



International Paruresis Association, Inc.

Celebrating 15 Years!

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2011 (15th Year) State of the IPA Report

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This report is meant to be a reflective opinion of the CEO of the state of the organization in the last year in particular, but also of where we have been, where we are, and where we are going. I will try to cover the most relevant topics, but it cannot be an all inclusive report. This will complement our 15th Anniversary Report.

Overall Snapshot

It's been a remarkable 15 years in many ways. Started out of my University office, the International Paruresis Association (IPA), Inc., co-founded with Carl Robbins, M.S., LCPC, to borrow a phrase, has "come a long way, babe." A few bucks in a bank account, a few dozen members, and email lists is basically all we had. Today, we have the equivalent of a full-time staff person, an office in Mt. Washington, and a combined budget of over \$135,000.

While my dream of paruresis being a household word by now hasn't been achieved, I do think a random survey would show that around ½ of the U.S. population (not including many docs) has heard of "shy bladder." We are financially healthy at the moment. Our board is functioning well. We've made strides on two of our key issues: 1) alternatives to urine testing in the workplace and 2) understanding the underlying mechanism of paruresis. We have support groups all over the world. Not bad after 15 years.

Staffing and Office

At the moment, we have three staff, working the rough equivalent of full-time: Myself as CEO for 4 hours per week, Melissa H. as my supervisor working .75 hours per week, and Yvonne Y. working as our COM (Corporate Operations Manager) at roughly 25 hours per week. We have had others working on a temporary basis over the last year and in the past as well.

For about 5 years now, we have had our office at 1609 Sulgrave Ave. in Mt. Washington Village. It has served us well and continues to do so. Not only does it accommodate our staff needs, but it allows me to see individual clients as well. Barring unforeseen circumstances, I see it meeting our needs for the foreseeable future.

Board of Directors

Currently, we have 9 people on the Board, with one on a leave until January and one a “silent” member. Several people on the board have served for quite awhile. The Executive Committee, in my opinion, is quite strong. Many of the other board members are “newbies” and are integrating into the board nicely. I feel we need to grow the board, but slowly and filling key positions along the way. In my opinion, these include the need for a lawyer, a psychiatrist, and someone with fundraising.

Membership

We have over 1500 members (very nice coinciding with our 15th anniversary). Last year, I believe about 400 of these people were active on their dues, giving us a roughly 30% paid up percentage (PUP). Not bad for a nonprofit like ours.

We are like a typical nonprofit in that our active members form a pyramidal structure; most pay \$50 or \$100 per year and are at the “bottom” of the pyramid; as the contribution level goes up, the numbers decrease, forming an apex at \$15-20,000 per year.

IPA has much to do in the area of membership cultivation. Suffice it to say that we have some work to do in this area, though we do get better and better each year. Ultimately, the long-term survivability of the organization will rest with its members, both past, present and future.

Finances/Fundraising

These are perennial issues. Every year around this time, I can’t imagine how we are going to raise enough money for the following year. (As a note, this is even more true for this year.) Somehow we do (our members are great in this regard), and I am both pleased and amazed. For the last several years, we’ve started fundraising earlier and earlier and have had a growing surplus each year (2011 probably won’t be an exception). We have been able to maintain steady operations as a result.

However, we are stagnant where we are. I set a very ambitious goal for 2012 (\$150,000 to celebrate 15 years of existence), but do not think we can achieve it. If we did, we might be able to address the issue that has been one of our goals for a long time: a full-time Executive Director. I don’t think our ability to do so is on the horizon for the next several years.

But perhaps even more important, we need to think about long-term strategic fundraising down the road. Do we want an endowment to perpetuate the organization forever? Do we want to launch a bona fide Shy Bladder Center? What about the unfulfilled potential of the ARA?

Our 15th anniversary is a good time to pause and reflect on a long-term vision for IPA.

Media/General Education

As usual, we’ve had a few good media pieces this past year. Two things that stand out are the MSNBC.com story and the BBC radio interview. There was a lot of coverage of shy bladder in general this year, with both the coming out of Ryan Reynolds as one of us and all the legal blogging about paruresis as a disability with the issuance of the EEOC letter.

Also, as usual, we did not get the “big” media hit(s), as hard as I tried to make it happen. In particular, I thought my LinkedIn strategy would work, and to date, it hasn’t panned out. However, I’m sure LinkedIn to a lot of people at ABC news. We also have a nice press packet produced by one of my work-study students (http://paruresis.org/press_packet.htm).

Social Media

This is a new category for me to report on. You all know that social media is the biggy right now. I am using LinkedIn, Facebook, and Twitter (I hope you are all following me on at least one of these outlets). Every day, I post something new about paruresis on each of these venues. Thus, in a year that's well over a thousand "posts" out there.

I cannot judge the impact of all this quite yet. I have over 1500 LinkedIn connections (including a lot with various media people), 300+ Facebook connections, and 250+ following my tweets. Hopefully, this will lead to some positive impact for IPA in the very near future.

Website Updates

As we speak, our website is going through a major overhaul. I was hoping the new look would be by now, but I guess not. Very soon, though, our newly designed site will be up and running. I think everyone will be pleased with the changes.

With the improvements and easier methods to donate, for example, we should be getting even more traffic. Last I looked, we were getting about 30,000 unique hits per month on the IPA and SBC sites. This still amazes me.

Key Issues

1) Drug Testing in the Workplace

Well, I think you are all pretty much up-to-date on this one. We pulled off a "coup" by getting the EEOC to issue a favorable "informal opinion" on the issue of whether shy bladder is a disability under the new ADA. One positive outcome of this is all the blogging by lawyers and HR people on the issue, which overall has also been favorable to us. As one lawyer summed it up: just do alternative testing to avoid potential problems (i.e. a discrimination suit). The key now will be an actual test case.

However, there is still the big unresolved issue of whether or not we can get someone to "force" HHS, SAMHSA, and/or the DOT to recognize shy bladder and permit alternative testing for us.

2) Understanding the Mechanism of Paruresis

Well, we've made major progress here as well. Dr. Greg Nicaise from Belgium, an advisory board member, did a MRI of my bladder and someone else last year. He has written up a report of what he thinks causes our condition. Dr. David Gordon, also a member of our advisory board and a neurourologist, is looking over Greg's work and tweaking it. By the end of the year, we should have a "position" paper on it. What happens then is another question. Bottom line: it appears that the external, not internal sphincter(s), is/are the culprit in our disorder.

IPA Member Survey

The IPA Board retreat facilitator was kind enough to develop a member survey for us. The returns, I feel, were amazing. Almost half of those who received it (493/1152) opened it, and of those, 40% (233) answered the member profile and almost 60% (342) answered the priorities survey.

Here are some of the highlights: over 70% want to see improved restroom design, 67% a cure, and 60% more awareness among docs. A whopping 88% utilize the website, and 60% have been to workshops. Without mentioning numbers, the level of membership satisfaction with our services was lower than I would have expected. Moreover, the priorities members wanted to see us working on were not exactly what I expected either. Most surprisingly, the number of people wanting to help out (volunteer) was quite amazing.

SBC/ARA

Just a few words here. As you all know, the SBC is an informal subsidiary of IPA; that is, we are not an official 501c3, but really a project of the parent organization. This has worked well for now, but I do think in the not too distant future, we should consider SBC becoming its own not for profit or possibly even for profit entity. Or maybe not.

The other organization, ARA, as you all know is dormant. Something needs to be done here, especially in light of member survey data indicating how important restroom design is to people with paruresis.

The Future

Our 15th Anniversary Board Retreat offers us a perfect opportunity to do strategic planning on a short-term basis (3-5 years), discuss a intermediate vision for 5-10 years down the road, and think about the long-term of the organization (10+ years).

I've been thinking about a few things along the intermediate and long-terms lines. First, I am already thinking about retirement at around 65. On the one hand, that leaves me 10 more years of service to IPA, and on the other hand, it forces us all to think beyond one of the co-founders and the long-term sustainability and survivability of the organization.

The second thing is related. You have all heard me say that the need for the IPA (or some such organization) will surpass all our lifetimes. In fact, I see the eradication of paruresis as easily a 100+ year project. So what legacy do we want to leave? From one vantage point, I see an endowment (a large one: \$5-10 million) as the only way to do this. That would provide a modest operating budget (\$100,000+?!) for the organization, given today's interest rates. Can and should this become a priority for the organization?