FR DOC#04-7984 PUBLIC COMMENT 8400034

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Date: 6/24/04 8:53PM

Subject: PUBLIC COMMENT ON FR DOC # 04-7984 Submitted June 24, 2004

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Public Comment ON:

http://a257.g.akamaitech.net/7/257/2422/14mar20010800/edocket.access.gpo.gov/2004/pdf/04-7984.pdf Notice of Proposed Revisions to the Mandatory Guidelines for Federal Workplace Drug Testing Programs (69 FR 19673, April 13, 2004, FR Doc#04-7984)

FROM: Richard L. Ziprin, Ph.D.

Member, Board of Directors, International Paruresis Association, Inc.

I am one of the authors of a lengthy and detailed response to FR Doc# 04-7984 which is being sent separately by the International Paruesis Association.

The following comments are mine, and do not necessarily reflect that organization's opinions.

I had not planned to write my own comment, but after reading the Public Comment written by Joseph A. Thomasino, M.D., M.S., F.A.C.P.M. Certified Medical Review Officer, which has been posted on your SAMHSA web site, and after exchanging some e-mail with him to get a better idea of his views, I feel that you need to hear directly from me as an individual.

The major flaw in present and proposed protocols comes from an inappropriate and incorrect belief that people can always void volitionally, and that if they fail to void volitionally and fail to provide a urine sample on demand, they must be viewed as having refused to be tested AND PUNISHED.

This thinking defies logic, defies medical reality, and inflicts injustice on those who fail to provide a urine sample through no fault of their own. In absurd extensions of this logic, people on dialysis, with no kidneys, have been fired.

I'll discuss paruresis, or what you euphemistically call shy bladder a few paragraphs later. I wish to make some more general comments at this point.

I must comment that the rules which allow for the punishment of people who fail to provide urine samples due to dehydration or situational anxiety are simply unjust. Does it really make sense to punish people SOLELY because they can't produce a specimen on demand? The underlying assumption of course is that the individual is trying to cheat or hide something. This may happen indeed. But many people have valid reasons for an inability to produce urine, and present procedures do not adequately or fairly address the needs of these HONEST people who seek only to have a fair shake at earning a living. It can happen that an individual may not know or understand the true reason why he/she could not produce a sample. Medical exams done after the fact are not sensitive enough or reliable enough to accurately determine if a medical condition existed at the time a sample was demanded. The MROs are exaggerating if they have led SAMHSA and DOT to believe otherwise. Many medical conditions go undiagnosed or are improperly diagnosed, even under the best of conditions.

SAMHSA has lost track of what it is trying to determine. It is not in the business of determining whether or not people suffer from voiding dysfunctions, situational anxiety, enlarged prostates, neurogenic bladder, or whatever. It is NOT in the business of collecting urine samples as an end unto itself. It is about determining if the person being tested demonstrates evidence of present or past drug abuse. It is about making certain that impaired workers don't engage in safety sensitive occupations.

Solid evidence of drug use or abuse, or of job performance impairment, should be the only justifications for either disciplinary action or refusal to hire. Inability to pee should not be punished.

Punishing people solely on the basis of an inability to provide a urine sample is wrong. It is morally wrong, and it is legally wrong. We know it is legally wrong because there have been several significant high dollar judgments against employers who did just that. We know it is medically incorrect to assume everyone can pee on demand because there is an extensive scientific literature on voiding disorders. Since the underlying assumptions are both medically and legally incorrect, continuing the practice is morally indefensible.

As a paruretic, I experience difficult to impossible voiding daily in my life. This is stressful enough. I don't need the added stress of misguided testing protocols whenever I think about possibly looking for new or different employment.

I am personally aware of many people who remain unemployed, or underemployed, or who have chosen to engage in self-employment activities, solely because Government imposed urine-based drug testing rules make it impossible for them to compete in the employment marketplace. Conservatively, two million people have been so affected.

There is plenty of technology available today in the form of hair testing, sweat testing, oral fluid testing, blood testing, and computerized performance testing, that no testing subject should ever be punished for a failure to provide a urine sample.

The proper response when someone can't pee (or even when someone refuses to pee) should be to immediately offer a different type of test.

There is no need for Agencies or employers to probe into the health reasons that might have contributed to an employee or applicant's failure to provide a urine specimen. There is no need for MROs to look into why someone couldn't pee. There is no need to require prior documentation and written statements from physicians verifying the prior existence of a condition.

Instead, simply ask the person being tested to take a different test of the testing company's choice.

Only when the employee or applicant fails to comply with requests for a second form of test sample, should discipline (or refusal to hire) become an issue. And even then, there MUST be a swift and reasonable administrative review at which the employee or applicant can explain what happened and be represented by legal counsel if desired. We can't have summary judgments being made, particularly with respect to Federal Employees and Federal job applicants. Here, the highest standards of ethical conduct and fairness MUST prevail toward both applicant and employee alike. There must be fairness to all. That isn't the case under the proposed guidelines.

We are talking about nothing less than the civil right to seek and hold gainful employment on a fair playing field that is not distorted by The Government. This playing field has been trampled by SAMHSA, DOT, and by the private sector in their zeal to root out drug users. Two wrongs don't make a right.

Present SAMHSA and DOT regulations fail to provide any mechanism for administrative or judicial review of incidents. IPA can't even find a single office in SAMHSA or DOT with the function of handling complaints by applicants and employees. There are mechanisms for testing companies to appeal decisions against them, but there are NO mechanisms for the ordinary applicant or employee to dispute results or to dispute the facts about incidents that may have taken place at a testing site. Not a thing of the sort is mentioned anywhere in the proposal or in past posting in the Federal Register.

Returning now to the specific issue of paruresis:

I had some e-mail discussions with Dr. Thomasino, who identified himself as a past President of the AAMRO. He objected to changes in the length of time a person must be held at the testing station before shy bladder protocols apply. He wanted to retain the old 3 hour 40 ounce rule. I object to the 3 hour 40 ounce rule. No one should be asked to try for more than 30 minutes. If they can't produce a sample, a different test should be used.

Consider the real life experience of a paruretic presenting for testing. You have consumed a can of diet cola 30 minutes before arriving at the testing company in the hope that you will be able to produce a specimen. You then are commanded to consume 40 ounces and wait 3 hours. This is YOU now. You can't pee, you can't leave. You are in physical agony from an overfilled "fighting bladder." You want desperately to relieve the pain and coincidentally to provide the urine specimen so you can save your job or career, or get the job you applied for. But you can not pee. Then, when the 3 hours are up, you are stuck in continued agony for the 30 additional minutes afterward that it takes you to get to a "safe" restroom-usually your home. If you are truly unlucky, you not only lose your job but end up in an Emergency Room. And when you are done with this barbarity, you then must quickly obtain medical documentation, plead with an MRO (who might not know or care about paruresis), and plead with the employer for some understanding. The latter requires speaking up about a most intimate and personal aspect of one's life.

That is what paruretics face with urine testing all of the time. It puts their careers and their health at risk.

Dr. Thomasino writes us that under present rules the paruretic who knows before hand that he will not be able to produce a sample may refuse to drink, and simply wait for the 3 hour period to elapse. This is indeed the rule that is published in the Federal Register. Yet, SAMHSA has posted upon

its web site that "a refusal to drink is a refusal to test." SAMHSA can't have it both ways. You can't publish one set of rules in the Federal Register and post another set of rules upon your website. Nor should you encourage, as you do, the private sector to follow "must drink" rules that aren't in SAMHSA's own legal documentation of the rules-the Federal Register.

A paruretic who follows Dr.Thomasino's advice would still have to produce documentation of his disorder. This is something that many find impossible to do. There is something inherently very shameful (in the mind of the paruretic) about their disorder and many also hold the erroneous belief that they are the only person in the world so afflicted. Hence, they refuse to discuss their condition with their spouses, their physicians, or anyone else. It is unrealistic to expect paruretics to have prior documentation of their condition. (It has taken me a decade of very hard work to get to the point where I can openly sign my name to this letter. It took me several years of membership in IPA before I was able to publicly speak about my disorder.)

Because IPA receives many complaints about improper conduct of testing companies, I have recently had quite an exchange with one company over precisely this issue of whether or not a subject must drink. If nothing else, SAMHSA needs to do a much better job of educating, testing, and monitoring companies that do urine collection. You would not believe the abuses that come to IPA's attention. Indeed, we are now something of a clearinghouse for complaints, and that is not what IPA wishes as its main function, nor is it what I wish to spend my time on, as one of their Directors.

SAMHSA needs to stop its reliance on urine, and on urine sample production, if it is to continue with a testing program. The present illogical and unjust approach to things is a shame on our country and a public embarrassment for many Federal Employees who are not drug users and are solid law abiding productive citizens.

The entire program needs reconsideration to maximize the use of new and different technology, and to protect the rights of those being tested.

Although I am writing this as a private citizen, not a representative of IPA, I can assure you that IPA is not going to sit idly by. We have backed litigation that is in progress and we won't tolerate continued abuse of our membership. Something has to change. And now is the time for change.

In the official IPA response an offer is made to work with SAMHSA in a

cooperative fashion to solve some of these problems. As a citizen, I sincerely hope that SAMHSA pays some attention to what has been said and does indeed elect to work with IPA on solutions.

I want to make one comment concerning school testing, though this isn't directly related to FR 04-7984. I understand that many in Congress have been agitating for mandatory testing of all school children using SAMHA regulations. This, should it be enacted, would be a social disaster resulting in increased drop-out rates, and increased teen suicide. New rules would need to be formulated that take into account the special sensitivities and maturity level of the students. It will NEVER be proper to do what some testing companies presently do in some school districts. That is, line up 10 guys in a men's room with one monitor, thus leaving the last guy to finish open to teasing and humiliation, or suspicion that he was trying to avoid the test. It will never be proper to hold students for hours on end while demanding that they drink. School testing must be done on an individual basis, handled discretely by the school physician or school nurse, and conducted in a way that takes into account the special sensitivities and emotional volatility of teens. It must be coupled with adequate resources for follow-up counseling and treatment where appropriate Otherwise, nothing constructive will be achieved. Only destruction will follow. Kids will drop out. Kids will be forced into depression. And kids will kill themselves. SAMHSA may need to construct an entire new set of regulations for school testing, depending on what course Congress takes.

SAMHSA has gotten the entire drug testing process off to a very wrong start. Innumerable people have been harmed by its policies. Perhaps more harm has been done than good. No one knows, because there are no statistics on the number of good people who did not apply for jobs due to the testing requirements; there appear to be no statistics on the number of people who have simply walked out of a testing site in disgust; there are no centralized statistics on improper attention to protocols because there is no formalized complaint process. There are no centralized statistics on disciplinary action taken in the private sector; there certainly are no centralized statistics on how many position applicants have been improperly turned away. In the Official IPA response we suggest that these errors, in percentage form, may be quite high. It is time to take some swift active steps to fix the numerous problems that exist.

The single most effective corrective action SAMHSA can do, and can do now, immediately, is to mandate the use of oral fluid tests, hair tests, and sweat tests as alternatives for anyone who either can't produce a urine specimen or simply asks for a different kind of test. I am certain IPA officials will be glad to work with SAMHSA and DOT people toward this end. I know I will.

No doubt any such effort will be met with considerable resistance from those entrenched by special interest in keeping the status quo. SAMHSA will be

given false or misleading information about the quality and validity of alternative tests. It will be given misleading if not disingenuous advice by MROs who don't want to see such advances as Oral Fluid POCTs, which will reduce their business volume. IPA neither supports nor opposes drug testing. We have members on both sides of the issue. We have scientists and physicians and attorneys who are well positioned to help SAMHSA make sound decisions. I personally hope that SAMHSA will take this opportunity for a new beginning, so that much heartache and future litigation can be avoided.