



International Paruresis Association, Inc.

Celebrating 15 Years!

1996 - 2011

The Shy Bladder Center & The American Restroom Association

Letter from CEO, Steven Soifer, Ph.D., LGSW

Dear Members and Friends,

It is my heartfelt pleasure to write this letter of introduction to the 15th anniversary report for the International Paruresis Association (IPA). When Carl Robbins and I started the organization a decade and a half ago, we never imagined that we were creating something that would forever change the lives of people with paruresis (shy bladder) worldwide.

When IPA started in 1996, we ran it out of my university office, with just one work-study student and me handling everything. It was easy when the Internet was young, message boards were an innovation, and only a few dozen people expressed interest in what we were doing.

Then, everything changed. Donations, even big ones, came pouring in. We found Richard Z., who had set up a discussion board for people with shy bladder. Websites, which were new back then, became a vehicle for us and many others to start connecting people, first in the U.S. and then around the world. In the summer of 1997 Carl and I held the first workshop, with five participants, for people with shy bladder.

The rest is history. Any of you reading this know what we have collectively created. Today, the IPA has over 1500 members. We've gone from a few bucks in the bank to having an annual budget of \$130,000 between IPA, the Shy Bladder Center and the American Restroom Association. We've held over 150 workshops around the world, serving close to 1100 people in 7 different countries. And we are tackling and making significant progress on issues such as alternatives to urine testing in the workplace, understanding the underlying mechanism of paruresis, and establishing support groups across the planet.

I invite you to look over our report and see what this organization has been doing for you, its members, and its supporters. Together, we will eradicate paruresis in our lifetimes.

Warm regards,
Steve

Letter from IPA President, Brad Kaltenheuser

Dear Members and Friends,

On behalf of the IPA Board of Directors I would like to thank you for being a member and supporter of IPA. Your donation of time and money supports a caring organization whose mission is to better the lives of those affected by paruresis and to continue the search for a cure.

Our Board of Directors meets monthly throughout most of the year via a conference call and then has an annual two-day, in-person meeting every fall. At this year's annual meeting, which was held in Chicago at the end of October, we worked on a new strategic plan, relying heavily on a recent profile and survey completed this fall by over 270 of our members. Barry R., who volunteered his time and expertise, led the strategic planning session. All in all, this year's meeting was the most productive that I have attended since joining the Board in 2005.

Under our new strategic plan, we have an updated mission, a new vision, and we have defined major initiatives for the Board to focus on in the next 1 to 3 years. First, we plan to expand the number and diversity of people who are assisted by IPA three-fold by 2014. To reach this goal, IPA will increase the number of workshops and develop and implement new outreach and support programs. Second, we plan to increase the number of women served by IPA three-fold by concentrating on how to adapt the organization to meet their needs. Third, we will work to stimulate research on the causes of paruresis with the goal of cure or more effective treatments. Fourth, we will press to have alternative drug testing regulations approved and implemented. This is the area that many of us (both current and past Board Members) have worked on and will continue to work on until those affected by paruresis are treated fairly in the drug testing process.

In our dedication to maintaining and improving IPA, your Board wishes to say thank you to all who directly and indirectly help our members on a regular basis. Thank you to our IPA staff and volunteers, thank you to our posting board monitors, thank you to our support group leaders, thank you again to our members and to all others who are supportive of our needs.

Sincerely,

Brad

Our Mission, Vision and Values

The International Paruresis Association (IPA) was founded in 1996 to raise public awareness about paruresis, provide support, and give out 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.

Our Mission

The mission of IPA is to cure paruresis (shy bladder) and to improve the lives of those affected.

Our Vision

A paruresis-free world. Until then, people with shy bladder will live life to the fullest.

Our Values

Integrity, Confidentiality,
Compassion, Caring,
Understanding, Availability,
Respect, Diversity,
Teamwork, Continually
increasing our knowledge
base.

Thank You IPA Volunteers!

Our Support Groups

After 15 years IPA has over 60 support groups worldwide in 16 different countries. These groups are all staffed by our volunteers. The groups are a great resource for people with paruresis to practice desensitization, find a pee buddy, and be supportive of one another. Ongoing practice with a support group can help begin or continue recovery.

“Good work is seldom done by accident. It is done by people who care.” ~Unknown

Our Talk Forum

The IPA Talk Forum is kept running by 9 dedicated volunteers: Richard Z., Phil Baumgaertner, Carl Robbins, Carol Olmert, David Levine, Brad Kaltenheuser, Andrea Weyant, David-Calif, and DerekAUS. The forum is another place where people with paruresis go for support and advice. With over 7,300 registered users it's another great resource.

Issues and Programs

Prisoners with Paruresis

Every year IPA receives dozens of letters and emails from prisoners and their family members asking for help. Most of them are looking for an alternative drug testing procedure, education for those in charge, and advice on how to start recovery.

Some states, Department of Corrections (DOC), throughout the country have alternative drug testing procedures other than urine for prisoners with documented cases of paruresis. However, the procedure used most is a “dry cell” where the prisoner is put in a cell alone after removing all clothing. This helps to reduce the anxiety of the prisoner because no one is standing over him/her and watching.

Sometimes prisoners need IPA to advocate for them with the correctional system. For example, many prisoners with paruresis have lost “good time earned,” been put in the “hole,” been ridiculed by the guards, lost visitation with family and even refused a diagnosis of paruresis despite a clear history of the disorder. Although, we do not have attorney services, we do write letters to wardens, medical staff, administrators and ADA (Americans with Disabilities Act) coordinators on behalf of the prisoners.

Drug Testing in the Workplace

Ever since IPA was founded, we have been struggling with this issue in one form or another. Not a week goes by in which we don't have to deal with a story about drug testing in the workplace, and it angers us.

We've tried so many things over the years, making a bit of headway here and there, negotiating with a company over denial of a job to someone who was unable to give a urine sample, and helping people who had been fired for the same reason. Yet nothing seemed to budge on the bigger level, at least not until this year.

In 2011 we have seen a major development in our efforts to finally bring justice to people with paruresis in the workplace in the area of drug testing. We succeeded in getting the Equal Employment Opportunity Commission (EEOC) to issue a letter that comes just short of recognizing shy bladder as a disability when it comes to the workplace. This letter should result in reasonable accommodations being given to people with paruresis, certainly in the area of urine drug testing (e.g., by providing alternative testing) and possibly in the kinds of restrooms provided. We hope to have a test case in the near future.

Shy Bladder Center

Fifteen Years of Therapeutic Education

A program of IPA, the Shy Bladder Center has conducted 150 workshops worldwide over the last 15 years. We have held workshops in over 40 cities and in 7 countries across the globe. The success of these workshops has been so encouraging. Our long-term goal is to establish a fully operational center here in the Baltimore, Maryland, area.

List of Countries:

Australia ~ Canada ~ France ~ Germany ~ Russia ~ United Kingdom
United States of America

Testimonials

“I attended the Atlantic City workshop. Although I knew I would be in the company of people who would totally understand and be empathetic to having trouble urinating in public restrooms, I approached the weekend with trepidation. The experiences we shared, the information discussed and practice sessions were all extremely helpful to me, even though it was not always easy. I thoroughly enjoyed getting to know the fellow workshop participants. It was cathartic to be able to be so open and honest about this subject. On the way home, I stopped three times at crowded restrooms to pee. Each time, I used a urinal and not a stall, with little to no trouble. This for me was BIG! Among the many useful things I learned over the weekend was the need to continue to practice, and to consistently build on positive experiences. Thank you Dr. Soifer, and to the people in the workshop for helping me develop more confidence and optimism. Having struggled with this problem for more than 15 years, this workshop was the single most important thing I have done to effectively cope with it.” - Sean

“Great workshop! (Miami) I wish I would have attended one sooner! Got to practice at the hotel, then ventured out to the mall, airport, even a casino! I have a whole different attitude about public restrooms! I would definitely recommend anyone suffering with this condition to attend a workshop!” - Monty

“We appreciate all your effort and commitment to the IPA. With your help I made it to the Gator Bowl New Year’s Day and watched Mississippi State thump Michigan 52 to 14.”
– Daniel

“Now I'm convinced. This workshop (Germany) is by far the most important thing that happened in my life for the last 2-3 years. I finally had the courage to tell my best friend about my situation, and I never felt so freed from paruresis. Now it will become a matter of time until I tell my other close friends, and I can finally start going out again without the constant fear and shame. This would have never been possible without the workshop.” - Dominic

“I was a bit hesitant to attend (Toronto) being the only female with paruresis, but after hearing everyone's story on the first night, any fears I had were soon dispelled with the realization that I could relate to something that everyone said, regardless of the fact that they were males. Seeing the wide variety of men who attended... from athletes, to fathers, to other university students, helped dispel previous thoughts that I was a freak... abnormal... and that I was less of a person because of my problems... paruresis can affect anyone for many different reasons.... and I find the more I talk about it with others, the more people I discover have experienced it at some point in their lives to varying degrees.” - Robin

Testimonials

“It has been truly exciting to see how far you have taken this movement. Thank you for all you do. It has helped me so much.” - Frank

“I remember finding out about the IPA 10 years ago. I was in college at the time, and had suffered from this condition as far back as I could remember. I was so relieved to find out that this condition had a name and that there were others out there like me. Steve was kind enough to offer me a "student rate" to attend a workshop. It was a great experience, being able to meet and bond with fellow SBS sufferers, learn more about the condition, and practice graduated exposure. I've made great progress in the last 10 years, and while I'm not yet cured, my condition is much less severe thanks to the IPA.” – Chris

“This recent event is a perfect example of why I am a member of IPA: I drove about 2 hours to visit a friend up in PA. When I pulled into town I stopped at the "Subway" for a sandwich, and needed to pee very urgently. When I walked into the men's room, which was just a toilet, I discovered a ladder going up into the ceiling tile and a man working on a hot water heater. I said "mind if I pee?" He said "No". And I went to the bathroom, got my sandwich, and was on my way! This is a situation you could never plan for, way outside the norm of average distractions in a restroom, but because of my progressive work over the past years, I was able to pee and get on with my day. I'm a member of IPA because every time I'm able to navigate a situation like this I know it is a direct result of my desensitization work with other sufferers.” - Don

“An important way that the IPA has been helpful to me is by informing me of the serious consequences of not being able to urinate for a drug test. After learning about that, I informed both of my doctors that my difficulty urinating is worse with other people around, so that it would be on the record. Fortunately, the last place where I worked decided against instituting random drug tests, so I have never had to have a drug test, but it was a close call. The IPA also provided helpful details about catheter use. So far I have only used catheters for practice, but it is a great comfort to know that I can use a catheter if I ever can't urinate. I really appreciate the fact that the IPA established the American Restroom Association as an affiliate. Reading articles on the website of the American Restroom Association helps me to realize that I am not the only one who believes that there is not adequate availability of restrooms for people with bladder problems.” – Norma

Testimonials

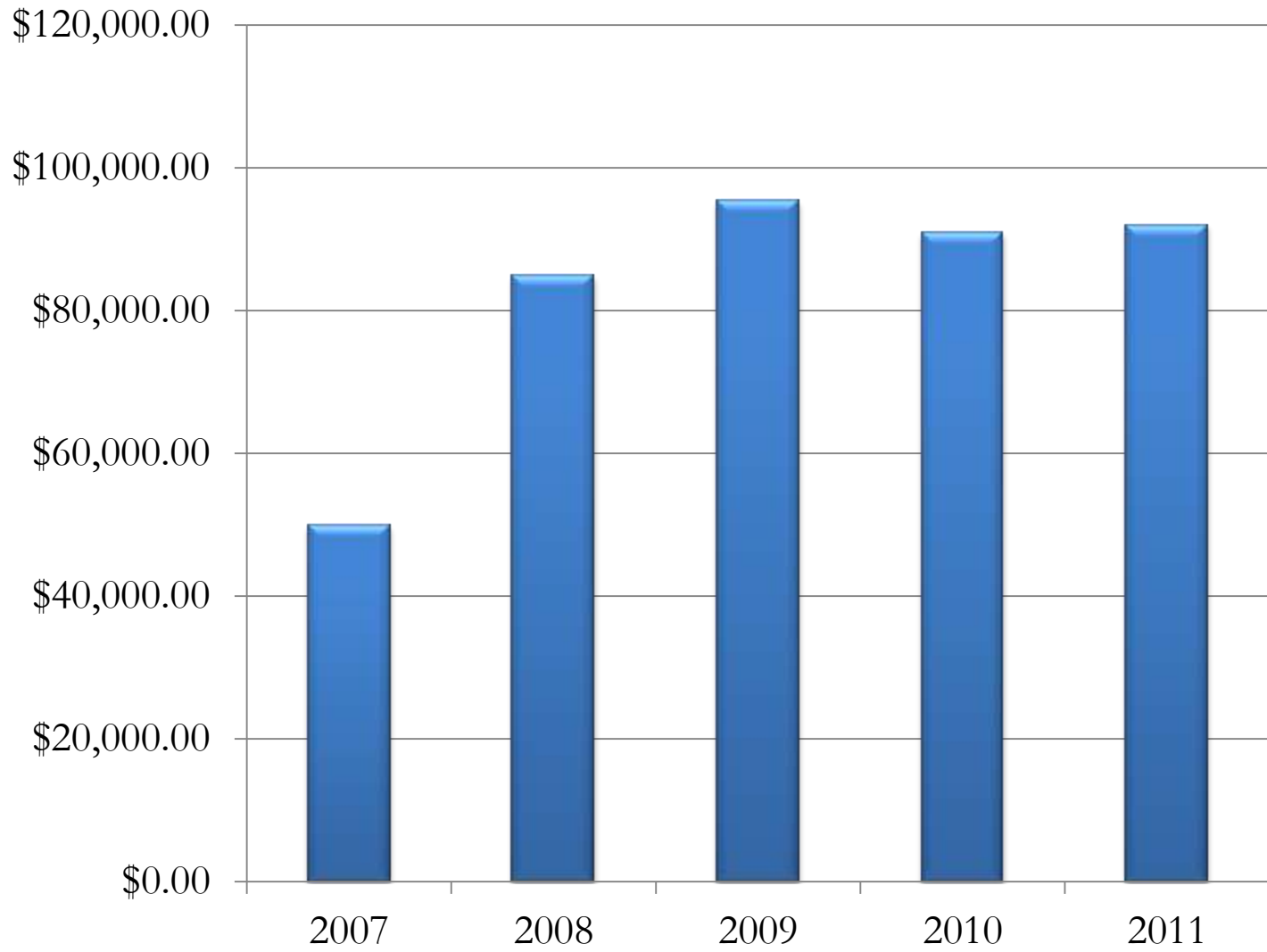
“After decades of suffering I feel some vengeance towards the educational and medical industry. Their lack of information has really been a disability. I have lost a lot of respect for them. Not one book anywhere before the internet. Now I can see there is a lot of work to be done. I am really happy there is a place like IPA that tells what needs to be done. Not easy. But a lot better when there was nothing. Try looking for help in your state health department or a public library. Not even in the back of a magazine!”
- JGT

“I have so few problems with shy bladder these days and I have IPA and you to thank for all the progress I have made. God bless you and everyone at IPA for the work you do to make our lives richer.”
- Mike

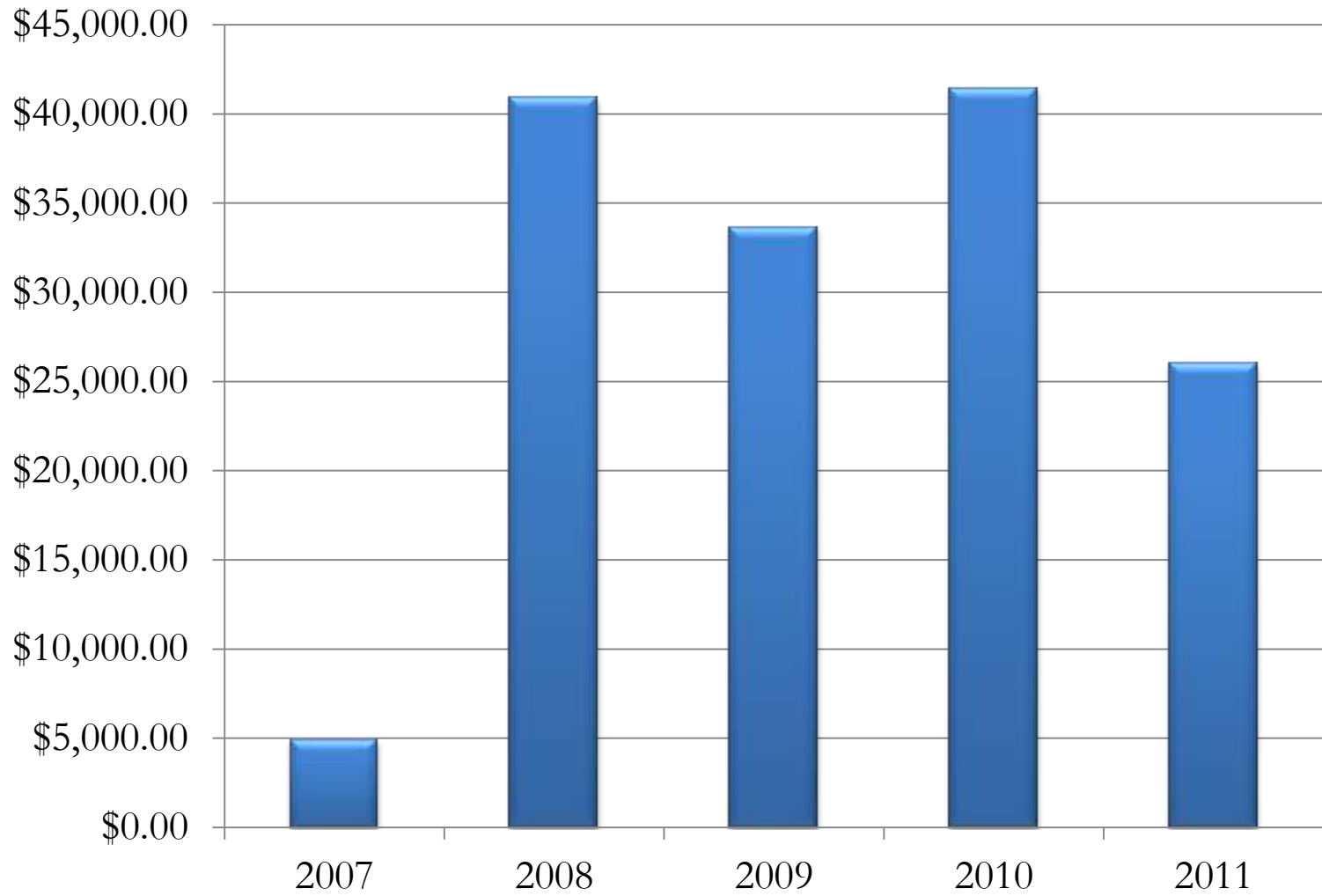
“The understanding of the problem paruresis and the methods of breaking the cycle have been most effective in my recovery. I don't think about the next place to void or how I am going to deal with the situation anymore. I attended a workshop in Baltimore about 8 years ago and was involved with a regional group for awhile, but we have all moved on in our recovery. I practice at every opportunity by habit. Thanks” - Dan

“I am an inmate in a state Department Of Corrections (DOC) facility and I suffer from Shy Bladder Syndrome (SBS). I have been incarcerated for two and a half years, and in that time my problem really came into focus. I was unable to urinate in front of my cellmates, not knowing that this was a problem more common than I thought. I had to find creative ways to urinate, mainly waiting for my cellmates to leave the cell. Sometimes I would hold my urine for hours causing great pain. About 10 months ago I was asked to submit to a random drug test at the facility. I was unable to give a sample due to SBS. At the facility it is considered a refusal every time you do not submit a sample. A refusal is considered the same as admitting you're guilty of drug use. One of the consequences of a guilty finding is that you are drug tested every two weeks. Over the next few months I received three additional charges of drug use due to my inability to provide a urine sample. The additional consequences of a guilty finding for each charge is incarceration in solitary confinement along with the loss my good time, no more contact visits with only one hour allowed for the visit, no books, and no chance of being treated for my SBS. Instead, each charge would double the length of time for each of these punishments so that I would have spent the rest of my time in solitary. However, thanks to the International Paruresis Association (IPA), and Dr. Soifer, they intervened on my behalf by writing to the DOC and educating them about SBS. Because of them, I am no longer living in fear of punishment for being unable to urinate. As of today, all institutional charges have been dismissed and my good time restored. Also, the DOC is working with IPA to institute alternative drug testing methods for people with SBS. I am greatly thankful for their support and concern for all SBS sufferers. Thank you” - Tom

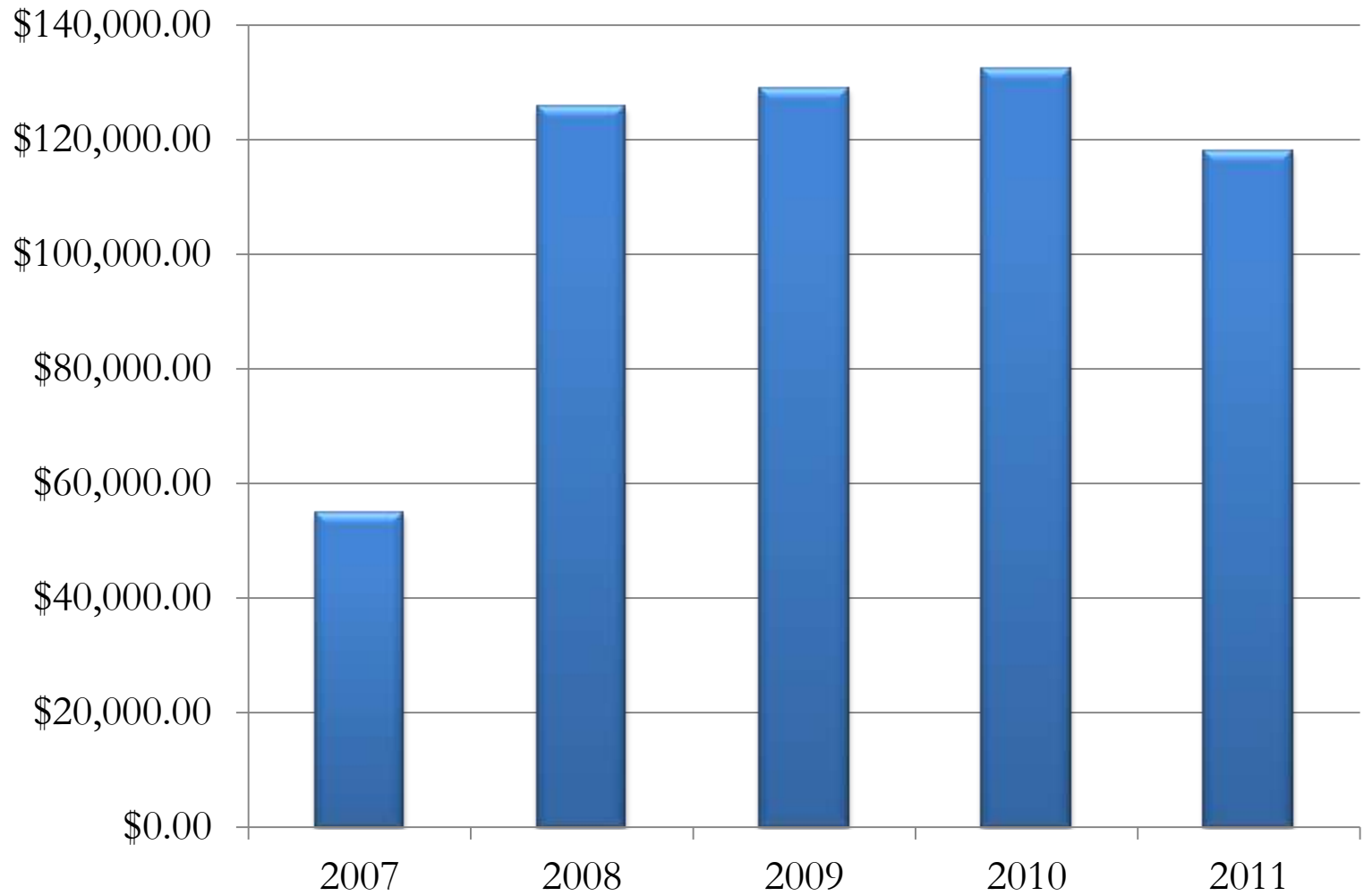
Contributions to IPA



Shy Bladder Center Revenue



IPA and SBC Combined Revenue



Our Dedicated Board of Directors and Advisory Board

(All Volunteers)

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Historical Timeline

IPA highlights over 15 years

1996

- National Paruresis Association founded by Steve Soifer and Carl Robbins

1997

- First presentation on paruresis to the Anxiety Disorders Association of America (ADAA) conference in New Orleans, Louisiana
- First workshop held in Baltimore, Maryland, with 5 attendees
- First Support Group established in Baltimore, Maryland
- First media breakthrough on paruresis – NPR's "Sunday Rounds" segment airing on 140 U.S. radio stations
- Release of the Harvard Medical School Study, with findings that almost 7 percent of the U.S. and Canadian population has difficulty using bathrooms away from home

1998

- The organization's name officially changed to the International Paruresis Association
- First article about paruresis published on the internet at Scienceagogo.com

1999

- Media coverage in major news outlets: New York Post, Los Angeles Times, and Salon.com
- Steve Soifer on the Howard Stern show
- IPA web site launched

2000

- Eight support groups established across North America and first support group established in London, England
- IPA's first newsletter (IPA eZine "Freedom Press") e-mailed
- As a result of IPA intervention, the Maryland Department of Corrections adopted regulations which recognized paruresis as a legitimate handicap for certain prisoners
- IPA Talk Forum established with the help of Richard Z.
- Financial support from 235 "friends of IPA"

2001

- First printing of *Shy Bladder Syndrome: your step-by-step guide to overcoming paruresis*. By Steve Soifer, George Zgourides, Joseph Himle, and Nancy Pickering
- Grant of \$2,100 given by the William G. Baker, Jr. Memorial Fund in Baltimore for outreach to professional communities (still our only grant to date)
- Statistical results from IPA workshops presented at the World Association of Mental Health Conferences in Vancouver, British Columbia
- A presentation on paruresis at the Urology Grand Rounds at Sinai Hospital in Baltimore
- Steve Soifer interviewed by Joan Rivers
- Feature article about paruresis on WebMD.com
- Financial support from 368 "friends of IPA"

2002

- IPA moved into its first office.
- A presentation on paruresis at the American Psychiatric Association Conference in Toronto, Ontario
- Media coverage in major news outlets: The New York Times, Slate.com, FederalObserver.com, and Scotsman.com
- Support groups established or forming in 23 states in the U.S. and 12 other countries
- Three paruresis international web sites; Ontario (Toronto), South Africa, and the United Kingdom
- Women's Forum maintains a separate e-mail list, for now bridging the gap of a predominantly male membership and message board.
- Financial support from 476 "friends of IPA"

2003

- A presentation on paruresis at the World Federation Mental Health conference in Melbourne, Australia
- Media coverage in major newspapers: The Wall Street Journal, The Sydney Morning Herald, The Boston Globe, and the Las Vegas Sun
- Steve Soifer interviewed on The Health Report with Dr. Norman Swan on the Australian Broadcasting Corporation (ABC)
- Steve Soifer met with Jack Sim, president of World Toilet Organization (WTO) in Singapore
- A presentation on paruresis at the American Association of Medical Review Officers in Las Vegas, Nevada
- Financial support from 586 "friends of IPA"

2004

- The American Restroom Association, an affiliate of IPA, founded to advocate for improved, modern restroom design and availability for the general public
- The Shy Bladder Institute founded

2004 (continued)

- The IPA web store operational, giving everyone easy access to self-help materials and information on paruresis
- Media coverage in major news outlets: The Associated Press, CNN.com, ABC News, Montreal Mirror, redorbit.com and The Times-London online
- Financial support from 686 “friends of IPA”

2005

- “Paruresis” added to the Oxford English Dictionary
- A presentation on paruresis to the Anxiety Disorders Association of America (ADAA) conference in Seattle, Washington
- Media coverage in major news outlets: BBC News, the Baltimore City Paper, and Medindia.net
- Financial support from 846 “friends of IPA”

2006

- Website given its first “facelift” to meet the demands of the website traffic
- Google starts running free ads online for IPA
- The American Restroom Association, Inc. gets a much needed program manager, Bob Brubaker, who volunteers his time.
- Media coverage in major news outlets: The Kansas City Star and St. Louis Post-Dispatch
- Financial support from 948 “friends of IPA”

2007

- IPA’s 10th anniversary!
- Media coverage in major newspapers: New York Post, New York Daily News, the Melbourne Herald Sun, HBL Media-London and Blakely, Georgia Early Country News
- First pod cast featuring paruresis on The Psych Files
- More than 10,000 copies of *Shy Bladder Syndrome: your step-by-step guide to overcoming paruresis* sold
- Financial support from 1,065 “friends of IPA”

2008

- First printing of *Bathrooms Make Me Nervous: A Guidebook for Women with Urination Anxiety (Shy Bladder)*, By Carol Olmert
- The Shy Bladder Institute became the Shy Bladder Center, a program of IPA.
- The Royal Society of Rabbits donates over \$20,000.00 to IPA.
- Media coverage in major news outlets: Bloomberg.com and Manchester Evening News
- Financial support from 1,195 “friends of IPA”

2009

- A presentation on paruresis at the Society of Urological Nurses and Associates (SUNA) convention in Tampa, Florida
- Steve Soifer with key staffers in Senator Tom Harkin's (D-IA) office to discuss accommodations to people with paruresis.
- IPA's 1st Scientific Symposium conference call
- NBC's Saturday Night Live premiere season opener airs a parody commercial about paruresis called *Bladdivan*
- Media coverage in major news outlets: The Times-London, Huffington Post, and Scientific American
- Financial support from 1,292 "friends of IPA"

2010

- IPA now on Facebook, Twitter, and LinkedIn
- A presentation on paruresis to the Anxiety Disorders Association of America (ADAA) conference in Baltimore, Maryland
- Media coverage in major news outlets: Impact Magazine, New York Post, Chicago Tribune, Detroit Free Press, and aolnews.com
- IPA hosts three free workshops for women
- Financial support from 1,391 "friends of IPA"

2011

- The Equal Employment Opportunity Commission (EEOC) issues a favorable "informal opinion" on the issue of whether shy bladder is a disability under the new Americans with Disabilities Act (ADA), as amended by the ADA Amendments Act of 2008 (ADAAA).
- More than 15,000 copies of *Shy Bladder Syndrome: your step-by-step guide to overcoming paruresis* sold
- Media coverage in major news outlets: MSNBC.com, Lansing State Journal, and American Psychological Association/WGN-TV News
- Famous Hollywood actor, Ryan Reynolds, admits publicly to having paruresis (shy bladder)
- Steve Soifer interviewed on the BBC London radio with Paul Coyte
- Anonymous donation options instituted
- Financial support from 1,500 "friends of IPA"
- IPA celebrates 15 years!



International Paruresis Association, Inc.

Celebrating 15 Years!

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