# Continence



# worldwide

# # \# \# news from HE ICS CONTINENCE PROMOTION COMMITTEE

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

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# **The ICS Continence**

# Promotion Committee (CPC)

The Continence Promotion
Committee (CPC) was formed
following a workshop at
International Continence Society
(ICS) meeting in Rome in 1995,
where it was agreed that the ICS
should act as a facilitator for
various international continence
organisations to meet and
address relevant issues to do with
continence promotion, awareness
and prevention. The principle
aims were:

- To look at opportunities for networking across various countries;
- To increase awareness amongst ICS members of continence related issues;
- > To facilitate development of continence organisations
- To facilitate interchange of information about continence awareness and promotion;
- To identify opportunities for continence prevention strategies.

held each year at the ICS meetings.

The CPC became an official committee of the new Board of the ICS in 1998, and has the important role of providing input into the important areas of continence awareness, promotion and prevention.

The current committee consists of:

David Fonda (Geriatrician from Australia) Co-Chair;

Christine Norton (Continence Nurse Adviser from United Kingdom) Co-Chair;

Peter Lim (Urologist from Singapore);

Cheryle Gartley (Consumer from USA);

Ilan Gruenwald (Urologist from Israel)

Helmut Madersbacher (Urologist from Austria)

Jean Jacques Wyndaele (Urologist from Belgium)

# **FUTURE ICS MEETINGS**

Seoul, Korea: September 18th-21st, 2001.

Heidelberg, Germany: 2002.

ICS Membership: werner.schaefer@rwth.aachen.de

The Continence Promotion

Committee would like to

thank:

Daniel and Bengt

**Bengtsson** for development and maintenance of the

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Luke Norton for supervising,

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Continence organisations

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Annual workshops have been

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# Association for Continence Advice (UK)

The great non-event of 1999 must have been the long awaited government Review of Continence Services: required by the previous junior Health Minister, Paul Boetang, to be delivered in early 1999: it eventually appeared in Spring 2000! ACA members have been fully involved with both the Working and Reference Groups, with the Professional Development Officer, Veronica Haggar, seconded to the Department of Health to assist with the final draft for Ministers. Unfortunately instead of coming out as "Action Guidance", which is mandatory, the document has been issued as guidance on "Best Practice. There was however personal endorsement from the Minister for Health, saving that he is keen to see this guidance implemented within the NHS. The ACA is currently working with its members to ensure that they take a strategic. proactive approach to the guidance.

Other interesting developments are within the Eastern Health and Social Services Board of Northern Ireland. A strategic development for Continence led by the Board has made some outstanding achievements during the year.

The ACA, in partnership with the Board and Help the Aged Northern Ireland, appointed a Continence Strategy Implementation Officer, Claire McCammon. Claire has been working on implementing the strategy from April 1999, as well as supporting the work of the ACA Northern Ireland. Perhaps the most tangible achievement has been in education and training with the production of a comprehensive training manual. Of equal importance has been the work to develop a Commissioning Statement from the Board, which will be implemented by the Belfast area NHS Trusts for the year 2001. ACA members from those NHS Trusts have been crucially involved at every stage of this development.

The Millennium Conference, 'Continence - A Global Partnership', was addressed by a variety of international speakers led by Queen Thandi, of Zulu Natal. There were a record number of abstracts submitted, including several from overseas. New this year was the introduction of two annual ACA bursaries enabling delegates from developing countries to attend conference.

Our 21<sup>st</sup> conference in Torquay in 2001 will be a celebration of our coming of age. The dates are 21<sup>st</sup> - 24<sup>th</sup> May; further information can be gained from the Conference Secretariat, Davies Cahill, Tel: 44 (0) 1275 340331, fax: 4 (0) 12745 349081 and email: davies\_cahill@cableinet.co.uk

Some of the most exciting developments from the ACA have been international: two associations with the same aspirations as us have been formed. Firstly, in Austria, ÖVKB, by a group of nurses, many of whom are ACA members. Secondly, CASA in South Africa, by a group of nurses and doctors covering all of South Africa, following the visit of Dr Margaret Fockema to the UK last autumn.

Finally, given all these international developments, it seemed appropriate to consider a network of organisations that could share developments and work to improve knowledge and standards. As a result ENCO, the European Network of Continence Organisations, has been formed and a European Congress is planned in Le Touquet, France from 9<sup>th</sup> - 12<sup>th</sup> October 2001. Further information is available on the website: www.enco.org.uk and email: info@enco.org.uk

Veronica Haggar Professional Development Officer

# ENURESIS RESOURCE AND INFORMATION CENTRE

The Enuresis Resource and Information Centre (ERIC) is a UK-based charity that gives information and support on childhood bedwetting, day-time wetting and soiling.

During 1999 the charity extended its existing Helpline service to include advice for children with special physical needs and associated bladder and bowel problems. In November 1999 ERIC recruited a specialist nurse continence advisor to take the more complex telephone, letter and email enquiries and provide support and training to other members of the Helpline team. Overall the number of enquiries increased by 19% during the period 1st April 1999-30th March 2000, with a 68% increase in the number of more complex calls.

To complement the new advice service, ERIC published a book for parents entitled "Bladder and Bowel Management in Children with Special Physical Needs: A Guide for Parents". This 36 page book gives practical information on how parents and health professionals can help children to achieve bowel and bladder control, or to manage the condition effectively if this is not possible. The next book in this series will be published during the coming year to help parents children with learning difficulties with the toilet training process.

ERIC was delighted to launch its

new interactive website (www.eric.org.uk) in May this year. With the emphasis on fun, the new site features a number of zones including a play pit, a treehouse, a clubhouse and a teenzone where our younger visitors can swap jokes and stories, take part in a quiz and paint pictures as well as share their worries and concerns. There are also informative zones for parents and a separate area for professionals which contains research and practice articles, an events calendar and the facility to order research references. zones have their own message boards (which for security reasons are monitored by ERIC staff) and "Frequently Asked Questions" sections - so there are opportunities to share tips and experiences and post up specific queries that can be answered by an expert. response to demand, we have also incorporated an online ERIC shop, using encrypted code, so that goods can be purchased online with the minimum of fuss. We do hope that you will pay us a visit!

Penny Dobson, Director

# INCONTACT (UK)

Incontact is the UK organisation of people affected by bladder and bowel problems. We believe that people who live with these conditions are the experts on what they need, and also that cooperation between consumers and service providers is the way

forward. Incontact's management committee is made up of 9 people with continence problems, one informal carer and one health professional. Through this diversity we are able to face the real issues that affect us all in the field of continence care.

Incontacts main areas are support and information. The website (www.incontact.org) is developing slowly, with more and more consumer-friendly information, features, and visitors' comments. You can also download a copy of our everpopular information booklet, 'Bladder and Bowel Problems'. Plans for the forthcoming year include making the website more accessible, developing a wider range of user-friendly information, and developing formats other than plain old leaflets.

On the support side, Incontact is moving ahead with a programme of local initiatives to provide informal self-help and support. We will shortly be employing a project worker who will offer training and support for local volunteers. There is no set formula for local support - it may be a phone line, group meetings, or an e-mail list. We believe that different people have different needs, and it is important to have a range of options to choose from.

On a broader scale, public awareness - and even the

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awareness of health professionals - still needs to be increased. Slowly but surely, Incontact is getting the message across that the consumer's voice needs to be listened to, that these conditions can be helped, and that people living with continence problems don't have to suffer in silence. "You are not alone" is the message we have been using for three years, and it will remain the focus of our activities.

Jolyon Rose, Education Officer

# JAPAN CONTINENCE ACTION SOCIETY

It has now been 10 years since the Japan Continence Action Society was established. We now have 9 branches, 12 study groups and a membership of about 1000. We have promoted a free telephone clinic, seminars and Research and Development activities.

One of the remarkable activities is our free telephone clinic, which has been held for 10 years. The number of clients has been increasing day by day. Last year we got about 2,500 calls per line.

We are also emphasising our education activities. JCAS has 3 sequential courses to train continence advisers and we plan an advanced course for advisers soon. Our problems include difficulty in raising funds, securing talented people and not increasing the number of our members. Although we have such problems, the mass media

are willing to help us. Therefore we have gradually become well-known. Most of our members are professionals at present, but we hope to become a more consumer-orientated society in the 21st century.

Kaoru Nishimura, Director.

# NEW ZEALAND CONTINENCE ASSOCIATION

The past year has seen continued growth and challenges for the Association. One of the highlights has been a new initiative aimed at convincing the health funding bodies that a national policy for incontinence services is imperative. A draft discussion document has been developed by the National Executive and circulated to the membership for their feedback. It is proposed that a multi-disciplinary Expert **Advisory Committee** representative of a wide range of interested parties including health professionals, consumers, representatives of special needs groups, managers, purchasers and national policy developers be appointed to develop strategies aimed at improving the care of all with continence problems. Our intention is to convince the Health Funding Authority and Ministry of Health that current services for incontinence are fragmented, inequitable and

insufficient for community needs and that developing a national policy on purchasing and providing continence services is not only vital but cost effective. The prospect of getting more funding is limited. However, if all the current funding was brought together under national continence guidelines there is real potential to significantly improve the standard and deliverance of appropriate assessment and management to all, regardless of geographic or socioeconomic circumstances. Our other activities including the annual public awareness week and conference which were again very well received this year. A cartoon competition run as part of the awareness week last year fielded a surprising number of quality entries both pictorial and poetic. As previously publicity, particularly via television, radio or newspapers and magazines, always stimulates a significant increase in the calls to the 0800 Helpline. The website is also increasing in popularity with 30 - 40 hits per month. We plan to survey these services to try to assess their effectiveness. We are currently looking at the possibility of a closer alliance with the Continence Foundation of Australia and. with them, looking at ways this might happen.

Jill Brown, Secretary

# 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 we want 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. gastroenterologist, gynaecologist, general practitioner, incontinence nurse, paediatrician, clinical neurophysiologist, psychologist, urologist, midwife. 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. Our research committee can help investigators in setting up protocols and by organising multidisciplinary, multicenter trials.

# Education

We are involved in and setting up education programs for physiotherapist, 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. Every year two meetings are organised. Last year the subjects were: "The overactive bladder and the underactive pelvic floor" and "Talking about sexual function, dysfunction and trauma".

#### Journal

All members of Pelvic Floor Netherlands receive an issue of the International Urogynecology Journal and Pelvic Floor Dysfunction, 6 times a year.

# 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 will be presented to the ICS this year.

# **Patient foundation**

On the initiative of Pelvic Floor Netherlands the 'Society of pelvic floor patients' will start in September 2000. This society will take care of the patients need for healthcare, social contacts and information. The co-operation with Pelvic Floor Netherlands will yield a platform for pelvic floor care in all its aspects. This platform will be a body the government and the insurance companies will be talking to.

Bert Messelink Chairman

# Continence Worldwide on the Web

The interest in e-health. created by the convergence of healthcare and the Internet, is growing. The Internet and health-related web sites are transforming health care. It is increasing access of consumers and physicians to health information including products and services. Ehealth is enhancing the communication between consumers, professionals and providers. Consumers increasingly seek medical information on the Internet and are using the Web to take a more active role in managing their health.

For continence promotion the internet facilities. Continet. Continence Worldwide and all the **National Continence** Organisation's sites are evolving as new tools for improved communication. Continence promotion programmes about what incontinence is, what can be done about it, and where to get help, and most importantly to de-stigmatise this condition are available. The Web can be used for public awareness activities,

professional education programmes and continence prevention strategies.

The traffic to Continence Worldwide is increasing. At present the Web site has well over 15,000 user sessions per year and the number of hits is over 150.000. Continence Worldwide has been submitted to a great number of search engines and many links have been established from health related sites. We have created links from our listing of continence organisations to each national organisation's site as it becomes available. In the year 2000 more than 20 national organisations have own sites. Our intention is not to duplicate the excellent information available at those sites, but just to make them as widely accessible as possible. Continence Worldwide is important in making ICS members aware of the activities of all the continence organisations around the world. It is increasing the transfer of skills. It seems that an international network of information is well under way. At the Networking Forum, at

ICS 2000, the use of Internet and the web facilities will be discussed. Hopefully the discussion will trigger new ideas on how the Internet can be used.

During the year Continence Worldwide has received a lot of mail regarding different issues; new established continence organisations, updates of details of existing organisations, questions regarding the First WHO Consultation on Incontinence and the Networking Forum coming up in Tampere at ICS 2000. If you have any questions or ideas about how our site can be improved feel free to contact us.

Bengt Bengtsson

The Editors would like to acknowledge the support of SCA Hygiene in producing this newsletter and the continence worldwide website:

www.continenceworldwide.org

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# INTERNATIONAL CONTINENCE ORGANISATIONS

# **AUSTRALIA**

# Continence Foundation of Australia Ltd

AMA House, 293 Royal Parade, Parkville, Victoria 3052. Tel: (61) 3 9347 2522 Fax: (61) 3 9347 2533

Website: www.contfound.org.au Email: peter@contfound.org.au Contact: Peter Schmidt, Chief

**Executive Director** 

# **AUSTRIA**

# Medizinische Gesellschaft für Inkontinenzhilfe Österreich

Speckbacherstrasse 1, A-6020 Innsbruck.

Tel: (43) 512 58 37 03 Fax: (43) 512 58 94 76

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inkontineng@gihoe@1012surfnet.at

Contact: Professor H. Madersbacher, President

#### CANADA

## The Canadian Continence **Foundation**

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Fax: (1) 514 932 3533

Website: www.continence-fdn.ca Email: help@continence-fdn.ca Contact: Malvina Klagg, Executive

Director

#### **DENMARK**

# Kontinensforeningen (The Danish Association of Incontinent People)

Vesterbrogade 64, 1620 Copenhagen V.

Email: info@kontinens.dk

# **GERMANY**

# Gesellschaft für Inkontinenzhilfe e.V. (GIH)

Geschäftsstelle, Friedrich-Ebert-Strasse 124, 34119 Kassel.

Tel: (49) 561 78 06 04 Fax: (49) 561 77 67 70 Email: GIH-kassel@t-online.de Contact: Frau Christa Thiel

# **HONG KONG**

# **Hong Kong Continence Society**

c/o Department of Medicine and Geriatrics, United Christian Hospital, 130 Hip Wo Street, Kwun Tong, Kowloon, Hong Kong.

Tel: 852 237 94822 Fax: 852 234 72325 Email: emfleung@ha.org.hk Contact: Dr Edward MF Leung, President

# **INDIA**

#### **Indian Continence Foundation**

C/O Bangalore Kidney Foundation, CA6, 11th Cross, 15th Main, Padmanabhanagar, Bangalore 560

010.

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# **ISRAEL**

# The National Centre for Continence

Rambam Medical Centre, POB-9602, Haifa 31096. Tel: (972) 485 43197

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continence

# **JAPAN**

# **Japan Continence Action Society**

Continence Centre, 103 Juri Heim, 1-4-2 Zenpukuzi 1 -Chome, Suginami-Ku, Tokyo, 167 0041. Tel: (81) 3 3301 3860 Fax: (81) 3 3301 3587 Email: nisimura@jcas.or.jp Website: www.shodouka.com/nphsh.cgi/http://www.jcas.or.jp

Contact: Ms Kaoru Nishimura

# **KOREA**

# **Korea Continence Foundation**

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Email: hykwon@mail.donga.ac.kr Contact: Dr Heon-Young Kwon

#### **MALAYSIA**

### **Continence Foundation** (Malaysia)

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# **NEW ZEALAND**

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# INTERNATIONAL CONTINENCE ORGANISATIONS

# **NORWAY**

NOFUS (Norwegian Society for Patients with Urologic Diseases)

Fornebuveien 10 A, N-1366 Lysaker. Tel & Fax: (47) 67 59 05 35. Contact: Alf Salvesen, Chairman

### **PHILLIPINES**

Continence Foundation of the **Phillipines** 

Room 201, #319 Katipunan Road, Loyola Heights, Quezon City 1108. Tel (63) 2 4333602 email: dtbolong@pacific.net Contact: David T Bolong M.D.,

President.

# **SINGAPORE**

Society for Continence (Singapore)

c/o Division of Urology, Dept of Surgery, Changi General Hospital, 2 Simei Street 3, Singapore 529889.

Tel/Fax: (65) 787 0337 Website: http://www.sfcs.org.sg Contact: Rani Vadiveloo, Executive

Director

# **SWEDEN**

Swedish Urotherapists

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# **TAIWAN**

**Taiwan Continence Society** 

Department of Urology, Taipei Medical College, 252 Wu-Hsin Street, Taipei.

#### **UNITED KINGDOM**

**Association for Continence Advice** (ACA)

Winchester House, Kennington Park, Cranmer Road, London SW9 6EJ.

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307 Hatton Square, 16 Baldwin Gardens, London EC1 N 7RJ.

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Email:

continence foundation@dial.pipex.co

Contact: David Pollock, Director

# **Enuresis Resource and Information** Centre (ERIC)

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Tel: (44) 117 960 3060 Fax: (44) 117 960 0401 Website: www.eric.org.uk

Email: enuresis@compuserve.com Contact: Penny Dobson, Director

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Royal College of Nursing **Continence Care Forum** 

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# **UNITED STATES OF** <u>AMERICA</u>

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PO Box 815, Wilmette, Illinois 60091.

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Contact: Cheryle Gartley, President

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PO Box 8310, Spartanburg, SC 29305-8310.

Tel: (1) 864 579 7900 Fax: (1) 803 579 7902 Website: www.nafc.org/ Email: losby@nafc.org

# International Foundation for Functional Gastrointestinal **Disorders**

PO Box 17864, Milwaukee WI 53217

Tel: (1) 414 964 1799 Fax: (1) 414 964 7176. Website: www.iffgd.org Email: iffgd@iffgd.org

# Society of Urologic Nurses and Associates (SUNA)

East Holly Avenue - Box 56, Pitman, NJ 08071 0056 Tel: (1) 609 256 2335 Fax: (1) 609 589 7463 Email: suna@mail.ajj.com

Website: www.iNurse.com/~SUNA Contact: Gerry Sue Young, President