

Committee 23

**Continence Promotion: Prevention,
Education and Organisation**

Chairman

D. K. NEWMAN (USA)

Members

L. DENIS (BELGIUM),

I. GRUENWALD (ISRAEL),

C. H. EE (SINGAPORE),

R. MILLARD (AUSTRALIA),

R. ROBERTS (USA),

C. SAMPSELLE (USA),

K. WILLIAMS (UK)

Consultants

N. MULLER (USA),

N. NORTON (USA)

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APPENDIX 1 National Continence Organisations

Continence Promotion: Prevention, Education and Organisation

D. K. NEWMAN,

L. DENIS, I. GRUENWALD, C. H. EE, R. MILLARD, R. ROBERTS, C. SAMPSELLE, K. WILLIAMS

N. MULLER, N. NORTON

I. INTRODUCTION

Continence promotion involves informing and educating the public and health care professionals that incontinence (both urinary and faecal) and pelvic organ prolapse in women is not inevitable or shameful, but is treatable or at least manageable. Taboos on mentioning disorders of the bladder and bowel are gradually lifting in most cultures. Two decades ago it was almost impossible to have urinary incontinence discussed in the media. Today, in most countries, consensus panels, government funding of continence initiatives and practice guidelines have been developed in the area of urinary incontinence. In the USA, research priorities through a consensus panel have suggested that these two conditions, urinary (UI) and faecal incontinence (FI) be combined through a multidisciplinary approach to further research priorities. Thus, there have been advances in promoting awareness of both urinary and faecal incontinence.

Popular magazines, local and national papers, radio, and television, regularly cover topics on UI in most developed countries. Many countries have run national or local public awareness campaigns, usually spearheaded by a national continence organisation. Many also have confidential help lines, which can be accessed anonymously. The World Wide Web provides a convenient source of health information for a growing number of consumers. There are more than 100,000 health related sites, but all information may not be accurate and timely. Some believe that persons with incontinence might get valuable advice and comfort by using interactive services such as email. However, in developing countries, public information and campaigns is limited or non-existent.

This chapter presents continence promotion through three specific approaches: primary prevention, education of consumers and professionals, and organisations that can spearhead much of the promotion and delivery of medical services.

It is evident that progress has been made in the promotion of continence on a worldwide basis. However, although there is a great deal of published information on building public and health care professional awareness of incontinence, there is minimal information on the effectiveness of changing public and professional attitudes and knowledge about it.

There is a lack of evidence on translating awareness into behavioural change and on what triggers help-seeking behaviour. Success of campaigns should be measured by behavioural changes and ultimately by improved patient outcomes. Evaluation and outcome measures should be built into all projects and their funding. There is a need for further research to substantiate the benefits of preventive strategies, including long term follow-up.

This chapter provides an overview of current research in the areas of prevention, education of the public and health care professional, organisation for the delivery of continence services and the results of a survey of national organisations. What is evident is that these activities are growing faster than the efforts to evaluate their effectiveness.

II. PRIMARY PREVENTION OF INCONTINENCE

1. BACKGROUND

Because of its high prevalence and chronic but preventable nature, urinary incontinence (UI) is reasonably framed as a public health problem with an emphasis on primary prevention. Using this approach, key populations at risk of developing the condition will be identified, risk factors demonstrated, and public awareness strategies developed to help individuals alter modifiable risk factors [1]. Although the evidence base for faecal incontinence (FI) and pelvic organ prolapse is more limited than that for UI, the conditions share many similarities with respect to risk and treatment, suggesting that similar benefits may derive from population-based strategies.

2. POPULATION-BASED PREVENTION

Prevention should include education about behavioural changes that increase the probability of continence, the normal functioning of the urinary tract, expected age related and developmental changes, and how to find the appropriate treatment providers. Primary prevention should be the goal of all health-care professionals as it means taking an active part in preventing the initial development of UI. All preventive measures require a high level of community awareness, public education and health professional education [2]. The evidence for population-based prevention strategies is Level 4.

From the literature and from previous survey results it is clear that there is a lack of public knowledge of UI as a common medical problem, and there is limited awareness of the negative effects of UI on quality of life, economics, social functions, etc [3]. The public is not aware that UI can often be cured (and may be prevented) with conservative, non-invasive or minimally invasive techniques. Given that the process of storing and expelling urine is shaped by social rules for acceptable times and places for elimination, stigma is attached to incontinence. Stigma is also associated with faecal incontinence [4]. Thus, shame and denial of these problem constitute significant barriers to seeking treatment. Programmes to increase health promotion and education about UI and FI may serve to deconstruct these barriers.

Prevention messages should be targeted to government bodies (especially health departments and also agencies dealing with education and employment),

health insurance companies and funding agencies, national organisations and societies whose members may have incontinence risks (e.g., organisations of people with neurological diseases), health professional organisations and commercial companies producing continence-related products. Persons at the administrative and clinical level need to be educated about the basics of pelvic health and precipitating factors for incontinence before attempting to impart a prevention message. New partnerships should be developed with relevant commercial organisations to facilitate dissemination of prevention messages to individuals who may be highly receptive. For example, collaboration with “Weight Watchers” and other groups who promote weight loss could place prevention information in the hands of obese individuals who are at higher risk of UI.

3. GENERAL RISK FACTORS

Identification of individuals who have the potential for becoming incontinent or developing pelvic organ prolapse is one important primary prevention activity. Level 3 evidence exists for the risk factors of age, pregnancy, parity, and body mass index [5,6,7]. Others such as cigarette smoking, hysterectomy, and menopause are suggested, but evidence is mixed [7,8]. Childbirth related factors that have been associated with UI during the postpartum year or at mid-life include older age at first delivery, birth weight, epidural analgesia, midline episiotomy, and forceps or vacuum extraction [9,10].

Pregnancy, although not the exclusive cause of faecal incontinence is certainly a prominent association [11]. Obstetric injury is one of the primary causes of faecal incontinence [12]. Direct injury to the rectal sphincter complex may occur as a result of uncontrolled second-stage delivery, epidural anaesthesia, instrumental delivery, and episiotomy [13]. Quantitative assessments of risks related to pregnancy and various methods of delivery have only recently been performed. Irritable bowel syndrome has been shown to be an important correlate with postpartum faecal incontinence [11].

The most prominent association with faecal incontinence by far is nursing home (NH) residents. The prevalence of FI is probably around 2% to 3% for community dwelling persons and may increase with increasing age to greater than 10%, among nursing home residents the prevalence approaches 50%.

In a survey of 18,000 Wisconsin nursing home residents, risk factors for FI were directly observed by

nursing personnel. In this very old population (mean age, 84 years), age, gender and diabetes were not found to be associated with faecal incontinence. Urinary incontinence was the greatest risk factor for FI, followed in order by the loss of ability to perform daily activities, tube feeding, physical restraints, diarrhea, dementia, impaired vision, constipation and faecal impaction [11].

There are several specific diseases that have been associated with FI; these include diabetes, multiple sclerosis, Parkinson's disease, spinal cord injury, systemic sclerosis, myotonic dystrophy and amyloidosis [11]. In the Real World Survey conducted by the IFFGD in 2002, 34% of 264 individuals with diarrhea-predominant irritable bowel syndrome reported loss of bowel control [14].

Surgeons are often concerned about the possibility of FI originating from surgery that is associated with approaches to treating fissures and fistulas. Patients with inflammatory bowel diseases who undergo ileal pouch anal reconstruction remain at high risk for FI [11].

4. OCCUPATIONAL RISK FACTORS

Women employed in certain occupations that place constraints on the elimination of urine have been shown to be at increased risk of developing UI with Level 3 evidence.

Nearly 30% of women employed full-time in a pottery manufacturing production line with set times for breaks reported involuntary urine loss at least monthly [15]. Nurses, teachers, and women in the military are also occupational groups that have demonstrated urinary health problems related to toilet access [16,17,18,19]. These studies raise important questions about the long-term deleterious effect of such self-management strategies as fluid restriction, absorbent pad use, and prolonged periods between voiding. Although scheduling of breaks is an employment practice that the preceding research has associated with poor bladder habits and increased UI, no intervention studies have been reported in these at-risk populations.

5. PREVENTION OF CHILDBIRTH-RELATED INCONTINENCE

There is persuasive Level 1 evidence that demonstrates the protective effect of pelvic floor muscle training (PFMT) practised during pregnancy. Several carefully controlled randomised trials have demon-

strated significantly lower incidence of UI up to six months postpartum.

Controlling for baseline UI, nulliparous women who received individual PFMT at 20 weeks gestation were significantly less likely to experience UI at 6 weeks and 6 months postpartum [20]. At 3 months postpartum, primigravid women who participated in supervised PFMT prenatally were 59% less likely to demonstrate UI and those who practised 28 or more contractions per day were more likely to remain continent than those who practised a lower number [21]. Nulligravid women randomised to supervised PFMT, as compared to those who received routine care, were 39% less likely to report UI at 3 months postpartum [22].

PFMT initiated in the postpartum period has also demonstrated efficacy. At three months postpartum, prevalence of UI in a PFMT group was 31% as compared to 38% in a usual care group with significantly fewer women classified with severe UI in the treatment group [23]. At 10 months postpartum, UI incidence decreased in 19% of women who received PFMT as compared to only 2% in the control group [24].

The Cochrane review group on physical therapies for the prevention of urinary and faecal incontinence in adults concluded that there was insufficient evidence to determine the effect of physical therapies on prevention of UI in childbearing women [25]. However, studies too recent to be included in that review provided evidence for the preventive capacity of PFMT for UI [22,23]. Moreover, the effectiveness of PFMT in preventing childbirth related UI, in conjunction with the non-invasive nature of this self-care strategy, makes it a logical focus for UI prevention efforts among women during the period of childbearing.

Only two studies have examined the benefit of PFMT for childbirth-related FI and/or pelvic organ prolapse [24,26]. No preventive effect was demonstrated in either study.

Elective caesarean delivery has recently received attention as a UI prevention strategy based on Level 2 and Level 3 evidence.

Postpartum UI was found to be higher in primiparous women who gave birth vaginally as compared to those who had caesarean delivery, but those in the caesarean group had significantly more UI than did nulliparous women [6]. However, when elective caesarean was differentiated from caesarean births due to obstructed labour, significantly less UI was obser-

ved among the group undergoing the elective procedure [27]. Other investigations have not demonstrated a difference between UI following elective versus emergency caesarean [28,29].

In assessing a protective effect of elective caesarean, hereditary factors should be taken into account. The emergence or severity of UI during pregnancy has been found to be a stronger predictor of postpartum UI than type of delivery [27,30,31,32]. It is also noteworthy that studies of women at midlife demonstrate that those with a history of caesarean birth had rates of UI comparable to women who gave birth vaginally [33,34]. It is clear that further research will be necessary in order to determine the validity of a protective effect of elective caesarean section.

6. PREVENTION OF FAECAL INCONTINENCE

It may be possible to reduce the risk of FI at childbirth by selective use of elective caesarean delivery, especially for women with a history of prior obstetric tears and sphincter repairs. PFMT with or without biofeedback before or after childbirth might also affect the development of faecal incontinence. There is a need to further the dialogue between colon and rectal surgeons, urogynaecologists, and obstetricians, and for more randomised controlled trials of primary prevention techniques [14].

7. PREVENTION OF PROSTATECTOMY-RELATED URINARY INCONTINENCE

Prostatectomy is an established risk factor for UI in men [35] resulting in postoperative pad use [36] and decreased quality of life [37]. Improved surgical techniques for men undergoing prostatectomy have been associated with earlier return of continence and an increase in 3-6 month postoperative continence status [38,39,40,41].

Level 2 evidence is mixed regarding the value of PFMT pre and postoperatively with some studies finding decreased UI of at least 14% [35,36] and others showing no effect [42,43]. Teaching correct technique is essential, thus appropriate patient education and verification of motor skill are key confounders in the evaluation of the efficacy of PFMT [44,45].

8. PREVENTION OF URINARY INCONTINENCE IN OLDER ADULTS

Studies investigating risk factors for incontinence in older adults are scarce and sometimes conflicting. Level of evidence is 3.

One study in older men showed an increased risk for UI in hip fracture patients [46]. In elderly women, risk factors were hysterectomy after the age of 60 years, age (OR 1.3 per 5 years); higher body mass index (OR 1.6 per 5 units), history of stroke (OR 1.9), diabetes (OR 1.7), chronic obstructive pulmonary disease (OR 1.4), and poor overall health (OR 1.6).

In frail older persons in nursing homes, other risk factors included incontinence and poor adjustment to the nursing home at two weeks post admission, and both mobility and cognitive impairment at two months post admission [47].

In 100 hip fracture patients, men had a higher incidence of incontinence than women (48% versus 24%, $p < 0.03$). Individuals with cognitive impairment also had higher incidence of UI (56% versus 25%, $p < 0.030$) [48].

It has been reported that UI in Caucasian, community dwelling older persons is associated with reports of poor self-rated health, after adjustments for age, co-morbidity and frailty [49].

Another report lists antecedents of UI including impaired mobility, impaired cognition, poor pelvic muscle tone, lack of access to bathroom, decreased fluid intake, medications, lack of knowledge regarding normal functioning, abrupt changes in cognition, functional status and physical health, depression and social withdrawal [50]. Primary prevention strategies should be developed for these high-risk populations.

A recent report of a randomised clinical trial provided Level 1 evidence of the preventive effect of behavioural intervention (bladder and pelvic floor muscle training) demonstrating the preventive capacity of these self-care strategies in older women [51]. Women (N=359) from 55-80 years who were essentially continent (0-5 episodes in the past year and no observed urine leakage during deep coughing with a full bladder) were randomised to treatment and control groups.

Those in the treatment group attended a two-hour group session that presented information about UI and the role of bladder and pelvic floor muscle training in bladder health. A single brief individualized instruction was provided as needed. At one year post instruction, women in the treatment group were more than twice as likely to remain or become absolutely continent as compared to their control group counterparts (OR=2.3, 95% CI=1.04-3.98, $p=0.04$).

RECOMMENDATIONS FOR PRIMARY PREVENTION

Based on the literature reviewed in this section, the following recommendations can be made:

- Primary prevention studies should not be limited to individual interventions, but also test the impact of population-based public health strategies (**Grade C**)
- PFMT should be a standard component of prenatal and postpartum care (**Grade B**)
- Randomised controlled trials (RCTs) should be conducted to test preventive effect of PFMT for men post-prostatectomy surgery (**Grade B**)
- Further investigation is warranted to assess the efficacy of PFMT and bladder training (BT) for primary prevention of UI in older adults (**Grade B**)

III. CONSUMER EDUCATION

1. BACKGROUND

There is little research evidence investigating public education to promote continence, urinary or faecal. In the area of UI, building awareness among the general public is usually attempted via the media. Using the media to disseminate information in the form of Public Service Announcements (PSAs) has been used extensively in the USA to promote AIDS awareness and as anti-smoking campaigns. In 2001, the National Association For Continence (NAFC) produced and disseminated television PSAs to 380 media markets, including Hispanic outlets, in the USA for the purpose of promoting continence awareness.

In many cultures, one of the best vehicles to reaching the public is through an informed journalist. Journalists often use a “media hook,” an interesting story that will take priority over other news on the television, radio or newspaper. Having a spokesperson with the problem or finding a celebrity who is willing to speak for the cause can help [52]. These individuals can act as “influence leaders.”

A promotion program for raising awareness must consider several aspects:

- **Target population** – Population studies reveal that older women followed by younger women are

most affected by incontinence. The prevalence of UI and the lack of knowledge about incontinence are sufficient to justify a health-promotion program without segmentation by age or gender [53]. Faecal incontinence is almost as common in men as in women [11].

- **Target issues** – A promotion program should identify the issues that warrant promotion effort, as well as, barriers to promotion. Issues such as lack of willingness or readiness to seek treatment prevent people from seeking help [54].
- **Content of promotional material** – Any type of advertisement that deals with incontinence, even advertising campaigns for absorbent products, can have a positive impact on lessening taboos about talking about incontinence. This increased willingness to discuss both urinary and bowel incontinence can be followed by advice on effective methods of coping with these conditions.
- **Channels of communication** – Health care professionals may launch campaigns to increase practice revenues. Commercial companies often fund public campaigns in order to sell their products. Continence organisations may be driven by missionary zeal or organisational growth. Regardless of motivation, care should be taken to avoid raising public expectations beyond what the services or products can deliver.
- **Outcome assessment** – Prior to implementing an UI awareness campaign, it is important to identify outcome variables that will evaluate its effectiveness.

2. PUBLIC AWARENESS MATERIALS

The interventions that best reach the public and trigger the desired behaviour seem to vary between countries and cultures. The Japan Continence Action Society held a “Toll Free Telephone Clinic” and callers were asked how they heard about the line. Sixty five percent replied from a newspaper, 26% from television and 8% from a poster. In a UK campaign, it was found that newspapers were by far the most common source of information, followed by radio [55]. Television and newspapers work best in Singapore, with a “cured” patient bearing testimony to former suffering and its alleviation having the most impact. In the USA, television advertising targeting overactive bladder, funded primarily by pharmaceutical companies, has yielded a significant response. Nationwide TV reaches more people than the circulation of any single newspaper or the distribution of a booklet through physician offices.

Experience from a toll-free help line in Australia suggests that television exposure produces a better response than radio, Sunday newspapers are better than dailies, tear-off reply slips are well-used and engaging a celebrity as a spokesperson is more effective than a physician or nurse. The Australian toll-free help line started with an AUD5000 donation and ran for 18 months before attracting a major (AUD900000) government grant. The Australian Continence Strategy grants have covered multiple projects including epidemiology of incontinence, outcome measure, toilet surveys, and service delivery. Terminology used when discussing urinary and bowel incontinence is important. The words “continence” or “incontinence” are poorly understood and simpler terms achieve greater public recognition in many languages and cultures. The use of overactive bladder in advertising has increased reporting of the condition to primary care professionals in the USA. In the area of bowel disorders such as FI, it is felt that persons find it difficult to find the right words to discuss their symptoms [4]. The International Foundation for Functional Gastrointestinal Disorder (IFFGD) in the USA has found that people will often report having diarrhea to their physician. If the physician or nurse does not question the patient any further regarding the ability to control gas, liquid or solid stool, the incontinence may not be discovered.

Little evaluation of the importance of leaflets or brochures has been undertaken. An information booklet has been found to improve patients’ knowledge, acceptance and management of an indwelling catheter at home [56]. More evaluation of the impact of educational materials is needed.

3. EVALUATING THE EFFECTIVENESS OF PUBLIC AWARENESS CAMPAIGNS

It is important to assess whether efforts to educate the public have the desired effect and to define the criteria by which to judge “success.” Measures of success could include the number of media “impressions” through newspaper, television or radio, the number of people who sought help, or the numbers who were actually helped. The message should be crafted to encourage and motivate the desired action.

A media campaign should use multiple channels to insure the broadest coverage [57]. An initial channel should include print media, television and radio. A second channel would be specialized age and health publications. A third channel is the use of posters and brochures placed in physician’s offices, hospitals, senior centre, pharmacies and churches. A final chan-

nel is direct presentations to the public, such as at senior centres (over 60’s club).

In France, the effect of health education was evaluated in a randomized study in sheltered accommodations for the elderly [58]. Twenty centers were randomized to either a single one-hour health information meeting or control group. During a 30-minute talk, a nurse encouraged people to visit a physician if they had urinary problems. A questionnaire three months later found that the experimental group was much more likely to have had treatment if they were incontinent (41% vs. 13% controls) and 82% said that they had received some information about incontinence in the previous 3 months (compared to 22% controls).

A health promotion project called ‘Dry Expectations’ was developed and implemented in six ethnically diverse, predominantly minority, and inner city senior centres in the USA in 1996 [59]. The program was designed to address an older population. The project consisted of three phases: orientation and training of key staff members/peer educators at the centres (train-the-trainer model); educating seniors through four one-hour weekly sessions involving visual aids and completion of bladder records and quizzes; and follow up sessions with senior staff/peer educators to reinforce the previous training. The program was very well received by the participants and roughly 80% felt they had more control over their bladder by the end of the last session.

Palmer and Newman reported on a health promotion project to determine the needs of senior citizens concerning bladder control issues [60]. In 2000, focus groups of older adults attending health seminars in an urban, community and church settings were conducted. The primary objective of the project was to determine the understanding of older adults in the areas of general health and their beliefs surrounding the problem of UI. The 82 participants were predominantly African-American women representing all socio-economic levels. Seniors expressed confusion when asked if “overactive bladder, bladder control issues and urinary incontinence” were the same condition. Most seniors said they felt comfortable about discussing bladder control issues, but most admitted that their physician had never asked them, nor had they raised the issue. However, they did discuss UI with family members and friends and they were aware that many persons with whom they socialize might have a problem with UI. The majority of seniors answered “no cure” when asked if treatments were successful.

A 2004 USA survey of the general population by the National Association For Continence (NAFC) showed that on average, women wait 6.5 years and men 4.2 years before seeking a professional diagnosis once they begin experiencing loss of bladder control symptoms [61]. The survey results are based on 1,420 internet interviews with a national sample of men and women ages 30 to 70 years. This survey also indicated that when women did tell their physician or nurse about their problem many were told to “live with it.” The most common reasons cited for failure to seek treatment are either that incontinence is not seen as abnormal or that there is a low expectation of benefit from treatment. A 1999 NAFC survey was mailed to 98,000 members. Of the 2,000 that returned the surveys, 62.1% indicated dissatisfaction with treatment outcome [62]. Only 3.3% of all respondents considered themselves “cured” following their most helpful treatment and only 6.8% overall explicitly expressed that they were “very pleased” with their outcomes. It appears that a gap continues to exist between outcome objectives of consumers and what is available among preferable treatment options.

IV. PROFESSIONAL EDUCATION

1. BACKGROUND

There is a paucity of published work on professional education on UI or FI. Similarly there are few studies addressing the effectiveness of education in improving the knowledge of learners, or on whether improved knowledge impacts on patient outcomes. The level of evidence on the effectiveness of professional education is 4.

Internationally, continence care provision in the area of UI has developed at different rates within differing care models resulting in scattered and inconsistent services [63]. There are wide variations in health care professional input and a lack of continuity of care between primary and secondary care providers [64]. Central to the provision of high quality continence care is the education of the individuals providing care, including physicians, nurses, and allied health care professionals. There is limited literature on the educational preparation and ongoing training of those health care professionals engaged in continence promotion, care, and referral. It is well recognised that professional education with reference to UI and FI remains only a small part of the basic training of

physicians, nurses, or allied health professionals. An early survey in the UK found minimal attention given to incontinence in both medical and nurse training, and a key recommendation for improving continence care was an increase in quality and quantity of professional education [65]. While educational initiatives have been undertaken, they remain fragmented and inconsistent internationally. Most notable is the absence of evidence demonstrating an impact of professional or public education on the burden of suffering posed by overactive bladder and urinary incontinence.

The International Continence Society (ICS) has recently established an Education Committee to establish, promote, organise and co-ordinate all educational advances undertaken under the aegis of the ICS (See **Table 1**). This promises to be a step forward in defining core competencies and educational goals and objectives for trainers and trainee alike. Subcommittees in medical student and resident education, nurse education, physiotherapy education are established. Details are available on the ICS website (www.icsoffice.org).

Table 1. ICS Education Committee’s Educational Directives

-
- Education courses to be arranged by the ICS office and held in association with the ICS annual meeting
 - Scrutinising and approving submitted courses and workshops at the ICS meetings
 - Setting standards for teaching and training related to incontinence and allied subjects for undergraduates, postgraduate doctors, specialty registrars and subspecialty trainees as well as nurses, physiotherapists and technicians
 - Setting standards for CME
 - Accrediting urodynamic courses
 - Liaising with the ICS Continence Promotion Committee to provide information for incontinence sufferers, carers and providers of services.
 - Working with the Scientific Chairman to ensure the annual ICS Meeting, scientific programme has a high educational standard
-

2. PHYSICIANS

Most physicians have received little education about incontinence, fail to screen for it, and view the likelihood of successful treatment as low [66]. At the same time, it should be noted that there are no data

confirming the benefits of screening as a method to reduce the burden of suffering from UI and its related overactive bladder (OAB). A mail survey noted that only 18% of respondents said providers asked to them to complete a questionnaire about bladder control during routine office visits and a majority (69%) felt it would be very helpful in prompting discussion if their physician or health care professional provided a form for them to check off symptoms of incontinence [67].

• Medical education

Urinary and faecal incontinence have traditionally been only a very small part of the undergraduate medical curriculum. Education on UI has usually been fragmented across different organ systems, with training scattered between gynaecology, urology, and geriatric medicine. Bladder and pelvic floor anatomy is poorly covered in preclinical training and relevant physiology is rarely mentioned. Co-ordination between the disciplines is rare, although there are some international examples of joint seminars/modules on urinary and faecal incontinence (University of New South Wales) and inter-disciplinary input into curriculum (University of Newcastle). IFFGD in the USA sponsored an interdisciplinary meeting in 2002 titled “Advancing the treatment of faecal and urinary incontinence through research, trial design, outcome measures, and research priorities“. Minimal training is provided on paediatric continence issues.

In few medical schools are undergraduates exposed to more than five hours of lectures or tutorials on incontinence in the 5-year medical course. In a 1995 survey in UK, undergraduate medical students received an average of 3.3-hours on incontinence causes and treatment, compared with 4.2 hours for physiotherapists and 9.4 hours for pre-registration nurses [68]. It may be unrealistic to expect more input than this, given the overburdened medical curriculum. In-depth education may be best given at the postgraduate level for those who will manage incontinence in clinical practice.

• Family physicians

The training of family physicians is extremely heterogeneous, varying between different regions and nations. In the UK, two-thirds of newly qualified family physicians received between 1 and 4 hours of formal training on incontinence; one third had no training at all [69]. In their survey of 1,861 general practitioners (GPs) with a response rate of 69%, Jolley and Wilson reported that 80% felt that their

continence training was totally inadequate. Ninety-two percent of physicians in practice for over 5 years had received no formal training on incontinence and expressed a desire for specific post-graduate education on incontinence. Knowledge about incontinence was found to be limited, with 76% having “no idea of its prevalence.” Only 30% of family physicians felt confident diagnosing and managing incontinence.

There have been few concerted efforts to educate family physicians. However, in Australia in 1989, the New South Wales state government gave AUD 25000 to the Continence Foundation of Australia to develop an educational package (15000 copies) on incontinence to be distributed to all family physicians in the country [70]. An evaluation of the package was undertaken to determine whether the package significantly improved knowledge of incontinence. There was no difference in initial knowledge between the intervention and control groups, but there was a significant difference in post-pack scores between the groups with no difference in scores on questions not in the pack. Sixty-three percent continued to use components of the package later in clinical practice. However, response rate from the 510 family physicians contacted was only 16%.

Another Australian study in 2001 showed similar results in a survey of family physicians. However, after using an educational flip chart and lectures over one evening, family physicians and their practice nurses showed significant changes in their attitude, with 64% indicating that they would adopt a more pro-active role in the future. Only 10% remained unchanged by the educational intervention. These results were based on a small unpublished study [71].

Two studies have reported that family physicians can be effective in treating UI by using conservative treatments when educated and motivated [72,73] with cure or improvement rates reported at 60 - 70%. Education can also increase referral rates to specialist practitioners [74]. However, the best format for education initiatives to all professionals needs further delineation. The use of road shows (e.g. continuing medical education [CME] seminars), teleconferences, guidelines, booklets and face-to-face teaching are commonly used but rarely evaluated.

• Impact of UI guidelines

The development of guidelines, primarily on UI, has increased significantly throughout the world over the

past twelve years [75,76,77,78,79,80]. In 1992 and 1996, the USA Agency for Health Care Policy and Research (AHCPR), now known as the Agency for Healthcare Research and Quality (AHRQ), sponsored the development of clinical practice guidelines that were produced to help standardize the assessment and management of urinary incontinence in adults [75,76]. Aimed at health care professionals, the guidelines are widely quoted, but they have failed to impact the practice of physicians or trainees [81]. A more recent study in North Carolina, USA used a multifaceted educational intervention based on the 1996 AHCPR guideline in 20 of 41 primary care practices (PCPs), and failed to show an effect in increasing screening or management of UI by PCPs [82]. They concluded that guidelines may not be the best approach to treating UI in this setting. Similar disappointing results have been reported in Denmark [83]. However, nurses have used the AHCPR recommendations more effectively than physicians, incorporating them into curricula, evidence-based clinical practice, and care pathways [82,84,85,86].

Changing the current patterns of medical care with respect to detection and management of incontinence through education is a difficult task [87]. Guidelines for medical practice can contribute to improved care only if they succeed in moving practice closer to the guideline recommendations [88]. Unless there are other incentives or the removal of disincentives, guidelines are unlikely to effect rapid changes in actual practice. It is recognized that other tools or strategies are needed to augment and build on educational endeavours [89]. Strategies that aid in implementation of a guideline include reminder systems to remember when to implement guidelines, tracking systems to identify patients who need follow-up, and continuous quality improvement monitoring and regulations. Educational programmes alone may change knowledge and attitude, but rarely change behaviours. Guidelines combined with continuing medical education programmes may be more successful [90].

Even evidence-derived guidelines may not always result in better practice or outcomes. The implementation and evaluation of such a guideline in one primary care practice in the UK from which 1503 patients were randomly selected has been reported [84]. Thirty-five percent of women and 9.9% of men suffered from incontinence in the previous two months, but 61% had never sought help. Of those who did, 63% were referred to specialists, 53% had a urine test, 1 in 4 women had a vaginal examination,

and 4 of 206 persons with UI were asked to complete a frequency/volume chart. After implementing the guideline, two abdominal examinations and one new rectal examination were performed, but no new vaginal examinations were performed. Frequency/volume charts were given to three people. Two patients used fewer drugs. The severity of incontinence was unchanged following the intervention. Family physicians did not effectively implement the guideline. It remains to be tested whether, properly used, guidelines can improve incontinence in practice.

In a 1999 repeat of a 1996 survey, among 6481 patients older than 50 years, it was found that after numerous UI awareness and education campaigns, German physicians were even less likely to address incontinence than 3 years earlier [91]. The “don’t ask, don’t tell” attitude between physicians and patients, has significant fiscal implications for health care. The consequence of not treating the condition may increase the annual cost of care by an estimated USD 3941 per individual [92]. Funding for conservative management of UI, or better-informed public demand, may stimulate more interest and improved performance among this important group. It remains critically important that primary care physicians have an understanding of how to manage UI effectively [93].

A number of CME programmes for PCPs on UI are now available through Internet sites. One by the American Geriatrics Society covers screening for UI, history taking, ruling out other factors, urinalysis, behavioural therapy and challenges in impaired people. Pharmacy Times site offers a free Temple University program with 2 CME credits on medical management of UI. It covers differentiation between transient and established incontinence, identification of medications which can contribute to UI and agents which can be used to manage the various types of UI, how to assess, choose appropriate pharmacotherapy and identifying which agents should not be used. A similar course from Temple is available through American Medical Seminars (www.ams4cme.com) as part of a Gynaecology CME program for PCPs. In addition, the Merck Institute of Aging Health (www.miahonline.org) offers CME for practicing physicians (supported by a grant through the American Geriatric Society) on geriatric syndromes, guideline, and tools for evaluation, diagnosis and treatment.

• Medical specialist training

Specialist training in incontinence is not always ade-

quate. A survey of urological trainees between 1988 and 1994 in Australia showed many felt their training in the management of incontinence had not been adequate [94]. The Colleges of Obstetrics and Gynaecology in the United Kingdom and Australia and the American Board of Obstetrics and Gynaecology have developed courses and credentialing of specially trained urogynaecologists with separate examinations. Similarly, both the American Urologic Association and the European Board of Urology conduct courses, CME programmes and set standards in UI management. However, both UI and FI still may be perceived as exclusive to “super-specialists,” potentially alienating colleagues.

A recent survey of 163 urodynamic services in the UK found that only 43% of physicians, nurses and others performing urodynamic investigations felt that training to do these studies had been adequate [95]. Committee 7, Dynamic Testing, of the ICI recommends that invasive urodynamic studies should be performed in accredited urodynamic laboratories, by trained and certified staff, with formal control of the quality of the results. This committee highly recommends the establishment of national accreditation, training, certification and quality-control programmes.

The plethora of meetings held by medical specialist groups (International Continence Society, Pelvic Floor Society, Asian Society for Female Urology, International Urogynaecology Association) and meetings of recently-formed national Continence Foundations in Thailand, Philippines, Taiwan, and India serve both as stimulants to trainees, and as continuing education for practising clinicians, although their impact on clinical knowledge and translation into practice has not been evaluated. The impact of the Asia Pacific Continence Advisory Board (APCAB) has been to spawn Continence Foundations in 10 Asian countries including India, Pakistan,

Malaysia, Indonesia, Taiwan, Korea, Hong Kong, Philippines, Singapore and Japan (countries with 230 million people with UI), each with an impact on specialist and undergraduate training. These societies face huge challenges and scarce resources and funding. They are already sharing educational materials, translating and adapting material to individual nations needs.

3. NURSING PROFESSIONALS

Nurses have often been more closely involved in continence care and management than physicians or allied health professionals. Only in the last 15 to 20 years has education really enabled nurses to change the continence status of their patients, rather than coping with its consequences.

A common theme that runs through the international nursing literature over the past two decades is that nursing staff recognise a lack of knowledge of incontinence and indicate that they would like further training [96,97,98]. There are significant gaps in knowledge and clinical practice adoption related to both UI and FI although nurses worldwide have played a major role in developing new information and testing interventions [99]. In 2003, nurses in the USA convened incontinence nurse clinicians and researchers to a symposium to identify the knowledge deficit by practising nurses as one of the main barriers to optimal continence nursing care [100].

a) Specialist nurses

Educational courses on incontinence are available for nurses in the UK, USA, Europe and Australia and are beginning to appear in Asia, notably Hong Kong and Singapore. These courses vary from 2 to 4 weeks of face to face didactic courses to distance learning courses lasting 4 - 6 months that lead to a post-basic nursing certificate (see Table 2).

Table 2. Examples of specialist nurse training programmes according to country:

| Country | Types of specialist nursing course available | Website |
|-----------|---|---|
| Australia | 1 year graduate courses, Masters programmes, distance learning and certified courses | http://www.flinders.edu.au/courses/postgrad/contin.htm |
| Canada | Nurse Continence Advisor, distance education programme [101] | http://www.fhs.mcmaster.ca/nursing/nca/ |
| Denmark | Specialist 5 module programme | |
| Japan | Specialist 6 month course and 4 day primary and secondary programmes [102] | |
| Sweden | Programme to gain urotherapist qualification | |
| UK | Undergraduate and graduate modules, distance learning and certified courses [103] | |
| USA | Certification programmes offered for basic nurses by the Wound Ostomy and Continence Nursing and for advanced practice nurses by the Society of Urologic Nursing and Associates [104] | http://www.wocn.org http://www.sunu.org |

Williams, et al., conducted a small study in 1999 in the UK that showed improvements in both knowledge and attitudes of nurses who undertook a specially designed full time, 3 month programme that included a continence module [103].

Internationally there is inconsistency in the provision of specialist education to prepare nurses to practice as experts in the field of incontinence. Programmes of study are developed, but rarely fully evaluated. The need for innovative web-based learning programmes incorporating modern information and communication technology (e-learning) may offer one way of providing standardised programmes of study to practitioners.

The Internet also offers education courses, CME accredited courses and Nurse Continence Advisors (NCA) distance education packages for nurses. McMaster University, for example, has a CAD1200 course consisting of 150 hours of clinical experience of which 75 hours are preceptor and 75 hours are independent practice involving 20 case studies. The course covers leadership in promotion of continence, anatomy, physiology and pathophysiology, holistic assessment, conservative behavioural and educational intervention and recognition of the impact of UI on quality of life. "Nursing Best Practice" guidelines such as, "Promoting Continence Using Prompted Voiding," are available free from www.rnao.org/bestpractices.

b) Standard setting

Standard setting has been one method by which general nurses can acquire skills to meet set standards of practice. In Australia, for example, government funding to nursing homes is dependent upon their reaching certain standards in continence assessment and management. Standards set are based on advice from the Continence Foundation, which was commissioned in 1991 to produce an educational resource for nurses working in elder care, and was distributed to 1,400 nursing homes [105].

c) Care pathways

The use of Continence Care Pathways has been evaluated amongst generalist nurses. It was found that the use of such pathways has aided in the identification of reversible causes of incontinence (e.g., UTI, medication, fluid intake, constipation, dexterity and mobility issues), and addressed poor quality of life and bothersomeness issues [106]. By using care pathways, patients could be referred to specialist

nursing care more appropriately for specific treatment beyond the scope of the generalist nurse, or when they failed to respond to first line therapy. The care pathway identified the needs of the patient, directed simple investigation and primary therapy, but also identified the resources needed by the nurses (e.g., urine testing dipsticks, lists of drugs, frequency/volume charts). The pathway could be modified according to the equipment and expertise locally available. Educating large numbers of general nurses to follow a simple pathway with basic continence-care competencies [107] may allow better use of specialist nursing time and specialized skills [108].

d) Level of continence knowledge

The level of knowledge about UI within the general nursing community appears to be less than ideal in both the USA [107,109] and Sweden [97]. Many non-specialist nurses (referred to as general nurses) desire, and have a need for, more education about what they can do to better manage incontinent individuals. Moreover, the quality of life of the incontinent nursing home resident is often more dependent upon the skill, education, and attitudes of the nursing aide or assistant than of the qualified nursing general staff.

In an older UK study of learner and qualified nurses' knowledge, only 12% of qualified nurses had received any education on incontinence in the previous 12 months, and for those who had, most was on products [110]. Forty-four percent of charge nurses and 81% of staff nurses had received no additional training on incontinence since qualifying. Further work on attitudes via a questionnaire to qualified nurses on hospital wards found predominantly therapeutic, rehabilitative attitudes, but also a number of misconceptions. Twenty one percent thought their primary role with incontinent patients should be supplying products and 11% saw incontinence as an inevitable part of aging. Sixteen percent agreed that incontinence was often due to laziness and 28% thought that incontinence was more distressing for a younger than for an older adult [111]. In a further survey of trained nurses, the author found that nurses still focus primarily on palliative rather than therapeutic care and lacked knowledge on which to base care [96]. However, nurses with a post-basic qualification or in-service education were more likely to have positive attitudes, although it was not clear whether this was as a result of the education, or whether these nurses already had a positive attitude and had therefore self-selected to receive further education.

More recently, Rigby explored whether increased continence knowledge amongst general nurses resulted in changes in clinical practice using an opportunistic sample of 130 general nurses achieving a 54% response rate to all stages of the study [112]. The results demonstrated a significant change in knowledge score for nurses following a continence study day, but showed that application in clinical practice of this knowledge posed significant problems. This study had a number of limitations using a small opportunistic sample with poor response, however the real challenge remains of not simply increasing knowledge, but translating that knowledge into improvements in clinical practice.

In the USA, although there are a growing number of nurses who are developing expertise caring for incontinent patients, there are no academic or clinical proficiency requirements to be considered a “continence nurse practitioner or specialist.” In 1993, the Wound, Ostomy, and Continence Nurses Society (WOCN) developed the first certification program for continence care nurses in the USA. The norm is that most nurses in the USA obtain their knowledge and skill through self-motivated activities. A survey of nurses attending a national nursing conference on UI asked about educational preparation related to this condition [113]. Respondents reported that less than half (40%) received academic education including course work in accredited post-baccalaureate or graduate programmes related to UI. However, most nurses (76%) obtained instruction at professional conferences, continence clinics supervised by nurse practitioners or physicians, “on-the-job” training, self-study, or in-service programmes.

In another UK study of general nurses’ knowledge of UI, a clinical handbook was evaluated using a pre- and post-test design with an experimental and control group [114]. This study showed that the use of the handbook, which consisted of a decanted, user-friendly, research-based resource on continence care, improved nurses’ knowledge of incontinence. A significant improvement in reported clinical practice was found for 86% of variables in the experimental group compared to a 59% improvement in controls. However, only 54% of those approached agreed to enter the study, suggesting a lack of interest and motivation generally.

As with physicians, it is unlikely that improving nursing knowledge alone will translate into improved clinical practice, or into the ultimate goal of improved patient outcomes. A review of hospital policies

and community nursing practice in an area with a well-established continence service and education program demonstrated very little evidence that improved education had a tangible effect on practice. The authors concluded that nurse specialists are most usefully employed providing a clinical service to individual patients rather than spending their time educating other nurses [115].

There is a lack of consensus on what should be taught to different nursing groups at each educational level. It is not clear how educational needs can be met or who will pay for the time and expertise required to provide educational initiatives. Governments, as primary payer of nursing home care, have a vested interest in promoting continence in order to minimise costs. It is likely that the continent nursing home resident requires less nursing time than an incontinent resident. It therefore falls to the payer to underwrite the education that is needed to promote continence. More emphasis on incontinence care and the nurses’ role in continence promotion should be encompassed in basic nurse training courses. Specialist continence nurse practitioners and nurse continence advisors are likely to be the best instructors to provide this education.

4. ALLIED HEALTH PROFESSIONALS

Physiotherapists or physical therapists (PT) have long played a part in continence care and the management of incontinence. In some countries, patient self-referral to specializing physiotherapists has become commonplace. Physiotherapists’ involvement in incontinence appears to be either on the basis of individual interest or through association with women’s hospitals or obstetric departments, rather than as part of a general physiotherapy practice. As such, they tend to be highly motivated and enthusiastic.

Pharmacists have a variety of roles to play in continence care. In Australia, they have been avid consumers of continence education programmes. In 2004, the Pharmacy Guild launched an educational and promotional program for their members with appropriate outcome evaluation measures. The public sees pharmacists as important and approachable sources of health information. Many retail pharmacies display health promotion literature on a range of subjects including UI. Pharmacists may also advise the consumer on appropriate continence products. Educational seminars for pharmacists are generally well

received. There are a growing number of CME programmes for pharmacists on the Internet either through new products (e.g. www.oxytrol.com) or through sites such as www.worldwideLearn.com which aims for on-line CME for pharmacists and technicians.

There is also a need to address the training needs of nursing assistants and aides, particularly in the nursing home setting. In the USA and many other countries, one concern is the high turnover rate among first-line caregivers in institutional and home care settings, making it difficult to maintain desired training levels. Nursing assistants are often the people providing 'hands-on' incontinence care and yet, often with the least training.

Reimbursement policies often determine which professionals are able to provide continence care. In the Netherlands, for example, the government pays for up to 14 visits to a physiotherapist for incontinence (e.g., biofeedback therapy).

5. EDUCATIONAL MATERIALS AND FUNDING

There is a range of teaching packs, videos, and books on the topic of UI available. The Continence Promotion Committee (CPC) of the International Continence Society (ICS) publishes a directory of material available from national continence organisations. There have been many advances in the field of information technology and interactive and distance learning methods which are starting to be applied to continence.

One interesting innovation in delivering continence education was reported by Teleac, a Dutch broadcasting company, who offered sufferers training therapy consisting of pelvic floor muscle exercises, bladder training and advice on relaxation and posture. They reached an average of 140000 viewers per broadcast; 51% of participants reported an improvement in their incontinence, and 83% were satisfied with the results of the course [116].

Education can be expensive, for courses or production of materials, and also the need to replace personnel who are away from work. The first two specialist nurse courses in Australia cost AUD110000 to train 20 nurses. In other countries, there is minimal evidence of the cost of providing education to professionals on incontinence.

In practice, much education and many materials are produced or sponsored by commercial companies marketing incontinence-related products. While many fund broadly based materials without product mention, others attempt to influence the content to market their product. A partnership between companies and health care professionals can be mutually beneficial, but the boundary between education and marketing is not always clear.

6. INTERNET EDUCATION RESOURCES

Many Internet sites now exist for the education of professionals and the public. Health care professionals have developed web sites and educational materials, which are available in CD format (Japan) and as computerized decision pathways. In future, online real-time video may be accessed through the Internet.

The CONTInet, a site sponsored by the ICS, provides interchange between national continence organisations and the public. A number of sites now exist from trade and professional bodies providing up-to-date information about new products and operative interventions. Interactive educational sites have yet to appear. Diering and Palmer reported on the accuracy of UI information provided on web sites developed by organisations based in the USA [117].

A total of 265 web sites were located, but only 15 sites met the inclusion criteria. The authors felt there is a rapid proliferation of information on the World Wide Web (www) and there is a need to critically evaluate new sites or updated information as it becomes available. A physician evaluated the Internet as a source of interactive information about UI by posing as a fictitious woman with symptoms of stress UI. The author found that few sites provided comprehensive information, but most information was correct [118].

More recently a study was undertaken to describe interactive information about continence health promotion for women on the internet [119]. The authors found that while web sites are informative, they lacked an emphasis on self-care and sufficient information to promote self-care. Information about ratings for websites and examples of the most popular websites on incontinence found using the Google search engine, are provided in **Table 3**.

Table 3. Websites: rating systems and websites on incontinence

1. Rating systems for websites

Three organisations have been identified whose origins stem from concern with the reliability, accuracy, and quality of health information that is available on the Internet:

Health On the Net Foundation (1995): www.hon.ch

Health Internet Ethics (Hi-Ethics) (1999): www.hiethics.com

MedCIRCLE (2000): www.medcircle.org

Health on the Net (HON) Foundation located in Geneva, Switzerland, is a not-for-profit organisation that provides a source of “authoritative, trustworthy Web-based medical information.” Health information providers can become accredited and use the HONcode on their website by participating in a review process that requires professionals to meet the HONcode standards. Upon approval, the information provider is also added to HON’s database of accredited web sites. The HONcode membership is free.

Health Internet Ethics (Hi-Ethics) is a non-profit organisation that accredits U.S.-based health websites through the URAC review process, using the 14 quality standards established by the Hi-Ethics board members. The accrediting body, URAC, is an independent, nonprofit organisation that charges an annual accreditation fee ranging from \$3,800 to \$8,000, based on annual company revenue. Membership in Hi-ethics is \$6,000 annually.

MedCIRCLE (Collaboration for Internet Rating, Certification, Labeling, and Evaluation of health information) is a consortium of three European medical organisations and government agencies in Spain, France, and Germany, which developed a systematic approach of rating and evaluating/accrediting health websites. They are hoping to form a broader international collaboration with others who are willing to implement “HIDDEL (Health Information Disclosure, Description and Evaluation Language)” software to ensure the standardization of rating/evaluation services.

Websites: Top 5 Websites on Urinary Incontinence (Google Search)

| <u>Website</u> | <u>Sponsor</u> |
|--|---|
| www.incontinence.org | American Foundation for Urologic Disease, USA |
| www.nafc.org | National Association for Continence, USA |
| www.incontinet.com | Dr. John Perry, USA – focused on pelvic floor disorders and biofeedback |
| www.uib.no/isf/people/inkter.htm | Dr. Hogne Sonvik, Dept of Public Health and Primary Health Care, University of Bergen, Norway |
| www.seekwellness.com/incontinence | Ms. Diane Newman, Nurse Continence Specialist, Division of Urology, University of Pennsylvania, USA |

RECOMMENDATIONS FOR CONSUMER AND PROFESSIONAL EDUCATION

Based on the literature reviewed in this section, the following recommendations can be made:

- There is a need for rigorously evaluated continence education programmes which adhere to defined minimum standards for continence specialists, generalists and the public/consumer, utilizing web-based and distance learning techniques alongside traditional methods. The following should be considered:
 - Compulsory inclusion of incontinence in the basic curriculum (physicians, nurses, physiotherapists and allied health professionals). Incontinence should be identified, planned and preferably taught as a separate topic.
 - Specific education programmes adhering to approved standards should be reported to a recognized central body.
 - Public education programmes should be independently evaluated. **(Grade D)**
- There is a need for research on the most effective means to educate the public and professional groups on continence issues. Specifically, there is need for research on:
 - Translation of research into improved clinical practice and identification of methods by which this happens.
 - Mechanisms for increasing professional motivation to acquire education and improve performance.
 - Effectiveness and impact of consumer education initiatives. **(Grade D)**
- There is a need for collaboration at national, international and practice level to ensure that effort is not duplicated. Information banks of continence education material should be shared. This could be facilitated by the ICS. **(Grade D)**

V. ORGANISATIONS

1. DELIVERY OF CONTINENCE CARE AND SERVICES

a) Background

The provision of continence care and services in each country will depend on the organisation and infrastructure of its health services generally. It is difficult to make recommendations that will apply in such a variety of contexts. In addition, incontinence is so widespread and affects so many different types of people that they can present for help to literally any health care professional. This means that there will seldom be one portal of entry to a continence service.

When new services are created, there is a temptation to focus on the high technology investigation and medical treatment elements without considering the infrastructure needed to support that service [120]. However, there has never been a comprehensive examination of an optimal service. It is not known whether academic, specialist-led centres will achieve better and more cost-effective results than primary care clinics, domiciliary services or any other model.

In 2000, UK's Department of Health issued guidance on continence services that outlined a good practice model to achieve more responsive, equitable, effective continence services [121]. In the USA, the primary source of care for the majority of Medicare patients (primarily elderly population) are family physicians and primary care physicians [122]. Less than 1 person in 1000 is admitted to an academic, medical centre hospital [123]. Thus, in the USA, elderly persons with UI and FI will probably be seen by primary care physicians (PCPs) for initial assessment. This same model is likely to address the needs of developing countries in the Asia Pacific area where dissemination of expertise to rural communities and isolated community health care workers is more logical. Services are being implemented in several countries using shared teaching and educational resources through co-operative arrangements of the respective Continence Foundations. Thus, the general practitioner plays an important role in the first line treatment of UI that may be treated successfully with conservative treatments in the majority of patients [124,125].

In some health systems, both UI and FI has traditionally been seen solely as a nursing problem, with litt-

le interest or input from other members of a multidisciplinary medical team. Except for a few isolated areas, the main intervention has been trying to help the individual and caregivers cope with symptoms rather than attempting to treat the underlying cause of the incontinence. For example, in the UK, it is common for an elderly person presenting with incontinence to be referred directly to the district nurse "for assessment for pads and pants," with no physical examination or further investigation considered.

Individual care is time-consuming and therefore, costly. In an attempt to streamline a proven technique, a trial of BT in a group setting was attempted and proven to be effective [51].

In fact, incontinence is often a complex and multifaceted problem, particularly in frail or dependent individuals, and it may require input from a wide variety of disciplines to tackle it effectively. While it may not be practical for all specialities to work in close proximity, there is a need to consider carefully who does what, with protocols to guide appropriate referral and ensure good liaison. It is important that there are neither gaps, nor overlaps, in the service.

In countries such as Australia, New Zealand and the UK, where there is a national network of Continence Nurse Practitioners (CNPs), part of their job is to organise this liaison, integrate services, and guide individuals through the referral route most appropriate to their individual needs. The ability of a CNP to do this was studied by Matharu and associates [126]. Four hundred and fifty (450) women over 40 years of age underwent urodynamic studies after seeing a trained CNP. In patients diagnosed with detrusor overactivity, the nurse had prescribed 79% to have drug therapy and 64.8% to have pelvic floor muscle training (PFMT). In those with urodynamic stress incontinence 88% had been assigned to have PFMT. Nursing assessment has the potential to assign patients to the correct conservative treatment thereby shortening waiting times for urodynamics and specialist assessment.

Although some might see multidisciplinary working as the ideal, the reality is not always smooth. In some situations, rivalries and competition between disciplines and medical specialities is evident. This may be because of competition for patients and revenue, or because of disputes over the demarcation of the scope of different disciplines (such as the boundary between urology and gynaecology, or between nursing and physiotherapy).

There are no studies directly comparing the effecti-

veness of specific delivery systems for continence care. In certain cases, enthusiasts have conducted research and results may not generalize to the wider setting. Others have combined the expertise of multidisciplinary teams to maximize service delivery. The level of evidence on service delivery models is 4.

b) The need for service.

The majority of people (60-70%) who admit to UI in prevalence surveys do not seek professional help [127,128,129]. Not all incontinent people want or need help, and this may vary considerably between different cultures. For example, a postal questionnaire asking about urinary symptoms found that nocturnal problems caused the most bother (69% were bothered by nocturnal enuresis, 63% by nocturia). Only 50% found stress UI a bother and 56% were bothered by urge UI [130]. A community based study found that only 15% of severely incontinent women (daily incontinence requiring protective pads most of the time) were worried about it, 15% felt that their activities were restricted, the majority seemed able to cope. Overall, 78% were not worried by their incontinence and the authors suggested that services should be targeted towards the minority who do find it a problem [131]. In Japan, it has been found that 55% of elderly incontinent people do not consider incontinence a bother, but 15% did not leave home, 10% found it difficult to leave home, and 10% felt that they caused bother to family and neighbours [132].

This same survey [132] of over 1,000 caregivers of elderly incontinent people in the community found that more than 80% of caregivers are female and over half were more than 60 years old. The caregivers felt that incontinence caused problems with the home getting dirty (10%); extra laundry (9%), need to wake at night (7%), and not being able to go out because of incontinence (9%). When asked what kind of government service they wanted, caregivers replied “health training” (10%), “knowledge about incontinence” (10%), and “supply of a portable toilet” (3%). Only 6% wanted the government to send them professional caregivers and 4% desired referral to a specialist physician.

In a USA survey, UI was seen in 53% of homebound patients and was a leading reason for caregivers to place a family member in a nursing home [133]. The relatives of 50 patients admitted to the hospital because caregivers could no longer cope were asked which factors, if alleviated, would have enabled

coping. Nocturia, FI, and UI in an opposite-gender parent who needed intimate care, were among the least tolerated problems [134].

Some people seemed to cope better than others with symptoms, and some had coping strategies, which were easily undermined by any suggestion that professional help was required [135]. Few people seemed prepared to take action to prevent incontinence.

This can create a dilemma and raises many questions. Should health professionals attempt to persuade people who do not see incontinence as a problem that it is an abnormal condition? Should a patient who is “not bothered” by symptoms be treated because the partner or caregiver requests the physician’s assistance? Is lack of bother genuine or simply a defence against having to tackle an unpleasant problem? Does early intervention prevent later deterioration in symptoms? Does delay in treatment mean that success rates are lowered? There is scant evidence on any of these issues, or on the most acceptable way of providing help.

It is the impression of all members of this committee that, specifically for the field of UI, due to the high percentage of people not seeking help (for all the above mentioned reasons), that professionals must develop a concept of a “reaching-out” service and to actively provide service for incontinence care, meaning promoting awareness, actively detecting UI and providing simple and efficient therapy.

c) Models for continence care

Service models that specifically target “incontinent patients” are viewing health care only through the healthcare professionals’ eyes. As previously mentioned, in the USA, less than one in 1000 patients will be seen at a university-based (academic) specialist centre [123]. Thus, if all elderly persons with UI are expected to be seen by a specialty centre, then services will, of necessity, be limited to a very few sufferers. In fact, it is unrealistic and inadequate to streamline patients into such service models. In addition, patients and physicians do not necessarily rate UI and OAB as their most important health concern, especially when they may be struggling with numerous other issues. Therefore, single specialist models, while helpful conceptually to think through how care is and might be organized, will be less efficient than linking and coordinating incontinence services through multidisciplinary models

1. SINGLE SPECIALIST MODEL

This is a service led by a consultant or specialist phy-

sician (urologist, gynaecologist or geriatrician), often focused around an “urodynamic unit” providing medical or surgical treatment. This is the most common model in developed countries; the best of them have a nurse continence advisor or physiotherapist as an integrated part of the service.

In some countries, physiotherapists (PTs) have also developed a specialized practice with incontinent patients. In France, all women, after childbirth, are entitled to a maximum of 10 sessions of pelvic floor muscle rehabilitation physiotherapy, paid for by the government. In Australia, Scandinavia and the UK, research on PFMT has been led by PTs. However, there is a lack of consensus as to best practices for incontinence. In a postal survey of British PTs, many were providing specialized service. Gynaecologists were the most common source of referral. The majority said physiotherapy was the first line of treatment. Pelvic floor muscle exercises and electrical stimulation were the most used modalities. However, there was little consensus about optimum treatment regimes amidst a wide variety in the details of therapies used [65,136].

2. NURSE CONTINENCE ADVISOR MODEL

The nurse continence advisor (NCA) may be independent but is usually associated to community/area health centres, where they may have variable professional support from general practitioners (GP) and family physicians. Continence nurses often work in both hospital and community, and the service is focused on primary care (particularly district nurses) assessment of patients and organisation of free incontinence product delivery to the home.

The Department of Health in the UK has commissioned an evaluation of different models of nursing services, with and without specialist nurse continence advisers. It was found that where there is a continence nurse, incontinent people are more likely to receive targeted referral to specialists such as an urologist, and are more likely to have had investigations and to receive more appropriate treatment and care for their incontinence. These patients were also more likely to report satisfaction with the service. In most areas, the continence nurse is involved in individual patient assessment to identify simple problems at the primary care level and implement conservative therapy where appropriate.

In a series of studies performed in Leicestershire UK, the short and long-term outcomes of a new continence nurse practitioner (CNP)-led service for urinary symptoms (3 and 6 months after implemen-

ting the program) were examined and evaluated [126,137,138]. The experimental group was comprised of 2,958 patients. The standard care was the control group (n=788) who accessed GP services and existing continence services in the area. The experimental group received an 8-week primary intervention package by the CNP, which included advice on diet, fluids, bladder training, pelvic floor muscle awareness and healthy eating. Individuals whose symptoms persisted after primary intervention were offered urodynamic testing. The CNP led service had a 10% higher cure rate than standard care with statistically and clinically significant reductions in urgency, frequency, nocturia and UI. In addition, quality of life (QoL) improvements were greater in users of the CNP led service and higher levels of patient satisfaction were achieved. This is the first study to show the effectiveness of nursing services on urinary storage symptoms (rather than simply incontinence) and associated QoL.

A similar RCT in Australia compared outcomes in 145 women presenting with stress UI, with or without urge UI, randomly allocated to a standardised regimen with the NCA or treatment by an urogynaecologist [139]. After 12 weeks, 110 were evaluated. Sixty-four percent (n=58) of the NCA group and 52% (n=52) of the urogynaecologist group were asymptomatic with a dry pad test. There were no significant differences between the groups for incontinence scores, pad test changes, voids/day or scores on UDI (Urogenital Distress Inventory) or IIQ (Incontinence Impact Questionnaire). The treatment by the NCA took a median of 160 minutes, but cost AUD59.20 compared with 90 minutes of gynaecologist time at a cost of AUD189.70. At 2.5 years 29% of the NCA group and 41% of the other group were dry. The authors concluded that similar results were achieved at lower cost using the NCA.

An additional number of studies support the efficacy of specialist nurse NCA in the delivery of community continence care [72,124,140].

A 2000 study in the USA demonstrated significantly improved outcomes for three clinical problems: urinary incontinence, depression, and pressure ulcers when advanced practice gerontological nurses (APNs) worked with nursing home (NH) staff to implement scientifically based protocols [141]. In addition to working with NHs to provide resident evaluation as physician extenders, this research indicates that this service model using an APNs can be an effective link between current research based knowledge about clinical problems and NH staff.

This study also showed that consistent educational efforts with staff and NH residents demonstrated that interventions could improve or stabilize the level of UI in these individuals.

A similar program has been implemented in the Hunter Valley region of Australia [71]. A single experienced CNP set up a series of continence clinics in this extended area and trained community nurses to administer a series of programmes including bladder training, PFME, as well as, standardised catheter care and intermittent self-catheterisation regimens. There are now 22 clinics and centres with this expertise in the Hunter Health district. Some services are associated with Continence Organisations of various countries. In developing countries such satellite clinics are the only way to provide access to services in rural and poor areas. Outcome studies are lacking in reports of such services.

The Multiple Sclerosis Society of New South Wales with over 4,500 patients has funded a NCA to provide similar services on a state-wide service to its patients. The NCA trained 4 other staff to assist in this task. As news of the service spreads, the demand for the service grows. A single consultant urologist backs up this service and runs a referral clinic every other week with access to video-urodynamic investigation when needed.

In some countries the NCA is attached to a district nursing service providing expert advice and support for non-specialist nurses with patients who have continence problems.

3. MULTIDISCIPLINARY RESOURCE AND REFERRAL CENTRE MODEL

Multidisciplinary clinics, as service models, have been shown to provide comprehensive continence care. In multidisciplinary clinics, such as a “Pelvic Floor Clinic,” gynaecologist urologist, colorectal surgeon, physiotherapist and continence nurse work together [142].

An Australian study took all community referrals of those who had been incontinent for at least two months and had at least one episode in the preceding 2 weeks to a continence clinic. Patients were randomised to conservative treatment or control, with a crossover design. Patients were asked subjective questions about embarrassment, odour, depression, family relationships, isolation and laundry on a 4-point scale ranging from no effect to major effect upon life. The questionnaire was completed at the start, and at 2, 4, 8, and 12 months. Seventy-eight

patients entered the study: 87% improved with treatment (vs. 41% controls). Fifty-two percent were moderately or severely embarrassed at the start of the study period, but at 4 months, only 17% were. Depression decreased from 49% to 22% and isolation from 28% to 12%. Odour and the use of extra laundry also decreased. All benefits were maintained at 12 months. Controls did not improve on these items until crossed over to active treatment, despite feeling better. The authors conclude that conservative treatment in a multidisciplinary community clinic improves continence and well being [143].

An expansion of this service provision is exemplified by the National Centre for Continence in Israel, which aimed to provide an integrated service [144,145]. The Center’s professional team not only treats incontinent patients but also educates GPs and nurses who come from pre-selected peripheral/outlying clinics, and provides ongoing support and advice as well as a pathway for tertiary referral. A local team (GP and nurse) are also selected to be in charge of promotion, detection and treatment of incontinence at the clinic. They later become “in charge” of incontinence in their region. This model allows national distribution of continence services with support from the resource centre and provides interdisciplinary exchange, as well as, maximum co-operation between Medical Centres and community health services. The national centre is funded by government and industry to provide a “Hotline” for the public, to promote education programmes in nursing and medical schools, hospitals and nursing homes, and to develop guidelines for diagnosis and management of incontinence by primary healthcare staff.

A report on continence care services worldwide noted that services were scattered, inconsistent and considerable discrepancies exist in their funding. The authors concluded that there was a need for accessible (and affordable) continence care and multidisciplinary teamwork [63].

4. PRIMARY CARE MODEL

There are many factors that can persuade health care planners about the importance of adequate investment in community continence services: the prevalence and the number of incontinent people is likely to increase with an aging and increasingly dependent population and many frail, disabled or elderly people are incontinent for reasons extraneous to the urinary system (such as poor mobility, an inappropriate physical environment or lack of an individualised care regime). It is often best to provide an initial assess-

ment for such individuals in their usual surroundings and to reserve hospital or clinic (specialist or academic) referral for those who do not respond to simple measures such as treatment of constipation, modifying a diuretic medication, or provision of accessible toilet facilities. A number of guidelines have suggested an algorithmic, step-wise approach to assessment and treatment of incontinent people and many conservative treatments have a good success rate in primary care [76,90,80].

A New Zealand study of 600 family physicians found that most respondents provided continence care and 2.6% offered special clinics for continence promotion [146]. Fewer than half felt confident to diagnose the causes of incontinence. Confidence in managing incontinence in children was consistently lower than for other childhood problems. There was no difference by sex in confidence, although female respondents were more likely to consider management of continence care as part of a practice nurse's role and to routinely ask women about UI during a "well" visit. Most respondents (71.9%) could not remember having had any formal training in the management of incontinence either at the undergraduate or postgraduate level. Recall of postgraduate education was associated with greater levels of confidence in management of incontinence problems.

In a questionnaire study in the UK, replies were received from 560 family physicians. They were more likely to refer men than women and younger rather than older patients with UI to a specialist. Fifty-three percent had seen 3 or more incontinent patients in the past month. Twenty-nine percent routinely ask about incontinence at "well-man" clinics; 54% do so at well-women clinics and; 6% do not ask men or women during routine screenings, over a 7 year period of time. Women and older physicians were more likely to refer and felt that the most helpful professionals were the community nurse, gynaecologist and urologist. Only two-thirds used geriatricians or continence nurses; half use physiotherapists. The author concluded that family physicians see a large number of patients with UI, and vary in how they manage it [133].

Family physicians have been shown to be successful in treating UI. A UK study examined assessment and treatment of 65 women, who were treated according to their type of UI. Those with stress UI were treated by pelvic floor muscle exercise, those with urge UI by bladder training and medication, and those with mixed UI by both. Patients with stress UI or urge UI,

but not mixed, improved compared to controls at 12 weeks [148]. A Dutch study of 110 women reporting UI to a family physician were randomly assigned to the treatment or control group. Treatment was PFMT for stress UI and bladder training for urge UI. Patients were interviewed at 3 and 12 months, with crossover at 3 months for controls. At 3 months, 60% were dry or only slightly incontinent. Mean wet episodes were down from 27 to 7 per week. Seventy-four percent felt improved or cured and there was further slight improvement at 1 year [73].

A study in a community clinic in Israel showed that after training, family physicians detected 98 patients with UI during a period of 19 months. Mean age of the 94 females and 4 males was 71 years (range 56-89). Most patients (53) were detected by the physicians on direct questioning, some by nurses (29) and only 18 by self-referral. After a mean follow up of 10 months, 35 were dry and 32 significantly improved. Cure or improvement was achieved at the clinic with no involvement of a urologist or gynaecologist [149].

5. OTHER SERVICE MODELS

• Acute or subacute care to community

Patients with UI who receive care in acute care hospitals have been shown to lack appropriate care because of the lack of knowledge amongst acute care nurses about assessment or management of UI [150]. Nursing education will have to change to affect this situation. The value of tackling this is shown in a retrospective review of 6,773 episodes of care in 54 medical facilities [151]. The discharge destination was altered by the presence or absence of UI – 57% vs. 82% being discharged home, respectively, and 29% vs. 12% being discharged to a nursing home or other health care venue. In addition, the time in rehabilitation was 185.6 days with UI compared with 156.8 days without UI, and geriatric costs in evaluation and management were higher in the UI group. The level of functional independence and motor function also impacted outcome.

• Services in developing nations

The potential demand for UI services in developing nations far outstrips the resources that are available. The provision of services will depend on an dedicated health care professionals with support by government or industry and by a local continence organisation to educate a new generation of service providers who will carry the services to remote communities. In some instances, consideration will have to be given to cultural, social mores and taboos.

For example Ethiopia's Health Minister has stressed the need to develop rural health services to reduce the incidence of fistula and to have first time mothers examined by Traditional Birth Attendants (TBAs). It is planned that TBAs will be trained to identify high-risk women, and thereby divert expenditure from high cost physicians and urban health services to training community health workers and health education. Attitudes on female circumcision, contraception and women's health, which are often decided by their husbands, obviously have much wider implications than just continence care.

A demonstration project in northern Nigeria has reported training obstetric fistula patients to act as peer educators to help prevent vesico-vaginal fistula [152]. The concept of peer health educators has been used in many developing countries. Given local traditions of seclusion of women, only their peers may have access to women of childbearing years.

Continence services are a relative luxury, to which countries with a low per capita income are unlikely to devote scarce resources until more "life and death" issues are addressed. For example, in Brazil, priorities for their health budget are childhood immunizations, AIDS/STDs, basic sanitation, healthy environment and literacy to help with the problem of street children.

• **Childhood enuresis service**

Very few countries have well-developed services for nocturnal enuresis in childhood. These are seldom well integrated with adult continence services, although some continence nurses do run enuresis clinics. Most clinics are the responsibility of paediatric, school health or psychology services.

RECOMMENDATIONS FOR DELIVERY OF CONTINENCE CARE AND SERVICES

- Based on the literature reviewed in this section, the following recommendations can be made:
- Government support and co-operation are needed to develop services, and responsibility for this should be identified at a high level in each Health Ministry. Incontinence should be identified as a separate issue on the health care agenda. There is a need for funding as a discrete item and for funding, not to be linked to any one patient group (e.g. elderly or disabled), and not as an optional service. **(Grade D)**

- No single model for Continence services can be recommended. In all health care systems much will depend on the local health care structure. Because of the magnitude of UI prevalence, detection and basic assessment will need to be performed by primary care providers. Specialist consultation should generally be reserved for those patients where appropriate conservative treatments have failed, or for specified indications. **(Grade D)**
- There is a need for research on outcomes, not just the process of service delivery. This research should have patient-focused outcomes, evaluate the outcomes for all sufferers who present for care, use validated audit tools/outcome measures and longitudinal studies of the outcomes of services provided. **(Grade D)**
- There is a need for cost-effectiveness studies of services currently being provided. **(Grade D)**

2. NATIONAL ORGANISATIONS

a) Background

The International Continence Society (established in 1971), in setting up a Continence Promotion Committee and in hosting the International Consultation on Incontinence (in 1998, 2001 and 2004), has recognised a broader responsibility than its former role as a forum for scientific research. Many in the scientific and medical community have also been active in developing national policies, services and organisations, in teaching professionals and in public awareness activities.

Although it may not be practical to develop global and uniform strategies for continence promotion and public awareness, much can be learned from the positive and negative experiences of other organisations in other countries.

Continence promotion is a most challenging endeavour. Although the ratio between affected patient populations and continence organisations funding has not been formally studied. Anecdotal information suggests that fund-raising for continence programmes is among the most difficult of medical problems for which to obtain funding. In view of all these challenges, the proliferation of new continence organisations, especially in the Far East, is a validation of both the need for continence promotion and the dedication of those who have recognized and are addressing this need.

b) Continence organisations

The summary of current continence organisations is based on historical data and on a survey sent in September 2003.

National organisations, which promote continence, are as diverse as the cultures they serve. They represent a wide diversity of models, including consumer-led, company sponsored, professionals only, and organisations which have deliberately set about trying to bring together all relevant stakeholders in a relatively democratic model. In every part of the world these organisations play a dynamic role in building both public and professional awareness of this under-served and under-reported condition. Most continence organisations are poorly capitalized, being either under or unfunded (i.e., run by volunteers) and are held together initially by either a dedicated patient advocate or an energized health care professional. Yet, despite this limitation, these organisations often provide their country with the first wake-up call that incontinence is common.

An organisation that is well funded, typically has strong support from the Government. The Continence Foundation of Australia, a non-profit organisation established in 1989, receives Community Sector Support Scheme funding from the Government, and specific funding to operate the National Continence Helpline and to distribute educational and continence awareness material through the Helpline. Many other initiatives in continence promotion have been achieved as part of the National Continence Management Strategy, where AUD31 million has been allocated over a 7 year period [153].

Although the exact founding date of the first continence organisation is not known, the oldest apparently is the Association for Continence Advice, United Kingdom (1981). Even so, the wealth of experience, the creativity of endeavours which have been tried, and the method in which older organisations are evolving into established foundations are all worth studying. However, the challenges of cross cultural communications, language barriers, and the costs of travelling to international meetings make information sharing a unique challenge.

Organisations that primarily target the general public generally do not participate in educating health care professionals. Those countries where a consumer-based organisation does not exist do engage in educating health care professionals as well as raising the awareness of incontinence to the population in general. In those countries that have consumer-based

Continence organisations, there are national public awareness campaigns (e.g., USA has a designated “Bladder Health Week” every fall). It is generally felt that media coverage is inadequate. However, in a recent article, the National Association For Continence (USA) strongly advocates enlisting the help of the media as one of the 3 main strategies that will help to improve the quality of life for many incontinence sufferers in future [154].

The 2003 survey of national organizations showed that besides UI, many organisations do address FI, but pelvic organ prolapse is apparently addressed by only one organisation.

There is a paucity of published work on the formation of national organisations that target consumers or the general public. Appendix 1 gives the contact details of various national continence organisations. The level of evidence on the impact of national organisations increasing continence awareness is 3.

c) Networking of continence organisations

In 1993, the first networking meeting for continence organisations and others interested in promoting continence from around the world was held during the ICS meeting in Rome. The networking group was gradually formalised and known as the “Continence Promotion Committee” (CPC), and updates with an annual newsletter “Continence Worldwide.” The website for CPC, established in 1997 can be found at: <http://www.continenceworldwide.org>. In 1998, the CPC became an official committee of the ICS. The principal 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.

On behalf of ICS, the CPC started “ContiNet” in 1994, an electronic network for ICS on the World Wide Web [155]. The initial focus has been networking of continence organisations and internal ICS business, but there is facility for announcements of meetings, publication of abstracts, rapid sharing of resources and teaching materials, and co-ordination

of multi-centre research. This service will eventually develop an index system to facilitate rapid easy communication of information between organisations and individuals. The “ContiNet” can be found at: <http://www.continet.org>.

While there is little data on the outcomes of the use of organisations to change consumers’ views and awareness of incontinence, sharing of experience and collaboration amongst countries could lead to more efficient use of resources. For instance, in 1998, the Asia Pacific Continence Advisory Board (APCAB) was established with a mission to develop “Continence Promotion” programmes that work together with healthcare professionals and the general public to develop strategies to increase awareness and reduce the social burden of UI in the Asia Pacific Rim. The APCAB member countries are Thailand, Korea, China, Hong Kong, Taiwan, Malaysia, Indonesia, India, Philippines, Singapore and Pakistan.

This sharing of information, ideas and materials has helped new countries get started. In Asia alone, 9 new continence organisations were formed between 1994 and 2000. As of November 2004, there are 42 listed continence organisations in 31 countries (see Appendix 1).

d) Detailed results of 2003 survey

1. METHODS AND RESPONSE RATE

The summary of current continence organisations is based on a survey sent in September 2003. The survey consisted of 31 questions that was sent to 36 organisations from 28 countries. The survey was in English and was emailed and/or faxed to the organisations. Twenty-four from 19 countries responded, giving a response rate of about 66.7%.

2. MEMBERSHIP

Membership of most organisations consists of both professionals and the public. Most of the professional members are doctors and nurses. Of the 16 with public membership, seven (43.8%) have strong public representation of more than half their entire membership. Incontact of the UK, the International Foundation for Functional Gastrointestinal Disorder (IFFGD) and the Simon Foundation for Continence (SFC), both USA organisations, comprise 80-90% of public membership. Membership fees are chargeable in 17 organisations, ranging from 5 to 1,000 USD.

Of the 15 organisations that have been established for more than 10 years, 7 (all from Western coun-

tries) have been in operation for more than 15 years. Five organisations (3 from Asia and 2 from Europe) started less than 5 years ago.

Eight organisations have fewer than 100 members in their mailing list. Five reached out to more than 10,000 people, and the 2 with the largest mailing list of 135,000 are in the USA.

Of the 22 (91.7%) organisations with paid employees, only 4 have between 11 and 20 staff members. The rest have only 1 to 10 staff. Twenty (83.3%) organisations have advisory boards of between 3 and 61 members. The majority of board members are health care professionals, only 6 (33.3%) consist of lay people on the board. One organisation has only caregivers in the board.

3. MISSION

Two-thirds of the respondents indicated more than one primary mission. This includes “educate healthcare professionals” (18), “educate consumers / lay public” (17) and “promote continence via public education” (14). Three of them cited “advocacy” (2) or “influencing policy” (1) as additional primary mission. One organisation declared “defend promotion of continence in different ways” as its primary mission.

As expected, all organisations cover UI, but FI is not covered in 6 of them. Twelve organisations include interstitial cystitis and 10 include pelvic pain disorders in their coverage. In addition, 9 organisations reportedly include other topics in their coverage, such as radical prostatectomy surgery, electrical stimulation, physiotherapy, incontinence in children, gastrointestinal disorders, neurogenic bladder, pelvic organ prolapse, prostatic obstruction, erectile dysfunction and voiding disorders of varied aetiology.

Seventeen organisations have developed medical guidelines for continence care which represented solo efforts by organisations themselves (8), the medical community (3) and the government (2). Three were combined efforts from government and medical community, and 1 was developed by all 3. Some of the publications (with release date in bracket) include:

- Australia – Managing incontinence in general practice (2002)
- Belgium – Workbook for GPs (1999)
- Canada – Promoting a collaborative consumer-focused approach to continence care (2001)
- Holland – Guidelines on stress incontinence (2002)

- New Zealand – Female urinary incontinence (2002)
- Philippines – Take control (2003)
- Poland – Therapy (2002)
- UK, Enuresis Resource and Information Centre (ERIC) – Minimum standards of practice in treatment of enuresis (1996)
- USA, IFFGD – Advancing the treatment of faecal and urinary incontinence (2004)

4. FUNDING AND SUPPORT

Members contributed between 1.5% and 50% of funding in 15 (62.5%) organisations. Support from charity accounted for about 1% to 80% in 7 organisations. Of the 4 organisations that received government funding, 3 received 30%, 35% and 90%, respectively. Most organisations (87.5%) received support from industry or manufacturers of drugs and products. Except for Poland which received 100% funding from this source, the rest received between 5 and 90%. Education grants of between 5 and 90% are available in 11 organisations. Ten organisations reported other types of funding with amount from 1 to 98%.

A majority of respondents (83.3%) felt their government have “a little” or no interest at all in incontinence services. Only 4 cited “quite a lot” of government interest. Ten organisations did lobby their government for funding. Strategies that help in the lobby include direct mailing, working with an umbrella group of charities to change attitudes, through grants, and applications to specific funds on a project basis like production of guidelines and maintenance of a national help-line which indirectly helps to fund other administrative and promotion activities. One USA organisation mentioned “working to educate Congress.”

Payment method of the continence services varies from countries and types of services. In India, Japan, Korea, Philippines and Holland, the government is apparently not involved in payment of any of the continence services. For the remaining 14 countries government funding is available for surgery, medications and investigations / research (12), conservative treatment (11), specialist nurse and physiotherapy (10), and other incontinence services (5). Insurance may be used in paying for surgery and physiotherapy in 12 countries, conservative treatments and medications in 11, specialist nurse (7), investigations/research (6) and other incontinence services

(4). Holland and Korea are the 2 countries where all incontinence services are payable by insurance/private only. However, in India, Israel and Hong Kong, insurance does not pay for any incontinence services.

5. SERVICE PROVISION AND ACCESS

Four countries reported the urologist as the primary health care professional of specialised incontinence service and the advanced practice nurse was reported as the primary provider in 2 countries. The remaining 13 countries appeared to have no single primary health care professional of specialised service, and they include urologist (12), urogynaecologist (10), gynaecologist (9), geriatrician (7), general practitioner (7), advanced practice nurse (5), registered nurse (4), physical therapist (4), gastroenterologist (1) and colorectal surgeon (1).

Eleven countries have a “continence advisor” in their health care structure, and in 8 countries, the nurse is the “advisor.” In Taiwan and Indonesia, the physiotherapist is the “continence advisor,” while either the nurse or physical therapist may be the “advisor” in UK.

In 13 countries, referral by a family doctor is the most common way a person gains access to a continence specialist. The other ways include: self-referral to specialist continence nurse (9), self-referral to hospital doctor (7), through National Health care System (4) and through organisations or other health care professionals (3). Two organisations reported that they were not sure of the referral system in their country,

A toll free number is offered by 11 organisations. Most (72.7%) received between 1 and 25 calls per day. Only 1 had received between 51 and 100 calls. Eleven organisations were able to quantify the number of “hits” or “visitors” to their respective websites per month. The number ranged from 100 to 200,000. The highest was recorded by NAFC, USA.

Fourteen organisations provide consumer education and brochures in a different language. The information provided includes “General information on incontinence” (11), “Use of products and devices” (5) and “Others” (5), for example, “clinical procedures,” “bedwetting information for parents” and “pelvic floor muscle exercise.”

6. PUBLICITY AND AWARENESS

A majority (20) of the organisations reported the understanding of the general public about incontinence as “a little.” Only 3 organisations reported

“quite a lot,” while one (1) felt that the public do not have any understanding at all. Ten (41.7%) organisations have conducted surveys of the lay public concerning incontinence issues. Only half had published the surveys. Four organisations felt that the media coverage of incontinence is poor, 17 felt they were fair, and only 3 reported the coverage as good. Eight quoted “uncomfortable with the subject matter” as the biggest obstacle to getting coverage from the media. Other reasons cited include “lack of education” (6), “stigma” (3), “no interest” (1) and “not newsworthy or nothing sensational” (2). There was apparently one request from the media for payment to support “editorial space.”

Most organisations (19) reported having had sponsored a National Public Awareness Campaign, Health Promotion Project, or Health Fair on incontinence or a related topic. Sixteen have had the most recent programmes in 2003 or on-going till 2005. Poland has the most number of programmes with 13. The rest varies from 1 to 5. Examples of the programmes include:

- Australia – Helpline promotion
- Belgium – GP and incontinence
- Canada – Incontinence awareness month
- Hong Kong – Continence promotion
- Indonesia – GP seminars
- India – Public awareness exhibition
- Japan – Let’s talk and think about continence
- Korea – Incontinence awareness campaign
- New Zealand – National bladder awareness week
- Poland – National billboard campaign
- Singapore – Women’s health issues & healthy aging
- Taiwan – A dry and comfortable spring
- UK, Continence Foundation – Continence awareness week
- UK, ERIC – Bed-wetting awareness in schools
- UK, Incontact – Healthy bladder campaign
- USA, IFFGD – IBS awareness month
- USA, SFC – Stigma in healthcare
- USA, NAFC – Women’s forum on lifelong bladder health

Seventeen of them were able to quantify the results of the Public Awareness Campaigns. Poland has seen

the highest number of articles (279) in newspapers, while the rest has between 4 and 141. ERIC has the highest number of programmes (20) on television; the rest have between 1 and 10. Other results consequent to the programmes include “increase in calls for information to the National Helpline,” “increased calls to helpline,” “increase number of website hits,” “radio programmes,” “more people coming for consultation” and “200 Million Impressions of Public Service Announcement.”

There were 15 respondents who shared experiences learned from the programmes they conducted. One commented that it was important to perceive the needs of the targeted audience for scientifically oriented programmes or it becomes too overwhelming. One felt it was not beneficial to organise an awareness programme unless the target audience has some incontinence related problems. Two claimed there was no media attention, with one adding that public was still embarrassed to come forward. One shared that a lot of people still do not know where to seek help. One mentioned that there was no interest from doctors except for a few. Another commented on the low priority given to address the problem. However, four said that media interest and awareness had increased although FI remained “taboo” as mentioned by one. One believed continence education should start in early years as school children are interested in continence.

Respondents felt that campaigns could be more successful if education of health care professionals and voluntary organisations working in health related areas were performed prior to educating the public. Getting funding and generating publicity or media interest, like working together with a leading newspaper, using TV, internet and billboards on public transport are felt to be important success factors. The interest may be increased if a sufferer is willing to publicise his or her own condition, or if programmes are made more attractive, such as offering prizes for quizzes or contests. Any message should be positive, direct to the point and in simple language that patients and consumers understand. Seeking new initiatives (e.g. National Toilet Card) to get the press interested, having celebrities to talk about the problem, provide free participation to encourage more attendances, and direct mailing are some of the other ideas.

7. OTHER INITIATIVES

Other comments or suggestions from respondents include building a data base of interested people who

could contribute using email as a medium to create public awareness, making web-site more interactive, establishing a parallel charity with professional trustees to get funding, collaborating with governmental agencies to put educational posters on incontinence in all public toilets, regular continence activity for elderly and children twice a year, focusing on providing advice and support to members to help them deliver a better service, and ensuring patient organisations work together with the medical community. The UKCF estimated that they are currently reaching over 250,000 people a year by phone, web, email, letters and leaflets distributed. ERIC mentioned they hold bi-annual conferences and offer training seminars to health professionals. Incontact hoped to produce more accessible booklets (e.g. in Braille). The NAFC suggested new ventures into diseases-specific publications, a website for outbound communication (e.g. webcast, bladder forum, advocacy), and computerized database for free unbiased matchmaking. Indonesia has plans to conduct a series of incontinence forums in all major cities.

RECOMMENDATIONS ON NATIONAL ORGANISATIONS

Based on the literature reviewed in this section, the following recommendations can be made:

- There is a need for the formation of a worldwide resource centre, preferably through the International Continence Society. The centre should update educational materials and verify best practice experiences or activities while ensuring efficient sharing and optimum use of resources for promoting continence, especially for countries with fewer resources. A regular update via survey is useful to independently monitor this activity. **(Grade D)**
- Continence organisations should establish long-term governmental, as well as, commercial collaboration, particularly in terms of continuing support and funding for mutual benefits. Agenda and funding priorities must be for the benefit of consumers and general public. **(Grade D)**
- Continence organisations should have the outcomes and cost-effectiveness of their programmes and activities independently evaluated. **(Grade D)**

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RECOMMENDATIONS FOR CONTINENCE PROMOTION: PREVENTION, EDUCATION AND ORGANISATION

Continence promotion involves informing and educating both the public and health care professionals that incontinence (both urinary and bowel) is not inevitable or shameful, but is treatable or at least manageable. Progress has been made in the promotion of continence awareness through primary prevention, education of professionals and consumers, organization of the delivery of care, and public access to information on a worldwide basis. However, incontinence needs to be identified as a separate issue on the world health care agenda. All governments are encouraged to take an interest in and to support the development of continence services by actively developing policies and providing adequate funding. These should include a primary prevention strategy.

1. PRIMARY PREVENTION

Primary prevention studies should not be limited to individual interventions, but also test the impact of population-based public health strategies **(Grade C)**

Pelvic floor muscle training (PFMT) should be a standard component of prenatal and postpartum care **(Grade B)**

Randomised controlled trials (RCTs) should be conducted to test the preventive effect of PFMT for men post-prostatectomy **(Grade B)**

Further investigation is warranted to assess the efficacy of PFMT and bladder training (BT) for primary prevention of urinary incontinence (UI) in older adults **(Grade B)**

2. CONSUMER AND PROFESSIONAL EDUCATION

There is a need for rigorously evaluated continence education programmes which adhere to defined minimum standards for continence specialists, generalists and the public/consumer, utilizing web-based and distance learning techniques alongside traditional methods. **(Grade D)**

- Compulsory inclusion of incontinence in the basic curriculum (physicians, nurses, physiotherapists and allied health professionals). Incontinence should be identified, planned and preferably taught as a separate topic
- Specific education programmes adhering to approved standards should be reported to a recognized central body.
- Public education programmes should be independently evaluated

There is a need for research on the most effective means to educate the public and professional groups on continence issues. **(Grade D)**

- Translation of research into improved clinical practice and identification of methods by which this happens.
- Mechanisms for increasing professional motivation to acquire education and improve performance.

- Effectiveness and impact of consumer education initiatives

There is a need for collaboration at the national, international and practice level to ensure that efforts are not duplicated or in conflict. Information banks of continence education material should be shared. This could be facilitated by the ICS. **(Grade D)**

3. ORGANIZATION

a) Delivery of Continence Care and Services

Government support and co-operation are needed to develop services, and responsibility for this should be identified at a high level in each Health Ministry. Incontinence should be identified as a separate issue on the health care agenda. There is a need for funding as a discrete item for funding, not to be linked to any one patient group (e.g. elderly or disabled), and not as an optional service. **(Grade D)**

No single model for Continence services can be recommended. Because of the magnitude of UI prevalence, detection and basic assessment will need to be performed by primary care clinicians. Specialist consultation should generally be reserved for those patients where appropriate conservative options have failed, or for specified indications. **(Grade D)**

There is a need for research on outcomes, not just the process of service delivery. These outcomes must be patient-focused outcomes, evaluate the outcomes of all sufferers who present for care using validated audit tools/outcome measures and assess the values of services in the long-term by the undertaking of longitudinal studies. **(Grade D)**

There is a need for cost-effectiveness studies of the services currently provided. **(Grade D)**

b) National Organisation

There is a need for the formation of a worldwide resource centre, preferably through the ICS. The centre should update educational materials, verify best practice experiences or activities while ensuring efficient sharing and optimum utilisation of resources for promoting continence. This is especially important for countries where there is little development of services, education and awareness. A regular update via survey is useful for this purpose. **(Grade D)**

Continence organisations should establish long-term governmental, as well as, commercial collaboration, particularly in terms of continuing support and funding for mutual benefits. Agenda and funding priorities must be for the benefit of consumers and the general public. **(Grade D)**

It is critical that Continence organisations undergo independent evaluations. This evaluation process should include a measure of cost-effectiveness for each continence promotion activity or programme. **(Grade D)**

Appendix 1 -NATIONAL CONTINENCE ORGANISATIONS

The following is a list of national organisation noting those who completed the 2003 survey.

| Country | Organisation Name | Survey Received |
|----------------|--|-----------------|
| AUSTRALIA | Continence Foundation of Australia Ltd AMA House, 293 Royal Parade Parkville, Victoria 3052 Tel: 61 3 93472522 Fax: 61 3 93472533 website: www.continence.org.au | X |
| AUSTRIA | Medizinische Gesellschaft für Inkontinenz Österreich Speckbacherstrasse 1 A-6020 Innsbruck Tel: (43) 512 58 38 03 Fax: (43) 512 58 94 86 Website: www.inkontinenz.at | |
| BELGIUM | U-Control vzw, (Belgian Association for Incontinence) Leopoldstraat 94 30000 Leuven Tel: 32 8161 6455/32 38213047 Fax: 32 816 16270/32 382 14475 Website: www.sosincontinence.org Email: jean-jaques.wyndaele@uza.be | X |
| BRAZIL | Brazilian Foundation for Continence Promotion Email: seabrarios@uol.com.br | |
| CANADA | The Canadian Continence Foundation 2100 Marlowe Ave, Suite 350 Montreal, Quebec H4A 3L5 Tel: (1) 514 488-8379 Fax: (1) 514 488-1379 Website: www.continence-fdn.ca | X |
| COLOMBIA | Calle 23 Norte # 2N-58 Tel: 660 10 62 Fax: 661 10 95 Website: www.urologiacali.com | |
| CZECH REPUBLIC | Inco Forum Ceska spolecnost podpory zdravi IKEM pavilion S2 Praha 4 PSC 140 00 Tel: (420) 02-61-082135 Fax: (420) 02-61-082135 | |
| DENMARK | Kontinensorenigen (The Danish Association of Incontinent People) Danish Continence Association Vesterbrogade 64, 1620 Copenhagen V Website: www.kontinens.dk/ Executive Manager Tel: 45 33 32 52 74 Fax: 45 33 32 52 75 Email: info@kontinens.dk | |
| FRANCE | Femmes pour Toujours Nicole Kremer, President 15/17, rue des Nanettes Paris 75011 Tel : 43 74 36 93 Email : francoise.kremer@femsante.com Website : www.femsante.com | |

| Country | Organisation Name | Survey Received |
|-----------|--|-----------------|
| GERMANY | Gesellschaft fur Inkontinenzhilfe e.V. (GIH) Friedrich-Ebert-Strasse 124 34119 Kassel Tel: (49) 0561 780604 Fax: (49) 561 776770 Website: http://www.gih.de | X |
| CHINA | Hong Kong Continence Society c/o Dept of Medicine and Geriatrics United Christian Hospital 130 Hip Wo Street Hong Kong Tel: 852 237 94822 Fax: 852 234 72325 Email: emfleung@ha.org.hk | X |
| HUNGARY | Inko Forum Levelezeski cm Budapest, pf 701/153, 1399 Phone: 06 80 730 007 Email: level@inkoforum.hu Website: www.inkoforum.hu | |
| INDIA | INDIAN CONTINENCE FOUNDATION 273/1005 I N Block, 19th C Main Rajaj nagar Bangalore 560 010 Tel: 91 80 313833/3424728 Fax: 91 80 313833/3225824 Website: www.indiancontinencefoundation.org | X |
| INDONESIA | INDONESIAN CONTINENCE SOCIETY Sub Dept of Urogynecology Dept of OBGYN Medical Faculty of University Dr. Cipto Margunkusuma Hospital Indonesia Tel: 62 21 392874/3923631/392/3632 Fax: 62 21 392874/3145592 Email: urogyn@centrin.net.id | X |
| ISRAEL | National Center for Continence Rambam Medical Centre, POB-9602 Haifa 31096 Tel: 972-4-8543197 Fax: 972-4-8542098 Email: ig054@hotmail.com | X |
| ITALY | Fondazione Italiana Continenza (The Italian Continence Foundation) Via dei Contarini, 7 2 01 33 Milano Website: www.continenza-italia.org Email: info@continenza-italia.org Associazione Italiana Donne Medico (AIDM) Tel: 39 335 282045/39 065 811390 Email: pcecchi@opbg.net Website: www.donnemedico.org The Federazione Italiana Incontinenti (FINCO) Tel: 080-561.91.81 / 800-050-415 Email: finco@finco.org | |

| Country | Organisation Name | Survey Received |
|----------------|--|------------------------|
| JAPAN | Japan Continence Action Society Continence Centre 103 Juri Heim, 1-4-2 Zenpukuji Suginami-Ku Tokyo, 167 0041 Tel: 81 03 3301 3860 Fax: 81 03 3301 3587 Website: www.jcas.or.jp | X |
| KOREA | Korea Continence Foundation 1-19, Mukjeong-dong, Jung-gu Department of Urology Samsung Cheil Hospital Pusan City, Korea Tel: 82 2 2000 7585 Fax: 82 2 2000 7787 Website: www.kocon.or.kr Email: jtandro@samsung.co.kr | X |
| MALAYSIA | Continence Foundation (Malaysia) c/o University Hospital, Lembah Pantai Kuala Lumpur 59100 Tele: 603 7956 4422 Fax: 603 758 6063 Email: lohcs@medicine.med.um.edu.my | |
| NETHERLANDS | Pelvic Floor Netherlands PO Box 23594, 1100EB Amsterdam Tel: 31 20 69 70 304 Fax: 31 20 69 71 191 Website: www.pelvicfloor.nl Pelvic Floor Patients Foundation (SBP) Stichting Bekkenbodem Patienten PO Box 10032 3004 AA Rotterdam Website: www.bekkenbodem.net Vereniging Nederlandse Incontinentie, Verpleegkundigen (V N I V) Postbus 1206 3434 CA Nieuwegein Tel: (31) 30 606 0053 Fax: (31) 30 608 1312 Website: www.vnic.nl/ | X |
| NEW ZEALAND | NEW ZEALAND CONTINENCE ASSN INC PO Box 270 Driry, Mickland New Zealand Tel: 64 9 2947738 Fax: 64 9 2947116 Website: www.continence.org.nz | X |
| NORWAY | NOFUS (Norwegian Society for Patients with Urologic Diseases) Linjeveien 178, N-1400 Ski Norway Tel: 47 64 87 28 45 Fax: 47 64 87 42 08 Email siralf@sensewave.com | |

| Country | Organisation Name | Survey Received |
|-------------|--|-----------------|
| PHILIPPINES | Continece Foundation of the Philippines Division of Urology Philippine General Hospital Taft Avenue Manila, Philippines Tel: (63)-2-525 5453 Fax: (63)-2-525 5453 Email: mela@info.com.ph | X |
| POLAND | NTM (INCO) Forum (The Polish Continence Organisation) Ksiecica Janusza 64 Street 01-452 Warsaw Poland Tel: 48 22 833 59 764 Website: www.ntm.pl Email: tomasz.michalek@ntm.pl | |
| SINGAPORE | Society for Continence (Singapore) Gleneagles Medical Center 6 Napier Road #06-02 Singapore 258499 Tel: (65) 6787 0337 Fax: (65) 6588 1723 Website: http://sfcs.org.sg Email: rani@pacific.net.sg | X |
| SPAIN | Asociacion Nacional de Ostomizados e Incontinentes (ANOI) Tel: 34 98. 556 322 Email: javier@coalicion.org Website: www.coalicion.org | |
| SWEDEN | SWEDISH UROTHERAPISTS Nordensjoldsgatan 10, S-418 04 Goteborg Tel: 46 31 50 26 89 Fax: 46 31 53 68 32 Email: birgtha.lindehall@vgregion.se Sinoba Tel: 46 8 585 826 89 Email: marta.lauritzen@hs.se Website: www.sinoba.se | |
| TAIWAN | TAIWAN CONTINENCE SOCIETY Division of Urology Taipei Veterans General Hospital. 201 Sec. 2, Shih-Pai Road Taipei, Taiwan 112 Tel: + 886 2 2871 1132 Fax: + 886 2 2871 1162 Website: http://www.tcs.org.tw Email: msuuf@ms15.hinet.net | X |
| THAILAND | Incontinence Center Ramathibodi Hospital & Medical School Rama6 Road Bangkok 10400 Thailand Tel: 662-201 1315 Fax: 662-201 1316 Email: ravkc@mahidol.ac.th | X |

| Country | Organisation Name | Survey Received |
|----------------|--|-----------------|
| UNITED KINGDOM | ASSOCIATION FOR CONTINENCE (ACA) 102a Astra House, Arklow Road New Cross, London SE14 6EB Tel: (44) 020 8692 4680 Fax: (44) 020 8692 6217 Website: www.aca.uk.com/ Email: info@aca.com.uk | X |
| | THE CONTINENCE FOUNDATION, UK 307 Hatton Square 16 Baldwin Gardens London EC1 N 7RJ Tel: (44) 207 404 6875 Fax: (44) 207 404 6876 Website: http://www.continence-foundation.org.uk Email: continence.foundation@dial.pipex.com | X |
| | Incontact United House, North Road London N79DP Tel: (44) 0870 770 3246 Fax: (44) 0870 770 3249 Website: www.incontact.demon.co.uk/ | X |
| | Enuresis Resource and Information Centre (ERIC) 34 Old School House, Britannia Road Kingswood, Bristol BS15 8DB Tel: (44) 117 960 3060 Fax: (44) 117 960 0401 Website: www.eric.org.uk | X |
| UNITED STATES | American Foundation for Urologic Disease Bladder Health Council 1128 North Charles Street Baltimore, Maryland 21201-5559 Tel: 410-468-1800 ; Fax: 410 468 1808 Website: www.afud.org | |
| | International Foundation for Functional Gastrointestinal Disorders P O Box 170864 Milwaukee WI 53217-8076 Tel: 414 964 1799 Fax: 414 964 7176 Website: www.iffgd.org And www.aboutincontinence.org Email: iffgd@iffgd.org | X |
| | Interstitial Cystitis Association National Association For Continence P O Box 1019 Charleston, SC 29402 62 Columbus Street Charleston, SC 29403 Tel: 843 377 0900 Fax: 843 377 0905 Website: www.nafc.org Email: nmuller@nafc.org | X |
| | Simon Foundation for Continence P O Box 815 Wilmette Illinois 60091 Tel: (1) 847 864 3913 Fax: (1) 847 864 9758 Website: www.simonfoundation.org Email: cbgartley@earthlink.net | X |

