



# Continence worldwide



"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 public's 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



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*





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## 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 15<sup>th</sup> 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



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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](http://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 7<sup>th</sup> 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 SS*  
*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



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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 women's 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](http://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

