Toward The Year 2000

(Editor’s note: New technologies concerning incontinence reported in this article are not yet widely available in the United States. Some are still being examined and tested in clinical trials. When the Simon Foundation has further knowledge about their widespread availability we will keep you informed. If you feel that some of the research reported here might be of use to you because of your own incontinence condition, perhaps you might ask your doctor to watch his or her medical journals for further information.)

At the turn of a decade, no newspaper or newsletter editor can resist a look back at the past ten years and a look forward at the hopes of the future. The 1980’s were years of enormous change for all issues and problems surrounding incontinence. In 1980 incontinence products were not yet advertised on television; the National Institutes of Health had not yet taken an active look at the problem; articles in the lay press or books about the problem could not be found in your local library; and the Simon Foundation did not exist. The decade of the 80’s were truly a time for change. The problem was “discovered” by journalists, industry, physicians, nurses, and the federal government. But we still have much to achieve in many areas before incontinence receives the attention it deserves, especially the number of people affected by it.

As scientists apply themselves to curing and treating incontinence, new treatments and hope for millions will follow. Because of the myriad causes of incontinence and the complex ways it presents itself, incontinence is in all likelihood not amenable to one miraculous cure. Rather, exploration and research will take place on many fronts to either alleviate the problem completely, or to better contain those types which cannot be cured.

One new area of investigation being conducted in the United States, Europe, and Great Britain involves research into the use of vaginal cones to alleviate genuine stress incontinence in women. The equipment used is a set of nine equally shaped cones of the same volume but with different weights. Some types of cones are composed of differing proportions of perspex and stainless steel with a nylon thread attached to facilitate removal. Inserted into the vaginal canal (like a vaginal tampon for menstruation), a cone can be used both to measure the strength of the pelvic floor muscles and to help women increase the tone of these muscles by insuring that the correct muscles are identified and exercised correctly. After successful cone therapy, the patient must continue standard pelvic floor exercises (Kegel exercises) in order to maintain strong muscle support for the bladder neck.

In a study currently being conducted in the United States, patients are instructed to choose the heaviest cone which they can hold comfortably in place and wear it for periods of ten to thirty minutes, four times daily. After some practice, the patient is then asked to insert the next heaviest cone to ascertain if this next cone can now be held in place. If so, the heavier cone is substituted in the treatment. The patient will be able to hold progressively heavier cones as the vaginal muscles increase in strength.

In The British Journal of Obstetrics and Gynaecology, October 1988, a study conducted with a group of 39 premenopausal patients using cones was reported. All the patients had genuine stress incontinence and were waiting for corrective surgery. The authors stated that “of the 30 women who completed one month of the exercises, 70% felt they were improved or cured, and 90% found it an acceptable method of treatment.”

The authors conclude: “The objective results showed a highly significant correlation between ability to hold heavier cones and a reduction in urine loss.

This suggests that it may be reasonable to offer all patients with genuine stress incontinence cone training whilst awaiting corrective surgery. (Note: In England due to the socialized health care system, the patient often experiences a considerable wait before any elective surgery can be performed.)

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Simon Says...

CUSA... Catholics United for Spiritual Action is a pen pal group open to everyone who has a physical state of health which is an occasion for sacrifice, both lay people and religious, as well as persons of all faiths. A circulating group letter unites members in eight-person groups. When a member receives a letter, he or she reads the messages and then adds one’s own thoughts. For those of you who never have enough pen pals, you can write to CUSA for further information and a membership application: CUSA, 176 West 8th Street, Bayonne, New Jersey 07002.

SPEAKING OF PEN PALS... Our club is growing and the reports we receive at Simon headquarters indicates that many of you are enjoying your pen pal correspondence enormously. The following is a list of new people who would like to have pen pals: Joel Alvarez, 3026 Emmett, Dallas, Texas 75211; Robert Siders, 81 Water Box 143, Newaygo, Michigan 49337; Edgard C. Benedetti, 153 West Street, Worcester, Massachusetts 01609; Mr. Kenneth Hill, 1203 Columbia, Lawton, Oklahoma 73507-6550; Mike Davis, 1170 Maiden Lane, St. Joseph, Michigan 49085; Bill Sparten, P.O. Box 6408, Evansville, Indiana 47719-0408; Mrs. Gloria M. Paine, 1062 Willet Avenue Apt. 205, Riverside, Rhode Island 02915; James Ritchie, 3109 Commander Drive, Louisville, Kentucky 40220.

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One Voice: an editorial

As this editorial is being written Valentine's Day is right around the corner. It made me stop to think. Did I remember to send a Christmas card, birthday card, or just plain thank you note to my health care providers last year? Did you? If they are not currently one of the special people on your greeting card list perhaps it is time to remedy that situation. I have always felt that the best way to make a friend is to be a friend. When is the last time you told your health care providers what a good job they did? Have you thanked them for the referral to that great specialist you are now seeing? Asked about their children? When Americans lament the loss of the house-calling image personified by Dr. Marcus Welby, I believe what they are really missing is a personal relationship with their doctor or nurse. That's something we can still have if, as patients, we take the time to build it. Here are just a few thoughts on the matter:

- Allow your health care professional to know you as a person. Include pictures of your new house, family cat, or new grandchild next time you visit. It only takes a minute.
- If the wait is long at the office of the doctor or nurse and you feel hostile by the time you are seen, take some preventative action prior to the next visit. When scheduling, ask for the first or last appointment of the day. Most first appointments see the physician on time. If you are the last appointment of the day, call ahead shortly before your scheduled time and ask for advice as to how late visits are running. Reduction of waiting time can help you be a more cheerful patient!
- Provide your nurse or doctor with interesting medical information. If you see an article about a new medication or treatment, clip it out and send it along. They will be delighted with your help in keeping up to date.
- Are you good at something... needlepoint, carpentry, cooking? At the recent visit to a friend's home, I was admiring the beautiful new hand-carved front door. The family loved it too, but mostly because it was a gift from a patient.

I could go on and on, but I'm sure you get the idea. Besides I must run to the card shop for more Valentines to send my very "you are special greetings" to my internist, Harry Jaffe, who I can call at 3:00 p.m. and see at 5:30 p.m. because he will stay late if I'm sick; to my orthopedist, Robert McMillan, who after he calmed down, really tried to understand when I admitted I had delayed taking a prescription which causes bowel incontinence until after my speaking engagement; to my rehabilitation physician, Jean Cavanaugh, who came to my home personally to conduct post-operative monitoring so that I could leave the hospital early; to my neurologists David McClure and Tom Brown, who treated me cheerfully as I slowly drove them crazy with the last and millionth question even as they rolled me into the operating room; to my pedorthists Barry Ullman, Harriet and Roger Dart, and Arnie Davis, who work on Saturdays when necessary in order to keep me walking... to all my health care providers a special thank you just in case you haven't noticed I appreciate you all.

I can promise readers who want to join my "caregivers admiration society" an intangible reward of their own... needing medical care isn't quite as bad when you are off to see a friend!

THANK YOU. Editor's Note: This issue of The Informer was underwritten by an educational grant from Kimberly-Clark Corp., makers of DEPEND. The Simon Foundation does not endorse specific incontinence products or medical treatments. Inclusion in this column in no way implies endorsement.

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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 $15.00 for my membership. I understand that all mailings will come to me in an unidentified envelope.

The Simon Foundation
Box 835, Wilmette, Illinois 60091

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NOTE: Your annual membership will begin with the next edition of The Informer. Contributions and membership in the Simon Foundation are tax deductible.
INTERESTING READING... People with disabilities are often looking for books which can make their personal and professional lives better. Quokki-Mini Stress-Management Strategies for You—A Person with a Disability might be of interest to some of our readers who are looking for relaxation techniques which they can use while also coping with problems such as multiple sclerosis, cerebral palsy, and other physically limiting illnesses. It is available for $12.50 from Guild Hall Publications, P.O. Box 135, Manhattan, Kansas 66502-0002. Parents raising children who are struggling with disability issues would enjoy a new series from Turtle Books for pre-kindergarten through second grade readers. These books are written to help children feel good about themselves. A synopsis of each book and ordering information can be obtained from Jason & Nordic Publishers, P.O. Box 1123, Exton, Pennsylvania 19341, (215) 363-0352.

BEGIN THE NEW YEAR RIGHT... Help Simon spread the word that incontinence can be cured, treated, and managed. When you are finished with this issue, please pass it on. Why not leave it at your doctor’s office, local senior center, or church so that others can educate themselves about incontinence.

MANY THANKS... This is a very special thank you to all of you who contributed to the work of the Simon Foundation for Continence as part of your year-end giving. Readers from as far away as Switzerland remembered the cause of bringing continence to the next decade. The staff at Simon, and all of our members whose financial situation does not allow them to pay dues, extend your deep gratitude for financial support. Happy New Year!

UPCOMING PROGRAMS... Physicians and nurses may wish to consider attending Urology Update: 1990, September 24 and 25, Organized by Ananias C. Dickno, M.D., Chief, Department of Urology, University of Michigan Medical Center, the Program includes lectures on the “Multidisciplinary Approach to the Management of Urinary Incontinence and Urinary Frequency” by several well known researchers including: Joseph G. Ouslander, M.D., Thelma J. Wells, Ph.D., R.N., Rodney A. Appell, M.D., and Patricia Burns, Ph.D., R.N. For a complete programs and registration information write or call: Dr. Ananias C. Dickno, William Beaumont Hospital, Department of Urology, 3601 W. 13 Mile Road, Royal Oak, Michigan 48072, telephone: 313-288-2554.

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they improve and are happy with the results, surgery, with its recognized complications and failure rates, may be avoided. This innovative approach to pelvic floor exercises is an advance in our management of genuine stress incontinence in the menopausal woman.

Research in the area of new products and devices is also of interest for there will be those who cannot find a care for their incontinence, at least in the foreseeable future. Susan Gies Godsey, author of "Urology Products Markets" a major market research study writing for Health Industry Today, November 1989, talks about recent changes in the urology products market and what she has discovered in her research: “In the last several years, for example, many internal catheters have been made to feature hydrophilic or antimicrobial coatings, which lower the risk of urinary tract infections.”

Looking to the future, she talks about new compounds which will spawn a new generation of catheters and an “evertig catheter. Currently in the prototype stage, this device uses an evertig element which turns inside out to eliminate friction between the instrument and pathway walls.” Another prototype is an external urine collection system that she claims is “an even better example of an innovative product which will make existing modalities obsolete... unlike other devices, it depends neither on gravity nor a tight seal with the body.”

Perhaps the best news for the decade of the 90’s is that change in the world of incontinence is accelerating. Products, devices, and medical treatment protocols which were on drawing boards and in obscure research laboratories just a short few years ago are becoming realities. The following quote from the January 8, 1990 edition of U.S. News and World Report describes a new pharmaceutical.

“Parents whose children wet their beds past the age of 6 often treat the problem as psychological, when the cause may be physical. These children may be helped by the drug desmopressin acetate (DDAVP), approved by the Food and Drug Administration for bedwetting. According to several studies, some older children wet their beds because, while sleeping, they fail to produce enough of a hormone that regulates urine production, so their bladders overfill. DDAVP acts as a synthetic hormone until the child’s own endocrine system matures sufficiently.”

A hormone test is complicated, so most doctors will prescribe DDAVP, taken before bed as a nasal spray, and see if it works. Success rates among bed wetters have ranged from 50 to 70 percent. Children who respond to DDAVP usually stay on it for three to 18 months, after which they are weaned away with progressively lower doses every two weeks. The drug costs about $160 a month but is usually covered by insurance. Side effects are minimal.”

As the twenty-first century approaches, most of us may not be visiting satellite way stations as portrayed in the movie “2001”, but we can hope that today’s research becomes tomorrow’s reality. Once again, if you feel that new technology information might be of use for your condition, be sure to ask your doctor for advice.

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:

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To order reprint articles, send $1.00 per article ($2.00 for Reprint No. 9) with a business-size self-addressed stamped envelope to:
REPRINTS, The Simon Foundation
Box 835-R, Wilmette, Illinois 60091
Letters to the Editor

The Simon Foundation:
This money is not for membership, it is
a donation. Thank you for sending me
the “Informer”. In 1978 my regular doc-
tor and two surgeons lead me to believe
that I would have urinary incontinence
for the rest of my life. In exactly 30 days
after surgery I became normal. I will be
88 years old in June. Reading “The In-
former” helps me guard my health.

California

Dear California:
According to my calculations you
would have been 76 years old when
your successful surgery was com-
pleted. Although many types of inconti-
ience respond to other treatments,
your experience demonstrates that
when surgery is indicated advanced
age should not necessarily rule it out.
Guarding your health at 88 sounds
very positive, if we could bottle and
sell your positive attitude the Simon
Foundation could raise millions of dol-
ars to fund necessary research for
cure and treatment.

Letter to the Editor:
Due to many emotional problems asso-
ciated with losing my mother in death
at age 4, being shifted from one uncle
to two others until age 8 when I went to
live with my father, new stepmother
and her children, I grew up as a bed-wetter.
My father took me to a few doctors in
my home town. They only examined
urine specimens and did not find any-
thing wrong with me physically. This
made my father upset with me. He tried
desperately to stop me wetting the bed.
He gave me many whippings and tried
to shame me into stopping by making
me take off all my clothes and having
my stepmother diaper me in the pre-

dence of all the family. Sometime he
would deprive me of my pants and I
had to go around dressed only in a dia-
aper for days at a time at age 10. I be-
came strong enough at age 13 to put up
enough resistance that he stopped hu-
miliating me this way.
I’ve had surgery to have a mechanical
shincher implanted and during the
healing process I wore diapers. A few
teenagers in my area call me “diaper
man”. I do not let it bother me. I
learned to have a sense of humor.
Humor is the key to survival.
On December 31, 1986 my wife and I
were invited by my landlord to a New
Years Party next door. At 11:50 p.m. I
excused myself and came home, got un-
dressed down to the diaper, and went
back the party. On January 1, 1987 at
12:04 a.m. as The Baby New Year, I be-
came the star of the party.

Dear Daniel:
I hope that everyone reading this letter
who was traumatized by adults with
poor attitudes will find a pen pal or
someone such as yourself to talk to
about their experiences. You were
right in that I couldn’t print all of your
letter because some of the actions your
father took to shame you out of
bedwetting were almost too painful to
read. All of us who study history even
slightly know of famous instances of
triumph of the spirit. When a small
child is punished by adults for a prob-
lem with their body which they cannot
control, and has the sense of self-
esteeom you exhibit . . . I think one can
clearly say you testify to the triumph
of the spirit!

Dear Ms. Garbey:
The enclosed letter is one I wrote as a
result of inquiries I received about how
to deal with telling a prospective mate
about enuresis. Since it was written, one
of the people who contacted me went
ahead and told the girl he was engaged
to. Her response was one which could
be expected from an intelligent and
loving person. It is my understanding
she suspected some sort of condition
like enuresis because he declined to
spend the night with her on several oc-
casions. She also said that she had en-
countered a similar problem herself in
the past, and was not at all upset about
his condition. As in the past, you are
welcome to use any or all this material
as you see fit.

Sincerely,

C.M. Beckwith

Dear Mr. Beckwith:
I am beginning to suspect you are really
Dear Ann or Dear Abby in disguise, as
your constant flow of good advice
seems to indicate long years of experi-
ence. Perhaps you’d like to volunteer to
write this newsletter? I’m printing your
letter so that all of our readers can
benefit from your thoughts:

Dear ________:

Telling your prospective mate about the
problem you outlined to me will proba-

bly be the most difficult task you have
ever faced. If she is as wonderful as you
say, she will probably understand. If
she is a compassionate person and
cares for you as much as you care for
her, she will accept it graciously. If she
is intelligent, it will not affect her feel-
ing about you. Unfortunately, however,
there are risks, but it is my opinion your
risk will be greater if you don’t tell her
before you marry. I cannot actually ad-
vice you what to do, but if I were in your
position, I would probably say (or
write) something like this:

“Dearest and most treasured love:
Before we go any further down life’s
road together, this is something I must
tell you. It is a matter which has caused
me many sleepless nights and corre-
spanding days of anxiety. It is a matter
which you should know about now, as
you would probably feel deceived if I
hesitate any longer. No, I am not some
kind of criminal, I don’t have a horrible
disease, I don’t have a wife or children
in another town, I am not on drugs, and
I am not insane, although I am madly in
love with you. I desperately hope and
pray that you will understand my prob-
lem and not let it interfere with our
beautiful future together.

I am sure you have seen the commer-
cials done by June Allyson on televi-
sion. If you recall, they are about an
adult size “Huggy” type garment. There
are millions of people in the U.S. that
buy them (or similar products) to pro-
tect against the embarrassment of blad-
ner leakage. That’s my problem. But I
am lucky—it only affects me at night.
You see, I was born with a small blad-
der and I am a deep sleeper. I can’t
help it—it was dealt to me in a genetic
‘hand of cards’ and I have learned to
live with it. The clinical name for it is
enuresis, and I am simply one of mil-

dions of other men, women, and chil-
dren who lose a little urine while
sleeping. At this moment, there is noth-
ing I can do except keep it from ruin-
ing the bedding. That’s not at all
difficult . . . what I have just told you, my
love, was the difficult part of the prob-
lem. I hope you will not let it adversely
affect our plans together.”

Again, I must warn you that this course
of action carries no guarantee and
should not be considered as advice—it
is simply what I would do under the cir-
stances. Also, this is not an en-
dorsement for a particular product; the
reference to “Huggies” was a matter of
convenience.

Best of luck,

Mr. C.M. Beckwith
13305 S.W. 109 Place
Miami, Fl. 33176