

Special Issue Containing 2004 IOA Congress & EOA Information

(Please note: Contact the IOA Vice President: vicepresident@ostomyinternational.org before reprinting any article from this newsletter.)

PRESIDENTS' MESSAGE FOR I.O.A TODAY



Dear Friends

This will be my last message before we meet in Porto.

Unfortunately I have been extremely disappointed by young and old, not registering for the World Congress. This unique opportunity to get together and meet friends and ostomates from all over the world comes but once every three years. It is not too late; we will extend the time limit of registration until the 1st of August. However try and book earlier as traveling to Portugal in the month of August might be difficult.

We have made every effort to make this Congress attractive for everybody, and it is the first time that the young (20/40) and the old are having their conferences at the same time. It gives us the opportunity of a better understanding between the two groups which are actually having the same health problem; yet do not always see things in the same way.

Come on my friends! Pack your bags, do not be afraid to travel, it will be great fun to be together.

See you in Porto!

Heinz Wolff
President I.O.A.

FREE SHUTTLE BUS

Yes, a shuttle bus will be available on days: 25th 26th & 27th from Porto Airport to both Hotels (Porto Palacio & Portus Calle) every Hour: starting at

09h00am & finishing at 8h00pm

This is a 22 seated bus Color: green & white, showing a plate EOA/IOA CONGRESS on frontal bus glass and FOCUS VIAGENS on the right side. You can pick-up the bus, after the exit door to the street on the right side.

If the bus is not there, please wait as it will be running to and from the airport to the hotels.



My Friends of IOA:

This will be the last newsletter with news from this current Executive Council. As many of you are aware, elections will be held in Porto at the Business meeting and the newsletter that will be sent electronically at the end of September will

introduce you to new members of the Executive Council. Most of the regions of IOA will be holding elections at their regional meeting and we will have new faces leading most of the regions. Look to see new leadership in Europe, North and Central American & Caribbean region, the South American Region and a new representative from the South Pacific Region. The Asian region will not elect new leadership until their next Asian Regional meeting the location and time will be decided at this meeting. We will bring you further details in the September issue of IOA TODAY.

Yes indeed, IOA TODAY will continue to be sent to you quarterly. We have been very pleased with the response to the newsletter and it is my intention to continue to work with our Webmaster and editor for the newsletter, Stuart Schaefer to bring the newsletter to you.

As the secretary I have sent out proposed changes to the IOA Constitution by both the Executive Council and Member Countries. Each full member association has had a chance to respond to these proposed changes to the Constitution and been given the opportunity to propose amendments to the proposed changes. On 27th July 2004, I sent out the amendments from member countries and I have also included them in this newsletter. Read the proposed changes and the amendments carefully and come to Porto prepared to make an informed decision when it comes time to vote.

As you will see, this edition is taken up with information regarding the upcoming IOA World Congress in Porto, Portugal in a few weeks. Many of you will remember Porto from the European soccer competitions that we all followed so you will have seen pictures of this lovely area of the world. It is not too late for you to join us in Porto. As you have heard from Heinz, attendance is disappointing so if you are still undecided, please join us; we would love to see you.

In this issue we are publishing the programme for both the European meeting and the World Congress. We have

tried to make the programme as interesting and interactive as possible. We want you to be able to participate and share your experiences with others so we can all learn from one another. I would draw your attention to the following programming details:

- 20/40 programming under the leadership of the Chair, Anne Hafner from Australia. If you are 40 years of age and under – this is for you.

Each of the members of the IOA Executive Council will participate.

- Gerry Barry from Australia is looking for your responses and ideas on World Ostomy Day.
- Harikesh Buch will be discussing with you “Adaptation after Ostomy Surgery.”
- Brenda Flanagan wants to review the World Ostomy Report and get feedback from the attendees on this most important document. As well Brenda will be addressing a most important issue, “The Future of Iscap.” You will not want to miss this.
- Martha Velez De Nieves and Maureen Flynn will conduct a foreign language workshop in Spanish as well as “Life After Cancer.”
- Vladimir Kleinwächter will be discussing with our Russian speaking delegates the “Care of Ostomates in Central and Eastern Europe.”
- We have an Italian workshop conducted by Professor Carlo Pezcoller.
- Dr. Smeja will lead a workshop in Polish
- Our Portuguese hosts, Luis Filipe Pinto and Dr. Armandio will present in Portuguese, “Life as an Ostomate.”
- I want to work with you and hear your views on the “Coordination of International Support.”
- Stuart Schaefer, our Webmaster will be leading “On the Web” sessions. We are hoping that Stu will be able to “go live” and get on the IOA Website. Stu is leading four sessions – smaller groups that can be interactive. Bring your Internet and Web concerns to Stu.
- Stuart and I are also conducting a session on the Internet and the IOA Website.
- Linda Aukett, editor of the OI magazine, will be chairing a most important session on the “Future of the OI Magazine.” Come prepared to let us know what you think. We need your opinion.

I refer you to two special sessions:

- Judith Weller of WCET will be conducting a workshop on “Nutrition for Ostomates”

- Mrs. Joana Tavares (ET nurse from Hospital de Santo António - Porto) will present "Skin Care for Ostomates".

These two programmes are of special interest to our attendees, you will be able to get your questions answered. In case you forget at the last moment, write your question so you can read it.

We have two sessions led by two past presidents:

- Gerhard Englert will address the topic of “The Ostomates Bill of Rights”
- Ken Aukett will discuss with all of us “Leadership Issues.”

Always of interest to our attendees is a session on sexual issues.

- Dr. Laslo Riter will present a workshop, “Sex After Ostomy Surgery.”
- A most important session for all of us is , “Working together with Health Care Professionals” Anne Demick of the UK will be leading this discussion for us.

A topic that is of special interest to the Executive Council is

- “Publicity/Raising Awareness” lead by Linda and Ken Aukett.

I believe that we have a forceful programme for you – all sessions geared toward your participation and interaction. We need your input and ideas. So come prepared to be involved and enjoy the experience of contributing to the future to your organization, IOA.

As you know, I am running for the position of the president of our organization. I not only look forward, but need your support in this endeavour. I will do the very best that I can to move the association forward but this will only happen if we work together. I look forward to working with all of you.

Until we meet in Porto, take good care and stay well.

Travel safely.

As always

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11TH WORLD CONGRESS AND

20/40 FOCUS AGENDA

Saturday 28th

IOA Programming

20/40 Programming

9:00 – 10:30		Grand Opening	IOA & 20/40
10:30 – 11:30		Grand Opening Exhibits	With morning coffee break
11:30 – 13:30	World Congress Business Meeting		20/40 Information & Ice-breakers – all committee
13:30 – 14:30		Light lunch in the	Exhibit Hall
14:30 – 16:00	World Congress Business Meeting		Open discussion led by Paula West
16:00 – 16:20		Coffee break in the	Exhibit Hall
16:20 - 17:30	World Congress Business Meeting		Participate in this session
19.00 -		Opening/Closing Dinner Combined	EOA & IOA & 20/40

Sunday 29th

8.30 – 10:00 Workshops

8.30 – 9.15	Skin care for Ostomates On the Web hosted by Stuart Schaefer World Ostomy report presented by Brenda Flanagan		Participate in this session
9.15 – 10.00	Adaptation after Ostomy surgery – Harikesh Buch World Ostomy Day – Gerry Barry On the Web hosted by Stuart Schaefer		Quality of life after Stoma Surgery hosted by Marc Bekkers

10:00 – 10:30		Coffee break in the	Exhibit Hall
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10.30 – 12.30 Workshops

10:30 – 11:30	Sex After Ostomy Surgery presented by Dr. Laslo Riter Nutrition for Ostomates - Judith Weller (WCET) On the Web hosted by Stuart Schaefer		Participate in this session
11.30 - 12.30	Organising Youth Camps hosted by Pat Cimmeck The Coordination of International Support – Di Bracken Sharing Experiences among Ostomates: - English - Martha Velez De Nieves - Polish – Dr. Smeja The coordination of International Support – Di Bracken		Participate in this session

12.30 - 14.00		Light lunch in the	Exhibit Hall
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14:00 – 15.30 Workshops

14.00 – 14.45	Future of ISCAP – Brenda Flanagan Leadership Issues – Ken Aukett		Body Image / Relationships led by Paula West
14:45 – 15:30	Ostomates Bill of Rights – Gerhard Englert The Internet & the IOA Website – Di Bracken & Stuart Schaefer		Visitation workshop hosted by Tracey Walker

15:30 – 16:00		Coffee break in the	Exhibit Hall
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16.00 – 17.30 Workshops

16:00 – 16:45	Ostomy Related Problems – Dr Smeja		Open discussion (the future of 20/40 within IOA)
16.45 – 17.30	Working together with Health Care Professionals – Anne Demick		Open discussion (the future of 20/40 within IOA)

Free Evening

Monday 30th**9.00 – 10.00 Workshops**

9.00 – 10.00	Publicity/Raising Awareness - Linda and Ken Aukett Life after Cancer – Maureen Flynn & Martha Velez de Nieves On the Web hosted by Stuart Schaefer	Reports from around the world – as in Hamilton, Canada, chaired by Anne Hafner
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10:00 – 10:30	Coffee break in the	Exhibit Hall
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10:30 – 11:30	OPEN FORUM IOA OFFICERS AND CANDIDATES	Participate in this session
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11.30 -13.00 Workshops

11.30 – 12.15	Future of OI magazine – Linda Aukett On the Web hosted by Stuart Schaefer	Organising meetings with young ostomates led by Marc Bekkers & Damaris Morais
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12.15 – 13.00	Foreign Language workshops <u>Portuguese</u> – Life as an Ostomate - Luis Filipe Pinto & Dr Armandio. <u>Spanish</u> – Ostomates throughout Latin America – Maureen Flynn & Martha Velez de Nieves <u>Russian</u> – Care of Ostomates in Central and Eastern Europe - Vladimir Kleinwachter <u>Italian</u> – Professor Carlo Pezcoller	Future of the 20/40 hosted by Gerry Barry & Anne Hafner
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13:00 – 14:30	Lunch in the	Exhibit Hall
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15:00	Afternoon Evening in town at various	City Tour Restaurants per coupon
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Tuesday 31st

9:00 – 10:30	World Congress Business Meeting	Stress Relief session led by Luis F. Pinto
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10:30 – 11:00	Coffee break in the	Exhibit Hall
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11:00 – 12:30	World Congress Business Meeting	Open discussion - Feedback from Meeting
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12:30 – 14:30	Lunch in the	Exhibit Hall
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14:30 – 17:30	Conclusion of World Congress Business Meeting	Participate in this session (Election of IOA Executive)
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1900 – 12:00 midnight	Grand Closing	Banquet & Dance
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CALLING ALL THOSE INTERESTED IN DISCUSSING YOUTH CAMPS.

On Sunday, August 29, 2004 at the IOA Congress in Porto, Portugal, there will be a one hour workshop on Organizing Youth Camps.

If your country wishes to set up a program for youth where children can get together in a safe, fun environment to share their life experience and companionship, this workshop is for you.

If you are interested in an exchange of youth program information with other countries around the world, this will also be discussed.

To participate in this workshop, please contact the moderator, Pat Cimmeck of Canada at pvc@shaw.ca



Snezana Cmiljanic

Association "ILCO" Srbija

Association "ILCO" Srbija – association of patients with stoma was founded in April 2002 in Belgrade. There are 1,500 patients in Belgrade, around 4,000 patients in Serbia.

Our Association is on duty daily from 5:00 to 8:00 p.m., and we respond to the messages left on our answering machine. During working hours patients visit our premises. Every Wednesday a stoma nurse, doctor and psychologist visit the

premises for consultation. Patients exchange experiences, support each other and get new confidence during these meetings.

We also visit patients in hospitals and clinics before and after operation and help patients in foundation clubs in all parts of Serbia.



In July of 2003 Health Insurance Fund, based on an initiative from our Association, has approved 10 base plates and 30 colostomy pouches, 10 base plates and 30 ileostomy pouches and 10 base plates and 10 urostomy

pouches, or 30 pieces 1pc pouches. However, we still do not receive the creams, pastes, belts and other accessories.

The work in the Association is organised on a voluntary basis.

We are proud on the fact that we join the family of IOA.

This is a first shy step, but we would appreciate if you would help us in our path.

Sincerely yours,
Snezana Cmiljanic dipl. ecc.
President Association "ILCO" Srbija

www.ilco.org.yu
ilcosrbija@hotmail.com

Congratulations to such a young organization. Only two years old and you have achieved so much.

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Discussion Forum



<http://www.ostomyinternational.org/forums.htm>



E.O.A. CONGRESS PROGRAMME AND AGENDA

Wednesday 25th August Arrival of the participants and registration in the Porto Palácio Hotel Dinner on your own

Thursday 26th August

- 09.00 - 10.30** Congress opening...
Welcome addresses by the host country, the IOA President, Heinz Wolff and EOA President, Vladimír Kleinwächter.
Roll call. Proposals and election of new members. Announcement of proxies
- 10.30 - 11.00** Coffee break
- 11.00 - 13.00** Acceptance of meeting rules Approval of Agenda
Approval of the 5th EOA Congress Minutes & Matters arising
Amendments to the EOA Constitution
Reports of the EOA Co-ordination Committee:
 President's Report: Vladimír Kleinwächter
 Treasurer's Report: Thomas Keily / Approval of Accounts / Approval of Budget
 Editor's Report: Klaus Schröter
Report on activities within the European Union: Ria Smeijers
- 13.00 - 14.00** Lunch on your own
- 14.00 - 15.30** Country Reports (Reports must be submitted in written form at the registration)
- 15.30 - 16.00** Coffee break
- 16.00 - 16.30** Report of the Nominations Secretary, Maria Hass
- 16.30 - 17.30** Introduction of nominees for the new EOA Co-ordination Committee Country Reports
- 19.30** Opening Dinner (Porto Palácio Hotel)

Friday 27 August

- 09.00 - 10.30** Presentation of motions... Decision on the date of the 7th EOA Congress
Presentation of bids for the 7th EOA Congress / Venue proposals for the 8th EOA Congress.
- 10.30 - 11.00** Coffee break
- 11.00 - 13.00** Selection of the 7th EOA Congress venue Country reports
- 13.00 - 14.00** Lunch on your own
- 14.00 - 15.00** Country reports. Proposals for Nominations Secretary and Auditor
- 15.00 - 15.30** Coffee break
- 16.00 - 18.00** Elections for EOA President, EOA Vice-President, EOA Treasurer, Nominations Secretary and Auditor.
Any other business
Installation of New Officers.....Speeches of the outgoing President and the new President.
- 18.00** Close of the Congress
- 19.00** Dinner

Saturday 28 August 09.00 - 17.30 Programme of the 11th IOA Congress
19.00 Opening/Closing Dinner Combined EOA & IOA & 20/40

Welcome from the President of the European Ostomy Association



Dear Friends,

I have the pleasure to welcome you all to the 6th EOA Congress and the 11th IOA Congress.

I suppose that you are aware of the unfortunate circumstances that forced us to join the two Congresses. This change resulted in a certain limitation of the EOA Congress; The fact that the workshops and exhibits will take place

in the framework of the IOA Congress gives us more space for discussion of particular problems of ostomate organisations in Europe, where great differences in the care of ostomates still persist.

There will also be more opportunities to exchange mutual experience and establish new personal contacts.

I look forward to meeting all of you and hope that you will enjoy the atmosphere of the beautiful City of Porto and the Congress itself.

Dr. Vladimír Kleinwächter
President
European Ostomy Association

3RD 20/40 FOCUS

“CREATING A BETTER LIFE”

August 28th – 31st 2004



Porto, Portugal

Place: QUALITY HOTEL PORTUS CALE PORTO

(just 300 metres from PORTO PALACIO where the Focus will take place)

Avenida Da Boavista, 1060

4100-113 Porto, Portugal.

Don't miss it; just be there, we count on all of you!

For the first time the 20/40 Focus will be held in conjunction with the IOA World Congress.

The 20/40 focus agenda combines some parts of the program, like the Grand Opening, the Opening Dinner and the Grand Closing Banquet with the IOA World Congress attendees. The rest of the program is completely up to us!

Interactive sessions on topics like psychosocial adjustment, fatigue, relationships, body image, work, sports and stoma care are scheduled; you can take part in a workshop on visiting young fellow-ostomates; listen to reports from many countries around the world and learn how to organise meetings with young ostomates.

See you there!

The registration form can be found at <http://www.ostomyinternational.org/Congress2004/RegForm.pdf>

If you have any questions on the 20/40-Focus program,

Please contact your regional 20/40-Focus committee member:

Damaris Morais - South American region damaris.morais@terra.com.br

Paula West - South Pacific region paulawest@clear.net.nz

Marc Bekkers - European region marc.bekkers@home.nl

Anne Hafner (chair) ahafner@bigpond.net.au



NEWS FROM CANADA

3rd annual golf charity event at Granite Ridge Golf Club in Milton Ontario. The day was warm but not humid for the 95 golfing enthusiasts. The winning team came in at 60(12 under par). We had a great evening that included a silent auction. The guests of honour were a radio personality (from Am 740) Mr. Bob Durant and the Speaker of the Legislature of Ontario the Honourable Alvin Curling. The meal was attended by a total of 105 people and the silent auction garnered more than \$4000. All told the 3rd annual event was a great success. Doing events such as this does a lot to build the awareness of our organization and what it stands for!

Our Ostomy Youth Camp just concluded. We had 30 young people from all over the country participating. Most are sponsored by chapters across the country. The camp is held in beautiful Bragg Creek Alberta in the Rockies. As is said by some campers this is the week that I wait for all year. We thank all of the volunteer councillors and nurses who used their precious vacation time to participate at our annual ostomy youth camp now in its 18th year.

Now that these two events are over we are preparing for our 7th annual conference in Gander Newfoundland. Please join us for the fun and experience the beautiful east coast of Canada August 17-19. For more information please visit our website at www.ostomycanada.ca

Lorne Aronson, President

IOA REPORT FOR THE PERIOD 2001-2004

ia continues to meet the objectives of the organisation by offering help and support to people with ileostomies and ileo-anal pouches. Our membership currently stands at 9500, spread over 56 groups operating locally throughout the England, Ireland, Scotland and Wales.

Since we last met at an IOA World Council meeting, we have lost two of our most valuable executive committee members. Many delegates will remember our former executive committee chairman, Donald Currie who was a very popular figure at the meeting in Amsterdam when he appeared in his dress kilt at the conference dinner and was photographed with just about everyone. Donald died very suddenly in June 2001 and this was a great loss to our organisation. You

will also remember Tony Stammers, who delighted the delegates at Calgary by carrying the country flag in typical English style dressed in a sombre suit and wearing a bowler hat. Tony was *ia*'s finance sub-committee chairman and his sudden death in May 2004 has left us feeling stunned and shocked. These two young men unselfishly gave of their time and talents to help others in a similar situation and their efforts will be long remembered and greatly valued.

Bruce McKenzie, who had been *ia*'s national secretary for four years, resigned in May 2002 and it was decided that I should take over. This resulted in a move of office, as it is normal practice that the national office of *ia* is run by the national secretary from their home base, so 2002 turned out to be a turbulent and busy year.

We continue to be well represented at major professional conferences wherever appropriate. Several delegates attended the EOA Conference in Copenhagen in May 2001. Carolyn Stammers and I were honoured to be afforded the opportunity to present our accredited visitor training scheme at the WCET Conference in Florence, Italy in July 2002. Several of our young people attended the 20-40 Focus meeting in Canada in 2002 and Tracy Crosser, our Young *ia* co-ordinator at the time, was part of the organising committee. Our representation at IOA continues to be handled in a most efficient and effective manner by Brenda Flanagan and at EOA by Tom Keily.

For World Ostomy Day in 2002 and in conjunction with our sister organisations BCA (British colostomy Association) and UA (Urostomy Association) and the United Kingdom Nursing Organisations, we organised seven Roadshows throughout the British Isles. These Roadshows, which proved to be popular and highly informative, attracted high profile personalities and our members had the opportunity to speak with the ostomy equipment manufacturers, listen to expert presentations and raise issues of personal concern.

The *ia* Journal has long been a well respected and much praised publication, thanks to the efforts of David Eades who was the editor for ten years. John Smail succeeded David in 2001 and has maintained that high quality but has also brought a fresh look to the Journal, with lots of new and interesting features. John has also been responsible for updating our website which has been very well received. Its clarity, speed, ease of

navigation and content have all been favourably mentioned. All of our literature has been updated and presented in a corporate style to give existing and future members good quality information and assistance.

We have a well qualified, experienced visiting team, headed up by Tracy Walker and our success in providing accredited visitor training courses has been very well accepted by the professionals in their choice of visitors for new and existing patients. This is an area that we hope to develop further in the very near future.

A close working relationship exists with the nursing organisations and our representative, Carolyn Stammers, who is a stoma care nurse, also has regular contact with the ostomy equipment manufacturers as well as keeping us up to date with the new initiatives constantly being introduced by Government bodies.

We have a vibrant young group who concentrate their efforts on helping other young people come to terms with living with an ostomy and getting them involved in our organisation. Our Young *ia* co-ordinator, Sarah Maill, spent summer 2003 in America at one of the camps and at the Young Adults Conference. This wonderful experience will be very valuable in helping her carry forward some of the ideas for the future.

The needs of those members with ileo-anal pouches continue to challenge us and our co-ordinator for this section of the organisation, Dan Jones, and his committee are constantly thinking of new ways to meet these challenges. A booklet written by one of our members "Is that a New Pouch You've Got?" takes a light-hearted look at living with an ileo-anal pouch and is one of the most requested pieces of literature that we have available.

Our interest in research continues and, because of the large sums of money involved in such projects, we have entered into joint sponsorship of research fellowships with other organisations such as the Digestive Disorders Foundation and the Royal College of Surgeons.

The National Council meetings bring together delegates from our member organisations and these annual events are the highlight of the *ia* year. The *ia* Bryan Brooke Lecture was established in memory of our founder, Professor Bryan Brooke and this is usually given by an eminent surgeon at these annual meetings, where we

mix business with social activities, useful workshops and plenary sessions. Our executive committee is made up of a team of very qualified and experienced volunteers who willingly give their time to undertake the important service that *ia* has to offer. We are also very fortunate to have as our President, Professor Norman Williams, who is highly regarded by his peers in the area of colorectal surgery. His expertise and guidance is very much appreciated.

All of the above, working together, have enabled *ia* to provide help and encouragement to those who need it at a most vulnerable point in their lives.

Anne Demick
National Secretary.

NORILCO, NORWAY ARNE RE - ELECTED



Arne Holte (60) was re-elected president when NORILCO, Norway's, House of Delegates met in the city of Aalesund in the beginning of May. It's Arnes second two-year period as president. The constitution was changed at some points, the most important one was to reduce the number of board-members from nine to six. From now on the leaders of the parents group and the visiting service will be elected separately, and they will have personal substitutes. From the annual reports it can be read the NORILCO has continued the work for ostomates in St.Petersburg. The cooperation with ASSCOL is very good, and this autumn NORILCO will arrange another course for ostomates and health-personell.

NORILCO has a good and sound economy thanks to being affiliated to the Norwegian Cancer Union. But due to changing in the slot-machines market, and a complete change in the Cancer Union's organization it's expected less money in the years to come. Hopefully this will not affect NORILCO too much.

Near a hundred delegates and accompanying persons had a great week-end in this west-country city which gave us summer-temperatures at a time of year when sleet and snow may occur. The meeting was opened by the mayor of Aalesund, and the program also included interesting lectures by Norwegian surgeons about new ways of operations – including ostomy- and

IAA-operations. Successful organizers were the local chapter headed by Mr Roald Rekdal. He was lucky to have a handful of girls helping him. Next House of Delegates will meet in the city of Hamar in two years.

In the last issue of IOA-today I wrote about the Norwegian government taking steps to find out why Ostomy equipment is more expensive in Norway than in other near-by countries. In the beginning of May NORILCO represented by Arne Holte and newly elected board-member Knut Ellingsen had a meeting with representatives from the government. Two, more or less by coincidence, chosen ordinary members of NORILCO and the manager of a distributor also participated in the meeting which gave us some ease as we were told that no changes should take place in the near future. And if equipment no longer would be paid (mostly as today) by the social security it should be replaced by something better and more reliable. It's easy to understand that the government puts it searchlight on Ostomy-equipment as there are about 95 A-4 pages listing equipment paid by the social security.

Arne Holte will lead the Norwegian delegation to the congresses in Portugal. He will be accompanied by Mrs Rigmor Yttergaard, head of the visiting service and Mr Jostein Sandvik, head of the parents group. So to all friends in the world of ostomates: hope to see you in Porto to much work, but also to fine and beautiful days with time of fun and laughter.



Knut Ellingsen (left) has lead NORILCOs work in St.Petersburg since it started in 1993. AS newly elected member of the board he told the delegates that NORILCO recently had got reasonably amounts of money private persons. President Arne Holte is very glad for the money which will give NORILCO the possibility of sending appliances to At.Petersburg also this autumn.

Arne Holte, pres NORILCO



News from UOA

Since the last IOA World Conference we believe UOA has accomplished many of its key goals. We have now established four Youth oriented

national networks, one each for parents of children with

ostomies or related procedures, for teenagers, for young adults from 18 years old to about 30 and one for those over 30 but still young at heart. A network is like a national chapter that serves a very specific constituency that primarily communicates through the internet and possibly a newsletter but can only meet once a year at our annual conference because its members are scattered across the country. All of our networks have their own web pages either located on the UOA mother site, www.uoa.org or they are directly linked to it.

We have just completed our Annual Youth Rally and we brought 94 children aged 11 to 17 to San Diego, California for a 4 day summer camp. Last year our Youth Rally leadership team was a winner of the prestigious "Points of Light" Award established 13 years ago by George Bush, the father.

We have continued to improve our web page, winning a national award for it, and we now believe it is the most informative ostomy related web site in the world. It has four different message boards and it links to every other important ostomy site that we could find. If your country has a web page and you are not yet linked to ours, we would be honored to work with you to do this.

We have developed much stronger relationships with the other entities that serve our members; most importantly the manufacturers and distributors of ostomy supplies, the Wound and Ostomy Continence Nurse Association, the American Cancer Society, the Crohn's and Colitis Foundation of America and the American Society of Colon and Rectal Surgeons. Also about four years ago we initiated a program to aid in colon cancer prevention and we now are a member of the leading coalitions that share that objective.

UOA membership is currently at approximately 22,000 members and we have about 400 chapters throughout the country. More and more of our membership comes to us now through the internet or through our networks as opposed to the more traditional method of first joining a local chapter.

Since our last IOA meeting, we now have a new Executive Director, Nancy Italia and with the exception of only one person, we have an entirely new office staff at our Irvine, California office.

Our two newest goals are to conduct an awareness campaign that attempts to take away what many people in the US feel is the stigma of having an ostomy. Our other new goal is to further build our internet site to include not just links to other sites and service providers, but to provide what we call information pathways so that a patient, caregiver or nurse can find anything related to ostomy care.

It will truly be an honor for me to lead the US delegation to the upcoming World Conference. We know what it takes to build a good organization and we are will be humbled to be in the presence of so many others around the world that have accepted and fulfilled this challenge.

AMENDMENTS TO THE PROPOSED CHANGES OF THE IOA CONSITUTION FROM MEMBER ASSOCIATIONS

As the secretary, I have received further amendments from member countries following the proposed changes to the IOA Constitution that I sent to you on May 3rd 2004.

There are no further proposed changes from the IOA Executive Council but I am including in IOA TODAY, amendments to the proposed changes from the following member countries – Australia, Brazil and the United Kingdom. I wish to inform you that these proposed amendments were received well before the deadline of 28 JUNE 2004.

I would remind you that

- Full Member Associations must have paid membership dues in order to be able to vote at the World Council meeting. If you are in doubt about your status, please get in touch with treasurer John O'Neill at treasurer@ostomyinternational.org or myself at vicepresident@ostomyinternational.org
- Amendments which have not been previously circulated **MAY NOT** be made from the floor of the World Council meeting, but changes to the circulated / published amendments may be made from the floor of the World Council meeting.

If I can be of any further help to any one of you, please do not hesitate to get in touch with me.

On behalf of the Executive Council of IOA, I would like to say that we are all looking forward to meeting you in

Porto, Portugal this August. We anticipate a successful Congress and hope that until we meet you will remain safe and well. Travel safely!

With Warmest Regards

Di
Dielwen Bracken, Secretary

AUSTRALIAN COUNCIL OF STOMA ASSOCIATIONS INC.

Patron: His Excellency, Major General Michael Jeffery A.C.,
C.V.O., MC
Governor General of the Commonwealth of Australia

CHANGES TO THE CONSTITUTION.

Amendment proposed by Australia to Motion 2 regarding qualifications of the Treasurer.

Proposed further amendment:

The Members of the Executive Council shall be, or shall have been, ostomates with the exception that the Treasurer shall be, or shall have been, an ostomate or the relative of an ostomate. **Persons nominated for the position of Treasurer must be able to demonstrate by qualifications or experience that he or she has the accounting and financial skills necessary to carry out the duties of the position.**

Rationale: This amendment relaxes the requirement that the Treasurer must be, or must have been an ostomate, by providing that he or she may also be a relative of an ostomate. This change will widen the talent pool from which Treasurer candidates can be nominated.

An additional requirement is that the post holder must also be able to demonstrate that he or she has the skills necessary accounting and financial skills to carry out the duties of the position. It is considered that while possession of the necessary skills is important, requiring professional accounting qualifications is too restrictive. It may in the future result in IOA being unable to find a qualified Treasurer prepared to work on an honorary basis.

Submitted by Ed Webster
Secretary

On behalf of *ia* The Ileostomy and Internal Pouch Support Group, I propose the following amendments to the Motions to be considered at the IOA Congress in Oporto, Portugal in August 2004.

MOTION 1: We propose the following amendment to this Motion:

The words "or until he/she resigns from the position" shall be inserted after the word 'Council' in the third sentence. The motion will then read:

IOA shall have a Secretary. The Secretary shall be appointed by the Executive Council. Once appointed, the Secretary shall retain that position until replaced by the Executive Council or until he/she resigns from the position.

MOTION 2: We propose the following amendment to this Motion:

The following sentence shall be added to the motion. "The Treasurer shall be a qualified accountant, holding the recognised professional qualifications appropriate to the person's country of residence. (**Note:** for example, in the UK, a Chartered Accountant). The motion will then read:

The Members of the Executive Council shall be, or shall have been, ostomates, with the exception that the Treasurer shall be, or shall have been, an ostomate or the relative of an ostomate. The Treasurer shall be a qualified accountant, holding the recognised professional qualifications appropriate to the person's country of residence.

MOTION 6: We propose the following amendment to this Motion:

The following sentence shall be added to the motion. "This committee shall, on a three-monthly basis, publish a report on its activities, including accounts and shall circulate the report to the regions". The motion will then read:

Motion made by the IOA Executive Council to form a committee within the IOA Executive Council as presently constituted, called the Administrative Committee consisting of the President, the Vice President, the Treasurer and the immediate Past President, that shall be responsible for managing the day to day operational and administration of IOA between the World Council meetings. This Committee shall, on a three-monthly basis, publish a report on its activities, including accounts, and shall circulate the report to the regions.

MOTION 9: We propose the following amendment to the Motion to add paragraph 4.C.2.e(1):

After the word 'compliance', there shall be inserted the words "provided that this paragraph shall not apply in respect of Associations which are members at the time this amendment is approved". The motion will then read:

Associations not meeting the requirements of 4.C.2.e shall be accorded the status of Associate Membership until they are in compliance, provided that this paragraph shall not apply in respect of Associations which are members at the time this amendment is approved.

ANNE DEMICK
National Secretary.

PROPOSED AMENDMENTS FROM BRAZIL

1) IOA should establish a permanent office for its headquarters (I propose in Genebra) where there would be two full-time paid persons: a secretary and a journalist to execute IOA administrative work. The Executive Committee would hold a meeting once a year at these headquarters where all IOA documents and its history would be filed. Elections would be held every 3 years with possibility of only one more re-election.

2) The Executive Committee would be: President, Vice-President, 1st. Secretary, 2nd. Secretary (in the absence of the 1st. Secretary, 1st. Treasurer, 2nd. Treasurer (in the absence of the 1st. Treasurer), "vogal" (past-president, who finished his term of office) and the IOA Regional Presidents.

3) The Executive Committee has international status, thus Brazil advocates that those on the Committee be Ostomates.

Commentary: if we accept non-ostomates as international officers we shall be asserting that Ostomates from all over the world are not capable of managing international representation.

Commentary: The Regional President must be active and capable to be a Regional Leader - to employ all his/her available resources solving national problems and only appealing to IOA when issues concerned are beyond Regional frontiers.

I agree with a Past President, whom I call Executive Committee "vogal", due to his/her accumulated experiences and knowledge should be the liaison element to advocate in favor of those venues that have no Regional Presidents.

Commentary: The Executive Committee term of office should be 3 years, with only 1 re-election for everyone. If we include a 2nd. Secretary and a 2nd. Treasurer, they automatically fill in the vacancy for 3 years. There, it is not necessary to hold elections via e-mail.

Commentary: I do not foresee the necessity to create an Administrative Committee to help IOA. We should strive for an IOA permanent headquarters in order to receive all world correspondence, requests for help, file material and maintain 2 paid employees to perform administrative work approved by the president and Executive Committee.

Commentary: IOA world-wide subjects of interest which need attention within the space of 3 years and/or 1 year could be via each country electronic vote.

Commentary: The President of an Association Full Member should be an Ostomate.

Commentary: We support the idea that each country - Association Full Member - be delegated with only 2 proxies.

Regards, Candida Carvalheira (ABRASO/Brazil)
Proposals for IOA Constitution

Charter of Ostomates Rights

It is the declared objective of the International Ostomy Association that all ostomates shall have the right to a satisfactory quality of life after their surgery and that this charter shall be realized in all countries of the world.

- Receive preoperative counseling 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 and stoma nursing care in the preoperative and postoperative period both in hospital and in their community.
- Receive full and impartial information about all relevant supplies and products available in their country.
- Have the opportunity to choose from the available variety of ostomy management products without prejudice or constraint.
- Be given information about their National Ostomy Association and the services and support which can be provided.

- Receive support and information for the benefit of the family, personal careers and friends to increase their understanding of the conditions and adjustments which are necessary for achieving a satisfactory standard of life with a stoma.
- Receive assurance that personal information regarding Ostomy surgery will be treated with discretion and confidentiality to maintain privacy.

**ISSUED BY THE IOA COORDINATION COMMITTEE
JUNE 1993, REVISED JUNE 1997**

IOA POSITION ON TOBACCO SMOKING AND CHEW

RESOLUTION:

WHEREAS cancer is the disease which necessitates almost 80% of all ostomy surgeries; and,

WHEREAS a body of medical evidence has been compiled that clearly demonstrates the existence of a definable link between the incidence of bladder and colon cancer and the use of tobacco products: and,

WHEREAS the International Union Against Cancer (UICC) and the World Health Organization (WHO), in recognition of this harmful relationship between cancer and the smoking and/or chewing of tobacco products, have published warning and initiated tobacco anti-smoking products and chewing programs for the betterment of health worldwide;

BE IT THEREFORE RESOLVED that the International Ostomy Association (IOA) does applaud the International Union Against Cancer and the World Health Organization for their humanitarian efforts to eliminate a major cause of disease, and joins with them in their efforts to discourage and reduce the use of all such injurious tobacco products.

**RESOLUTION APPROVED BY IOA WORLD
COUNCIL 20 APRIL 2000**