Continence worldwide

news from

THE ICS CONTINENCE PROMOTION COMMITTEE

also available at http://www.continenceworldwide.org
and on Continet at http://www.continet.org.sg

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Cheryle Gartley (Consumer from USA);

Ilan Gruenwald (Urologist from Israel)

Helmut Madersbacher (Urologist from Austria)

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FUTURE ICS MEETINGS
32nd Annual meeting: Heidelberg, Germany: 27-29 August 2002.

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NEWS FROM CONTINENCE ORGANISATIONS

Association for Continence Advice (ACA) (UK)

The Association for Continence Advice, (ACA) has just celebrated its "Coming of Age" at its 21st annual conference. This was a happy event, and quite an achievement as we are very aware that continence is not a "sexy" subject.

The aims and ideals of the ACA are to work towards the promotion and expansion of continence issues, providing information and support for professionals involved in continence care. Both urinary and faecal incontinence issues are tackled. Promoting good bladder and bowel health and prevention of problems are high on the agenda for the ACA and we work closely with user groups, for example *In*contact.

Our aim is to share good practice, and the recent formation of special interest groups within the ACA has further enhanced the educational input and professional development that we are proud of. We are truly multi- disciplinary: physiotherapists, doctors, midwifes, occupational therapists, commercial companies and of course nurses can join the ACA.

The ACA organises an annual international conference and a quarterly journal, with additional input to, and editorial control of, continence supplements in other national nursing journals. This year, the conference was held in Torquay, attracting 300 delegates. Conference is the ideal forum for education, dissemination of new research and ideas and forging links with other allied professionals. There is opportunity to browse around a large exhibition of continence related products. Glasgow is the venue for conference 2002, from 29th April to 2nd May.

The ACA networks with other continence associations within the UK and globally. Regional groups are set up throughout the UK aiming to keep members up to date with current issues and providing other supportive roles.

To raise the profile of continence issues, the ACA acts as a political forum and will lobby elected members of parliament. Nationally recognised, the ACA has worked in collaboration with other continence organisations to produce "The Good Practice in Continence Services Guide" and " Making a Case for Investment in an Integrated Continence Service."

Despite the realisation that continence issues are perhaps not viewed as the most dynamic of specialities in the world of healthcare, we must recognise the huge financial and social implications of incontinence. The ACA continues to strive to push forwards the boundaries of professional education and practice within this field.

NEWS FROM CONTINENCE ORGANISATIONS

Continence Foundation of Australia

The Continence Foundation of Australia - like so many similar organisations worldwide - is undergoing restructuring to enable it to operate more effectively in today's changing socio-economic environment.

The Australian government, increasingly utilising not-for-profits and non-government organisations to deliver community services, draws on the commitment and deep knowledge of health and social issues of dedicated community organisations. This puts the onus squarely on these groups to operate in a more corporate style, with tight accountability and a higher consciousness of budgets and deadlines, with meaningful business plans underpinned by entrepreneurial strategies.

The Continence Foundation of Australia has put into place a process to broaden the skill-mix of its Board Members to meet these requirements. This includes marketing and project management expertise, and representation strongly focused on the key "customers", those with incontinence problems.

Following our re-engineering, in June this year the Commonwealth Government awarded "peak body" status to the Foundation. Its grant-type funding contributes to the administration infrastructure supporting government projects. The principal project managed by the Foundation is the National Continence Helpline which has developed over three years into a meaningful, expanding, quality resource, not simply a referral service.

The Helpline is one of around 60 incontinence-related research and service projects being carried out under the government's National Continence Management Strategy (NCMS). Other projects in which the Foundation is involved include Australian Continence Services Mapping and a prevalence study. The Hunter Project, completed in April 2001 and based in a region of New South Wales, is a proposed model for coordinated continence care which may be replicated nationwide. It brings together differing sectors - Allied Health Professionals (Continence Nurses, Physiotherapists), GPs and Practice Nurses, and Pharmacists and Pharmacy Assistants to improve their continence knowledge and collaborate to bring the "hidden incontinent" into treatment. A local community awareness campaign fuelled the project.

The theme for this year's Continence Awareness Week (August 5-11) is *"Can't Bear to Talk About It?"* The grizzly bear motif highlights the lifestyle component and the taboo aspect – how incontinence can make one feel and behave, how its impact on enjoyable social activities and healthy exercise ranges from subtle to dramatic, where a problem can deteriorate into isolation and depression.

With this "talk about it" focus, consumers are encouraged to be pro-active in seeking help, to not settle for a problem being dismissed by anyone as "because of ageing", "because of childbirth", or "not important enough" - to persist until they gain clear information and guidance. The Foundation believes that the "cringe factor" surrounding incontinence also extends to the media, who generally considered it not important, and that their audiences would not want to hear or read about bladder or bowel control or not consider it "relevant". Changing this view has been an objective over the past two years, resulting in a marked upsurge in journalists contacting the Foundation and the Helpline for background, and with articles and airtime increasing.

A further step for the Foundation's Helpline promotion is taking the marketing down a notch into earlier age groups as a preventive approach. The Foundation believes the issue should be discussed in secondary schools at late-teenage level. Here again, the marketability of awareness can be improved by packaging it also as a sexuality issue.

Further, the importance of pelvic floor care in the pre- and peri-natal timeframe offers a prime opportunity to expand awareness. This is at a pivotal time in the younger woman's life where family and cross-generational interaction is intense, where "inherited family wisdom" is spotlighted, influencing women's (and men's) health, sexuality issues, and childhood toilet training where lifetime habits and attitudes are established.

Anne Haag , Administration & Marketing Manager

The Canadian Continence Foundation (TCCF)

TCCF is the only national non-profit continence organization in Canada. Our Mission Statement is: "To enhance the quality of life for people experiencing incontinence by helping, them and/or their caregivers, to confidently seek and access cures and treatment options. To this end, The Foundation will implement and encourage important public and professional education, support, advocacy and research to advance incontinence treatment and/or management."

The Canadian Continence Foundation promotes a multidisciplinary approach to continence care with a partnership between healthcare professionals and their clients who experience incontinence.

For care providers, policy makers and fund agencies, *The Canadian Continence Foundation* focuses on increasing awareness and commitment to the issue of incontinence, with regard and respect for client's quality-of-life needs.

Finally, TCCF is committed to multi-sectoral partnerships with various stakeholders, working together with them in a positive, ethical and professional manner to optimally help those affected by incontinence.

The Canadian Continence Foundation continues to provide a wealth of information through information sheets, booklets and videos. TCCF operates a

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1-800- number that serves all of Canada, and where consumers are able to seek information in private and are encouraged to seek help from a healthcare professional. One of the biggest challenges is still to remove the embarrassment consumers face and to encourage the family physician to address the issue of incontinence with all their patients as a manner of routine. A list of professionals who have an interest and expertise in incontinence is provider by means of a hard copy or on our web site, that assists the consumer find a healthcare professional in their local area.

For the past two years The Foundation has been working on developing clinical practice guidelines for Canada. This was made possible with a contribution from Health Canada and the project is titled "Promoting A Collaborative Consumer Focussed Approach To Continence Care In Canada". We are pleased to announce that we are currently in the process of disseminating the results of this The Guidelines and reports may be viewed on our Website www.continence-fdn.ca. Other exciting components of this project were to produce a user-friendly consumer booklet "Let's Talk About Bladder Control", which provides a guide for consumers and enables them and/or their caregiver to provide their healthcare professional personal information that will assist in the assessment of their incontinence.

The Canadian Continence Foundation continues to promote its services by participating in conferences an by organizing conferences of interest to consumers and healthcare providers. In October 2001 we will be holding our first joint Canadian Urodynamic Professionals and The Canadian Continence Foundation conference with the theme being "New Trends In Treating Urinary Incontinence In The New Millennium" in Montreal. The Foundation will continue to strive to bring the issue of incontinence out of the closet and improve the quality of life for consumers.

Ruth Keatley Pelletier

Continence Foundation (UK)

The UK Continence Foundation has had an energetic year. Its campaigning work related to government policy was given fresh impetus because of a new Health & Social Care Bill passing through the Westminster parliament. The Foundation joined other organisations in lobbying about the definition of "nursing care", which was to be provided free, versus "personal care" for which charges would be made. The subject was particularly fraught because the Scottish Parliament had decided that both should be free. A small success was achieved at the last possible moment when free NHS provision of continence products was extended to people currently paying for themselves in nursing homes. Another recent success in national policy was the welcome announcement that continence products through retail outlets would be sold free of VAT (purchase tax) so that people did not have to sign a declaration to gain exemption.

In April, the Foundation launched a new video for the general public: *An Everyday Problem: How to cope with bladder and bowel problems.* This video presents the experiences of three people whose continence problems were greatly improved by treatment, uses cartoons figures that are amusing without making fun of incontinence, and is excellently presented by the continence nurse specialist who takes the lead on our helpline. It has been well received by the public. A new leaflet is entitled *Only When I Laugh* – about stress incontinence. The Foundation is looking at all its literature to ensure that all new leaflets and reprints are user-friendly and present a positive image.

A major task in the last year has been the development of our website, now to be found at www.continence-foundation.org.uk. The website contains information for both the public and professionals, includes the text of some of our literature, and has sections detailing all the other literature available (it will soon be possible for people to order directly on line). There are still some aspects of the website to be completed, particularly the links to other sites.

The Foundation has a new Director, Dr. Judith Wardle – not a medical doctor—who has long experience in the field of voluntary organisations concerned with carers, children with special needs and especially neurological problems.

Gesellschaft für Inkontinenzhilfe e.V. (GIH) (GERMANY)

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 against incontinent people is far from having become a thing of the past. Moreover, due to tighter budgets in 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, 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.**

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There is one aim that dominates the work of the GIH: That 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.

Additionally, the GIH organises its own annual congress on the diagnosis and treatment of incontinence, and participates also in conferences on urology and incontinence. A highly important event was undoubtedly the GIH/WHO CONSENSUS CONFERENCE 1997 in Bonn, the results of which will have a policy-making influence upon the future efforts of the GIH.

Last but not least, the GIH , includes more than 200 incontinence service centres, 4 interdisciplinary centres of competence which are associated with large hospitals, co-operates with 8 rehabilitation centres, and presents 36 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.
Frau Christa Thiel

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*IN*CONTACT (UK)

I*n*contact is a consumer led UK charity, providing information and support to people affected by bladder and bowel problems. *In*contact is one of seventeen organisations joining together to find out the views of people with incontinence. 180,000 postcards were sent out earlier this year asking the single most important thing that would improve the lives of people with continence problems. "This is the biggest public consultation of people with continence problems in Britain and has generated much interest and discussion" said Claire Stevens, Project Manager. The results have been collated to form a Manifesto for Continence and will be launched at the *In*contact conference in September with support from politicians, media personalities and consumers.

Continence problems can affect all aspects of a person's life from their personal relationships and social activities, to their employment and finances. The fact that there are so many people out there feeling isolated and alone prompted *In*contact to launch the Continence Support Network (CSN). Through groups, telephone links and a pen pal/epal scheme people can contact others for support. Many have found great comfort in being able to talk through their experiences with others who have similar problems. The main message *In*contact is trying to relay is "You are not alone": help and support are available.
Claire Stevens

International Foundation for Functional Gastrointestinal Disorders

As we move into our 11th year of operation, we continue to focus on fecal incontinence education and awareness.

In 1999, IFFGD sponsored the first Consensus Conference on Fecal Incontinence. The meeting brought together 150 international experts in the field of incontinence to draft a consensus statement that identifies effective and appropriate treatment options. The full report of this landmark meeting was published in the January, 2001 issue of *Diseases of the Colon and Rectum*. In addition to providing a diagnostic algorithm and methods of treatment, research priorities are emphasized in order to improve the quality of life of the patient with fecal incontinence.

We will hold a second faecal incontinence meeting September 6-8, 2002 in Milwaukee, Wisconsin. Please contact IFFGD for more information.

IFFGD has developed a website, www.aboutincontinence.org, to provide more focused information for patients. Characteristics, treatment, management, and issues surrounding daily life are discussed.

IFFGD has begun a collaborative effort with the former American Pseudo-obstruction and Hirschsprung's Disease Society to create a reliable and comprehensive source of support and information concerning gastrointestinal disorders - including incontinence - in children. Our new publication, *Digestive Health in Children*, provides information about these disorders. Please visit the Web site www.aboutkidsgi.org for more information on this initiative.

We continue to offer information for those affected by fecal incontinence in our quarterly newsletter *Participate.* Additional fact sheets available by contacting the foundation or by visiting our Web site www.iffgd.org.

NEWS FROM CONTINENCE ORGANISATIONS

Korean Continence Society

Our society held the fourth National Incontinence Awareness Campaign for the public this year. The Korean Continence Society (www.kocon.or.kr) which was established in 1991 has held this campaign annually since 1998. This time we organised lectures for the general public, who have an interest in the overactive bladder (OAB), in 64 hospitals over the country. More than 4,000 people visited hospitals to attend the lectures and ask questions. Among them more than 1,000 people registered in the OAB Patients Association, which has the goal to give information and consultations about OAB to the members. During the preparation of this event we made use of mass media to advertise the Korean Continence Society and overactive bladder disease itself. Therefore people started to know more about our society and OAB. In particular we held the seminars about OAB for urologists and general practitioners this year. Many doctors became interested in OAB. The brochures about overactive bladder were distributed to doctors who take care of OAB patients. The titles of former campaigns were general urinary incontinence, stress urinary incontinence and geriatric urinary incontinence. We learned from these campaigns that education and advertisement were necessary for patients and doctors once again. The President of KCS is Won Hee Park.

The Continence Foundation of Korea is finally in its initial stages of inauguration. The ICS meeting in Korea in 2001 was a significant motive in this inauguration. In particular, some members of KCS have encouraged and supported the preparation of this inauguration. Many specialists who are interested in continence promotion have gathered for the inauguration of continence foundation. Nurses and professors who work on the areas of urology, obstetrics, and rehabilitation have participated in the preparation meeting for the inauguration. They have held various meetings to make concrete future plans and have attempted to find the way to activate their meetings. Before the official inauguration, they plan to provide an education program on the management of incontinence as a basic course in August 2001. Presently, the members are performing various activities such as inviting new members, preparation for future inauguration, making the Internet homepage and so on.

Heon-Young Kwon M.D

Pelvic Floor Netherlands

Pelvic Floor Netherlands is a Dutch foundation working on an optimal care for 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. Internationally she wants to be a model for multidisciplinary organisations in the world. We want to stimulate the disciplines to consult each other and to share their specific knowledge.

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, urologist. At this moment there are more than 500 care-givers supporting the activities of Pelvic Floor Netherlands.

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.

Education

We are involved in and 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 almost unidisciplinary approach is combined with a program on the importance of a multidisciplinary approach. In June this year our annual meeting dealt with "The floor of existence" (pelvic floor and childbirth) and was meant for midwives and general practitioners. The midwife, with an important role in postpartum pelvic floor function, has become a new discipline PFN is focussing on.

International activities

Pelvic Floor Netherlands has initiated the ICS Pelvic Floor Clinical Assessment Group. This is an international, multidisciplinary group that started in 1998 to make 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.

E.J. Messelink, Chairman

NEWS FROM CONTINENCE ORGANISATIONS

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

The SBP is a foundation for patients with pelvic floor problems. All patients with whatever type of problems 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 there is a website.

Contacts
The foundation will stay in close contact with the doctors and other care-givers. For this reason they do have 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.

The Society of Urologic Nurses and Associates (SUNA)

SUNA is a professional organization committed to excellence in patient care standards and a continuum of care, clinical practice, and research through education of its members, patients, family and community.

SUNA has approximately 2,600 members. National meetings are held in the Spring (Annual Conference, Fall (Annual Fall Institute), and Winter (National Multi-Specialty Conference on Urinary Continence) each year and 30 chapters provide local meetings to their members. Membership includes a bimonthly newsletter, the UroGram, and professional journal, Urologic Nursing. Publications available at a discount to members include Standards of Practice, Standards of Advanced Practice, Patient Access to Continence Services: Protecting It Under Managed Care, and Telephone Nursing Practice in Adult Urology Manual.

Cheryl Underhill
Executive Secretary

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