SIMON FOUNDATION HONORED BY THE NEW FREEDOM FOUNDATION

The Simon Foundation for Continence was honored this summer by the New Freedom Foundation. The Foundation was chosen and selected from hundreds of nominees as a semi-finalist "for the organization whose work is deemed to be most extraordinary towards helping people with disabilities."

The New Freedom Awards are presented annually at a black-tie event, held on July 30th in the Grand Ballroom at Navy Pier in Chicago. This event is held to properly acknowledge those individuals and organizations that help to bring focus on ability rather than disability.

"Tonight brings together government leaders, corporate America, philanthropists, and those organizations who work directly to support people with disabilities into one arena with a common mission...to celebrate the achievement...continued on page 5

THE IMPORTANCE OF DIAGNOSIS

There are many reasons why it is important to report the onset of incontinence to your doctor. One of the most important and pressing reasons for early diagnosis is that incontinence is always a symptom of something else happening in the body. For most people the symptom of incontinence is not an indication of a serious underlying medical condition. For instance, incontinence can be precipitated by the natural changes in the body due to aging, such as loss of muscle tone and strength in women or the enlargement of the prostate gland in men. However, incontinence can also be a warning of developing and possibly serious medical problems such as multiple sclerosis, a tumor, or urethral blockage which left untreated can result in kidney failure. The importance of talking to your doctor so that he or she can determine the reason for your misbehaving bladder cannot be overstated.

A second important motivation for early diagnosis of incontinence is that by determining and treating the underlying...continued on page 2
cause, your incontinence may be cured. For instance if a urinary tract infection (UTI) is discovered to be the cause of your incontinence, treating the infection with antibiotics will lead to regaining bladder control. Also, once the causes are determined, the most appropriate and effective approach can be formulated. In general, the milder incontinence is at the time treatment is begun, the easier it is to treat.

A third benefit of diagnosis is that you will become knowledgeable about how your bladder works and more aware of the circumstances which precipitate your bladder leakage. The mechanism of urination is easy to understand. In a normal bladder, as urine filters from the kidneys into the bladder, the muscular wall of the bladder begins to expand to retain the urine. When a certain point is reached in the filling process nerves in the bladder wall send a signal to the brain that the bladder is becoming full. Then (at an appropriate time and place) the brain will send a message for the urethral closure muscle at the base of the bladder to relax while the bladder muscle contracts to force the urine through the urethra to the outside of the body.

The ways in which bladder control is lost are more complex. Another benefit of early diagnosis is that you will learn which type of incontinence you have. Knowing the type of incontinence can help you and your doctor determine what treatment options are available for you. When you are reading about new developments in the incontinence area, you’ll know whether they apply to your particular type of incontinence.

There are three main types of incontinence: stress urinary incontinence (SUI), urge incontinence (and overactive bladder or OAB), and mixed incontinence. Each type of incontinence describes a different way in which the bladder is malfunctioning.

If you are diagnosed with stress urinary incontinence you have probably reported symptoms which include loss of urine when you cough, laugh, sneeze, exercise or lift. SUI occurs when pressure on the bladder overcomes the mechanism which normally keeps the bladder closed.

If you are diagnosed with urge incontinence your symptoms most likely include a sudden urge to urinate with loss of urine before you can reach a toilet. Millions of Americans are affected by an overactive bladder (OAB) and symptoms of frequency and urgency although they may not actually leak urine.

The diagnosis of mixed incontinence is a combination of stress urinary incontinence and urge incontinence. If your diagnosis is mixed incontinence, you need to discuss carefully with your doctor which type of incontinence is most distressing to you. Some interventions for SUI may be successful in curing your leakage, but have the potential to worsen the urgency component of your bladder problems.

Perhaps the most important reason of all to seek diagnosis for your incontinence is to live life to the fullest. There are many social consequences and ongoing changes that people make in their lives because of incontinence. Changes in sexual relationships, or reluctance to actively participate in the play of grandchildren are not uncommon reactions to urine leakage. Alterations in daily life impact other people and do accumulate if action is not taken to diagnose and treat bladder control problems.

**DIAGNOSIS BEGINS WITH GOOD COMMUNICATIONS:**

Fortunately, most of the evaluation for incontinence is not invasive. In fact, some of the most important tools for diagnosing the cause of your bladder problems are not high tech at all, but rather an observant patient who reports his or her medical history and symptoms accurately and concisely, a physician who is both a good listener and a skilled medical detective, some basic tests such as a urinalysis to rule out a urinary tract infection, and a record of how your bladder works each day, called a bladder diary.

A bladder diary is a record you keep for anywhere from three to five days. Often your doctor will send you a packet of materials before your first visit which will include the particular type of bladder diary he she prefers. Or you can make your own by recording the times during the day and night when you consume fluids (and the amount), when you use the toilet (and the amount voided) and when incontinence episodes occur along with the activity which was associated with the leakage.

It may be possible that once the bladder diary has been completed and you have had your first office visit to discuss your incontinence, that your doctor will already have a fairly good understanding of your particular bladder problem and may recommend some initial therapies for you to try.

The National Institutes of Health recommend that the least invasive therapies be tried first. Exercises to strengthen the muscles which support your bladder neck (with or without the help of devices like electrical stimulation, biofeedback, or exercise cones) may be prescribed if your symptoms point to stress urinary incontinence. If you have an overactive bladder or are experiencing urge incontinence, your doctor may prescribe a medication to see if this alleviates your incontinence symptoms.

Depending upon your bladder’s reaction to these first steps in treating your incontinence, further diagnosis may be indicated. There are several possible choices depending on the nature of your condition. A cystoscopic exam allows your doctor to have a clear image of the interior of the urethra (the tube leading from the bladder to the outside of the body) and the inside of the bladder. To provide these images, a well lubricated tube, often made of optical fibers, is gently inserted into the urethra and bladder. This exam is normally conducted in a doctor’s office and is not a lengthy procedure.

Another possible diagnostic test which will give your doctor a great deal of data about your bladder is cystometry, a test which shows how well your bladder is functioning. Cystometry may be one of a group of tests called urodynamics. Cystometry involves filling the bladder with water or gas through a catheter. An instrument called a

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Courage is most often recognized on the occasion when ordinary individuals, who find themselves in extraordinary circumstances, respond instantaneously with an action which saves the lives of others. However, courage comes in many forms. Personally, I believe that Amy McElroy is a young teenager who exhibited an outstanding example of courage at her school last year. The following, in her own words, is how she explained her incontinence to her teenage classmates. We reprint her story (edited due to space limitations) with permission from FTN News, A Publication of the Pull-thru Network. The original article, entitled “Explaining ‘It’ to My Peers” was published in December 2003.

“Openness may be one of the keys to happiness; at least it has been for me. In late August, I decided to let the world (or the one as seen through a teenager’s eyes) know about a little/big something that affects my everyday life; my incontinence.

“Everyone in this room knows being a teenager is not always easy.”

Over the course of my academic life my mom has explained “it” to my peers. Well, at least that’s how it worked until middle school. For the past two years I have kept “it” a big, annoying secret. My teachers and the school administration all knew and I had special bathroom privileges and accommodations to help me. But it was still awkward to leave class suddenly and then have all my friends ask me if I was okay or where did I go when I came back to class. They were never rude so it seemed to me that I shouldn’t be rude by saying that it was none of their business. It upset me that because the average teenager has no way of knowing about kids like me that there was not a quick, easy way to answer their questions. I got sick of lying to people who cared about me. This year I took it upon myself to walk around to each homeroom in my section of the eighth grade and explain “it” to my peers. Here is what I said:

‘Everyone in this room knows that being a teenager is not always easy. Some of us spend endless hours in front of the mirror trying to figure out why that special guy or girl doesn’t like us. We want to do things we aren’t allowed to do, and get mad at our parents for being parents. Yet, it’s pretty tough being a teenager with just that simple list of things. Do you know someone who has asthma, or diabetes, or cerebral palsy? Have you ever met someone with cancer? If not, I’ll bet you’ve read about someone with at least one of those medical issues. What if you met someone with a medical problem that isn’t very popularly known, but affects a large amount of people across the world?

Well...you just did. I was born with something called VATER Syndrome. VATER stands for a group of birth defects that can happen together, occurring on average in 1 out of every 10,000 births. Each letter stands for a different defect: V stands for vertebra, the vertebra is malformed; A stands for anorectal, a part of the colon or intestines is malformed; T stands for trachea, the trachea is malformed... I was born without my esophagus, so when I was about 1 year old I was made one (this is the cause of the scar on my neck). I have hemic-vertebra and butterfly vertebra in my lower back. I also am fecally incontinent due to numerous past surgeries and VATER Syndrome.

Fecal incontinence is when nerves are damaged and the body can no longer process nerve signals fast enough to tell when you have to go. Well, not always, but sometimes. I have a morning routine that helps me manage this, but it is not 100% guaranteed to work every day. Some mornings I will be coming in late or there may be a time when I have to leave the room. This is probably because I had a problem during my routine, but I assure you I will be fine.’

Now, most would have expected a negative reaction to this, but here is where most are proven wrong. As I said earlier, my mom had been explaining this since kindergarten. Never have I been teased or treated differently. I have always been treated like just a regular “chic” and that has helped me in amounts not imaginable. Basically, although logic would tell you the opposite, kids aren’t bad, rude, or cruel in these situations. It’s when they aren’t in the know, or don’t understand, that bitterness and rudeness come about.

The experience I had this year was uplifting. It gave me more confidence within myself more than anything else. I learned that no matter what I should never be ashamed of my incontinence, it’s part of who I am. Now I feel as if I could do anything. I am a Peer Mediator, a Peer Tutor in math and I hope to make it into the talent show this year. This year has so far proven to me that absolutely anything is possible if you put your mind to it.”

“Now I feel as if I could do anything.”

In this editor’s opinion, Amy, in talking so candidly to her classmates, showed an example of courage that millions of adults with incontinence have yet to discover within themselves and in so doing, one brave teenager in a classroom somewhere in America, rolled right over our culture’s taboos and set an example of how each of us can do something wherever we are to help lead the way to defeating the stigma surrounding incontinence.
SIMON SAYS:

AWARD ANNOUNCED...
The Simon Foundation recently announced that the Society of Urologic Nurses and Associates (SUNA) is the first recipient of the Foundation’s Defeating Stigma in Healthcare Award. SUNA is a national, non-profit membership association with over 2,800 members. The Award recognizes outstanding contributions to removing the stigma that surrounds a wide variety of health conditions. Jasmine Schmidt, the Foundation’s Director of Education will present the Award to the President of SUNA, Marie Page, RN, CURN, at the Awards Luncheon to be held during SUNA's annual meeting in Florida in October.

DR. NEIL RESNICK...
was recently invited by the Alliance for Aging Research to speak on Capitol Hill to representatives of Congress on the topic of ‘Diseases in the Shadows’. 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. He is a member of the Simon Board of Directors and is the 2003 recipient of the John J. Humphal Award for Outstanding Dedication to Finding Incontinence Solutions. Dr. Resnick will be speaking on what is UI, how common is it, who is at risk, what is the average yearly cost, how does it affect independence, what are the treatment options and efficacy, and hope for the future.

RONALD H. ROZENSKY, PH.D....
long time member of the Simon Board of Directors, has just been elected to the Board of Directors of the American Psychological Association (APA). The APA is the world’s largest professional and scientific organization in psychology with more than 150,000 members including over 60,000 licensed psychologist healthcare providers. Dr. Rozensky is currently Professor and Chair of the Department of Clinical and Health Psychology in the College of Public Health and Health Professions at the University of Florida, Gainesville, FL.

HELP MAKE A DIFFERENCE...
In defeating stigma in healthcare. Purchase copies of “I Am More” (the anti-stigma in healthcare theme song) and give them to your friends, family, church and community choir directors, and your local schools. Stigma is personally, interpersonally, and socially costly. Many if not most people living with a chronic disease or disability experience stigmatization. It is long overdue that society addresses this issue. You can play a part. Order your own copies of “I Am More” directly from the Simon Foundation for Continence, Post Office Box 815, Wilmette, Illinois 60091. The cost per CD is $4.95 plus $1.00 for shipping and handling.

LEARN MORE ABOUT CHILDREN AND INCONTINENCE...
and order the National Institute of Diabetes and Digestive and Kidney Diseases educational publication “Urinary Incontinence in Children”. It is available at www.niddk.nih.gov or from the National Kidney and Urologic Diseases Information Clearinghouse, 3 Information Way, Bethesda, MD 20892-3580. The publication is free.

LOOK FOR THIS REFERENCE IN YOUR LIBRARY...
the new fifth edition of the Older Americans Information Directory, 2005 is now available. This resource offers easy access to thousands of information resources helpful to older Americans, all in one directory. It includes up to date information on social, health and financial issues facing older Americans in the 21st century, as well as recreational and educational opportunities to enrich their lives. This directory can be found in most libraries under ISBN:1-59237-037-3.

WOMEN’S HEALTH FOUNDATION...
announces the expansion of its Total Control™ program to the Chicago marketplace. Total Control™, the first fitness and educational program for women with incontinence and/or those at risk to develop incontinence, premiered in Chicago at Loyola University Medical Center on September 21st. The first two classes are

continued on next page

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.

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Your annual membership will begin with the next edition of The Informer.

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ments of the New Ability Industry and to directly encourage improvements in the lives of people who have a disability,” stated John Chimela, co-founder of the New Freedom Foundation.

Bill Smith, co-founder, added: “When you submit a resume to a potential employer, you don’t tell them that you don’t drive, that you don’t know how to cook, and you speak only one language...you focus on what you can do. Tonight we are here to focus on ability.”

In addition to the Simon Foundation for Continence, other top nominees in the best organization category included: The Buoniconti Fund to Cure Paralysis - a major supporter of the Miami Project; Crotched Mountain Foundation - which has provided rehabilitation services for thousands of people with disabilities; The Marriott Foundation - whose mission is to enhance employment opportunities for people with disabilities; and Sorenson Media - creators of the first easy-to-use videophone for the deaf and hard-of-hearing community.

Award presenters included several nationally recognized individuals, including Heather Whiteston McCallum, Miss America 1995; Bob Love, NBA basketball star; Kathleen Qulan, actress and Oscar nominee; and Kim Peek, the real Rain Man on whom the film was based.

A highlight of the evening was the announcement of the winner for the 2004 Best New Ability Organization Award which went to The Sam Schmidt Paralysis Foundation and was accepted by its founder Sam Schmidt, a race car driver who competed in three Indy 500s until a crash in 2000 left him paralyzed from the shoulders down. Today Schmidt is the impetus behind an organization that raises funds through the power of motorsports for medical research, as well as the treatment and rehabilitation of others dealing with spinal cord injuries.

“It is an honor for incontinence to be recognized in this manner,” said Cheryle B. Gartley, Simon Foundation’s President and Founder. “Millions of Americans find incontinence a disabling health problem which lessens their quality of life. I hope that the entire incontinence industry becomes involved with the New Freedom Foundation and their awards program. Over the last two decades, doctors, nurses, physical therapists, researchers, and dedicated individuals in industry have designed innovative incontinence solutions which have made enormous contributions to new freedoms for people with incontinence. There are so many deserving individuals and companies in the incontinence arena who should be recognized in this way, for they have truly changed peoples lives.”

The Simon Foundation has been a supporter of the New Freedom Foundation since its inception. At their 2003 Awards Gala the Simon Foundation introduced its Anti-Stigma Healthcare Campaign, and the Campaign’s theme song, “I Am More” was performed by three-time Emmy Award winning vocal artist Gala Tossing.

SIMON SAYS:
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being run as an eleven week research study in partnership with Loyola’s Department of Obstetrics & Gynecology, under the direction of Dr. Linda Brubaker. Total Control® classes will continue at the Loyola Center for Health & Fitness in January 2005. Future classes will be open to the public. For more information, contact Jennifer Andersen at 312 377 8202.

NEW PROSTATE INFORMATION SOURCE...
If you or your loved one is suffering from prostate-related health issues, visit the Alliance for Aging Research at www.agingresearch.org to assess your knowledge and view a comprehensive directory of prostate health. The private, not-for-profit organization is the nation’s voice for Baby Boomer health, developing, implementing and advocating for programs in research, professional and consumer health education and public policy.

Thank You

(editor’s note: This issue of The Informer was underwritten by an educational grant from SCA Personal Care, the manufacturers of Serenity and TENA Incontinence products. The Simon Foundation for Continence does not endorse specific incontinence products or medical treatments. Inclusion in this column in no way implies endorsement.)

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Introducing a new, fresher Serenity®
featuring:

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cystometer is attached to the catheter to measure the capacity of the bladder and its internal pressure when it is filled. Other urodynamics tests may also be conducted to further understand how your urinary system behaves when it is called upon to store and empty urine, the two basic functions of the bladder.

**IS DIAGNOSIS OF INCONTINENCE UNCOMFORTABLE?**

Some people may feel a natural emotional discomfort or embarrassment when involved in testing their bladder for incontinence. The testing is intended to reproduce your symptoms of incontinence so involuntary leakage of urine during the test is expected. But remember that doctors and nurses perform these procedures every day and will help put you at ease. Also, there may be some physical discomfort when the catheter is inserted, but the tube is very thin and well lubricated to keep discomfort to a minimum. You may also feel very strong urges to urinate at various times during some of the testing.

**YOUR BODY, YOUR CHOICE...**

Remember, the most important reason for early diagnosis of incontinence, is that incontinence is a symptom of something else happening in your body. Once you know the reason that your bladder is misbehaving, and the possibility of a serious medical condition has been ruled out...the choice is yours. Your body, your choice...absorbent products, medications, surgery, implantation of a device...thanks to dedicated medical researchers and the creativity of scientists employed by industry the options are increasing every year...help is on the way, the first step is yours...find out what is causing your incontinence, make an appointment today with a professional who is interested and knowledgeable about incontinence.

**Medications for Stress Urinary Incontinence**

Stress urinary incontinence (SUI) is caused by failure of the urethra to remain closed during physical stress on the bladder. This stress may be caused by activities such as coughing, sneezing, lifting, or exercises. Though this failure of the urethra is mainly attributed to loss of support of the bladder and urethra, weakness of the urethra itself may contribute. Medications which tighten the urethra have been used for SUI with some success. Both prescription and non-prescription medications are used. Current research on new medicions which act through different mechanisms may prove to be more effective alternatives.

**PRESCRIPTION MEDICATIONS USED FOR SUI:**

One category of medications, called alpha adrenergic agents, can increase the closure or "squeeze" in the urethra. These drugs have many effects on the body, so side effects can limit their use. The most commonly used prescription agent is imipramine, a drug with multiple effects and multiple uses. It not only is thought to increase the resistance to leakage in the urethra, but may also calm bladder contractions in the overactive bladder. Side effects of imipramine relate to its multiple effects in the body include increased heart rate or palpitations, dry mouth, and constipation.

Because of the side effects, imipramine is usually started at a low dose and gradually increased to obtain the maximum benefit with the fewest side effects.

A newer drug being investigated for use in SUI works through neurotransmitters in the brain called serotonin. Neurotransmitters work to convey information from one part of the brain to another. The brain controls bladder function through pathways in the spinal cord that connect the bladder to the brain.

This new medication, with a different mechanism of action, may offer a more effective alternative for SUI in the future.

**NON-PRESCRIPTION MEDICATIONS:**

A drug used in over the counter cold medications called phenylpropanolamine has also been used in SUI with limited success. It works through the same alpha adrenergic tightening of the urethra as imipramine. It is available in several commercial products such as Entex LA. This medication can also cause palpitations and increased heart rate, as well as urinary retention.

For any of these medications to be effective, they must be taken on a regular basis. If you can obtain relief of your symptoms while taking the medication note that they are still likely to return if you stop taking the medication. Individuals with high blood pressure, heart problems, or urinary retention should not use these medications.

**BEFORE YOU BEGIN TAKING A MEDICATION FOR YOUR BLADDER:**

There are many things that you should understand before beginning a prescription:

- Why are you taking the medication and what you can expect it to do?
- How often and how you should take it (for instance, with or without food)?
- What are the most common side effects?
- What, if any, side effects should be considered an emergency?
- How long do you need to take the medication?

You might also wish to ask your doctor or nurse the most common side effects of your prescription and if he or she has any suggestions regarding how to cope with these side effects so that you can more easily tolerate the medicine.