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Continence worldwide

news from

The ICS Continence Promotion Committee

Continence Promotion Committee Chair: Prof. David Fonda, Co-chair: Prof. Christine Norton

CONTINENCE PROMOTION COMMITTEE CELEBRATES ITS 10th ANNIVERSARY

Welcome to the 10th anniversary celebration edition of "Continence Worldwide". In 1993 at the International Continence Society (ICS) meeting in Rome we held our first networking meeting for continence organisations and others interested in promoting continence from around the world. We were amazed at how many people were interested, how much we had in common, and how much we have to learn from each other. We decided to formalise a networking group and called ourselves the "Continence Promotion Committee" (CPC). Since then, we have held meetings in conjunction with the annual ICS meetings and produced this newsletter to inform the broader ICS membership about continence promotion activities around the world.

In 1993 there were a handful of small continence promotion organisations scattered around the globe, with almost no contact with each other. Today there are 35 organisations in 25 countries (see the back pages of this newsletter), as well as "umbrella" organisations such as the Asia Pacific Continence Advisory Board to co-ordinate activities on a pan-regional basis. We have shared information, ideas and materials and helped new countries to get started and learn from the experiences (good and not so good) of others. Initially, most organisations had no paid employees and were run by volunteers. Today you will see contributions in this newsletter from "Director", "Communications Manager" and "Promotions Manager". We have come a long way.

During this decade the ICS has formally recognised the CPC as one of its constituent committees, with a seat on the ICS Board. The International Consultation on Incontinence has included a committee on "Promotion, organisation and education in continence care" in its first two meetings and this will continue for the third consultation in 2004. Many health care systems have started to pay attention to incontinence as a serious health care issue and national governments have funded major initiatives (such as the AHCPR Guidelines in the USA and the National Continence Management Strategy in Australia). The climate for continence promotion has changed, thanks mostly to the efforts of ICS members in their different countries.

Few would have envisaged a "Black Tie Gala for Continence" (see Simon Foundation) or a "Urologists Continence Rope-jumping Marathon" (see Korea) a decade ago. As competition for public and media attention intensifies from all quarters, we will need to be increasingly creative and ingenious in our efforts to promote the positive continence message. To share our ideas with each other will lessen the burden on each of us.

Thanks are due to many people for the success of the CPC and we cannot mention all. But we would like to acknowledge particularly the support of Paul Abrams as Honorary Secretary of the ICS in establishing the CPC as a formal entity of the ICS; and the help of Bengt Bengtsson who has supported and maintained our networking website www.continenceworldwide.org

At the ICS meeting in Florence we are formally retiring as joint chairs of the CPC and handing over to Diane Newman as the incoming chair. We wish her well and will support her however we can. New blood is always welcome, so please contact any of the committee members if you are interested in becoming involved with the CPC. And please join us for a "Continence Fair" to exhibit the activities of continence organisations during the lunchtime of Thursday 9th October, and for our networking meeting on the theme of promoting continence to ethnically diverse communities on the same afternoon.

A decade ago the International Continence Society was a well-established scientific society dedicated to the promotion of scientific research on incontinence, presented each year at its annual conference. But there is little point in excellent research if the majority of incontinent people have no accessible services or are too embarrassed and ashamed to seek help. Through the activities of the Continence Promotion Committee the ICS and its constituent members have come, over the past decade, to see their mission as broader than scientific research. Today the home page of the ICS website carries the message "The ICS actively encourages continence promotion throughout the world". Long may it continue to do so!

Christine Norton & David Fonda, outgoing co-chairs, CPC

PIONEERS

CONTINENCE FOUNDATION OF AUSTRALIA

The Continence Foundation of Australia (CFA) was founded in 1989, having grown out of a small interest group comprising doctors, nurses and company representatives. The CFA has since weathered some difficult financial times, but has now become stronger and larger as it benefits from government policy that recognises the medical issues facing an ageing population. Incontinence is now recognised as one of the major burdens of Australian society, both financially and socially.

In the early 1990's, CFA achieved a small amount of government financial support. However, the Foundation had been almost entirely funded by membership fees until it achieved "Peak Body" status in 2002 and the accompanying payment under the government's Community Services Support Scheme (CSSS). As a not-for-profit organisation operating projects on behalf of government, the Foundation's Board recognised the need for a more corporate style of operation with a strong marketing focus. This resulted in a restructuring of CFA Board Membership, with a smaller number of Directors and a more streamlined representation.

The Foundation has lobbied governments for a higher profile for incontinence as a major and largely hidden health issue. In 1998, the Prime Minister announced a special program (the Staying At Home Package Care & Support for Older Australians initiative) and the National Continence Management Strategy (NCMS) was established. With a grant of $AUS15 million of funding over five years, over 70 national research and service development initiatives have been funded.

Over 80% of the CFA membership are health professionals, mainly nurses, physiotherapists and to a lesser extent doctors. Corporate and organisational members and consumers make up the balance of membership. Because its consumer membership is quite small, the Foundation is acutely aware that its health professional membership represents and advocates for those Australians with incontinence and their carers. The Continence Foundation values this group as its primary stakeholders.

Major projects of the Foundation have included the Hunter Valley Project, a model of continence care (involving doctors, allied health professionals and pharmacists in a large New South Wales community) and the national development of a directory of continence services. A campaign to prompt new mothers to be aware of pelvic floor problems around childbirth and pregnancy is managed by the Foundation on behalf of government. A recurring project is Continence Awareness Week. Each year during the first week in August, awareness-raising strategies focus on a variety of topics. This year's theme is pregnancy and childbirth.

However, the main boast of the Foundation is its management of the government's National Continence Helpline, a free national service staffed by continence advisors. The Helpline provides advice and information to consumers, professional and home carers, families, doctors, physiotherapists, industry representatives, pharmacists and anyone interested in any aspect of incontinence. A "parallel project" to the administration of the Helpline is the management of a marketing contract, Helpline Printing and Promotions, which aims to increase the call rate and is responsible for development and promotion of its printed resources. Information leaflets on 15 topics have been produced. Some have been translated into 14 languages and there is also a range of materials for Aboriginal & Torres Strait Islanders. This wide range of free information leaflets, posters and information kits are available to callers, including doctors and allied health professionals who can order these in quantity to use as resources for their clients. Much of this information is also freely available to other health professionals and consumers alike throughout the world via the NCMS website www.continence.health.gov.au.

As the Australian Peak Body for continence, the Foundation has influenced the focus of the government and the Helpline service towards addressing not only aged care issues, but preventive strategies as well. NCMS and Helpline awareness marketing now targets, for example, new mothers, childhood bed-wetting and younger men and women. The CFA has also been actively involved in lobbying government to provide more equitable continence product schemes for disadvantaged consumers.

A major task for CFA as the Peak Body is the hosting of its annual National Conference, this year to be held in early December in Sydney. Although this year's focus will be on women's pelvic floor dysfunction, other topics cover assessment, urinary tract infections, cystitis, childhood bed-wetting, faecal incontinence and surgery for prolapse and incontinence. A large industry exhibit ensures that delegates see the latest and best in aids and appliances.

In developing its direction and resources, the Foundation has recommended to Government the need for a cultural shift in attitudes about bladder, bowel and toileting issues and the Helpline project has broadened its marketing accordingly. Awareness and education in the younger age groups, with an emphasis on prevention - alongside its traditional aged care focus - are now being solidly addressed.

Anne Haag
Promotions Manager

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JAPAN CONTINENCE ACTION SOCIETY

The Japan Continence Action Society (JCAS) celebrated its 10th anniversary last year. The anniversary forum was not only the anniversary celebration but also for publication of the first Japanese book which was written by Japanese incontinent patients. The title of the book is "The control guidebook for incontinence".

In the anniversary forum, 5 sufferers from incontinence (3 men and 2 women) spoke of their experience and how they had managed their incontinence problems. The audience of nearly 300 people felt deep sympathy. It took a decade for incontinent patients to come out in public, speak, and write about their difficult experiences in Japan.

When we started our activity, we focused our activity on the medical profession. We strongly needed them to have interest in continence care. In those days there were only a few clinics specialized in continence in Japan, and we were not sure how many medical doctors could give proper treatment to their urinary incontinent patients. There were also only a few nurses who were interested in continence care. Most people thought that incontinence could not be helped and it was a problem associated with ageing.

Therefore we set our mission as "Aiming for our ideal society where an incontinence problem can't be any problem", and started our activities. To give actual examples, we gave lectures for the general public over and over, ran four-day fundamental education seminars for nurses and care-workers, operated a free telephone clinic, published care manuals for incontinence and an education kit.

At present we have more than 300 medical facilities specialized in incontinence care listed and about 2,000 people have finished the fundamental education seminar. Clients of the free telephone clinic have exceeded 15,000 people.

As our activities expanded, we set up 10 branches all over Japan. As we had listed many medical facilities where we can refer or introduce patients, we changed our mission to "Aiming for ideal society where all people can excrete comfortably" to reflect the change in our promotion target to the person concerned and the general public in the year of 2000. We wanted to remove psychological barriers by changing our slogan from the negative phrase to a positive phrase. As a result our first self-help group was organized in JCAS this year. We plan to start peer counseling.

By the way, when we look over the bowel care system in Japan, it reminds us of the former situation of urinary incontinence care. We now plan to start a new promotion to improve the bowel care system by making full use of our 10 years of experience in tackling urinary incontinence.

Kaoru Nishimura
Chairperson

SOCIETY FOR CONTINENCE (SINGAPORE)

Introduction

The Society for Continence (Singapore) (SFCS) originated from the dedicated efforts of a group of doctors, nurses and rehabilitation therapists who recognised the special needs of the incontinent way back in 1988. This pioneering group consisted of Dr Anne Merriman, Dr Rilly Ray and Professor Peter H C Lim. In 1988, a symposium on the Management of Urinary incontinence was held for the first time in Singapore for all health care professionals to address this growing malady. The enthusiasm and interest shown by medical professionals in treating incontinent patients prompted Professor Peter H C Lim, a Consultant Urologist, to form an organisation to educate public & professionals in this emerging new sub-specialty. The Society for Continence (Singapore) (SFCS) was officially set up in Toa Payoh Hospital as a non-profit welfare organisation registered with the Singapore government in 1991.

SFCS started its promotional activities soon after its formation. Health talks on incontinence management were organised at Singapore's community centre and public forums were organised several times a year to address and inform people about this problem and to create greater awareness among the general public. The effort paid off as many people came forward for advice and treatment. As a result of this exercise, in 1992 the Ministry of Health, Singapore invited Professor Peter H C Lim for a dialogue session to discuss further developments in continence services in Singapore hospitals.

Recruitment

An Executive Committee was formed to focus on this issue. The Society adopted a multi disciplinary approach in the recruitment of doctors and nurses as members of the Executive Committee. Urologists, gynecologists, geriatricians, uro-gynaecologists, proctologists/colorectal surgeons, physiotherapists and nurses from these disciplines were co-opted as members to start continence work in Singapore

Public Education

The Society used audio/video media technology effectively for its promotional activities by addressing the public through Television shows. Information on incontinence was made available to the general public

on internal HTV broad casting systems, which are relayed in General Practitioner's clinics throughout the day. SFCS and the National University of Singapore jointly produced a movie named "Dirty Laundry". The movie was fully funded by the Golden Village Theatre Company and was screened at all GV chain of Theatres. A hot-line service was set-up to help members of the public and patients on incontinence problem.

Publications

In 1992, an editorial board was set up to launch the Society's official magazine "New Dimension". This magazine is published twice a year. The Society has also published one book on "Management of Urinary Incontinence" for Doctors and Nurses and one book on "Bowel Incontinence" handbook for Doctors and patients. It has also published several educational brochures, leaflets and fact sheets for patients. Posters carrying message on incontinence are at polyclinics, hospitals and GP clinics.

Continuing Medical Education

In 1993, SFCS started a five day course on "Contemporary Management of Urinary Incontinence" in order to promote continence management in hospitals, polyclinics and to train up continence advisors. This course has been running for the past ten years and has trained some 1,000 nurses. By the end of 1995 there were twelve continence clinics and twenty continence advisors in Singapore. Thereafter, formal training was provided to nurses as part of their HMDP training. Ministry of Health Singapore collaborated with various institutions worldwide to provide training in "Incontinence Management" for Doctors and Nurses. SFCS regularly organised seminars for General Practitioners to educate them as they are the first line health providers in Singapore.

In the same year SFCS was invited by the Australian Continence Foundation to participate in their biennial continence convention. The Society had an opportunity for networking and made good contacts to develop continence activities locally. It was in 1993, "Continence Promotion Committee" (CPC) of the International Continence Society invited SFCS to present its work at the annual meeting in Rome. Thereafter, SFCS participated as an active member of CPC. Since then SFCS has been working with the CPC to promote continence in the Asia Pacific Rim and encouraging Doctors and Nurses to present papers at the ICS, ACA, AUA, EAU and other similar scientific meetings.

Training & Education

SFCS provides an overseas training scholarship for nursing members and financial assistance for doctors and nurses to participate in international meetings related to incontinence.

Alliance

It was in 1994 that the SFCS received requests from the region to help set up similar organisations in their countries. SFCS helped Malaysia, Hong Kong, India, Indonesia, Thailand and The Philippines to set-up their own continence foundations / societies.

The SFCS received more and more requests from the Asia Pacific Rim for resource materials and issues related to incontinence management. In 1998, the SFCS designed a strategic plan to expand its networking throughout Asia. SFCS invited 20 opinion leaders from eleven Asian countries and conducted a two-day seminar on strategic planning with the help of a research grant from Pharmacia. At the end of the two-day seminar and brain storming, all the Asian countries which participated agreed upon the objectives and proposed guidelines to initiate a work-group and "Asia Pacific Continence Advisory Board" was formed.

Asia Pacific Continence Advisory Board

APCAB was established with a mission to develop "Continence Promotion" programmes and to work together with health care providers and the general public to develop strategies which will increase awareness and reduce the social burden of urinary incontinence in the Asia Pacific Rim by associating with other countries. Composition of APCAB countries are: Thailand, Korea, China, India, Pakistan, Indonesia, Taiwan, Hong Kong, The Philippines, Malaysia and Singapore. APCAB runs scientific meetings in one of the member countries annually.

Research Award

In year 2000, SFCS introduced a clinical research grant program for doctors and nurses from APCAB countries to encourage young clinicians to do research work in the field of incontinence. Two Doctors have been awarded this research grant.

National Survey

Currently, a random national survey on "Prevalence of Urinary Incontinence in Women" aged 20-65 has been conducted. This exercise is a joint project between the Society and CTREU (Clinical Trail Research and Epidemiology Unit, Ministry of Health, Singapore). The study is conducted in 2 phases. Phase I involved a face to face interview with the subject and phase II was more extensive with investigations as needed, as well as an Urodynamic procedure. There are several other projects and we are constantly innovating to ensure that this malady is comprehensively addressed and there is an overall improvement in the quality of life.

Rani Vadiveloo
Executive Director

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THE CONTINENCE FOUNDATION UK

The Continence Foundation was founded in 1992 with four broad aims: to provide advice and information to the public; to raise awareness of the condition; to provide professional support; and to influence policy makers and providers of continence services.

Advice and Information

Our Helpline, which is staffed by continence nurse specialists, offers advice, product information and, if required, the contact details of an enquirer's local National Health Service (NHS) continence service. The nurses also routinely send callers a relevant selection of our leaflets and factsheets. Most calls come from the public, but information is also requested by healthcare professionals, other charities and the media.

The Helpline has had an average of 10,000+ enquiries a year during the last decade. The bulk of these has been by telephone, but we also receive letters and - increasingly - e-mails. Many of our callers have never revealed their condition to anyone before, and use the Helpline because of the anonymity it affords. Perhaps the greatest achievement of this service, therefore, has been to provide a link between individuals and healthcare services that might not otherwise have been made.

Over the years we have produced a large number of publications for the public, several of which have been through a number of reprints and revisions. We now have eight 'first line' leaflets on subjects such as urge incontinence, stress incontinence and good bladder habits. We also have a range of 19 factsheets, some covering the same subjects in greater depth, others addressing more particular topics, such as 'washable pads and pants' or 'pelvic floor exercises for men'. This range of publications is constantly growing and is clearly well-received: literature orders from the NHS have almost doubled in the last 18 months.

To reflect our multicultural society, we have produced some written and audio materials in ethnic minority languages, and distribute similar publications sourced from local UK sources, companies and other charities. We have also produced a video giving a general introduction about continence problems for people who find written materials difficult.

Our website has proved a great success. Since May 2002 there has been a steady increase in visitors (as opposed to 'hits') from 5,000 a month to a regular 8-9,000 month. Our database of NHS continence services in the UK is accessible on the website, allowing any member of the public to search for their nearest service simply by inputting their postcode. There is also a facility to call up a local street map for each clinic. The site is recommended by Electronic Quality Information for Patients, a branch of the NHS which vets websites for clinical accuracy.

Awareness

Since 1994 we have been running annual Awareness Campaigns to encourage open and positive discussion of the condition, and persuade more people to seek professional help. Each year we focus on a particular area - previous examples include 'pregnancy, childbirth and continence' and 'coping with the emotional effects of a bladder or bowel problems' - and produce a leaflet and other campaign materials to promote the theme.

Over the years we have achieved media coverage in Vogue, Marie Claire, Bella, The Daily Telegraph, The Mirror, BBC 2's Trust Me I'm a Doctor and Radio 4's Woman's Hour to name but a few. However, to ensure that our message is not just heard in the national media, we have enlisted the help of Continence Services and other healthcare professionals across the UK - more than 600 individuals in all. They each receive a pack containing a free supply of the campaign leaflet, posters and a press release which they can customise for their local media. The pack also contains a guide to running local awareness campaigns. This approach is now tried and tested and generally results in healthy coverage across the country. In 1998 the Foundation was the runner-up in the International Continence Society's Continence Promotion Award.

Professional Support

We research and maintain a database of all non-drug continence products available in the UK. This lists all products currently available and includes information such as brand names, guide prices and descriptive comments. It has been paper-based, but we are in the process of putting it onto our website.

We produce a Resource Pack for primary care teams. This outlines the causes, assessment and treatment of incontinence, and includes a selection of our leaflets and posters. We also publish the CF Review, an irregular periodical of abstracts relevant to primary care.

We have arranged conferences for professionals. These include a seminar about continence problems caused by pregnancy and childbirth, and one concerning continence products. We also co-sponsor 'Incontinence - the Engineering Challenge' - a biennial 'brainstorming' seminar of scientists to discuss new approaches to continence products.

Influencing Policy Makers and Providers of Services

The Foundation has always been at the forefront of trying to change the world - at least as far as continence is concerned. At every opportunity we press for a higher priority, more logical organisation and better funding for continence services at all levels.

We brought pressure on Ministers to establish a strategic review of NHS Continence Services. The review's panel was chaired by Foundation trustee Professor Paul Abrams, and included three other trustees. The resulting document in 2000 took the form of 'guidance' not regulation, and lacked information needed by professionals wanting to improve their services, so we published, 'Making the Case for Investment in an Integrated Continence Service' which included prevalence and costing details.

Since the government Health Department had no intention of monitoring implementation of the guidance, we began a two-year joint project with the Royal College of Nursing to do just that. What could have been a depressing task was transformed by the decision to make this 'action research' - not just finding out what was happening but helping people to make changes. When, in October 2002, an interim report was ready, we used the opportunity to showcase examples of good practice at a very successful conference - overbooked and enthusiastically received: this happily coincided with our 10th Anniversary celebrations. We now have a CD and documents on the 'how to' of creating integrated continence services, our Director is energetically offering her services to facilitate planning meetings, and we have another conference coming up in November that includes workshops to help everyone to carry things forward.

Ian Holland
Fund Raising and Publicity Officer

THE SIMON FOUNDATION FOR CONTINENCE

In June 2003 the Simon Foundation for Continence launched its third decade of service with several events, including a groundbreaking international conference entitled Stigma in Healthcare: Understanding the Psychology of the Stigma of Incontinence. This event began the Foundation's celebration. Held in the heart of Chicago's Magnificent Mile, this two-day conference attracted physicians, psychologists, psychiatrists, nurses, patient advocates and representatives from the incontinence industry as well as other areas of healthcare. The goal of the Conference was to examine stigma in healthcare throughout time and across cultures, in order to develop a strategy to remove the stigma surrounding incontinence, thus enabling millions of individuals to be more comfortable in seeking help and treatment to improve their quality of life.

Incontinence experts came from throughout the United States and from around the world (German, Canada, Sweden, England and Australia were represented) to help contribute to finding solutions to the challenge of removing stigma in healthcare. Co-chairs of Stigma in Healthcare included: Alan Cottenden, Ph.D., Senior Lecturer in Medical Physics, University College, London, England; Cheryle B. Gartley, President and Founder, The Simon Foundation for Continence, Chicago, IL.; Christine Norton, R.N., Ph.D, Nurse Consultant, St. Mark's Hospital, London, England; and Anita Saltmarache, R.N. MHSc, Past Chairman of the Board, Canadian Continence Foundation, Toronto, Canada.

The Conference ended with a Town Meeting on Stigma moderated by Martha Teichner from CBS News Sunday Morning, a national television show broadcast from New York City each Sunday. Individuals with various disabilities and health conditions (including incontinence and people with ostomies) voiced their opinions in an open forum. Over a two and a half hour period discussions ranged over a wide variety of topics around stigma including: "Who is the enemy?" "Are there any ways where different disabilities can come together and bring about change or raise consciousness about stigma?" and "What issues do you have with the doctors, nurses, and the medical profession in general vis-a-vis stigma?"

"I Am More", the first anti-stigma song was performed at the Conference and Town Meeting. This song was commissioned by the Simon Foundation for Continence in the summer of 2003 to be used as the theme song for the Foundation's anti-stigma in healthcare campaign. "I Am More" is the creation of an EMMY Award winning song writing team and has already been highlighted at America's first New Freedom Awards Gala where the Foundation's spokesperson, Cheryle Gartley, along with celebrities such as Marlee Maitlin (Academy Award Winning Actress) and Mike Ditka (world-renowned NFL football coach) presented awards.

Highlighting the Foundation's week of launch activities was America's first black tie Gala for continence. At the Gala, Dr. Neil Resnick was honored for his outstanding dedication to people with incontinence and his relentless pursuit of knowledge to find a cure, with the Foundation's John J. Humpal Award for Outstanding Dedication to Finding Incontinence Solutions. Frau Christa Thiel (head of Gesellschaft fur Inkontinenzhilfe in Germany) was also presented an award, the Foundation's Mimi Van Slyke Award for Excellence in Incontinence Not for Profit Management.

During the Gala just a few of the Foundation's achievements over the last two decades were highlighted. The Foundation published the first book ever written on incontinence for the lay public and promoted it widely during a twenty-city media tour (resulting in coverage in TIME Magazine and columns such as the Ann Landers column); established an 800-line and website; produced several videos; established educational/self-help groups under the "I Will

Manage" program in communities across America; founded Simon Canada (now the Canadian Continence Foundation); hosted the first International Conference on Prevention of Incontinence (London, 1997) and in 2001 saw our efforts recognized as part of a permanent exhibit on healthcare in the Women's Museum in Dallas, an affiliate of the Smithsonian Institutes.

The Foundation's major focus in the next decade will be to take the message of cure, treatment and management to individuals in the community, in unique and creative ways. Following are just a few examples of the projects we intend to introduce in our third decade. We have already begun work on The Bladder Mobile. Like traveling book mobiles which are so popular in many communities in America, the Bladder Mobile will provide visitors with a wealth of information on incontinence. In addition, these vehicles will also help to bring incontinence further out of the closet, by creating media interest on arrival in town-after-town across America.

The Foundation is also working (in conjunction with the New England Research Institute) to produce a shopping mall exhibit which will tour America's shopping malls. Kiosks with computers will not only give the public the ability to select information most vital to themselves and their loved ones, but will also offer the opportunity to obtain information from the public regarding their incontinence needs. Over 200,000 people visit a typical mall during a normal week, thus making malls an excellent place to open the publics' eyes to the help and hope available for individuals with incontinence.

The Simon Foundation also intends to fight stigma in healthcare at every turn. In addition to popularizing the anti-stigma song, soon we will announce American's first Anti-Stigma Award... an award which will be presented annually in several different categories to individuals, not-for-profits, and companies in recognition of their efforts in erasing stigma in healthcare.

To support the projects we are initiating, the Foundation has also increased its staffing. There is a decade of challenging and exciting work ahead of us in order to accomplish our mission: "to bring the topic of incontinence out of the closet, remove the stigma surrounding the condition, and provide help and hope to individuals with incontinence, their families, and the health professionals who provide their care."

Cheryle B. Gartley,
Founder & President

THE MOVEMENT

THE AUSTRIAN CONTINENCE FOUNDATION (GESELLSCHAFT FÜR INKONTINENZHILFE, GIH)

The aim of our society is to enhance the knowledge about incontinence among the Austrian population, to encourage incontinent people to contact professionals and to convince them that an active treatment of incontinence is possible. The second important aim is to provide professionals with an up-to-date information on incontinence as regards diagnosis and therapy.

Each year, an Annual Meeting is organized with the congress, location changes altering between the Austrian provinces with an attendance of approx. 250 people. In addition to this, from 1999 and onward, Incontinence Awareness Days are being organized just before the Annual Meeting. So far, five such Incontinence Awareness Days have taken place. In 1999 in Vienna 2000 people attended the meeting and discussed their problems with the experts. During these days the participants also have a possibility to get into direct contact with the experts in special book booths.

A representative opinion poll among the Austrian population carried out in 1999 and again in 2002, reflected some progress as regards the level of knowledge about incontinence of the Austrians. In 1999 23% still felt that pads were the therapy for incontinence. However, this percentage decreased to 7%, whereas the acceptance of pharmacotherapy increased from 14% to 24%. Moreover, we were very pleased to see that the part of the population that were familiar with the term incontinence increased from 85% in 1999 to 96% in 2002.

In order to get professionals more interested in the field of incontinence, in 1999 the first postgraduate course of nurses, becoming continence and stoma advisors, was organised at the University of Innsbruck. This was followed by five further courses during the years. The lectures and practical work were organised in six blocks spread over a year. So far, 60 female and male nurses from Austria, but also from Germany, Switzerland and Southern Tyrol (Italy), have successfully passed the course and are now proved to be utmost helpful in promoting and managing incontinence.

The main office in Innsbruck, and the eight sub-offices, each located in one of the nine provinces in Austria, is offering free counselling to incontinent people, mainly performed by Continence and Stoma Advisors. More than 5 000 people have used this service during the past 10 years, either in person or by letter, mail or telephone.

In addition to this, since 1999 doctors being experts have taken their time to offer special telephone

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In order to get professionals more interested in the field of incontinence, in 1999 the first postgraduate course of nurses, becoming continence and stoma advisors, was organised at the University of Innsbruck. This was followed by five further courses during the years. The lectures and practical work were organised in six blocks spread over a year. So far, 60 female and male nurses from Austria, but also from Germany, Switzerland and Southern Tyrol (Italy), have successfully passed the course and are now proved to be utmost helpful in promoting and managing incontinence.

The main office in Innsbruck, and the eight sub-offices, each located in one of the nine provinces in Austria, is offering free counselling to incontinent people, mainly performed by Continence and Stoma Advisors. More than 5 000 people have used this service during the past 10 years, either in person or by letter, mail or telephone.

In addition to this, since 1999 doctors being experts have taken their time to offer special telephone

counselling for one hour once a week free of charge. 400 people have taken the opportunity to talk with these experts about their problems. To spread the topic of incontinence in different media, the lectures given at the Incontinence Awareness Days and Annual Meeting are published in separate volumes. The Austrian experts are also involved advising social security organizations about continence aids and pharmacotherapy to the benefit of the incontinent population. A newsletter is circulated four times a year to our members. And the Austrian Incontinence Help Society is also presented in the journal of the German sister organisation.

During the past 10 years, the number of memberships has almost doubled, from 272 to 523. At the moment the list of members consists of 287 doctors, 124 registered nurses, 89 physiotherapists as well as some other professions e.g. pharmacists. Not to forget the 23 incontinent people who are also members of the organisation.

The Austrian Incontinence Help Society is organized as follows;

A board with the president and two vice presidents are responsible for all the activities of the society. The composition of the board reflects the interdisciplinary approach to incontinence. Specialists in different fields dealing with incontinence, nurses and physiotherapists are all working for the board. A circle of supporting industries is important for financing the activities of the society. Another source of income is from the membership fees of the 523 members and from the benefit of our annual meetings.

HR Univ.-Prof. Dr. H. Madesbacher
Chairman of the Austrian Continence Foundation (GIH)

THE BELGIAN ASSOCIATION FOR CONTINENCE (U-CONTROL VZW)

Several important facts need to be reported:

1. The organisation Ucontrol "you are in control" which gathers all involved in continence promotion has developed a work book for general practitioners. It contains two main parts: the first is a general part with all practical information on incontinence and with guidelines on how to perform a consultation for an incontinent patient with the highest accuracy and in an acceptable time limit. History taking, physical examination, urine tests, and pelvic floor evaluation are explained in an easy to follow way. From these data a tentative diagnosis can be made and first line treatment can be decided. The different treatment modalities are described: advice, drugs, physical therapy. Also clearly explained are the alarm signs which should incite the GP to send the patient for more elaborate tests. Urodynamic tests and endoscopy are explained. The first part ends with practical information, for example referral to a physiotherapist, advice on reimbursement and useful addresses. The second part contains detailed information on treatment options: drugs are explained in detail, as are external appliances, types of surgery, neuromodulation and more.

2. The Ministry of Health and the Ministry of Social Affairs have declared incontinence to be on the top list of priorities. A national working group of physicians, nurses, physiotherapists and pharmacists together with representatives of health insurance under the presidency of JJ Wyndaele, CPC member, are working on proposals for care improvement in the council for chronic diseases. There is hope that for incontinent patients reimbursement and care will improve.

3. A patient group has been formed, "Pirus", which has started activities to get incontinence more openly discussed between patients and in the general population. We hope to see a first public event organised by them at the end of 2003 or at the beginning of 2004.

4. Four universities of the Flemish Community have together started one specialised course for training of physiotherapists. The course has been successful during the academic year 2002-2003 and there will be a second edition in the fall of this year. Theory of complete pelvic floor treatment and one month personal practical training help to develop highly specialised physiotherapists for private and hospital practice. A similar course will be organised in the French Community during the academic year 2003-2004.

5. The Belgian organisation of Urological Nurses "Urobel" has finished its first specialisation course for "Reference Nurse Incontinence". The first cohort has successfully defended its end thesis and has started work in the community.

6. Els Bakker, CPC member, has successfully defended her doctor's thesis at the University of Antwerp on a study of voiding habits and dry training in children. This research continues in order to evaluate good methods to train children to be dry and thus to prevent the development of lower urinary tract dysfunction.

JJ Wyndaele

Continence worldwide

ICS

THE DANISH INCONTINENCE SOCIETY (KONTINENSFORENINGEN I DANMARK)

(The Danish Incontinence Society in Denmark)

The Danish Incontinence Society (Kontinensforeningen) is an association for patients with urine and bowel incontinence. The Society has existed for 15 years and has always been active in helping patients with incontinence and by demystifying the suffering of incontinence. The means of communication has been public relations and the Society has been active in arranging public meetings on the topic.

The incontinence publication, called "News about Continence" (Kontinens Nyt) is issued quarterly and several papers and leaflets on the subject have been published; three last year. These publications are available at general practitioners offices, pharmacies, libraries and other public places and give guidance to the many elderly people, for whom an incontinence problem may lead to isolation.

Furthermore we have established a free hotline where the patients can call in anonymously to get help and guidance from continence advisors and medical doctors.

The Society has 1,650 members and the number is increasing every year. The board consists of patients as well as doctors, nurses, continence advisors and physiotherapists working on a voluntary basis.

The Danish Incontinence Society tries to help and guide every patient individually with problems as well as addressing the social aspects of incontinence. In Denmark the yearly cost for incontinence is between 1 and 2 billion DKK for diapers and pads. By focusing on alternative and better ways to treat incontinence the Danish Incontinence Society believes that the patients will increase their quality of life, increasing well-being.

It is estimated that in the Danish population there are approximately 400,000 500,000 people suffering from incontinence.

President
Lars Alling Møller
Specialist in Gynaecology, PhD

Chairman
Merete Thuesen Stokkeland.
Continence Advisor and nurse

THE GERMAN CONTINENCE SOCIETY (GESELLSCHAFT FÜR INKONTINENZHILFE, GIH)

The GIH (founded Nov.18.1987) 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 2,300.

The society's efforts to achieve its objectives have intensified especially over the last years and are now showing results. There is no doubt that, in Germany, 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.

Summary of our achievements during the last fifteen years :

Initial stages: Win private members, industrial sponsors, well known experts as members for the advisory board. Developing new ideas for corporation within the industry. In the last 10 years we initiated 77 Self-Help Groups.

Communication with different media; 28 press conferences, more than 3,000 Press Reports and 165 Radio or TV interviews, contact with other societies.

GIH Publications:

- Flyers or brochures for education of affected people, distributed approximately 145,000 copies
- Books for layman and books for health care professionals and doctors distributed a total of 66,000 copies,
- 73,000 copies of the annual Abstract book distributed.

Member Journal: since 1996 "*GIH aktuell*" published quarterly, with 10,000 copies

Website: since 1999 actually 120 daily clicks

Participation in national and international congresses: 152, sometimes with a booth. We have organised 85 events: 54 regional advanced training, 16 symposia and our 14 annual congresses, since 1989.

Each year, the annual congress is the important event of the GIH. Here, also like other activities, we can see a visible progress of interest in Incontinence! Participation has increased from 300 people up to 1,304 people last year.

We hope that our 15th congress this year on 14 / 15 Nov. 2003 in Berlin, will get more than 1,500 participants.

The GIH congress each year is for doctors, health care professionals and patients. This year the main topic is "Prevention", other topics are Stress Urinary Incontinence (women and men), physical therapies, bowel incontinence.

Last but not least the GIH includes 308 service Centres

and 10 interdisciplinary Centres of competence which are associated with large hospitals. It shows that more and more doctors encourage patients not to stay alone with this disease. So we have to go ahead with our activities and spare no effort so that incontinence should no longer be a taboo subject.

Christa Thiel

THE INDIAN CONTINENCE FOUNDATION

The Indian Continence Foundation (ICF), a Trust, was established in May 1998 by a group of doctors, primarily urologists, gynecologists and doctors specializing in other related areas, to provide affordable and effective treatment to people afflicted by urinary incontinence. The Trust functions as an open society where the membership is open to all healthcare professionals.

The first activities of the foundation started in the form of continence advisory clinics, which were held on a two monthly basis. These clinics are meant for assessment and advice for patients suffering from incontinence. It is our sincere hope that with adequate funding, subsidized treatment could be made available for select groups of patients.

A workshop on Continuing Medical Education for urologists and gynecologists was held to educate the fraternity on various aspects of incontinence, in October 1998.

In November 1999 a two-day course for 90 nurses was held to empower the nurses in the aspects of incontinence both by training and demonstration of techniques. Comprehensive course materials were handed over to them. Simultaneously, several patient information brochures, available on request for doctors, care providers and general public were also brought out and distributed.

Incontinence in India is still not perceived as a major problem nor is it yet a quality of life issue. To stimulate and provide quality information a newsletter aimed at medical professionals was published. The response to the newsletter, "ICON" was a tremendous success.

In February 2000 a web site was developed with help from TENA, SCA Hygiene Products for the benefit of both patients and doctors. Web site: www.indiancontinencefoundation.org

A great deal of training material by way of videos on incontinence, comprehensive display material for educating the general public on incontinence, training materials and mannequins for simulation during training sessions were also prepared. In 2001, aids and appliances were procured for training workshops on incontinence.

On the 7th of April, 2001, World Health Day, a public exhibition on various aspects of urinary and fecal incontinence and related health issues for advising both the patients, doctors and the lay public was held as part of an awareness program in several small cities and villages in the state.

In 2002, a dedicated free clinic became operational. A comprehensive incontinence camp was held in March and attended by 65 patients. In the same year, the Indian Continence Foundation bid for hosting the Asia Pacific Advisory board meeting & Asian Society for female Urology to be held in Bangalore in 2003 and was accepted. This will be an international event for focusing mainly on urinary incontinence with all the leading experts in the fields from south east Asia participating and will be held from 14-17 November 2003. A monumental effort of the trust was a comprehensive book on urinary incontinence wherein leading experts from around the world have contributed their experiences and opinions and it is a leading book on urinary incontinence in the Asia Pacific region. Workshops for doctors were also conducted on a regular basis.

The twin objectives of the ICF were to offer affordable and effective medical care to patients and also to create an awareness of the symptoms of incontinence at an early stage. To facilitate this ICF contacted the umbrella organization of all NGOs in the city and major NGOs in the state, furnished them with details of the organization in order that they would include the Trust in their database as well as use it in their Newsletter, thus gaining access to thousands of poor persons. A database for individual correspondence was also obtained from the organizations. Brochures were printed in easy to understand language and sent to select NGOs including the large organizations, those whose interventions were in the areas of geriatrics, children, women, the physically and mentally challenged.

The activities of the Indian Continence continue in many areas by persons drawn from multiple fields.

Dr. Vasan S S
President

Dr. A Mohan
Secretary

THE ITALIAN CONTINENCE FOUNDATION (FONDAZIONE ITALIANA CONTINENZA)

The activities carried out by FONDAZIONE ITALIANA CONTINENZA give special emphasis to the need of supplying information regarding urinary/faecal incontinence and hyperactive bladder. The Foundation was presented to all institutions: Ministry, Regions, Local Health Authorities, Hospitals, Nursing Homes, Clinics and Scientific Associations, by sending a newsletter in which the goals of the Foundation and the relevance of urinary incontinence among population were clearly pointed out.

In Italy the critical areas are related to the following:

-the problem is hidden, since the patients feel uncomfortable to explain their troubles to doctors and nurses

-incontinence is considered by patients as an unavoidable problem, something to be ashamed of

- often, no rehabilitative, surgical or pharmacological solution is taken into consideration

-families taking care of incontinent relatives are in great trouble, and there is the need for more support from doctors and nurses

-specific information and knowledge in medicine and nursing has to be promoted.

There is also some indifference towards the troubles caused by this pathology and the support that could be given in terms of assistance , medical and nursing advice, quality of supplied aids, in order to help the patients and their families.

One of the most significant goals of FONDAZIONE ITALIANA CONTINENZA is to improve the quality of life of people suffering from incontinence. In this direction were organised, in 2001 and 2002, the following activities:

- Congress: “Continence Therapist”

Urologists, geriatricians, physicians, nurses and therapists met to discuss and define the "Continence Therapist" professional role.

- Course: "Urinary incontinence in elderly people"

Head nurses working in hospitals and nursing homes was trained in the best practise in incontinence management.

- Congress: “The role of medical specialists in prescribing incontinence aids "

A group of urologists discussed their role in advising patients and following their needs.

The aim of all above-mentioned activities is promoting the understanding of the problem of incontinence, spreading knowledge and creating qualified nurses. We are just at the beginning and we have still a lot to do in the coming years.

Professor Walter Artibani

THE KOREAN CONTINENCE SOCIETY

The majority of sufferers with incontinence / overactive bladder (OAB) perceive it as an aging process, not as a treatable condition. There is still low or lack of public awareness of incontinence/OAB and also the media underestimates the seriousness of incontinence/OAB in terms of quality of life. The Korean Continence Society (KCS) president is Park Won-hee, M.D. It is a medical organization with around 300 urologists, gynecologists, nurses and health-care professionals as members under the Korean Society of Urology, need to educate public/patients so as to drive patients to see a doctor, to draw doctors' attention to potential patients and to educate media about incontinence/OAB.

A nationwide Public Awareness Campaign event has been held in either June or May every year and the event is aimed to draw the nation's attention to incontinence/OAB. The objective of the campaign is to increase public awareness of incontinence/OAB which is a medical condition negatively affecting quality of life, to induce as many urologists as possible to participate in the campaign to draw their attention to patients with incontinence/OAB and to maximize media publicity. The first Public Awareness Campaign in 1997, was a workshop jointly with urologists, nurses and citizens. The second nationwide Public Awareness Campaign topic was stress urinary incontinence in 1999. The topic of the third Campaign in 2000 was geriatric incontinence, the fourth in 2001, overactive bladder and fifth in 2002, incontinence.

The KCS held the sixth nationwide Public Awareness Campaign in 2003 and this comprised several events to draw our Korean people's attention to incontinence, such as 'Incontinence rope-jumping marathon', 'public lectures', 'public advertisement', 'incontinence essay contest', and 'the prevalence survey of sufferers with incontinence'.

The effect of the following five events mingled together in harmony and achieved the ultimate goal of the event for Nationwide Public Awareness Campaign, which was to attract attention to incontinence.

The first event was 'Incontinence Rope-jumping Marathon' with 50 urologists participating, 883 people

signed up for this event. While rope jumping together, they played various kinds of games related to coping with the incontinence and also had some time to talk with the urologists. This event was quite successful and certainly pulled in local media's attention, and eventually led to nationwide broadcasting on incontinence.

Secondly, a 'Public Lecture' has taken place continuously for the last six years. This week's event, which was held with 35 different regions participating, paved the way for the delivery of the straight information about incontinence treatment to the public.

The third major event held during this week was an 'Incontinence Essay Contest', which proceeded with the help of a famous radio program called "Beautiful World". It was the second contest and there were 46 fine essays received in total. The results and contents were aired nationwide for 2 hours.

Fourthly, we had the first nationwide prevalence survey of incontinence. The statistical analysis was based on the survey and interview with 2,577 persons of different sexes and therefore it is very accurate. This survey successfully attracted public attention and paved a way for public awareness of incontinence's negative influence on quality of life.

Lastly, was the active publicity campaign that actually unified the above four factors. Media coverage during this campaign added up to a total of 43 media items (7 TV programs including "TV Clinic", 4 radio programs, 16 daily media, 8 women magazines, and 8 medical media). The exposure population was calculated at 37,522,365 and this indicated that almost every person in Korea was exposed to knowledge about incontinence during this week. This media advertisement was rather very unique in some ways as we published books on incontinence in concert with a famous womens' magazine and distributed 50,000 copies to the readers of it and another 10,000 copies to the attendees. Other than that, we produced 3,000 posters, 76,000 pages of advertising paper for distribution, issued hundreds of invitation cards, and opened a web site regarding this campaign. We can say that this year's campaign was very meaningful, for KCS successfully published the first Incontinence Newsletter and distributed them to the sufferers with incontinence and several public bodies, which eventually resulted in better public awareness of incontinence.

Yousik Lee, M.D.
Public affairs director of Korean Continence Society

NEW ZEALAND CONTINENCE ASSOCIATION

The New Zealand Continence Association is a multidisciplinary body that actively facilitates continence promotion throughout New Zealand.

The NZCA was originally incorporated in 1986 as the Association of Continence Advisors (AK) Inc. Membership consisted mostly of concerned health professionals who wanted to learn more about urinary incontinence and were interested in promoting public awareness of this remediable, generally ignored and potentially embarrassing medical condition.

In 1991 it was established that there was a need for a national organisation. The Association of Continence Advisors was developed into a national and multidisciplinary organisation and re-named the New Zealand Continence Association.

The NZCA was established to provide a service to incontinence sufferers, caregivers, health professionals and the general public by providing information and education on topics of incontinence.

The NZCA has developed a service in an area that has largely been ignored in the past by health professionals and health care providers. The sufferers have been too embarrassed or unable to access appropriate help and in a majority of cases have suffered in silence. From small beginnings the public awareness campaign has developed into an effective method of promoting awareness of continence problems and providing access to professional help. This has been greatly assisted by the establishment of a national toll free 0800 help line and web site at www.continence.org.nz.

We have put a lot of work into health professional education to ensure that people who request help get quality care wherever they live in New Zealand and we are also lobbying Government and the Ministry of Health to get continence put on the agenda and formulate minimum guidelines for services in all regions.

We have also established regional training workshops for high-risk groups such as Maori and Pacific Islanders in an appropriate forum organised in liaison with people in these groups e.g. on local marae (traditional Maori meeting place).

Jan Zander
Executive Officer

THE POLISH CONTINENCE SOCIETY (NTM)

The "NTM - Normalnie Zyc" (Incontinence - Living a

Normal Life) Social Program was created in 2002 in order to overcome the barriers of shame surrounding the problem of incontinence by raising awareness of the existence and possibilities for treatment. This is the first initiative of this kind related to the problem of incontinence in Poland.

As part of the Program, Polish society is familiarized with the idea of functioning normally as a result of successful treatment or the use of modern absorptive products. The activities run by the Program receive the support of remarkable Polish authorities in the field of medicine (including Prof. Andrzej Borkowski - urologist, Prof. Anna Cz³onkowska - neurologist, Prof. Longin Marianowski - gynecologist and Prof. Tadeusz To³³oczko - surgeon) and are also supported by many organizations and societies representing patients and medical circles in Poland.

To facilitate social communication, the abbreviation "NTM" has been used as part of the “Incontinence - Living a Normal Life” Social Program. The abbreviation corresponds to the key letters in the Polish expression "nietrzymanie moczu," meaning incontinence. "NTM" is an abbreviation that is not as funny for people who hear about the problem, as opposed to situations when the full name of the ailment is used.

The unfavorable reactions of most Poles result from the fact that the problem of incontinence is a taboo topic in Poland, even though the disorder affects 10-15 percent of the population in every society. The majority of Poles feel ashamed of incontinence, are insecure and begin to isolate themselves from others. Incontinence effectively disorganizes their lives and many people affected by this problem do not benefit from medical assistance. Therefore, a number of instruments to increase discrete access to information related to this issue have been created as part of the Program.

Apart from brochures and posters, the Program's activities are supported by the “NTM Quarterly”, which has been published since April 2002. It focuses on medical issues and problems concerning the current situation of patients. In the last issue of the “Quarterly”, for instance, a discussion on the future system of supplying the Polish market with refundable absorptive products was initiated as part of the Program. Many people suffering from incontinence turn to the “Quarterly” with questions which are answered by doctors Piotr Radziszewski and Piotr Dobroñski from the Medical Academy in Warsaw, who are medical consultants for the Program and famous specialists in the field of incontinence.

So far “NTM Quarterly” has received a great deal of recognition and has become a vital medium for information and education. Because of the character of its distribution, it also plays an important role in lobbying, understood in a broad sense, for improving care for and the treatment of people suffering from incontinence.

The “Incontinence - Living a Normal Life” Social Program is also committed to actions aimed at improving the financial situation of patients. In spring 2002 a questionnaire for members of societies which bring together patients and workers in social welfare homes was prepared. It was intended to investigate existing needs for absorptive products. The results of the questionnaire, prepared in the form of a report, were submitted to institutions responsible for health policy in Poland. This brought about the creation of a new list of refundable absorptive products, which was extended to include flexible pants and anatomic sanitary towels. Still, the insufficient quantity of absorptive products to be refunded remains a problem (60 items a month).

In March 2003 the country-wide infoline 0-801-800-038 became another element of the Program. It is first and foremost addressed to those suffering from incontinence. In 2002 the www.ntm.pl website was established. The Program also actively participates in many medical congresses, seminars and meetings organized for patients.

One of the latest projects undertaken by the Program was a more than month-long all-Polish billboard campaign in the biggest urban areas in Poland.

Magdalena Kowalewska
Coordinator of the “Incontinence - Living a Normal Life” Social Program