AUA Meeting Holds Hope For All

The American Urology Association's (AUA) recent Annual Meeting (May 1990), demonstrated in several ways how much progress has already been made in bringing more medical attention to the topic of incontinence. Like most formal medical meetings designed for practicing specialists, a variety of educational opportunities were made available to all attendees. For instance, this year's industry exhibit had over 200 exhibitors. Urologists were able to see and learn about advances in products such as operating room and urodynamics equipment or purchase the latest textbooks in their field. And of special importance to our readers, products concerning the treatment and management of continence were conspicuously displayed. Products concerning continence occupied more booth space at the exhibition halls than ever before.

The Scientific sessions also featured more papers presenting research data covering incontinence than in the past. The subject of incontinence clearly consumed more time at the podiums in the lecture halls. An example of the increased attention could be observed at the Urodynamic Society's session. In past years, the Urodynamic Society's meeting and papers presentations were scheduled after normal meeting hours in the evening. This year, not only was the meeting on the AUA agenda during regular conference hours, but the crowd was standing room only in the designated meeting room. Practicing urologists had the opportunity to listen to and discuss reports on topics which included: pelvic floor exercises, incontinence after radical prostatectomy, teflon injections in the treatment of urinary incontinence, the artificial sphincter in male incontinence, and geriatric incontinence. Even though the meeting ran unexpectedly late, the conference room remained packed with an interested audience.

Another indication of the strides the topic of incontinence is making can be found in the priorities now being established by the newly organized Ameri-

can Foundation for Urologic Disease. AFUD was established by the AUA as a non-profit organization whose purpose includes encouraging research into urine and treatment of all urology related problems. Incontinence is one of the medical areas they will be focusing upon in the near future.

As medical specialty areas such as urology, family practice, gerontology and gynecology continue to devote increased amounts of effort and attention to continence, can cures and improved treatment protocols be far behind? The hope for more effective attention to this problem, as exhibited at the Annual Meeting of the American Urology Association, surely indicates that the decade of the 90's will bring discoveries of new options which will make life easier for us all.

(Editor's Note: Future Informers will carry articles covering information from scientific papers presented at the 1990 AUA.)

Simon Says...

THE ILLUSTRATED DIRECTORY OF HANDICAPPED PRODUCTS... is a new directory which might interest those Informer readers whose continence is related to other disabling medical conditions. The directory features sixteen categories of products which include items like pressure sore prevention devices; power scooters; communications assistance; bathroom hygiene and safety products; walking aids; and other equipment and services. The 192 page directory can be purchased for $12.95 from Trio Publications, 497 Cameron Way, Buffalo Grove, Illinois 60089.

The publisher states that the directory "grew out of a need we discovered when buying a wheelchair for our daughter several years ago. Suzy, now 11, was born with spina bifida. The dealer we visited had only two wheelchairs to choose from." Only later did the publisher discover the wide choice of products available if one knows where to look. You might also ask to be put on their list for the quarterly Handicapped Products Postcard mailing.

INTERNATIONAL CONTINENCE SOCIETY... conducts an annual meeting to present scientific papers about the current research being conducted on urinary incontinence worldwide. The majority of the society's members are physicians, nurses, physiotherapists, medical engineers and other professionals interested in continence. This year's meeting will be held in Aarhus, Denmark in September. For membership and meeting registration information write: Dr. Jens Peter Norgaard, Institute of Clinical and Experimental Research, Aarhus Kommunehospital, DK-800 Aarhus C, Denmark.

TRAVELIN' TALK NETWORK... is a national network of people who provide assistance to disabled travelers. The network is glad to share knowledge with any disabled person traveling to or through their area. Members realize the value of helping other people by responding to a telephone call and providing information as simple as how to continued on next page
Simon Says...

find the closest medical supply store, or where a truly accessible hotel can be found. If you would like to join the network, receive their newsletter or be listed in their directory contact: Travelin’ Talk, P.O. Box 3534, Clarksville, Tennessee 37043 (615) 358-2503.

PEN PALS... The reaction to our pen pal club has been tremendous. Many people report that they cannot keep up with the number of letters they receive, so please be patient if your letter is not answered right away. New listings are: Andrew Rimol, 31 Calumet Road, Randolph, New Jersey 07869; Dave Walters, 321 East Walnut Avenue, Altoona, Pennsylvania 16601; Chris W. Sommers, 2281 Rosecrest Court, Sparks, Nevada 89434-0760; Katherine Brown, P.O. Box 269, Mayberry, West Virginia 24861; Richard T. Quinn, 122 Aurora Avenue, Reno, Nevada 89506; Sarah M. Ferguson, c/o Church Home of Hartford, 295 Ridge Road, Westerfield, Connecticut 06109; Donald Ballard, P.O. Box 769, Oak Grove, Kentucky 42262; Sam Reilly, 1003 21st Street, Canton, Ohio 44709; Sandi Williamson, P.O. Box 12888, Seattle, WA 98111; Deen S. Adolphe, 12820 39th Avenue, Vancouver, Washington 98685; Ms. Norma Werkhaven, 265 N. 13th Street, Newark, OH 43055-4357; Andrew J. Rimol, 31 Calumet Road, Randolph, New Jersey 07869-1001; and Dale Volovar, P.O. Box 206567, San Antonio, Texas 78220-0367.

THOUGHTS FOR THE DAY... "It's not how old I am, it's how I am old." Groucho Marx. An optimist goes to the window every morning and says, "Good morning, God." The pessimist goes to the window and says, "Good God, morning!"

Letters To The Editor

Dear Informer:
I have greatly appreciated being able to read a friend's copy of the Informer. Please include my name in your next issue of the IPPY (Incontinent Pen Pals) Yakking) Club. If I can help one person who feels about themselves as I did in the past, then I would be pleased. We have nothing of which to be ashamed. The volume of disposable diapers that my hospital supply store sells in a month in just my little area shows how many of us there really are. Reading your last article about research always gives new hope and I completely agree with Mr. Bechwith about how to tell sweethearts about our "disabilities.

Sandi Williamson
P.O. BOX 12888
Seattle, WA 98111

Dear Sandi:
Your letter and willingness to speak up illustrates the success of what we've been encouraging all of our readers to do, which is to share their newsletters with others who need to know about the help and hope. So readers, please give the Informer to a friend or neighbor, a member of your church, or leave it at your doctor's office after your next visit. It could make a difference in someone's life.

Dear Editor:
One concern I have is that in your emphasis on how to stay dry, that you don't forget those of us, who due to the nature of our problem have no hope of obtaining bladder control. I am totally

Getting To Know You

(Editor's Note: Like all hardworking charities, the Simon Foundation has many caring, dedicated staff, professionals, and volunteers joining forces behind the scenes to enhance the quality of life for those they serve. This feature begins a series of introductions to our small army so that our readers can know us better.)

Claire "Mimi" Van Slyke first came to the Simon Foundation for Continence as a dedicated volunteer. Now as Director of Support Services she is in charge of daily operations including our toll free information line and all volunteers.

There is no obstacle which doesn't get reduced to a challenge in Mimi's capable hands. Take for example the unexpected 15,000 pieces of mail which arrived one day last year when the volunteers were busy at home on Christmas holiday with their children.

Undaunted, Mimi saw that every letter was answered in one short week. She simply delivered the project to our volunteers' homes. Several volunteers reported experiencing the happiest holiday ever as they put their whole family to work opening mail while the Christmas turkey was browning.

A 1976 graduate in fine arts from Northwestern University, Van Slyke began her career in commercial design. However, she soon found that her interests were constantly drawn to the non-profit world. She is active in the local Junior League, Women's Club, Art Council, and her alma mater to name just a few of her charitable interests. But fortunately, her heart belongs to Simon, after her husband and two cats stake their claim, that is.

REQUEST FOR MEMBERSHIP

Yes, I would like to be a member of the Simon Foundation for Continence. Please mail to me the Foundation's quarterly newsletter, The Informer. Enclosed is $15.00 for my membership. I understand that all mailings will come to me in an unidentified envelope.

The Simon Foundation
P.O. Box 815
Wilmette, IL 60091

Name ____________________________
Address __________________________
City ____________________________ State __________ Zip Code __________

NOTE: Your annual membership will begin with the next edition of The Informer. Contributions and membership in the Simon Foundation are tax deductible.
One Voice: An Editorial

Recently, I fell in love with a beautiful book called "All I Really Need to Know I Learned in Kindergarten" by Robert Fulghum. In the book, the author speaks about an incident when he was leading eighty children in a game called Giants, Wizards, and Dwarfs. After explaining the rudiments of the game, he instructed his pupils to "decide which you are—a GIANT, a WIZARD, or a DWARF!"

Fulghum continues: "While the groups huddled in frenzied, whispered consultation, a tug came at my pants leg. A small child stands there looking up, asks in a small, concerned voice, "Where do the Mermaids stand?"

"Where do the Mermaids stand?" asks the other child. "A long pause. A very long pause. 'Where do the Mermaids stand?' says I. 'Yes. You see, I am a Mermaid.' 'There are no such things as Mermaids.' 'Oh yes, I am one!"

She did not relate to being a Giant, a Wizard, or a Dwarf. She knew her category. Mermaid. And was not about to leave the game and go over and stand against the wall where a loser would stand. She intended to participate, wherever Mermaids fit into the scheme of things, without giving up dignity or identity. She took it for granted that there was a place for Mermaids and that I would know just where.

Well, where DO the Mermaids stand? All the "mermaids"—all those who are different, who do not fit the norm and who do not accept the available boxes and pigeonholes?

Answer that question and you can build a school, a nation, or a world on it.

What was Fulghum's answer at the moment? "Every once in a while I say the right thing. 'The Mermaid stands right here by the King of the Sea' says I. (Yes, right here by the King's Pool, I thought to myself.)" So we stood there hand in hand, reviewing the troops of Wizards and Giants and Dwarfs as they rolled by in wild disarray.

It is not true, by the way that mermaids do not exist. I know at least one personally. I have held her hand.

What a beautiful story about self-esteem. A little girl who had enough of that scarce commodity to be herself. What wonderful parents she must have had to instill within her such a sense of self-worth. Unfortunately, many of us have reached adulthood without a full measure of self-esteem. Now it is up to each of us to acquire it ourselves. Becoming incontinent can make that task more difficult.

So, how can we build self-esteem at this late date? One way is to be very careful what we say to ourselves. Here's an example of the choices each of us have. You've just had your third job interview at a company where you would love to work. They've informed you that from a pool of twenty candidates, only three are left. But when the final decision is made, the job goes to another. You can choose whether to say to yourself: "Obviously, I wasn't good enough." Or "If I made it this far in the running, I'm sure to find a position I like soon."

The second statement not only helps us to build self-esteem, but also energy for creativity. For instance, you might decide to call the people who just interviewed you to ask for some improvement tips.

Of course, being careful how you talk to yourself about incontinence is crucial to self-esteem. Do you say to yourself after an incontinence episode: "No one would want to marry me and wake up in a wet bed." Or, do you choose to say, "When I get married, I think I'll offer my partner the opportunity to push two beds together and then I won't have to awaken her or him when I need to change the sheets."

If you are in the habit of punishing yourself with destructive self-talk, I have a question just for you. Don't you deserve the same courteous treatment you reserve for others? Maybe you haven't had much practice. If you are having difficulty thinking of something good to say to yourself, try: 'I'm doing a lot to overcome my problems with incontinence. Why just look at me now, taking time from my busy schedule to read this great newsletter.'

By continually working on building one's self-esteem you will eventually learn, in the deepest part of your soul, one of the most important secrets of life... the answer to the question: "Where do the Mermaids stand?"

Where DO the Mermaids stand? Personally, I hope they all stand with Simon, because we believe Mermaids belong standing right out there living with the rest of the world.

THANK YOU (Editor's Note: This issue of The Informer was underwritten by an educational grant from JOHNSON & JOHNSON, makers of SERENITY®. The Simon Foundation does not endorse specific incontinence products or medical treatments. Inclusion in this column in no way implies endorsement.)

Johnson & Johnson has introduced an important new kind of incontinence protection—Serenity Guards®. Especially designed for women, Serenity provides effective protection in a discreet, compact shape and size even if your condition is serious.

Unique Superabsorbent System

A compact Serenity Guard gives you the protection you need—right where you need it most. That's because Serenity contains a unique superabsorbent system that traps liquid quickly and effectively. A fine powder locks this liquid into a gel that won't leak.

Contoured Fit for Better Protection

Serenity Guards are contoured to fit a woman's natural shape for better protection against leakage. Each guard has a soft, waterproof outer lining and a smooth top layer that keeps wetness away from the skin.

Call or Write for Your Free Sample

We would like you to try Serenity Guards, free of charge. To receive your free sample pack of three Regular or Super Serenity Guards call our toll-free number, 1-800-637-8600 X367, or write to: Johnson & Johnson, P.O. Box 5234, Clifton, NJ 07015-5234 (please specify Regular or Super absorbency). Then, try them for yourself so you too can experience the protection and comfort of Serenity Guards. Limit one per household.
incontinent due to a birth defect and a spinal injury. The cost and risk factor is too great to operate. I need continued help and encouragement that life can go on even though I have no choice but to wear diapers and rubber pants. It is great for those who can obtain control and I'm glad for them. Just don't forget those of us that have no hope, but to make the best of it.

“In a diaper”

Dear Friend:
Our continued advice which suggests that people see their doctor is due to two widespread problems in our society. One is that many people believe the myth that nothing can be done about incontinence. The second is that without discovering the medical reason for an incontinence problem, a person may have a potentially dangerous underlying cause which is going untreated. However, once an individual is fully informed about their condition and the available treatment options, protective garments may be their preferred choice, or only choice. The editorial staff of this newsletter in no way wishes to discourage our readers who are managing their incontinence with products. We do hope that you, and other with similar conditions, understand our reasons for promoting continence and thus will feel no lack of support for your choices simply because we continue to urge people to see their doctor. Many of our readers have just discovered the Simon Foundation and may not yet have consulted a physician. Hopefully, with time and adequate financial resources directed towards continence research, there will be a cure for all of us.

Dear Ms. Gartley:
My problem with incontinence is bedwetting. My little nephew has the same problem, but my sister claims to have no trouble keeping the bed dry because large baby diapers have enough absorbency. So, why doesn’t this happen with adult diapers? I feel that it is because manufacturers of adult diapers are overly concerned with making a discreet, acceptable product that can be worn and not seen under clothing. I am going to write to them all and ask that they make a thick super absorbent diaper for those of us that could care less about looks, but instead want more security and creature comfort. I would encourage the readers of the “Informer” to do the same. I feel that is the only way we will get the products that we need.

Florida

Dear Florida:
We are always happy to hear that our readers intend to write to the companies that make adult incontinence products. They want to hear what all of you need. The staff at the Foundation is called upon constantly to tell manufacturers about the unmet needs of incontinent individuals. For years I have spoken up on behalf of members like yourself and asked them for product that would afford the wearer a good night's sleep and a dry bed, regardless of the bulk. Perhaps all of you who would like such a product could write a letter each quarter to your favorite manufacturers. Put down this paper, pick up your pen, and let's make them tired enough of hearing from us on this issue that they make the product!

Dear Informer:
I am incontinent and have worn diapers and plastic panties now for over 10 years. I am a 34 year old female. I was very pleased to read about others who prefer using cloth diapers and plastic panties versus disposables. I was really concerned that I was one of the few who felt this way. I realize that the image of using diapers is a negative one, but isn’t the real concern what will effectively help one manage his or her incontinence? I only hope that someday we can be more open about this whole subject area and share more of ourselves with others. This is an attempt to do that. Use my name and address as a way for me to begin my journey out of the closet.

Chris W. Sommers
2281 Rosecrest Ct.
Sparks, NV.
89434-0760

Dear Mr. Adolphe:
Congratulations on your success! I'm sure part of it is due to the fact that your letter shows your knowledge about your condition and that you are not blindly ignoring treatments options. As a model for all our readers I've printed your well written letter which proved so successful below.

“Gentlemen:
I strongly object to the exclusion from coverage of adult diapers, when required by disease or accident. I am bladder and bowel incontinent due to Multiple Sclerosis, diagnosed (finally) in 1981. In my case there is no medically viable alternative to diapers. My bladder condition cannot be corrected or helped by medication or surgery; and catheters, both indwelling and condom style are not useable. An artificial sphincter can’t be used because the bladder spasms I have would force the urine out and through the sphincter. The bowel incontinence is also due to muscle spasms; and again, no option is available.

My disability is not serious enough to qualify for disability retirement, but far too serious (and certainly not socially acceptable) to ignore!

Why should certain types of treatment or urine collection devices be acceptable when it can be shown that none of those devices are usable for me? Please reconsider your coverage for adult, disposable diapers, when it can be shown to be medically necessary in my case.”