U.S. Public Health Service Releases
New Clinical Practice Guideline On
Urinary Incontinence In Adults

The Agency for Health Care Policy and Research (AHCPR) was established by Congress in December 1989 to promote effective, appropriate, high quality health care; increase access to care, and improve the way health services are organized, delivered, and financed.

Within this agency The Office of the Forum for Quality and Effectiveness in Health Care released on March 23, 1992 a Clinical Practice Guideline on Urinary Incontinence in Adults. Clinical practice guidelines are recommendations for patient management, based on scientific research, that help medical practitioners decide what care is appropriate for a specific health problem. The significance of incontinence as a major health concern is underscored by the fact that incontinence was the second topic upon which the AHCPR focused.

In his opening comments to the press, the head of the U.S. Public Health Service, James O. Mason, M.D. stated: "Just over two weeks ago we released a guideline on acute pain management. It was the first clinical practice guideline produced and reviewed by private experts assembled by the AHCPR. It justifiably received a great deal of attention. Secretary Sullivan and I described it as nothing less than the beginning of a peaceful revolution in American medicine.

"Today we continue that revolution. Today we have a guideline on a condition (incontinence) that is at least as important as post-operative pain, causing not just a day or two of distress but many years of it."

The Simon Foundation for Continence co-sponsored the press conference announcing the availability of these guidelines in conjunction with the American Urological Association, the American College of Obstetricians and Gynecologists, and others interested in promoting continence. Lynda B. Austin, R.N., a member of the Foundation's Governing Board represented the Simon Foundation for Continence and spoke to the press.

"For over a decade, The Simon Foundation for Continence has worked to bring incontinence out of the closet, remove the stigma associated with incontinence and educate the American public," stated Ms. Austin. "Today, on behalf of all our members, we'd like to thank the co-chairmen of the committee, Dr. Ananias Diokno and Dr. Kathleen McCormack, and all of their committee members for their dedication and hard work. As a nurse, and also a person who has been cured of incontinence, I can testify that these guidelines are going to make a crucial difference in the quality of life.

IFBD...A New Organization
For People With Bowel Problems

In 1985 Nancy Norton was an excited soon-to-be mother, healthy and involved in her career as a textile artist. Folk wisdom states that nothing changes life exactly like having the addition of a new baby to the household. Nancy would have to face not one but two enormous changes over the next few months. Due to an obstetrical injury, a fourth degree rectal/vaginal laceration, Nancy became fecally incontinent. After two attempts to surgically repair the damage failed, and over two years of consulting experts around the country to determine if any new techniques or research in process would be of help to her, Nancy felt she had explored the options for cure. She would learn to cope. There was nothing in her decision to cope or background to suggest that seven years later she would be the founder and executive director of a new not-for-profit organization addressing the issues of bowel dysfunction, The International Foundation for Bowel Dysfunction (IFBD).

Founded in 1991, IFBD addresses the many forms of bowel dysfunction including abnormalities in anorectal function such as constipation, levator ani syndrome, spastic pelvic floor, rectocele or rectal prolapse. The foundation also helps people who have fecal incontinence.
Incontinence Guideline continued

of care in America. All of us are present today to support the guidelines for one purpose, to see that every American hears the message that incontinence can be cured, treated, and managed. As journalists, you can make sure this happens.

Cheryle B. Gartley, President of the Foundation, along with Anaril C. Diokno, M.D., Guideline Panel Chair, was featured in a Video News Release which was produced by the American Association of Retired Persons and broadcast by satellite shortly after the press conference to television stations throughout the United States.

According to a fact sheet released by the Agency for Health Care Policy and Research, the purpose of The Clinical Practice Guideline is to improve diagnosis and treatment of urinary incontinence; reduce variations in treatment and thereby improve the quality of patient care in clinical practice; educate health professionals and consumers about the condition; and encourage further biomedical, clinical, and cost research on the topic.

"Let me emphasize that these guidelines are not Big Brother telling doctors and nurses what to do," states Dr. Mason. Although commissioned by the AHCPR, the guidelines are the result of the work of a private sector multidisciplinary panel of specialists in urinary incontinence composed of urologists, obstetrics/gynecologists, gerontologists, primary care practitioners, nurses, an occupational therapist, psychologists, a health educator, an administrator, and a consumer representative. Together this panel reviewed over 7,000 studies or reports on incontinence issued from 1965 to the present. Before being released the guideline was tested in doctors offices and hospitals and subject to peer review.

Several versions of the guidelines are produced to meet different informational needs according to the index of the guideline book. The Guideline Report contains the clinical practice guideline with complete supporting materials, including background information, methodology, scientific evidence tables, and a comprehensive bibliography.

The Clinical Practice Guideline and the Quick Reference Guide for Clinicians are companion documents for use as desk-top references for clinical decision-

PEN PALS ARE GREAT FRIENDS...
Julian Mitchell (age 26), 1321
Birchwood Avenue, Apt. 303, Chicago, Illinois 60626; Dan Martin Jr., P.O. Box
225, Tupelo MS 38802-0225; Philip S.
Gold (age 43), 211 Harvard Ave., Santa
Clarita, CA 91351; Martin Mooneyham,
Forty 7 Trinity Circle, Little Rock, Arkansas
72209; Henry Jacob Parker (age 33),
SID #4832498, Oregon State Peniten-
tiary, 2605 State Street, Salem, Oregon
97310; Tom Ford (age 41) P.O. Box 2855,
Loop Station, Minneapolis, Minnesota
55402; Troy Brown, 6425 Lawrenceville
Highway, Suite 1-182, Tucker, Georgia
30084-1706; Spencer Friedman, 5941
Woodway Place Court, Houston, Texas
77057; John Fleming, 631 Frank Street,
Huron, South Dakota 57350; Cortland
Dale, P.O. Box 34311, Chicago, Illinois
60634; John Coleman, 2002 Nancy Ann
Terrace, Ocoll, Florida 32761; Brooke
Norman (age 12), 225 Russell Road,
Hurley, New York 12443; Tim
Christensen, 1709 Perkins Road,
Orlando, Florida 32809; Beverly Wil-
liams, P.O. Box 84, Hernshaw, West Vir-
ginia 25107; and John Steward, 29
Hickory Drive North, Raynham, MA
27767.

NEW GUIDES YOU MIGHT FIND USEFUL... How to Choose and Check Out A Doctor: A Patient Friendly Guide is a twenty-two page booklet written by Joan Saxton, M.D. who is Board Certi-

fied in Internal Medicine and Nephro-
logy. Although not written specifically for people who are looking for help in incontinence, it contains several suggestions for locating a physician that will be complimentary to an individual's needs. The booklet is available by writing to Dr. Joan Saxton, 2100 Webster Street, Suite
401, San Francisco, CA 94115. The cost is $4.00. Informer readers might also be interested in the Illustrated Directory of Handicap Products available for $12.95 from Trio Publications, 3600 West Tim-
ber Court, Lawrence, Kansas 66049-
2149. The second edition of the directory is a 300-page buying guide showing approximately 1,000 photos and descriptions of handicapped products designed to aid the physically disabled. The listings range from such products as conventional canes and wheelchairs, to sophisticated electronic devices which enable the blind to "read" and people with severe disabilities to operate a computer. New chapters including listings of organizations that help the disabled and manufacturers' catalogs featuring new and useful products.

THOUGHT FOR THE DAY... "Even if you're on the right track, you'll get run over if you just sit there," Will Rogers. Restlessness and discontent are the first necessities of progress," Thomas Edison.
making in day-to-day care of patients. Recommendations, algorithms or flow charts, tables and figures, and pertinent references are included.

_A Patient's Guide_, available in English and Spanish, is an informational booklet for the general public to increase consumer knowledge and involvement in health care decision making.

"It is my hope," states Ms. Cartley, "that everyone affected by incontinence will not only read _A Patient's Guide_ but will also request the complete Clinical Practice Guideline: Urinary Incontinence in Adults_ and read it from cover to cover. Then give it to your physician or nurse.

All versions of the guideline can be obtained by writing to the Center for Research Dissemination and Liaison, AHCPR Clearinghouse, P.O. Box 8547, Silver Spring, MD 20907 or calling 600-358-9293

Lynda B. Austin, R.N., spoke at The AHCPR press conference on behalf of The Simon Foundation for Continence members.

---

**Letters To The Editor**

Dear Informer Reader:

In the summer issue of The Informer, Mr. Foss wrote and told us how his loving wife accepted and dealt with his incontinence problem. Up until a year ago I would have thought that people like Mrs. Foss were long gone. At the age of 22 I had never had a steady boyfriend or been invited on many dates. I have a birth defect that left me with a club foot and bladder and bowel incontinence. I have good control of my incontinence through diet, catheterization, and medication, and I don't limit my activities, but I didn't think there was a boy out there who would accept all of my problems.

A friend introduced me to an attractive boy who seemed to have no problem dealing with my limp, but I never told him of my other problems. Three months into our relationship I had my first real "accident." I cried and was sure he would never see me again, but the next night he called. Now, 18 months later we are planning to get married.

This letter is for the people out there who are confining themselves to a life alone. Understanding people are not a thing of the past. You may meet a lot of insensitive people before you find the one that loves you enough to accept everything about you, but do people without a continent problem. Do everything you can to be happy. It's worth it.

Kimberly

Dear Informer:

Thanks for the uplifting, insightful letter. You hit the problem on the head when you said that able-bodied people may also have many unpleasant experiences before they find someone who loves them. I once had the pleasant experience of spending a few hours with Miss America. One of the laments she had about her beauty and title was she could no longer sort out who had befriended her for herself!

Have a wonderful wedding and be sure to send the Informer pictures!

Dear Informer:

Just a quick question that you or a pen pal might have an answer for: I like to go to the beach, but find that I can't go into the water without then having to go home immediately to change my diaper. It fills with water and balloons out. I have tried putting bicycle shorts on over

continued on next page
Letters continued

the diaper and under my swim suit to keep the diaper compressed, but the bike shorts all have long legs which show under my swim suit. Could you print this letter so that someone might come up with a solution. Also, I'm 26 and would like to come out of the closet and hear from young people with hints on diapers, dating and drinking beer. Thanks for all your help.

Julian Mitchell
1321 Birchwood Avenue #303
Chicago, Illinois 60626

Dear Simon Foundation for Continence:
I have found it very helpful to laugh at my problems—such as embarrassing accidents—it is obviously a defense mechanism, but the alternative, feeling sorry for oneself—is to me unacceptable. I would like to suggest that you start a column or feature called “Embar- rassing Moments.” People could submit their most embarrassing accidents or occurrence related to incontinence. I would think that such a feature would not only be humorous, but would also illustrate that having an accident in the middle of a movie theatre or at a football game is not really the end of the world. I have included one of my most embar-rassing moments, perhaps it will stimulate others to submit similar events.

While driving from Los Angeles to San Francisco I had a sudden and strong urge to empty my bladder. This was on a long stretch of California freeway and the next service station was about 20 miles away. It was daylight, and there was no place to pull over and head into the bushes. I must have been really nervous and speeding to get to the service station when I was pulled over by the highway patrol. When she asked the inevitable question: “Where do you think you are going in such a hurry?” I decided to be truthful. I told her that I had a bladder problem, and was, to say the least, desperate! She remarked that she had heard that story before and proceeded to write out the ticket. My bladder couldn’t wait, and shortly there was quite a large puddle in my seat. When she returned to give me the ticket, it was obvious what had happened—and she apologized to me! I think that she was more embarrassed than I was.

Marvin from California

So let’s put the question to our readers and see if there are some great stories awaiting us. Readers please send your tales to “Special Moments,” The Simon Foundation for Continence, P.O. Box 835, Wilmette, Illinois 60091.

Dear Cheryle:
Today, I really feel like a new person. I’m sure that you remember the old one that wrote you a couple of years ago and said, “Don’t print this letter and don’t even think about revealing my name!” I really feel that that is all behind me now. To date, I have corresponded with about 200 Pen Pals and shared about my incontinence. I have also talked with many over the telephone. Recently, I shared about my bed-wetting with my mother and step-father for the first time. Also for the first time, I have openly discussed the problem with my urologist, and gained a lot of valuable information. I was contacted by a writer who was working on a book on incontinence, and I even gave a “first person” interview. I guess the icing on the cake occurred the other day when I went to my favorite discount store to pick up a couple of packages of diapers. Another shopper was standing in the incontinent products aisle looking quite confused, so I offered to help. We ended up having a lively discussion about the various products, incontinence in general, the Simon Foundation for Continence and our own personal struggles with incontinence.

How did this wonderful transformation happen? Certainly not overnight. It happened a small step and one small victory at a time. When kind people applaud my courage, I have to chuckle as they just don’t know how many times I have stepped out with a pounding heart, sweaty palms, and a quivering voice. What will you get by taking risks? First you will get rid of a lot of old useless feelings such as shame, fear, and guilt. You will stop wasting time and wearing yourself out trying to find ways to conceal the problem, and finally, you will probably find yourself going more places and doing the things you once told yourself you just didn’t do.

If I can help anyone to take the first step to come out of the “closet” I would indeed feel privileged if they would write to me.

Craig Thompson
P.O. Box 405
Doctors Inlet, Fl. 32030

Dear Craig:
One of the tenets of self-help is that people who have increased their ability to cope and no longer need help stay involved with the group in order to give back to others some of what they’ve gained. We are certainly thankful for your willingness to help others and hope that once again your post office box is overflowing.

Dear Simon Foundation:
I just have to pass this along to you. One of my regular Pen Pals, a fellow named Gary, has an absolutely wonderful sense of humor. He has a suggestion which might interest you. Gary’s job requires him to travel almost constantly, and being incontinent, he has a lot of problems with motel living. He claims that when the cleaning people see him coming, they spread out the rubber sheets! At any rate, his idea is for the Simon Foundation to open up a chain of motels called the “INCONTINENTAL INNS.” Their slogan could be “We Pamper You,” or better yet, “You can Depend on us to Attend to your every need!” Isn’t that absolutely great! Beats crying about the problem doesn’t it?

Sincerely, Florida

Dear Florida: Sure does!

REQUEST FOR MEMBERSHIP

Yes, I would like to be a member of the Simon Foundation for Continence. Please mail to me the Foundation’s quarterly newsletter, The Informer. Enclosed is a check.

☐ $1,000.00 Life Membership
☐ $15.00 Annual Membership
☐ $5,000.00 Corporate Sustaining Membership
☐ $100.00 Individual Sustaining Membership
☐ $5.00 Caring Membership
☐ $35.00 Professional Membership
☐ _______ Other

The Simon Foundation for Continence
P.O. Box 835
Wilmette, IL 60091

Name ________________________________
Address ________________________________
City __________________ State ______ Zip Code ________

NOTE: Your annual membership will begin with the next edition of The Informer. Contributions and membership in The Simon Foundation are tax deductible.