Simon Foundation Helps Develop Worldwide Standards for Incontinence Products

Adequate absorbency, concealability, good fit, freedom from noise—these are only a few of the many product attributes Simon Foundation members report they look for when purchasing absorbent products. Often consumers are confused as to how well the contents of a package will meet their needs. Today there are few ways to comparison shop between brands except to purchase and try the product.

In the future, thanks to a group working for standardization, comparison shopping may become easier. In an ideal world internationally recognized standards for each attribute of absorbent products would be conspicuously printed on the side of every product container. These attribute standards would be like the labels on sleeping bags which tells the consumer what temperature the bag will keep you warm. An international group of scientists and incontinence experts are currently working with the International Standards Organization (ISO) to create these standards.

The ISO, based in Switzerland, is an organization which helps to establish standards for a variety of products. In 1981 a group from Sweden petitioned the International Standards Organization to address the topic of incontinence. Today an international working group of delegates from England, Germany, Sweden, France, Denmark, The Netherlands, Finland, Belgium, Japan and the United States is focusing on urine absorbing products and drainage systems. The Simon Foundation’s President, Ms. Cheryle B. Gartley, is a member of the U.S. Delegation to the ISO. Ms. Gartley will help to represent the consumer’s viewpoint. “Upon delving into the task of worldwide standardization, one quickly discovers that achieving this goal is an enormously complex task,” commented Ms. Gartley.

Current ISO product research is studying freedom from leakage. From the consumer’s vantage point, this criteria may seem simple and straightforward. How difficult can it be to establish standards for products that indicate which products will leave no wet spots on one’s clothing, bed, or furniture? For the scientists challenged to establish this rating, it is a bit more complex. Scientists must consider and measure many factors—how quickly a product absorbs urine, how fast the absorbed urine is distributed within the product or moved away from the strike zone, how well the absorbed urine is retained by the product so that there is no “rewet” when the wearer sits down or moves around in the bed. Most importantly, do the products which test well for all of these attributes in the laboratory perform equally well in real life? Therein lies the first task, to identify which of the laboratory tests measuring absorbency correlate or match best with real life experience.

Under the direction of Alan Cottenden, Ph.D. (from the U.K.) a worldwide study entitled the ISO Pad Leakage Project 2 is underway to help provide the answer to which laboratory tests best measure real world experience. Several companies have anonymously donated all

Simon Says...

CONTINENCE WITH BIOFEEDBACK...

is a research monograph covering new treatments for fecal incontinence written by Susan Trunnell. As a parent of a child with spina bifida, Ms. Trunnell understands the frustrations of fecal incontinence. She writes: “Continence with Biofeedback” is quite different from other books on the subject of fecal incontinence because it presents advances in medical research that are not generally available to the public. The book includes chapters on physiology, biofeedback training, and biofeedback research. This rather technical book includes an extensive glossary which will help the determined layperson interpret the scientific passages. The book costs $24.95 at bookstores. Simon Foundation members can purchase this book for $15.95 plus $3.00 postage and handling direct from Advantage Publications, P.O. Box 489, Carmichael, CA 95609, 916-944-7454.

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Standards
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of the necessary pads for the worldwide testing. Packaging which might identify a product has been removed and products are labeled with a code letter. These unmarked products were then distributed to the User and Technical Test Centers around the world.

At the Technical Test Centers product scientists using equipment, not live subjects, will devise and use their best laboratory tests to determine which products hold the most urine. Concurrently, at User Test Centers physicians and nurses have recruited patients to wear each of the different pads being tested for approximately one week. The patient volunteers save each used pad in a separate well-sealed plastic bag for collection, recording the pad's alphanumeric code and whether the pad leaked a lot, a little, or not at all. These bags are then returned to the test center where they are weighed to determine how much urine each holds.

At the completion of these trials, the ISO working group will compare the information the users reported about each product with the results from their laboratory tests. If all goes well, a laboratory test will be found which correlates with the user's reports. Then scientists can be sure that the work they do in the laboratory gives them useful real-world knowledge about the products' ability to deliver to the customer a promise of freedom from leakage.

Simon Says
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PEN PALS…
The Foundation's pen pal list continues to grow. Since its inception several hundred people have asked to be included. If you would like to exchange correspondence with other members of the Simon Foundation for Continence, simply send us a note giving permission to include your name and address in this column. Those currently seeking pen pals include: Curt Morse, P.O. Box 450864, Kiss, Florida 34745; Harold L. Glass, 209 Locust Street, Fort Collins, Colorado 80524; Chris Martel, Box 262 Maynard, MA 01754; Henry Joseph Hurst, 79 North Henry Street Apt. I, Brooklyn, New York 11224; Janet Cohen, 2084 Bronx Park East, Bronx, NY; Dikk Sharden, 29 Mariner Street, Buffalo, New York 14201 (age 45); Laura Rumsey, 7 South 3rd Street, McSherrystown, PA 17344 (age 10); Pat Supplee, 373 Hermann Street, San Francisco, CA 94117.

CONTINENCE: EVERY NURSE'S RESPONSIBILITY…
is a two-part video series offering a comprehensive examination of nursing care for urinary incontinence in adults. Created by the Rehabilitation Nursing Foundation, the videos reflect the new guidelines published by the federal Agency for Health Care Policy and Research. Nurses who wish a content description and price list for these videos and other continence educational materials may write to: RNF Publication Orders, 5700 Old Orchard Road, Skokie, IL 60077.

AMERICAN UROLOGICAL ASSOCIATION ALLIED WORKSHOP…
Professionals attending this May’s American Urological Association Allied Annual Assembly, are invited to attend "Promoting Continence in the Community." This workshop will include information on becoming an "I Will Manage" Program Director, tips for securing publicity for education programs; and media training. Registration information for this conference can be obtained from the AIUA, 11512 Allinglie Parkway, Richmond, VA 23235.

THOUGHT FOR THE DAY…
"People can achieve meaning in their lives only if they have made commitments beyond the self—religious commitments, commitments to loved ones, to one's fellow humans, to excellence, to some conception of an ethical order. You give life meaning through commitments." — John Gardner.
One Voice... An Editorial

A chance meeting with a stranger, a passing remark made by a colleague, an overhead conversation at a busy airport—some call these occasions a happening, others call them serendipity. Whatever name you give to these events, they often have life shaping impact. For me, such events are usually reminders of the power of a positive attitude. Recently, two of these occasions served as examples.

The first happened on my way to a Bladder Health Council meeting. The airlines had once again lost my luggage, which in my mind was a real feat, given the fact that I was on a direct flight from Chicago to Baltimore, and had checked in forty minutes before flight time. Fuming about this event to a colleague as we checked into a Baltimore hotel, she responded: “Oh, I never mind when they lose my bags. The bags always turn up in a few hours and then I don’t have to lug them to the hotel. The airlines deliver the bag right to my room.” Now there’s a positive perspective for you!

The second example of a positive happening occurred when I accidentally overheard a conversation at an airport coffee shop. Two fortyish executives seated right beside me were catching up over coffee. “By the way,” said one, “I meant to tell you George has just returned to work. His wife died suddenly and he was occupied settling his children. We’ll have to backtrack some to bring him up to speed. She was only 40. It was so tragic, she had a heart attack on their church steps Christmas Eve.”

The second businessman, lost in thought for a moment, spoke about what a lovely woman their client’s wife had been, and then said softly “Christmas must have been a great time to arrive in heaven.”

Perspective often is the critical lever upon which much of our life is hinged. As I travel the world promoting continence, many of our members offer me the opportunity to examine my own life perspective. Just last month I had the surprise and fun of unexpectedly meeting “sock-em” (see letters to the editor). I don’t mean to be rude attaching a nickname to her, but I honestly can’t remember her name! Her spunky articulation of what it is like to be old and have incontinence was so poignant that her letter has stuck with me while her name has not.

At my long forgotten suggestion written in response to her letter, I had mentioned she might like to come into Denver to a public education lecture. Not knowing the geography well, I didn’t realize it would take her over an hour’s drive to follow this advice. But as I took my seat in the front of the auditorium, she handed me the letter I’d written her so that I’d remember and know why she had come. One of her first comments was that “Dr. Davila looked sooo young” spoken as she looked at me accusingly.

Throughout the morning session “Sock-em” was outspoken and challenging in her remarks. At one point the speaker jokingly asked her if she’d like the podium. Most of all she made the morning of learning fun for the audience and the speakers. She’s 79 years young and is never going to give up looking for a cure. By late morning, it was clear, young or not, the good doctor Davila was the one for her and she was asking how to schedule an appointment.

Due to the privileged relationship between patient and physician, I’m never going to know what went on in the examining room when those two met head to head. However, I’ll make a hefty wager that the visit was a first class “happening” for both parties,—I’ll also bet that someday “Sock-em” will write to all of us one of those wonderfully rewarding “I’m cured” letters.

That’s what seems to happen when people don’t give up. Never give up.

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Letters To The Editor

Dear Simon Foundation:
I just finished reading your article on urge incontinence. I had surgery (bladder suspension) a year ago and the urologist never informed me that it might make my urge incontinence worse. In fact, the result is that I am much worse than I ever was. Another urologist suggested I empty my bladder by using clean intermittent catheterization, but I have not been able to accomplish it. Needless to say I am very discouraged. My nights are worse than my days.
I am 79 years of age and if anyone mentions “Golden Age” to me again I think I’ll smack ’em in the mouth! Thanks for listening.

A reader from Colorado

Dear Colorado:
We hear from many women who have mixed incontinence (a combination of stress and urge) who have similar complaints. Surgery is often performed to help relieve leakage which happens when you laugh, cough, or sneeze (stress incontinence). Treatments for urge incontinence usually involve behavioral techniques and/or medication. Your frustration is very understandable especially if you were not aware of the possible adverse outcomes before entering into the surgery. Please don’t hit anyone yet. There are treatments which can still be tried to lessen your feelings of urgency. You are never to old to find a cure for incontinence, or to be arrested for “smacking” someone either, for that matter! Please read on.

Dear Cheryle:
Just read your editorial about how much you’ve loved your decade of promoting continence. I thought I should say thank you for all the help I received over the past ten years. It was through reading the “Informer” that I learned I could get help. I am 75 and had a corrective operation one year ago. I am now good as new and so thankful to be “free” again.

Writing from Boston

Dear Boston:
All the staff at the Simon Foundation appreciated your letter. You are living proof that age is not a barrier to the cure and treatment of incontinence. In the hands of health care professionals who are interested and knowledgeable about incontinence, most people can be cured or improved. Thanks for helping us to reinforce this message to all of our readers.

Dear Informer:
This letter is to “avid reader” who wrote to you concerning his feelings about being a bed wetter. We read the “Informer” avidly on this side of the Atlantic too! Cheryle Gartley has visited us here to help start our “Simon Foundation” an organization which we call National Action on Incontinence. I am a lifelong bed wetter and have tried a gamut of pills, buzzers, etc. with no result. For me the stress of bed-wetting was compounded by first my life in a boarding school, followed by service in the army for 25 years. I have a legacy of school beatings, shaming, teasing, and exclusion from overnight camps/trips. These experiences were then followed by rough treatment in the barracks.

Therapy has helped me to release all the anger and shame. Last year I was able to speak to a national conference about my experiences. I have also spoken to groups of nurses in training and at incontinence support groups.
Now I always tell friends and hotels I visit that I am a bed wetter and will need a rubber sheet—or that I will bring one with me. The response is usually positive, helpful and sometimes hilarious. Some examples were—a gossipy garbage bin bag, which slid about all over, or once on a sleeper train, a solid red rubber sheet was used as a bottom sheet, top sheet and over the pillow—more like a turkish bath or sauna! I wear a medical alert ID disc round my neck saying Enuresis, which has helped me in assuring hotels of my medical problem they always assume too much beer! With best luck for coming out, there are millions of us, and as I always say: “My brother is left handed—poor chap!”

Colin McLean
2 Tynemouth Street
London, England SW6 2QT
UK

Editors Note: While wishing to begin Simon U.K. patterned after Simon Canada, the British found that the name Simon was already well recognized in England addressing a totally different medical problem! Therefore, the name National Action on Incontinence was chosen. National Action on Incontinence was founded by James Malone Lee, M.D. after hearing Ms. Gartley speak at an international meeting. Today, the group is headed by a highly motivated nurse continence advisor, Helen White.

Dear Colin:
Enuresis may indeed be the most worrisome type of incontinence because it usually affects people at a young and vulnerable age. Readers who have children with enuresis are encouraged to see their doctor for a physical evaluation to rule out any physical problems which could be causing bladder problems. Parents may wish to order How You Can Be Boss of the Bladder by Janet Hall, Ph.D. (see advertisement). Dr. Hall is a clinical psychologist in private practice in Melbourne, Australia. Her book is written in three sections, the first section is for children, the second section is directed to parents, although older children may find it interesting to read, and the third section describes the types of treatments which may be obtained from professionals.

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