

## **FACT SHEET ON PARURESIS ("Shy Bladder Syndrome")**



**By**

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Chief Executive Officer**

**International Paruresis Association  
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Fact 1: Paruresis is a social anxiety disorder. Those who suffer from it are fearful of using the bathroom when other people are nearby. It can interfere with major life activities such as work, social relationships and travel.

Fact 2: Paruresis affects about 7% of the population: 17 million people in the U.S., and another 3 million in Canada. Countless other people worldwide also suffer from it.

Fact 3: Hundreds, if not thousands, of U.S. workers have been unjustly fired because they were unable to urinate in a cup on demand during a random drug test. Federal drug testing rules *must* be changed to allow for alternative testing (hair, saliva, sweat patch) for those who have this problem.

Fact 4: Paruresis is a very treatable disorder. Many studies show that cognitive-behavioral therapy over 8-12 sessions or a weekend workshop helps at least 4 out of 5 sufferers.

Fact 5: The International Paruresis Association (IPA), is the world's only organization working to raise public consciousness on this issue. The IPA serves as a clearinghouse, encourages research, conducts workshops and runs support groups in many U.S. cities and in 10 different countries.

## CEO Biography



**Dr. Steven Soifer**  
**CEO International Paruresis Association**  
**(1996-Present)**  
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### **Additional Experience**

Associate Professor  
University of Maryland School of Social  
Work  
(September 1994 – Present)

Board  
Chesapeake Safe Energy Coalition  
(2006-2009)

Organizing Director  
Central Vermont Community Action  
Council  
July 1992 – August 1994  
Organized a statewide tenants' union  
called TUFF-VT

Assistant Professor  
University of Washington School of  
Social Work  
1988-1992

Organizer  
ACORN  
1976 – 1978

### **Education**

Brandeis University  
The Heller School for Social Policy and  
Management  
Ph.D., Social Policy  
1988-1992

Washington University in St. Louis  
M.S.W., Social Work  
1979-1980

Denison University  
B.S., Psychology  
1972 - 1976



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## **Agency Profile**

### **International Paruresis Association**

**[www.paruresis.org](http://www.paruresis.org)**

**[www.shybladder.org](http://www.shybladder.org)**

**[www.americanrestroom.org](http://www.americanrestroom.org)**

**800-247-3864**

IPA is a non-profit 501(c) 3 tax-exempt organization formed in 1996 to raise public awareness about paruresis, provide help, and distribute the latest information. 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 others with paruresis, advocating for their rights, and advancing scientific knowledge about the disorder.

The International Paruresis Association's mission is to support and advocate for those suffering from paruresis (shy bladder syndrome).

Scope of IPA: Currently there are 1500 IPA members worldwide. IPA has treated over 1000 people for shy bladder through workshops and individual treatment. Almost half of the 50 states and 15 countries have support groups for paruresis. There are 55 total support groups world-wide.

IPA leads advocacy efforts in the areas of restroom access and design and drug testing reform. IPA's stance on drug testing is:

*The inability to provide a urine specimen does not equate to a refusal to take a drug test. Those citizens who are or were unable to provide a urine specimen should be allowed to participate in one of the alternative drug test methods suggested by SAMHSA in a 1994 proposed Regulation Revision. Alternative drug tests include hair, saliva, sweat (aka patch), or blood specimens (if a medical technician is available).*

IPA has a voluntary 14-person board of directors and a 39-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 About Paruresis (Shy Bladder Syndrome)



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### 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 than impotence or incontinence.

### 2. How do I know if I have Paruresis?

The easiest self-test is to see if you 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 you're OK at home alone but not at other times, you most likely have paruresis. If you have trouble ALL the time, then you may have a medical condition that should be treated. Please consult your family doctor or a physician to rule out physical causes for your bladder difficulties.

### 3. Why do I have 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, which can be as harmless as a sharp remark from a parent or peer, or as serious as sexual abuse, seems to trigger paruresis in those who have a tendency toward it.

### 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 you are introduced to the feared situation in small steps, you gradually learn to relax in social situations and become able to urinate much 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” me? Do I 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 you to be able to urinate in public situations. However, complete remission of symptoms is possible, and if you join or start a support group for people with paruresis in your area, your chances of leading a more normal life dramatically increase.

**6. Is there any medication that would help me with my condition?**

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 your anxiety level enough to begin to make improvements. They can be especially effective in conjunction with graduated exposure therapy.

**7. I want to apply for a job, but I understand that the employer requires a drug test beforehand. I cannot produce a urine sample on demand. Is there anything I can do?**

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

**8. Who should I 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 mission is 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 e-mail:

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