Coalition Calls for Real Answers To Health And Aging Challenges

Over sixty of the nation's largest health and aging groups called on Congress to fund a new scientific research plan to improve the health of and control the spiraling costs associated with the rapidly growing aging population. The coalition, organized by the non-profit Alliance for Aging Research, is seeking one billion dollars in federal research funding into chronic diseases and conditions often associated with aging, including Alzheimer's disease, arthritis, incontinence, and hearing loss.

"The best way to improve any health care system is to save lives, reduce disability, and prevent illness in the first place," stated the coalition in a report released in Washington entitled Independent for Older Americans: Real Answers to Health and Aging. "With each day that we can keep older people healthier and out of hospitals and nursing homes, we not only improve the quality of human life, but we save the nation precious health care dollars."

Increased medical research could provide answers to the diseases and conditions that most often afflict older people and could result in significant cost savings for the nation as a whole. For instance, a 20 percent reduction in the incidence of osteoarthritis, the number one cause of adult disability, would save $86.4 billion by 2000 and $182 billion by 2010.

The problems of incontinence are also highlighted in this report: "The cost of managing urinary incontinence in the U.S. is conservatively estimated at over $10 billion annually, more than $3.3 billion of which is spent in nursing homes. With current growth rates of the aging population, the U.S. could face a $30 billion annual health and long-term care bill for incontinence within the next generation, if current research efforts are not increased. It is estimated that we

New Developments In The Treatment Of BPH

Benign prostatic hyperplasia (BPH) is a non-malignant enlargement of the prostate gland. When the prostate gland enlarges it presses on the urethra, (the channel from the bladder to the outside of the body), often causing obstructive symptoms. Over 75% of all men over age 50 are affected by BPH, which causes one or more of the following symptoms to occur: urinary urgency; the need to get up several times at night; a weak urine stream; a sensation that the bladder is not completely empty; and of course leaking.

Until this summer when the FDA approved a promising new drug called Proscar for BPH, most men suffering from BPH symptoms underwent trans-urethral resection of the prostate, a surgery most commonly referred to as TURP. Although usually effective for relieving the symptoms of BPH, complications including incontinence, impotence, and "dry" ejaculations can occur. Now, many of the 400,000 men who are candidates annually for surgery may find their doctors suggesting medication as a less invasive first step. Over time, use of this new medication can relieve BPH symptoms and in some cases actually shrink the prostate. Proscar works by blocking the production of the male hormone which stimulates prostate growth.

According to a recent Johns Hopkins Medical Letter, clinical trials of the drug in over 1,600 patients showed that the prostate gland shrank by an average of 24% in men who were treated for two years. The study also showed that almost three quarters of the study participants had improved urinary symptoms. The medication is not effective in all the men who take it however, and those that it will help may need to take the medication for several months before symptoms begin to alleviate. Like all new drugs, until a large number of patients use this medication for long periods of time, both the long term effectiveness and the side effects remain unknown.

Men who experience the above listed urinary symptoms or any other bladder related changes should always report these conditions to their physicians. Only after a thorough patient/physician discussion and a medical history and physical examination can a suitable individualized course of treatment be decided.

Because Proscar may shrink the prostate some physicians are concerned this could mask the detection of a cancerous growth. Prostate cancer is the most common cancer in men. Dr. Patrick Walsh, a urologist from Johns Hopkins Medical Institute was quoted in the Johns Hopkins Medical Letter as saying: "..."
GUIDELINES RELEASED... Healthcare professionals and patients too should send for and read the new 'Clinical Practice Guidelines for Urinary Incontinence in Adults' and the accompanying 'Patients Guide.' Published in March by the Agency for Health Care Policy and Research, the purpose of the 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. All versions of the guideline can be obtained for free by writing to the Center for Research Dissemination and Liaison, AHCPR Clearinghouse, P.O. Box 8547, Silver Spring, MD 20907.

BOOK AVAILABLE FOR PROFESSIONALS... Reimbursement: A Sourcebook for Healthcare Providers is a comprehensive reference written for healthcare providers who bill third-party payors for their services. Among other information, this book provides: the fundamentals of Medicare; critical information for completing billing forms and obtaining prior authorization; details on completing the certificate of medical necessity; and sample letters to insurers requesting reviews and appeals. Written by Glenda J. Motta, RN, MPH, ET and Kathi Thimsen-Whitaker, RN, CETN, BSN, the book is available from G.K. Publishers, 2210 N. Illinois Street, Suite 126, Belleville, Illinois 62221, (314)-436-9023. The cost is $49.95 plus $3.50 for postage and handling.

UPCOMING CONFERENCE ANNOUNCED... Sponsored by Health Management Publications, Inc. "The Symposium on Advances in the Management of Incontinence: Focus on 1992 Clinical Practice Guidelines," will be held October 11th and 12th at the Marriott Crocker Center in Boca Raton, Florida. Among the numerous topics to be covered will be information on the 'Clinical Practice Guidelines for Urinary Incontinence,' pelvic floor dysfunction, establishing collaborative practice for treating incontinence, and current trends in evaluation and treatment of fecal incontinence. Faculty include: Glenda J. Motta, RN, MPH, ET (Conference Chair); Kathleen A. McCormick, PhD, RN, FAAN; Ananias Dikno, MD; Jeannette Tries, MS, OTR; David Staskin, MD; Diane Smith, RNC, MS, CRNP; Christopher R. Steidle, MD; Karen Lou Kennedy, RN, FNP; Ruth Mooney, PhD, ARNP; James Fleshman, MD; Cheryle B. Gartley, President of the Simon Foundation for Continence; and Diane K. Newman, RN, MSN, CRNP. For registration information telephone Health Management Publications, Inc. at 800-237-7285.

PEN PALS ARE GREAT FRIENDS... The following are people who would like to have our readers write to them: George A. Shwab, R.N., 429 Players Court, Nashville, TN 37211; Charles Renner, P.O. Box 604, Aepolka, FL 32704; Don Smith, P.O. Box 27, Two Buttes, CO 81084; Robert H. Blue, 269 West Bomford Street, Richwood, OH 43344; John R. Root, 338 South Sherman Street, Rushville, IL 62681; Jim Dressel (age 28), 298 Coolidge Court, Streamwood, IL 60107; and Timothy Roneker, P.O. Box 8994, Penroke Pines, FL 33584.

HOW YOU CAN BE BOSS OF THE BLADDER... is the title of a new 57-page softcover book for children with enuresis, and their parents. Published in Australia by psychologist Dr. Janet Hall, this book gives children the motivation, knowledge and the encouragement to take control. Recommendations and descriptions of available types of treatment are provided for parents. Praised in a recent edition of Parent Magazine, this book is distributed in the United States exclusively by the Simon Foundation for Continence. The book is available for $9.95 by writing to Post Office Box 835, Wilmette, Illinois 60091. A cassette tape set based on the book can be purchased for $29.95.

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Medical Letter as offering the following suggestions to men considering taking the medication in light of these concerns:

- Have a screening for prostate cancer—a digital rectal exam and PSA measurement before beginning treatment. (PSA or prostate specific antigen, is a protein found in the blood which is produced by the prostate and can help in diagnosing cancer.)

- If your PSA is elevated, a biopsy may be needed to determine if a tumor is the cause. If everything is okay, then you can start on Proscar.

- Once on the medication, be sure to have a yearly PSA test and a digital rectal exam.

- If your symptoms haven’t improved after six months of taking the medication, you may want to discontinue use.
Recently a reader wrote: "I believe in the 10 years of service, you people have made remarkable progress in bringing this problem before the public." It made us all stop to think, has a decade really come and gone while we’ve been busy promoting continence? Yup, a quick look at the calendar says it’s true. How time flies while you are having fun! Our small staff passed the letter from hand to hand and began to cite the various accomplishments they each enjoyed, such as: convincing TIME magazine to do an article on incontinence, watching staff and board members appear on television shows such as Good Morning America and 20/20, processing 35,000 pieces of mail in less than two weeks from an Ann Landers column, and more recently assembling hundreds of I WILL MANAGE program director kits and mailing over 150,000 Informers each quarter. The staff was on a roll and rather than risk being an ogre by insisting it was time to get back to work, I returned to my office where my thoughts turned more personal. A decade! Ten whole years since I sat down at my kitchen table to write a book to help others while I searched for an answer to my own neurogenic bladder so that I could return to my banking career. Today, a decade later you can buy Managing Incontinence: A Guide to Living With Loss of Bladder Control in Japanese in Tokyo, in Spanish in Barcelona and in Sydney, Auckland or London, it has been translated into English, as our British publisher is so fond of reminding me.

Pulling out my calculator I thought it would be fun to estimate how many hotels I’ve slept in, airplane meals I’ve eaten, speeches I’ve agonized over, letters I’ve answered, videos I’ve supervised, manufacturers I’ve consulted with, and reporters I’ve talked to... all in the name of promoting continence. My hand stilled, ... numbers just don’t stick with me. I also find it hard to look at accomplishments when there is so much left to do.

There is, however, one thing I do remember exactly. Whether it has been in Australia, Japan, New Zealand, Germany, France, England, Canada, Norway or right here in America in one of the 36 states I’ve visited, I remember every single person who told me their story. I remember each person who stopped me to talk about what the Simon Foundation for Continence has meant in their life. Not all the names I admit, but the faces and places are etched in the memory bank.

I remember the woman in an elevator in Sydney who didn’t make it to the washroom on time, burst out crying, spotted me as one of her companion passengers, wiped her eyes, lifted her chin and stated "I can’t think of anyone I’d rather have an accident with," as she marched off the elevator to change her clothes and return to the conference. I remember the young D.J. in Florida who admitted on the air while interviewing me that he was a bedwetter. I remember the woman from Portland who sent a lovely thank you donation while requesting us to stop sending the newsletter. Seems her dog was cured after she passed her "Informer" on to their veterinarian. I remember every single traumatized face at our first self-help group when we accidentally became locked into our meeting room. We broke the ice by taking an inventory of the incontinence products we had hidden among us. In case it became necessary to share! I remember the first recipient of the Foundation’s Volunteer of the Year Award, my father, talking until the day he died about the letters he received from all of you wishing him well. He sealed envelopes and licked stamps from his hospital bed, feeling useful until the end.

Of course, it’s not always been easy and yes, there have been many embarrassing moments on the trail of promoting continence (which I will leave for now to your vivid imaginations). For me in the last decade time has not flown while I’ve been having fun. It’s gone ballistic! As I contemplate a sign on my desk which reads, "Take Me To Your Leaker," (one of our volunteers’ idea of an appropriate Christmas present) I’d like to say to you its been a joy working on behalf of each and every one of you for the last (who’s counting) 4,000 plus days of my life! Thanks for the memories.

Cheryle B. Gartley
President, The Simon Foundation for Continence
Letters To The Editor

Dear Cheryle:
Five years ago this winter I severely injured my back in a sledding accident. Incontinence is one of the minor outcomes from this injury considering I could have been paralyzed. Being a registered nurse, I thought I was immune to the emotional effects of incontinence. No big deal, I took care of numerous patients with incontinence before my injury. I thought I knew it all! How wrong I was. Those accidents in public, the wet beds from soaking through the diapers, the rustling pants, and yes, buying products in public, all taught me both humility and most of all respect for incontinence. Those of us who lead active lives are truly miracles at work!
The most important thing which I found was don’t give up and isolate. I get regular bladder check-ups and am willing to try medicines, exercises, and new products as they come along. I must admit nothing really helps a neurogenic bladder but I keep trying.
By all means use my name for the Informer’s pen pal list.

George A. Shwab, R.N.
429 Players Court
Nashville, TN. 37211

Dear George:
Your letter certainly covers most of the issues of people with incontinence. Like yourself, many people are able-bodied when they become incontinent. Perhaps this makes it tougher to have your attitude of thankfulness that your accident could have had much worse outcomes than incontinence.
Because you both have the problem and are a registered nurse, I suspect that your mail box will be overflowing with letters full of medical questions. When you answer all of them, don’t forget to pass along your good attitude: “Enjoy life, this is not a rehearsal!”

Dear Ms. Gartley:
Just the day after reading the letter in the last issue from Marvin in California, I had my own very embarrassing moment. During the work day I manage my incontinence with disposable diapers. On the day in question, a computer program that I was working on needed to be printed. One of the new secretaries was trying to print it with no success. I walked into the small cubical where the secretary was and showed her how to print the program. We were waiting for it to stop printing when she asked me: “What is that rustling noise.” I stated, “It must be my change or keys.”

“No,” she insisted, “it sounds like plastic. Are you wearing a diaper?” I turned beet red and my expression spoke for itself. The next day I built up enough courage to go back to work. In looking back on this event, it was not the end of the world.

Jim Dressel (age 28)
298 Coolidge Court
Streamwood, IL 60107

Dear Jim:
Most of us, when looking back, discover that very little which has happened to us qualifies as “the end of the world!” In fact, most of us waste a lot of time speculating about what could happen, thus keeping us paralyzed in the present. Hopefully, hearing how others handle embarrassing moments will help us all. “Life is what happens when we are all busy planning something else.” Read on . . .

Dear Embarrassing Moments:
I have a memory for you. I have been incontinent for years—most family knew. I got married in a typical Orthodox manner—lots of people and a drawn out ceremony. The Rabbi was giving a long speech when I said, “Excuse me,” and walked out. I returned a few minutes later to the applause of everyone except the Rabbi.

New Mexico

Dear New Mexico:
Sounds like you have a great family, wonderful friends, and a Rabbi who is now well informed about incontinence. Thanks for writing.

Coalition
continued from front

will save $22.5 billion by the year 2000, and $49.8 billion by the year 2010, if we could reduce the incidence of urinary incontinence in older people by just 20 percent.”
In addition to the Simon Foundation for Continence, some of the other groups endorsing the report include: the Alzheimer’s Association, the American Cancer Society, the American Heart Association, the Families USA Foundation, the National Osteoporosis Foundation, and the National Women’s Health Network.
For more information, a copy of the report, or to join the Task Force for Aging Research Funding, contact: Alliance for Aging Research, 2021 K Street, N.W., Suite 305, Washington, D.C. 20006, 202/293-2856.

Dear Juliana:
Many children your age have incontinence because the nerves to the bladder do not function properly due to a condition called spina bifida. Perhaps you’d like to write or telephone the Spina Bifida Association of America newsletter editor Ms. Tina Head, Rt.4, Box 190, New Castle, Indiana (317-332-2287) and ask her to publicize your request also.