The Concensus Development Conference—
A Meeting You Should Know About

The Journal of the American Medical Association (JAMA) called it “The Town Meeting of Medical Technology.” Around the Simon Foundation for Continence, it was called “Mrs. Gartley goes to Washington.” “It” is the National Institutes of Health, Concensus Development Conference on Urinary Incontinence in Adults. Although highly scientific, with the greater part of attendees being researchers, Ph.D.’s, nurses, and physicians, this public forum for the discussion of controversial medical topics will affect Informer readers in the years to come as the conclusions from the conference lead to a call for action and change.

The Concensus Development Conference is a finely tuned procedure designed to assimilate the known research on a given medical topic, and to discover directions for future research and treatment modalities. The process begins months before the actual meeting takes place when the National Institute of Health calls together a planning committee which defines the questions to be answered at the meeting, identifies the experts who will be asked to present their testimony, and selects those who will serve as a panel of impartial experts to listen to the facts and arrive at the concensus report.

Last October this process commenced and an extremely intensive three days were spent examining the following questions concerning Urinary Incontinence in Adults:
- What is the prevalence and clinical, psychological, and social impact of urinary incontinence among persons living at home and in institutions?
- What are the pathophysiological and functional factors leading to urinary incontinence?
- What diagnostic information should be obtained in assessment of the continent patient? What criteria should be employed to determine which tests are indicated for a particular patient?
- What are the efficacies and limitations of behavioral, pharmacological, surgical, and other treatments for urinary incontinence? What sequences and/or combination of these interventions are appropriate? What management techniques are appropriate when treatment is not effective or indicated?
- What strategies are effective in improving public and professional knowledge about urinary incontinence?
- What are the needs for future research related to urinary incontinence?

The first two days were filled with testimony and research presentations. The panel and an audience of over seven hundred attendees were active participants in the proceedings. Once the research for each sub-topic was presented, the meeting was open for questions and discussion from both the floor and the panel. Many Board members from the Simon Foundation participated: Neil Resnick, M.D., Joseph G. Ouslander, M.D., Alan J. Wein, M.D., Cheryle Gartley, President, Simon International, Marisa Zoritzo, M.D. (Simon Canada) and Anita Saltmarche, R.N. (Simon Canada).

At the end of the second day of testimony the panel began work in earnest to arrive at a concensus answer for each of the questions posed. Working all night and into the early morning hours, a draft statement was prepared and presented to the audience early on the morning of the third day, when once again a long and often somewhat heated floor discussion took place. This thorough process melded reports from long research hours in quiet laboratories with information from the hectic clinical experience of practitioners, questions from the public, and viewpoints of industry. Drafting, arguing, rewriting... the panel forged a 30-page document, the Concensus Development Conference Statement, documenting the state of incontinence in America.

“To see so many talented people taking three days from their professional and private lives to devote time to incontinence was a very uplifting experience for me,” stated Mrs. Gartley, President of the Simon Foundation for Continence in a television interview shortly after the meeting. “This focus on continence is sure to bring long needed improvements in the care and treatment of people with incontinence.”

The following conclusions of the report focus attention on the changes needed in our society:
- Urinary incontinence is very common among older Americans and is epidemic in nursing homes.
- Urinary incontinence costs Americans more than $1 billion each year.
- Urinary incontinence is not part of normal aging, but age-related changes predispose to its occurrence.
- Urinary incontinence leads to stigmatization and social isolation.
- Of the 10 million Americans with urinary incontinence, more than half have had no evaluation or treatment.
- Contrary to public opinion, most cases of urinary incontinence can be cured or improved.
- Every person with urinary incontinence is entitled to evaluation and consideration for treatment.
- Inadequate nursing home staffing prohibits proper treatment and contributes to the neglect of nursing home residents.
- Medical and nursing education neglect urinary incontinence. Curriculum development is urgent.

A major research initiative is required to improve assessment and treatment for Americans with urinary incontinence.

The complete report from this conference is available from the Simon Foundation for Continence. We urge all of our readers to send for it, read it thoroughly, and then give it to the physicians and nurses who manage your care. To receive your copy, send $2.00 to: CONCENSUS DEVELOPMENT STATEMENT. The Simon Foundation for Continence, P.O. Box 815, Wilmette, Illinois 60091.

Disseminating this information that so many worked so hard to achieve is the responsibility of all of us. Please do your part in helping us to CARE—Continence Awareness, Research, and Education.
Simon Says:

WELCOME TO MY WORLD . . . is a 35 minute video program which provides viewers with a unique opportunity to visit the daily world of a person with a disability. One of the disease processes which can cause incontinence is multiple sclerosis. Welcome To My World is the story of a woman who because of multiple sclerosis must learn to cope with quadriplegia. Anne Shuell is a teacher with graduate work in counseling. In this film she speaks about learning to cope with disability and how to lead a productive life. Welcome To My World represents the world of disability at large, not just multiple sclerosis.

Health-care professionals and individuals alike will enjoy the learning experience which can be gained from this film. Purchase price, $80.00, 1 to 3 day rental, $10.00 plus shipping. To order write: Media Library, Educational Communications Center, 24 Genen Hall, State University of New York at Buffalo, Buffalo, New York 14260.

TRAVEL RESOURCE . . . Ten Questions and Answers About Air Travel for Wheelchair Users can be obtained by writing to the Eastern Paralyzed Veterans Association, 75-20 Astoria Blvd., Jackson Heights, NY 11370-1178. This booklet contains a chart locating aircraft seats with movable aisle armrests and other accessibility features which help make air travel easier and worry free for those traveling with a wheelchair.

THE MERRY CHRISTMAS . . . The staff at the Simon Foundation had a very merry Christmas thanks to many of our readers who sent us Christmas cards. We were delighted to hear about all of your progress, and to be included in your Christmas wishes. Thanks to each and every one of you for your thoughtfulness.

NEW BOOK AVAILABLE IN U.S. EXCLUSIVELY THROUGH THE SIMON FOUNDATION . . . Urinary Incontinence: A Practical Guide for People with Bladder Control Problems, Their Careers and Health Care Professionals, by David Fonda and Cynthia Wellington. Written and published in Australia, this book has plenty to offer people with incontinence the world over. Chapter titles include: The Bladder; the Nervous System; Urinary Symptoms Associated with Incontinence; What Causes Incontinence; Urological and Gynaecological Causes of Incontinence; Reversible or Modifiable Causes of Incontinence; Managing Incontinence; Using Bladder Charts; Bladder Retraining Programs; Pelvic Muscle Exercises; Dealing with the Psychological Consequences of Incontinence; Other Practical Hints; Achieving Social Continence; and Preventing Incontinence. You can order this 51-page softbound book direct from the Simon Foundation, P.O. Box 835, Wilmette, Illinois 60091 for $6.95 plus $1.00 postage and handling.

THOUGHT FOR THE DAY: “It is not the critic who counts, not the man who points out how the strong man stumbles or where the doer of deed could have done better. The credit belongs to the man who is actually in the arena, whose face is marred by dust and sweat and blood, who strives valiantly; who errs and comes short again and again; who knows the great enthusiasms, the great devotions, and spends himself in a worthy cause; who, at the best knows in the end the triumph of high achievement; and who, at the worst, if he fails, at least fails while daring greatly, so that his place shall never be with those cold and timid souls who know neither victory nor defeat.”

Theodore Roosevelt.

CHANGING YOUR ADDRESS? If you move and want to keep your Informer coming regularly, let us know your new address. Please be sure when corresponding to us to always include the eight digit code found above your name on the mailing label.

One Voice: An Editorial

When he announced he was going to retire, we all worried about him. After all, he had been a busy and successful proprietor of a retail store for most of his life. Long ago, while in the military services, he had written a column for Stars and Stripes with the byline, Mild Lee Nutts . . . maybe now with nothing to do he would begin to live up to his journalistic name. And although Mom had married him for better or for worse, she had not expected to have him for lunch everyday! No one could imagine the store without him and what would he be doing with himself? Little did any of us imagine that he’d become THE VOLUNTEER.

While we worried about his retirement, I don’t think any of us knew that there were so many organizations in one small American town that could use a volunteer. But, THE VOLUNTEER found them. The most of the local church of course, the local concert series, Tag Day, Diabetes Day. . . Need I go on? Somehow, when he became a candy stripper at the community hospital he seemed to fit in just fine with all the high school girls. After all it is hard to argue with the most concert membership sold, the fullest canister on Tag Day, the most volunteer hospital hours, and all the rest of his “retired” accomplishments.

Most important to me, he has never been too busy when the Simon Foundation needed some manpower. He believes wholeheartedly in the work of the Foundation of course, but I think his ready availability might also have something to do with the fact that Dad and I belong to a mutual admiration society. Who else but a father would painstakingly freeze off all the unused stamps which come in the mail on return envelopes which are too small to fit our mailboxes? Dad reserves them onto a usable envelope to help us pinch pennies. Who do you think tabulates all the surveys from our faithful readers? THE VOLUNTEER, of course!

Much has been written recently about volunteerism in America. Jane Bryant Quinn of the Washington Post Writers Group wrote: “Charities are trying to set up a new standard for Americans that they call ‘Give Five’, or 5 percent of your income. The charities also are encouraging Americans to give five hours a week to nonprofit organizations.” TIME Magazine in an article “For Goodness’ Sake” (January 9, 1989) found that when examining volunteer motives “the most common reason cited (for volunteering) is the desire to do something useful.” The article goes on to say the “105,000 new service organizations were born between 1982 and 1987.” The Simon Foundation for Continence, “born” in 1982, is one of these organizations. Although I founded Simon in order that others would not have to suffer through the same health care frustrations I experienced, I had already learned the virtues of volunteering during my childhood at home. In my home, long before “Give Five” became a slogan, my family gave “twenty-five” because we believed that doing something useful with one’s life was the prime reason for spending time on planet earth.

So, for the first time in six years, I’m about to use my founder’s perorative and name THE VOLUNTEER (my dad), Simon’s 1968 Volunteer of the Year. With the title comes my respect, thanks, and appreciation Dad, and hopefully a little surprise. You see, readers, THE VOLUNTEER is not able to travel very much and lives miles away from Foundation Headquarters. He has always envied our other volunteers when 12,000 pieces of mail hit us all in the space of three short days. Digging through this mountain of mail would be his idea of a volunteer’s dream come true!

So, for all of you who are always asking how you can help, you are needed now! The Simon Foundation is over 50,000 strong, so let’s show THE VOLUNTEER what volunteerism is worth. If each of you would mail a simple postcard to our Volunteer of the Year (say 49,999 pieces — after all one of you might be out of the country), together we could demonstrate what a “little mail” and a big thank you looks like.

Please take a moment to mail your postcard or note of thanks to: The Simon Foundation Volunteer of the Year, P.O. Box 107, Ottawa, Illinois 61350. Oh yes, don’t forget the postscript: “Get well soon,continent And thank you!” And I am sure the writer sees all, this mail should keep THE VOLUNTEER on the planet for years. . . Why? He will try to answer all of it of course!
New Video Tapes from England Available Through Foundation

The Simon Foundation for Continence is pleased to announce the availability of Understanding and Treating Incontinence: A Series of Seven Videos by Dr. J.C. Brocklehurst from the Department of Geriatric Medicine at Manchester University (England). Dr. Brocklehurst has been referred to as “the father of modern research into incontinence” and has long been an advocate of information dissemination. He was recently a featured speaker at the National Institutes of Health Consensus Development Conference on Urinary Incontinence in Adults held in Washington, D.C., (see story this issue).

The Series of Seven Videos was developed as a teaching tool for medical professionals. The tapes can be used in many ways—for private study, in medical and nursing schools, at health centers or in postgraduate studies. The program includes:

1. Urinary incontinence—causes, investigations and treatment options (16 minutes);
2. Urinary incontinence—principles of management for the General Practitioner (27 minutes);
3. Pelvic floor muscle re-education (24 minutes);
4. Promoting urinary continence—who and how? (21 minutes);
5. Fecal incontinence (19 minutes);
6. Urethral catheterization—intermittent and continuous (35 minutes);
7. Aids and appliances used for the management of incontinence (33 minutes).

The series is accompanied by a booklet detailing the material presented and providing references for further study. A copy of this booklet will be provided with all orders.

The Simon Foundation invites the professional community to take advantage of this fine series by integrating these videos into teaching programs. If you would like a synopsis of each video before ordering, please send your request to: SYNOPSIS/VIDEO SERIES, The Simon Foundation for Continence, P.O. Box 815, Wilmette, Illinois 60091.

(EDITOR’S NOTE: Although this teaching series was developed with the physician and nurse in mind, we believe it is also appropriate for viewing by the layman with incontinence. We feel that everyone involved with incontinence will find the information of great value.)

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Dear Betty:

You sound like a member of the Foundation who is bound and determined to get to the bottom of your problem. Please let us know about the results you obtain from your quest for information.

Dear Fellow Adult Bedwetters:

You are not alone! Millions of us wake each morning in a wet diaper. It is the last thing we put on at night and the first thing to come off in the morning. The fact that our bladder leaks while we sleep should not affect our self-esteem. Nor should our buying diapers or adult plastic pants be any more embarrassing than a woman buying sanitary napkins. I am a happily married 32 year old man with a successful career who happens to be a chronic bedwetter—condition I have tried to cure in vain. I used to hate myself for waking up soaked wet, yet my wife and daughter didn’t love me any less, so why did I feel so badly? I was out of town with a female business associate last month. When I went in her hotel room to pick her up for dinner, I noticed a small stack of adult disposable diapers next to her bed. She turned red when she realized they were visible, but soon relaxed as we got into a discussion about adult bedwetting. As I said, we are not alone!

Eric Ross
P.O. Box 2762
Sepulveda, CA. 91343

Dear Eric:

Thanks for your comments. We hope they will help someone else to see that incontinence in all of its forms, is a common problem. Be prepared for some mail. We understand from other readers who asked that we publish their name and address that they spent several weeks answering letters!

Dear Informer:

I read the Informer and like it very much. I am incontinent and wear diapers. I am also 25 years old. A lot of people think incontinence is only for old people, but a lot of us young people have the problem too and like thick diapers. Maybe older people want thin things, but I know I don’t. I wish diaper makers could understand this. Young people are active and need thicker diapers for protection. Please print my name and address so that others can write to me if they wish to do so.

William P. Lacey
Box A
Oakdale, Iowa 52319

Dear Mr. Lacey:

The need for more absorbency in incontinence products is often expressed by our readers. Many people would like to obtain two levels of absorbency, a thinner diaper which can be concealed beneath clothing for daytime wear, and a maximum absorbency diaper, regardless of bulk, which will last through the night. The Simon Foundation continues to express the needs of our members to the manufacturing community. We need everyone’s help in this matter. If your needs are not being met by available products in the marketplace, write to the product manager of the brand you purchase and request changes. Your input can make a difference.

Reprint Series

If you’ve been an Informer reader for just a short time you may have missed an article which would be valuable to you. The Simon Foundation Reprint Series may be just what you need. Titles currently available:

**Reprint No. 1:**

"ADVANCED AGE NOT A CAUSE FOR INCONTINENCE"

**Reprint No. 2:**

"FINDING AN INCONTINENCE PRODUCT TO SUIT YOUR NEEDS"

**Reprint No. 3:**

"URINARY INCONTINENCE – ROLE OF THE ENLARGED PROSTATE IN THE OLDER MAN"

**Reprint No. 4:**

"CLEAN INTERMITTENT CATHETERIZATION FOR THE MANAGEMENT OF INCONTINENCE"

**Reprint No. 5:**

"OPERATIONS FOR THE TREATMENT OF GENUINE STRESS INCONTINENCE IN FEMALE PATIENTS" and "KEGEL EXERCISES" (This is one reprint)

**Reprint No. 7:**

"ARE YOU READY TO TALK TO YOUR DOCTOR ABOUT INCONTINENCE?"

**Reprint No. 8:**

"THE LAST OF THE CLOSET ISSUES"—Time Magazine and "THOSE EMBARRASSING AILMENTS: HERE’S HELP!"—Good Housekeeping (These two articles are considered one reprint).

**Reprint No. 9:**

"NATIONAL INSTITUTES OF HEALTH CONSENSUS DEVELOPMENT CONFERENCE STATEMENT: URINARY INCONTINENCE IN ADULTS" (This is a 30 page document).

To order reprint articles, send $1.00 per article ($2.00 for Reprint No. 8) with a business-size self-addressed stamped envelope to: REPRINTS, The Simon Foundation Box 835-R, Wilmette, Illinois 60091

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**REQUEST FOR MEMBERSHIP**

Yes, I would like to be a member of the Simon Foundation for Continence. Please mail to me the the Foundation’s quarterly newsletter, The Informer. Enclosed is $15.00 for my membership. I understand that all mailings will come to me in a unidentified envelope.

*Contributions and membership in the Simon Foundation are tax deductible.

Name

Address

City

State Zip Code

*NOTE: Your annual membership will begin with the next edition of The Informer.