FOUNDATION BEGINS THIRD DECADE

On June 25th, 2003, the Simon Foundation for Continence launched its third decade of service with several events, including a groundbreaking international conference entitled, "Stigma in Healthcare: Understanding the Psychology of the Stigma of Incontinence." A Town Meeting on Stigma, led by Martha Teichner from CBS News Sunday Morning, and the first North American black tie Gala for Incontinence, held at the Chicago Historical Society, were also part of the week-long launch activities.

The Stigma in Healthcare conference was held in cooperation with The International Foundation for Functional Gastrointestinal Disorders and co-chaired and led by Alan Cottenden, Ph.D., Senior Lecturer in Medical Physics, University College, London, England. Other co-chairs included Christine Norton, R.N., Ph.D., Nurse Consultant, St. Mark's Hospital, London, England; Anita Saltmarche, R.N., MHSc, past Chairman of the Board of The Canadian Continence Foundation (previously Simon Canada) and Cheryle Garstley, President and Founder of the Simon Foundation for Continence.

Experts in incontinence came from throughout the United States and from around the world (Germany, Canada, Sweden, England and Australia were represented) to contribute to finding solutions to the challenge of removing stigma in healthcare, and to celebrate the Foundation's achievements over the past two decades.

During the Gala dinner two special awards were presented. Ronald Rozensky, Ph.D., ABPP, (from the Foundation's Governing Board) presented the first John J. Humpal Award for Outstanding Dedication to Finding Incontinence Solutions, to Neil Resnick, M.D.

Dr. Resnick founded the first continence clinic in America and is a world renowned geriatrician whose research has added tremendous understanding about how the bladder works and what causes its malfunction.

In accepting the award Dr. Resnick stated, "I have received many awards over the years, but none so important to me as this one from a patient advocacy group representing the people I serve."

The award honors Dr. John J. Humpal, the first Chairman of the Board of the The Simon Foundation. Before his untimely death, Dr. Humpal, a University of Chicago Business School professor, gave countless hours to leading the Foundation's Governing Board.

Professor Christine Norton from England (from the Foundation's Advisory Board)

CONTINENCE AND INCONTINENCE

Constipation is the most common chronic digestive condition - an incredibly common daily health problem for many men and women. It is estimated that in the U.S. over $330 million is spent annually on laxatives. Constipation is a symptom which affects individuals differently. Lifestyle changes, dietary changes, and exercise can all help to alleviate constipation.

WHAT IS CONSTIPATION?

Constipation is a problem in the alimentary canal or gastrointestinal tract, the medical terms for our bowels. One definition of constipation is having a bowel movement less than three times per week. However, constipation is a series of complaints which are expressed differently depending on the individual. The most common are: difficulty and
be affected by many things - the amount of food, the chemical makeup of the food, the effects of hormones, and emotions.

Referred to as colon transit time, food takes from one to three days to travel through the body, but most of this time is spent in the colon. High fat meals take longer than high fiber meals to travel through the colon. Once the nutrients and water have been removed from the bowel content, the waste, known as stool or feces, collects in the end portion of the colon and moves into the rectum.

When stool enters the rectum you will become aware that your bowels need emptying. This urge to go can be put off until an appropriate time and place.

EMPTYING YOUR BOWELS CORRECTLY

Successful emptying of the rectum requires you to respond to the urge to move your bowels by going to the toilet and allowing the pelvic muscles around the rectum to relax, very much like relaxing to urinate. Sometimes some straining is needed to initiate or complete the passage of stool. You should avoid prolonged repeated straining efforts as this contributes to hemorrhoid formation and possibly pelvic organ prolapse. Leaning forward and elevating your heels can help in passing stool.

Childbirth often damages the muscles and nerve supply to the pelvic floor. Supporting the perineum (the area just in front of the anus) during bowel movements can assist in bowel emptying. This can be done by covering your hand with toilet paper and placing it over the perineum to provide upward pressure. This is sometimes called “splinting” the perineum.

Kegel exercises to strengthen the pelvic floor muscles, once correctly learned, can be done throughout your lifetime to maintain strength in this area and prevent complications such as urinary incontinence and constipation.

WHAT IS NORMAL?

For most people regularity lies somewhere between three times a day and three times per week. The stool color may vary related to the

SIMON SAYS:

STRATEGIES FOR ESTABLISHING BOWEL CONTROL...

This brochure, written by Mary Plummer, OTR is available by writing to the International Foundation for Functional Gastrointestinal Disorders, Inc. (IFFGD) at P.O. Box 170864, Milwaukee, WI. 53217-8076. For a list of further information on problems of the bowel, IFFGD can be reached toll-free at 888-964-2001 or on line at www.iffgd.org or www.aboutincontinence.org.

FRIENDS MAKE ALL THE DIFFERENCE...

Is a wonderful nonprofit support network that connects people with similar health problems. Participants are matched based on age, health problems, personal background, hobbies and interests. People of all ages participate, and their health problems range from the most common to very rare disorders. Family members, friends and caregivers of people with health problems are networked as well.

To find out more about this organization and the help it can provide to you or a loved one, visit their website at www.48friend.org, or call 1-800/48-FRIEND

“I AM MORE”...

is the Simon Foundation’s brand new anti-stigma song, commissioned to help launch the Foundation’s third decade of service and our upcoming decade of working to defeat stigma in healthcare. For your very own copy on CD, send $4.95 plus $1.00 for shipping and handling, to The Simon Foundation for Continence, Post Office Box 815, Wilmette, Illinois 60091.

CONTINENCE WORLDWIDE...

celebrates the tenth anniversary of its publication this fall. Continence Worldwide is a newsletter about promoting continence around the world, which was conceived by co-editors Professor Christine Norton (U.K.) and Cheryle Gartley (U.S.) to help organizations share programs and educational materials cross culturally. Today, it is the official publication of the International Continence Society’s Continence Promotion Committee. You can read the current edition on line at www.continence worldwide.com.

HELP SIMON LAUNCH THE THIRD DECADE OF SERVICE...

with a special financial contribution to the Bladder Health Mobile fund. The Bladder Health Mobile (BHM) will travel throughout the United States promoting continence and good bladder health.

Visitors to the BHM will find several educational zones, free educational material, and an educator on board to answer any questions they might have. When the Bladder Health Mobile rolls into your community, wouldn’t you like to be able to say, “I helped make that happen?”

Please send your donations to the Bladder Health Mobile Fund, the Simon Foundation, P.O. Box 815, Wilmette, Illinois 60091.
SIMON FOUNDATION CREATES FIRST ANTI-STIGMA SONG

Mosby's Medical Dictionary defines stigma as "1. a moral or physical blemish, 2. a physical characteristic that serves to identify a disease or condition." The stigma surrounding incontinence contributes significantly to the fear which keeps people with incontinence hiding in their homes. Removing the stigma surrounding incontinence has been a part of the Simon Foundation's mission statement since the Foundation's inception.

In June 2003, at the launch of its third decade of service, the Simon Foundation for Continence announced its anti-stigma in healthcare campaign and hosted the premier performance of the first ever anti-stigma song "I Am More" sung by performing artist Gaia, at the Foundation's International conference on Stigma in Healthcare.

"I Am More" is the creation of Cheryle Gartley (Simon's President) and Ed and Gaia Tossing, a Chicago and Memphis based husband and wife team. The Tossings' compositions have been chosen as the theme songs for various world changing events. Their work has garnered three EMMY awards for their "Sing'n Sign" PBS television special. As in all their songs, Gaia signs "I Am More" whenever she performs it.

On July 22, 2003 a crowd of over 1,000 people gathered in the ballroom of Navy Pier in Chicago to attend the first New Freedom Awards Celebration hosted by the Jim Mullen Foundation. "I Am More" was introduced to this audience by Simon Foundation's President, Cheryle Gartley, and performed by Gaia. Included among the prestigious audience of celebrities and dignitaries who heard the first anti-stigma song were Marlee Matlin (Academy Award Winning Actress), Jim McMahon (NFL Quarterback), Mike Ditka (NFL Player and Coach), Joe Ahern (President of CBS/WBBM TV) and Jim Williams (CEO National Easter Seals Society), to name just a few.

"I Am More" will be one of the key elements of the Simon Foundation's anti-stigma in healthcare campaign. "Incontinence is an area of healthcare which is highly stigmatized," stated Cheryle Gartley. "By working to remove the stigma surrounding all aspects of healthcare, we will have constant opportunity to draw attention to the needs of people with incontinence."

You can obtain your own copy of "I Am More" - available on CD from the Simon Foundation, P.O. Box 815, Wilmette, Illinois 60091 at the special introductory price of $4.95 plus $1.00 for shipping and handling, until December 31, 2003.

CELEBRATING THE LAUNCH OF SIMON'S THIRD DECADE

FROM TOP LEFT TO BOTTOM RIGHT: Neil Resnick, M.D. accepting the first John J. Humpal Award; Bette Rank, Simon's Director of Special Projects, welcomes Anthony Caputi from the American Foundation of Urologic Disease, and Dr. Monica Liebert from the American Urology Association to the Gala; Dr. Kristene Whitmore, a Philadelphia urologist at the Town Meeting; Nancy Norton, President of the International Foundation for Functional Gastrointestinal Disorders answers a question at the Town Meeting; Jeff Albaugh, R.N., from the Society of Urologic Nurses contributes to the Town Meeting; Cheryle Gartley (on right) congratulates Christa Thiel from Germany, the recipient of the Mimi Van Slyke Award; Dr. Alan Cottenden (on left) conference co-chair from the U.K., confers with Martha Teichner from CBS News Sunday Morning and Dr. David Fonda (Australia) prior to the Town Meeting; Professor Christine Norton (U.K.) and Anita Saltmarche, R.N., MHSc, (Canada) co-chairs of the Stigma in Healthcare Conference.

Gaia sings and signs "IAm More" the first anti-stigma song.
The Urinary Incontinence Treatment Network

The Urinary Incontinence Treatment Network is a group of urologists and urogynecologists from all over the country who are conducting research on the treatment of urinary incontinence.

This research is being funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Child Health and Human Development (NICHD).

Surgery is one of the most common treatments, specifically the Burch procedure or the sling procedure, which have been performed for decades. The UITN is conducting a study to compare the long-term outcomes of these two commonly performed surgeries.

Both of these surgeries have estimated cure rates of 60% to 90%, but long-term outcomes have not been studied. It is unclear whether one of these procedures is better than the other and should be offered to all women. The UITN plans to answer this important question.

Women who are age 21 years and older, who have stress urinary incontinence, and want surgery for this problem are being enrolled in the study. Stress urinary incontinence is the accidental leakage of urine during activities such as coughing, laughing, sneezing, or lifting heavy objects.

Women interested in the study need to be evaluated to see if they are eligible to participate. This evaluation includes a physical examination and some tests that are routine prior to surgery.

After surgery, patients will have "study" visits with research staff in addition to their usual post-surgery visits. That is, in addition to the 6-week and 3-month visits after surgery, there will also be "study" visits at 6 months after surgery, and every 6 months after that, for up to 4 years.

At some of these times, patients will have physical examinations and repeat tests of bladder function that were also conducted before their surgery. At all visits, patients will be interviewed by a research nurse and asked to complete some questionnaires.

These questions will ask about bladder function, urine leakage, any other treatment for incontinence, satisfaction with the results of surgery, and the ability to conduct typical daily activities.

All of the information collected from study participants will be kept confidential. Patients' names will never appear in any report about this study. Only the results of the medical visits, the physical examination, the bladder function tests, the surgery, and the record of the hospital stay will be kept in patients' medical records. All other information obtained for this study will be kept in a separate research file.

Participation in this study is completely voluntary and patients can choose to remove themselves from the study at any time.

There will be no costs to patients for participation in the study. The costs of the surgery, hospital stay, and physician visits will be charged to health insurance plans just as they would if patients were not participating in this study. Depending on what type of health insurance patients have, there might be a co-payment for visits.

If you would like more information about the study or if you are interested in participating, please call the office nearest to you.

This issue of The Informer made possible in part by an educational grant from Eli Lilly and Company.

REQUEST FOR MEMBERSHIP

Yes, I would like to be a member of the Simon Foundation for Continence.

Please mail me the Foundation's newsletter The Informer.

Enclosed is a check.

☐ $1,000. Life Membership
☐ $15. Annual Membership
☐ $5,000. Corporate Sustaining Membership
☐ $100. Individual Sustaining Membership
☐ $5. Caring Membership
☐ $35. Professional Membership
☐ Other

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

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

NAME __________________________

ADDRESS _______________________

CITY ___________________________

STATE __________ ZIP ___________
### URINARY INCONTINENCE TREATMENT NETWORK RESEARCH SITE LOCATIONS

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<thead>
<tr>
<th>Site Name</th>
<th>Contact person</th>
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<tr>
<td>Beaumont Hospital Royal Oak, MI</td>
<td>Renee Fadel, RN</td>
<td>248-551-1225</td>
</tr>
<tr>
<td>Oakwood Hospital Dearborn, MI</td>
<td>Rosemary Bradt, RNC</td>
<td>313-436-2243</td>
</tr>
<tr>
<td></td>
<td>Kathryn Koches, RN</td>
<td>313-593-8954</td>
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<tr>
<td>Loyola University Medical Center Chicago, IL</td>
<td>Kathy Jesse, RN</td>
<td>708-216-8944</td>
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<tr>
<td></td>
<td>Mary Tulke, RN</td>
<td>708-216-2067</td>
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<tr>
<td>University of Alabama Birmingham, AL</td>
<td>Alice Howell, RN</td>
<td>205-975-8592</td>
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<td>Jefferson Clinic-Cooper Green Hospital</td>
<td>Alice Howell, RN</td>
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<tr>
<td>UCSD Thornton Hospital San Diego, CA</td>
<td>Lynn Kalinoski, PhD</td>
<td>619-543-2169</td>
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<tr>
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<td>DiAnn Ogawa, RN</td>
<td>858-657-8636</td>
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<tr>
<td>Kaiser Permanente San Diego, CA</td>
<td>Lynn Hall, MSN</td>
<td>619-528-6376</td>
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<tr>
<td>Balboa Naval Hospital San Diego, CA</td>
<td>Terry Rogers, RN</td>
<td>619-532-6781</td>
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<tr>
<td>University of Maryland Medical Center</td>
<td>Rosanna Dinh, RN</td>
<td>410-328-7736</td>
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<tr>
<td>University of Pittsburgh Medical Center</td>
<td>Judith Gruss, RN</td>
<td>412-641-5388</td>
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<tr>
<td>Pittsburgh, PA</td>
<td>Karen Debes, RN</td>
<td>412-641-6680</td>
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<tr>
<td>University of Texas-Southwestern Medical</td>
<td>Norma Pope, RN</td>
<td>214-648-3891</td>
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<tr>
<td>Center, Dallas, TX</td>
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<tr>
<td>Parkland Health and Hospital Dallas, TX</td>
<td>Norma Pope, RN</td>
<td>214-648-3891</td>
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<tr>
<td>University of Texas-San Antonio Medical</td>
<td>Sylvia Sluder, CCRP</td>
<td>210-567-0550</td>
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<tr>
<td>Center, San Antonio, TX</td>
<td>Caren Prather, RN</td>
<td>210-567-0548</td>
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<td>Wilford Hall Medical Center Lackland AFB, TX</td>
<td>Sylvia Sluder, CCRP</td>
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<td>Caren Prather, RN</td>
<td>210-567-0548</td>
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<tr>
<td>University of Utah Medical Center Salt Lake</td>
<td>Shelly O'Meara, RN</td>
<td>801-581-6874</td>
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<td>McKay Dee Hospital Center Ogden, UT</td>
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<td>Latter Day Saints Salt Lake City</td>
<td>Shelly O'Meara, RN</td>
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**THIRD DECADE**

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presented Frau Christa Thiel with the Mimi Van Slyke Award for Excellence in Incontinence Not-for-Profit Management. Frau Thiel has headed Gessellschaft fur Inkontinenzhilfe in Germany for fifteen years and has initiated many conferences and successful programs on behalf of people with incontinence.

This award is dedicated to Mimi Van Slyke who, prior to her death, served the cause of continence promotion for fifteen years as the Foundation’s Director of Support Services.

"As the Foundation launches its third decade, the major focus of our efforts will be to take the message of cure, treatment and management to individuals in their communities in unique and creative ways," said Bette Rank, Simon Foundation’s Director of Special Projects.

The Foundation has already begun work on one such project, the Bladder Health Mobile. This vehicle will not only provide visitors with a wealth of information on incontinence, but will also help to bring incontinence further out of the closet by creating media interest on arrival in town-after-town all across America.

Additional projects announced during the launch activities included the Foundation’s traveling shopping mall exhibit (which is being developed in conjunction with the New England Research Institute) and an anti-stigma in healthcare campaign.

"There is a decade of challenging and exciting work ahead of us," concluded Ms. Gartley as she thanked the supporters of the Stigma in Healthcare Conference (Eli Lilly and Company and Boehringer Ingelheim, Gynecare, and Pfizer Global Pharmaceuticals); the Celebration Committee (Elaine C. Austin, Humancare International, Inc.; Bruce Grench, Home Delivery Incontinent Supplies, Co. Inc.; Ray Laborie, Laborie Medical Technologies Corp; Al Maslov, Hollister Incorporated; and Charles A. Stocking, Principle Business Enterprises, Inc.) and all those individuals who had traveled from around the globe to participate.
CONSTITUTION

continued from inside page

food you eat. Bacteria in the bowel causes stool to be brown and the chemicals produced by the bacteria cause odor. About one third of the volume of stool is made up of bacteria so you can see why it is so important to wash your hands after bowel movements. This also helps us understand the importance of wiping from front to back to avoid carrying bacteria toward the vagina and bladder.

If your stool turns black or red it may suggest bleeding in your bowels. You should report this to your doctor immediately. Normal stool is well formed, not dry and hard.

CAUSES OF CONSTIPATION

Though poor fiber intake contributes to constipation, the biggest cause is the failure to relax the muscles around the rectum which control elimination, the pubo-rectalis muscle. Along with good water and fiber intake, relaxation is one of the most important tools to use to avoid constipation.

Unfortunately, today’s hectic lifestyle causes tremendous stress for many people, leading to muscle tension and changes in bowel motility. The constant demands of a hectic lifestyle lead to rushing when emptying the bowel, or worse still, ignoring the urge to empty.

Changes in daily routine can often lead to constipation. Well known is the effects of jet lag when traveling. However, changes in everyday routine can also impact the bowel: change in sleeping patterns, the amount of walking you do, or a stay in the hospital. Many women report constipation during the last half of their menstrual cycle, as bowel motility can be affected by hormones. Changes in eating patterns such as fasting, using fad diets, or the nature of your fluid intake all can affect bowel activity.

People with constipation can begin to look for the source of the problem first by examining what changes have occurred in their daily lives, their dietary habits, how long they allow themselves to open their bowels, and whether they respond when they feel an urge.

SELF-Help FOR CONSTIPATION

Adequate fluid intake and exercise like aerobics or simply walking are two very important components for helping to keep bowels regular and end constipation. Emptying your bowels when you feel the urge to go is another important component of healthy bowel habits.

Eating a balanced diet which includes adequate fiber is also necessary. Beans, peas, prunes, dried apricots, high fiber cereals, and bran are just a few foods that are high in fiber. Fiber absorbs a lot of water; thus fluid intake must be adequate for fiber to be helpful. Some people find caffeine triggers the urge to move their bowels. It may be helpful in limited amounts.

LAXATIVES

There is a variety of products that can be taken to stimulate bowel activity. Fiber is a good option because it is not habit forming. You can start out adding a small amount of fiber to your intake and increase the amount until you move your bowels regularly. Be sure to drink sufficient water if you are using fiber laxatives.

Other laxatives include products that draw water into the bowel like milk of magnesia. Another large category of laxative is the habit forming chemical stimulants found in both herbal laxatives and over the counter medication. They work by directly stimulating the muscular action of the wall of the bowel.

Stool softeners are available to counteract and can be taken regularly to soften hard stool.

There are also products that can be used by direct insertion into the rectum, called suppositories. Simple glycerin suppositories provide lubrication. Stimulant suppositories work much like chemical stimulant laxatives by causing bowel wall muscle activity.

Ask your pharmacist or doctor if the laxative you use can be habit forming. Regular laxative stimulation can result in less and less spontaneous bowel activity over time. And ultimately the bowel may stop responding to the chemical laxative. If you find you are using a habit forming laxative you may successfully control constipation by switching to fiber laxatives which are not habit forming.

SEEKING MEDICAL HELP

If the problem cannot be solved by simple means, speak to your doctor. After taking a thorough medical history, he or she may order some tests which may include some of the following: specialized x-rays, endoscopic examination, and/or a colon transit time test. A colon transit time test shows whether your bowel is simply slow or if there is a problem of obstruction.

There are additional tests which can be performed to investigate muscle tone, elasticity, sensation and reflexes of the bowel.

Information from these tests will help you and your doctor establish a plan of treatment. Most people can be helped by non-surgical means.

Surgery may be necessary to drain abscesses, control hemorrhoids, or repair tears in the anal lining. The pain from any of these conditions may prevent normal bowel movements, thus leading to constipation. Surgery may also be necessary to repair a rectocele, a "pocket" of the rectum which has bulged into the vagina, causing obstruction and contributing to constipation.

UNDERSTANDING THE RELATIONSHIP BETWEEN CONSTITUTION AND BOWEL INCONTINENCE

Chronic constipation can lead to fecal impaction, a condition where dry, hard lumps of feces collect in the rectum, making it difficult to expel this material. Often with impaction, the lining of the bowel can be irritated and mucus may be formed which can move past the mass and leak from the bowel. This leakage may be misdiagnosed as bowel incontinence, leading to inappropriate treatments that worsen the constipation and impaction.

If you have never had bowel control problems and receive a diagnosis of bowel incontinence, a careful evaluation by a doctor including a physical examination of the rectum should be done in order to determine if an impaction is present.