

NETWORKING MEETING AT ICS 2001

Medical experts from around the world assembled for the annual meeting of the International Continence Society, ICS, in Seoul, Korea, on September 18th - 21st, 2001. During the meeting the Continence Promotion Committee, CPC, of the ICS, arranged a Networking Meeting. It was an opportunity for those running national organisations to exchange ideas and information. The Networking Meeting was coordinated by Peter Lim and Rani Vadiveloo. A comprehensive article, "CONTINENCE PROMOTION IN ASIA", by Marie Carmela M. Lapitan, sums up the Networking Meeting on our website (www.continenceworldwide.org).

NEWS FROM THE ICS CONTINENCE PROMOTION COMMITTEE (CPC)

The CPC exists to promote education, services and public awareness about incontinence throughout the world, and to facilitate communication, exchange of information and partnerships between continence organisations. The members of the CPC are: Dr David Fonda, Australia (Co-chair), Professor Christine Norton, UK (Co-chair), Ms Elisabeth Willemina Bakker, Belgium, Mrs Diane Newman, USA, Ms Cheryle Gartley, USA Dr Ilan Gruenwald, Israel, Dr Marie Carmela M. Lapitan, Philippines, Professor Peter Lim, Singapore, Professor Helmut Madersbacher, Austria, Dr Vasan Satya Srin, India, Ms Rani Vadiveloo, Singapore (Co-opted), Dr Jean Jacques Wyndaele, Belgium (Co-opted).

The Canadian Continence Foundation

In addition to regular activities such as producing new information sheets, booklets, and the Informer, *The Canadian Continence Foundation* continues to work on behalf of consumer's experiencing incontinence. We constantly respond to the consumer inquiries received on our Help Lines and via the Internet

Special Events

The First Joint Canadian Urodynamic Professionals and The Canadian Continence Foundation (CANUP/TCCF) Conference was held on October 2001 in Montreal. The theme was "New Trends In Treating Urinary Incontinence In The New Millennium". Participation was excellent with 244 individuals from all over Canada attending. The first day offered presentations and workshops with the consumer in mind. The second day provided a scientific approach to several continence issues and care.

The Second Joint Conference will be held in Montreal in 2003. We expect this to be a great success as well.

Completion of Health Canada Project

The Canadian Continence Foundation is pleased to announce the completion as of December 2001, of Canada's first Clinical Practice Guidelines for urinary continence care in Canada.

This 3-year project "Promoting A Collaborative Consumer-Focused Approach To Continence Care In Canada" was made possible with a financial contribution from Population Health Fund, Health Canada.

There were four phases that included:

- 1) An Environmental Scan: Worldwide

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- 2) A Guidelines Committee consisting of representatives from each of the following medical disciplines, Nurses, family Physicians, Urologists, Urogynaecologists, Physiotherapists, Gerontologists and Consumers. Recommendations were developed looking at the impact of incontinence on Women, Men and the Frail Elderly living in the community.

A Working Models Committee developed "Models of Care" taking into account the geographic differences within Canada, such as Small Cities, Rural/Remote, and Urban/ Academic settings.

- 3) In May 2000 a Consensus Conference was held where participants representing many health disciplines, community organizations and consumers from across Canada were presented the recommendations from the working committees and following break out sessions, final modifications were made and conference participants were asked to vote on the recommendations. The vote was positive and consensus was achieved!
- 4) The phase four of the project was to hold Reactor Panels in several Canadian communities. The purpose was to identify the current available services, challenges and ask local stakeholders if the Guidelines were viable. The response was an overwhelming "yes".

Concurrently a Consumer Committee produced a consumer guide " Talking Together About Bladder Control". Dr. D. Griffiths and Dr. K. Moore oversaw the accuracy of the medical information.

The Foundation continues to maintain a list of professionals working with incontinence on our website. This service

has been well received by consumers looking for a healthcare professional within their local region.

For additional information on urinary incontinence, please contact the Canadian Continence Foundation at www.continence-fdn.ca.

Ruth Pelletier

Executive Director

The Canadian Continence Foundation

Gesellschaft für Inkontinenzhilfe e.V. (GIH)

Since it was founded in 1987, the GIH (*Gesellschaft für Inkontinenzhilfe*) has become a highly respected "lobbyist" for people with incontinence. The society's efforts to achieve its objectives have intensified especially over the last two years and are now showing results. There is no doubt that, in Germany, the awareness within the population of incontinence has grown, and professionals like doctors, nursing staff, physiotherapists and pharmacists have become actively involved in the field of incontinence – and so has the manufacturing industry by providing products for incontinence care.

However, incontinence is still a highly unpleasant disability, and the social discrimination of incontinent people is far from having become a thing of the past. Moreover, due to the tighter budget of the health care system the high costs of care that incontinence generates, are being discussed with increasing vociferousness. As a result, some substantial challenges are still there to be met by the GIH.

Aims

The GIH is a scientific organisation whose members are medical practitioners, nurses,



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pharmacists, and affected people, supported by companies with special experience in the field of diagnosis, medical treatment and incontinence care. The membership has increased to **2,100**.

There is one aim that dominates the work of the GIH: **Incontinence should no longer be a taboo subject.**

Measures of prevention, diagnostics and treatment of bladder and bowel incontinence as well as the interdisciplinary research and teaching on incontinence are being promoted and co-ordinated by the GIH.

Patients and their relatives must be motivated to discuss their problems with their physicians. Doctors and researchers should be encouraged to devote their attention to the problem of incontinence. Experienced practitioners should also be encouraged in dealing with the subject.

Activities

Public relations campaigns in the printed media, on radio and TV help to break the taboo. The GIH gives general and individual information and support through brochures on the various types of incontinence, by answering requests, both from professionals and patients, and by providing addresses of experts for further advice, etc.

Additionally, the GIH organises its own annual congress on the diagnosis and treatment of incontinence, and participates also in conferences on urology and incontinence.

Last but not least, the GIH , co-ordinates more than 260 incontinence service center, 5 interdisciplinary centers of competence which are associated to large hospitals, co-operates with 7 rehabilitation centers, and presents 37 self-help groups which work very

successfully all over Germany.

To achieve better communication, the GIH publishes a journal for its members, called "*GIH aktuell*", which is also distributed to other societies and individuals interested in the management of incontinence and to the industry in Germany, as well as in Austria. The circulation of the journal is 10,000; it is published quarterly, and financed through advertisements from manufacturers and suppliers.

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Incontact

Incontact is the UK organisation for people with bladder and bowel problems. Formed in 1989 by a group of patients and health professionals, the organisation provides information and support to people affected by these common conditions, as well as their carers and the health professionals who look after them.

Incontact has been expanding its range of user-friendly information materials, to cover issues such as stress incontinence, urgency and bedwetting. There is also a set of new product information sheets, which give consumers all the details of manufacturers and their products and the procedure to procure them. The quarterly *Incontact* magazine is more popular than ever, the circulation increasing every month.

People with bladder and bowel problems also benefit from our network of local groups

and helplines - talking to someone who 'knows what it is like' is so important for many. These groups are also a resource for healthcare workers, providing a local referral point for support and self-help. *Incontact's* support network has grown a lot over the past year, now with around 25 local groups in action.

Incontact's annual conference, this year being held on the 4th and 5th September, is a chance for patients, carers and health workers to meet, share points of view, and hear about the latest progress in managing and treating bladder and bowel problems. Companies that manufacture products will also be on hand to show their wares.

As a consumer-led organisation, *Incontact* views the patient's voice as paramount. We work closely with the National Health Service and the voluntary sector to ensure that this voice is heard. *Incontact* believes that partnership between the consumers and service providers is vital, and we are always looking at new opportunities for collaboration.

For more information you can visit our website at www.incontact.org, call us on 0870 770 3246 or write to United House, North Road, London N7 9DP.

Pelvic Floor Netherlands

Pelvic Floor Netherlands is a Dutch foundation working for the optimal care of patients with pelvic floor problems. We do this by promoting a multidisciplinary approach to pelvic floor pathology. Our activities are based on transfer of information and on sharing knowledge between different disciplines. Pelvic Floor Netherlands wants to be a co-ordinating foundation for the national health care in the

field of pelvic floor pathology. Pelvic Floor Netherlands is working closely together with the patient foundation for pelvic floor problems (SBP). Internationally we would like to be a model for multidisciplinary organisations in the world.

Members

The disciplines that are represented within Pelvic Floor Netherlands are: anatomist, colorectal surgeon, physiotherapist, gastro-enterologist, gynaecologist, general practitioner, incontinence nurse, paediatrician, clinical neurophysiologist, psychologist and urologist.

Research

We initiate research projects on pelvic floor pathology and on the multidisciplinary approach. One project deals with the possibility of preventing pelvic floor problems by giving pelvic floor muscle exercises during pregnancy. Another project develops a strategy for delivering information about pelvic floor problems to patients. This is a combined project of care givers and patients. A patient information booklet has been developed and the network of incontinence care-givers was made available for patients. At this moment this booklet is implemented in daily healthcare.

Education

We are actively involved in setting up education programs for physiotherapists, general practitioners and medical specialists. These educational programs are set up to elucidate the role of the pelvic floor in specific complaints like urinary incontinence. This unidisciplinary approach is combined with a program on the importance of multidisciplinary approach. The subject of our yearly congress will be pelvic floor problems in elderly people and in people living in nursing homes.



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International activities

Pelvic Floor Netherlands has initiated the ICS Pelvic Floor Clinical Assessment Group. This is an international, multidisciplinary group that was started in 1998 to provide a report on terminology and standardisation of pelvic floor pathology. This group is chaired by the chairman of Pelvic Floor Netherlands. The document on pelvic floor terminology is ready in concept and is available on the website of the ICS. During the ICS 2002 a workshop on the male pelvic floor is organised in coordination with Pelvic Floor Netherlands.

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New Polish Continence Organisation - NTM Forum

On 14th May 2002, NTM (INCO) held a press conference launching the Polish forum. The NTM Scientific Council consists of representatives from different fields associated with the issue of incontinence, of which the following members were present:

- Prof. Tadeusz Tolloczko, former Head of the Dept. of General, Vascular and Transplantation Surgery of the Medical University in Warsaw, former President of the Warsaw Branch and Secretary General of The Association of Polish Surgeons.
- Prof. Longin Marianowski, Head of the Obstetric & Gynecological Department and the Medical Academy's clinic in Warsaw.
- Prof. Anna Czlonkowska, Head of the

Neurology Department and the Institute of Psychiatry and Neurology clinic in Warsaw.

- Dr. Piotr Radziszewski, Urologist and co worker to Prof. Andrzej Borkowski (Head of the Medical Academy's Urology Department & clinic in Warsaw). The latter could not participate in the conference due to a business trip abroad.
- Elzbieta Szwalkiewicz, Head of the Niebieski Parasol Nursing Centre.

The main aim of the conference was to promote the idea: "Urinary Incontinence: A Normal Life", as well as to increase the awareness of incontinence among Doctors and sufferers via various media. It was also an opportunity to launch the NTM Forum's web site www.ntm.pl.

Some of the issues discussed during the conference were: incontinence as a disease, the scale of the problem, reasons for incontinence, its effect on quality of life, diagnostics, treatments, the availability of medical help and the reimbursement process for urinary absorbent products.

Media interest in the event was high, with journalists from the daily press, television, radio, medical publishing houses, internet portals and women's magazines were invited. Afterwards the NTM Scientific Council received many telephone calls, asking for the possibility of personal contact with its members in order to obtain more information on the programme "Urinary Incontinence - A Normal Life".

The council desires and is now looking for wide media coverage of the incontinence issue and welcomes people to visit the new NTM web site www.ntm.pl. The goal of the site is very clear: *To not only provide the*

public and professionals with useful information, but also to bring together everyone working in the area.

Prof. Tolloczko

Pelvic Floor Patients foundation (SBP)

Background

Pelvic floor pathology can give rise to many different problems. Urinary and faecal incontinence are amongst the most frequent ones. Most patients with incontinence and other urinary tract problems are aware of concomitant complaints. Sexual dysfunction and pain are well known in these situations. The pelvic floor is not only an important organ in the origin of these complaints, but it is also an organ which can easily be treated. This has made conservative therapy become very popular during the last 10 years.

Patients

The SBP is a foundation for patients with pelvic floor problems. All patients irrespective of the type of problem, are welcome. For patients there may be less taboo on pelvic floor problems compared to incontinence. Within the foundation they will meet other people with the same complaints or combination of complaints. Patients will get the opportunity to talk with other patients. They can get information on the pelvic floor, its problems and the therapeutic options. There is a telephone line, where patients can get answers and also there is a website for additional information.

Contacts

The foundation will endeavour to stay in close contact with the doctors and other care-givers. Due to this, sufferers develop a

strong relationship with Pelvic Floor Netherlands, the organisation for the multidisciplinary approach to pelvic floor pathology. The co-operation with Pelvic Floor Netherlands yields a platform for pelvic floor care in all its aspects. It provides a unique opportunity for patients to contact doctors and vice versa. The foundation will also start a discussion with the government and with the insurance companies. This will hopefully result in more financial support for the treatment procedures and for incontinence materials.

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Simon Foundation

The Simon Foundation for Continence is a not-for-profit organisation headquartered in Chicago. This is a very active year for the Foundation. Late in 2002 we will release two CD-Roms in our new patient education program. The Interactive Patient Library and a group of unique computer software resources. The first disks are designed for urology and gynaecology/urogynaecology offices. Each disk will contain patient information fact sheets which can be personalised with the patient's name, the doctor's name and office details. These user friendly information sheets can be "prescribed" for patients during their office visit or mailed ahead to new patients before their first visit. The Interactive Patient Library will eliminate the need to order, inventory and manage a large assortment of patient literature from different sources. In addition to complete coverage of incontinence, the

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urology disk will contact fact sheets on topics pertinent to urology such as impotence, prostate cancer, prostatitis, benign prostate hyperplasia, and bladder cancer, to name just a few. The gynaecology disk will likewise cover practice specific topics such as prolapse, sexually transmitted diseases, osteoporosis, breast cancer and many others. Another priority for the Foundation this year is to increase the awareness for the need for further resources to be devoted to research. In November, the International Foundation for Functional Gastrointestinal Disorders, in conjunction with the Simon Foundation, will hold an interdisciplinary conference – “Advancing the Treatment of Faecal and Urinary Incontinence Through Research: Trial Design, Outcome Measures and Research Priorities” – to build consensus on a clear agenda for treatment related research. Speakers will present state-of-the-art talks summarising what is known about the pathophysiology of different types of incontinence, outcome measures, predictors of outcome and trial design. The proceedings will be published in detail.

Interest continues to build due to the proceedings from the First International Conference on the Prevention of Incontinence (P97) held at Danesfield House, U.K. in June 1997. The proceedings have helped to draw the attention to the topic of prevention of adult urinary incontinence. In the P97 Consensus statement, authors agreed that the promotion of prevention, to the general public is also essential and developed recommendations for Healthy Bladder Habits for use in educating the public and professionals worldwide. Posters promoting healthy bladder habits are distributed by the Foundation. One of the growing outcomes of P97 is that, the topic of prevention, is now being routinely included in several future programs.

In June of this year a day long workshop was held in Chicago to give stakeholders in the Foundation an opportunity to help define the Foundation's strategic plan for our third decade of promoting continence. The think tank included members from industry, health professionals, and consultants. A Celebration 2003 Committee was formed and plans are underway to host a gala celebration, for the Foundation's twentieth anniversary in the month of June 2003. In conjunction with this event, and in keeping with the Foundation's mandate to host conferences addressing areas not previously focussed upon, next year's conference will bring together psychologists and other experts from around the world to examine what issues affect the behaviour of people with incontinence. A few of the topics to be included are: what motivates people to seek healthcare, what are the origins of stigma, the psychology of hope, the mechanism of defeat, adherence vs. compliance and behavioural similarities among people with chronic health conditions. The objective of the conference is to identify methods to overturn the attitude of defeat which otherwise leads to acceptance of the condition and withdrawal from society.

The Foundation's work is currently being honoured at a new museum in the United States. The Women's Museum: An Institute for the Future. An affiliate of the Smithsonian Institution, The Women's Museum is located in Dallas, Texas. The museum's exhibits honour women in many areas of endeavour: science, industry, culture, politics, aviation, entertainment and many more. American women known the world over, such as Coretta Scott King, Janet Reno, Maedline Albright, Eleanor Roosevelt, and Amelia Ehrhardt are recognised. Ms Gartley, Simon Foundation's founder and president, and the first President of the Simon Foundation of Canada (now known as the

Canadian Continence Foundation) are honoured in "Pathways to Health", a permanent exhibit that explores significant healthcare advances for women. Annually, many thousands of visitors to this health exhibit are learning that incontinence can be cured, treated, and successfully managed.

We continue to grow and strengthen our alliance with the Canadian Continence Foundation through reciprocal members of the Board. In 2003 the Foundation will celebrate twenty years of service with a black tie event to launch several exciting new projects, which will be held in conjunction with the conference described above. We are delighted to be embarking upon the launch of many new programmes early in our third decade of promoting continence and feel confident, that these measures, will be a major driving force in bringing hope to people with the problem of incontinence.

SOCIETY FOR CONTINENCE (SINGAPORE)

The Society for Continence (Singapore) had another busy year.

1. Primary Nocturnal Enuresis Treatment Guidelines

The guidelines for the Management of Nocturnal Enuresis has been published and circulated to all Pediatricians in Singapore. This project was joint collaboration between Society for Continence (Singapore), Academy of Medicine and Singapore Pediatric Society.

2. Publications

The 2nd edition of Clinical Handbook on 'Management of Incontinence' has been published and well received by the local and overseas medical professionals. It was reported that \$7,000 worth of books has

been sold in the year 2001. The Society plans to sell the book at the forthcoming APCAB/ASFU Meeting at Kuala Lumpur in August 2002.

3. Asia Pacific Continence Advisory Board - Update

The 4th ABCAB and the 3rd ASFU Scientific Meeting was organized by the Indonesian Continence Society in Bali from 26 – 28 August 2001. Dr Rudy Yuwana Chaired the Scientific Committee. Professor Peter Lim reported that the meeting was well attended to by the APCAB countries and by the Indonesian Doctors. The governor of Bali graced the event by opening the meeting.

4. Continence Promotion Committee – CS 2001, South Korea

To strengthen the networking of the Asian Continence groups with the rest of the world, the Society organized a workshop on "Networking" for the ICS Continence Promotion Committee in Seoul, on 18 September 2001. The workshop served as a venue for the different Asian countries to present their goals, achievements and problems in continence promotion to the rest of the world. A total of 10 continence organizations from 10 different countries presented their work. These includes the Indian Continence Foundation, Continence Foundation of the Philippines, Taiwanese Continence Foundation, Pakistan Continence Foundation, Malaysian Continence Society, Society for Continence (Singapore), Hong Kong Continence Society, Chinese Society of Urinary Incontinence, Continence Society of Indonesia and Korean Continence Society. A/Professor David Fonda, Chairman of the CPC of the ICS and Professr Peter Lim, President of the APCAB, moderated the meeting. A total of 120 participants from several countries



attended the workshop.

5. Female Urology - Pelvic Floor Workshop

The Society in conjunction with the 2nd Biennial Asian Surgical Association Meeting organized a two-day workshop on "Female Urology – Pelvic Floor Workshop" at Shangri-La Hotel, Singapore during 2-3 November 2001. About 70 participants comprising doctors, physiotherapists, nurses and continence advisors from countries in this region, viz., Hong Kong, Indonesia, Malaysia and Singapore.

World renowned speakers Professor Jacques Corcos, Jewish General Hospital, Canada; Professor Kari Bo, Norse Idrettshfsgskok, The Norwegian University of Sport and Physical Education, Norway and Professor Mela Lapitan, Philippine General Hospital, Philippines were the members of the teaching faculty. The focal topic of the workshop was addressed as "Multidisciplinary Approach to Manage Pelvic Floor Disorders". Live demonstration on the pelvic floor muscle exercises, had active participation by the attendees who enthusiastically took part in the exercise. A good number of our nursing members, sponsored by the Society benefited from the workshop.

6. Toilet Seat Project

Continuous efforts have been made to promote this project but we were unsuccessful due to problems of company sponsorship and we hope overcome the same soon.

Toilet Sticker Project

The Society has initiated another project with the Restroom Association of Singapore. Stickers educating the public on treatment options for incontinence will be pasted on the inner-door of the toilet at all

the public toilets at the Commercial buildings in Singapore. The second phase will include the toilets at the universities, polytechnics and other educational institutions. This is the first of its kind in Asia. The project is collaboration between the Society, Restroom Association and the Ministry of Environment.

7. National Survey on "Prevalence of Urinary Incontinence in Women"

The National Survey on "Prevalence of Urinary Incontinence in Women" is a joint project with Clinical Trial Epidemiology Research Unit (CTERU) of Ministry of Health, Changi General Hospital's Urology Department and the Society for Continence (Singapore). The pilot study commenced in November 2001. A total of 2000 women subjects randomly selected would be interviewed by the research nurses of the CTREU. The study will be conducted in II Phases:

Phase I : face to face interview

Phase II : urodynamics investigation procedure

A total of S\$150,000 is required to complete the project successfully. The project would be fully funded by the Society as no pharmaceutical companies have come forward to fund the project and the society will also utilise it's resources and provide treatment options for these sufferers of incontinence.

8. Movie – "Dirty Laundry"

Another joint project of the Society for Continence (Singapore) with and National University of Singapore, in which, a movie was produced and screened at the Golden Village theatre, New World City, between the 18-24th March 2002. This is a romantic comedy revolving around a young-adult suffering from bedwetting. Golden theatre group has

planned to screen this movie in all their outlets by end of year 2002. This movie was aimed as a public awareness programme.

9. Research Award Program

Two applicants were awarded the Research Awards. Dr Mela Lapitan was awarded \$3,000 and Dr Pearllyn Quek was awarded \$5,000 for their projects. This biennial award is open to all medical professionals in Asia and Singapore.

10. College of Family Physicians & SFCS – Survey

The Society and the College of Family Physicians are jointly conducting a survey to know the family physician's perception of "incontinence patients". This project will run through year 2002. The results would be presented at the ICS meeting 2002 in Germany.

11. Free-Treatment for patients

Forty patients were given free treatment on our "Extracorporeal Treatment Equipment" in year 2001. Each patient has to undergo 18 sessions @20 minutes per session treatment. Therefore total sum incurred for forty patients was S\$21,600.

New Zealand Continence Association

Greetings from the Land of the Long White Cloud - Aotearoa - New Zealand. The New Zealand Continence Association is a small but enthusiastic group with members

spread from the tropical north of the North Island through to the alpine southern regions of Invercargil and Dunedin. This year we have been working on the translation of our NZCA information handouts into both Maori and Samoan and are in the process of developing further translations into Chinese and Arabic. Increasing Continence awareness and the profile of the NZCA has been helped by the 0800 bladderhelp line which averages about 300 calls over a 2 month period. Complimenting the helpline is our website www.continence.org.nz, with on average 3200 hits a month. User feed back indicates that the website is great to use and has just been updated. Our focus for the coming months is to attempt to place continence higher on the health agenda. As part of this strategy we are in the stage developing a series of research projects - the first, looking at incontinence and its relationship to patients admission into Rest Home care. At the other end of the age spectrum NZCA has welcomed the development of the Kiwi Enuresis and Encopresis Association (KEEA). This group was set up by a Nelson Public Health Nurse -Shirley Reid, and offers valuable support and information to Kiwi kids and their parents on the issues of enuresis and encopresis. NZCA has also been working on the development of a G.P. education package which is based on the work of Australian R Millard but will have New Zealand modifications. It is hoped that these will be available by the end of the year.

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