At the National Institutes of Health...

Urinary Incontinence Research

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The National Institutes of Health (NIH) is the largest government agency in the world with a mission focused on understanding, effectively treating and preventing human disease. NIH is located just outside of Washington D.C. in Bethesda, Maryland. It is an agency of the Federal Government within the Department of Health and Human Services.

The NIH is not just one institute, but is comprised of fourteen separate institutes or agencies, each of which has a Congressionally mandated area of health focus. Each institute accomplishes its health related mission by developing programs for public and health professional education, and by funding research studies throughout the United States and the world which focus on the disease and disorders which affect the citizens of the United States.

As an example, cancer studies are primarily funded by the largest institute, and perhaps most prominent of the NIH

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SURGERY FOR STRESS URINARY INCONTINUENCE

Stress urinary incontinence (SUI) is the uncontrolled loss of urine caused when abdominal pressure overrides the closure mechanism of the bladder, allowing urine to leak out. Most women experiencing this type of leakage do so when coughing, sneezing, laughing, exercising, or lifting. Usually SUI is associated with loss of support of the bladder and the urethra.

One of the treatment options for SUI is surgical correction of this loss of support. Surgical treatment for SUI has been refined over the years so procedures with good cure rates and low complication rates are now available. A thorough evaluation needs to be done before surgery to consider non-surgical options and design the best surgical procedure if surgery is the treatment of choice.

THE GOAL OF SURGERY:
Muscles and tough connective tissue in the pelvic area hold the pelvic organs, including the bladder, urethra, rectum, uterus and vagina in place. When these supporting tissues weaken, one consequence can be stress urinary incontinence. All surgery for SUI returns the organs to their original position in the body and allows the urethral closure mechanism, or sphincter, to function normally. There are several types of operations that may be suggested to you depending on your symptoms, your anatomy, and the particular surgical method in which the physician has had the most training and experience. Differences in the procedures include the incision site which is used to approach the urethra, the exact location of the sutures placed in the urethral suspension, and the use of graft material.

Because the goal of surgery is to make you dry, it is most important to explore with your physician if SUI is the only reason for your bladder leakage. Many women have mixed incontinence, a combination of stress and urge incontinence. Urge incontinence, the sudden feeling of having to rush to empty your bladder, has a variable response to surgery. Sometimes surgery for stress incontinence will relieve urge inconti-

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Simon Says Updates
Understanding Biofeedback

Injury and/or weakness of the muscles supporting the pelvic organs results in several types of dysfunction, including incontinence. Your doctor may prescribe Kegel exercises to strengthen the pelvic floor muscles and help the closure mechanism of the bladder to protect from stress urinary leakage when sneezing, coughing, or lifting. They also help relieve urgency and urge incontinence symptoms. Many people have difficulty learning these exercises successfully, because of weakness, disuse and injury.

Biofeedback can help (1) identify the correct muscles, (2) determine the degree of weakness in order to prescribe an exercise level, and (3) determine that the exercises are being done correctly. Biofeedback measures pelvic muscle activity and translates this activity into images on a computer screen, or into light or sound. This visual or auditory feedback allows you to learn to perform pelvic muscle exercises properly and to follow your progress.

How Does Biofeedback Work?
The pelvic muscles are situated inside the pelvic bone so their actions cannot be seen. They are often weakened or damaged by various factors including childbirth and disuse, so that a woman's awareness of their action is diminished. Visual or auditory feedback of the muscle activity enables women to learn to exercise these muscles properly.

Biofeedback for incontinence can be thought of as assisted pelvic muscle exercises. This assistance may be as simple as incontinence 'cures', tampon like weighted devices that are inserted into the vagina. The effort to retain the cone exercises the pelvic muscles. A more complex type of assistance is provided by using special machines with various types of displays.

There are three components of biofeedback: (1) a body response (like muscle contraction) is measured, (2) this measurement is amplified by a machine, and (3) the measurement is fed back to the person via a computer screen, lights, or sound. There are many different types of equipment that can be used to help learn to contract and relax the pelvic floor muscles at will. All measure and display the muscle activity by recording the electrical activity or pressure of the muscles.

Using Biofeedback To Improve Incontinence:
Biofeedback can be used to help people with stress incontinence, urge incontinence, and mixed incontinence, a combination of both urge and stress. Like any exercise, the work must be done by a determined individual who sticks to their exercise regimen. Biofeedback can help by: (1) providing the information to locate the correct muscles, (2) determining their initial strength so that your exercise program can be tailored at a level appropriate for your ability, and (3) measuring your progress so that an individualized program can be designed to fit your needs.

Biofeedback for Stress Urinary Incontinence
Stress urinary incontinence (SUI) refers to leakage of small amounts of urine when coughing, laughing, jogging or doing anything that causes the abdominal pressure to override the bladder's closure mechanism. Biofeedback to help SUI will measure the activity of the muscles near the vagina, urethra or anal opening. A few tiny patches may be placed on the skin near the anal sphincter, inside the vagina or inside the urethra.

Alternatively, a small probe may be inserted into your vagina or rectum. These instruments will give your therapist information on muscle activity at rest and when you squeeze.

Also you will be able to tell whether you are exercising the correct muscles. Once the baseline information has been recorded, your progress and the increasing strength of the pelvic floor muscles can be measured at each of your return visits.

Biofeedback for Urge Incontinence:
Biofeedback was first used to learn pelvic floor exercises for stress incontinence. However, learning to contract these muscles also helps urge incontinence, the compelling desire to urinate and the inability to delay voiding long enough to get to a toilet. Kegel exercises help to prevent urine leakage during involuntary bladder contractions that cause urge, by activating a neurologic reflex which calms the involuntary contractions.

In some instances a different biofeedback method will be used to help calm the involuntary contractions. With this method a catheter is inserted into the bladder and you can watch the pressure increase in your bladder as it is filled. With this feedback many women can learn to relax the bladder muscle so they can calmly locate a toilet rather than feeling the need to rush.

When To Expect Results
It may take up to twelve weeks of regular exercise to be able to see an improvement in your incontinence. Most patients see their therapists at least four to six times over a twelve week period. Some therapists prefer to see their patients weekly. Improvement will depend on your particular anatomy and your effort. Determination is the best predictor of success with pelvic muscle exercise. You should spend up to fifteen minutes or more each day exercising. Your doctor may instruct you to spend part of this time doing the exercises quickly, and some slowly, as each method strengthens different components of the muscle. Once you have learned the exercises correctly, they can be done anywhere, at your desk at work, while preparing meals, or riding in your car.

Remember, Kegel exercises like all exercise must be done regularly. Once you stop exercising the muscles will weaken again. Biofeedback is a safe way to learn the Kegel exercises. There are no reported complications from this method. Scientific reports in medical literature find that the majority of patients are improved or cured, once the correct way to exercise the pelvic floor muscles is learned and done faithfully. Exercising for incontinence is a lifelong commitment as is exercising for all health benefits.
Institutes, the National Cancer Institute (NCI). Studies related to eye problems are funded primarily by the National Eye Institute. In many cases, research and education is funded by more than one institute, each of which provides its own specific area of emphasis. Urinary incontinence is one of those health disorders which is funded by many institutes within the NIH.

The Congress has directed the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) to be the lead institute in developing research studies and educational programs focusing on urinary incontinence. The responsibility for these studies rests within the Urology Program of the NIDDK.

Other NIH institutes focusing on incontinence research are the National Institute of Child Health and Human Development (NICHD) and the National Institute of Aging (NIA). All of these institutes have responsibility for developing research programs for many diverse diseases in addition to incontinence.

For example the NIDDK has responsibility for research on diabetes, on gastric ulcer disease, and hepatitis. The NICHD has responsibility for research on many of the childhood diseases, the NIA has primary responsibility for research on Alzheimer’s disease. Prioritizing the diseases to be studied and the amount of money to be spent on each disease rests with the director of each institute.

The director of each institute sets funding priorities based on many factors: the perceived impact of the disease on the public health of the citizens of the United States; the intent of the Congress when the fiscal year budget is appropriated at each institute (the budget from the Congress is accompanied by written directives called the appropriation language, which specifies certain areas which the Congress feels the citizens of the U.S. wish to be priority areas for research); the expressed concerns of the public citizen, patient advocates and health professionals; and the advice of the Institute staff.

Most of the diseases have patient advocacy groups which meet with members of the Congressional Appropriations Committees to make them aware of the impact of the disease on the citizens of the U.S. and the importance of research funding to develop new and effective methods of prevention, treatment, cure and public education. Citizens frequently write to their Congressional representatives or meet with them to explain the need for additional research focusing on new and effective treatments, prevention, cure and/or education.

All of these concerted endeavors provide both the Congress and the NIH Institutes with an impression of both the impact of the disease on the U.S. population and the support for the expenditure of public funds focusing on the disease. An excellent example of this concerted focus for increased research has been the efforts of the patients and advocacy groups for research on the battle against breast cancer. A similarly successful advocacy effort has been developed by those in support of research for defeating AIDS.

Patients and advocacy groups should seek to educate the Congress and the NIH Institutes about the impact of the disease on the health of the citizens of the United States, they should seek to determine the priority level that has been set for research for their specific disease (i.e. the amount of money being spent and the amount projected to be spent) and if they are not satisfied with the priority, they should feel free to express this viewpoint and suggest areas that need additional research expenditures.

Urinary incontinence is a health problem which affects untold millions of Americans of all ages. The patient and his or her family can express those concerns to all agencies and individuals within the government (both in the Congress and at the NIH) in a far more meaningful and effective manner than any health care practitioner.

SEE US ON THE WEB...

at www.simonfoundation.org.

Rebecca Chalker, co-author of Overcoming Bladder Problems states: “This is one of the best websites I've seen.” We welcome ideas to make the site more helpful to our members.

FACT SHEETS FOR PARENTS OF CHILDREN WITH URINARY PROBLEMS AVAILABLE...

from the National Institute of Diabetes and Digestive and Kidney Diseases. Urinary Incontinence in Children and Urinary Tract Infections in Children can be found at www.niddk.nih.gov or a single copy of each fact sheet is available free to the public. Please contact: NKUDIC, Attn: UIC; 3 Information Way, Bethesda, MD 20892-3580.

A VERY SPECIAL CONFERENCE—SAVE THE DATES...

One of the many projects we intend to launch in our twentieth year, is a very special conference. We do not hold an annual conference, instead we attempt to focus our efforts on groundbreaking work for important topics that have not previously been explored. For instance, the Foundation organized the First International Conference for the Prevention of Incontinence held in the United Kingdom in 1997 which has led to increased attention to prevention worldwide.

In 2003 we will host “The Psychology Behind the Stigma of Incontinence” to bring together experts in health psychology, rehabilitation psychology, social psychology, anthropology, medicine, nursing, health policy, and of course, individuals with the problem. These experts understand the psychological, social, and policy dynamics that help to create the defeat common among people with incontinence. Some of the topics which will be explored at the conference include: body image formation; interventions for change; stages of change inclusion/exclusion in societies; the psychology of hope; adherence vs. compliance; influencing health policy; general health decision making; empowering patients; and stigma. In addition, interactive discussions between psycholo...
gists and people who are incontinent will be included.

Save the dates of June 25-27, 2003 and join us in Chicago for this conference and twentieth anniversary celebration gala. Watch Simon Says in upcoming Informers, or at our website www.simonfoundation.org for further details.

A SPECIAL THANKS...
You may have discovered the Foundation and be reading this newsletter after having seen one of our recent advertisments, or perhaps you discovered us through a call to our 800-line. Both of these opportunities are thanks to the generous financial support of Bruce Grench and his staff at HDIS (Home Delivery Incontinence Supplies). A special thanks to this team for their continued efforts to promote the Foundation and help the American public discover the help and hope available through us.

ADVANCING THE TREATMENT OF FECAL AND URINARY INCONTINENCE THROUGH RESEARCH Trial Design, Outcome Measures, and Research Priorities...
is a conference you shouldn't miss if you are interested in the advancement of cure and treatment for incontinence. Jointly sponsored by the Office of Continuing Medical Education, University of Wisconsin Medical School and The International Foundation for Functional Gastrointestinal Disorders (IFFGD) in cooperation with The Simon Foundation for Continence (November 3-5, 2002).

The purpose of this conference is to:
summarize the state-of-the-science regarding epidemiology, pathophysiology, and available treatments for fecal and urinary incontinence; summarize available literature on outcome measures, predictors of successful treatment, and research design; and identify the priorities for research from the perspective of each professional subspecialty concerned with the management of incontinence. A partial speakers list includes: William E. Whitehead, Ph.D., John DeLancey, M.D., John F. Schmele, Ph.D., Christine Norton, Ph.D., Linda Brubaker M.D., Kathryn Burgio, Ph.D., Ingrid Nygaard, M.D., Jeannette Tries, Ph.D., Clare Fowler, FRCP, and many others who have dedicated their careers to solving incontinence - including Simon Foundation Board members Nancy Norton, Founder and President of IFFGD, Neil Resnick, M.D. and Cheryle B. Gartley, President of the Simon Foundation. For further information contact Cathy Means, Office of Continuing Medical Education, University of Wisconsin, 2715 Marshall Court, Madison, Wisconsin 53705; telephone (608) 263-6637, E-mail: cjmeans@facstaff.wisc.edu.

PREVENTION CONSENSUS STATEMENT AVAILABLE...
The Simon Foundation for Continence and The Continence Foundation of the U.K. were co-sponsors of the First International Conference on the Prevention of Incontinence. A Consensus Statement developed by forty-two internationally recognized experts in this field is available from the Simon Foundation, Post Office Box 835, Wilmette, Illinois 60091. Please enclose two dollars for shipping and handling.

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

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One Voice: An Editorial

2003 marks the twentieth anniversary of the founding of the Simon Foundation for Continence. For many people their birthdays are a time to reflect on the past, give thanks for the present, and plan for the future. And that is exactly what we've been doing at the Foundation this year. The Simon Foundation for Continence is the largest patient-led education and advocacy group for incontinence in the world. Our mission has been “to bring the topic of incontinence out of the closet, remove the stigma, and provide education for people with the problem, their families, and the health care professionals who provide their care.”

As readers can see from perusing this edition of The Informer, progress promoting continence has been substantial. Twenty years ago, there were only a few voices calling for action, there was just one book, Managing Incontinence, for the layman, very few product choices, and limited training of doctors and nurses in their respective schooling. Today, the National Institutes of Health and the World Health Organization are focusing their substantial medical clout on incontinence.

We’ve come a long way. As the Foundation celebrates this anniversary, it is also time to say thanks. Thank you to our faithful members, the foundations who have given us grants, and all the corporations in the incontinence industry who throughout the years have financially supported the work of The Foundation.

From one coast to the other, thanks to all of you: Abbott Laboratories; Advanced Surgical Interventions; Alza Pharmaceuticals; AARP: American Medical Systems; Barna, Ltd.: Biotechnology; Chattem: Coloplast Corporation; Convad; Convatec; C.R. Bard, Inc.; DeWitt, U.S.A.; Diagnostic Ultrasound Corporation; Eli Lilly & Company; Empli; Ethicon; Finally Natural Care; Geri-Care Products; Hollister, Inc.; Home Delivery Incontinence Supplies (HDIS); Humancare International, Inc.; Kendall Company; Johnson & Johnson; Kimberly Clark Corporation; Laborie Medical Technologies; Marion Laboratories; Medical Device International; Medtronic; Med-I-Pant; Mentor Urology; National Institutes of Health; Neutonus, Inc.; New England Research Institute; PharmaCorp Corporation; Principle Business Enterprises; Procter & Gamble; Retirement Research Foundation; SCA Hygiene Products; Scott Health Care Products; Sherwood Medical; Smith & Nephew, Inc., Squibb, Inc.; TransAqua Corporation; UroMed; Upjohn Pharmaceuticals; and Whitestone Corporation.

Although we have listed your companies, it is all of you very special people within them who deserve the credit for helping to see and communicate the vision of continence for everyone. We salute you.

Promoting continence has never been an easy task. In fact, it has been a most difficult challenge. As we look to the future, there is an obvious piece of the continence promotion puzzle still missing which must be put in place. It is voices for the millions of Americans who have the problem.

It is your voice and your dollars. Medicare, the National Institutes of Health, Congress, medical schools, and nursing schools need to hear from the people they serve. Institutions like The Simon Foundation need your dollars. If every Informer reader pledged just $10 annually, the Simon Foundation could contribute more than $1,500,000 to research each year. The stigma is lessening, the general public is becoming educated, attention has been focused on incontinence. What does the future hold? It’s up to you.

Letters to The Editor

Dear Cheryle:
After reading your book Managing Incontinence, I thank God that I always treated my son’s incontinence with extreme compassion and understanding. Never was he made to feel ashamed or embarrassed. It has always been treated as a medical problem. I have taught him that in spite of his medical condition he is as normal as every other child. Never have we allowed his condition to be an excuse for bad behavior or to be spoiled. We never hide his condition from anyone and always explain it to people who are around him.

It was a long hard struggle with his school, but after three years at the same school, his condition is no longer such a big deal. Although they are still uncomfortable with it, I am no longer fighting with them every day. As much as I have protected my son and taught him the skills he needs to cope with incontinence, it is very difficult for him to deal with some days. The teasing and embarrassment that is placed upon him from others is horrible, but I have also taught him that there will always be kids who will be mean, tease other kids for whatever reasons. A lot of children must deal with teasing, so I’ve taught Ryan that he is not singled out because of his incontinence. He has wonderful self-esteem and feels very good about who he is.

It is not how he feels about himself, but it is the way that others treat him that is the problem.

I have found it very difficult to fight the ignorance of both adults and children, but as long as he feels good about who he is, then we have won.

Your book has helped me to realize that I have done a good job raising him and helping him to cope with his incontinence. Thank you so very much.

Illinois

Dear Illinois:
We are glad that our book helped you to feel good about your efforts. In my opinion the greatest gift a parent can give a child is the tools to face the world with high self-esteem. So many people, without the obstacle of incontinence, fail to achieve raising a child with healthy self-esteem. Thank goodness, ignorance is curable.

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Surgery for Stress Urinary Incontinence

continued

dence as well; other times urge incontinence may be worse after surgery for stress incontinence. It is also possible that urge incontinence may occur as a new symptom after surgery.

Discussion with your physician and simple tests will determine if you have mixed incontinence. Mixed incontinence can be treated with a combination of therapies, often including medications.

Surgical Procedures:
Surgical procedures vary and the procedure recommended to you will depend upon your particular medical history and your physical exam. The abdominal procedure is done from above through an incision in the lower abdomen near the pubic hairline. Sutures are placed into the walls of the vagina behind the urethra. These sutures will reposition the urethra and bladder neck juncture, holding them firmly in place by anchoring the sutures to a tough ligament or fascia. This procedure may also be done with a laparoscope, minimizing the size of the incisions.

The sling procedure’s goal is very similar to the abdominal procedure. A strap or band of material called a sling is wrapped under the urethra and bladder neck to return these structures to their correct position in the body and provide a “backboard” of support. The sling actually helps to compress the urethra and prevent leakage during increased abdominal pressure due to coughing, sneezing, laughing, etc. An incision is made in the lower abdomen and also in the wall of the vagina so that the sling may be put into place. The sling material varies; it may be human tissue or a synthetic.

New procedures and materials help the physician to obtain exactly the right tension so that postoperative complications are minimized.

OTHER SUPPORT PROBLEMS:
Other pelvic organs may have also been affected by weakened pelvic floor muscles and connective tissue, and moved out of place — a condition called pelvic organ prolapse. Vaginal vault prolapse occurs where the walls of the vaginal canal collapse, with the vagina turning itself inside out. When the bladder support is damaged the bladder may bulge into the vagina causing a “cystocele.” When the rectum bulges forward into the vagina it is called a “rectocele.” Loss of support of the uterus is known as uterine prolapse, or in its most severe form “uterine procidentia.” When a sac of small intestine bulges down into the vagina it is called an “enterocoele.”

If you are affected by any of these conditions your physician will probably suggest that he or she repair them during the surgery for stress urinary incontinence.

WHAT TO EXPECT AFTER SURGERY:
Part of the success of any surgery depends on the patient’s willingness to comply with postoperative instructions. You should prepare to avoid certain activities after surgery. For two to three months afterwards, the amount that you are allowed to lift will be restricted, first to under 5 pounds, then gradually increasing as per your doctor’s instructions. Pushing and pulling heavy items must also be avoided while you are healing. It is also important to drink plenty of fluids and avoid constipation so as to not put any strain on the area when having a bowel movement.

All or many of the following changes in lifestyle will also temporarily be necessary until complete healing takes place. Avoid sexual intercourse, take showers instead of baths, do not use tampons or douches. Jogging, lifting weights, and other such exercise should be avoided. Your doctor may also have further suggestions for you and will give you permission to resume activities as your individual healing permits.

DECIDING ON SURGERY:
Surgery for incontinence is an elective surgery, so you have plenty of time to understand your particular situation and ask all the questions you have in order to make an informed decision if surgery is right for you. A thorough discussion about the details of the operation, the expected benefits and the associated risks should be held with your surgeon before making a final decision on your operation.

Letters to The Editor

continued

Dear Simon:
I am looking for support. Everywhere I go, my bladder acts up. The most protection I want to wear are the belted undergarments, which feel more like disposable panties rather than the diaper-style briefs. The briefs hold the water, but are noisy and bulky under my clothes. I’ve worn the briefs in public before and they are an inconvenience, especially whenever I must go to the ladies room. They are hard to pull down and once I ended up emptying my bowel into the briefs.

If that wasn’t enough, I didn’t have an extra brief or anything else with me and had on a skirt. I had to just keep my legs closed tight until I got home.

I don’t know anyone else with my problem. I am a grown woman who wears conservative business attire (suit, blouse, skirt, pantyhose), but also has to wear diaper-like underwear. Sometimes, I feel like a little girl trying to wear her mother’s clothing before completing potty-training.

California

Dear California:
You didn’t say whether you’d seen a physician who is interested and knowledgeable about treating incontinence. There are new medications, surgeries, and products which may not have been available last time you asked your physician for help. There are over 12 million Americans with bladder control problems, that’s one in twenty-five, so in all likelihood you know several people with the problem, men and women in business clothing who may also feel very alone. You may wish for us to publish your name and address in our pen pal list, or visit us at www.simonfoundation.org to make some friends and find advice.