



# IOA TODAY

An Online Quarterly Newsletter provided by the International Ostomy Association

Bringing You Ostomy Related Information From Around the World

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(Please note: Contact the President: [president@ostomyinternational.org](mailto:president@ostomyinternational.org) before reprinting any article from this newsletter.)

## Hello to all my friends in IOA:

I am truly excited to be writing my first message as the new president of IOA in IOA TODAY. I understand the responsibilities of the position but I know that I will not be alone. There are many competent people in our organizations around the world who I know will help if asked. I hope that working together over the next three years, we will be able to make a difference in our organization.

We had a very successful World Congress in Porto with 34 countries in attendance; some 10 other countries sent proxies so that their country could participate in the voting procedures. It is always of great interest to be able to interact with ostomates from around the world and this time was no exception. The largest number of attendees from any one specific country was Japan with a delegation of 20 people.



It is important that we recognize the sponsorship of the major manufacturers without whose support we would not be able to carry out the work of the organization. Heinz Wolff introduced and presented representatives of the major sponsors, Jytte Gliim, Coloplast; Margo Skinner, ConvaTec; Søren Frisk, Dansac and Al Maslov, Hollister; Rania Abi Saad, B.Braun.



The President expressed his appreciation of our sponsors. In acknowledging the contribution made by these companies Heinz explained that each of the companies had provided most of the sponsorship funding for the

Congress. In addition they had all assisted with, and contributed to, the operations of IOA over the preceding 4 years by sponsoring meetings and other activities which had allowed the Executive Committee to operate efficiently over this period.

As you are aware, the World Congress is where the business of IOA is conducted and elections take place. I will high light some of the things that may be of interest to you.

### Election Results

Di Bracken, President, Canada  
Vladimir Kleinwachter, Vice President, Czech Republic  
Gene Zapf, Treasurer, Canada

### New Regional Presidents

Arne Holte, Norway, European Region  
Linda Aukett, USA, North & Central American & Caribbean Region  
Barry Maugham, New Zealand, South Pacific Region

### Remaining in office

Harikesh Buch, India, Asian Region  
Maureen Flynn, Argentina, South American Region  
Heinz Wolff, Past President, Israel

I have included information about the new people on the IOA Executive later in this newsletter. At this meeting it was agreed that there was a need for IOA to have a **secretary**. This will not be an elected position but one appointed by the Executive Council of IOA. I have included an advertisement in this newsletter regarding the position for any one who is interested.

Also, please note that Linda Aukett as the newly elected president of NCACOA, will not be able to continue her duties as editor of the Ostomy International so we are looking for a new editor for the OI magazine. Again, there is an advertisement for a new editor included in this newsletter.

Copies of the minutes from the business meetings have been sent electronically to all country presidents. Where a country has no e mail access, the presidents of the regions are asked to download and mail out to that specific country. Let me know if you have a problem.

If there are changes to the information re country president as a result of an election etc. please let me know so that our Webmaster can make the change on our Website. Your regional president will want to know changes as well.

**PUERTO RICO** will be the host for the next IOA World Congress. The World Council of the INTERNATIONAL OSTOMY ASSOCIATION, meeting on 31 August 2004 in Porto, Portugal, accepted the offer made by the

ASOCIACION de OSTOMIZADOS de PUERTO RICO to organize the 12<sup>th</sup> IOA World Congress. This Congress will be held in San Juan, Puerto Rico, on 22 September to 28 September, 2007. I know this is an early announcement but let's book the date now to enjoy a holiday as well as attend the World Congress. A World Congress is so different from a national conference. Just plan to come and start saving your pennies. The location is delightful and the Caribe Hilton Hotel has much to offer. Martha Velez De Nieves past president of the NCACOA Region will be the chair and Ken Aukett from the USA will be the liaison between IOA and the Association in Puerto Rico.

**WORLD OSTOMY DAY** will be held on Saturday 7<sup>th</sup> October 2006. We will decide on the theme in the next few weeks but I know that some countries have already assigned a contact person for this important job.

An unplanned feature of the Congress was the **photographs**, shown daily on an overhead screen in the lobby. Our Webmaster, Stuart Schaefer, is also a photographer by profession. He was taking his candid shots and lo and behold, he got them on the screen next day – just like a Sports Bar!! It proved to be so popular that Stu burned a number of photographs on to a CD; IOA collected \$10.00 per CD and thanks to Al Maslov of Hollister Incorporated who made copies and mailed them out, those who wanted, have a great memento of the World Congress.

**IOA AWARDS**

Our awards were presented at a dinner held in the Casino Povoia.



The winner of the **Coloplast Merit Award** for celebration of World Ostomy Day 2002 was the Czech Republic, with Thailand awarded the second prize.



The Coloplast Millennium Award for promotion of Youth Activities was awarded to Sweden.



The **Professional Services Award** for service to IOA was presented to Professor Dr. Carlo Pezcoller of Italy by IOA President Heinz Wolff. Dr Pezcoller received his award in recognition of all that he has done for the development and

expansion of Ostomy Services in Asia during the past few years, and also for his work for Ostomates in Italy and Europe in general.

The **Archie Vinitsky Award** was presented to Ken Aukett of the USA by previous recipient Gerhard Englert. Ken was recognized for his many years of commitment and service to IOA, including holding the position of president from 1994 to 1997.



The award presentations were followed by a spectacular floor show.

**20/40 Focus Group**



This was the first time that the young people had been a part of the World Congress. Although they had organized their own programme, they were present at social events

and I believe we all enjoyed the interaction. The 20/40 committee for the next three years are as follows:

- Paula West, Chair from New Zealand, SPOA
- Sarah Maill from the UK, representing EOA
- Monica Sagastume from the USA representing NCACOA
- Demaris Morais from Brazil representing ALADO
- Aggie Cohr from Malaysia representing AOA

Barry Maughan Regional President SPOA, will be the Executive Liaison for the 20/40 Group.

An important part of any World Congress is the social events as we get to know ostomates from around the world. Porto, an historic city, and designated a World Heritage site by UNESCO offered us the opportunity to become involved in history with interesting companions. All attendees were taken on a tour of the Porto by bus with our destination being the Port Wine Caves. We had a tour of a port cellar, and were offered tastes of tawny, white and ruby port. Dinner was in a waterfront restaurant. August 31 was the last day of the Congress. The closing dinner was in the large wine cellars of Ferreira, followed by a dance. Many delegates left the next day, while the newly elected Executive held a board meeting.

I would be remiss if I did not acknowledge the work done by the organizing committee, especially Luis Pinto, President of LOP, Dr. Amandio, and Mario Correia to ensure the success of the Congress.

I believe that IOA has a new exciting team to continue the work of those who have previously led the organization. I look forward to letting you know of our activities in the winter edition of IOA TODAY.

Until then, please take good care of yourselves. Stay safe and in good health.

With very best wishes.

*Di*

## MEET THE NEW OFFICERS OF IOA



**DIELWEN BRACKEN, PRESIDENT IOA.**

Di was born in a small Welsh village and graduated from university with a BA degree as well as a teaching degree in Education. She began a teaching career in England before she was seconded to the British Army where she taught school in the then Crown Colony of Hong Kong. It was this experience that initiated her life long interest in international affairs. When Di retired from her teaching position in 1992, she had taught school on three continents.

Di had ileostomy surgery in 1980 and immediately became involved in the Canadian Ostomy Association. She founded a chapter in her home town and served in all executive positions. She established the chapter's visitation service and its newsletter.

The Canadian Association at this time was under the umbrella of UOA where Di served as Provincial representative for UOA Inc. and in 1991 was elected to the Board of Directors. She assumed the chair of the Membership Committee and became a member of the Annual Conference Planning committee of UOA Inc. in 1993 and served as the chair of the committee from 1996 - 1998.

Having lived and worked on three continents ( teaching in the United Kingdom, Hong Kong and Canada ), it was natural for her to be interested in the international scene and she became very active in FOW Canada. She worked very closely with the late Maria Siegl organizing many shipments of ostomy supplies to developing countries. This remains a passion with her today.

Di assumed the presidency of the UOAC following the untimely death of Maria Siegl and was elected president for a two-year term in 1998.

At the World Congress in Amsterdam in 2000, Di was elected to the position of Vice President of IOA. She was appointed by the president to the position of secretary.

As the incoming president of IOA, Di is prepared to work closely with the IOA Executive Officers and country presidents throughout our ostomy world to ensure that goals, programmes, projects are completed which will improve the quality of life for those ostomates who at this time have no access to ostomy supplies or adequate medical care.

On a personal note Di lives with her yellow Labrador named FFION in Toronto where visitors are always welcome. She has two adult children a son and daughter and she is the very proud MAMGU ( Welsh for grandmother ) of two grand children; Tywen aged nine and Brynne aged 6.



**Vladimír Kleinwächter IOA Vice President**

Vladimír Kleinwächter was born in 1933 in Brno, Czechoslovakia. He is an ileostomate since 1958, because of ulcerative colitis. In 1973 he was diagnosed with cancer in the remaining part of the rectum and underwent chemotherapy with a successful result.

He became involved in a local Brno ostomate organisation since its origin in 1987. In 1993, after division of Czechoslovakia in Czech and Slovak Republics he participated in the organisation of a national ostomate association, which was founded at a meeting of all then existing Czech ostomy clubs on the 1<sup>st</sup> World Ostomy Day in October 1993. This association, Czech ILCO, became a member of IOA in 1994. As the Czech ILCO Chairman Vladimír made Czech ILCO an organisation, which was able to provide effective help to ostomates in the country.

At the 8<sup>th</sup> EOA Congress in Israel in 1995 he was elected member of the EOA Co-ordination Committee; at the EOA Congress in Venice (1998) the Vice-President and at the next EOA Congress in Copenhagen President of EOA. His activities in the EOA Committee were aimed mainly at co-ordination of help and advocacy programmes yielding assistance to ostomates in those European countries where the care of ostomates was at inadequate level.

With the help of the respective national associations Vladimír initiated regular meetings of ostomates from countries of Central and Eastern Europe, which took

place in Brno (Czech Republic) in 1995 and 1997, Poznan (Poland) in 1999 and Kaunas (Lithuania) in 2002. He participated also at several national meetings in Poland, Ukraine, Belarus and Italy and was engaged in establishing contacts with countries which were not yet members of IOA.

After being elected the EOA President he resigned on the position of chairman of Czech ILCO, but he continues to work with the new committee; in particular in the field of legislative concerning the social rehabilitation of disabled citizens.

As the IOA Vice-President Vladimír wants, besides his standard duties, to get involved in the advocacy programme, which would include all IOA regions.

### Personal

Vladimír lives in Brno, is married and has two adult children. He is the grandfather of three girls and a boy. He studied physical chemistry at Masaryk University in Brno and then worked in the Institute of Biophysics of the Czechoslovak (later Czech) Academy of Sciences, where he obtained PhD. degree in 1960. After the fall of the Communist regime in 1989 he had the position of the Institute's Deputy Director and before his retirement in 1997 he was shortly the Director of the Institute. He was mostly engaged in research of spectroscopic properties of nucleic acids and modification of their genetic properties with anticancer agent. At present he continues in lecturing biophysics at the Masaryk University and Palacký University in Olomouc. In pursuing the scientific activities he developed numerous contacts with research Institutions abroad, in particular in Germany, England, France, Poland, Russia and United States, where he worked for more than two years as a postdoctoral fellow and later as visiting professor. For his scientific activities he was awarded the Golden J. Heyrovský Medal in 1993.



**GENE ZAPP**

I was most pleased when attending the 11<sup>th</sup> IOA World Congress in Porto this summer to be a part of making history in that, for the very first time, a non-ostomate was to be considered for the position of Treasurer. I am most honored and humbled to have been chosen for this most prestigious position.

I received my Bachelor of Commerce degree from the University of Alberta in Edmonton and then went on to pursue further education in the accounting field by obtaining a professional accounting designation, that of Certified Management Accountant. My entire working

career was in the accounting/auditing environment. I spent 15 years as a tax auditor/investigator with the federal department, Revenue Canada, Taxation, and then 22 years with the provincial government as a tax auditor/manager with Alberta Treasury, Tax and Revenue Administration. I retired from my employment with the province of Alberta on March 31, 2003 and am now enjoying the leisurely lifestyle.

Sheelah and I are the proud parents of two grown children. Our daughter, Patty, is a tenured professor at a college of criminology in New York city and our son Bill and his family now reside in Tampa, Florida and he has several business interests ongoing even though he is a quadriplegic and is paralysed from the neck down. Three grand children round out our family and they are royally spoiled whenever the opportunity arises.

I am really looking forward to the future and the duties and responsibilities of the Treasurer of IOA knowing full well that I have a set of very large shoes to fill. I can only promise that I will do my very best to maintain and enhance the image of the International Ostomy Association around the world. Thank you for entrusting me with these responsibilities.



**ARNE HOLTE, PRESIDENT EUROPEAN OSTOMY ASSOCIATION**

### Personal:

President of NORILCO, Norway  
Age 60 Married, 2 grown children, three grandchildren, Retired

### Education:

Electronics  
Management and personal development  
Data-courses, job-related courses in Norway and abroad

### Work-experience:

Electronics repair and management  
1961 - 2002

**Ostomy-experience:** Ileostomy from 1974

### Organization- experience and work within organizations:

President of a local chapter 1979 – 1996  
VP NORILCO 1996 – 2002  
President NORILCO 2002 –  
Head of NORILCOs visiting service 1996 – 2002  
President of a sportingclub 1996 – 2000  
Head of several projects within NORILCO  
Head of courses for ostomates in St.Petersburg, Russia  
Participated in IOA congresses and EOA-conferances

### **Present occupation and hobbies:**

Head of patients group at Norways National Hospital  
President NORILCO

Member of EOAs task force

Member of two groups within the Norwegian Cancer union

Member of a group planning courses in St. Petersburg, Russia

Skiing and running – keeping fit

Part-reponsible for a sports-event to take place 2004

Garden-work

### **Most important work to be done within EOA:**

Follow up the charter of ostomates rights

Help creating a better life for ostomates in all countries

Help creating a visiting service in all countries



**LINDA K. KING AUKETT,  
PRESIDENT OF THE NORTH &  
CENTRAL AMERICAN and  
CARIBBEAN OSTOMY  
ASSOCIATION**

### **VOLUNTEER INVOLVEMENT IN OSTOMY REHABILITATION**

- President, North & Central America and Caribbean Ostomy Association, a Regional Association of IOA
- Served a term as Member of the NCACOA Executive Council, 2000 - 2004.
- Editor, Ostomy International, a journal of the International Ostomy Association (IOA), since 2000, and Associate Editor from 1997 through 2000.
- Chair, United Ostomy Association Government Relations Committee, USA
- Member, International Ostomy Association, World Ostomy Report II Taskforce
- Past President, United Ostomy Association, Inc., USA (1992 – 1994)

### **Writings and presentations:**

- Authored the UOA manual "Implementation of a Chapter Visiting Program" and participated in the review and development of other UOA publications; authored several articles in the UOA periodical, *Ostomy Quarterly*.
- Presented many conference workshops at regional and national UOA conferences. As a UOA trainer, facilitated numerous day-long "Volunteer Leadership Development" sessions on a variety of leadership topics. Internationally, has made presentations at international conferences and symposia in Adelaide, Australia; Bangkok, Thailand;

Calgary, Canada; Shanghai, China; Santo Domingo, Dominican Republic; Penang, Malaysia; Hangzhou, China; Noordwijkerhout, the Netherlands; Manila, Philippines; Porto, Portugal.

- Ileostomy surgery was performed in 1970, after 13 years with ulcerative colitis.
- Spouse of an ileostomate since 1988.

e-mail: [regionncacoa@ostomyinternational.org](mailto:regionncacoa@ostomyinternational.org)



**Barry Maughan**

I have been an ostomate for 17 years and I am a member of the New Zealand's Waikato Ostomy Society. Since 1993 I have been on the Federation of New Zealand Ostomy Society's Executive, with 2 years as Vice President and 6 years as President and 3 years as senior vice President.

At the last 3 IOA Congresses I have been proud to present FNZOS as a Delegate. Since 1997 I have been on the SPOA executive becoming President in Porto, I look forward to the challenge we have in supporting ostomates in the South Pacific and working on the IOA executive's many projects.

My profession has been Education and I have in 2004 retired after 30 years as a principal of 4 different Primary Schools. I also taught in London and Colorado as well as other rural NZ schools. I have had many senior roles within my profession and was chair of the NZEI National Principals Council for 2 years. This meant working closely within the Government's Ministry of Education. A week after retirement I took up a fulltime position with NZEI (The Primary Teachers Union) and work as a field officer in many different schools and early childhood centres.

My partner Jackie is a Principal also and supports my work for ostomates locally, nationally and internationally. We have four grown up children the eldest 33 and the youngest 24. We have 2 grandchildren aged 3 and 6. We live in Hamilton, in the North Island, a city of 110,000.

Over the years I have been an active sportsperson and still play tennis and when the opportunity arises go walking the many scenic tracks NZ has to offer from the mountains to the sea. I am also a keen gardener.

# JOIN THE IOA TEAM

Delegates at the 11<sup>th</sup> World Council held in Porto in August 2004 approved the formation of the voluntary position of secretary to the organization. IOA is now looking for a person to fill this voluntary position of secretary.

## RESPONSIBILITIES:

1. Take minutes of the IOA Executive Council, the World Council, the Strategic Planning and other special meetings the IOA Executive Council may convene. Finalise and distribute the minutes as pursuant to the Standing Policies and Procedures.
2. Distribute notices to Member Associations as directed by the President.
3. Maintain the Standing Policies and Procedures making additions, deletions and changes to reflect decisions made by the IOA Executive Council.
4. Provide information and opinions as appropriate in the Council's efforts to resolve issues.
5. Accept assignments as deemed appropriate by the IOA Executive Council, undertaking the work in a professional manner, with enthusiasm and within established time and financial limits.
6. Prepare an annual Secretary's expense budget and, once approved, accept fiduciary responsibility for the expenditure and reporting of these funds.
7. Communicate in a constructive and timely fashion with other members of the IOA Executive Council.

## QUALIFICATIONS

- be an ostomate
- able to communicate in oral and written English
- must own a computer
- experienced with Microsoft Office or equivalent
- able to update and maintain IOA data base
- familiar with electronic communication and general office equipment including copiers, fax machines, and 10-key calculators.

Able to communicate in a second language will be given additional consideration

## NOTE:

The secretary is appointed by, and reports, to the IOA Executive Council through the president.

The Secretary shall serve until replaced by the Executive Council or resigns his/her position.

If you are interested in this out of the ordinary position and would like to be of help to fellow ostomates, please send your personal information to: Di Bracken, the IOA President at [president@ostomyinternational.org](mailto:president@ostomyinternational.org)

The **International Ostomy Association** seeks a qualified and interested person to become editor of Ostomy International, effective with the 2005 issue. The Editor of the OI carries out a portion of the IOA mission to inform the ostomy world and other related persons about developments at national, regional and international levels, and about advances in the medical, management and technological field surrounding ostomy.

It is expected that Ostomy International will be published once a year. The Editor of the OI:

- conceptualizes and develops each issue, interacts with the IOA Executive Council to determine a theme, and solicits input from IOA member countries and from medical professionals and other sources;
- secures advertising so that each issue is self-supporting financially;
- edits the material received and employs desktop publishing software to develop a final layout for the printer;
- interacts with the printer to obtain a final proof and provides a print order based on IOA membership and subscriber needs;
- interacts with the IOA Treasurer to facilitate timely and accurate invoicing to advertisers and others, and to facilitate accurate reporting to the IOA Executive Council;
- reports to the IOA Executive Council periodically, attends each World Congress at IOA expense, and may be invited to interim meetings of the IOA Executive Council as appropriate.

Qualifications include:

- familiarity with the ostomy world
- sensitivity to multi-cultural issues
- facility in the English language
- ability to interact with advertisers (soliciting, contracting)
- computer, electronic communication and editing skills
- experience in journalism/desk-top publishing
- creativity and ability to be self-starting

Interested persons are invited to communicate with the IOA President, Di Bracken, at [president@ostomyinternational.org](mailto:president@ostomyinternational.org).

## SOUTH AMERICAN REGION REPORT ASOCIACION LATINOAMERICANA DE OSTOMIZADOS (A. L. A. D. O.)

### MARIA CECILIA FLYNN, ALADO PRESIDENT

In October 2001 we celebrated a Regional Meeting in Bogotá, Columbia.

The following countries were represented:

Brazil, Columbia and Argentina, Chile, Bolivia, Peru and Venezuela were unable to attend. Martha Velez from NCACOA was present representing IOA.

It was pointed out that practically all countries in South America ostomates are in a difficult situation and are in need of support. Most of the countries do not have government support and ostomy products are very expensive. On general terms, people cannot afford them and they are not supplied by health care.

It is a general aim in South America to fight for the ostomates rights and obtain recognition at government and health care levels in order to get better services and free ( or less expensive) supply of products.

It is also an aim to organize to organize ET courses in the region, since some countries do not have professional ET nurses.

We hope to have our next regional meeting in 2005 and also to develop an ISCAP programme.

Chile, Bolivia and Argentina have recently received donations from FOW USA and are very thankful for this help. These products are distributed among the needy ostomates.

In Argentina, a Federation has been formed, uniting three different associations from different provinces, with the main objective of forming a national organization.

Brazil successfully organized their National Congress last year and had very good attendance. In May 2002, the WCET held their Congress in Florianopolis. It was also a very successful meeting.

Bolivia which will be present at the World Congress is also going through difficult times.

Columbia is at present fighting for their ostomates rights since the government has withdrawn the help

they were giving the ostomates in relation to the supply of ostomy products.

Paraguay has started a new association and we are hoping that they will soon join the IOA.

Chile has a well formed association and is looking forward to participate in the next regional meeting.

## YOUNG OSTOMATES IN BRAZIL

By Damaris Morais



Since the launching of the Focus 20/40, ABRASO (Brazilian Ostomy Association) has been making efforts to mobilize the young ostomates

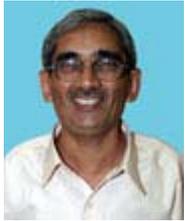
of Brazil to form a strong group. With this objective in mind, after the Denmark Congress we held our first Young Ostomate Meeting in Rio de Janeiro, 2001 attended by some 20 ostomates. During this event two ostomates were elected to represent Brazil in Focus 20/40 – Canada, 2001. Following the Canadian meeting another event was held in São Paulo in 2002. This time attended by a much larger group of about 40 ostomates. During the National Ostomates Congress in 2003 held in Guarapari, state of Espírito Santo, an expressive group of young ostomates were present and we were given a whole day for workshops and discussions at national level.

The president of the National Ostomy Association of Brazil makes every effort to encourage a specific work with young ostomates, but this meets with great resistance on the part of the ostomates who are over 40 who strongly resent being left out of the group. They think this will segregate rather than unite the ostomates as a whole. We also noticed that when we have young ostomates as heads of regional associations, they too seem to think that it is not worth having separate groups, maybe because of coordinating difficulties.

Our experience in the state of Goiás has shown quite the opposite. We had four encounters for young ostomates only. Out of 100 young ostomates that were invited, only 20 showed up, but out of these, five are already engaged in activities for the whole association. For example, they were extremely cooperative during the celebration of the ostomates day in October 2002 and also in organizing the group that attended the National congress in 2003. More recently during the celebration of the silver jubilee of our regional association they were extremely helpful.

Another great obstacle faced is getting people from very different walks in life – some barely able to read and others who are fairly educated – to want to socialize.

However, we will continue to work to improve the lives of the young ostomates because we believe in this cause and daring to quote the great Portuguese poet Fernando Pessoa we would say that “Everything is worthwhile if the soul is not small” (Tudo vale a pena se a alma não é pequena).



**ASIAN OSTOMY ASSOCIATION  
REPORT** by Harikesh Buch, Regional  
President

Last year Major events in Bangkok of IOA (world ostomy meeting), ASSR meeting & ET nurses meetings were cancelled because of SARS 2nd ASSR Meeting will be held in Bangkok in late August this year, in conjunction with the APETNA (Asia-Pacific ET Nurses' Association) meeting.

We had established a direct contact with an English speaking young Colorectal surgeon before Shanghai ostomy association meet last year but now he does not write back to us. But apparently they had a good meeting last year. I had written to him about AOA as well as about statistics regarding different ostomy surgeries in India & ostomy support services in India.

The work done, by efforts of Dato' John Cardosa our AOA secretary/treasurer, by ET Ms. Shanti for ostomates in Nepal & the help she has received for ostomy products for poor ostomates in Nepal by FOW thru Di Bracken is known to every one in IOA EC as it is high lighted in IOA Today's last edition.

This is what Mr. John Cardosa has to report from his recent visit to Nepal.

" In my recent visit to Nepal (7th to 15th January 2004) I learned from Dr Bhaktaman Shrestha in Bharatpur Hospital that they are having problems there because of the MAOIST insurgents. Only about 20 of their regular 50 to 60 ostomates now come for their monthly clinics. The doctors are also being harassed by the Maoists, and several have left for other jobs elsewhere. Dr Shrestha himself is trying to get a job in Kathmandu because of this. He is afraid his wife and two young children will be hurt. Another thing he told me was that the FOW shipment of ostomy supplies which had been sent by ship via Calcutta could NOT be delivered to Bharatpur because of documentation problems for about 6 months. Finally the shipment had to be abandoned in Calcutta. What a pity! However, Dr

Shrestha and another surgeon as well as three nurses are still servicing the ostomates who still attend the regular monthly clinics, as well as those who come to the hospital on a casual basis. But they have run out of free supplies to give them. Dr Shrestha suggests that it might be better to send him small batches of supplies by air freight direct to Khatmandu, from where they can be transported by road to Bharatpur. There are regular bus services and lorry services between Khatmandu and Bharatpur, a distance of about 120 kilometers. The road journey takes 4 to 5 hours depending on the weather and the condition of the roads.

It would be a good idea if IOA EC could assist the President of the Nepal Ostomy Association, Mr Ganga Lal Tuladhar, to attend the Porto Congress. He is English speaking and very dynamic, and needs some encouragement. Shanti has already been to Malaysia also to Florence for the WCET Congress last year. I think that assisting Mr Tuladhar to go to PORTO would be MOST beneficial to the growth and development of Ostomy services in Nepal."

As regards India, there are problems with OAI EC & the court cases against them

Banglore has become an associate member after paying their dues to IOA & they & Hyderabad group has become active. There is a possibilities to start a group in Calcutta now since I have developed some contact with a patients there. We have managed to get railway concession in Mumbai for ostomates & are trying to get all India wise in Railways. Most of the other countris in Asia are quite active in their own countries as far as meeting for ostomates & help & supplies of ostomy products to them. New countries are being targeted for development of Ostomy services in Asia, such as Myanmar, Laos, Cambodia, and Mongolia. Doctors from these four countries will be attending the Modena workshop in late May. I am somewhat disappointed that even though we brought one doctor, a professor and colorectal surgeon, from Bangladesh to Modena in 2002, he does not seem to have done anything to initiate an Ostomy Association there. I would follow this up later, and encourage them to form an association and join AOA as a member.

Most countries in ASIA do not get covered by health insurance for buying supplies through them & have to buy with their own money or depend on charity because of unaffordable prices of ostomy related products.

At the 1st ASSR Meeting in Osaka in 2002, Mr John Cardosa presented a paper in which he appealed to manufacturers to produce a cheaper line of "no-frills" products for ostomates in the poorer countries of Asia, Africa, South America, and even the former Soviet

republics. They promised they would work on it. That is why there is so much need for manufacturers to think about pricing of ostomy products as well as think of manufacturing these in Asia . Dansac has started this in China. Convatec is thinking to start a direct selling facilities in India because of too much price hike by dealers or middle man's profits & they probably might establish a office in Mumbai soon.

Iranian nurses had an workshop training by Mr. John Cardosa's as well as Prof Carlo Pezcoller's efforts(from Italy). I had a letter from Elizabeth English few weeks ago that Iranian nurses will be going to Malaysia for ET training soon. The ET Training will be held for 6 weeks in Kuala Lumpur and attachments for another 4 weeks in KL and Penang. 4 Iranian nurses will be attending the WCET course - one male nurse and three females. This should result in an explosion of Ostomy services in Iran. Already, several new chapters of the Iranian Ostomy Association have been formed in other major cities of Iran such as Shiraz and Isfahan.

There will be a work shop organised in Modena univesity by Prof Carlo Pezcoller .to train Asian doctors about taking care of ostomates in ASIA . This will be in end of May year. Mr. John Cardosa and I will be taking part in this.

## "Training for stoma care in Modena"

This workshop was organised by Prof.Dr.Carlo Pezcoller at medical school hospital , Modena , Italy from 24th to 29th May 2004.

This was meant to train doctors from economically less fortunate countries in Asia where stoma care hardly exist or not at all .

The participants from Asia were as follows :  
Dr.Harikesh Buch - Surgeon , Mumbai , India.  
Dato' John Cardosa - KL , Malaysia.  
Dr.Kyaw Sint - Surgeon , Myanmar.  
Dr.Rasachak Bouachan - Physician , Laos.



Dr.Yasan Erdene - Orchin - Surgeon . Mongolia.  
Dr.Bayarsiakhan Luvsandroj - OB-GY , Mongolia.

Prof.Dr.Pezcoller along with his team of professors including  
Prof.Massimo Federico - Tumor Registry.  
Prof.Bruno Cola - Colorectal surgery.  
Dotto Piero Benatti - Geneticist.  
Prof.Gianpaolo Bianchi - Urologist.  
Prof.Carmelo Militello - Colorectal Surgeon from University of Paduva.  
Dott.Gabriele Luppi - Medical Oncologist.  
Dott.ssa Silvia Galettie - Nutritionist.  
Prof.Anna Maria Falchi - Radiation Oncologist.  
Dr.Raffele and ET nurses Ms.Luciana and Ms.Lidia Biondani.

These people did the training.

From Doctors of Myanmar,Laos and Mongolia all of us learned about the plight of ostomy patients in absence of ostomy care as well as near non existence of availability of ostomy products. Specialized ostomy nursing training or care also does not exist in those countries. It was sad to learn that specially urostomates are virtually abandoned by their families because of non existence of urostomy appliances. Cancer of colon and rectum is more common as compared to IBD or bladder cancer. Political situations in those countries also make it difficult for them to have ostomy associations without support and knowledge about stoma care from other parts of the world.

With this background in mind , Prof.Dr.Pezcoller had organized excellent training for these doctors with the help of his team of assistants as well as ET nurses and other professors specialized in different fields of treatment.When required for lectures as well as in out patients , there was help of Dott.ssa Claudia Allegretti , as an English translator , was also available and provided.

There was excellent practical demonstrations of how to deal with different types of ostomates , their needs and how to deal with different complications of stoma in out patient department in medical school hospital. The stoma clinics are extremely well organised and are run very professionally in that hospital.

There was a practical demonstration of management of end colostomy with irrigation technique by a patient in out patient department , one morning. This proved to be very useful to all the doctors.

There were lectures by various experts on various subjects including hpw to construct various types of digestive and urology stoma , cancer epidemiology and

cancer registry , cancer genetics , IBD , current concept of chemo and radio therapy for colorectal and urology cancer , importance of nutrition for ostomates , and rehabilitation of new ostomates in society .

Dato' John Cardosa spoke about the importance of IOA , AOA and The International Stoma Care Advocacy Programme (ISCAP) . He also delt with how these can help their countries for development of stoma care and starting new ostomy associations.

Almost all types of stoma appliances were demonstrated by various manufacturers including Dansac , Hollister , Coloplast , Gallini , Convatac and B.Braun.

It was not only teachings and training but also was mixed with fun and flair in some evenings like visit to Ferrari fast track , visit to local farmhouse and practical demonstration parmesian cheese manufacturing process with cheese and wine reception for all of us by a friend , Mr.Azienda Panini , of Prof.Pezcoller . On the last evening , local Lion's Club members and members of the local ostomy association had organised a spring party where all of us were invited guests.

Dato' John Cardosa and all our doctor friends from Myanmar , Laos and Mongolia as well as I as a AOA president and ostomate surgeon have not enough words to thank Prof.Dr.Carlo Pezcoller for what he has been doing for ostomates and ET nurse training specially in economically less fortunate countries of Asia.He has a tremendous vision for the future of ostomy patients specially in developing countries.

Dr.Harikesh Buch.  
President AOA

## **EUROPEAN PRESIDENT'S REPORT 2001 - 2004**

It is my pleasure to give the following report on activities of the EOA Co-ordination Committee during the period from May 2001 to August 2004.

### **EOA / IOA MEMBERSHIP**

To the date of the 11<sup>th</sup> EOA Congress the European region has 42 member Associations, 30 full members and 12 associate members.

During the last three years 2 Associations asked for full membership (Federazione Associazioni Incontinenti e Stomizzati from Italy and Expatriate Ostomates of Spain) and 2 Associations for associate membership (Association ILCO Serbia from Serbia and Montenegro and Odessa - ILCO from Ukraine. It is anticipated that

these Associations will be accepted at the Porto Congresses.

An intention to join EOA / IOA was also expressed by Turkish Ostomy Surgery Association, but this Association has not yet fulfilled all requirements.

Including the new members EOA will have 32 full members and 14 associate members, in total 46 members, representing ostomates from 38 countries.

### **EOA CO-ORDINATION COMMITTEE**

#### **Committee Membership:**

Vladimír Kleinwächter (Czech Republic),  
President

Thomas Keily (United Kingdom), Vice-President  
and Treasurer

Klaus Schröter (Germany), Editor

Ria Smeijers (The Netherlands), Member

The members of the Co-ordination Committee served EOA in their free time and committed themselves in developing activities of EOA. We worked as a good team and only in the last few months Tom Keily and Klaus Schröter were handicapped by sudden health problems. I would like to thank all the members for the devotion with which they worked for EOA and the support they have to me in my position.

#### **Meetings**

20<sup>th</sup> May 2001

Hotel Radisson, Copenhagen, Denmark  
18<sup>th</sup> - 19<sup>th</sup> July 2001

Haus der Parität, Frankfurt/M., Germany  
30<sup>th</sup> November - 2<sup>nd</sup> December 2002

Canterbury, England

4<sup>th</sup> - 5<sup>th</sup> May 2003

Haus der Parität, Frankfurt/M., Germany  
1<sup>st</sup> - 2<sup>nd</sup> May 2004

Haus der Parität, Frankfurt/M., Germany  
25 August 2004

Hotel Porto Palácio, Porto, Portugal

Minutes of each EOA Co-ordination Committee Meetings were published in *EOA Newsletter*, to copies of which were distributed to all member Associations.

### **MAJOR ACTIVITIES**

The activities carried out by the Co-ordination Committee followed from the resolution of the 10<sup>th</sup> EOA Congress in Copenhagen. The principal issues were advocacy programme for economically weak European countries and extension of activities within the European Union.

#### **EOA Constitution**

Several amendments to the EOA Constitution were accepted at the preceding two Congresses, in Venice

in 1998 and in Copenhagen in 2001. These changes were now incorporated into the new version of the Constitution, which was distributed to all members in June 2004.

The Co-ordination Committee proposes to add a new paragraph to the Constitution, which would ensure that the EOA Constitution will conform with the IOA Constitution. This proposal will be submitted to the House of Delegates for approval.

### **Advocacy Programmes**

Europe is still very heterogeneous region as regards the medical and social care of ostomates and the supply of stoma appliances. Therefore the Co-ordination Committee developed activities directed at bringing the living standard of ostomates in problematic regions, mostly in countries of Eastern and Southern Europe to conditions common in other European countries. In this effort the Co-ordination Committee continued in the work of carried out in the preceding periods.

These activities included mainly help in establishing national ostomate associations and organisation of sub-regional meetings, in which ostomates from countries which are linguistically related could discuss their particular problems and exchange the experience. In several instances (Hungary, Serbia and Montenegro, Ukraine) I was asked to intervene at Governmental institutions in order to improve the care of ostomates.

### **4<sup>th</sup> Meeting of Ostomate Associations from Central and Eastern Europe**

Like most of the preceding meetings of this group (in Brno, Czech Republic in 1995 and 1997 and Poznan, Poland in 1999), the 4th Meeting took place in parallel with the 7<sup>th</sup> Central European Congress of Coloproctology and Viscerosynthesis in Kaunas (Lithuania from 31<sup>st</sup> May to 2<sup>nd</sup> June 2002. The Meeting was organised by the Lithuanian Stoma Patients Association and was fully sponsored by Coloplast and ConvaTec. I would like to thank the organisers for their excellent work and to the sponsors for the financial help and interest they had in the meeting.

Delegates from the following countries were present: Belarus, Croatia, Czech Republic, Latvia, Lithuania, Poland, Russia (Moscow), Slovakia and Ukraine. IOA was represented by the President Heinz Wolff. It was planned that the IOA Immediate Past President Brenda Flanagan will lead a workshop on the advocacy programme ISCAP, but she was unable to attend because of a recent surgery.

Before the opening of the Meeting we had an opportunity to visit a rehabilitation centre in a small spa Birstonas, where ostomates receive the post-operation instructions and care. Every Lithuanian ostomate has this stay free of charge.

The main part of the Meeting was devoted to country reports and discussion concerning the specific problems occurring in individual countries.

The delegates of the ostomate Meeting also participated at the opening ceremony of the 7<sup>th</sup> Central European Congress of Coloproctology and Viscerosynthesis, at which Heinz Wolff and I had the opportunity to address the medical audience and ask the physicians for co-operation in improving the situation of ostomates in countries of the Eastern Europe.

Full account of the meeting and the country reports were published in the *EOA Newsletter* (October 2002), *IOA Today* 2003/3 and *Ostomy International*, Vol. 25 (2003) No. 1.

### **National Surgery Conference in Romania**

I had the opportunity to participate at the National Surgery Conference (Colorectal Surgery and Stoma Care), which took place in Sinaia (Romania) from 16<sup>th</sup> to 18<sup>th</sup> May 2003. The conference was organised by the Romania Society of Surgery and the British Romania Ostomy Patients Foundation. Special sessions of ostomates and stoma therapists were held at this Conference. Even though it was expected that the ostomate meeting would result in formation of a national ostomate association, no agreement in this direction was reached between the existing five local organisations. Thus, the Cluj-Napoca organisation still remains the only Romanian member of EOA / IOA.

I want to express my thanks to ConvaTec, which financed my stay at this Conference.

A report on this Conference by Bob Bailey, Project Director of ROPSF, appeared in *IOA Today* 3003/3 and *Ostomy International*, Vol. 26 (2004) No. 1.

### **1<sup>st</sup> Congress of Ukrainian Ostomates, Lviv, 19<sup>th</sup> March 2004**

I was invited to participate in the 1<sup>st</sup> Congress of Ukrainian Ostomates, which was organised by the Association ILCO, a charity foundation acting in the Lviv region presided by Docent Yurii S. Lozynskii. Financial support was obtained from the distributors of stoma appliances in Ukraine, Pofam (Coloplast) and Delta Medical (ConvaTec). The meeting was attended by more than 100 ostomates from several regions of Ukraine. The other Ukrainian ostomate organisations were represented by Lily Kuznetsova from ILCO Ukraine in Kiev and Efim Krasner from Odessa. The guests from abroad included Gerhard and Helga Englerts from German ILCO and Peter Malter, head of the German organisation Active Help to Ukraine, which both supply Ukraine with stoma appliances as well other medical materials, and Vyacheslav Sukhanov from the Russian ostomate association ASTOM in Moscow.

The main speakers outlined the difficult situation of Ukrainian ostomates. According to a bill issued by the Ukrainian Government the ostomates have the right to be supplied by stoma appliances free of charge, but no institution takes care to implement it. The 50 thousands of Ukrainian ostomates have thus two choices: very few of them, who are sufficiently rich, can buy the appliances in pharmacies in larger cities, the majority of ostomates fabricate appliances themselves (sometimes quite ingenious, as we could see during a visit to the Lviv Consultation Centre for Ostomates) or must rely on a limited supply through humanitarian help. However, this help cannot cover all needs of Ukrainian ostomates and it can be expected that in the future it will be more and more difficult to organise it. It was generally acknowledged that it is necessary to establish a national ostomate organisation, which would become a strong partner for negotiations with the Government.

The Meeting decided to make necessary preparations to create such national Association - to form Co-ordination Council and publish quarterly a journal.

An extensive report on this Congress appeared in *IOA Today* 2004/2.

### **1<sup>st</sup> Meeting of Federazione Associazioni Incontinenti e Stomizzati (F.A.I.S.), Bologna , 3<sup>rd</sup> April 2004**

In 2002 a new ostomate association was formed in Italy, which applied for the membership in IOA. It has now organisations in 15 from 20 Italian regions. In three regions no ostomate organisations exist, in two regions ostomates are members of the older Italian association, A.I. STOM.

Thanks to the support of Coloplast I was able to attend the first national meeting of F.A.I.S.

The momentous problem of Italian ostomates are differences in the care of ostomates in different regions. It is now the main task of the Association to have the Government to accept a law, which would codify the same system of medical and social care of ostomates in all regions.

Full report of this meeting was given in *IOA Today* 2004/2.

### **International activities of member Associations**

Unfortunately the Co-ordination Committee had only limited information on activities of member Associations, which has been collected in most cases indirectly. The difficult situation with the supply of stoma appliances in several countries of Eastern and Southern Europe is being solved by sending surplus appliances by associations which have either patron or partner relationship with ostomates in countries needing help.

For several years German ILCO delivers appliances to Ukraine, Israel and Denmark support the Odessa organisation. British Ileostomy and Internal Pouch Support Group helps to build ostomate organisations in Romania. Norilco has partner relationship with ASSCOL, the ostomate association in St. Petersburg in Russia. Besides sending material help they organised a course in St. Petersburg in June 2002, in which ostomates, physicians and nurses participated. (The report on Norilco activities appeared in *IOA Today* 2002/3.) Finnilco supported the Estonian Ostomate Association in its beginnings. It should be also mentioned that the Moscow association, ASTOM, is active as a consultant in Belarus, Ukraine, and other Russian regions, even though it cannot offer any material help.

The Co-ordination Committee asked the economically well situated countries to offer any sort of help, in particular in the Balkan region, but no response has been received.

### **Activities within the European Union**

**EOA Advocacy Workshop, 1<sup>st</sup> – 4<sup>th</sup> May 2003, Frankfurt/M. (Germany)**

As decided by the delegates of the 10<sup>th</sup> EOA Congress, Deutsche ILCO organised an Advocacy Workshop aimed at activities of ostomate organisations in Europe and in the European Union in particular. The EOA CC wishes to express thanks to Professor Gerhard Englert and other organisers from Deutsche ILCO for perfect preparation and conduction of the Workshop. Our thanks are also due to Dr. Özgür Öner, EU representative of Deutsch Paritätischer Wohlfahrtsverband, who gave a lecture on Guidelines of Advocacy Management in the EU.

The Workshop was attended by 10 ostomate associations mainly from countries of the European Union or countries which will join EU in May 2004 (Belgium, Czech Republic, Germany, Hungary, Italy, The Netherlands, Norway, Poland, Ukraine and United Kingdom). The President of IOA, Heinz Wolff, also participated at the meeting.

Ostomate situation in European countries was discussed on the basis of a questionnaire distributed before the meeting. It followed from the discussion that certain limitations in the supply of appliances could be expected even in countries where they do not exist at present. It was suggested that the *Charter of Ostomates' Rights* could be used as a suitable tool for standardising the care of ostomates in European countries. Slight modifications of the Charter were proposed to be discussed and eventually approved at the 11<sup>th</sup> Congress.

In the second part Dr. Özgür Öner, a representative of DPWV at the EU, gave a lecture on guidelines of advocacy management in EU. On the basis of

information we received, it was decided to form a working group for contact with EU agencies. Its members are Maria Hass from Germany, Ria Smeijers from The Netherlands, Wilfried Eynatten from Belgium and Arne Holte from Norway. The first task of this group is to identify in EU institutions the persons, who might be important for us. It was decided that EOA would ask for expert registration in an advisory committee of the European Economic and Social Committee. The registration of EOA in the CONECSS database was carried out in August 2003. Full report on the EOA Advocacy Workshop appeared in *IOA Today* 2003/3.

### **Membership in European Institutions**

Already in the previous period EOA became a member of the European Disability Forum and, as mentioned above, was registered in the CONECSS database. Recently the EOA Co-ordination Committee has been contacted by the European Cancer Patient Coalition, which offered us to become a founding member. You can find an information letter of ECPC in your materials. The decision about our membership in ECPC will be submitted to the House of Delegates for decision.

### **Charter of Ostomates' Rights**

It has been recommended at the Advocacy Workshop that the *Charter* should be used as a basic document in negotiations with governmental institutions about the health and social legislature concerning ostomates. Even though the social and health care policies of individual members of the European Union are the matter of national legislature, it may be expected that in the future there will appear a tendency to certain degree of unification. We should be prepared for this situation and also unify our views in these matters.

At the Advocacy Workshop several items of the *Charter* were slightly modified, so that the *Charter* might be used for this purpose. The modified version of the *Charter* will be submitted to both bodies, EOA and IOA, for approval.

The working group established at the Advocacy Workshop prepared a questionnaire based on the *Charter*, which yields the information how the *Charter* items are observed in different countries. The questionnaire was distributed in the *EOA Newsletter* in November 2003, but up to now only about 20% of the members responded.

### **World Ostomy Day 2002**

World Ostomy Day IV was celebrated through the ostomy world on Saturday 5th October 2002 under the motto *Yes, we can*. The day was marked by celebrations, seminars, information sessions, fund raising and media awareness in over 30 countries. A number of participating countries submitted articles

outlining their activities for publication in *IOA Today* and *Ostomy International*. Many European countries also participated in a world wide message chain, which started in New Zealand and ended in Canada.

Four European countries (Czech Republic, Poland, Slovakia and Spain) entered the Merit Award competition for the best WOD celebration, which is sponsored by Coloplast.

### **CONTACTS AND COMMUNICATION**

It has been stressed at the last EOA Congress that the exchange of information is essential for the effective functioning of the Association. However, we were not very successful in this respect. I tried keep updated the EOA Directory placed on the IOA web page and published frequently in the *EOA Newsletter*, but in many cases I was not informed by the members about the changes in addresses, telephone numbers or in the names of officers. We also expected more reports by the members, which could be published in the *EOA Newsletter*. I must say that the flow of information in the opposite direction, from the Co-ordination Committee to the member Associations was better. We published minutes of all meetings of the Committee, reports from other important events as well as all necessary information, in particular concerning the Congress.

The EOA Newsletter reached under the management of Klaus Schröter a very good quality. I would like to express him and his wife, Birgit Schröter, my sincere thanks for their work.

### **Internet**

Internet became in the last years the main source of information and communication in IOA. The IOA web site ([www.ostomyinternational.org](http://www.ostomyinternational.org)) contains all information about IOA and its regional Associations and offers a forum for discussion and exchange of experience among ostomates as well professionals.

IOA publishes on Internet a quarterly *IOA Today*, which substituted already the IOA Newsletter and might, in the future, substitute the printed journal *Ostomy International*.

The majority of European Associations have access to Internet and have their own web sites, which yield information in national languages. However, there are still about seven member Associations, which do not use e-mail. All Associations cannot be thus simply and quickly contacted if necessary and also distribution of documents requires the printing and copying and slow and often unreliable delivery by post.

I urge therefore all those who have not yet connection to Internet to find a possibility to use e-mail (e.g. with help of some other humanitarian organisation or appliance distributors) and inform the Committee about the address. This will certainly simplify our work and speed up our mutual communication.

## **Contact Offices**

The IOA Contact Office ceased its operation and all communication should be directed to the IOA Officers. The EOA Contact Office in Freising functions thanks German ILCO without any change. It is, however, advisable that you send your mail directly to the EOA Officers.

## **CONCLUSION**

In conclusion I would like to thank you all for giving me the opportunity to serve in the EOA Committee for the past nine years - as a Committee member, Vice-President and in the last term as a President. It was a great honour to serve the European Association and I used my best efforts to extend the Association over all Europe and to help the new members to achieve good standard of the care of ostomates.

And finally I want to thank my collaborators in the Co-ordination Committee, Ria Smeijers, Tom Keily and Klaus Schröter for their devoted work.

Vladimír Kleinwächter  
President

## **ARNE HOLT, PRESIDENT OF EOA**

It is with both deep respect and some anxiety I start my work as EOA-president. As this organization consists of 42 countries where condition for ostomates vary from very good to less than poor, it may seem to be close to impossible to get much done. However with good helpers, first of all in the EOA-coordination committee, but also from those associated to the committee I know that we will move EOA in the right direction. I also know that there are many persons as well as countries willing to do their best.

So what is to be done? Of course we will try to improve the situation in countries where ostomates live under dreadful conditions. But how? I do have my thoughts about how, and will discuss those when we have our first CC-meeting in Frankfurt in January. So far it is necessary that we with the Charter of ostomies rights as an aim will get an overall picture of the situation for ostomates in Europe. We will also start a survey to find out what countries which can give help – and what countries that need help.

Of course there will be to kinds of help. First is what I call a relief operation – which include sending appliances trying to make an acute situation better. We must, however, be aware of the enormous need there will be in some countries. For instance Ukraine has 50.000 ostomates and great shortage of appliances. Therefore our second aim, which will be a long term aim, will be to help creating “democratic organizations

for ostomates, run by ostomates”. I have no trouble applauding organizations created – and for some time, headed by doctors or nurses. The overall goal must be there anyway!

All EOA-members will in some time receive an “easy to understand” survey about the situation in their country. From the answers we will consider twinning – which means that we put together in couples countries which give help with countries that need help. Examples will be Germany – Ukraine, Belgium – Algeria (new from this autumn), Norway – St.Petersburg, and so on. Of course this will be a volunteer basis, but I hope all of you reading this come forward with a big YES, WE WANT TO TAKE PART IN THIS!!!

## **20/40 Visiting Workshop Oporto, Portugal. August 2004**

The 20:40 delegates enthusiastically took part in a Visiting Workshop, led by Tracy Walker, who is the National Visiting Co-ordinator for the Ileostomy and Internal Pouch Support Group in the United Kingdom.

Tracy began by introducing herself and explaining her plans for the workshop, entitled ‘Who makes a suitable visitor’.

The delegates began by assembling in groups of four, where they discussed whether they had received a visitor before or after their surgery and if they had, the most significant thing they remembered from the visit. Some commented that it was the clothing the visitor wore, whilst others had remembered particular things the visitor had talked about. Discussion then followed, on whether or not the visitor had been suitable. The majority had been, however, one delegate commented that her visitor had been at least three times her age!

Those who had not had visitors either before or after surgery discussed why this was the case and described the sort of qualities they would have looked for in a visitor.

Following the discussion in groups, one person from each group gave an overview of what had been discussed, at which point others were able to contribute. This feedback led onto general discussion, as to the sort of qualities a visitor should have in order to be suitable. During this discussion, some delegates described how visiting was organised in their own country.

The workshop closed, with Tracy thanking all delegates for taking part.

"Appearance is State of the Mind " - Published in "BALKAN" 12. September 2004.

At this very moment there are 4000 people in Serbia who had an operation resulting with their stoma opening on the stomach. "Appearance is state of the Mind, " it is been recommended from ILCO - Society of Ostomy patients of Serbia, founded 2 years ago in Belgrade. Last week Portuguese city Porto was hosting two very important congresses, European and World Ostomists Congresses. Our Stoma Society ILCO that was founded 2.5 years ago has been admitted to the World and European Association of ostomist shortly before the Congresses, and it was only society of this kind from Former Yugoslav boundaries.

"There are 4000 people with artificial stoma opening on their stomach living within our country, and it is third group of patients concerning number of patients here, just after diabetics and chronically kidney patients on dialyses. Only in Belgrade there are 1.400 patients.

"Stoma is an opening on the stomach as result of surgical intervention on Colon cancer, ulcerative colitis, Crohn s disease or some other serious medical reason" has been said for "Balkan" news by Sne`ana Cmiljani}, chairman of ILCO who has been living with stoma for whole 13 years.

I was in great shock when doctors explained what I should expect. But shortly I assumed that it is matter of life and decided to accept circumstance, rather than to fight it " says Sne`ana and adds that one member of ILCO has been having stoma for more than four decades, getting it as 14-year-old girl. "ILCO Society mainly works on education of patients, but in forthcoming period tends to do more to obtain rights to a patient in order to choose what stoma appliance to wear, according to circumstances, possibilities and living conditions of spare patient. " said Smiljani}

Dr Aleksandar Filipovi}, surgeon at "KBC Zvezdara" said that reason for stoma opening is mainly serious illness threatening patients life. Though, with this solution, patient can extend his life dramatically, but majority of patients hardly accept this condition to differ from rest of people. "I had patients that hardly accepted operation and even a few that refused procedure that could save their life" said Dr Filipovi} mentioning that more should be done on better informing about this problem.

Milina Jankovi}, clinical psychologist in Health Center "Savski venac" said that patients with stoma face two

fears, fear to be rejected from family or friends and the fear that they can not adjust to new situation. She adds that those fears are so strong even that members of families sometimes do not know that their closest relatives after operation has stoma.

"We have to improve not only the patient attitude but also the family, aswell as whole Society, to give support to this people in order to return to normal life, in the way that it is possible" - thinks Jankovi}.

Sne`ana Cmiljani} is true sample of lady who conquered illness aswell as prejudices. "Illness does not choose the person. Nobody can predict when he will have to accept something that life brings in order to save it! "Admits this brave woman".

How it is done In Italy Sne`ana Cmiljani} said that on Congress in Porto she had chance to meet patients from 56 different countries, as well to exchange different experiences. In Italy for example, there are many stoma centers where nurses train patients to accept new way of living. They exchange the pouches and teach them how to do it themselves, but also acquaint them with different stoma programs in order to choose one that is most suitable for them.

Training is very important Surgical procedure resulting stoma opening is always same, but post-operative treatment is completely individual, and though everything is done according to standards, sometimes stoma instead being in level of stomach, due to state of muscles protrude or retract. In such cases it is important that patient gets training how to treat stoma and how to choose right appliance for himself says Dr Filipovi}

Published in "BALKAN" 12. september 2004. Zorica D. Markovi}

## **NCACOA – COUNTRY REPORTS**

**By: Martha Vélez de Nieves**

Many achievements and a new country have been part of our growth during the past four years in our region. One of the most important advances during these years has been the internet which made all of us communicate through e-mail in a faster and more economical way.

### **UNITED STATES**

The United Ostomy Association (UOA) is one of the most active associations in our region. They have made many changes in their office management structure which has improved in many ways their

productivity. They designed a new web-page that won the **“2003 Asculapius Award of Excellence”** from the Health Improvement Institute for informing consumer lifestyle choices and healthcare decisions. They also are the recipient of the **“Daily Points of Light Award”** for outstanding volunteer services. The **OQ Magazine** has been over the years a good source of information for all ostomates.

## **CANADA**

The United Association of Canada (UOAC) is also very active. They have annual conferences each time in a different region of Canada. They revamped their website [www.ostomycanada.ca](http://www.ostomycanada.ca) with a brand new look and have made it easier to navigate. The Canadian Ostomy Youth Camp is another of their successful events. The **“Connection”** which is a monthly newsletter sent to over 170 members (presidents, newsletter editors, etc.) is now sent electronically by e-mail. This is cost effective and it gets to the intended recipient faster.

## **DOMINICAN REPUBLIC**

The “Asociación Dominicana de Ostomizados” (ASODOMI) has been working very hard during the past years and finally they are well known by doctors who refer their patients to the association.

Membership has increased due to the efforts of their volunteers and to the members themselves, who continually inform people about the association. They don't charge any membership fee to their members. The economic situation of their country has been affected with the worldwide events of the past years.

## **PUERTO RICO**

We were so impressed by the organization of the Parents of Ostomy Children (POC) group at the UOA, we decided to organize one locally. Our group meets the third Saturday of each month at the Children's Hospital which is located at the Medical Center of San Juan. We always have educational meetings with the participation of medical professionals, who educate the parents with their child care. Parents are always very enthusiastic about our meetings.

We celebrated our 25<sup>th</sup> Anniversary with a full day conference held at the facilities of the new Cancer Center of Auxilio Mutuo Hospital. Prevention, Early Screening and Management of colorectal Cancer was the theme of our conference. We also had a social celebration which included our two groups at the Children's Hospital of the Medical Center of San Juan.

A two page article was published in the health magazine “Buena Vida” announcing our anniversary with a complete guide of how to prevent colon cancer. And the services we offer to ostomy patients. We participated on a TV Morning Talk Show on Channel 2.

We work very closely with the American Cancer Society's clinic for ostomy patients. Actually we have three clinics that serve the metropolitan area of San Juan, the city of Arecibo located at the north, and Mayaguez located at the west side of our island.

## **PANAMA**

Panama changed their name to “Fundación Panameña de Ostomizados Padre Javier Gorroxategui”. This name is in honor to late Father Javier Gorroxategui who was an Ostomate Jesuit Priest. They will receive a grant from his brother who is also a priest. With this grant they plan to improve the service they give to ostomates. They have a clinic where any ostomate can go and talk to a nurse about their stoma problems, and hope to open three more in the other cities with this economic grant.

Our regional meeting was held in Panama on January, 2003. We had the opportunity to see how ostomates live in this country. An FOW shipment of ostomy supplies was received and distributed among the poor ostomates.

## **MEXICO**

Sheila de Carral has introduced Mayor Jorge Vargas Morales who is the president of OSTOCOL. This group is located in Colima, Mexico. They have approximately 60 ostomates, and meet the third Saturday of each month at the Clinic of the Social Security Institution.

The products distributed by the Social Security Institution are not of the best quality, and some ostomates have to buy products of Convatec and Hollister at a local store to reach their needs, but they are priced very high.

## **BERMUDA**

A small membership of fifty composed of senior citizens. Their President, Lovina Flood informs that she is not able to attend the World Congress due to health and economic situation.

They have two members who are on the visiting program. Meet on a monthly basis and have an annual special dinner.

## CUBA

Sección de Atención al Ostomizado (SAO) is our newest member, and was formed by ostomates, family members, medical professionals and people interested in helping them. They started organizing the group in 1996 and became official in March 2001.

Actually they have a total of 100 members and 80 of them are ostomates. Their main objective is to improve the quality of life of ostomates and educate them. They work very closely in order to help ostomates return to their social activities, work, and family relations educating them with information about stoma care and management.

### Activities:

- Weekly specialized ostomy clinics
- Monthly educational meetings
- Social activities
- Participation in two Radio/TV programs informing our mission.
- Two educational seminars specialized in ostomy patient care with the participation of nurses and medical professionals.

SAO contacted WCET and they gave them two educational grants for ET Nurses which will be completed by next year.

In May, 2002, the President of IOA, Mr. Heinz Wolff and I were invited to Cuba.

We had the opportunity to meet with the Cuban ostomates and discover their personal needs. The product they actually have comes from China.

FOW-Canada has sent them a shipment of ostomy supplies. These products will be distributed among the very poor ostomates.

In the near future, they continue working to obtain their main objectives, and plan to print an educational brochure, make our web page, a project for Special Care for Ostomates, promote and expand activities at a national level, and establish communication with associations of other countries.

## COSTA RICA

Asociación Pro-Ayuda al Ostomizado (APAO) ceased operations in 2002, due to administration problems. Some government reports were not presented on time and they lack of capable persons for completing all these requests. They organized a new group under the name of Fundación Costarricense de Ostomizados (FUCO). This foundation will require less government

reports and they claim they will be able to complete them. As of today, they have not completed the association and informed me that they will not pay any pending dues as this is a new organization.

Martha Velez de Nieves  
August, 2004

## MEET THE NEW CANADIAN PRESIDENT PAT CIMMECK, PRESIDENT UOAC

At the age of 15, I was diagnosed with Crohn's Disease. After numerous surgeries, I had an ileostomy in January 1984. I became involved in my local chapter 4 months after surgery by taking on the position of Secretary. I have held the positions of Vice-President and President of our local chapter as well as Visiting Co-ordinator with a local hospital. I am also a trained visitor since 1985.

I have participated as a counselor in the CAET (Canadian Association of Enterostomal Therapists) Youth Camp 1990-1991 and in 1992 became the co-ordinator of the camp. At present I am still the co-ordinator.

I joined the Board of Directors of UOAC in 1993 and served until 1997. Maria Siegel appointed me to the position of Assistant Congress Chair when the IOA Congress was held in Calgary in 1997. I was the Chairperson for the first Canada Day meeting held in conjunction with the IOA Congress in 1997.

From 1999 to the present I have held the positions of Secretary, Vice-President and I am currently the President of UOAC.

After high school I worked as a secretary for seven years until my surgery. Most of my time since has been occupied by almost full time volunteer work with my local UOAC chapter and the National Board; Crohn's and Colitis Foundation; my church and helping a friend with a handicapped child. My husband, Dietrich, and I have been married for 23 years. We currently live in Calgary, Alberta, Canada.

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## NEWS FROM CANADA – UOC

Hello. My name is Pat Cimmeck and I am the newly elected President of UOAC. It is my pleasure to bring IOA the warmest of greetings on behalf of the board of directors of UOAC.

We in Canada have a very busy year ahead of us. But first, a few news worthy items from the past year.

In April 2004 we launched our newly redesigned website. It was made more user friendly and now includes a lot of information that an ostomate can download or print off the web. It is still a work in progress and we've had favourable reports from those who have visited the site. We can be reached at [www.ostomycanada.ca](http://www.ostomycanada.ca).

In the past year we have updated and revised some of our publications and included new works on our list. We've put the camp video production by CBC, one of our national television networks, on video and DVD for our members and sent a copy to each chapter free of charge. Hopefully this will aid in public awareness and help with chapter and national fund raising. The Chapter Handbook was completed and distributed on CD rom to all our chapters. We've re-established relationships with the Canadian Cancer Society and the Spina Bifida Association and have an exchange of publications and information. Our Youth Camp was a great success again this year with 32 children participating in the program. There were many new children this year and they decided to start their own website to keep in touch. They come from all across Canada which is a lot of country and it is not easy to stay in touch by phone or personal visits.

Some new initiatives undertaken by the new board of directors at our last meeting were: Going to once a year dues billing; we're in the process of obtaining a corporate identity to help with awareness and fund raising; we plan to implement a group for Parents of Ostomy Children and implement more programming for our young adults (20/40).

Gander, Newfoundland hosted a very successful annual UOAC conference August 19-21, 2004. This small chapter of 25 members did a fantastic job of organizing and welcoming delegates from across Canada and guests from other agencies and the United States.

There were only 5 people on the organizing committee. Their commitment to hard work and the enthusiasm which they carried throughout the week was an inspiration to all and will be hard to surpass.

Our Canadian Association is still very young, only seven years old, but we certainly have come along way in that time. It is my wish that we continue to grow and flourish in aid to ostomates in our own country and to those all over the world.

Pat Cimmeck, President  
UOAC



## MEET THE NEW UOA U.S. PRESIDENT

Dean Arnold

On October 1 of this year Dean Arnold became President of the United Ostomy Association (UOA). Dean is from Winnebago, IL. He has lived and worked in the machine tool industry in Rockford since 1972. That same year he married Beverly Shelangouski. They have two grown daughters, Elizabeth and Rebecca.

Dean was raised in northwestern Illinois. He earned his Bachelor's degree from Bradley University in Peoria, Illinois in 1971. During his final months at Bradley he was diagnosed with ulcerative colitis. Over the next eight years he tried several drugs and many other medical solutions to control the frequent flare-ups of the disease. In August 1978, he entered the hospital and had a total proctocolectomy resulting in a standard ileostomy. Dean joined the local UOA chapter in September of the same year. It was two months later when he was added to the election ballot for the Rockford Ostomy Association running for treasurer.

After serving in most of the officer positions in the local chapter, he became involved in the national organization. His first assignment was to host a regional meeting in the Rockford area. With the success of the regional conference, Dean was asked to serve in the UOA regional program as a State Representative. In 1995 he was asked to serve on the Annual Conference Planning Committee. He served as chair of the committee in 1999 and 2000. In 2002 he was elected Vice-President of UOA.

His major goals as President of UOA are to increase membership, continue aggressive advocacy activities, and improve financial viability.

## NEWS FROM UNITED OSTOMY ASSOCIATION

President Dean Arnold

The UOA delegation attending the World Conference in Portugal in August of this year enjoyed the educational experience and camaraderie of the International meeting. Our organization looks forward to the next World Conference in Puerto Rico in 2007. Now is the time to start planning to attend this event.

We have begun our committee meetings for the Youth Rally and Annual Conference next summer. For those

thinking of attending our Annual Conference, it will be held next to Disneyland in Anaheim, California August 3-6, 2005.

We continue to make improvements in our award winning web site. Check out the updates by going to [www.uoa.org](http://www.uoa.org). If you have a web site and it is not linked to our page, we would be honored to work with your organization to make the link happen. We are closer to establishing the information pathways on the web site where the patient, caregiver or nurse can find the answers to their questions.

UOA is featured on July and August in the 2005 Colondar, a 12-month calendar of young female colorectal cancer survivors. The Colondar is the newest project of The Colon Club, a nonprofit group dedicated to educating the public in innovative ways about colorectal cancer. The Colondar is available for \$15 (US dollars) at [www.colondar.com](http://www.colondar.com).

UOA remains very active with many coalitions that share our overall mission. Some of the organizations are the International Ostomy Association, the United Ostomy of Canada, Friends of Ostomates Worldwide, Wound and Ostomy Continence Nurse Association, the American Cancer Society, the Crohn's and Colitis Foundation of America, the American Society of Colon and Rectal Surgeons, Digestive Disease National Coalition, and National Colorectal Cancer Roundtable. We also continue to develop stronger relationships with the manufacturers and distributors of ostomy supplies.

The UOA membership is currently at approximately 23,500 and we have about 400 chapters. We are changing our national communications to include each member of the organization. Our chapters remain our direct contact to the members. Any member who cannot attend meetings for any number of reasons, will be receiving the correspondence sent to the chapter leaders.

We are embarking upon finding funding to develop the campaign for our public awareness program. The overall plan is to make "ostomy" a household word. Imagine the possibilities if we can talk about ostomies without feeling ashamed or inferior.

We continue to strive to be the organization that provides help and encouragement to those in need.

## **SOUTH PACIFIC OSTOMY ASSOCIATION REPORT**

Australia and New Zealand comprise the South Pacific Ostomy Association being the only two National Associations in the South Pacific. This presents many difficulties in establishing effective contacts with other

countries in our vicinity; however some progress has been made especially by New Zealand with Fiji, the Solomon Islands and Indonesia.

### **New Zealand**

New Zealand has continued to send appliances to Fiji with the latest shipment being sent in April 2004, the Fiji Cancer Society received the supplies for distribution. The Wharfage charges were funded by the FNZOS from cash received for being placed in the World Ostomy Day project 2000. Nurse training has been explored in Fiji but no progress has been made at this time.

In Indonesia, Robert Patton a New Zealand Stomal Therapy Nurse has provided the necessary contacts for distribution of appliances and New Zealand is waiting for two things to happen:

- An application be made to the International fund created by Australia to cover shipping costs.
- The coordination of distribution arrangements needed in Indonesia.

A request has been received for assistance from a former missionary in the Solomon Islands, and from information supplied and contacts provided; this needy country should be able to receive assistance. The NZ air force has indicated that it will deliver the appliances when ready. When further information is provided the project will get underway.

### **Australia**

Australia seems to be dragging the chain in comparison to New Zealand but not for the lack of trying. Australia has taken on the role of exploring what assistance can be provided to Papua New Guinea and East Timor. After contacting Australian Surgeons who operate in these two countries on a regular basis, they have provided new contacts in Port Moresby and other groups who would distribute appliances on our behalf. We understand the majority of Ostomy Surgery in PNG is as a result of trauma, other information being sought is:

- The number of Ostomates in need of assistance
- How appliances are accessed
- What medical support is available, eg. Stomal Therapy
- How best can aid be provided.

When communication channels are established and the above information is provided assistance will be able to be progressed.

Peter McQueen  
SPOA Secretary

## Season Greetings to All of Our IOA Friends



With this being our last issue of the IOA Today for 2004 both Di and I would like to wish you and your family a happy holiday season. We hope that 2005 will bring you much happiness. We look forward to bringing you Ostomy related reports in the new year.

Season Greetings

*Stu & Di*