ANN LANDERS UNLEASHES AN AVALANCHE OF MAIL TO THE SIMON FOUNDATION

There no longer can be any doubt that incontinence is a major health problem. A recent mention of the problem and the work of the Simon Foundation in an Ann Landers column has already triggered thousands of letters from those looking for help. From every corner of the country people are writing for information. A team of volunteers is working long hours each day to insure that each inquiry receives a prompt response. The response to the Ann Landers column proves beyond a doubt that incontinence is one of the major health concerns of our age.

If you sent us a personal letter along with your request for this newsletter, we will respond as quickly as possible. Future issues of the Informer will include information about products and devices available for managing incontinence. The Simon Foundation’s book Managing Incontinence: A Guide to Living With the Loss of Bladder Control, has both a chapter and a product information index packed with current product information. This book, along with the Informer, is helping to communicate to the thousands of people with incontinence that they are not alone.

Urinary incontinence is a symptom, not a disease. It is estimated that in the United States alone, over 12 million Americans suffer with some form of the problem. INCONTINENCE CAN BE CURED AND/OR MANAGED. The first step to dealing with incontinence is to consult a knowledgeable physician for an evaluation of your incontinence. You can also help yourself by becoming well informed. The Simon Foundation is a not-for-profit health service organization devoted to assisting those suffering from urinary incontinence and to removing the stigma many people feel is associated with urinary incontinence. It is our intent to continue to speak out about this problem until incontinence becomes a household word and the American society, with all its Yankee ingenuity, has conquered this problem.

Our first project, a book for laymen, is completed. The long hidden problem of incontinence is being brought into the open. The self-help group begun in our headquarters city of Chicago, is being extended to other communities. There is much more to be done.

We need to expose a problem that has long been a taboo subject in this culture. We need to help people to rethink their opinions about incontinence. We need to find and effect solutions to the problem. All of these are tremendous challenges. It takes all of us working together. Thank you for writing to us and sharing with us your needs, hopes, and ideas. Together we can change the world for those suffering with incontinence.

ONE VOICE, an editorial

Americans have taken on a quest in space, moved the computer into the home, brought college education to the masses, and yet, the challenge of dealing with incontinence in our society remains unmet.

It does not seem to be from lack of trying. From coast to coast, it is evident that there are professionals working on this challenge. Engineers are creating artificial sphincters, research and development specialists are discovering absorbent materials, and urologists are working patiently on teaching children intermittent catherization.

Why hasn’t the problem of incontinence been solved? The solution requires more than input from engineers, specialists, and urologists; it depends on each of us.

In our society, incontinence still evokes a negative attitude. Part of the reason that we cannot help solve the problem is because we cannot publicly address the problem.

Think about the following: One stormy evening, your neighbor returns home to find water on the

This edition of the INFORMER is sponsored by an educational grant from Convatec — a Squibb Co., makers of Dignity® Products for bladder control problems.
CLEAN INTERMITTENT CATHETERIZATION FOR THE MANAGEMENT OF INCONTINENCE

Editor's note: the following article was written by William Kaplan, M.D.

Dr. Kaplan is director of neurologic urology, Children's Memorial Hospital, Chicago, and assistant professor of Urology, Northwestern University Medical School. Bill is a leading advocate of the use of clean intermittent catheterization for children with spina bifida.

CIC was introduced three decades ago as the initial therapy for patients with spinal-cord injury. Over the years, numerous reports have documented that CIC reduces the incidence of pyelonephritis (kidney infection), hydronephrosis (kidney and ureter swelling), reflux (urine backing up into the kidneys from the bladder), and kidney stones.

CIC alone has significantly reduced the need for urinary diversion in patients with incontinence.

The procedure is simple. The hands and an appropriately sized catheter are washed with soap and water. The urethral opening (meatus) is washed, and the catheter is inserted into the bladder. All the urine is drained, and the catheter is washed again and stored. This process is repeated every three to four hours during the daytime and occasionally as needed once in the middle of the night. In our experience, there is no child too young, male or female, for this procedure. If manual dexterity is present, no individual is too old for the procedure. Children can generally be trained to perform self-catheterization between the ages of four and six. In our myelomeningocele population (spina bifida), with the addition of pharmacotherapy in 80 percent of the patients, 85 percent of the children are dry for three to four hours with this program.

Intermittent catheterization is less effective or not desirable when there is total sphincter incompetence (that is, the sphincter muscle below the bladder does not function or has been traumatically or surgically injured), or urethral stricture (narrowing), or disease, or severe uninhibited bladder contractions (bladder contracts with little control or forewarning) that are not controlled with medication.

ONE VOICE (continued)

floor. His roof has a leak. The following day, he does not call the roofer for an estimate on fixing the problem, and he does not attempt to fix it himself. Instead, he resigns himself to a puddle every time it rains. Strange behavior, don’t you think?

There are millions of Americans who are handling their bodies the same way. Research findings point out that the primary coping behavior for persons who are urinary incontinent is to withdraw from society and remain in their homes. They have resigned from life at a time when they need to fight.

The stigma, shame and embarrassment, predicated by an outdated public attitude, could be abolished by public enlightenment and understanding. The solution depends on you. What good is research and development if no one takes the product off of the store shelves? What good is reading the Informer if no one takes action?

The key is action . . . one determined step at a time. If you are incontinent and have not discussed it with anyone, please tell somebody today. If you think you can’t be helped, prove it! Make an appointment with your physician or health care professional. He or she is the only one who can make a proper diagnosis or recommend proper treatment. Do it today!

Go to the store and purchase a protective product; if it fails, try another!

One step at a time. One person at a time. One voice at a time. The answer to the challenge of incontinence depends on your next action. There is hope, through individual action, for a new tomorrow for everyone coping with urinary incontinence.
NEW PUMP HELPS SOLVE BLADDER CONTROL WOES

By Jon Van

A new surgical treatment offers hope for millions of people unable to control leakage of urine from their bladders.

Urinary incontinence affects more than 8 million Americans. It may be caused by birth defects such as spina bifida, a condition in which the spine of a newborn child is partially exposed, or by afflictions more common to the elderly such as prostate cancer, which can result from the surgical removal of the prostate gland.

In women, the condition may be manifested as extreme "stress incontinence," occurring when the woman coughs, laughs or exerts herself in other ways, such as lifting something.

The problem is socially embarrassing as well as physically troublesome. Adults may wear diapers to control the effects of incontinence, but living with constant wetness can produce psychological despair as disabling as any physical trauma.

"Many people just become recluses, staying at home all the time," said William Furlow, M.D., a professor of urology at the Mayo Clinic Medical School. "The psychological impact of being wet all the time is something that no one who takes being dry for granted can ever understand."

Furlow was in Chicago recently to lead a seminar about the new incontinence correction technique for more than 100 surgeons. This involves implantation of an artificial sphincter that closes off the tube through which urine passes out of the body.

The sphincter, a small pump, a reservoir and tubes connecting them are implanted inside the bodies of men and women suffering urinary incontinence. When a person wishes to void his or her bladder, squeezing the pump, which is placed in the testicles of men and the labia of women, will open the sphincter, relaxing pressure around the urethra and allowing urine to flow out of the bladder.

Key to the system is a small but intricate configuration of tiny screens within the pump. As fluid is pumped away from the collar around the urethra, it goes into a storage area, something like filling a balloon with water. The balloon exerts pressure on the fluid, causing it to flow back into the collar and reassert the pressure that closes the urethra.

The system of tiny screens slows this process, giving a person three to five minutes before the urethra closes again.

Success rates for the artificial sphincter vary according to the cause of incontinence. But for most common conditions, successes have exceeded 90 percent, Furlow said.

Artificial sphincters have been under development for more than 10 years, but the current system, made by the American Medical Systems and called AMS Sphincter 800, has been available only since spring. Rush-Presbyterian-St. Luke's Medical Center and Children's Memorial Hospital are two of the hospitals in Chicago where the procedure is offered.

Furlow said that the interest among surgeons in the seminar indicates that more area hospitals will offer the procedure soon.

About 4,000 people have received sphincter implants in the last decade, Furlow said, and that number is likely to increase dramatically with the new system, which is much easier for patients to use and for doctors to implant than its predecessors.

It may take a week or two for a patient to recover from the surgery and the cost runs $8,000 to $10,000. Many male patients, especially those who have had their prostate gland removed, will receive the artificial sphincter and a penile implant during the same surgery, he said.

Penile implants use a similar principle to the sphincter, with a pump in the scrotum that forces liquid into structures in the penis to produce an erection as desired. Removal of the prostate gland can cause both urinary incontinence and impotence.

People interested in either the artificial sphincter or the penile implant may write to American Medical Systems, P.O. Box 9, Minneapolis, Minn., 55440, for more information, including names of urologists in their area who offer the surgery.

"This isn't for everyone with urinary incontinence," he said. "Each individual must be assessed by a physician."
Dear Colorado:
Finding the light side in any situation is a great coping mechanism. In fact, we believe in this so strongly that a chapter in the book "Managing Incontinence: A Guide to Living with the Loss of Bladder Control" is devoted to humor. Thanks for sharing.

Dear Editor:
I have to tell you how I feel about my visit to my first self-help group. I was elated after talking to others who share our problem. I felt so good about myself that when we had friends over last weekend I felt very comfortable discussing my incontinence with them, something I would have never, never done in the past. Although I'm sure I'll always be aware of my problem, I'll give my very best effort to never be ashamed or to curtail any social activity I wish to attend.

Dear Ontario:
Your words brought a new meaning to mind about the word self-help group. That's exactly what our group is, a way to help ourselves. It is true that we all talked, shared, and encouraged each other, but as you point out, each of us must return to face the world alone -- each of us is indeed responsible for our own self-help. Thanks for the insight.

Dear Simon Foundation:
Dear Canada:
We wish there were room to print your whole letter. Congratulations on your fine adjustment to this often difficult problem. Transporting additional products is indeed a creative challenge which the Simon Foundation has long been aware of. Some people sew them into linings of their apparel, others carry gym bags. Readers, any good solutions for this problem you can share?

Dear Editor:
I have a water bed and two cats, and have had pinhole leaks from them getting under the covers and flexing their claws. They also sleep with me, so when I would wake up in a puddle I would threaten to declaw up to their elbows. Then I tore the bed apart trying to find pinhole leaks at 4:00 a.m. Well, after a couple of weeks of this I discovered I was the one leaking, not the bed. After apologizing and over-feeding the cats, all has been forgiven.

The Simon Foundation
P.O. Box 815 - Wilmette, IL 60091

William Kaplan, M.D.
Director of Neurologic Urology
Children's Memorial Hospital
Illinois

Rosemarie B. King, R.N., M.S.
Assistant Director of Nursing
Rehabilitation Institute of Chicago
Illinois

Mary Radtke Klein
Longterm Care Management Services
Oregon

Joseph G. Ouslander, M.D.
Assistant Professor Geriatric Medicine
UCLA School of Medicine
California

Neil Resnick, M.D.
Director of Aging & Urology
Harvard Medical School
Massachusetts

Doris J. Rouse, Ph.D.
Director, NASA Biomedical Applications Team
Research Triangle Institute
North Carolina

Martha A. Teichner
CRS News Correspondent
Texas

Steven M. Tovian, Ph.D.
Department of Psychiatry
Northwestern Medical School
Illinois

Carroll J. Wendland, Ph.D.
Executive Director, Beverly Foundation
California

*Director

The Simon Foundation is a 501 (c) 3 tax exempt organization.