our Relief Co-ordinator who oversees the whole picture for IOA and is always ready to act. He can be contacted at regioneuropean@ostomyinternational.com

On the ostomy front we have had our challenges. Two long-time Associations, UOA Inc., USA and the British Colostomy Association have closed their doors. New associations have emerged in both regions. IOA will continue to accomplish great things but only if we all work together to ensure a better quality of life for those who struggle to live with an ostomy under very difficult circumstances. Co-operation is the key to success, not only among our member countries and the regions, but with our allied organizations such as WCET, the Cancer Society and colorectal surgeons.

I look forward to meeting as many of you as possible in my future travels. If any of you visit Canada and are in the Toronto area, please get in touch with me. We may be able to meet but at the least, have a conversation.

Please take good care of yourselves. Stay well.

With my best wishes for 2006

Di

Di Bracken

From the Editor’s Desk

Welcome to the first issue of the new-look Ostomy International Yearbook.

I would like to take this opportunity to introduce myself; my name is Anne Hafner. I am married to Reinhard (20 years), and we have two children, Michael, 19 and Katrina, 15. I have been an ileostomate through Crohn’s disease for almost 12 years.

I have been a volunteer at my association, the Ostomy Association of Melbourne Inc. (Victoria, Australia) for eight years by serving as Secretary since 1998, Vice President/Secretary from 2001 to 2004. I was also involved with the Organizing Committee for the Australian National Conference (ACSA) held in Melbourne in 2003.

In addition, I have been involved with the Youth group, on a National and International basis. I have received the Visitation Certificate from Young Ostomates United Inc. Victoria. I was a member of the 20/40 Focus Planning Committee for the meeting in Hamilton, Canada in 2001, and in 2004 I was the 20/40 Focus Chairperson in Porto, Portugal.

I am now employed by my Association as Assistant Manager, after many years of swim coaching. I have also completed many years in retail, ranging from sales assistant to floor and store manager.

Early in 2005 I accepted the position of Associate Editor for the Ostomy International Magazine which has now led to this position of Editor.

To all who have contributed to this edition and I look forward to hearing from all of our Member and Associate Member countries.

Please take the time to read all the exciting news from around the world.

Best wishes,

Anne

For more information on: United Ostomy Associations of America (UOAA) please visit the website www.uoaa.org.

Colostomy Association www.colostomyassociation.org.uk please visit http://www.bcass.org.uk/ if you would like to read the official announcement on the website.
Vladimir Kleinwächter  
IOA Vice President

In the IOA web page (http://www.ostomyinternational.org) you will find a Comment & Question Form, which offers ostomates or interested persons from all over the world an avenue to ask questions, which would help them to solve their individual problems with the stoma, social or psychological difficulties, etc.

The questions reach the Webmaster, Stuart Schaeffer, who redirects them to me for further clearance. Given that I reply personally I only reply to enquiries of a general nature. In case of questions, which require specific knowledge of health care and social system in particular, countries Regional Presidents are asked for their help. They are better qualified to deal with such enquiries, answer them or contact directly.

In the last year IOA has received 110 enquiries. About 40 % I was able to answer myself, and the other 60 % were redirected to Regional Presidents. The distribution of questions from different countries or regions is shown in the cake graph below.

The far highest number of questions came from the United States, followed by Europe (divided in the graph into the United Kingdom and the rest of Europe) and Canada. The interest from the other parts of the world was only marginal. The fact that this service was used mostly by ostomates from English-speaking countries reflects roughly the frequency of visits to the IOA web page. For instance, there came no questions from the Eastern Europe and very few from Asia or South America, where certainly ostomates face many shortcomings in both the medical and social care, including the lack of freely available stoma appliances.

The highest number of ostomates or their relatives asked for advice with difficulties in nursing the stoma. Questions concerning social and psychological problems and request looking for contacts with other ostomates or with ostomate organizations acting in their vicinity yielded, together, the same number.

A special problem is represented by enquiries from ostomates looking for medical advice. As an impartial organisation IOA is not qualified to answer these types of questions. The patient can only be directed to consult a physician or a stomal therapist. In most cases these requests do not contain enough information, so it is not possible for us to find a physician, who would be able to give some advice via e-mail.

Another group of questions, those of commercial nature, deserves a comment. Several requests were received to put links on the IOA web page to sites where products or services useful for Ostomates are offered. We intend to put such links on a new-look IOA web page, which is under preparation now. However, we reserve ourselves the right to decide what can be considered as a help to ostomates and what will be classified as commercial advertisement. The advertisement will be subject to a charge, though a small one.

It is our objective to provide ostomates with the best possible help. It is therefore necessary that the request contain maximum information about the particular problem. Very often the basic data, for example, the type of stoma or the type of appliances, are missing. It would also be helpful if the enquirers from larger countries such as the United States or Canada give more detailed information about their place of living, i.e. the state and city. Last but not least, we urge that everybody check carefully the e-mail address to which the reply should be sent. Quite a lot of our responses, sometime quite elaborate ones, have been returned as undeliverable.

Only a few enquirers responded (even though it is not required) on the advice obtained and thus we have just a little feedback. It will certainly help us in preparing the answers if we know whether our effort was useful, and thus contributing to the improvement of this service.

<table>
<thead>
<tr>
<th>Request</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>stoma care</td>
<td>24</td>
</tr>
<tr>
<td>way of living with stoma</td>
<td>9</td>
</tr>
<tr>
<td>social and psychological help</td>
<td>13</td>
</tr>
<tr>
<td>medical help</td>
<td>13</td>
</tr>
<tr>
<td>stoma product information</td>
<td>6</td>
</tr>
<tr>
<td>contact information</td>
<td>11</td>
</tr>
<tr>
<td>travel information</td>
<td>9</td>
</tr>
<tr>
<td>IOA Business</td>
<td>14</td>
</tr>
<tr>
<td>general information</td>
<td>3</td>
</tr>
<tr>
<td>commercial contacts</td>
<td>6</td>
</tr>
</tbody>
</table>

The nature of the questions is summarised.
Complication Free Stoma Surgery

Dr. Harikesh G. Buch
Past President AOA
Consultant Surgeon Mumbai, India

*Excerpts from report Dr. Harikesh Buch presented at the 5th Asian Ostomy Association Conference held in Bangkok, Thailand, November 2005.

The best way to avoid complication is not to do the procedure - in this case NO STOMA – NO COMPLICATIONS. But this is still not possible yet.

Patients who have had Stoma Surgery need the following;
1) Information about his / her disease
2) Psychological support
3) Physical requirement & support
4) Post stoma rehabilitation
5) He / She must get back to life prior to stoma surgery

How do we achieve these? During first consultation informed counselling is done by the doctor who examines the patient. Patients must be given all information regarding his/her disease and treatment plan is explained.

After the patient is admitted for surgery, counselling of the patient as well as family members should be done by doctors and ET nurses. Inclusion of family members is important as they are the main support to patient when he/she goes home after surgery.

During the pre-operative period, in the hospital, physical preparation is done. First, the correct site of stoma is chosen and marked by ET nurse in a planned surgery. The patient is made to wear a bag at that site to make sure that it is the correct site and the patient is comfortable wearing the bag in all the different postures. Allergies are enquired into to avoid post op. general and skin complications. Bowel is prepared by enemas and liquid diet or with complete bowel wash out. This is done to avoid post op. infection. Correct choice of site of stoma is done for easy and better management of stoma that can be done by patient him self. It also makes easier for patient to irrigate in case of Left iliac fossa end colostomy. Stoma site should be marked so that it is for patient to see his stoma for better management.

Proper technique for creating various types of stoma to avoid post operative complications: It is essential to follow proper technique to avoid anatomic leakage and closure of lateral dead space is essential to avoid post operative internal herniation. It is also essential to give thorough peritoneal wash at the end of surgery to reduce chances of post operative sepsis.

During early post operative care the patient needs physical and emotional support. He should be properly fitted with correct stoma appliances to avoid leakage and avoid peristomal skin problems. He needs to be trained to manage his own stoma. Should close family members also be included? They can support him at home after discharge from the hospital.

Peristomal hernias can occur in patients but the majority of patients are asymptomatic and do not need corrective surgery.

Post-operative long-term support needed in the following areas.
1) Peristomal skin care.
2) Peristomal hernia - in symptomatic patients.
3) Regular supplies of proper stoma appliances.
4) Continuous education for stoma management.
5) Education for nutrition.
6) Continuous hope is required to stoma patients as many have cancer.

Industry, manufacturing stoma appliances, can help stoma patients to avoid complications by manufacturing efficient and easy to use appliances at economical prices. By manufacturing skin friendly adhesives which are long lasting along with good skin barriers many complications can be avoided.

Stoma associations at National, Regional and International levels make a powerful voice of ostomates and can help not only each other but to deal with governments for making better and suitable laws for ostomates and to deal with stoma appliances manufacturers for better and economical appliances.

In the future the following areas need to be addressed which can help ostomates to prevent complications of surgery.
1) Research into Medical management of Inflammatory diseases of the bowel (IBD).
2) Techniques in surgery to avoid creating stoma.
3) Early diagnosis of cancer.
4) Better Quality, Efficient and Economical Stoma Products.
5) Bio degradable stoma appliances.

The 2006 World Ostomy Day Photo Contest

Get out your camera and participate!

Hollister Incorporated is announcing a world wide photo contest open to every Ostomy Association around the globe. Here’s why: World Ostomy Day, October 7, 2006, is a very special day, so we’re sponsoring a very special contest The 2006 World Ostomy Day Photo Contest The Contest is a unique way to showcase talents and people, and to create lasting memories in conjunction with World Ostomy Day.

The 2006 World Ostomy Day theme is “Living Life to the Full.”

We know there are thousands of you who live that way each day—and in every way. You live life to the till in your families or on vacation, during work and with grandchildren, while volunteering or tending to pets. We know you’re out there “living” and that’s the type of image we want you to capture.

Winners: 20 photos will be chosen by the judges: Stuart Schaefer, IOA Webmaster and professional photographer and Hollister.
- All winning photographers will receive a certificate of recognition
- Each Ostomy Association / chapter / group, represented by the photographer, will receive $250.
- All IOA member countries will receive a CD-ROM of the winning photos to show how persons with ostomies ‘live life to the full” around the world
- Entries from individuals not affiliated with an association will be disqualified.

Rules: Photographers must be people with ostomies.

Images: must be of people with ostomies “Living Life to the Full”

Photos: may be digital or processed film

Size: doesn’t matter.

Color: use color or black and white, it’s your choice.

Caption: submit photos with the photographer’s name, association name and location, the occasion, place, date and names of people in the photo.

Please be aware: Submitted photographs will not be returned. Also, the photographs will become the property of the sponsoring organization, Hollister Incorporated, and may be shown publicly.

Please submit your entries by August 1, 2006 to:

WOD 2006 Photo Contest
Al Maslov, Global Marketing
Hollister Incorporated
2000 Hollister Drive
Libertyville, IL 60048

e-mail: wod2006pc@hollister.com
Tel. 847-680-2140 Fax: 847-918-3981
Let me wish you all the readers and friends throughout the world a very Happy and Prosperous 2006.

**Important events that took place in 2005 in Asia.**

**February 2005:** IOA EC Meeting held in Humlebæk, Denmark in the headquarters of Coloplast. Mr. Daniel Grant, President of IOA, Mr. Vladimir Kleinvächter, Vice President IOA, Mr. Heinz Wolff, Immediate Past President IOA, Mr. Gene Zapf, Treasurer IOA, Dr. Harikesh Buch President AOA, Mr. Arne Holst, President EOA, Mrs. Linda Aukett, President NCACOA, Ms. Maureen Flynn, President ALADO and Mr. Barry Maughan, President SPOA along with local observers attended the meeting. Coloplast had also kindly sponsored the EC Meeting. Once again we were given a tour of R & D of ostomy products at Coloplast Manufacturing Facilities. It was a fantastic educational experience for all of us to learn about R & D of adhesives that are used for ostomy products. It was also heartening to know that they are working on biodegradable and environmentally friendly products development. World Ostomy Day was discussed in detail and the upcoming Asian Ostomy Association conference and other regional meetings were discussed. We did experience local weather in Denmark and local hospitality.

**March 2005:** I was invited to the 3rd ASSR and the 10th Asian Federation of Coloproctology Surgeons meeting in Singapore. In the 3rd ASSR Meeting we were five surgeons from different countries of Asia including Dr. Yu-cun Lia (China), Dr. Harikesh G. Buch (India), Dr. Seung-kook Shon (Korea), Dr. Yunus Gul b. Alif Gul (Malaysia) and Dr. Tzu-chi Hus (Taiwan). All of us spoke at a luncheon Symposium, “Stoma Care from Colorectal Surgeon’s Point of View” This was moderated by Professor Shindo of Japan. This Symposium was sponsored by ALCARE, a company of Japan.

**Excerpts from different Speakers were as follows.**

**Dr. Yu-cun Lia (China) :** Incidence of IBD is low in China so permanent ileostomy is much less constructed as compared to Colostomy which is constructed primarily for rectal cancer. In China patients of rectal cancer are much younger as compared patients in the western world. Diagnosis of rectal cancer is also made at a much advanced stage as compared to western world. Therefore prognosis is of these patients is poor in China.

It is estimated that there are about 100,000 new patients who undergo ostomy surgery every year in China and it is because of ET’s that stoma patients overcome difficulties and return to normal life.

**Dr. Harikesh Buch (India) :** Our aim should be taking stoma care from stoma clinics to community based stoma care programmes specially in Asia. This is because patients have to travel long distance from their homes to stoma clinics to receive stoma care at present. By doing this we also can teach family members about stoma care and it's importance to support ostomates in their family.

**Dr. Seung-kook Shon (Korea) :** Careful stoma construction is the most important point of stoma care management and in doing this the surgeon plays an important role in stoma care. To complete ideal stoma care management, a team approach between doctors and ET nurses is very important.

**Dr. Yunus Gul b. Alif Gul (Malaysia) :** For improving quality of life after stoma surgery, adequate numbers of ETs are required along with adherence to best surgical techniques to construct the stoma and improved standard of patients care is required. Other factors which require to be addressed are improvement of stoma devices by the Industry and community based care of stoma patients needs to be developed for improving quality of life of stoma patients.

**Dr. Tzu-chi Hus (Taiwan) :** Stoma construction can be life saving. Everything about life after stoma surgery should be counselled to patients and family members prior to the surgery. By providing good stoma care quality of life can be improved and patients can be rehabilitated back to normalcy.

There was another symposium where participants spoke on “Stoma Support Groups” from different countries and I gave my Indian experience. I also read a paper at the 10th AFCP Surgical Meeting on “Rectal Prolapse” and also had a chance to chair a session on IBD.

I interacted with some of the active members of the Singapore Ostomy Club, especially with Ms Debra Mok-Chan, Head of welfare programmes of the Singapore Cancer Society. It was necessary for re-establishing contact with the Singapore Ostomy Club so that they can become active once again in AOA as well as IOA.

**May 2005:** IOA President Mrs. Di Bracken and Dato’ John Cardosa visited Bangkok to interact and finalise the details of AOA Conference to be held in Bangkok in November 2005. Both of them had good opportunity to re-establish friendship with new TOF CC. Mr. Sunan Silapabanieng the President of TOF again showed very good hospitality to both of them.

**July 2005:** A stoma care training work shop was held at the National Cancer Hospital, Ulaanbaatar, Mongolia with the kind courtesy of Lions Club Of Modena and rotary club of Khuree, Ulaanbaatar, Mongolia. Dr. Bayarsaikhan and Dr. Ochir were the main organizers of this workshop locally. About 35 doctors and nurses from different provinces of Mongolia attended this. Local surgeons, urologist, medical and radiation oncologist also were trainers along with Professor Carlo Peczoller from Modena Italy, Dato’ John Cardosa secretary / treasurer of AOA from Malaysia, Dr. H G Buch, surgeon from Mumbai and Past President AOA, from India, and two ET nurses from Penang, Malaysia, Ms. Tai Seow Beng and Ms Phang Fook Yoong. The workshop lasted for five days and this was the most successful and interactive workshop ever done by us. Participants were very enthusiastic and very eager to learn. Most of the participants could not understand English therefore they had organized translator Dr. Enkhamgala Tsiregzen for us who is a surgeon himself at National Cancer Hospital.

We, with the help of local doctors and nurses and the local ostomates could help them start the Mongolian Ostomy Association. The first President of the Mongolian Ostomy Association is Dr. Geleg Davasaambuu who is a physicist and ostomate. Some of the manufacturers had kindly donated stoma products for them to begin the association activities. Mr. Oscar of Modena and also a member of Modena Lions Club had kindly donated the first year subscription fees for MOA to join IOA/AAO.

Local Rotarians, Friends of Ostomates and staff of a local medical school showed extremely good hospitality and were very friendly. They went out of their way to take us one evening to a local musical concert and on the last day they took us out to see their country side which is quite different and very pure. We also had an opportunity to visit ‘ger’ and a chance to test local barbeque.
November 2005: As planned earlier with financial support of the Lions Club of Modena for travel to Vietnam and local support by ostomy manufacturing company B/Braun we successfully conducted a stoma care training workshop for about 32 nurses in Ho Chi Minh City at University Medical Centre from 7 - 12 November 2005. Professor Nguyen Dinh Hoi, Director of University Medical Centre, kindly inaugurated the Workshop. Dr. Nguyen Trung Tin & Dr Vo Tan Long, along with local surgeons and Radiation & medical oncologist and Professor Carlo Pezzicoli from Italy, Dato` John Cardosa from Malaysia, Dr Harikesh Bouch from Mumbai, India, and Ms. Tai Seow Beng and Ms Phang Fook Young, ET nurses from Penang, Malaysia were educators. Most importantly IOA President Mrs. Di Bracken was not only present to see for herself how these workshops are conducted but also took an active role in the training programme as well. There were a few ostomates that also attended this workshop. President of Vietnam Ostomate Club Mrs. Dao Ngoc Nu and Vice President Mrs. Do Thi Phuc Chau, and Mr. Bii Huu Que, also attended the workshop and were very grateful about what they learned, especially irrigation techniques for management of colostomy and how to make irrigation set at a low cost during this period and implemented in their day to day life.

We were also taken to local sight seeing specialty, to Co Chi Tunnel and nearby Buddha Temple on the mountains where previously war had taken place between guerrillas and the USA army. We also had a chance to taste local food at dinner parties hosted by local surgeons and B/Braun.

The 5th Asian Ostomy Association Conference was held in Bangkok Thailand. There were quite a few delegations from around the world and local delegates as well. The IOA Executive Members were present in large numbers. Under the chairmanship of the Mr. Sanan Silapabanleng (TOF President) and the Organizing Committee members had really put in very hard work to organize a very successful and memorable AOA Conference at the First Hotel in Bangkok.

On the first day after the different countries flag parade and the opening ceremony Mr. Komol Poonawalla, the founding member of Thai Ostomy Foundation and Mrs. Prakang Rungkasiri were given the honorable plaque. In the following session “Voice of Ostomates and Friends” Mrs. Di Bracken and many doctors spoke about various stoma and ostomy organisation related topics. It was very educational for all of the delegates.

During the House Of Delegates Meeting, the new Committee was elected. The new President is Dato` John Cardosa of Malaysia, Vice President is Mr. Sanan Silapabanleng (TOF President) and Professor Takaishi of Japan , is a Committee Member . At present Professor Takaishi will also be working as Secretary / Treasurer of AOA because of the proposed Constitutional amendment (Ostomate’s close family member but not an ostomate himself/herself could take up as Secretary/Treasurer of AOA) was not passed for technical reasons.

The Official Delegates from Hong Kong, Japan, Indonesia, Malaysia, Singapore, Iran, China, Mongolia, Thailand attended the Meeting. All the Countries presented their country reports. The most important presence was from Mongolia of Dr. Geleg. Davaasambuu, the President of the Mongolian Ostomy Association and from and Vice Chairman Mr. Yeung Shu Xuan and Ms. Wang Ling Yan ET Nurse from the Guangzhou Stoma Association (GZSA), China. Both Associations had their presentations and they kept all the delegates spellbound. The Hong Kong Stoma Association (HKSA, new Chairman Mr. Wong Fook Cuing and new Executive Secretary Ms. Kathleen Tang) has done a remarkable job by helping GZSA and other provinces of China to develop both stoma care and ET Nurse training programmes in China.

Many manufacturers had their booths at the venue. Alcare, B/Braun, Coloplast, Convatec, Dansac and Hollister also generously supported the conference. The farewell banquet dinner was excellent along with local cultural programme from Thailand and it coincided with the Loy Kratong Festival where decorated banana leaf cups with candle were floated on water and make-a-wish was done. This was the most memorable event of the AOA Conference.

Future Vision: We have planned several Stoma Care training workshops in different countries of Asia in coming years. In February-March 2006 we shall organize two such workshops in the Northern part of Karnataka state (Provincial India) where awareness and knowledge of stoma care does not exist among the doctors and nurses. In September 2006 we will plan another two such work shops in the Provincial part of South India. In both places local surgeons and nurses will also be a part of training team along with us. Mrs. Anjali Patwardhan (Asia’s first fully trained ET nurse) from TATA Memorial Hospital, Mumbai has kindly agreed to send two of her ET nurses for all these workshops.

Similar work shops will be carried out in Bangladesh, Cambodia, Laos, Myanmar, Pakistan, Sri Lanka and other less privileged countries in Asia where this knowledge and awareness does not exist. Our aim is to create awareness and give knowledge about Stoma Care in as many countries in Asia as possible and help them to form a group of Ostomates or Ostomy Club so that they can fight for their rights with the Government to make their life more comfortable.

We also plan to have more interactive sessions with the manufacturers of stoma products to make no frill, cheap and more reliable stoma products specially for poor Ostomates in Asia.

We would like to take this to other less privileged countries / regions of the world. We visualize in future more and stronger co-operations between developed countries and less privileged countries not only in Asia but also in the world. This already has been shown by Hong Kong working in close co-operation with China and Japan working with Mongolia and Taiwan.
The 5th Asian Ostomy Association (AOA) Conference and the 8th House of Delegates Meeting held at the First Hotel in Bangkok, Thailand, Nov 13 - 16, 2005

Report by Di Bracken, IOA President

130 Ostomates, 32 Observers, 102 nurses / E.T. nurses were in attendance as well as 7 members of the Executives of IOA.

Following registration in the afternoon, delegates mingled with members of the IOA Executive at a Reception Cocktail party. We were welcomed by Mr. Apirak Kosayodhin, the Governor of Bangkok and treated to a Thai cocktail dinner. We were all enthralled with the Thai Classical Dance and Music that followed.

OFFICIAL OPENING MONDAY 14TH NOVEMBER, 2005 provided memorable moments as the invited speakers addressed the meeting:
Mr. Sanan Silapabanleng, President, Thai Ostomy Foundation; Ms. Dielwen Bracken, President, International Ostomy Association; Mr. Oinit Jarusombat, Minister of Public Health and Dr Harikesh Buch, President Asian Ostomy Association

A special moment at the Opening was the presentation of a special plaque honouring the services and dedication of Mr. Komol Poonawalla, Father of the Thai ET and Ms. Prakong Rungkasiri, longtime supporter of the Thai Ostomy Foundation.

PROGRAMME VOICE OF OSTOMATES AND FRIENDS

<table>
<thead>
<tr>
<th>Topic</th>
<th>Presenter</th>
</tr>
</thead>
<tbody>
<tr>
<td>IOA and AOA</td>
<td>Ms. Di. Bracken, President IOA</td>
</tr>
<tr>
<td>Why Couldn’t the Rectum Be Saved?</td>
<td>Assistant Professor Parinya Thavichaigarn</td>
</tr>
<tr>
<td>Stoma Care from Colorectal Surgeons Point of View</td>
<td>Professor Carlo Pezcollar</td>
</tr>
<tr>
<td>Ostomates’ Requirements - Preventing Complications of Stoma Surgery</td>
<td>Harikesh G. Buch, MD.</td>
</tr>
<tr>
<td>Life is God’s Gift, Live it, and Share It</td>
<td>Professor Danai Bunnag, MD.</td>
</tr>
<tr>
<td>Energy Balance as Therapeutic Tool in Traditional Thai Medicine</td>
<td>Chawengsak Disthaporn, MD.</td>
</tr>
<tr>
<td>The Future of Ostomy in the Asian Region</td>
<td>Dato Dr. John Cardosa</td>
</tr>
<tr>
<td>World Ostomy Day</td>
<td>Mr. Barry Maughan. President SPOA</td>
</tr>
<tr>
<td></td>
<td>Co-ordinator WOD</td>
</tr>
<tr>
<td></td>
<td>Fund Raising for Stoma Rehabilitation</td>
</tr>
</tbody>
</table>

TUESDAY 15TH NOVEMBER, 2005 9th House of Delegates Meeting: General business agenda was followed with previous minutes read and discussed, and the treasurer’s report considered. Short reports were presented by individual member associations with written reports distributed.

ELECTION RESULTS
President Dato John Cardosa, Malaysia
Vice President Mr. Sanan Silapabanleng, Thailand
Acting Secretary/Treasurer Michiaki Takaishi, Japan
Member at Large: Michiaki Takaishi, Japan

Excerpts from address by the Elected President Dato John Cardosa: The Asian Region is easily the largest in the IOA in terms of population and therefore of potential number of ostomates. Ostomy Services and Stoma Care nursing is by and large, sadly lacking, inadequate, or totally non-existent except for Hong Kong, Japan, Korea, Malaysia, Singapore, Taiwan, and Thailand. India has its own highly developed ET school in Mumbai but lacks Stoma Care Services outside the large urban areas. China is in the same position.

TARGET FOR AOA: Developing Stoma Nursing in the rural areas of Bangladesh, Cambodia, China, India, Indonesia, Laos, the Philippines and Vietnam

POTENTIAL MEMBERS: In 2005, two other associations were formed but will join IOA in 2007: - the Mongolian Ostomy Association and the Nepal Ostomy Association.

COUNTRIES IN PROCESS OF FORMING AN ASSOCIATION: Bangladesh, Brunei, Laos and Myanmar

TARGET COUNTRIES: Afghanistan, Bhutan, North Korea, Pakistan and the Republic of the Maldives

This is Asia’s vision for the next three years: high standards for the region but judging on past performance, the goal is attainable. It will take close cooperation among IOA, our Partners in Industry and WCET but by working together, great achievements are possible.

WEDNESDAY 16TH NOVEMBER, 2005: This was a most interesting day devoted to two quite unusual topics :

Morning Session
Empowering Mind, Spirit and Psychology in Ostomy Care
Asst. Prof. Saichai Puopan, MD.

Afternoon Session
Nature and Environment: Wellness and Illness
Prof. Wallop Piyamanontham, MD.

Farewell Banquet Wednesday; Incredible camaraderie, great food and national culture shows made this an evening that all attendees will remember. We celebrated the Loy Kratong Festival (Floating banana leaf cup with a candle which you gently push into the water while making a wish for the future.)

Your IOA Executive members who were present at the meeting did
you proud. A modified rendition of "We've got the whole world in our hands" was a highlight that will be remembered by all in attendance. Individual member countries contributed to the evening festivities performing traditional numbers from their particular countries. The members of the Thai Ostomy Foundation arranged that we would end the evening with a show of togetherness through the Ramwong Thai Folk dance performed by members of the Thai Ostomy Foundation in traditional dress. Soon we were all involved in the folk dance taking the lead from our Thai hosts. What a great way to end the Asian Regional Meeting.

Team work was evident as the Conference Planning committee of the Thai Ostomy Foundation did a marvelous job in organizing this conference for us.

Congratulations to Mr. Sanan Silapabanleng, President TOF, Mr. Komol Poonawalla and Kiti Chindavijak M. D., Vice Presidents Saowanit Samakhaputra, General Secretary, Sonny Samonpal, Assistant Secretary and Dato John Cardosa, liaison.

Founding members - doctors, nurses and ostomates. There were 60 members at the beginning of 1994 and now in 2005 there are 600 members.

Mission of GZSA: Gather members together and provide opportunities of exchanging living experiences with stoma, mutual support and self-help for them.

So far, GZSA have organized “Guangzhou-Hong Kong Ostomate’s Gathering”.

Goals and Objectives
- Improve ostomates’ quality of life.
- Promote mutual help among ostomates.
- Advocate patients’ welfare in China.
- Strengthen exchange of life experiences among ostomates within Asian countries.
- Invited HKSA volunteers to share experiences of running mutual support activities.

The Hong Kong Stoma Association is a registered non-profit making organization, and is the first patients’ self-help organization in Hong Kong. It was set by and for ostomates in 1979 with the help of social workers and medical professionals. The Association is currently funded by the Hong Kong Cancer Fund and the Community Chest. It is a member of the International Ostomy Association and the Asian Ostomy Association.

Mission: To provide mutual support, to share members’ experience and information on stoma care, and to encourage members to resume a normal life.
- To advocate self-help spirit and supportive network among ostomates.
- To assist members to fully rehabilitate and re-integrate into the community through various social and rehabilitative services.
- To advocate patients’ rights and arouse public concern to the needs and problems faced by ostomates.
- To increase the public awareness of the symptoms and prevention of colon rectal and bladder cancers through public education, via -

Hospital visits, stoma care services/health talks, case counseling and referrals, district support group activities, volunteer enquiry services, social and recreational activities, interest development groups, publications, public education, liaison with suppliers of stoma appliances and work with local nursing professionals and overseas
ostomy organizations.

IRAN

Submitted by Farzarieh Naghibi Ghane BSN, MSN, ETN
Iranian Ostomy Society (IOS)

It is my great pleasure to have this chance as an Iranian ET nurse to give a brief report of IOS activities in 2005.

After passing the effective ETNEP course in Malaysia in 2004, the ET nurses’ concerns were how they can improve enterostomal therapy nursing in Iran and how they can help patients in this way. Our mission in IOS (Iranian Ostomy Society) is an extension of enterostomal therapy nursing in Iran through education programs for nurses to train at least one stoma care nurse in each hospital to help ostomates who need the special services about living with an ostomy, emotional support and product information for having high quality of life. To improve nurses’ knowledge and performance about stoma care to apply ostomy appliances, Education Committee planned a curriculum for one-day Stoma Care Workshop “Kinds of Appliances and How to Apply Pouching System” as the first priority of nurses’ educational needs, combining theory and practice. The program was designed to provide the nurses skills to apply pouching system.

We held two workshops in the Iranian Ostomy Society’s new building and trained 70 nurses from 36 different hospitals in Tehran and also the other four big cities. Also we held two workshops in Shiraz one of the big cities of Iran on June 22-24 (Oncology Congress) and trained more than 60 nurses. Another workshop took place on August 4 2005 in the Modarress Hospital in Tehran.

The last two workshops were held on October 8 and November 10 for 16 hospitals of the Iran University and trained more than 60 nurses from different hospitals. As a whole, by holding seven workshops in 2005 we have been able to train 235 nurses in Iran up to now.

By assessing the pre and post test, fortunately we could promote the level of nurses’ knowledge noticeably. Also the nurses’ satisfaction with the educational program of IOS was about 93%.

Also we planned several one-day workshops for nurses as “Stoma Sighting”, “Discharge Planning”, and “Irrigation” and in future. The overall role of the ET is education. Our great love to our people and ostomates motivated us to do our best to improve ET nursing in Iran to be able to train at least one stoma care nurse in each hospital in Iran to promote quality of life of our ostomates. We hope to be able to co-operate in extending ET nursing in our neighbor countries in the future.

Iranian ET nurses had an active attendance at their first APETNA Congress in Malaysia and presented four papers there which were received gladly by Ms. Elizabeth English and the other ET nurses. The IOS clinic was equipped for providing clinical care by ET nurses.

As the art of caring is a key concept underlying ET nursing practice. Our ET nurses, as providers of care, play their roles and activate clinical care by their presence three days per week in the IOS Clinic and visiting the patients and educate them. Topics of patient education include Stoma and Peristomal Skin Care; Pouching System; Irrigation; Stoma Sizing; Nutritional Guides; etc...

A computerized system for patients’ admission and the distribution of appliances among ostomates were planned.

As the IOS mission is to provide proper environment for new and experienced ostomates, ostomy support groups are open to any individual who has experienced ostomy surgery. Here the individual is able to interact with people who have lived with an ostomy and talk and laugh with friends who understand what it is like to live with an ostomy. This support group meets on each Saturday. These sessions are open to anyone who has had ostomy surgery or is thinking about having the surgery. Patients and families are welcome to attend. The support group has been holding meetings in the IOS while encouraging active participation of all ostomates in IOS activities.

IOS has been planning fun activities for members to participate in such as ceremonies, dinner parties and various trips. There is a free Yoga class at the IOS Clinic each Saturday for ostomates. Also many activities are offered in IOS by ostomates and under their responsibilities.

As a whole our ostomates indicate that those who learn self-care techniques and participate in support groups are less depressed, less stressed, gain more knowledge and rate the quality of their lives higher than those who did not take such action.

We also planned and started a serial “Caring for Ostomy Patients” education for nurses through the IOS Clinic with publication in two languages, Persian and English.

We gratefully express our appreciation to:
Ms. Tan Tang Peng, Sister Ravathy Ramamurthy, Sister Ng Ying Lai, Ms. Thai and Ms. Phook Yoong and all of the head nurses and ETs in Malaysia who taught this course.

We also thank NNGF, WCET, AOA, IOS (Dr. Vafaee and Dr. Mahjoobi) and a special thanks to Dato’ John David Cardosa, Ms. Elizabeth English and Ms. Judith Wellor for their special support and for providing much needed assistance to us to be ET nurses.

~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~

NATIONAL MEETING OF THE
JAPANESE OSTOMY ASSOCIATION

Report by President Di Bracken

I was very honoured to receive an invitation from the Japanese Ostomy Association to attend its National Meeting that was held in Miyazaki City on May 20, 2005.
Being the keynote speaker at the National Meeting, I have to tell you that I was a little concerned as to how this was going to work out. I speak no Japanese and the vast majority of those in attendance spoke no English but I need not have been concerned. President Kozo Inagaki, Noriko Takahashi and the members of the office of JOA had it all worked out. I had sent my address to President Kozo Inagaki in advance and before I even left for Japan, it had been translated into Japanese. As I stood on the podium to speak to the members of JOA on “The Ostomy World is United as One Family” up came the first slide – in English and Japanese.

I was very intrigued by the way in which the organization is run in Japan and I thought it may be of interest to our other member countries.

**ORGANIZATIONAL STRUCTURE OF THE JAPANESE OSTOMY ASSOCIATION:** President, four Vice Presidents, Senior Managing Director, five Managing Directors, twenty Directors, Secretary/Treasurer and non-elected Senior Adviser.

The business of the organization is divided into four major areas:

- Planning Division
- Welfare Division
- Public Relations Division
- International Affairs.

One of the four Vice Presidents is in charge of each division and can appoint people to his section. Every Director is a member of at least one division and one of the committees.

JOA has organized three different committees - Communications, Conference Planning and Nominations.

**Communications:** This committee meets every two months to work on the JOA magazine. It is responsible for deciding policy for all communications, publications and the website. Six of the twenty Directors work on this committee.

**Conference Planning:** There are five committee members who work on the organization of the annual conference of JOA. Local people at the location of the annual conference site also assist with the organization of the conference. A travel agent is engaged to assist with booking the hotel and meeting rooms, arranging meals, coordinating excursions and outside events, and making travel reservations for attendees.

**Nomination of new Directors:** Each Division Manager (Planning, Welfare, Public Relations and International Affairs Division) recommends the candidates capable of becoming Directors among the members of JOA and submit the names to Nominations Committee with their curriculum vitae.

The total number of Directors (President, Vice President, Senior MD, MD and Director) is not less than twenty but not more than thirty. The President is selected by a consensus of the above people for a two-year term, which can be renewed by agreement. After appointment, the President recommends for consideration the names for the four Vice Presidents to the Senior Managing Director and the five Managing Directors.

**JOA Office Staff:** Secretary/Treasurer is paid a fixed salary. The Accountant and Webmaster are paid on an hourly basis. JOA members pay 3,600 yen per year. One-third is forwarded to the JOA office to meet office expenses while the local chapter to which the member belongs keeps the rest.

There are two independent offices located in Tokyo. One is the office of the Japan Ostomy Association; the other of the Tokyo chapter of JOA. Across Japan, there are 66 active chapters.

JOA Office Staff: Mr. Takeuchi, Secretary, Miss Yamagishi, Accountant and Mr. Watanabe, Webmaster.

Because most people have had colostomy surgery and are over 50 years of age at the time of surgery, there are very few people who could potentially form a 20/40 group. Currently, there are approximately 10% under the age of 50 years.

The business of the organization was conducted at the meeting, and President Kozo Inagaki was asked to continue in this role for a further term. The rest of the meeting followed the usual pattern with a varied programme of interest to ostomates. The Exhibit Hall was strategically placed directly outside the conference rooms so attendees had good access to all exhibits. The Japanese are a warm and very hospitable people who like to be part of the entertainment at social events.

I cannot say enough about the warmth and caring that was evident throughout this meeting. My congratulations to all who made the national meeting such a success – especially the members of the Miyazaki chapter so capably led by President Shouji Fujiwara.

**MALAYSIA**

The Stoma Care Society of Malaysia was set up in 1988. The Society is based in Kuala Lumpur, the capital of Malaysia. There are currently two branches; one in Penang, covering the Northern Region and one in Johore covering the South while the main branch covers the central region.

Experience as a mother of a young ostomate

A section of the crowd at the public forum organized by the Society

Dispensing products to members at cost price in Penang
MONGOLIA
Mongolian Ostomy Association (MOA)
Submitted by Geleg Davaasambuu, President MOA

My name is Geleg Davaasambuu, the Chairman of the newly established Mongolian Ostomy Association (MOA). I have a PhD degree in physics, and I have a research fellowship at the Institute of Chemistry and Chemical Technology at the Mongolian Academy of Sciences. First of all, I am very glad to inform you all that the Mongolian Ostomy Association (MOA) was established just a few months ago. I have been elected as the first President, with Dr Enkh-Amgalan, a surgeon, as Secretary.

I take this opportunity to thank Dato’ John Cardosa, the newly-elected President of AOA, Professor Carlo Pezzoller, of Modena University, Italy, Dr Harikesh Buch, Past-President of AOA and a surgeon in Mumbai, India who conducted the very first stoma care workshop for some 35 doctors and nurses at the National Cancer Centre of Mongolia in the capital city, Ulaanbaatar. They generously collected some money to get us started and to pay our initial dues. At the end of this workshop in Mongolia we were very keen to form our own Ostomy Association.

Of course, I must say that with a great help from them, I had a chance to attend the Asian Ostomy Association Conference that was held in Bangkok, Thailand in November. I would also like to thank very much Miss Noriko Takahashi, an ostomate, and committee member of the Japan Ostomy Association who has collected some ostomy appliances on her own initiative and sent to the Mongolian Ostomy Association a parcel of appliances for free distribution to our poorer members. I have to be very open with you because of many problems and difficulties which face all the ostomy patients in Mongolia.

The main goal of MOA is to join all patients with the stoma and take care of them as we can. We will try to help ostomates to return to their social activities, work, normal family relations, support them and educate them in stoma care. The Association will do everything possible, favorable and beneficial for the people with an ostomy and their families.

Mongolia is divided into 22 administrative regions or aimags and cities. In the future we plan to establish a club in each regional aimag centre. The future activities of the clubs will be very useful for the countryside members. In the future we will try to expand our activities at a national level and establish a contact with associations of other countries.

At the moment MOA has 58 ostomate members in Ulaanbaatar, the capital city, but there are many more who need our help in other parts of Mongolia. As you know well, all the ostomates are mentally stressed people. First of all, they need all kinds of support, especially moral support. Consequently, our planned activities are as follows:

- Moral support to the ostomates.
- Fortify confidence in oneself and the family.
- Promote self-care and the return to the normal daily life and work.
- Promote and support their demands, requests and needs;
- Psychological rehabilitation, training on the proper use of stoma appliances and the correct care of stoma.
- Train the ostomates how to use the appliances.

We need to give them the knowledge and skills in ostomy care and rehabilitation. We very much need help from you in developing ostomy care in our country and to establish a close working relationship with the nursing organization closest to the patients. We also need to train medical professionals how they should work with IOA and AOA.

We are trying to attract the attention of well known medical experts, government officials responsible for health care and social policy to the problems of ostomates. We need to get some necessary help from IOA and AOA on how to work with local ostomates, especially in countryside to obtain ostomy supplies from donor countries and associations and to ensure their free distribution to the ostomy patients.

We want to ensure half working day and full salary system for the ostomy patients and to respond to the needs of all people with ostomies.

The people in Mongolia are by and large fairly well educated, but being mostly nomadic sheep-herders, they are very poor. The Mongols are a hard-working, proud race of people who are descended from Chinggis Khan and Kublai Khan. But, sorry to say, most of them traditionally do not like asking for help from others whatever difficulties they face. That is why many ostomy patients in Mongolia do not ask for any help. It is a very difficult situation in which the ostomy patients of Mongolia have found themselves.

Unfortunately, our ostomates receive very little attention from the health organisations of Mongolia. All the ostomates in Mongolia get poor medical after-care as outpatients in local hospitals. Unfortunately, there are no ostomy supplies available in Mongolia. Therefore, I have to tell you that we, the Mongolian ostomates URGENTLY need help. If you are able, please send supplies to the Mongolian Ostomy Association, where you can be assured that the supplies will not be misused, but will be distributed free of charge to the poorest members who cannot afford to buy their own supplies.

Mongolia is one of the economically less fortunate countries in Asia where there is little or no stoma care. As some of you may know that the life style in Mongolia, especially in countryside where it is very different from what it is in developed countries. The population of
Mongolia is only 2.5 million, almost 35% of which lives in capital city Ulaanbaatar. The life standard in Mongolia is much lower than in developed countries. Approximately 50% of the whole population of Mongolia live in traditional nomadic tents called ger. The traditional life style is one ger - one family basis. In another words the ger has only one round-shaped common room in which everything is joined together - kitchen, beds, dining and living area. An average family has 4-6 people (a couple and 2-4 children). There is no running water, shower, utility and rest room in ger. A common toilet is outside some 15-25 metres away from the ger.

Most of the ostomy patients in Mongolia live in the tents. So, you can imagine how difficult it is for the people especially for the ostomates to take care of themselves in Mongolia. In the countryside towns (suman) patients are often reserved, frightened and even ashamed, because the patients do not want other people to know of their stoma. As you can imagine, it is very sad that the ostomy patients of Mongolia have many difficulties due to the absence of ostomy care, as well as non-availability of ostomy products and specialized ostomy nursing. Lack of appliances is a main concern in Mongolia. At the moment there is no any medical company which legally imports necessary appliances to Mongolia. There is no help with ostomy supplies from anyone and not enough supplies available to provide a regular supply to the poorer ostomates. Some ostomy supplies are available on the black market but the quality ones are very expensive and not everybody can afford them.

Of course, it is practically impossible and difficult to have an Ostomy Association in Mongolia without any support and necessary knowledge about ostomy care from IOA, AOA and ISCAP. We are in urgent need of sponsorship from the major manufacturers, IOA and AOA because without this support it is almost impossible for us to carry out the ostomy care activities needed in Mongolia.

We have made an application to AOA/IOA for membership. We would also like to have own page on the IOA web site, because for some reason we can not set up a page at the moment. We would be very grateful to you if you could give us the chance to take advantage of this service.

It is my sincere hope that I, as the Chairman of MOA, will try to use many good lessons from the AOA conference and help people in need of ostomy care in Mongolia. Thank you all very much for your help, support and cooperation.

Mongolian President, Davaasambuu Geleg and Thailand Ostomy Foundation President, Asian Ostomy Association Conference, Bangkok, November 2005

Mongolian President and Ostomy International Editor , Anne Hafner at the Asian Ostomy Association Conference, Bangkok, November 2005

Mongolia Stoma Care Workshop 2005

Mongolian President and Ostomy Association - 2005

Farewell dinner with Rotary President Mrs. Enhtuya Ch., Mongolia

Memorable gift from Mongolia in its wilderness

Mongolian barbeque party
VIETNAM

Vietnam Stoma Care Workshop 2005

Educators team, Vietnam

Dr. Buch and Mrs. Di Bracken with Mrs. Dao Ngoc Nu (President) and Mrs. Do Thi Phuoc Chau (Vice President) of the Vietnam Ostomy Club

Dr. Buch, Ms. Tai, Mrs. Di Bracken, Dato’ John Cardosa, Ms. Phang and Professor Carlo Pezcoller

Discussion with local Ostomates at Lunch time

Live demonstration of irrigation of a colostomy

Enthusiastic Mrs. Di Bracken and delegates during a live demonstration

Delegates at a stoma care workshop

Answering queries

Hands-on experience

With local ostomates of Ho Chi Ming City, Vietnam

Participants, Vietnam

Certificates to participants, Vietnam

Precious gifts to educators

Outside the main entrance

Fun in the ropeway, Vietnam

Meeting with generals in the underground Co Chi Tunnel office

Siesta, Ho Chi Minh City

Thanks to Dr. Harikesh Buch for allowing these photos to be reprinted.

EUROPEAN OSTOMY ASSOCIATION

Submitted by Arne Holte, President EOA

With more than 40 associations for ostomates EOA is a great organization which gives the CC (Co-ordination Committee) some real challenges. Differences in culture and language are the main reasons, and we struggle quite a lot to keep our directory up to date. Fortunately, Maria Hass from German ILCO takes care of the directory on behalf of the CC. Maria is familiar with both French and English in addition to her mother tongue, of course!

The CC has had one meeting since the Congress in Porto last year.
IOA MEMBER NEWS

continued

The meeting took place in Frankfurt where we amongst many other things decided to send associated member of the CC, Rita Silanos, to Greece to try to start an organization there for ostomates. The CC also urged Rita to go to Spain if necessary to help create an umbrella organization there.

Ria Smeijers from The Netherlands is our finance minister. She takes care of our budget and checks that we do not use too much money! Fortunately our financial situation is reasonably good.

Our Newsletter has been published twice – which really can be called a miracle because the editor Efim Krasner from Ukraine became seriously ill and passed away in the middle of the year. He had started working with edition number three which we hope can be published some time in the autumn. With a kind contribution from Denmark, The Netherlands, Norway and the EOA-CC, Efim bought a laptop which enabled him to work from his bed to his last days. For the CC it very useful that Efim spoke and wrote in both English and Russian in addition to Ukrainian. He will be missed by all of us. Associated member of the CC, Trixi Schröter, from Germany also has something to do with our Newsletter.

For my part I do my best to answer both people and organizations sending me questions about personal problems and how to start organizations in countries where there are no organization for ostomates. One important issue has been to have a person going from Russia to Odessa in Ukraine to teach nurses there. We were grateful for sponsorship from the Australian fund, but due to lost contact with the person in Russia nothing has taken place so far. Hopefully we will solve this problem in a short time. As relief co-ordinator in IOA I use quite an effort to help whenever I can. Such help will often be to put applying persons in contact with somebody who can help. I also urge developed countries to “twin” with underdeveloped countries.

Our next meeting was held in Frankfurt in October. We concentrated on an easy-to-understand questionnaire, which will be sent to all member organizations. It is very important that we know as much as possible about how the situation is for ostomates all over Europe.

In 2006 there will be a meeting for visitors in England. This will be organized by ia (Ileostomy Association) of the United Kingdom. It is likely that we will start planning for a “twinning-workshop” in Lithuania, hopefully this will result in more Twins all over Europe.

Since 2000 the National Ostomy Association of Austria (Österreichische ILCO-Stoma-Dachverband) as a roof organization is managed by the executive board of 6 honorary persons. They are all ostomates. We are mainly financed by advertising of companies for ostomy supply and local suppliers in our journal “ilco Magazin”, published twice a year. The main topic of the last two issues was “Stoma and Sexuality”. You can also find further information and all dates of meetings in the regional ostomy groups.

There are 13 independent regional ostomy groups all over Austria and one group for younger ostomates in Vienna. Each group can be member in the roof organization for free. All members received our journal, other publications and information they want without any costs.

We know that there are nearly 100 members in the regional ostomy group of Vienna and we assume that there are nearly 250 members in the other regional groups all over Austria.

There were visitor advice services in most of the regional ostomy groups and excursions, periodical meetings with information from doctors, ETs, social workers, ostomy suppliers etc. In some of the hospitals the visitor service is not well accepted. It depends on good co-operation between doctors or nurses and ostomates of the visitor service. Usually the ostomates get medical after care as outpatients in the hospitals. Most of the ostomy supplies are free for the ostomates.

We also collected ostomy supplies and organized the transfer to countries in Eastern Europe and the Far East. Furthermore we are in good contact with Ostomy Associations in our neighbouring countries.

The highlight in 2005 was the 30th Anniversary of ilco Austria. The birthday celebration took place at June 11th, 2005 in Burgenland, the eastern part of Austria next to the Hungarian border. The day before there was a dinner with the presidents and colleagues from Germany, Switzerland, Czech Republic, Hungary, Slovenia and Northern Italy. Also the IOA Vice-President, Dr. Vladimir Kleinwächter joined the meeting, with the presidents and colleagues from Germany, Switzerland, Czech Republic, Hungary, Slovenia and Northern Italy.

Nearly 160 guests from the different ostomy groups in Austria and the neighbouring countries, doctors, stoma therapists, representatives of social politics and of companies for ostomy supply took part in the celebration. The program started with official greetings and speeches from Mrs. Kimbauer (our Chairwoman), social politicians, the IOA Vice-President and the Chairmen from our neighbouring associations.

Mrs. Deimel guided the attendees through 30 years of history. Some ostomates were honoured for long membership and a German flute orchestra set a wonderful background with classic music. The official part ended with a PowerPoint presentation by stoma therapist Mrs. Waltraud Unal concerning the “Daily Life With an Ostomy”.

After lunch a sightseeing tour for all participants was organised. The invitation to a typical local Austrian ‘Heurigen’-restaurant gave the
opportunity to finish this day in a good atmosphere.

Due to this event the ilco-Dachverband published a special brochure “30 Jahre Österreichische ilco” with notes from the Minister of Public Health Mrs. Maria Rauch-Kallat, the IOA President Mrs. Dietlen Bracken and others.

After this optimistic birthday event and 30 years of experience the Executive Board looks forward into the next decade. For the near future we know that there are many different tasks to fulfill by a few volunteers: the assistance for help seeking ostomates and their guiding to one of the 13 regional ostomy groups (there are nearly 350 members in these groups), the publishing of the “ilco Magazin” twice a year, the serving of our homepage www.ilco.at, the presentation of ilco in nursing schools, hospitals and info-points on special events, the care of sponsoring, the efficient relations to the Sanitary Board, to the companies for ostomy supply and to local suppliers etc.

The celebration was also an international occasion to meet new friends from the neighbouring countries. They told us about their experiences and the exchange of views supports us in our voluntary work. It makes us stronger and more optimistic to know that there are friends around us at any time.

Members of the Executive Board with guests from Germany, Hungary, Slovenia and Czech Republic

Above all we have already started with necessary preparations of the next EOA Congress in the city of Brno in 2008. Let me tell you some words about this second greatest city of the Czech Republic. Brno is an old town with wealth of history behind it. The slender spires of Petrov - the St. Peter and Paul Cathedral - unfold their story of birth amidst ancient settlements lying at the foot of the proud castle Špilberk, the fortress of the Bohemian kings, tower above the medieval city. Churches and palaces of the nobility all remind us of the city’s famous old guilds and the ancient wisdom of its ancestors.

At present Brno with 385 thousands of inhabitants is a city where commerce and business play an important role. Commerce accompanied the city’s earliest beginnings, when it served as a prominent marketing-place on the great road joining the Baltic with the Mediterranean.

Business interests intermixed here and the outcome of this ceaseless progress and tradition is reflected in the International Fairs and Exhibitions of our times. The 130 km distance from Vienna Airport provides a good connection to the whole world.

Brno is also a prominent science, education and art centre. About 35 thousand students study at four universities with twenty-six faculties. Ten theatres where the famous Janáček Opera and the Brno Philharmonic Orchestra are very well known in Central Europe. The art here had ample scope to flourish throughout the ages. Charm is the city’s chief asset. For the vast green strip of woods and fields stretching from the highlands penetrates to very core of Brno’s centre with its numerous gardens and parks.

We are looking forward to seeing you in Brno. If you are interested in attending the 12th EOA Congress 2008 e-mail me at krusin@seznam.cz and we will give you more details as they become available.

CZECH REPUBLIC

Czech ILCO

Submitted by Ing. Miroslav Šerý , Chairman

The Czech ILCO Annual Meeting has been held in Brno in November 2005. Delegates of 15 Ostomy Clubs from the whole country took part in evaluation of the activity in the period of 2003 – 2005. Each club provided information on their activities, collaboration between health care professionals and clubs and on building a support network among ostomates. The closing discussion was related to how to strengthen the membership of new ostomates and clubs, which are not members of Czech ILCO yet.


The new Executive Committee is ready to handle all main topics of ostomate activities so as to improve the quality of life of ostomates – finding of funding resources, improving information exchange and help from medical profession and manufacturers of ostomy appliances, organisation of rehabilitation courses and visiting service and maintaining contacts with authorities of the Ministry of Health.
Submitted by Henning Granslev
President of COPA

Here are some facts from the year 2005 in The Danish Ostomy Association COPA. COPA was founded in 1951, as the first national ostomy association in the world. The letters "COPA" stand for Colostomy PATient, as it was the most common ostomy at that time.

COPA is a member of the following associations or societies:
- IOA, International Ostomy Association
- EOA, European Ostomy Association
- NOA, Nordic Ostomy Association
- Kræftens bekæmpelse, Danish Cancer Society
- DSI, Danish Handicap Association

COPA co-works with:
- FS, Danish ET Nurses Association; CCF, Danish Colitis Crohns Association and all manufacturers of ostomy products in Denmark.

From the middle of April to the middle of June, Coloplast Denmark arranged for a bus to travel the whole country. Here it was possible for all interested people to visit the vehicle and see something new from Coloplast and to get some good advice about the products. It was also possible to have a little conversation with a person from the Danish Ostomy Association, COPA.

Junior COPA was held in the spring, with a weekend camping together with a couple of parents. They have some funny days together with swimming, bowling, making food and excursions etc. The age group is generally from 14 to 18 years.

From June 13 - 18 2005 the grown-up members together with their spouses vacationed in a hotel for five days in the beautiful little city Dragør, close to Copenhagen and had a pleasant time together with equal persons. There were also some excursions and a closing evening on Friday with dinner and dancing.

On the last weekend in August, 62 COPA members vacationed at a hotel in the town of Faaborg at the isle Funen. These participants were generally a mix of people who are working and retired and did not want to have a whole week together with other COPA people. A weekend is fine and long enough. Many of these members have been through this arrangement a lot of times, so it is like a big family who wanted to be together for a few days. Many members have warm and good friendships.

In autumn there is the family weekend. It is for parents with children who have an ostomy or reservoir or an illness which can be a reason to operate to make an ostomy or reservoir. During this weekend the parents listen to lectures from doctors, nurses or from the authorities that know and can give good advice about the life for parents who have a child with a serious illness. The children have activities together with their brothers and sisters.

All over the country there are 16 local COPA divisions. We conduct meetings with doctors, producers, dealers and elections for the local COPA board. The local divisions decide exactly what sort of activities they want. In COPA we have 3300 members. It is 100 more than the last year. So we are growing, maybe slowly, but in the right way.

COPA wishes all our friends all over the world a happy and healthy 2006.

Submitted by Dr. Naguib Elnikhaily, M.D.

On behalf of the Egypt Ostomy Association, I would like to send to you a report for 2005.

We received two donations, one from the United States of America and another from an Egyptian doctor living in England. We have also bought a lot of supplies from Egypt so as to distribute them to the needy poor ostomates to whom we give four pouches and wafers each month. We also train new ostomates, we give them and their relatives advice on how to deal with their stoma. We care spiritually, socially and financially.

FINLAND

Finnilco consists of 18 local chapters and two national associations, called IPAA (J-pouch) and Anniko (Anal Incontinence). The total number of members of Finnilco is about 3000. The oldest local associations began their activities over 30 years ago. Finnilco works in cooperation, among others, with Cancer Society of Finland, Cancer Patients of Finland, KELA -The Social Insurance Institution of Finland, RAY-Finnland’s Slot Machine Association, Enterostomal Therapists of Finland, NOA (Nordic Ostomy Association), IOA (International Ostomy Association), EOA (European Ostomy Association) and ESTILCO (Estonian Ostomy Association).

The board has six members consisting of the chairman and members and they are elected for a period of one year at the autumn Annual Meeting. The board has five meetings a year taking place in different cities around our country.

At the Annual Meetings (held in April and in September) each member association can send two representatives. The travel and hotel expenses of the representatives are paid by both Finnilco and the associations together.

The office is situated in Kerava near Helsinki, our capital. Tarja Smalen, the full-time secretary, takes care of all the routine matters of the organization.

The rehabilitation courses: During the year 2005 we had seven courses:
- One course designed for the recently operated ostomates.
- Two courses held for ostomates only.
- Four courses held for the ostomates and family member/s (wife, husband, sister, brother, daughter, son, etc.)

The length of the courses varied from three days to one week and the numbers of the participating persons were between 12 and 30.

We got about 70,000 euros from the society for our course activities,
so for the participants the courses were fully funded, with even their travelling expenses paid.

This year we have received from the society the same sum of money to be used for the rehabilitation courses. Naturally we in Finnilco are very proud and satisfied. We have really something valuable to give our members and other Finnish ostomates and so to help their lives as ostomates.

8th ECET Congress: “The Sun Never Sets in Stomacare” The Congress was organised by ECET 2005 (European Council of Enterostomal Therapists) for ETs and those interested in the care of ostomates and attracted 1100 participants from 38 countries to the Helsinki Congress Centre towards the end of June. The majority of the participants naturally came from Europe, but there were also guests from countries as far as India, Japan, Australia, South Africa and Brazil. The theme of the congress was in fact “The Sun Never Sets in Stomacare”. During those three days dozens of lectures and introductions of a high level were heard on stomacare, wound care and incontinence care both for children and adults. The number of poster presentations amounted to approximately fifty and more than ten international stoma care companies exhibited their products. Feel free to take a closer view of the summaries of the lectures at the following Internet address: http://www.congrex.fi/ecet2005/images/abstractbook.pdf

6th education period of ETs in Finland: At the end of November twenty-two new ETs were qualified in Tampere Vocational University. They work in different parts of Finland. At the moment we have the total of 105 qualified ETs, whose duties include to further educate the nursing staff in stomacare. Unfortunately however, they do not have all actual positions as ETs, but have to teach stomacare in addition to their own jobs in hospitals and health care centres.

~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~

FRANCE

Submitted by Thierry Schuster
on behalf of S. Janot, Secretary and G. Gatignol, President

The General Assembly of April 15, 2005 opened in the Maison de la Mutualité in Paris at 9.50 am. 28 associations were represented (total number of associations is 54).

All participants were welcomed. Programme: General report, financial report, election of 5 members for the Administrative Committee.

General report: The number of members is decreasing. The Ministry of Health and Ligue Nationale Contre le Cancer were asked for subvention to train people for an efficient visiting service, to train freelance ETs and to publish information material.

The financial report of the French Ostomy Association was adopted. The next National Congress of the French Ostomy Association will take place in Paris in 2006.

Dr. Ollier presented his project to train ostomates participating in a visiting programme which lasts one and a half to two days. Mr. Soler, President of URILCO Paris, and Mr. Humbert, President of A.S.H.B. Rennes, presented a project “Information – Meeting Point”. Mr. Humbert presented a project with the University of Rennes to facilitate access to hospitals, a project in co-operation with the League Against Cancer.

Thierry Schuster proposed a second meeting of young ostomates in 2007. Workshops on visiting service and help for people in difficulties were also conducted.

~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~

GERMANY

Submitted by Maria Hass
responsible for Public Relations and Social Politics

Bowel Cancer – A New Activity Field: Since January 2005 Deutsche ILCO has officially expanded its activity field to people with bowel cancer also without an ostomy: Now we are the national association of ostomates and of people with bowel cancer and – of course – their relatives. This had unanimously been accepted by the House of Delegates. Naturally such a fundamental decision has a lot of consequences for the daily work: The mission had to be changed (you will find the new one below), many persons and organizations had to be informed of the change, the regional chapter leaders of Deutsche ILCO had to be instructed how to realize the new tasks, all information materials must be checked and gradually adapted, new information material must be developed. So we do not fear any boredom!

In connection with this Deutsche ILCO has already created a new offer. A phone-network had been formed with experienced and
**New Mission of Deutsche ILCO:** Deutsche ILCO is the association of ostomates and of people with bowel cancer and their relatives in Germany. Its work is determined by the principles of self-helping, voluntary co-operation and independence related to the contents and finances. It orients itself only by the interests of ostomates and of people with bowel cancer. Deutsche ILCO is committed to assist all affected people in Germany to act in a self-determined and independent way also with the ostomy and with the bowel cancer. Deutsche ILCO offers individual assistance to them by literal and written information, the exchange of experiences and advice relating to questions of the daily life with an ostomy as well as the daily life with bowel cancer, and the representation of interests in ostomy related and in bowel cancer related matters.

Deutsche ILCO endeavours to remove tabooing the ostomy and bowel cancer. It advocates for high quality and for quality guaranteed professional care and it advocates as well for the availability of the needed ostomy appliances and medicine without an unacceptable financial burden. Deutsche ILCO supports initiatives advancing prevention and etiology.

Deutsche ILCO needs many members in order to carry out its task with emphasis and independence. Deutsche ILCO endeavours to improve and guarantee the quality of its offers by training and supporting its voluntary co-operators.

**Age Limit also for Voluntary Co-operators:** During the House of Delegates also another motion had been carried: All candidates for the national board and for the boards on state level must not be older than 75 years at the time of election, the candidates for the regional chapter-leaders must not be older than 80 years at the time of election.

**National Board Elected:** The election of the national board was another important task for the House of Delegates. All seven candidates have been elected. The former chairman of Deutsche ILCO is also the new chairman: Professor Gerhard Englert. He has been elected unanimously for the next three years.

**Standards for Out-Patient-Clinics:** Out-patient clinics in Germany offered a big variety in treatment and advice for ostomates however, not every clinic had satisfying offers concerning the needs of ostomates. Deutsche ILCO achieved an improvement and developed a list with the important ostomy-related offers in treatment and advice (medical, psychosocial and in stomacare). Those clinics which signed on these standards are published on the website of Deutsche ILCO. Every new member receives a little questionnaire concerning his experiences in the out-patient clinic. The answers allow a good control whether the clinics follow the signed standards or not – if not, Deutsche ILCO will contact the clinic again to discuss the problems. If a clinic does not take care for the improvement it will no longer be mentioned on the ILCO-website.

**New Fixed Amounts for Ostomy Appliances:** Since January 2005 the health insurance companies pay lower amounts for ostomy appliances. Therefore those companies, home-care services, suppliers and pharmacies who provide or give ostomy appliances to ostomates receive less money through the insurance. Naturally, this decision had been accompanied by protests and warnings that the touched companies could not guarantee the same service as before. A lot of ostomates had been worried by this information and contacted the office of Deutsche ILCO and the chapters. It took a lot of work to calm the disconcerted ostomates and to explain to them the coherence in phone calls and in written information.

Up to now Deutsche ILCO cannot see a real worsening as mostly the ostomates themselves are not directly touched, but it is necessary to pay further attention to this matter because if things worsen it is important to act immediately. Therefore Deutsche ILCO had organized a discussion forum in October 2005 in Berlin. Representatives of Deutsche ILCO discussed these problems with representatives of the Ministry of Health and of health insurance companies, representatives of the associations of companies, home-care services, suppliers, pharmacies and stomal therapists. It is of no surprise that it has been a very passionate discussion. The interesting information during this exchange of ideas will be helpful for the next steps of the advocacy work of Deutsche ILCO.

**Meeting of the “Kangaroos”:** The annual meeting of younger ostomates – the “Kangaroos” – took place in Dresden in the beginning of October 2005. For three days about 50 ostomates between 20 and 50 (and some of their relatives) came together. A warm welcome was given by an ostomate disguised as a kangaroo. Lectures about stomacare and healthy nutrition was the basis for many discussions.

Of course there was also plenty of time out of the official programme to exchange personal experiences in living with an ostomy. Visits of the town and a guided visiting tour to the famous sights had also been on the agenda of the meeting, and the dancing-party must have been really enjoyed by the participants.
ily member. The meeting was greeted by Professor E Robinson, the chairman or the Israel Cancer Association and the Past President of the IUCF. The lectures presented dealt with the following subjects: How to get old?, Who is at risk for colorectal cancer?, The importance of exercise, and News about the developments in the health system presented by Mr. M. Gissin, the President of the Israel Ostomy Association. The 20-40 group presented their new brochure and the aims of the group. Like every year there was a commercial exhibition of ostomy products and also round tables with stoma nurses for those participants who wished to discuss their problems.

Twelve new visitor volunteers were trained in Haifa; four day meetings were guided by stoma care nurses, Mr. Heinz Wolff, the Past President of IOA and a social worker of the Israel Cancer Association. They got a program that included detailed information on the underlying diseases that may indicate stoma surgery, types of stomas, physical and psychosocial problems encountered during different stages of rehabilitation and patient rights. In the last meeting simulation of visits was practiced and now the volunteers are supervised by a stoma care nurse.

"Pithon Pe", the newsletter of the Israel Ostomy Association is published twice yearly and is sent to all the registered members and health professionals. It publishes articles on topics concerning the membership, the two last issues presented articles on nutrition and stoma besides the usual columns about national and international meetings, contact information of stoma care nurses and also advertisement of stoma care products.

The 20-40 group is growing steadily; more young people contact the two volunteers who are very dedicated. They printed a special brochure, held meetings with surgeons, stoma care nurses and also are in the website of the Israel Cancer Association.

NORWAY

Submitted by Arne Holte, President NORILCO

This year there has probably been more activities in NORILCO, Norway, than ever before. Eager volunteers both in the executive board and outside have had a lot of gatherings and courses. In April all the 22 Presidents from the local chapters were gathered to a meeting in Oslo. The Vice Presidents, the three employees and the Executive Committee of youth groups took part in the meeting where several important issues had to be decided. The most important was if NORILCO should take over the employers’ responsibility for the employees. Up to then they had been employed by the Norwegian Cancer Union.

There were a lot of questions due to the fact that many feared for the future economically. Some also were afraid that the good relationship to the Cancer Union would be broken. However, a representative from the Union, in her speech, told everybody that both economically and in all other ways NORILCO had nothing to fear. The good relationship and the tight connections should be just like before, and the Union will pay the same amount to NORILCO every year as before. So then, when the three employees told the meeting that they wanted NORILCO to take over the responsibility, there was no doubt in almost every one, and the decision was that NORILCO shall take over the responsibility as soon as technically possible. The take-over took place July 1 2005 and so far it seems that everyone is happy.

In June the visiting group, headed by Rigmor Yttergård, arranged a course for new visitors. This was the first time a national course like this took place on a national basis; earlier such courses have been arranged locally. Just before the course Rigmor Yttergård became seriously ill, but the other members in her group managed to fulfill the course very successfully, which proves good organization. Now Rigmor is well again, and she has already been responsible for a new gathering. This time for urostomates only, the venue was Trondheim and close to 30 people with urostomies took part.

Our traditional summer camp for families took place in a hotel by the Oslo-fjord. The program was as it used to be, both of a social and professional character. Tours to museums and a barbecue are just two things the 60 participants experienced during the one-week-long camp. Camp leaders were former President of NORILCO, Jorunn Movold, and Eli Øvretvedt.

NORILCO is still working hard so that NORILCO’s visiting service shall be a mandatory part of the rehabilitation of people with an ostomy or internal pouch. President Arne Holte met the Minister of Health, Ansgar Gabrielsen, in Oslo in August stressing just this matter. Judging from that meeting and also from all signals from the authorities our goal is within reaching distance in the near future.

We are invited to co-operate with the health care service in accepting new appliances and also fade out the ones nobody seems to use anymore. A group has been established in which also the WCET members are represented. During the last months a new nationwide telephone system has been established. The idea is that wherever and whenever anyone wants to get in contact with NORILCO, they shall get such a contact.
The number of the ostomates people in Gaza Strip is now over 200. As a result of the attitude of the Association’s new Board of Directors in developing the service yielded to the patients to include health, psychological and social care, the Association rented a new place, in a better location compared to the old place, in order to serve the patients in a better way. The new place consists of three rooms; a meeting room and storeroom, a kitchen and a bathroom.

We have established a medical clinic inside the place of the Association. A surgeon and a nurse work in this clinic for the meanwhile and they follow up the health condition of the patients and offer them the needed guidance. We have founded a psychological and social support unit where a psychiatrist and social worker work. They offer the ostomates the psychological care and solve their social problems.

Seven employees are now working in the Palestinian Ostomy Association (General Manager, Secretary, Physician, Nurse, Social Worker, Psychologist and cleaner). For the meanwhile most of them are volunteers, and work for symbolic wages.

A Consultative Committee was formed at the Association which includes a number of specialists in different fields. It offers consultations concerning rehabilitation and health care to ostomates.

The Association is still offering ostomy bags and flanges to the patients according to its possibilities. The Association was supplemented with some of these needs from some local donors. It is worth mentioning here the necessary need for these materials because it is expensive in our country and the patients can not afford to buy their appliances especially in the hard economical conditions our people suffer from, as a result of the siege and closure. The Association suffers from a lack of these materials and we are trying to offer these materials through the donations that the local society presents for the Association on an irregular basis.

The projects and the studies: The Association made progress in the projects field in the past year. It prepared a number of important projects related to the ostomates and some of these projects were prepared and financed by sponsors. The Association executed these projects and sent its circulatory reports to the donor agencies, and this is a brief summary of the executed projects throughout the last year:

(A) Project of providing home care to ostomy patients: This project was financed by the Arab Doctors Union in Egypt. The budget was about $9,500. This project was executed throughout the three months from July to October 2004. A medical team consisting of a doctor, a nurse and a social worker made home visits to ostomy patients in Gaza strip to look after patient's health, social and psychological status. A health services and social support were presented to those patients and this project has a good effect for the patients and on their families.

(B) Providing stoma appliances project: This project was financed by the Emirates Red Crescent throughout Emirates Friends Association in Gaza. This project started in August 2004. The Association was provided with the colostomy bags and flanges for ostomy patients, and the total cost of this project was $10,000. This project covered the patients' needs for these medical appliances for a long time and it has had a good effect on the patients and their families.

(C) Project of enforcing health and rehabilitative services to ostomy patients: This project was financed by the charitable committee for supporting Palestine in France. Its budget was $20,000 and it was executed in accordance with Alwedad Association for society rehabilitation. This project started in April 2005 and lasted to September 2005 for a total period of 6 months. This project works to provide health, psychological and social care to ostomy patients through home visits and educational meetings for the patients and presenting guidance programs to their families.

A specialized staff worked on this project including a doctor, a nurse, a psychiatrist and a social worker in addition to the manager of the project who is following up the work for the Association’s Board.

(D) Project of checking up the genetic relationship of colon cancer: Lately the Association began to execute this project in co-operation with Professor Suhail Ayish, a consultant in Molecular Biology. This project aims to prove the genetic relationship in colon cancer through genetic checks of the patient and his family which helps in detecting intestinal cancer early to decrease its consequences. The Association cares for publishing the need for a specialized centre for revealing intestinal cancer to fight this disease.

The association has acquired land in Beit Lahia from a donation from one of the charitable men of our local society who was convinced of the important role the Association plays in serving the patients. This land is 600 square metres and the headquarters of the Association will be established on it. Now we are exerting all our efforts to have a fund in order to establish a building for the Association on this land and we will call it “Fixed Centre of the Ostomates Care “. We have prepared the design plans and engineering layouts for this building which we hope to establish soon because our recent place is rented and our financial conditions do not allow us to pay the high rent fees of $3500 per year. The Association has no constant income except the fees the members pay and some donations which are not enough for our work expenses. The new building we intend to build will consist of three floors and contain many of the important utilities for the ostomy patients.
approval from the U.S. Agency for International Development (US AID) and Save the Children Fund (SCF) in Gaza to fund the project of establishing and finishing the centre of caring and rehabilitating the ostomy patients. The centre (“Fixed Centre of the Ostomates Care”) will be the permanent headquarters of the association instead of the current rented place. We expect this project to contribute in developing and improving all the services offered to the ostomy patients in Gaza Strip whose number is over 200.

The agreement was signed by the chairman of the Palestinian Ostomy Association Mr. Rafeeq Mikki and Mr. David Hassel, the manager of Save the Children in Gaza Strip, in the presence of Mr. Wael Al-Sayegh, representative of the USAID in Gaza Strip.

The Association is organized into 21 Regional Branches. At least once a quarter ostomates are active in the Association. They hold coffee meetings, organize meetings with distributors of ostomy equipment, trips and meetings with ostomates from other countries (in Branches located near the border). At the end of the year at Christmas meetings our members wish one another all the best in the New Year. We have attended a lot of meetings organized by companies such as Coloplast, ConvaTec and Dansac.

In 2006 one of the Branches will host the national meeting of ostomates as a part of the World Ostomy Day (WOD).

We participated in the 2nd Congress of the Organization of Cancer Patients from Eastern and Central Europe and joined The European Cancer Patient Coalition (ECPC).

We hope that in the year 2006 we will manage to ensure that the number of reimbursed equipment is increased, which will provide a better quality of life to all ostomates in the country.

POLAND

POL-ILKO (Polish Ostomy Association)
Submitted by Jerzy Kasprzak, POL-ILKO President

In 2005 the new Management Board of the Association, elected in November 2004, started its operations. Ms Alina Matysiak, who had been the Association’s President for many years, was awarded Honorary Membership of POL-ILKO. Alina will be happy to advise and support the new Management in its operations. Mr. Jerzy Kasprzak, the former Vice President, was elected the new President.

The first meeting in February 2005 was devoted to setting the directions for the Association’s activities in the near future. They will be focused on two main areas:

1. Recruiting new members and enhancing voluntary work as well as close co-operation with the hospitals where ostomy surgeries are performed. The training of volunteers will be continued with the participation of a psychologist who has been working with our Association since its establishment.
2. Continuing the activities aimed at making the reimbursement limits on the equipment more realistic.

With Poland’s entry into the European Union in May 2004 VAT on ostomy equipment was introduced, which in turn resulted in limiting the reimbursed number of pouches by 4 to 5 a month. The efforts of the Association’s Management to make the quality limits more realistic (at least to reflect the amount of tax introduced) have had no effect so far. Apparently Poland is the only country where two types of limits are used - the quantity limit, amounting to 90 disposable pouches per month and the quality limit, which covers the need of ostomates only in ca. 45 – 60 % of the quantity limit. It seems that due to frequent changes in the management of the Ministry of Health (7 ministers since 2002) and the National Health Fund (8 Presidents since 2002) the issue of stoma and the equipment needs of ostomates has not received enough attention and understanding. Changing this situation will require a lot of efforts.

In 2005 the Association’s Management to make the quality limits more realistic (at least to reflect the amount of tax introduced) have had no effect so far. Apparently Poland is the only country where two types of limits are used - the quantity limit, amounting to 90 disposable pouches per month and the quality limit, which covers the need of ostomates only in ca. 45 – 60 % of the quantity limit. It seems that due to frequent changes in the management of the Ministry of Health (7 ministers since 2002) and the National Health Fund (8 Presidents since 2002) the issue of stoma and the equipment needs of ostomates has not received enough attention and understanding. Changing this situation will require a lot of efforts.

The main problem for stoma patients in Russia up to 2005 was the existence of the economic barrier in obtaining contemporary stoma care products. Only in 8 of 89 regions this problem has been solved by means of budget money and patients have got necessary stoma care products.

At the beginning of the elaboration of the social reform the organization “ASTOM” has offered to introduce stoma care products into “The list of technical means of rehabilitation for invalids of Russia” worked out by the Government of Russia. According to this ‘List’ every stoma patient can get necessary stoma care products free of charge in any region of Russia. This was our main achievement.
Other achievements. With the aim to unite stoma patients in Russia into a single organization, we suggested to create the Co-ordinative Council of Regional Public Organizations of Stoma Patients of Russia. Our initiative was supported by nine regional organizations of stoma patients. In August 2004 the Co-ordinative Council was created. It united Russian stoma patients and gave an opportunity to develop the process of the integration of stoma patients of Russia.

The next step was to sign the Protocol about the co-operation between the Co-ordinative Council of Regional Public Organizations of Stoma Patients of Russia and the Association of Russian Proctologists with the aim of mutual activity to develop stoma therapy and all directions of rehabilitation of stoma patients in Russia.

The important result of this co-operation has been the elaboration of the document “Standards of rehabilitation arrangements, provision of technical means of rehabilitation and the provision of service for stoma patients”.

These standards are necessary for conducting qualitative rehabilitation of stoma patients in Russia, systematization of rehabilitation arrangements, standardization of the provision of stoma patients by stoma care products with the aim of the entire re-integration of stoma patients into the society.

This document has been approved by the Ministry of the Health Care and Social Development in Russia and the Federal Fund of the Social Insurance in Russia. In accordance with the new social reform all invalids in Russia including stoma patients are provided by technical means of rehabilitation with the help of this Federal Fund. The organization ASTOM has played an important role working within the Co-ordinative Council with the Association of Proctologists of Russia in this process.

The result of the co-operation of the Co-ordinative Council of Regional Public Organization of Stoma Patients in Russia and the Association of Proctologists of Russia was a meeting with the delegation of American nurses specializing in caring of invalids with chronic injuries and stoma headed by Miss Laurie Mc Nichol the President of the Wound Ostomy Continence Nurses Society. This meeting was organized on the initiative of the American public organization “People to People Ambassador Programs” with the aim of exchanging experience.

We continue to co-operate with the Ministry of the Health Care and Social Development of Russia with the aim to increase the quality of services to stoma patients, development of therapy and the process of providing all stoma patients in Russia stoma care products.

With the aim of improving and increasing the level of the rehabilitation process of stoma patients the organization ASTOM co-operates with the Moscow State University of Service. We can cite as an example that the scientific seminar for the employees of the Office of the Medical and Social Examination has taken place. This seminar was prepared and conducted by the organization ASTOM together with the Moscow State University of Service and the Department of the Social Support of Moscow.

The other examples of the scientific activities are as follows:

- Defending dissertation Thesis for the degree of the Candidate of Sciences by the President of the organization ASTOM Vyacheslav Sukhanov. The topic of the dissertation is “The Social Rehabilitation of the Stoma Patients in Modern Russia: Sociological Aspect” and including the chapter “The social rehabilitation of stoma patients” into a textbook for University.
- Publishing materials about the problems of stoma patients both for the patients and for the specialists in the sphere of social service.

The organization ASTOM is financed on the basis of money given by Moscow through the Charity Council of Moscow and sponsors – companies Convatec and Coloplast.

This support gives us a chance to organize charitable activities:

- Providing home visiting service (hot meals) for disabled patients.
- Collecting, processing and entering social data about stoma patients into the computer program BD “Social Register of Stoma Patients”.
- Work of specialists with stoma patients in all directions of the rehabilitation after the operation.
- Conducting lectures and seminars connected with the problems of stoma patients.
- Providing invalids with stoma manuals containing recommendations about all problems which they face after operation and in everyday life.
- Organizing holiday arrangements devoted to the anniversary of the Victory in World War II and congratulating the participants of the Great Patriotic War – invalids with stoma and giving them presents.
- Establishing the hot-line in order to consult patient in the system “question-reply”.
- Helping of stoma patients in employment.
- Helping stoma patients by providing them with stoma care products.
- Helping needy stoma patients with money in special cases.
- Providing stoma patients places in sanatoriums.
- Organizing leisure – visiting theaters and concerts, museums, exhibitions and historical places in Moscow and around Moscow.
- Taking part by the representatives of the organization ASTOM in the European and World Congresses of Associations of stoma patients.
- Taking part by the representatives of the organization ASTOM in the all-Russian conference of proctologists.

Now we are preparing a magazine for stoma patients of Russia and medical and social employees and those who take care about patients. In this magazine we are planning to create an international column in which there will be interesting materials from the “Ostomy International” in order to exchange experience. We would be glad and grateful if you could send us yours wishes for stoma patients of Russia which we are publishing in the first number of the magazine.

ASSKOL - St.Petersburg Ostomy Association

Submitted by Ludmila Koltunenko

Member numbers 452 people.

Among them: Under 30 years old 48
Under 50 years old 61
Under 70 years old 196
Under 85 years old 147
Council members 12 people.
Volunteer numbers 20 people.

Among them 12 people participated in Norway - Russian seminars in 2005. 8 people graduated the special courses organised in ASSKOL. Sergei Smirnov commenced as a volunteer in 2005. Volunteers visit the ASSKOL patients at their homes once per month in order to
provide them with some psychological help. Volunteers visit the new patients in hospitals once per two months in order to provide them with psychological adaptation. ASSKOL has helped 6 patients find jobs.

Special courses “Stomie School” have been organized for the new patients for their psychological adaptation. The leaders of those courses were Dr. Michael Zavialov and volunteers.

The World War Two veteran’s festivities were organized for the occasion of the 60th Anniversary of the Victory. ASSKOL organized two festivities for poor people in 2005. The ASSKOL Board had a seating every month in 2005.

A meeting between the ASSKOL President and Vice-President with the St. Petersburg Administration took place in 2005 in order to improve the situation for stoma patients as up to now there has not been enough money from the local government to buy the special appliances.

Free distribution of remedies for the stoma patients was organized every week in 2005. On behalf of my colleagues and myself I wish you every success in 2006!

SERBIA AND MONTENEGRO

Submitted by Ms Snežana Cmiljanić, President, Association ILCO Serbia

Information on the past and future activities is regularly published in different media. Every month reports appear in newspapers, television and radio regarding work and activities of the Association.

We were guests in radio programs about health; they are contact programs, involving the listeners who can ask us questions during the broadcast. Every Wednesday afternoon we organise get-togethers with ostomates and physicians. We invite psychologists as well, if necessary. We have noticed an increase in the number of new members after these get-togethers.

In October we have founded BEO – ILCO in Belgrade. Only in this city there are approximately 1500 ostomates and about 70% of the surgeries are carried out here. The Chairwoman of the organization is Dr. Mirjana Popović. She has had her ileostomy ever since she was 14 years old and lives with it for 43 years. Despite being a stoma patient, she has completed University studies in medicine. She has lived and worked full time in Switzerland. Nowadays she has retired and lives in Belgrade and is happily married for the second time.

On October 31, 2005 we celebrated for the third time the “Feast of St. Luke”, our saint protector. The host of the celebration was the Head of the Department of Surgery of the hospital where stoma patient, she has completed University studies in medicine. She has lived and worked full time in Switzerland. Nowadays she has retired and lives in Belgrade and is happily married for the second time.

On October 31, 2005 we celebrated for the third time the “Feast of St. Luke”, our saint protector. The host of the celebration was the Head of the Department of Surgery at the hospital where stoma surgeries are carried out. Our parish priest from the Ascension church came and we attended the ceremony of cutting the “Slava” cake.

Over the past year we have organized seven one-day excursions for our members. We participated at a meeting of medical personnel, the 10th International Congress of Health Institutions (October 2 - 4). We had a booth there, where we distributed information leaflets on stoma care to different societies of stoma patients, inviting health workers to help us with organizing patients’ societies in their cities.

We were also invited to participate at the International Conference about Palliative Care, which took place on October 21 - 22. We managed to get a lot of new contacts there.

On April 16 - 21, 2006 we shall celebrate the fourth anniversary of the Association ILCO Serbia.

Ms. Snežana Cmiljanić

Dr. Mirjana Popović
BEO-ILCO Belgrade (right)

SPAIN

EXPATRIATE OSTOMATES OF SPAIN (EOS)

Ostomizados Extranjeros de España

Submitted by Cynthia Robinson, President EOS

EOS is a legal charitable association registered in Madrid, with its registered office in Jávea, Alicante province in the region of Valencia. It is also (as the law requires) registered with the local Town Hall - a feat which took a whole year to accomplish! Our members originate from England, Switzerland, Sweden, Norway, America, Ireland, Scotland, New Zealand and Spain. Our common language is English (although we are helping other nationals in their own languages wherever possible). We estimate that the average age of the members is about 70 years and some are learning Spanish with great difficulty! Because ours is a particularly elderly population, several poorer members have found it necessary to return to their families overseas. Nevertheless, although we miss their company, it is gratifying for us that some have asked to continue their membership from afar. Total membership now stands at 116 across the country and islands.

COMMUNICATION: EOS is grateful to many of our fellow associations in IOA for their friendly contact, help, collaboration and patience during the last 12 months. We have always tried to respond, but, due to our work pressures, have not always managed to achieve this. We send our greetings and offer our sincere thanks to all.
The absence of telephone land lines prevents EOS members from having personal computer facilities and the use of mobile phones is the norm in many parts of Spain. Our main method of contact with members is our EOS Newsletter which this year has seen a development. We started it in 1998 with a couple of black and white pages of simple information, mainly for those who had never, nor were ever likely, to be seen by an ET. The criterion is the same, but now, as well as tips, members and other friends are contributing and the use of color and photographs is very attractive.

The down side is the cost, of course. We have no financial support from public funds and so have to generate an income by a small annual subscription and fund-raising activities. However, fortunately, we have found an excellent professional Spanish accountant who not only has offered to prepare our accounts, but has also given us our full set of books and has done this free of charge! Without a correct presentation of the accounts we would be in great trouble with the Spanish authorities!

SOCIAL: We made a good start to the year after the Annual General Meeting with a good luncheon at a seafront restaurant on a near-perfect day! Monthly meetings have continued throughout the year: these are usually in the Social Centre of our base town, Jávea, in Alicante province, where we have ‘Meet and Chat Sessions’ over coffee, often followed by tapas. It is a modern building with good bathroom facilities where the lighting is not automatic, unlike the majority of bars and cafés which allow about three minutes of light before one is plunged into darkness! In those places, even if one has a torch handy, the question is: “How to cope with that as well as everything else in a cramped loo?” Our fund-raising events have been very jolly with a Spring Lunch held in a country restaurant near our home town, the Summer Barbecue 170km to the south, and then there was our Christmas Lunch and Raffle which was again close to home. Fortunately, a few of our members do enjoy driving the distances and some are planning to fill their cars and come in convoy in future. We are happy to see that more members appear keen to get out and enjoy life in this interesting country.

GROWTH: After considerable planning, the second branch of EOS is about to be formally inaugurated in the south of the province. This should remove a considerable burden from the central office as the new branch starts to plan its own events. There is also now the possibility of arranging hospital visits outside our base area. Additionally, in the south small groups are getting together in some towns.

Our helpline brings new members who find us through our newspaper advertising, or else they are put in touch by overseas associations. Their needs are very different from the Spanish nationals who have an extended family system. Expatriates are often isolated in terms of language and location. Overseas callers usually need to discuss their medical/pension status with a view to obtaining their equipment. Within Spain, calls frequently come from people who have left hospital with inadequate supplies (sometimes one pouch) and not knowing how to cope. We discover that some have had their appliance adhesive placed on top of their stoma causing them unnecessary pain. Skin problems are a frequent complaint because of leakage. Where we know that there is an ET within reach, we give information to solve the immediate problem, and then make appointments with her at the earliest opportunity.

PROJECTS: Following our constitution, we are dedicated to helping ostomates wherever they are. In January 2005 we started an appeal for surplus stocks for the Tsunami victims. This was in addition to the personal cash donations, which were sent mostly via the British Red Cross. We had a collection point and also received boxes from our members by post. After packing by our working group, three consignments (around 60kg) have been shipped to SHARE in Glenview, Illinois. There are further shipments being prepared. Although EOS is quite a young organization, this is the second time that we have been able to send supplies overseas. The first time - a so-called “one off” event, happened when we took advantage of an opportunity to co-operate with a Spanish NGO and the Social Services who were taking goods overland to the Red Cross camps in Kosovo. This was before the large international agencies became involved there.

Continuing our earlier efforts at WOD4, we have continued to work for some form of Spanish Federation. In December 2004, we gave the IOA European Committee a list of all known Spanish ostomy associations and Presidents so that they could pursue their project to bring about a federation.

EOS SENDS GOOD NEWS FROM SPAIN!

In December 2005 we were invited to participate in the two-day National Congress on Ostomy held in Bilbao (Basque Region). We were happy to meet again with old friends, the association presidents who had celebrated WOD4 with us at our garden party in Jávea in 2002!

Everyone had to brave storms, high winds and cancelled flights, to come together from all corners of Spain: in addition to our Bilbao hosts, the north was represented by associations from Pontevedra and Alava, the north east by Zaragoza, the east by Barcelona, and the deep south by Jerez de la Frontera in Andalucia. The previous Madrid association AEDO has not functioned since 1992, and so the capital was represented by another recently-formed association which is awaiting legal registration. Our own EOS is different in being national and having its members living in various regions. In all, we were eight association Presidents and around 200 other attendees.

Each of the Presidents spoke of their own association, the problems they encounter and their special concerns. The EOS delegation was able to play its part and was happy to be specifically accepted in this company as a Spanish association.

After a Round Table debate, we all signed a Manifesto setting out the ostomates’ needs in Spain. This ten-page document is intended to be used by the associations in their dealings with central and regional government, the hospital authorities, etc. Three of the larger associations, Barcelona, Zaragoza and Bilbao, formed a committee in order to further the preparation for a Spanish Federation of Ostomy Associations - for which there is a clear need and desire.

We find this development both interesting and exciting because at WOD 4 we had invited our friends from all these corners of Spain with the express intention of beginning the move towards the formation of a national body for ostomates in Spain - and our effort has finally started to bear buds - if not yet fruit! I think we can now assume that there will be Federation in place - possibly by the end of this year. There will be another meeting called when the promoters are ready and if EOS is able to attend this, we will keep you advised as things develop.
We are grateful to the Committee of the European Region of IOA, in particular Rita Silanos and President Arne Holte for supporting our work in Spain.

Round Table discussions

Signing of the Manifesto

Manjares Restaurant, EOS

Christmas Lunch

United Kingdom

Urostomy Association

Submitted by Hazel Pixley
National Secretary, Urostomy Association

The Urostomy Association has had a good year in 2005. Our membership has increased again and we now have just under 2,500 members, in the UK, Eire and overseas, some being from as far away as New Zealand and the United States of America.

Unfortunately, we had the news this year that Macmillan Cancer Relief, who had funded our only full-time employee’s wages for many years, would not be doing so after December 2005. This leaves a very large hole in our finances, which we will need to fill from other sources.

During 2005, we have been heavily involved in consultations with the National Health Service in England, and the Scottish Health Executive in Scotland, as the Health Service looks to change the way our appliances are paid for. This work will continue in 2006.

On a brighter note, our National Annual General Meeting, which took place in October, was very well attended and everybody enjoyed themselves (particularly the music and dancing). After the business meeting, we heard several reports on research projects which had taken place during the year. There was also an exhibition of urostomy products and services. During the weekend our National President Mr Clifford Moisey stood down and Mr Philip Powell took over from him. We also have a change of Chairman as Mrs Angela Cooke takes over from Mr John Willshire.

Our National Annual General Meeting for 2006 will be held in Newcastle upon Tyne at the end of September.

North and Central America and Caribbean Region

Canada

Submitted by Doug Graham, Vice President, UOAC Chair, International Relation Committee

adg.uoac@sympatico.ca

I send greetings and best wishes from the United Ostomy Association of Canada to members and friends of our global ostomy family. We thank you for providing us an opportunity to share with you some of the activities of the past few months.

Our 8th Annual Conference that was held in Winnipeg, Manitoba from August 18 - 20, 2005 with the slogan, “Feel Alive in 2005” was a great success. A review of some of the evaluations provided by many of the 224 attendees confirm our success in providing educational experiences, fellowship and a glimpse of the beautiful and friendly City of Winnipeg that will be fondly recalled by all.

UOAC’s annual golf tournament and major fundraiser that is held in Toronto, Ontario was also very successful. The success of this tournament is proportional to the efforts of the area UOAC Chapters that continue to come out each year to plan and participate in the event. Distant participants, Chapters from across Canada, help out by sending gifts and prizes to support the tournament. The players enjoy the game. UOAC enjoy receiving the financial benefit and the Ostomy community receives a higher level of recognition by the general public of this not often talked of experience.

Our Youth Camp was held at Camp Horizon, Alberta from July 4 -11, 2005 accommodated 28 children, 5 full-time counselors and 2 full-time enterostomal therapists. From all reports they had a wonderful and confident building time. Old friendships were rekindled and new friends were made. It is gratifying to hear of the experiences these children share and in the short time they are together how their confidence is increased.

Our Board of Directors meet in Toronto from October 28 - 30, 2005. We reviewed our experiences of the past year and planned for our future. The agenda is full and the challenges and opportunities of the coming year are many.

Friends of Ostomates Worldwide Canada Report (FOWC)

Submitted By Astrid Graham, Shipping Director

The Shipping Committee was very busy trying to help as many needy ostomates as possible and requests came in plenty. I had repeat meetings with Embassies, arranged
Early in 2005 we received, through our FOWC website (www.fowcanada.org), a request from a young lady in Morocco. For her to continue working and helping to support her family she needed proper supplies. A helpful doctor from the USA could not continue helping her. I contacted the IOA International Relief Co-ordinator, Mr. Arne Holte, to see if a country nearer to Morocco could help out. After his investigation he came back and asked if FOW-Canada could help. After a number of email exchanges with Morocco and just to try it out, we packed a small parcel and with Postal Service and it arrived in Morocco without any difficulties and no custom taxes had to be paid. FOWC made a young lady very happy. We received pictures, including some showing her ostomy... a sad state. Just recently we received her story (see Rachida’s Story on page 38). For now FOWC has adopted this Moroccan young lady and two more supply packages have been sent.

At the end of May 2005 a large ‘packing’ was completed at the Hollister warehouse in Toronto (Aurora). Since I had never participated in a packing, my husband Doug and I drove from Ottawa to Aurora and took part. It was a very interesting experience. Richard Olley (FOWC Director) together with Mike Durey (Hollister) kept all volunteer helpers very busy until all was packed. The packing generated 5 shipments, listed below, to different parts of the world and all shipments left from Toronto. FOWC will be making a lot of needy ostomates very happy.

<table>
<thead>
<tr>
<th>Country</th>
<th>Weight/Mode of Transportation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cuba</td>
<td>400 kg by air to Havana</td>
</tr>
<tr>
<td>India</td>
<td>675 kg by cargo to Channai Port</td>
</tr>
<tr>
<td>Iran</td>
<td>250 kg by air to Tehran</td>
</tr>
<tr>
<td>Pakistan</td>
<td>75 kg by air to Lahore</td>
</tr>
<tr>
<td>Mexico</td>
<td>125 kg by air to Guadalajara</td>
</tr>
</tbody>
</table>

We received ‘thank you’ notes, phone calls and pictures. Everybody was very thankful and happy to receive the shipments. Jean-Pierre Lapointe, at our Montreal collection site, completed two packings and one shipment has left for Iran. Another shipment is ready to go. We are waiting for completed papers from the Philippines Ostomy Chapter per request from the Embassy.

Mexico: I met the President of the Colima, Mexico Ostomy Chapter in Porto, Portugal in August 2004. We had a number of conversations and he asked if FOWC could include his chapter in assigning shipments to needy ostomates. His group is comprised of 51 colostomates, 4 ileostomates and 2 urostomates. He also wrote: “The equipment that our patients receive is of the national brand Ostomed, which is of poor quality and is administered through Social Security and it lasts less than 24 hrs. Supplies from ConvaTec, Coloplast or Hollister brands are brought in from Guadalajara (210 km) and the cost of it is too high for many of our members.”

A shipment to Mexico was sent and has arrived in Colima. It was a first shipment for me to Mexico; I had many meetings with the Mexican Embassy and many months of effort by the Mexican Embassy here in Ottawa and by our contact in Mexico. The Press Section of the Embassy of Mexico has issued Press Release number 145 in early August which can be used for publication by anybody and our story is published in a number of Mexican Newspapers. A copy of this story I have seen in the “Rumbo de Mexico” newspaper, with a circulation of 30,000 and dated August 5, 2005. It can also be seen at the Foreign Affairs Ministry of Mexico’s website.

SUPPLIES TO MEXICO: ANOTHER EXAMPLE OF BILATERAL CO-OPERATION: The Ministry of Foreign Affairs reports that a significant donation of medical materials was made today to the President of the Asociación de Ostomizados de Colima IAP, Jorge Vargas Morales, by the charitable Canadian organization Friends of Ostomates Worldwide (FOW). FOW is a non-governmental, not-for-profit organization run by volunteers whose objective is to improve the quality of life for people who undergo an ostomy, a surgical procedure performed when part of an individual’s urinary tract or bowel is no longer able to function. Since its foundation in 1986, FOW has provided medicine, medical supplies, and didactic related to this disease for over 52 countries worldwide.

It is appropriate to emphasize that this is the first time FOW-Canada has made such a considerable donation (approximately 125 kilos) of medical supplies to Mexico. This generous offering will satisfy the needs for an entire year for the various patients that require colostomies, ileostomies, and urostomies in Colima, Mexico.

Without a doubt, this donation, which supports such an important cause, is a direct reflection of the excellent collaboration and institutional co-operation that exists today between the governments of Mexico and Canada regarding the various scopes of their bilateral agreement, one of which is the health sector.

Finally, it is important to mention that the donation in question was made possible thanks to the help and support from Mexicana de Aviacion, that facilitated the transportation of the medical supplies free of charge, as well as the Junta de Asistencia Privada del Estado de Colima and the Servicio de Administración Tributaria (SAT). Also, it is important to mention the help that was given by numerous volunteers from Canada and Mexico, whose collaboration with the Embassy of Mexico in Canada and the Main Directorate for North America from the Mexican Ministry of Foreign Affairs contributed to the success of this process.

Algeria: Jean-Pierre, Past President of FOWC received two different requests from Algeria.

A ‘SOS’ request from an Algerian senior who has a real problem. Part of his letter reads: “...I solicit your help and assistance in sending 80mm flanges and pouches. I’m suffering because there are none available in my area, all stop at 60mm and they are too tight. At the present time I can only get 40mm and must change 3 times a day. I have no contact or can afford the products from the outside world adaptable to my stoma......” I am happy to say that an emergency parcel should have arrived at his address. I had a few products at my house and was lucky that a compassionate Eastern Canada ET answered our call for the larger size.

Another request came from a Dr. Smail in Algeria. He is asking for help for one of his patients, a 30 year old mother-of-one. He writes: “... after many treatments of radiotherapy and chemotherapy she ended up getting a colostomy. Seeing the social conditions of the young woman as well as the frequent shortages of colostomy products, I’m asking FOWC for help...” Since we did not have the lady’s address we sent a small parcel to the doctor and now await for a response.

It is an exiting responsibility being the Shipping Director, very time consuming, albeit frustrating at times, but most gratifying at the end. I do a lot of negotiation in regards to the shipment cost to ensure FOWC stays financially secure.
SOUTH AMERICA OSTOMY ASSOCIATION
ALADO
Submitted by Cândida Carvalheira, President of ALADO
As President of ALADO, I have the honour to inform you all that ALADO is finally an official entity - statutes and proceedings of our meeting were registered officially. Once we return from our trip to Brasilia, we shall remit registered copies.
Benefits accomplished from registering ALADO:
• Bank account in Uruguay: Now, we can present the Bank with official documents and, as from that date, ALADO will officially retain a Bank account.
• We can request financial support from Ford Foundation, Ashoka, OPAS and other Foundations considering ALADO’s official documents.
• We would like to emphasize the necessity for all IOA Regions how very important it is, nowadays, to register any type of NGO and thus have an “official voice” within other countries.

Total cost of US$200.00 was paid by ALADO.
Date of official registry August 23, 2005.
Congratulations ALADO!

ALADO REGIONAL MEETING,
CORDOBA, ARGENTINA
Reported by Di Bracken
I was able to make two formal PowerPoint presentations to the meeting and thanks to Maureen Flynn who translated the slides into Spanish, the bilingual presentations were very well received. The first presentation was on World Ostomy Day.

The second presentation was the IOA and ALADO and how can we work together on behalf of ostomates in this Latin American region. We know that if we are to make progress in South America we have to keep in touch on a regular basis and work together. It may take time but if we all work together including our partners in industry, we will make progress on behalf of ostomates.

Friday, 15th July 2005: BUSINESS MEETING OF ALADO was conducted in Spanish.

ELECTION RESULTS
President: Candida Carvalheira, Brazil
Vice President: Mariela de Romero, Columbia
Secretary: Teresa Antequera, Bolivia
Treasurer: Francisco Miguez, Argentina
Past President: Maureen Flynn, Argentina

The ALADO Executive:
L ► R: Francisco, Mariela, Candida, Maureen and Teresa.

As President of IOA, I was asked to present an inscribed plate to Walter Rossmaier thanking him for his services to ALADO over very many years. Newly elected President Candida Carvalheira presented Walter with a dedication from Brazil. The evening ended with a dinner to celebrate the end of a successful business meeting.

Saturday, 16th July 2005: EDUCATIONAL CERTIFICATION: Health practitioners present at the educational program of the ALADO meeting were able to obtain credit for attendance. The educational component was accepted by The International Congress of Education. This institution was informed that the Conference with sessions on ostomy-related topics was taking place and that the organization for the meeting was headed by OEI (Organización de los Estados Iberoamericanos) of UNESCO, with assistance from Asociación de Ostomizados Córdoba (ADCO). It was noted that this was an international event with the President of the IOA as well as the Latin American delegates from ALADO present. Permission was given to allow National Certificates of Attendance to be given to participating nurses and doctors.

Topics included doctors speaking on Sexuality, Urostomies, Prevention of Cancer of the Colon, Ostomies, Psychology of Living with an Ostomy, Irrigation and Nutrition. There were also presentations interspersed with the lectures from doctors by registered nurses who spoke on various topics associated with ostomy topics.

There were well over a hundred nurses in attendance at the meeting. Nurses are given one credit for attending accredited sessions with a possibility of two credits if a presentation is made by the attendee to his/her faculty on completion of the course. Doctors receive credit within their hospitals for presenting at an international meeting providing a report is made to the specific institution. A small Exhibit section was organized with representatives from Coloplast and Hollister in attendance.

I must commend Francisco Miguez, the President of the Cordoba Ostomy Association for his vision in seeing the potential in offering such a programme and then having the ability to ensure that the educational component was handled by a professional person Maria Nieves Diaz Carballo, who agreed to undertake the arrangements for the day free of charge. This involved a great deal of work on her behalf.

Sunday, 17th July 2005: The Business meeting held at the offices of the Cordoba Association was devoted to crafting an agreement among the countries that constitute ALADO to give permission to President Candida Carvalheira to register ALADO as a not-for-profit organization in Brazil.

Agreement was achieved and a document was signed by the following:
Candida Carvalheira, President
Mariela de Romero, Vice President
Teresa Antequera, Secretary
Francisco Miguez, Treasurer
Maria Cecilia Flynn, Past President
Directors:
Mercedes Nieto, A.A.D.O. Argentina
Francisco Miguez, F.A.O.D.R.A. Argentina
Victor Villarruel, A.B.O. Bolivia
Mariela de Romero, A.C.D.O. Colombia

On 30th August, 2005 I received an exciting e mail from President Candida informing me that she had been successful in establishing ALADO as a not-for-profit organization. Let us hope now that ALADO will be successful in raising funds to help the work in the region where
so much needs to be done.

The new ALADO Executive is young and Candida is anxious to see the countries working together. With the commitment that she has from Argentina, Bolivia and Colombia. I feel sure that we will see progress in the Latin American region. It may well take time but the enthusiasm is strong.

~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~

ARGENTINA

Asociación Argentina de Ostomizados

Submitted by Rafael Nestor Cranzi, Secretary of Mar del Plata Branch

For more than one decade a group of people, both professionals and patients with strong motivation and wish to offer their experience and time, pursued the following project and filled it with their experience and care. This group laid out a path in our town without deep knowledge, but it followed intuitively the instructions of the mother organization located in Buenos Aires.

We would like to inform by this communication that we intend to start with a reorganization of our branch in Mar del Plata, exploiting the norms and procedures set by the organization in Buenos Aires. The founders and many new members joined now to form a committee in order to fulfill this noble mission.

We meet at INARESP (ex. CERENIL) every Thursday in a room given to us by this prestigious organization. Even though we do not have large financial means, we decided to get funds necessary for communication. We set up an electronic mail address and made steps to establish web pages.

Our other ideas concern the exploitation of the media and health organizations, either public or private ones, to spread information about our organization, which does not seek any profit in its activities.

A part of our project are visits of the patients at home to have a good access to them and to have the possibility to share with them our experience. It is our priority to have individual contacts with the patients and their families, so that we can explain the new situation to them from the start.

The information about the rights of ostomates belongs to the early services offered, because the social network does not fulfill its function in these cases. Financial donations as well as other means enabled us to enlarge the selection of appliances in our pharmacy. We appreciate and are grateful for important donations yielded by AADO. From these gifts we started to build a library, still in initial state but quite nice. We have a logo created by an excellent Spanish painter and we undertake now the steps for obtaining permission of using it. The new Committee decided not to collect the membership dues. Funds are created from contributions of members present at our meetings and from gifts of various institutions. We prefer to purchase the most up-to-date appliances before the accumulation of property.

We have established a habit to thank specially in written form all persons and institutions who support us. We pay a particular attention to keep all our activities transparent. These are the most important things which, among others, the new Committee wants to realize. By means of these steps we want to create a basis for a sound exchange of information and for all measures which can contribute to the improvement of the quality of life in our community.

In our organization we count with the co-operation of professionals, paramedics, technicians and nurses in order to progress further. However, it is necessary to keep contacts with the whole world.

~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~

BOLIVIA

Submitted by Alexander Machaca
Colaboratore External of Asociación Boliviana de Ostomizados

We come to the close of 2005 and we are very happy, for this year was dynamic with many activities in favor and for the benefit of the people with an ostomy in our country.

Our activities were as follows:

- 3rd International course of Stoma Care and Management (April 21-23).
- National Ostomy Congress (April 22-23).
- We participated in ALADO Meeting Cordoba -Argentina (July 15-17).
- We published two articles (on October 2 and 23) in one of the most important newspapers of our country and especially of our city (Santa Cruz).
- We continue working so hard directly with Government authorities to eliminate the payment of duty or tax for donations from FOW-USA. We really hope to get good news soon.
- All member of the Board are already working to draw up a plan for the next WORLD OSTOMY DAY that will be held on Saturday October 7, 2006.
- We have new format of literature, banner and triptych to inform all new people that to have a stoma. It is one of our targets for most people to know about us.
- Monthly meeting in order to distribute stoma appliances to the members of our association.

Planned activities for the near future: One of the things that worries us is our office; at the moment we are in the Oncological Hospital. It is very small and old (8 m²), we are a lot of people and we need more space in order to carry out our meetings and to store material of donations. We are thinking to do some activities (fundraising) to get another place. We plan to start with monthly educational consultations (Stoma Care and Management) with the participation of Dr. Hugo Heredia (founder of ABO) and nurses from Japanese Hospitals.

~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~

SOUTH PACIFIC

OSTOMY ASSOCIATION

Submitted by Peter McQueen
Secretary, SPOA

The South Pacific region is unique with only two countries Australia and New Zealand, the only members. Our countries have the only organized Ostomy Associations in the region and therein lies the problem in establishing links to organize assistance and support.

(continued on page 33)

New Zealand has for a number of years been sending surplus appliances to Fiji, Tonga and the Solomon Islands through a support net-
work established by personal communication.

Australia through the Ostomy Association of Melbourne has tried many avenues to set communication links with Papua New Guinea but each promising lead has closed and back to square one again. The Royal Australian College of Surgeons provided contacts but the efforts to get someone in PNG to take ownership and responsibility of any assistance forthcoming has been to no avail. Efforts are now being focused on East Timor and preliminary research is promising.

Barry Maughan of New Zealand has taken over the role as regional president and in that role he has taken his place on the IOA Executive. His portfolios are World Co-ordinator for World Ostomy Day and the 20/40 group Executive Liaison Officer. Paula West of New Zealand is the 20/40 Chairperson taking over the role carried out by Anne Hafner of Australia at the last IOA meeting in Portugal.

AUSTRALIAN COUNCIL OF STOMA ASSOCIATIONS INC.
ANNUAL CONFERENCE HELD IN PERTH, WESTERN AUSTRALIA.
(ACSA)

Reported by Di Bracken

On holiday to visit my brother in Australia, I was able to accept the invitation from the Australian Council of Stoma Associations Inc. to attend their annual national meeting. It was my privilege to officially open the meeting as well as deliver the keynote address on "Future Directions For IOA."

Australia stands alone in the world with the Stoma Appliance Scheme which the Associations manage on behalf of the government. This is a great program for ostomates in Australia and I know that you will be interested to read of details of its operation in the annual report made by President Gerry Barry to the Assembly.

Excerpts from President Gerry Barry’s Report: In broad terms the activities of ACSA are to promote the general welfare of ostomates, to collaborate with the government in the operation of the Stoma Appliance Scheme, to provide means of communication of ostomy-related information, to promote ostomy-related research and to obtain and manage the funds necessary for these purposes.

In undertaking these activities the major focus of the Council and the Executive was the management of the Stoma Appliance Scheme. In this context the work of ACSA was to provide advice, support and guidance on the distribution to members of Associations of in excess of AUD $40M of ostomy appliances and related products.

The success with which this Scheme is managed within ACSA is reflected in the fact that it is regarded both internationally and within Australia, as one of the most effective in the world. In the period the Scheme continued to operate at this high level of efficiency under the guidance of the Executive, Associations and the Stoma Appliance Officers.

The communication of ostomy-related information was achieved through the meetings of the Council and the Executive (including the circulation of minutes), the publication of Ostomy Australia, the development of our Internet site and the work of the Resource Centre Co-ordinator. During the period an ongoing research project funded by ACSA and member associations continued. The research project in question was to investigate the characteristics of the output of ileostomies in the immediate post operative period. This research was undertaken by Diana Hayes under the auspices of the Western Hospital in Melbourne.

The general welfare of ostomates was promoted by the above activities and by the guidance, advice and assistance given by the Executive and the Council to Member Associations.

Membership: The secretary, Ed Webster reported that there were 22 Member Associations in Australia with some 30,339 declared members.

VICTORIAN CHILDREN’S OSTOMY ASSOCIATION REPORT by Sonia De Francesco: The trend in children's stoma surgery continues to move towards catheterizable stomas for either bowel washout purposes or for easy and regular bladder emptying thus preventing kidney damage. This is reflected in appliance usage as many of our 180 plus members do not use a great many flanges or bags, but use irrigation sets, mini pouches, catheters and protective/cleansing wipes and creams.

We have our smaller core group of permanent stomas, the transient group of temporary stomas and the group referred to earlier. The parent-run support group NIDkids is a valuable resource for many families and they are kept extremely busy keeping up with demand. The group has moved to new premises in an outer suburb of Melbourne.

THE AUSTRALIAN FUND: Excerpts from report presented at the Australian meeting by Jack Nicholls Correspondence has been initiated with John Cardosa regarding assistance to ostomates in need in the Asian countries: - Malaysia, Thailand, Aceh, Sri Lanka, South India and the Maldives.

With the assistance of Di Bracken, IOA President, a channel of communication has been established with ostomates requiring help in the Chinese province of Guangzhou where there are 600 members in the care of Professor Desen Wan in the Cancer Centre there. They have 6 qualified stoma therapy nurses there serving some 60 – 100 new patients annually.

We are in contact with Arne Holte, the IOA relief co-coordinator who requested assistance with a project to train nurses in Odessa, Ukraine. This request has been evaluated as worthy of financial assistance from the fund.

Note from Di Bracken: This project is on hold due to the death of Rafael Orhanski, the doctor who was to conduct the training and Efim Krasner who was Head of the ostomy-organization in Odessa.

More recently word was received from a stoma therapy nurse at the Ballarat Hospital, Victoria who is sponsoring a project towards setting up therapy nursing to the ostomates in the North Pacific area of Tonga. Ballarat is bringing a trainee nurse to Australia in November and I am sure that there are poor and needy ostomates who can (continued from page 32)
benefit from services there.

President Gerry Barry will supply the co-ordinator with contact details for Julie McCaughan the current president of the AASTN. Julie is undertaking a placement in Indonesia and has agreed in discussion with the President to take responsibility for setting up a distribution network in Indonesia to assist people in that country who have difficulty in affording supplies.

Nota from Di Bracken: The Australian Fund is not able to make any firm commitments for assistance without the approval of the Management Committee which consists of representatives of both the Australian Council of Stoma Associations Executive and the International Ostomy Association Executive.

OSTOMY AUSTRALIA: Report by Noel Dillon, Editor: The major advertisers have maintained regular bookings and in some cases increased their commitment; one new advertiser was welcomed during the year and there is an indication of at least one more to follow. Production costs continue to increase and this is due mainly to increases in print runs. Internet usage will need revising to better fit our requirements as previous low cost services are disappearing in favour of more sophisticated hook-ups and the minimum cost increases incurred as a result. As all advertising is now received in high-resolution files, our down loading time has greatly increased and we are looking for a more user-friendly method.

Noel thanked the advertisers, “whose continuing support ensures the success of Ostomy Australia. The quality of advertising copy continues to offer bright and appealing presentations, assuring new product awareness for ostomates and adding to the overall appeal of the journal.”

Noel concluded, “I cannot understate the fact that Ostomy Australia belongs to the nation’s ostomates, and as such its direction and success is in the hand of ostomates. Its ongoing success can only be assured by a constant flow of copy submitted by readers for consideration for inclusion.”

Ostomy Australia continues to enjoy a high level of acceptance in the ostomy community, both at home and abroad, and it is pleasing to receive so much positive comment from readers.

Note: If you have not had the opportunity of reading Ostomy Australia, please visit the IOA Website at http://www.ostomyinternational.org. On our home page you will be able to click on Ostomy Australia and read the magazine. While you are there please also read the European EOA Newsletter and the latest edition of IOA TODAY.

One of the outcomes from the General meeting was the appointment of an Overseas Shipping Coordinator as it appears hopeful that ACSA will now be able to send surplus supplies to countries in need. Specifically two countries, Indonesia and the Philippines are under consideration. This is great news indeed!

The venue for the Conference was Perth with the Western Australian Ostomy Association providing the organization under the leadership of Robin Gill, Conference Organizer. Her team of President Clare Bertolini, Vice President Jess Whitehouse, and Vice President Peter McLeod did an outstanding job and are to be congratulated. I understand that seven different states of Australia take it in turn to organize the annual conference so each region gets its turn every seven years. What a great idea!

I left Australia feeling very positive and excited at the interest that was most evident in IOA. I look forward to continuing working with Australian Council of Stoma Associations Inc. during the remainder of my tenure.

~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~

AUSTRALIA

AUSTRALIAN COUNCIL OF STOMA ASSOCIATIONS INC

ACSA


Submitted by Judy Lopez

The event was hosted by the Western Australian Ostomy Association. Perth is located at the South West extremity of Western Australia and delegates from 22 associations throughout Australia attended. Some had to travel as much as 4,500 kilometres (about 2,800 miles) through three time zones.

The first recorded sighting by Europeans of Western Australia was in October 1616, when the Dutch navigator Dirk Hartog landed at Shark Bay, near Carnarvon (900 kms north of Perth). British authorities settled at the Swan River in 1828 on which Perth is sited. In August 1829, Perth was founded by Captain James Stirling.

Perth has a population of 1.4 million out of 1.9 million for the whole of Western Australia. It is 4,200 kms west of Sydney and 2 hours behind. Offset by the vast tranquil waters of the Swan River – modern and vibrant, it was called the ‘City of Lights’ by astronaut John Glenn after his historic fly-over in 1962.

ACSA was fortunate to be graced with the presence of the President of IOA, Di Bracken, who undertook the task of officially opening the Conference. She presented the keynote speech and made herself openly available to all those present. She impressed all those she met with her dedication, energy, and bonhomie.

The first day (Thursday) was taken up with procedural matters and committee meetings. That evening all delegates and observers were guests of ConvaTec at the Aquarium of W.A. (about 20 minute drive from Perth City) We mixed with huge sharks, sting rays, sea dragons and a myriad of fish before sitting down to a splendid dinner.

During the course of the Conference many weighty matters were discussed including the question of co-payments, new Scheme guidelines, the Australian Fund, youth camps, emergency kits for disaster areas, World Ostomy Day, and the South Pacific Regional Ostomy Conference to be held in New Zealand, 2006.

There was an address by an official from the Department of Health on the subject of co-payments, i.e.- the need for ostomates to pay some portion of the cost of their appliances to conform with the
government's current over-riding policy of 'user pays'. As can be imagined this elicited a lively discussion with the result that the Department of Health (DOC) is to present an Options Paper in the near future. The official also spoke about the new guidelines for the Stoma Appliance Scheme and the prospect of a national Agreement between the DOC and ACSA.

As is their custom, all 22 associations presented their annual reports and this provided interesting information about the operation of the Scheme at the local level. One of the most interesting items was provided by the Victorian Children's Ostomy Association who said that "the trend in children’s stoma surgery continues to move towards catheterizable stomas for either bowel washout purposes or for easy and regular bladder emptying thus preventing kidney damage. This is reflected in appliance usage as many of our members do not use a great many flanges or bags, but use irrigation sets, mini pouches, catheters and protective/cleansing wipes and creams."

Finally a workshop was held on the subject of where and how to establish support groups, how to assist these groups, and how to encourage young members to be involved. This was enthusiastically undertaken by all the delegates with many useful observations and resolutions being made.

The Conference ended as usual with the Saturday night dinner dance and the Sunday outing which this year took us up the Swan River and back, with lunch being provided at a riverside restaurant located at a winery along the way.

NEW ZEALAND

FEDERATION OF NEW ZEALAND OSTOMY SOCIETIES

FNZOS

Submitted by Jill Newton, Member of FNZOS Executive

I have just returned from the 32nd conference and Annual General Meeting of the Federation of New Zealand Ostomy Societies, which was held in Invercargill, the southernmost city in the South Island of New Zealand.

The local society arranged a wonderful weekend of interesting speakers and entertainment including dancing into the wee small hours for some.

A highlight of the Saturday afternoon program was a presentation to John O'Neill in recognition of his outstanding voluntary service at International, Regional and National levels. John has recently retired after completing 19 years of service to the IOA, 14 of which were as Treasurer. With a background in accounting John dedicated many hours every week to keeping the books accurate with the full support of his wife Jan and two daughters, while also helping to run the family farm. Over these years John led by example to help ostomates in many countries, has attended many overseas conferences and meetings, often at his own expense and reached out well beyond the call of duty in an effort to ensure the smooth running of any committee he has been associated with.

John has also spent many years as Treasurer of the FNZOS a position he still holds. A well-deserved honor to a truly dedicated gentleman - thank you John, we are all very proud of you and wish you good health and a little more time for relaxation in the years to come.

YOUTH CAMP: The 6th Youth camp was held in Taranaki during the July term holidays with many of the campers from the initial youth camp returning along with some new young campers. As usual this was a huge success and special thanks must go to Paula West and her very dedicated team of helpers who spend many hours planning and running these camps. All the young camp attendees have grown immensely in confidence over the 5 years these camps have been held.

N Z OSTOMATE MAGAZINE: This continues to be published three times per year and is available free to every ostomate in New Zealand, pharmacies, doctors' surgeries and hospital waiting rooms as well as to several overseas countries.

SUPPORT FOR OSTOMATES OVERSEAS: Surplus appliances are collected at a North Island and South point, sorted and shipped to Fiji, Tonga and the Solomon Islands to ostomates less fortunate who have difficulty accessing sufficient appliances for their needs.

INTERNATIONAL SCENE: It was a great honor for New Zealand to have three members appointed to International positions at the world conference in Porto, 2004. Barry Maughan was elected President of SPOA, and as a member of the IOA Executive Committee he was appointed to the position of Liaison Person to the 20/40 group and World Co-ordinator of WOD. John O'Neill is Treasurer of SPOA and Paula West was appointed to the position of 20/40 Chairperson of IOA. All three members are also extremely busy people in their chosen careers and will do New Zealand proud in these appointments.

20/40 ALADO Regional Report

Submitted by Damaris Morais, ALADO Representative and member of the 20/40 Focus 2007 Organizing Committee

Our Brazilian association was invited to participate in the National Congress of Proctology here in my city in October, 2005. We had three days to show the doctors, who stop at our counter, how important the Ostomy Associations are.

I wrote a piece in Portuguese and my mother translated it into English to hand to the guest speakers, and all doctors (about 1000) received it with their congress material. I hope they will take the time to read it because it is much more a request than a thank you letter.

Thank you Doc for learning how to perform this life-saving surgery: the ostomy.

Thank you Doc, when performing elective surgery, for taking some precious minutes of your time to study our bodies to decide on
20/40 European Regional Report

Submitted by Sarah Maill, European Representative and member of the 20/40 Focus 2007 Organizing Committee

I would like to take this opportunity to introduce myself, my name is Sarah Maill and I am the European Representative for the 20/40 Focus 2007 Planning Committee. I am 30 years old and have a permanent ileostomy (since 1993) due to Crohn’s disease. I have been actively involved with ia (The Ileostomy and Internal Pouch Support Group) here in the United Kingdom since 1997 and in April 2002 was appointed to the role of Young ia Co-ordinator and now serve on ia’s Executive Committee.

I have attended all three ‘20/40 Focus’ Conferences and am delighted to have been appointed European representative on the 4th ‘20/40 Focus Planning Committee’ and look forward to raising the profile of young ostomates around the world.

As part of my new role, I was asked by the IOA Executive to make contact with all the member organizations within my region. This was a daunting task as the European region is the largest IOA region with 36 member organisations. I decided that my first aim was to find out whether each country had a youth program to support their young ostomates. So, I either wrote or e-mailed each member organization and asked them the following questions:

Do you know how many young ostomates there are in your country? Do you have a youth programme in your country?

If yes,

What does the programme do?
Do you have a Youth Co-ordinator?
Do you have annual events / activities / conferences?
Do you provide a support network?

If no,

Is there the need for a youth programme in your country? Would you like help to set up a youth programme?

I was very disappointed by the response I received, as only six countries responded and the majority of them did not know how many young ostomates there were in their country nor ran a successful youth programme. It appears that the main difficulties are recruiting a youth co-ordinator and breaking down the barriers or taboos of living with an ostomy.

By becoming involved with 20/40, I have established excellent relations with NORILCO’s Youth Group, and was invited to attend their summer camp in Gaufell, Norway in August. I had an excellent five days and learnt a lot from seeing how their youth camps are run. I came home with lots of ideas and am now determined to set up a camp in the United Kingdom for our members under the age of 18. I also hope we can continue to build on our relationship and set up an exchange program so we can participate in each other’s youth events. Or perhaps we could look into the possibility of organizing a European Youth Camp?

Another aim is to develop a youth network within our region, as I strongly believe that by sharing ideas and experiences we can help improve the quality of life of young ostomates in our region. It is also vital that we raise the profile of young ostomates in order for their voices to be heard. Therefore, if you would like to register your interest in the European youth network then please contact me at sarahmaill@blueyonder.co.uk.

I look forward to hearing from you all.

Club des Jeunes Stomisés
(Membre de la F.S.F.)

Submitted by Thierry Schuster, Responsible for young ostomates in France.

The French-German meeting of young ostomates was good fun and took place in the Bretagne’s way (a region located in the far North-west of France) and in its ecosystem. This was one of these rare occasions where young ostomates can talk about life, ostomy and appliances. It’s clear that such a meeting is exceptional. Next year it is Germany, which has the pleasure to organize this meeting.

Happy moments to meet some people again or to make new friends. Some participants travelled together. After a calm night we were ready to start the program which Chantal and the other members of ASBO (Association of Ostomates in the Western part of the Bretagne) had prepared.

We took a bus to Brest, direction Océanopolis and its three pavilions (tropical, polar and moderate climate) where different kinds of sea animals live: sharks, octopus, rays, penguins etc. A real discovery of the ecosystem. Do you know that the Bretagne has its own shark which is inoffensive like a lot of sharks? To recover from this journey around our planet a typical “Soirée bretonne” took place. The Mayor of Douarnenez was happy to welcome us and to present her region, the

OSTOMY INTERNATIONAL, YEARBOOK 2005, VOL.27
Many of you must know by now, the UOA ceased operations at the attempt to establish a relationship with the network members. As appointed Young Adult Network (YAN) Chairperson for the UOA, I am working diligently to get many young North Americans more involved with our organization. For the past several months, I have been working very closely with Kristin Knipp, the newly appointed Young Adult Network (YAN) Chairperson for the UOA, in an attempt to establish a relationship with the network members. As many of you must know by now, the UOA ceased operations at the end of September. While this news is extremely disturbing, we have been presented with a unique opportunity to integrate their young members into the IOA. During the UOA’s final Annual Conference in August, I met with the Network members to present the 20/40 and our programs to them so that they will be able to understand how we serve them. During this conference I also collected all member contact information and am setting up a database so that we can periodically send out e-mails to these new perspective members about our plans and upcoming events. The YAN is a large group and I am sure with proper information and tools we will be able to make the transition into the 20/40 seamless.

YODAA
Young Ostomate and Diversion Alliance of America

There is a nation-wide support group for young adults with ostomies and other bowel and bladder diversions. YODAA (Young Ostomate and Diversion Alliance of America) is the new and improved version of the Young Adult Network previously run by the now dissolved United Ostomy Association. YODAA now functions as an independent support group and is affiliated with the UOAA.

YODAA is dedicated to providing education, information, and advocacy as it addresses the concerns of those young adults 18 to 35 years of age who have or may have intestinal or urinary diversions or alterations. Our members consist of those who have or may have any of the following: ileostomy, colostomy, or urostomy; a continent procedure such as a J pouch, Koch pouch, caecostomy, BCIR, Malone, Mitrofanoff, or bladder augmentation; bowel or bladder incontinence; diseases resulting in any of the above (IBD, extrophy, VATER syndrome, cancer, Hirschprung’s disease, familial polyposis, spina bifida, etc). YODAA offers many ways to connect with young adults facing issues related to life with a diversion. We have a newsletter that is published bi-monthly and features articles written by YODAA members, an “ask the WOCN” section, “Spotlight” (a getting to know you section), and announcements about upcoming YODAA activities such as conferences, online chats, and much more. YODAA has its own discussion forum at www.uoaa.org, and in the coming months will have its own portion of the UOAA site for sharing information, stories, and pictures. YODAA also has a telephone visitation program. New ostomates or diversion patients may request to receive a phone call from a young adult with a similar diagnosis who has gone through the procedure and can offer support and a listening ear. Planning is underway for a YODAA Conference to be held in August 2006.

For more information on YODAA or its services, please contact us at yodaauoaa.org or contact YODAA Chairperson Kristin Knipp at kristinkjs@sbcglobal.net

Rachida’s Story

Submitted by Rachida Charaf

My name is Rachida. I am 27 years old and I am from Morocco in North Africa. I am from the town of Azrou, high in the Middle Atlas Mountains. I live with my family; my father who is retired, my mother who is a housewife, and 5 siblings. They include my 4 brothers Hicham, Zouhair, Moulay-Hamed, and Moulay-Ismael and my sister Fatim-Zahra. We live a beautiful and happy life. In our family we play, work, and laugh together in love and tenderness. We do not need anything else beside each other.

My life is full of hope. I hope to be able to study again. My dream has always been to work in the field of athletics somehow. I strive to always remain positive in my life and keep dreaming of all that is possible. Sometimes remaining positive is easier than at other times.

On March 29, 1998, I began feeling very exhausted. I began to lose weight. I was unable to eat. When I did eat something, I vomited it back up right away. I was unable to sleep. Each time I went to the bathroom, I stayed there a very long time. I became very, very frail. I
OSTOMATE STORIES continued

My mother took me to a different doctor. This doctor told me I just had stomachaches. He prescribed different medicines and when I took these new medicines, I once again had the same symptoms. As soon as I took them, I felt immediately sick and threw them up. In the coming weeks I went to six more doctors. Each told me something different and gave me new medicines. Each time I took new medicines, I once again had the same symptoms. As soon as I took them, I felt worse.

The last doctor I saw was a female doctor. She told my mother that I needed to go immediately to a hospital in Rabat, the capital city. She said I was extremely ill and my life was in danger. When I heard this, I began to cry. I cried and cried because I knew then that I was in a very serious situation. I knew that only people who were about to die were sent to the hospital in Rabat.

At that point my mother also began to cry. Though the city was only a few hours away, we had never been there. We did not have any family members there and did not know anyone living there. We also did not have the money to make the trip to Rabat. All the money we did have had gone to my emergency trips to the local hospital. My father was very old and ill with diabetes. He was not able to work to get the money for a trip to the hospital in Rabat. My mother became very nervous, not knowing how we would get to the hospital in the capital city. My youngest brother was only 4 years old at the time and my other siblings were in school. She would have to leave them and use all our money to make the important trip. Suddenly my health had placed our family in a very dire situation.

When we left the local hospital, we stayed one day in our house. My feet swelled, leaving me unable to walk. Early that next morning, an ambulance came to my house and took me directly to the emergency hospital in Rabat. When we arrived, doctors put me on an IV, took blood samples and x-rays. We stayed 4 days at that hospital. It was there that I had my first operation.

When I woke up, the doctor told me that my large intestine had been taken out. On my abdomen was a hole that was leaking fluids. The doctor told me I would have to wait at least a month before I could have another operation to fix this hole in my abdomen. At the time I did not understand anything the doctor was telling me. I lay there in shock and screamed uncontrollably until I passed out from exhaustion.

Later that afternoon my parents were allowed to come see me. They were also in shock and did not understand what had happened. My father seemed to be in denial and just said that everything was going to be all right. He calmly said that God would take care of everything. We were told I have a medical situation called RCH. To this day I still do not understand very well what RCH means nor do I comprehend the details of my medical situation.

My mother experienced such difficult challenges while in Rabat. She was not allowed to stay the night at the hospital and had to sleep in a cheap hotel far away. She had to buy medicines and food for me. The biggest problem was that she did not have the money. I stayed at the hospital for two whole months.

Finally I was allowed to return to my home with an appointment at the hospital in Rabat six weeks later. When I returned to the hospital I had my second operation. This second operation, unfortunately, was not a success. I stayed another month at the hospital in Rabat until my third operation. It was also not a success.

During the coming many months I experienced the same situation over and over again. My final operation was in early June 2001. I had undergone 12 operations by this time. After this final operation, my abdomen remained an open wound. If I moved from one side or another in my hospital bed, I would leak fluids onto the bed. I couldn’t even get out of bed to walk. I stayed 4 more months in the hospital in Rabat.

June, July, August and September. I was extremely weak and became severely depressed. I cried every day. All my friends and family were far, far away. These were the longest months of my life and I thought they would be my last. My mother stayed with me during this time, trying to convince me that everything would soon be okay. She bought my medicines, brought me food, and cleaned my clothes. It was a very tough time for her.

The medicines she was purchasing for me were bags to empty my stomach and a special antiseptic cream. These bags and creams are not made in Morocco. They are ordered from Europe, Canada, and the United States. My mother had to pay very high prices to get these imported medical products. After a while, these supplies were used up and no more were available.

When I used the bags and creams I cried, because I knew the problems this created for my mother and my family. I also knew these products were not always available. I did not want my family to have to suffer from my medical situation. I did not want my family to purchase these because the small amount of money in our bank was being used up quickly from my stays to Rabat. Over half our monthly income from my father’s small pension was being used on these products alone. My family back home needed this money to buy food and school supplies.

At the end of 2001 I left the hospital in Rabat. My abdomen was healing and I no longer needed to stay in bed. I came back to my family. I was still very weak. When I was in the hospital, sometimes I had gone seven days without being able to eat. I had not wanted to eat. I had not wanted to survive. Back at home surrounded by the warmth of my family I was able to eat. My mother cooked special foods for me, foods with lots of vitamins. Slowly I regained some strength. I spent time with my family whom I had missed so much. We ate together. We talked together. Sometimes I would go for short walks with them. I was still in need of something though, friends. Over the few years that I had been sick, my friends had disappeared. They had got married, gone off to study, or found jobs and were busy.

Two and a half years passed. Each month I made the long trip to Rabat to see a doctor. While in Rabat I tried to find my medical supplies. They were not always available and when they were, they were always so expensive. When the supplies were not available, I used a cloth Using a cloth is very painful and is always a last resort. Sometimes
I had to leave the cloth in for 3 hours. This turns my skin red with a burning pain. When the supplies were available, the bags were often the wrong sizes – either much too large or way too small. Somehow I usually made due.

I began to grow depressed again. My situation began to feel hopeless. The doctors told me that I need an operation that is not available in Morocco. They told me I would have to go to a foreign specialist, most likely in Europe or North America. Such a trip seemed an impossible dream. I could barely afford my monthly trip to Rabat after all. The doctors told me to find an association to help me.

Each time I went to Rabat to see the doctor; I was hoping she had news of some work I could do. Unfortunately, I was never able to last more than a week. Each time I got too weak and had to quit.

In 2003 I was looking for a job with little physical labor. In my town there lives an American woman known for helping people. She is known for doing good things in the community and organizing help for people. I went to her and explained my situation. I told her my whole story. I showed her the medical papers from various doctors and told her I needed to find work. I asked her to help me. We exchanged phone numbers and I left.

One day my phone rang. I answered the phone and she asked me to come see her. I was hoping she had news of some work I could do. I went to see her and she asked me if I could work for another American woman. This woman’s husband was a professor at the university. They had two children and were looking for someone to care for them a few days a week. I told her I would be so happy to take the job.

I met my new employer that same day. The only problem was that she did not know Arabic and I did not know English. Each of us only knew a little French. I have been working for this family for almost two years now. I watch the children when their parents are away. I cook them food and clean their house. I love this family now, as were they my own. They know my medical challenges and are very understanding. They are so kind to me. They are such good people. I love their children and look forward to the time I spend with them. They treat me as a member of their family. Since I am now working, I am able to purchase my supplies when they are available. I also support my own family with my income.

In September 2004 this family contacted their friend in the United States. Their friend is married to a doctor and was planning to come for a visit to Morocco. When she came, she brought medical supplies for me. These supplies were the correct size and have allowed me to lead a normal life again. I was so happy to be living a normal life again. I am so thankful for their help and caring.

I work several days a week. I help my parents around the house. I cook for my family. I have begun to be active again, going for hikes in the nearby mountains and bike rides across town. I am once again happy and so happy to be happy.

A couple months after I received these medical supplies, I met a good friend. He is an American Peace Corps Volunteer working in my town. He helps me often. I am so happy to know him and thankful for his help. He helps me contact associations on the Internet, translating my Arabic and French into English. I need to continue to look for assistance because my medical supplies are in short supply. Ultimately, I need to see a medical specialist outside my country and hopefully undergo more surgery. But for now that seems like a distant dream.

We contacted many medical associations across the world. Most did not reply. Those who did reply replied with questions and I did not hear back from them again. One association, however, did reply. This association was Friends of Ostomates Worldwide (FOW), a Canadian NGO. I began corresponding with a very friendly woman in their Ottawa office. She gave my situation a lot of attention, talking both to her organization as well as to the Moroccan Embassy.

The supplies I received in the previous September from the American doctor’s wife were about to run out. I had no way to replenish these except to go to Rabat in hope of finding something usable. As I mentioned earlier, obtaining these in Rabat is not always possible and when it is, they are often the wrong sizes and always very expensive.

When I read the e-mail from FOWC and that they had agreed to send me six months worth of supplies, I was truly overjoyed. I knew for at least the coming months I would be able to live in relative comfort and continue working. I am so grateful to FOWC and do not know how to properly express my thanks.

So many people have helped me these past years: my mother, my family, my friends, the family for whom I work, their friends in the USA and FOW in Canada. I am so lucky and thankful for them all, for it is they who have allowed me to survive. They give me strength to want to survive. It is now summer 2005. With thanks to FOW Canada, I have supplies for the coming few months. I do not know where I will obtain supplies after that. What I dream of most is to see a foreign medical specialist to get the operation I need. I do not know how that will happen, but I have faith that it will. Until that day I will continue living, continue dreaming and continue to appreciate each day.

A Trip to India

Submitted by Anita Singewald
OSTOMATE STORIES

continued

unpeeled fruit washed in tap water, NO ICE!!
made from tap water, and only drinking and
brushing teeth with bottled water. You’d be
surprised how many people get sick when
traveling because they don’t think about ice
being made from water (!) or about using tap
water to brush their teeth being dangerous.

Also, colostomates who irrigate need to use
bottled or boiled water for that as well, or
you’re just pouring parasite-laden water
directly into your gut. I checked at all the
hotels we ate in, and they all used reverse-osmosis water treatment, so the
salad, etc. was safe. We did eat in one
restaurant that looked like a hole-in-the-wall
(continued on page 45)

(type of place, (the Gazebo, in Mahabili puram,
outside Madras) but it was in the guide as
being healthy. I would not have taken the risk
otherwise, because you never know how long
things are cooked for, how long they sit
around before or afterwards in the hot
weather, how long the oil has been sitting out,
how clean the tableware is, what kinds of
bugs or rodents are running around in the
kitchen, etc... so even if you only eat cooked
things, you still ca not be sure it is safe to eat
in places like that, even for non-ostomates. It
can feel frustrating to travel to interesting
places and not be able to eat the street
vendors’ food, etc., but better safe than sorry.

Before I left I also talked to Di, IOA President,
because she has obviously travelled
extensively in countries where there are
non-western toilet facilities. I wanted advice
on how to manage squatting and holding up
my clothes with one hand while at the same
time trying to empty and clean my bag with
two hands. (short of quickly growing a third
hand!!) She suggested getting zip lock bags
to empty the pouch into while standing up
and then throwing that away. I thought it was
a great suggestion but decided I did not want
to use see-through bags, so I bought a pack of
colored doggie-doo disposal bags. I am glad I
did, because there was never any kind of
paper in any of the public bathrooms I used,
therefore no garbage cans, so there would
have been no place to throw away a bag with
output in it. What I ended up doing anyway
was just standing or bending slightly over the
“toilet” (the large ceramic hole in the floor)
and emptying straight into that and that was
no problem at all. I ended up using the doggie
disposal bags only when I had to change my
bag entirely, so the cleaning people who
emptied the trash in our bathrooms did not
have to see through the bags.

I also carried one of those little black Hollister
carrying cases with me at all times, with the
following supplies in it: Two bags, several
adhesive rings, a small travel tube of paste, a
piece of a wooden dowel with about a 1.5”


thick roll of duct tape rolled around it in case of
a nick or a leak (which happened in Asia),
a small pair of blunt-end scissors in case I
needed to recut an adhesive ring or cut some
duct tape, a small bag of thicker gel
capsules, a small bottle of M-9, a few doggie-
doo bags, a packet of Kleenex and a small
bottle of anti-bacterial “hand-washing” liquid
that you do not need to rinse off with water. I
brought many of those little bottles, and many,
many packs of Kleenex, both of which
came in very handy, since there was hardly
ever any toilet paper or hot water (and only
risky germy water at that) in most bathrooms.

So, I had no problems what-so-ever with
bathroom facilities or staying hydrated.
However, the only real problem I did have,
happened the second week of the trip. It was
extremely hot and I perspired a lot and the
adhesive around the entire bottom of my bag
and on a small area on the side was melting
off every single day. I would normally change
my bag about once a week, maybe after five
days, if needed, in the summer if I am not
swimming regularly. Even after going to Asia
in May and having to change bags every 2-3
days because of the incredibly high heat and
humidity, I figured that taking 16 bags for
twenty days under much drier conditions was
going to be overkill. (I also weigh more since
the Asia trip, and discovered that I now I have
a little crevice where the abdomen meets the
pelvic area, where the perspiration was
pooling. Who knew?....) By the fourth day of
that second week I began to panic. I had
been changing every couple of days in New
Delhi before the tour, now I was having to
change the bag every day. I had almost
another entire week to go including three
days in a much more humid city and was
going to run out of bags if I continued
changing that often. I was genuinely afraid
that I was going to get down to only a couple
of bags and have to go home early because of
that!

However, when I stopped panicking I did
notice that the bag was getting loose only up
to the adhesive ring that I use around the
stoma as a skin barrier. I had brought extra
rings, so I cut one up around through the
middle, essentially making two rings. Then I
stretched out one piece and placed it on my
skin right up against the first one, making a
second layer of ring right outside the first, all
around the worst areas. I also asked people
who were on that week’s tour with us if
anyone had talcum powder, and fortunately
someone did. I put some in a little zip lock
bag I had used for pills, added it to my
supply-kit, and spent the next few days
anxiously and discretely (I hope!) shoving
cruerpowder down the front of my pants every few
hours on the bus, trying to stay ahead of the
sweat problem. Fortunately these two things
worked very effectively, and with it being
monsoon season in the area we went to next,
the Bay of Bengal, we stayed inside more so I
did not get as sweaty. I actually ended up
coming home with five bags to spare, which
was a surprise and an enormous relief.

I still got a stomach bug in the second week
(which was before Mahabili puram, so it was
not that restaurant.) As soon as I realized
what was going on I added a third dose of
flagyl at noon, never getting to the point of
vomiting or diarrhea, which would of course
could have been serious with an ileostomy.
People who do this kind of traveling should
also think about the trip home. We can feel
great on the trip, but if we start to get really
sick on the extremely long first leg of the
plane ride home, we could get seriously
dehydrated. I assume there would be no way
to get hooked up to an IV on a plane, which
means we could get dangerously ill hours
away from land. I knew this was a risk
because I had thought of this after arriving in
Asia last spring (!), but I had wanted to go to
India for 32 years, since I was 16 years old,
and wasn’t going to let that fear stop me now.

I don’t want to lie and be unrealistic about the
risks, but I also don’t want to scare anyone off
this kind of travel, the point of this story being
to encourage everyone to not just sit at home
and have no life after surgery. I spent over
half of 11 years of my life with ulcerative
proctitis having very little “Life” from being
chronically ill, until I finally got sudden-onset
ulcerative colitis and almost died from it. I
may have lost my entire colon and rectum in
the process, but I have gained an amazing
LIFE! I love to travel, I love meeting people
from other countries and learning about how
they live, I love travel photography, and
there’s just too much interesting stuff going
on out there in other places for me to stay at
home and worry about what might happen.
(look at Di!) If my four doctors said it could be
done safely, then I’m outta here... if not, I would have had
to seriously think about the risks, having two teenage children at home,
a husband, and an aging mother who has no
other family left but me. I’m planning to hit my
one remaining unvisited continent, Africa, in 2
years, and my mother wants me to go back to
India with her that year as well. Last year I
was dying, and this year I went on three
major trips abroad in 7 months, having
incredible experiences that I will remember for
I now know that there are some bullies that we should evaporate as we mature. However, push us around and make life miserable for us, and we want those bullies to disappear. Those entities that are still bullying us must be put to rest.

When childhood is over, we expect the bullies in our life to disappear. Those entities that push us around and make life miserable for us should evaporate as we mature. However, I now know that there are some bullies that follow us not on the playground of our early days but are there on the genetic level with us all our days.

My mom and dad passed on to me the genes for brown eyes and brown hair. Little did I know that I also carried a gene that would become a bully, go awry, and cause cancer.

Thus, I lived my life happily married, raising four children, teaching school, involved in community activities and travelling until 1988. It was then that one bloody stool prompted me to call my doctor. I could easily have ignored it. Imagine my surprise to discover at age fifty-one that I had colorectal cancer, although I felt fine and recent Fecal Occult Blood Test (FOBT) results showed no sign of disease.

The bullies were at work. A series of four to seven genes that regulate “cell etiquette” had become damaged by chance or environmental influences. They no longer controlled normal cell behavior. They allowed cancer cells to grow without limit, invade the environment influences. They no longer played by the rules of normal cells.

The bullies were at work. A series of four to seven genes that regulate “cell etiquette” had become damaged by chance or environmental influences. They no longer controlled normal cell behavior. They allowed cancer cells to grow without limit, invade the environment influences. They no longer played by the rules of normal cells.

As a result of my work with the United Ostomy Association’s prevention initiative and the American Cancer Society, I have become acutely aware that those with inflammatory bowel disease or a family history of cancer are at high risk for colon cancer. However, age is the highest risk factor. 90% of colon cancer patients are over the age of fifty.

As the current ACS screening guidelines suggest, the children of a first-degree relative with colon cancer or cancerous polyps should begin screening at an age ten years younger than the age of onset of the parent. For my children that meant before they reached forty. My two sons and two daughters proceeded to have a colonoscopy.

Since no parent wants their children to test positive, I anxiously awaited the results. Had I passed on the genetic bullies to my loved ones? Three out of the four were fine. My oldest son had a number of adenomatous polyps removed. He will maintain a follow-up regimen of further screening. Passing on this vital family history and taking action has undoubtedly saved his life.

I am still challenging the bullies by attempting to spread the prevention message wherever I go. Now that I am a permanent Florida resident, I am raising my voice here, since statistics show that there will be 10,200 new cases in Florida alone over the next year. Early detection to remove polyps could save 90% of them. We can not change our genetic makeup but we can take action against this disease. I know from personal experience that colon cancer is Preventable, Treatable, Beatable.

INTERVIEW WITH AGGIE
Submitted by Aggie Chor, member of the 20/40 Focus 2007 Planning Committee

From 1994 to 2002 Aggie had seven major four minor operations and two courses of radiotherapy.

July 1994 - Cancer of thyroid gland. 1995 - Diagnosed multiple polyps, high risk to malignancy. 1996 - Operation to remove the gall bladder. 1998 to 2000 - Suffered from Depression. October 2000 - Operation to remove Desmoid tumor along with 34cm of the small intestine, earlier wrongly diagnosed as ovarian cancer. November 2001 - Total colectomy and permanent ileostomy constructed. (440 polyps found and colon and rectum cancer was diagnosed) September 2002 - Operation to remove Desmoid tumor with 39cm small intestine leaving two irremovable tumors.

The doctor informed Aggie, on her 27th birthday, that she had colon and rectum cancer.

AGGIE: “I do not know what an ileostomy is, and I do not have any knowledge about being an ostomate. I kept asking the doctor: Can I lead an ordinary life after the operation? Can I Exercise? Swim, jog?? A lot of questions in my heart.

I knew that, as an ostomate my life would not be ordinary anymore... Sounds sad! I decided life has to go on and I pledge to live life to the fullest in my remaining days before the operation.

Even though I have never given up, I was depressed. I felt my cloth stained and messy. Is that what I have to learn to live with? During that time, I felt it is like having a little ugly monster hanging out of my right lower tummy and I was suffering - both physically and mentally.

The truth was harsh. I left with no choice and I was depressed. I felt my cloth stained and messy. Is that what I have to learn to live with? During that time, I felt it is like having a little ugly monster hanging out of my right lower tummy and I was suffering - both physically and mentally. I decided life has to go on and I pledge to live life to the fullest in my remaining days before the operation.

The truth was harsh. I left with no choice and I was depressed. I felt my cloth stained and messy. Is that what I have to learn to live with? During that time, I felt it is like having a little ugly monster hanging out of my right lower tummy and I was suffering - both physically and mentally. I decided life has to go on and I pledge to live life to the fullest in my remaining days before the operation.

I was a physically active person before the operations. Even though I was depressed I went for a walk every morning and evening, and realized that life outside the house is beautiful after all.

From that moment I decided never to enchain myself and live life as a recluse. Therefore, life has a new beginning... to live life fully...as an ostomate.

I found out that, as an ostomate I can also do a lot of things like cycling, shopping, using the public washroom, and believe me - other fun activities such as swimming, travelling, ice-skating, snorkeling, dancing, hiking......

I accept cancer and stay peaceful. I will not say no to death, because I believe in impermanence.

How I can live is not matter, long live the matter.
I would like to thank all Associations and individuals for their kind permission to reprint all the photos and reports contained in this publication.

AOA - Dr. Harikesh Buch; Thailand Ostomy Foundation; Aggie Chor; Geleg Davaasambuu, Dato John Cardosa; EOA - Vladimír Kleinwächter; Arne Holte; Maria Hass; Susanne Deimel; Zohdi N. Shehatto; Snezena Cmiljanic; Sarah Maill; Ing. Miroslav Sery; Henning Granslev; Dr Naguib Elnikhaily; FINNILCO; Thierry Schuster; Heinz Wolff; Aliza Yaffe; Jerzy Kasprzak; Vyacheslav Sukhanov; Ludmila Kotunenko; Cynthia Robinson; Hazel Pixley; NCACOA - Doug Graham; Astrid Graham; Monica Sagastume; Gene and Sheelah Zapf; ALADO - Candida Carvalheira; Rafael Nestor; Alexander Machaca; Damaris Morais; SPOA - Australian Council of Stoma Associations; Peter McQueen; Judy Lopez; Federation of New Zealand Ostomy Societies; Jill Newton. Rachida Charaf (through FOW Canada and Arne Holte), Ann Favreau, Anita Singewald, Stuart Schaefer (webmaster) and Dielwen “Di” Bracken.