CEO Biography

Steven Soifer, Ph.D., LCSW-C, is a Professor in the School of Social Work at the University of Memphis. He co-founded and has been CEO of the International Paruresis Association (IPA) since 1996. Under his leadership, IPA has established support groups in 25 states and 11 countries.

He co-authored *Shy Bladder Syndrome: Your Step-By-Step Guide to Overcoming Paruresis* (2001), which is in its tenth printing. Recently, he revised that ground-breaking book, which is titled *The Secret Social Phobia: Shy Bladder Syndrome (Paruresis)* (2017), which is available on Amazon in paperback, Kindle, and audible versions. His publications on the subject include articles in *Urologic Nursing, Social Work in Health Care, Depression & Anxiety, The Behavior Therapist,* and *Journal of Anxiety Disorders.*

Professor Soifer has given hundreds of interviews in newspapers, magazines, on radio, and TV. They include CNN.com, Court TV, Citytv in Toronto, the BBC, Woman’s World Magazine, The New York Times, and The Wall Street Journal.

He has presented at several professional conferences which include the Anxiety Disorders Association of American (in Seattle), the World Federation Mental Health (in Melbourne), and the American Psychiatric Association (in Toronto). He has facilitated over 150 workshops around the globe, in countries as diverse as Australia, France, Russia, Germany, India, The U.K., Canada and U.S.A.

Professor Soifer is available for media interviews, employee workshops, journalist expert source, private consultation, and publication authorship.

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Organization Profile

IPA is a non-profit 501(c)3 tax-exempt organization formed in 1996 to raise public awareness about paruresis (shy bladder syndrome), provide help, and distribute the latest information about this social anxiety disorder. Most of IPA's members and leadership are treatment professionals, people suffering from paruresis or recovering from it, and their loved ones. Membership is open to anyone touched by paruresis as well as those with an interest in supporting paruretics, advocating for them, and advancing scientific knowledge about the disorder.

The International Paruresis Association’s mission is to cure Paruresis (shy bladder) and improve the lives of all people affected.

Scope of IPA: currently there are 1500 IPA members worldwide. IPA has treated over 1000 people for shy bladder through workshops and individual treatment. We also have support groups for people with paruresis in 25 states and 11 countries.

IPA leads advocacy efforts in the areas of restroom access and design and drug testing reform. IPA's stance on drug testing is that for those unable to provide a urine specimen, reasonable alternative methods should be permitted. Such methods as suggested by the Substance Abuse & Mental Health Services Administration (SAMHSA) in 1994 include hair, saliva, sweat, or blood specimens (if a medical technician is available).

IPA has a voluntary 9-person board of directors and a 47-member advisory board comprised of doctors, PhDs, psychiatrists, lawyers, therapists, social workers, and other professionals.

The Shy Bladder Center and the American Restroom Association are both subsidiaries of the International Paruresis Association.
Frequently Asked Questions

1. What is Paruresis?

Paruresis, or Shy Bladder Syndrome, is an anxiety disorder that affects over 20 million people in the United States and Canada (Harvard Medical School study, 1997). It appears to be the second most common social phobia after the fear of public speaking. Yet it seems harder for anyone to admit – even more so than impotence or incontinence.

2. How does a person know if they have Paruresis?

The easiest self-test is to see if they are able to urinate without a problem at home alone, but then have difficulty doing so at home with family members and/or friends at home, or in social situations or in public restrooms. If they are OK at home alone but not at other times, they most likely have paruresis. If they have trouble ALL the time, then there may be a medical condition that should be treated. In either case, a physician should first be consulted to rule out an underlying disorder.

3. Why does someone develop Paruresis?

This is an excellent question, and the truth is, we really don’t know yet. However, based on many people’s stories, it appears that for most, some traumatic event, often occurring in childhood, may trigger paruresis. This event may be as harmless as a sharp remark from a parent or peer, or as serious as sexual abuse. The psychological experience then has physical symptoms.

4. Is Paruresis treatable?

Absolutely! In fact, it is very easily treated in about 80% of cases by something called cognitive-behavioral therapy. Using what is called a graduated exposure procedure, in which the person is introduced to the feared situation in small steps, he or she gradually learns to relax in social situations and becomes able to urinate more easily in the presence of others. This averages about 8-12 sessions. Most people report moderate to enormous improvement in their condition after such treatment, which can occur through individual counseling sessions or in a workshop setting.

5. Will such treatment actually “cure” a person? Do they have to do anything else?

People who are paruretics may never be actually “cured.” If susceptible to stress, there may always be conditions which make it difficult for them to be able to urinate in public situations. However, complete remission of symptoms is possible, and if they join or start a support group for people with paruresis in their area, the chances of leading a more normal life dramatically increase.
6. Is there any medication that would help?

At present, not really. While we are encouraging the pharmaceutical industry to research this possibility, finding a magic pill to cure paruresis seems far off. However, there is anecdotal information that certain medications, particularly Selective Serotonin Reuptake Inhibitors (SSRIs) such as Paxil, Luvox, and Prozac, may help reduce their anxiety level enough to begin to make improvements. They can be especially effective in conjunction with graduated exposure therapy.

7. Let's say someone wants to apply for a job, but the employer requires a drug test beforehand. This person cannot produce a urine sample on demand. Can anything be done?

This is a difficult area. While it is our belief that people suffering from paruresis should be covered under the Americans with Disabilities Act as Amended (ADAAA), this has not yet been truly tested in the courts. Consequently, the best we can say now is that they should tell the prospective (or current employer, if subject to random drug testing) employer about the difficulty, and ask for alternative testing method, such as a saliva or hair sample. The employer may or may not grant this request. If tested and someone is unable to give a sample, they should immediately get and pay for their own hair test. They should also get a diagnosis of paruresis from a physician or psychiatrist.

8. Who should a person contact for further information?

The International Paruresis Association, Inc., a tax-exempt non-profit corporation, acts as an information clearinghouse for people who suffer from paruresis. Our goals are to help sufferers, provide information to the general public, research causes and treatments, and educate the mental health and health care communities about this anxiety disorder. For more information, write, call or email the office.
IPA
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Shy Bladder Syndrome Leads to Lawsuit
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MDOT Worker with 'Shy Bladder' Wins Battle
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Looking for Relief

'Shy bladder' syndrome is widespread. But in many cases it can be treated successfully.

BY PETER LANDERS
STAFF REPORTER OF THE WALL STREET JOURNAL

Tom Seehof's troubles with using the men's room go back a long way. He still remembers struggling for half an hour to give the Army a urine sample when he enlisted as a 17-year-old during World War II. For more than 60 years, including a long career as an entertainment-industry executive, he often skipped public events such as baseball games and concerts, fearing a call of nature that he would be unable to answer.

Mr. Seehof's problem may sound obscure, but it's probably more widespread than most people imagine. A 1994 survey found that 6.7% of Americans, or nearly 20 million people, have what might fit into a broad definition of paruresis -- commonly known as shy-bladder syndrome and sometimes pene-ophobia. That means nearly 20 million people have had trouble urinating in public at least once during the past year.

While there's a shortage of reliable data, some experts think as many as one million Americans, mostly men, have a serious enough problem that it disrupts their lives.

There's usually nothing physically wrong with shy-bladder sufferers, although they risk serious damage to their bladders if they repeatedly go for long periods without using the bathroom. Instead, their problem is psychological -- much as it is for musicians with stage fright or social-anxiety sufferers who panic when they encounter a large crowd. As a result, paruresis isn't a widely recognized condition, and few specialists know how to treat it.

YEARS OF STRUGGLE

"The vast majority of guys don't have any idea what you're talking about," says Mr. Seehof, 76 years old, who lives in Los Angeles. He struggled for years to find a solution, seeking help from urologists, psychologist and hypnotherapists. He even attended a "nude mara-
thon," a supposedly therapeutic event in which men and women spent 48 hours straight in the buff in an effort to "discover themselves" and possibly overcome any hang-ups they may have with their bodies. "It was an interesting experience," he recalls, "that had absolutely no effect."

But there's good news for people like Mr. Seehof. Today, you don't have to wait 60 years to get effective treatment for paruresis. Specialists now see it as a form of social phobia and have found it can often be treated successfully in the same way as other social phobias -- by gradually exposing sufferers to the situation they fear.

For instance, a person with an irrational fear of spiders might start in a reasonably comfortable situation such as watching a picture of spiders on TV and gradually progress until he or she can sit in the same room as a spider.

Similarly, people with shy bladders start out using a comfortable bathroom such as the one at home. Then they proceed, sometimes in painstakingly small steps, to more difficult situations, like having someone stand outside the bathroom door.

MAKING PROGRESS

Steven Soifer, a professor of social work at the University of Maryland, Baltimore, has carved out a busy second career as America's paruresis guru. He has co-written a book and he leads seminars around the country about the subject. The Long Island, N.Y., native, who calls himself a "recovering parurexic," charges $395 for weekend seminars in the graduated-exposure method, with people working in pairs to overcome their shyness. That's where Mr. Seehof finally was able to make progress.

In a seminar in 1999, Dr. Soifer was Mr. Seehof's partner in an exercise. The two men started out in Dr. Soifer's hotel room. Mr. Seehof drank a lot to fill his bladder -- that's called "fluid loading" -- but found he couldn't use the bathroom unless he sent Dr. Soifer out of the hotel room and locked the door. Mr. Seehof gradually emptied his bladder as he let Dr. Soifer move closer until they were separated only by the closed bathroom door.

Later they practiced in a public restroom. For the first practice round, Dr. Soifer stood outside the men's room door. The next time he stepped inside while still facing the door; then he turned sideways, and finally he faced toward the urinals where Mr. Seehof was standing. The process took several hours.

"It sounds ridiculous," Mr. Seehof says. "You can't help but laugh." But it worked. Mr. Seehof now can use public restrooms and leads a Southern California support group for people with shy bladders.

But the gradual method isn't for everyone. Dr. Soifer, who holds a Ph.D. in social-welfare policy but isn't a medical doctor, says some people who attend his seminars have problems beyond a shy bladder. The condition can overlap with other mental-health ailments such as depression or anxiety, and some people may benefit from taking the antidepressant drugs known as SSRIs, or selective serotonin reuptake inhibitors, such as Prozac and Paxil. Although there isn't a drug specifically targeted at shy-bladder sufferers, social-anxiety drugs like Paxil can help in some cases. (Before taking an SSRI, people need to visit a doctor, describe their symptoms and get a prescription.)

LITTLE AWARENESS

The fact that there isn't any drug specifically for paruresis may be one reason why the condition isn't widely known. Two equally embarrassing disorders -- incontinence and irritable bowel syndrome -- have become much better known thanks to the deep pockets of pharmaceutical companies. For instance, Pharmacia Corp. (now merged into Pfizer Inc.) enlists actress Debbie Reynolds to pitch its incontinence remedy, Detrol LA, and runs frequent TV
ads about the condition. Novartis AG, meanwhile, has publicized irritable bowel syndrome, which is marked by abdominal pain, cramping and constipation, as a way of selling Zelnorm, its pill for the ailment.

Dr. Soifer would love to attract a celebrity sufferer, but his only success so far is New York radio shock jock Howard Stern, who has talked about his problems urinating in public restrooms and has had Dr. Soifer on his radio show twice.

In the absence of drug-industry funding, there's little reliable data on how widespread shy-bladder syndrome is. That the general trend is that it is predominantly a male affliction, Dr. Soifer says only about 10% of his seminar attendees are female.

Michael Chancellor, a professor of urology at the University of Pittsburgh, points out that some situations make a lot of men uneasy -- such as sports events where the trough-like urinals in men's rooms are usually jammed with patrons at halftime. When you've got "50 drunk guys pushing," jokes Dr. Chancellor, "even I have a tough time getting started."

Such discomfort isn't a big deal for most men. They can always wait for a stall with a door. But some begin to obsess about their failure to perform on command, and that's when they get into trouble. "They think, 'Am I going to be in diapers? Am I going to be impotent?'" says Dr. Chancellor. After a quick examination, he's usually able to confirm that nothing is wrong. "The key to me is reassurance: You're healthy, you're OK," he says.

OTHER OPTIONS

For some people, though, the problem is more serious, and reassurance and graduated-exposure therapy aren't enough. A small minority of sufferers find their lives severely restricted by the condition, holding themselves up at home and turning down promotions that would require travel to places where the toilet conditions are uncertain.

The last-ditch treatment in such cases is self-catheterization -- which means the sufferer must insert a flexible tube up through his urethra every time he needs to empty his bladder. Learning how to use a catheter requires a trip to the doctor, and there's a risk of infection. But for some people, it's better than not urinating at all. While self-catheterization seems extreme, says Dr. Soifer, "people who have learned to do it and do it well swear by it."

And the curious upside-down psychology of paruresis means that people who carry around a catheter may not need to use it much. That's because the presence of an "out" in case of emergency relaxes them so much that they can use the bathroom normally.

A SURGICAL ROUTE

A Baltimore urologist, David Gordon, agrees that paruresis has a big psychological component but says, "I suspect there's a spectrum here. Some cases may be primarily physiologic."

Dr. Gordon says a minority of paruretics may develop chronic tension in the muscles of the pelvic floor, which most people control voluntarily and relax to allow urination. He is studying the use of a surgically implanted device to help people with paruresis. The device, called InterStim, is made by Medtronics Inc. of Minneapolis. It is implanted in the abdomen and delivers electrical pulses to a nerve that influences bladder function. The Food and Drug Administration approved InterStim in 1997 as a treatment for incontinence, with the idea that constant electronic stimulation of the nerve will correct false signals that tell a person with incontinence that his or her bladder is full when it isn't. There isn't any evidence yet whether it works for paruresis.

Last month, Dr. Soifer was among the first to get the device for paruresis, but found it didn't help him.

Back in Los Angeles, Mr. Seehof hopes more information about treatment will prompt people who have shy bladders to step forward and get help. "I think millions have it," he says. "We're getting ready to come out of the water closet."

-- Mr. Landers is a staff reporter in The Wall Street Journal's New York bureau.

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